HOW PARENTS OF CHILDREN WITH AUTISM NAVIGATE INTERVENTION

MAKING YOUR OWN WAY: A GROUNDED THEORY STUDY OF HOW

PARENTS OF CHILDREN WITH AUTISM NAVIGATE INTERVENTION

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A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the

Requirements for the Degree Doctor of Philosophy

McMaster University DOCTOR OF PHILOSOPHY (2015)

Hamilton, Ontario (Health Research Methodology Program)

TITLE: Making your own way: A grounded theory study of how parents of children with autism navigate intervention

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NUMBER OF PAGES: xiv, 445

LAY ABSTRACT

Parents of children with autism shoulder significant responsibility for navigating many varying services and treatments (intervention) to address autism-related concerns, and experience great uncertainty and stress as they do so. There is a lack of research explaining how these parents respond to the complexity and obstacles they encounter as they navigate intervention. Using qualitative research methods, I interviewed 32 urban and rural Ontario parents (mostly mothers) and 9 professionals with expertise supporting parents to understand in detail how parents respond to their situation by *making their own way* to intervention. The resulting analytic findings have implications for improving support for parents of children with autism to reduce stress in their lives and improve other outcomes. The theory developed is also relevant for understanding how other healthcare consumer populations navigate intervention, and contributes to general knowledge in different consumer-centered areas of health research.

ABSTRACT

Parents of children with autism shoulder substantial responsibility for navigating intervention to address autism-related concerns, and face conditions of high uncertainty and stress to do so. There is a lack of holistic research explaining how parents cope and respond to the complexity and obstacles that characterize their situation as they navigate multiple forms of intervention across multiple systems of care.

The purpose of this qualitative study was to develop a social psychological explanation in the form of a substantive theory of how Ontario parents of children with autism navigate intervention under complex informational conditions.

I used grounded theory methods, a constructivist approach and symbolic interactionist analytic framework for this research. The findings are primarily based on 45 in-depth (90-minute) interviews with 32 mothers from different urban and rural Ontario regions (fathers participated in 3 cases), and 9 professionals with expertise supporting parents. Documents were also analyzed. The central process of navigating intervention, labeled *making your own way*, consists of *adjusting to the need to navigate intervention*, in which parents construct the meanings that prepare and motivate them for *taking action to navigate intervention*. *Adjusting* consists of 4 interdependent sub-processes that together explain parents' action: *defining concerns*, *informing the self, seeing what is involved*, and *emotionally adapting*. I portray the central process according to three overlapping heuristic stages: *beginning the autism journey*, *handling transitions*, and *easing off*. Many parents develop a strong sense of urgency to which they can respond by *going into high gear*, expending substantial personal resources sometimes at unsustainable rates in the pursuit of intervention.

The findings have implications for supporting parents to improve outcomes including parent stress. The central process of *making your own way* is generically transferrable to other healthcare consumer populations. Other conceptual elements have theoretical relevance for consumer-centered areas of health research.

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LIST OF ABBREVIATIONS

ABA:	Applied behavior analysis
ADHD:	Attention-deficit/hyperactivity disorder
ASD:	Autism spectrum disorder
ATN:	Autism Treatment Network
CAT:	Complementary and alternative therapies
DAN:	Defeat Autism Now
DFO:	Direct funding option (for Ontario government-funded IBI)
DSM:	Diagnostic and Statistical Manual of Mental Disorders
EA:	Educational assistant
EBM:	Evidence-based medicine
GFCF:	Gluten-free, casein-free (i.e., diet)
GFCFSF:	Gluten-free, casein-free, soy-free (i.e., diet)
HiRU:	Health Information Research Unit, McMaster University
IBI:	Intensive behavioral intervention
IPRC:	Identification, Placement, and Review meeting
KT:	Knowledge translation
MCSS:	Ontario Ministry of Community and Social Services
MCYS:	Ontario Ministry of Children and Youth Services
MMR:	Measles mumps and rubella (i.e., vaccine)
PDD-NOS:	Pervasive developmental disorder not otherwise specified
PECS:	Picture Exchange Communication System
REB:	Research ethics board
SDM:	Shared decision making
SLP:	Speech and language pathologist
TA:	Teacher's assistant

CHAPTER 1: INTRODUCTION

In this chapter I introduce the research problem, research purpose, the guiding research questions, and aspects of my background that influenced the initial design this grounded theory study of how Ontario parents of children with autism[1] navigate intervention. I begin by describing how my original interests led to the decision to study parents of children with autism.

I arrived at my graduate program with a background in health information and desire to contribute to research knowledge about how healthcare consumers in use or interact with health information. In seeking out a group to study, I concluded that parents of children with autism, with their acute informational needs, would be a potentially highly informative group to study.

My awareness and interest expanded over the course of the study as I learned that parents' information use was inseparable from the greater process of navigating services and other forms of intervention. I discovered it was impossible to understand the former without first understanding the many other forms of action involved in this latter overriding process (see Appendix D: *Revising the research question*). The initial research decisions and approach, however, were guided by my interest in information use.

Research problem and study purpose

Problem. Here I summarize the research problem, primarily as I defined it after an initial scan prior to developing the research proposal, which involved informal interviews with a small number of professionals and parents. Parents of children with autism are, like other parents of children with serious health conditions, highly motivated to participate in the care of their children. As the primary caregivers, parents are positioned as the main decision-makers

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[1] Throughout, I use *parents of children with autism* to refer to the parent(s) or guardian(s) primarily responsible for the child.

regarding therapy and services for the children affected by this lifelong developmental disorder, often filling this role into adulthood. Parents of children with autism are also similar to other parents of children with serious health problems in that their quest for intervention is often pressing. In the case of autism, the greatest source of urgency comes as parents quickly learn that intervening as early as possible is key to achieving better outcomes in later life.

But the situation of parents of children with autism is unique because of the many sources of complexity they face. Since there is such variability in the presentation of autism from child to child, parents must struggle to understand how the disorder affects and is uniquely problematic for their particular child. Moreover, there are typically a multiplicity of concerns or problems that manifest for each child, many requiring different approaches to address. In addition, there are many types of possible interventions for addressing each problem, including many forms of behavioral therapy, medications, alternative treatments, and environmental modifications. Information about interventions, meanwhile, is not straightforward due to its many sources, sheer volume, and varying credibility. This is compounded by the fact that it is difficult to generate high quality research evidence for autism intervention for methodological reasons. Finally, systems of care generally lack the capacity to support the extensive needs related to autism as well as they do for most other conditions that are generally less complex; the result being that parents shoulder a greater proportion of the burden and responsibility for care related to autism. All these conditions contribute to an unusual level of uncertainty, stress, and informational need.

Unlike many other pediatric caregiver groups, such as parents of children with cancer, there are few studies of information use among parents of children with autism; and there is virtually no research to provide a holistic understanding of how parents cope and respond to their uniquely complex informational situation (see Chapter 2: Literature review).

Study purpose. The purpose of this study was to develop a social psychological understanding in the form of a substantive theory explaining how parents of children with autism navigate multiple forms of intervention under complex informational conditions.

Research questions

As stated, the original interest and focus at the outset was restricted to parents' interactions with information, but the scope was broadened early in the study to address the greater process of navigating intervention (see Appendix D: *Revising the research question*). The following research questions, which reflect this broader focus yet still maintain my original interest in information, were used to guide the majority of data collection and analysis in this study:

- How do Ontario parents of children with autism navigate intervention?

- How does information fit into this process?

Intervention includes any therapy or modification that the parent or professional may consider to address an autism-related concern affecting the child, parent, or family.

Researcher perspective and assumptions

I entered the field with a background of theoretical knowledge from fields that I considered relevant to this study at its outset. These include the fields of knowledge translation and library and information science, which informed my original interest and whose literature I draw on in Chapter 2 to develop the rationale for this study. As a result, I carried with me several specific understandings and preconceptions. According to the methodological principles of grounded theory and symbolic interactionism that guided the study approach (see Chapter 3, *Grounded theory approach*; Appendix C: *Reflexivity*; and Appendix D: *Revising the research question*), I occasionally needed to revise, adjust, or expand on these imported understandings after entering the field and discovering how they did not fit with parents' specific social worlds as my

participants represented them. For example, my understandings of *information use* and *information-seeking behavior*, while helpful, gave way to an expanded understanding of *information* and the ways that parents can interact with it (see Section 4.2, *Information*). Similarly, my understanding of decision making, informed by partial knowledge of the shared decision making literature, was initially limited to the idea of deliberatively choosing between two or more options; whereas, in this study I became aware of intuitive decision making.

Anticipated outcomes

The anticipated product of this study is a substantive theory outlining a human social psychological process by which parents navigate intervention. With its sample size, careful approach participant selection, and in-depth data collection, this study is positioned to account for substantial variation and the influence of numerous conditions including context. The resulting theory thus has the potential to explain many parents' individual experiences and action, both within Ontario and in other jurisdictions. The findings (including supplemental analyses; see Appendices) are therefore expected to have implications for making changes to improve conditions for parents navigating autism-related intervention.

In addition to its explanatory power with respect to the substantive case of parents of children with autism, aspects of this theory will likely be transferrable in specific ways, such as for understanding processes related to navigating systems of care more generally by healthcare consumers faced with conditions of complexity. Thus, the more generic aspects of this theory and the related supplemental analyses (see Appendices) have the potential to advance fields within health concerned with supporting healthcare consumer participation in and navigation of care, such as consumer-targeted knowledge translation.

CHAPTER 2: LITERATURE REVIEW

The literature review chapter includes a discussion of the state of relevant knowledge in three areas whose intersection overlaps the study focus: consumer-relevant knowledge translation, information use and information seeking, and autism. In each section, I propose areas where knowledge is lacking that this study may fill. Since this literature review was conducted prior to the research (with a few minor updates), the discussion of these three areas also provides a record of my interest and theoretical knowledge prior to primary data collection for the study.

Consumer-targeted knowledge translation

The goal of knowledge translation (KT) is to coordinate activities "to accelerate optimal use of the best available research evidence in the interest of the health of Canadians" (Canadian Institutes of Health Research, 2008). KT frameworks are broad theories used to promote and guide KT-related activities and research. They are developed through reflection, experience, synthesis of the relevant literature, and primary research. This synthesis often involves building on existing frameworks or theories as well as reference to research evidence.

KT activities can be targeted at different knowledge user audiences or adopter groups, including healthcare professionals, policy-makers, and patients or healthcare consumers (including informal caregivers, and citizens promoting their own health) (Graham & Logan, 2004; Lavis et al., 2003). In Figure 1.1, I schematize how different KT activities happen in different domains corresponding to each of these groups. The *patient domain* includes settings where healthcare consumers are exposed to or use health research evidence—both outside formal clinical settings (i.e., through informal public channels such as various media, or word of mouth) or within clinical settings (e.g., clinician advice). The *clinical domain* includes settings where clinicians become aware of or use research evidence to inform decision making and other

activities (e.g., informing patients). The *public policy domain* includes settings where policy-makers are exposed to or use health research evidence. A fourth domain, the *public patient domain*, contains the portion of the *patient domain* that is excluded from the *clinical domain*.

KT activities and strategies that fill the overlap between the *patient domain* and the *clinical domain* include patient-targeted knowledge tools such as clinician-provided information materials (including web sites), structured patient counseling, and patient decision aids. In addition to improving decisions that healthcare consumers participate in making in clinical settings, these tools may influence the decisions they make outside of it, in the *public patient domain*, such as behaviors underlying adherence, and the independent adoption of therapies or lifestyle changes. Shared decision making (SDM) is another valuable consumer-targeted KT strategy that influences patient decisions and behavior both within and outside the *clinical domain*. For example, behavioral theory suggests (Leventhal, 1985; Leventhal & Cameron, 1987) and some guidelines recommend (Canadian Diabetes Association Clinical Practice Guidelines Expert, 2008) that involving patients in a SDM process as a useful strategy to overcome behavioral barriers to accepting and acting on research evidence that is in their interest. As a result, KT tools such as patient decision aids have been developed that apply SDM principles to the goal of improving adherence (Lalonde et al., 2004; Sheridan et al., 2006; Weymiller et al., 2007).

Classical diffusion of innovations theory helps explain how adoption of innovations (in this case, health research evidence) occurs passively (i.e., where adoption depends on user-initiated behavior) (Graham & Logan, 2004; Rogers, 2003). Such theory is relevant to the *public patient domain*, where much awareness and adoption currently occurs through unmediated passive channels (e.g., news). Although an important starting point for KT framework development,

diffusion of innovations theory has failed to provide comprehensive guidance to effect change (Graham & Logan, 2004). This shortcoming has been addressed by the adoption of planned action KT frameworks, which were developed to explain what is required to accelerate change, and identify targets for implementation strategies. The main planned action KT frameworks, however, focus on healthcare providers or policy-makers, with little emphasis on healthcare consumers (Table 1.1). Although some of these frameworks acknowledge patients as a possible audience for KT implementation strategies, they lack any substantive reference to research evidence involving consumers in the *public patient domain*.

Table 1.1. Reference made to patients as targets or populations studied in supportive research or theories by influential planned action KT frameworks.

KT framework	Orientation or reference to patients/general public
Lavis Framework for Knowledge Transfer (Lavis et al., 2003)	KT activities may be directed at four target audiences, one of which is "general public/service recipients." Patients are agents that create change, although the suggestion is that this is by having an "influence on those who can act," rather than through their own decisions. Literature synthesis does not address patients.
Ottawa Model of Research Use (Graham & Logan, 2004)	"Societal and health-care external environments will affect all aspects of the process and must also be considered." Potential adopters may include, "even the public."
Knowledge to Action, or KTA, Framework (Graham et al., 2006)	"KTA has a broader focus with stakeholders including patients, …"
Jacobsen's Understanding	Presents a list of questions to help understand a user group

User Context (Jacobson et al., 2003)	including variables related to the group's use of research evidence; some questions may be useful for patient or public groups, while others are clearly for other audiences (e.g., policy-makers). Literature synthesis does not address patients.
Lomas' Coordinated Implementation Model (Lomas, 1993)	Research evidence-based decisions are made by practitioners (which apply to and are sometimes influenced by patients).
Stetler Model of Research Utilization (Stetler, 2001)	A practitioner-focused framework.

Some organized knowledge dissemination and implementation strategies exist in the public patient domain (e.g., public health-related messages, policies or laws, direct-to-consumer advertising and marketing). But these are relatively limited, and much dissemination and use of health research evidence in the public patient domain remains passive and uncontrolled. In addition, the fact that the main KT frameworks are not supported by research involving patients suggests that current patient-targeted KT efforts in the public patient domain are comparatively lacking or under-coordinated. This represents an opportunity for growth of KT.

Trends such as increasing emphasis on the informed patient, expanding respect for patient values and preferences in health care, growing public access to information, and the rise of SDM are all shifting health care decisions to the patient domain making it an important frontier for extending KT activity and research (Blair & Légaré, 2015). If patient-targeted interventions administered in clinical settings (e.g., strategies to improve adherence) are to be optimally

effective, efforts must also be directed to understanding the underlying factors and mechanisms of patient behavior and decisions that occur outside those settings, as this study aims to do.

Fidelity. The KT goal of achieving optimal use of the best available research evidence has been characterized by some authors as "improving the fidelity" with which medical advances are delivered (Woolf & Johnson, 2005). Within a population, fidelity is attenuated by barriers located anywhere along the path between generation of awareness about an innovation (best evidence) and its implementation. As a result, an innovation's effectiveness is progressively reduced from 100% of its original efficacy. In their empirically developed awareness-to-adherence theory, which focuses narrowly on guideline compliance by physicians, Pathman and colleagues (1996) proposed four steps where this attenuation can occur. Glasziou and Haynes (2005) expanded on this theory by recognizing the role of patient involvement, which they incorporated into a visual model. The first five steps in this model, which apply to the physician process of using information, "may begin all over again for the patient" (p. 9). Thus, we need to better understand how healthcare consumers approach these steps in the chaotic *public patient domain*, by both information seeking and information use, and identify the factors or conditions that affect the fidelity with which they incorporate best evidence into their care-related decisions.

Information use and information seeking

Here I define and discuss *information use* and *information seeking* as these concepts relate to the scope of the current study.

Information use. I define *information use* similarly to the idea of *knowledge use* as it is broadly described in the Lavis framework for knowledge transfer (Lavis et al., 2003). In that framework, knowledge use can be of three types: *instrumental*, where direct action is taken; *conceptual*, corresponding to general enlightenment that underlies attitudes and may play a

diffuse role in action-related decisions in the future; and *symbolic*, to justify a position or action already taken (Lavis et al., 2003; Pelz, 1978). This conception is broader than for traditional KT, where knowledge use requires its instrumental application (Canadian Institutes of Health Research, 2009; National Center for the Dissemination of Disability Research, 2009) or "putting it into action" (Graham et al., 2006, p. 17). While clinicians make instrumental use of research knowledge repeatedly in their day-to-day jobs, patients or caregivers more typically make only infrequent instrumental use of a given piece of research knowledge (e.g., deciding to start therapy). Conceptual use of knowledge may therefore be more important than instrumental use in the public patient domain. For example, parents of children with autism sometimes encounter results of studies of treatment effectiveness that contribute to their overall impression of different interventions, although they may not recall which studies underlie these attitudes.

Information-seeking. *Information-seeking* is a term from library and information science that refers to the process by which information users strive to locate information they consider useful. It is therefore an early stage in information use. The literature on health information-seeking behavior among healthcare consumers includes a moderate body of relevant publications, some of which are discussed here. One narrative review, emphasizing patients with breast cancer, noted that the decision to seek information is related to stress, the hope for reward, and level of self-efficacy (Dey, 2004). Another recent paper proposed a model to understand the health information seeking behavior that occurs in online mailing lists, newsgroups, and collaborative web sites. These channels involve collaborative information sharing between patients in the form of experience and anecdote, possibly resulting in a treatment decision. This phenomenon has implications for understanding how individuals decide what is a credible information source (O'Grady et al., 2008). The Pew Research Center recently described the importance of

information sharing on the internet by consumers in a report titled, "Peer-to-peer healthcare" (Fox, 2011). Its main finding was that, "Many people—especially those living with chronic or rare diseases—use online connections to supplement professional medical advice" (p. 1). Data from the US Cancer Institute's Health Information National Trends Survey have been used to explore hypotheses that link patients' trust in traditional information sources with their level of internet use to seek cancer information. Respondents who declared trust in their doctor were less likely to have used the internet (Rains, 2007). A survey assessing cancer patients' information use regarding complementary and alternative therapies (CAT) found, among other things, that although they understood the meaning of scientific evidence they often relied on poor quality sources such as patient testimonials (Verhoef et al., 2009). A mixed methods study explored information behavior of women faced with decisions related to hormone replacement therapy or CAT for menopause. Its author found that when reliable information is not available, women may turn to informal sources such as friends and relatives for information (Wathen, 2006). In a pure qualitative study, authors interviewed 40 rural women to discover the deeper underlying story of their experience with information seeking for themselves or a family member with a health concern. Ambivalence towards formal information sources and self-reliance emerged as themes (Wathen & Harris, 2007).

Only a few studies have addressed information use or information-seeking behavior in autism. A quantitative web site survey of mostly American parents found that books, web sites and list-serves, and other parents outranked professionals (e.g., physicians) as information sources, raising questions about the validity of the informal sources (Mackintosh et al., 2005). One qualitative study of 20 parents of children with disabilities, six of whom had autism, explored the reasons for parents' information needs. Not only did parents use information to

manage their child's disorder, but also to access services, and adjust emotionally (Pain, 1999). Note that these latter two uses of information do not align with the goals of KT. Interestingly, many of the findings regarding information seeking portrayed how information was used in a generic way, separating information use from the important condition of what consumers used it for (or why, specifically, information was being used). For example, in the Mackintosh article (2005), while some information sources outranked others, it remained unclear whether parents may have preferred using different information sources for different purposes. More detailed qualitative information is warranted to clarify similar questions in this literature.

Autism information-related context

A trend in the patient information-seeking literature is how serious health conditions that are commonly associated with high levels of stress (e.g., pediatric cancer) often correspond to an the urgent need for information among patients or their caregivers. Such healthcare consumers commonly turn to informal sources including information about CAT for which evidence is often lower quality. Autism appears similar, although additional realities make it a unique case. Autism is defined by the presence of both deficits in social communication, and stereotypic or repetitive behaviors and interests (American Psychiatric Association, 2013). Prevalence estimates have increased over recent years, and the latest U.S. CDC number of 1 in 68 is now commonly cited (Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators & Centers for Disease Control and Prevention, 2014). A South Korean study, which used sensitive methods and detected mild cases that often remain undiagnosed, estimated the prevalence to be as high as 1 in 38 (Kim et al., 2011).

The literature suggests (and pilot observations corroborated) that parents of children with autism make many intervention-related decisions independently, in the public patient domain.

An international survey found that parents had used an average of seven different treatments for their child with autism, many of which lacked empirical support (Green et al., 2006). A potentially important factor in independent treatment decision making is the enormous variation in symptoms and unique profile of each child, making parents experts on their child's unique treatment needs. Furthermore, parents may have pressing information needs related to the stress and urgency of their situation. Parents' stress is due to numerous factors including the considerable volume of often conflicting web-based information available (Mackintosh et al., 2005); knowledge that their child will require ongoing lifelong care; the time and frustration of obtaining a diagnosis (Siklos & Kerns, 2007); disruptive behaviors (e.g., hyper-irritability, self abuse, eating and sleep problems) (Konstantareas & Hoatidis, 1988); and low parent-child bonding due to the child's limited capacity for forming reciprocal relationships (Rivers & Stoneman, 2003). Parents' desire for information on how to intervene may be more urgent due to awareness of evidence that intervening earlier results in better outcomes (Charman et al., 2003).

In addition, the informational situation of parents of children with autism is substantially influenced by the popular media. An influential element, at least in the US, which has successfully promoted itself through multiple media channels, is the biomedical movement. In his book, *Autism's False Prophets*, Paul Offit (2008) describes how the biomedical movement emerged from the anti-vaccine movement, and is characterized by an antagonistic relationship with the traditional research community and mistrust of the evidence it produces. Up to 2011, the web site www.autism.com connected parents to *Defeat Autism Now* practitioners who provide CAT options that define biomedical therapy. Proponents of the movement in the US have included influential celebrities and politicians (Offit, 2008). Although occasionally drawing local news attention (for example, (Gorski, 2009)), it has not been established what role the anti-

vaccine and biomedical movements play in influencing information preferences of parents of children with autism in Ontario.

Conclusions

In summary, this review of the literature in the field of knowledge translation, the areas of information use and information seeking, and regarding autism information-related context indicates some knowledge gaps, both at specific empirical levels and at more general or theoretical levels, where this research has potential to make contributions. Moreover, currently, there is no research I am aware of to provide an in-depth holistic understanding of how parents of children with autism cope and respond to their uniquely complex informational situation.

At a general level, this study may improve understanding of some of the mechanisms of healthcare consumer behavior and decision making that occur outside clinical settings, which would be relevant to KT science. While parents of children with autism likely share similar information use characteristics with other types of healthcare consumers, such as cancer, some factors described above for the autism setting clearly make it a uniquely complex and informative case for understanding KT-relevant processes in the public patient domain. Novel findings have potential to inform consumer-targeted knowledge translation strategies and theory.

At a more specific level, the findings of this study will likely have specific utility and application for professionals and support agencies seeking to provide optimal support to parents of children with autism. In addition to contributing to professional understanding and sensitivity, the findings may suggest interventions to help this consumer group, for example, by addressing the complexity and stress that problematize parents' process of navigating intervention. Finally, transferable elements of the substantive theory could lead to similar benefits for other healthcare consumer populations with comparable information use characteristics.

Figures

Figure 1.1. Domains where decisions about treatment can occur, showing some examples of knowledge dissemination or other KT activities. The *public patient domain* (not labeled) is the portion of the *patient domain* that does not overlap with the *clinical domain*.
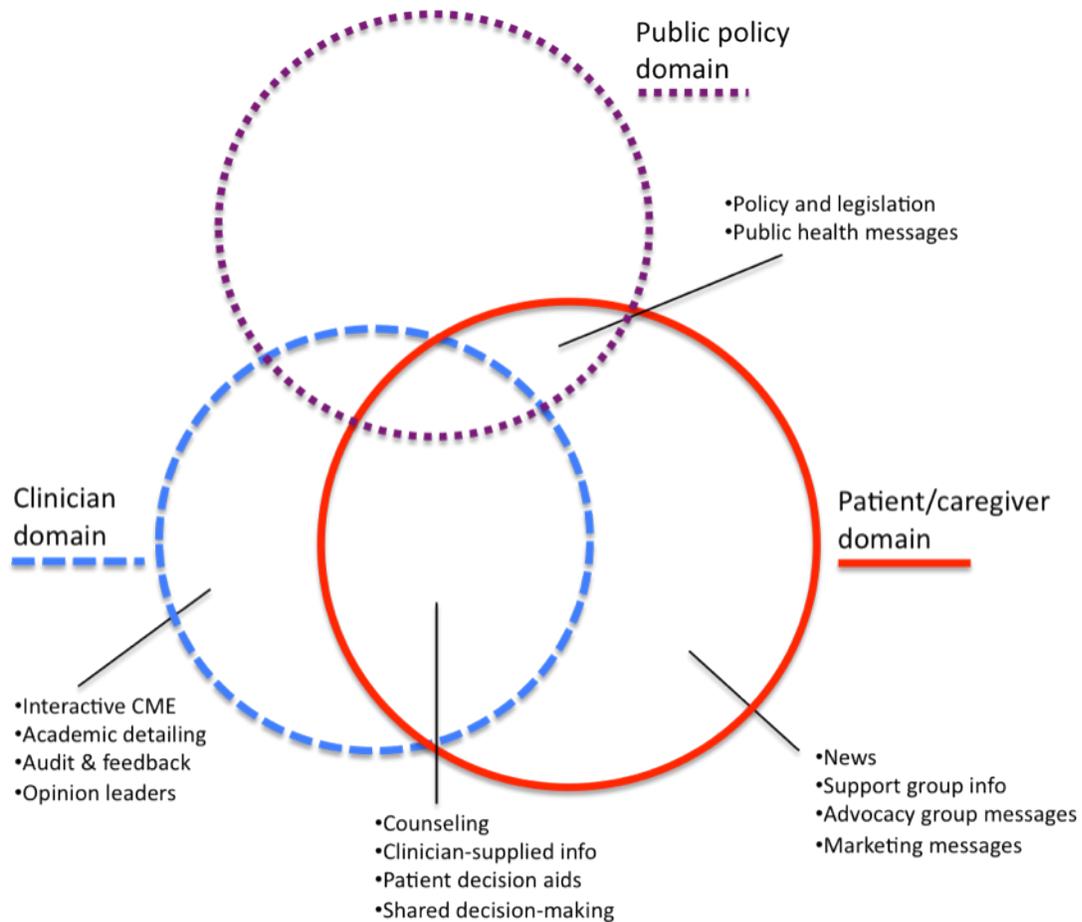
CHAPTER 3: METHODS

Characteristics of qualitative research

Qualitative research is useful to generate more complex and comprehensive knowledge of social and psychological human phenomena from participants' perspectives than can be achieved by quantitative methods (Creswell, 2007). As key decision-makers in the health care of their children and as targets of possible future KT interventions, it is the parents participating in this study whose perspectives will matter most to understanding the psychosocial process of navigating intervention. A major goal in selecting qualitative methods therefore is to generate an interpretive understanding that is as true to parents' perspective as possible.

Qualitative research has a history of being used to advocate for underrepresented populations or perspectives by emphasizing the voices of its participants (Creswell, 2007). This study advocates for underrepresented perspectives in two ways. First, although the SDM field has increased respect for patients' roles as decision-makers within clinical settings (the clinical domain), the proposed study will help explain and raise awareness of the independent decisions made by patients in the public patient domain, helping further moderate the patient-clinician power imbalance; similarly it addresses the under-representation of healthcare consumers in KT research. Second, autism has historically been a lower research priority because it is a less common disorder (e.g., research on patient information-seeking behavior has mostly been in cancer); considering the substantial burden autism represents to society (Szatmari, 2006), further qualitative research in this population is warranted.

Grounded theory approach

Grounded theory is a highly popular qualitative research method (Morse, 2009). Grounded theory studies produce substantive middle range theories whose abstractions are derived from,

and therefore directly supported by, data from the world of participants (e.g., interviews, observations, documents), as opposed to less direct data sources (Creswell, 2007). Glaser and Strauss (1967) describe how a substantive theory (i.e., corresponding to an empirical area of inquiry) developed with grounded theory methods can be extended by expanding the research to encompass multiple empirical areas, resulting in formal theory (i.e., corresponding to a conceptual area of inquiry); "both types of theory may be considered as 'middle range' " (pp. 32-33). Robert Merton (1968) first defined middle range theories as lying "between the minor but necessary working hypotheses that evolve in abundance during day-to-day research and the all-inclusive systematic efforts to develop a unified theory," (p. 39) and described how in a young field, they may be used as building blocks for more abstract unified "grand" theories.

Grounded theory is characterized by concurrent data collection and analysis throughout the study, developing analytic codes or categories from textual data, writing memos to elaborate the analysis, using theoretical sampling to guide data collection in a way that both responds to and develops the analysis, and applying constant comparative methods to the data, analytic codes and categories (Charmaz, 2006; Corbin, 2009). Its methods "can provide a route to see beyond the obvious and a path to reach imaginative interpretations" (Charmaz, 2006, p. 181).

Choice of grounded theory sub-approach: Corbin and Strauss. Within grounded theory, there are different versions or sub-approaches that researchers can choose to follow or adopt. Although the original methodology was developed by two authors, Barney Glaser and Anselm Strauss (1967), a split between them resulted in two early variations: that of Glaser (Glaser, 1978, 1992), and that of Strauss (Strauss, 1987) or later, Strauss and Corbin (Strauss & Corbin, 1990, 1998). More recently, Kathy Charmaz (2006) developed what she has labeled *constructivist grounded theory*; while Adele Clarke (2005) laid out an extension to Strauss' grounded theory,

called *situational analysis*. Morse (2009) provides a useful "genealogy" summarizing these important branches, including Leonard Schatzman's (1991) *dimensional analysis*. I primarily followed the methods of Corbin and Strauss, outlined in the third edition of *Basics of Qualitative Research, Techniques and Procedures for Developing Grounded Theory* (2008; hereafter called Basics).

Like the third edition, the first two editions of *Basics* (Strauss & Corbin, 1990, 1998) were aimed at researchers using this methodology for the first time. Thus, as the title states, all editions provide specific analytic techniques and procedures that may offer a useful guide to novices. Perhaps because these were explicitly laid out in a step-by-step fashion in the first edition (Strauss & Corbin, 1990), this guide was perceived and criticized for being to directive and rigid (Glaser, 1992; Robrecht, 1995). Despite clarification in the second edition that it was "*not* a recipe book to be applied to research in a step-by-step fashion" (Strauss & Corbin, 1998, p. xi), some authors, such as Charmaz (2006), continued to view it as such. Although it was twelve years after Strauss' death in 1996 that Juliet Corbin published the third edition of *Basics*, she retained him as an author on the premise of his fundamental influence on their method. This iteration of the method, however, is noticeably more flexible and "more open, analytically" (Corbin & Strauss, 2008, p. x). The way analytic techniques are described and displayed in examples throughout the book is more fluid and less linear. Elsewhere, Corbin (2009) reflects on her revised position on methods: "Analysis should be relaxed, flexible, and driven by insight gained through interaction with data rather than being structured or based on procedures" (p. 41). Corbin also claims "to have been influenced to some degree by the writings of contemporary feminists, constructionists, and postmodernists," (p. 9), and to especially admire Charmaz and Clarke's books (Corbin & Strauss, 2008). Even prior to publication of the second edition of

Basics, Annells (1996) observed based on her analysis the philosophical perspectives embedded in Strauss and Corbin's method that the "grounded theory method has an evolving fit to the constructivist paradigm of inquiry" (p. 391)—as an aside, she also observed that with Strauss and Corbin's conditional matrix, there are elements that allow for evolution towards postmodernism. Thus, Corbin and Strauss' version of grounded theory is one that both evolves to respond to criticisms, and is contemporary, being consistent with some of the recent philosophical and therefore methodological developments in qualitative research.

I have several other reasons for choosing the methods of Corbin and Strauss. First, I felt the explicit strategies and analytic tools they offered would be useful by providing specific guidance to build expertise as a novice qualitative analyst. Second, I originally classified my worldview according to Guba and Lincoln's (1994) four inquiry paradigms as partly post-positivist and partly constructivist. From an ontological standpoint, I believe that "reality exists and can be probabilistically, but not fully, apprehended," (Annells, 1996, p. 384) for most natural phenomena on the one hand, while for social or psychological phenomena I agreed that, "reality is a local and specific mental construction formed by a person and multiple mental constructions collectively exist regarding reality," (Annells, 1996, p. 385). Thus, Corbin and Strauss' approach, having evolved from a post-positivist to a more constructivist position as described above, was consistent with my ontological beliefs.

From an epistemological position, I disagree with Glaser's (1992) post-positivist argument that the researcher should occupy an objective position with respect to the data, and that one's background and biases should not influence the analysis. Corbin herself (2009) has reflected that the notions of an objective researcher and of theory *emerging* from the data, now seem outdated. In contrast to the second edition of *Basics*, which stated, "Objectivity is necessary to arrive at an

impartial and accurate interpretation of events" (Strauss & Corbin, 1998, p. 42), the third edition acknowledges that, "today we all know that objectivity in qualitative research is a myth" (Corbin & Strauss, 2008, p. 32). Not only is it impossible to separate one's background from the research process, but such background enhances researchers' sensitivity during analysis: "we are not talking about forcing our ideas on the data. Rather, what we are saying is that our backgrounds and past experiences provide the mental capacity to respond to and receive the messages contained in the data" (p. 33).

The grounded theory methods texts I chose to use was influenced by my sub-approach, but not limited by it. Thus, the primary text I cite is the third edition of *Basics* (Corbin & Strauss, 2008). As it excluded some useful content from Strauss and Corbin's previous writings, I also refer to earlier editions of *Basics* (Strauss & Corbin, 1990, 1998) and other publications they authored (Strauss & Corbin, 1994; Strauss, 1987). Since Corbin's stated methodological position is consistent with constructivism, I also refer to the guidance of Charmaz (2000, 2006, 2014). Occasionally, where I aim to comprehensively delineate approaches to a particular methods topic in grounded theory, I refer to the ideas of Glaser (1978).

Role of the researcher

As argued above, it is not possible to divorce the researcher's background knowledge from the analysis; moreover, this background contributes sensitivity and enriches analytic insights one can derive from the data. Following from this, (in contrast to Glaser) Strauss and Corbin (1990) permit exploration of the literature prior to embarking on the study in order to "stimulate theoretical sensitivity" (p. 50). Concepts from the prior literature search (or the researcher's prior knowledge), however, should not be allowed to enter the theory unless they "merit a place" (p. 50) in the analysis because they are clearly reflected in the collected data (Charmaz, 1990). Thus,

it is important "to always compare knowledge and experience against data, never losing sight of the data themselves" (Corbin & Strauss, 2008) (p. 33). Doing so requires reflexively declaring that knowledge in the first place, as much as possible.

Reflexivity is an iteratively unfolding process. I expanded considerably on the reflexivity methods I described in the original research proposal after the research was underway. I have since published my methodological approach to reflexivity as well as my reflexivity-related findings in the journal *The Qualitative Report* (Gentles et al., 2014), and include this report in Appendix C. Briefly, in defining my approach to reflexivity I reviewed the methods literature on the topic, mapped the broad scope of reflexivity, and chose among the varying understandings to define an approach that was methodologically consistent with grounded theory and the conditions of my particular study. Thus, the approach I used was comprehensive and involved accounting for the range of possible researcher interactions, including the different phases of the research process where they have influence: researcher influence on research design and decisions, researcher-participant interactional influences during data collection, researcher influences on analysis, on writing, and influence of the research on the researcher. Meanwhile, it was important to limit the extent of reporting, acknowledging *where* researcher interactions were influential, but not being exhaustive in analyzing (or speculating) *how* those interactions may have influenced the research. I used several tools to achieve this including a reflexive journal, reflexive and methodological memos, methodological and procedural aspects of the grounded theory method, prolonged engagement, and writing techniques. Most reflexivity-related findings are reported Appendix C, while others are described elsewhere in the Methods chapter and Appendices D through G. Overall, the reflexive report provides information regarding how the substantive findings were constructed.

Accounting for iterative methodological decisions

One aspect of reflexivity was to record my motivation for methodological decisions made while the research was ongoing. Thus, in several Appendices, I provide rationales regarding several important methodological issues and approaches I decided on iteratively. As mentioned, Appendix C lays out my detailed approach to reflexivity. Appendix D contains an explanation of why and how the research question was revised, providing a concrete understanding of the scope and focus of the research. In Appendix E, I describe my approach to selecting a central category and summarize how this process resulted in logically structuring the presentation of the theory in the Findings Chapter. In Appendix F, I account for my approach to analyzing context, which provides important background for understanding the supplemental analyses of context in later Appendices. In Appendix G, I justify the approach to member checking that was ultimately employed. Overall, the methodological content of these Appendices enrich the substantive findings and help locate the study. By transparently reporting the methodological decision making that came later in the research process, I aim to reflexively illustrate how the process of this research influenced my thinking and doctoral-level development.

Data collection

Sample size. The participant sample in this study of 32 parents and 9 professionals (45 interviews) exceeds the initially proposed estimate of 30 parents. One can never develop a priori estimates in grounded theory since this would require knowing the theoretical categories in advance of the study; meanwhile, theoretical sampling in grounded theory aimed at developing and saturating the properties of theoretical categories is ongoing during the study (Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Charmaz (2006) has suggested 25 interviews is sometimes appropriate for small studies, while more are

required for those with a wider conceptual scope. In a survey that included 174 grounded theory PhD dissertations, the median number of participants interviewed was 30 (Mason, 2010). Thus, the 45 fully transcribed 90-minute interviews in this study (see Section 4.1) represents a relatively large dataset.

Initial sampling of parents. The defining form of sampling in grounded theory is *theoretical sampling* (see *Theoretical sampling*, below). Although less emphasized, the main grounded theory developers also acknowledge the need for *initial sampling*, where sampling decisions are made before data collection begins (Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967; Glaser, 1978; Strauss & Corbin, 1998). Per Strauss and Corbin (1998), "In the initial sampling, the researcher is interested in generating as many categories as possible; hence, he or she gathers data in a wide range of pertinent areas" (p. 203). I describe some of these initial sampling decisions and approaches to select parents to interview here.

Since mothers are known to assume most of the responsibility for caring for their children with special needs (Marcenko & Meyers, 1991), and to be disproportionately affected by stress related to a child's autism (Gray & Holden, 1992), and because in one primarily US web survey about information seeking by parents of children of autism it was mostly mothers who responded (Mackintosh et al., 2005), I considered mothers more likely to provide important perspectives on treatment-related information use than fathers. I thus planned to recruit mothers only since limiting demographic heterogeneity has been described in the qualitative research literature as a strategy to obtain more in-depth information while limiting the required sample size. In addition, in pilot interviews three mothers reinforced this sense that it is primarily mothers who deal with treatment-related information and that developing a theory focusing on them would have more utility and be a better use of limited resources. As Sandelowski describes (1995), "purposeful

sampling for demographic homogeneity and selected phenomenal variation is a way a researcher working alone with limited resources can reduce the minimum number of sampling units required within the confines of a single research project, but still produce credible and analytically and/or clinically significant findings" (p. 182). My thesis committee and I thus agreed it was not feasible to include fathers since sufficiently representing their perspectives would require a larger sample to achieve saturation of important emergent categories, in turn demanding further resources (funds for transcription; time to complete the research).

While the overall focus of the study was the experiences of mothers, I allowed in the proposal for the possibility of interviewing other types of informal caregivers if this proved advantageous. For example, I interviewed one grandmother who considered herself a parent and whose insight proved valuable to the study. Similarly, three fathers participated alongside the primary mother volunteer, which allowed for insight into how parents interact in navigating intervention; moreover, it was important to have this option since denying these fathers the opportunity to participate would have damaged trust and rapport during the interview. Mothers also often described the roles of their spouses when their spouses were not there to participate, which contributed further findings regarding how parents share navigation of intervention.

In my recruitment I targeted mothers who spoke English fluently, identified as the main information-seekers and decision-makers regarding intervention, and whose children were diagnosed within the previous five years. Time since diagnosis corresponds roughly to the time spent navigating, and also helped ensure the parents recruited were exposed to the similarly recent information. The initial criterion of five years was relaxed in a few cases to allow contributions from four more seasoned parents.

Again, according to Strauss and Corbin (1998) "In the initial sampling, the researcher is interested in generating as many categories as possible; hence, he or she gathers data in a wide range of pertinent areas" (p. 203). Since qualitative research has suggested that consumers in rural Ontario experience and interact with health information in unique ways (Leipert et al., 2008; Wathen & Harris, 2007), I considered geographic locale as a pertinent condition for the sample. I thus sought heterogeneity by including parents from urban, rural, and northern areas of Ontario. Although including geographic region as a relevant conditional influence in the theory required a larger sample size to achieve theoretical saturation, it also increased capacity for recruitment. Moreover, Glaser and Strauss (1967) describe how increasing the scope of a study to different geographic areas allows for "maximizing differences among comparative groups [through theoretical sampling]," providing " a more powerful means for stimulating the generation of theoretical properties once his basic framework has emerged." Selecting for geographic variation was thus done to facilitate analytic development of the theory.

I expected that volunteers would tend to be more highly proactive and health literate parents—producing what Miles and Huberman (1984) have called *elite bias*. I sought harder-to-access parents with lower health literacy who appear less proactive, by recruiting from select sources that were more likely to refer such participants (*Recruitment and consent*, below).

Theoretical sampling. The main grounded theory developers agree on the key elements of theoretical sampling (Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967; Glaser, 1978; Strauss & Corbin, 1998)—that it is a process in which data gathering is guided by the evolving theory and the aim is to develop categories in terms of their properties and dimensions and integrate those categories (i.e., relate them to each other within the theory being developed) (manuscript submitted February 9, 2015 to *The Qualitative Report*) . Thus one samples examples

of the concepts one is developing, wherever they may be found, rather than data sources (e.g., participants, documents) per se (Strauss & Corbin, 1998, p. 202). The main strategy I used was to prepare and ask questions to elicit information to develop categories or concepts I carried forward from previous (concurrent) analysis. I did this flexibly, capitalizing on participants' particular backgrounds to seek information to develop concepts tied to their unique experience. I stopped data collection after I felt I had enough data to thoroughly develop the most important categories in my theory in terms of their properties and dimensions and establish the important relationships (i.e., by accounting for substantial variation) (Strauss & Corbin, 1998, p. 212).

Sampling other data sources. In addition to parents, I also set out to interview professionals with expertise supporting parents of children with autism. I sought professionals for their ability to provide insight into important aspects that parents might be not explicitly self-aware of or not disclose in interviews. I recruited from occupational therapists, speech language pathologists, developmental pediatricians, educators, and other types parent support workers who specialized in autism. As an inclusion criterion, professionals had to be endorsed (by parents, clinicians, or researchers) as being especially sensitive and thoughtful regarding parents' situations as a result of extensive experience or authority supporting parents. I interviewed professionals towards the end of the study as I predicted they would be a valuable source of conceptual information sampled theoretically, based on their knowledge of many parents.

I selected document data for review according to theoretical sampling.

Recruitment and consent. I recruited parents through multiple channels, including two major parent advocacy organizations, the Autism Treatment Network and Autism Ontario, and a regional board of education (see Chapter 4, Section 4.1, *Parent characteristics*) who agreed to promote my study to the parents they served via email, web site announcement, and direct phone

contact, respectively. I recruited two parents who contacted me in response to news coverage of my study, and 1 more who approached me at my poster at an international autism conference.

When parents expressed interest in participating I provided them with initial information about the study, its purpose, and what was involved in participating by phone or email. If they confirmed interest, I sent them an information and consent package by mail, unless they preferred to receive it by email, asking them to sign and return it in a pre-stamped envelope. Thus participants were informed twice about the study purpose, expectations (number and duration of interviews), benefits and possible harms, their right to withdraw at any time without consequence, measures to safeguard privacy and maintain confidentiality, and how results would be used. The information and consent package informed parents that childcare expenses or travel for purposes of participating in the primary interview would be covered, and that they would receive a $25 honorarium for completed interviews. At the beginning of each interview, I reminded participants of their right to withdraw from the study at any time.

I approached pre-endorsed autism support professionals directly and informed them about the study, usually by email. All whom I contacted consented to participate.

Collection of parent attribute data. Soon after consent, I arranged a pre-interview phone survey to collect attribute data including demographic information, internet use, information about the child such as age, diagnosis, and type of professional care received (Appendix A: *Pre-interview survey*). I entered answers directly to an anonymized survey form (Microsoft Word). When conducted efficiently, the survey took less than 15 minutes. Despite gentle encouragement to finish in a timely manner, most parents took the opportunity to expand on their answers and begin sharing qualitative aspects of their story. Thus surveys provided a valuable opportunity to establish rapport, gain some familiarity with parents' history, and collect initial qualitative data.

In addition to recording the parents' supplemental qualitative responses as written notes, I audio recorded (but did not transcribe) some surveys with parents' consent later in the study.

Collection of primary interview data. Per grounded theory methods, I alternated between data collection and analysis throughout the study—i.e., coding and analyzing interview data just collected (Corbin & Strauss, 2008; Glaser & Strauss, 1967; Strauss & Corbin, 1998).

I asked all parent and professional participants to participate in an audio-recorded 90-minute primary in-depth interview. Primary interviews with parents took place either 1) face-to-face at a familiar, and adequately quiet local public facility where they had accessed information before (such as public library or community center), 2) face-to-face at the participant's home provided that another responsible adult could be in the dwelling during the interview, or 3) by phone with the participant at home. In the primary interview, I solicited parents' experiences related to the primary research question using a semi-structured approach. The initial interviews were guided by an initial stage interview protocol (Appendix B). In later interviews, questions evolved according to theoretical sampling. Sometimes these new questions were planned prior to the interview, whereas other questions I formulated spontaneously during the interview.

While questions thus varied across parent interviews, I consistently asked parents to begin by describing their child, and later to describe the path they took to diagnosis. I was careful to remain non-judgmental with respect to all topics discussed, keeping discussion free flowing and participant-directed. I was careful, for example, not to reveal my biases such as the value I placed in information supported by research evidence. Approximately half of parent interviews were face-to-face, while the other half were by phone. Seven of 9 professional interviews were by phone, and two were face-to-face. The inability to observe body language in phone interviews was not a perceptible barrier to obtaining valuable in-depth information.

Collection of other data types. Parents sometimes shared artifacts and documents during the primary interview (binders, notebooks, clinical reports, etc.) on which I took field notes. They also occasionally voluntarily followed up with email communication, which I coded similarly to transcribed interview data. In addition, I reviewed books, magazines, list-serves and numerous web sites that parents recommended or that I otherwise decided were relevant (see Chapter 4, Section 4.1, *Document sources*), coding the content in small number of cases.

Participant data management. I digitally recorded audio of phone and face-to-face interviews with participants' consent. Upon completion of primary interviews, I transferred audio recordings from the digital audio recorder to an encrypted folder (using 128-AES encryption) on a password-protected computer hard drive. All primary interviews were transcribed by myself (4 interviews) or a professional transcriptionist who signed a confidentiality agreement. To share interviews with transcriptionists I uploaded the audio files to a secure encrypted file online sharing service. Transcriptionists accessed audio files with a password, deleting all copies upon completion of the transcription. Transcriptionists returned interview transcripts (averaging 30-45 single-spaced pages) by the same process.

I recorded participant identification numbers, dates, times, locations, mode of interview, and other notes on a de-identified Word file created to record details of each participant survey and primary interview. I labeled corresponding audio and Word files with the same participant identification numbers. I stored the key to participant identification codes on a password-protected desktop computer in a locked office connected to the secure Health Information Research Unit (HiRU) network but separate from the FTP server where I stored participant data. At least monthly, I backed up and archived digital audio recordings, surveys and transcripts

(Word files), and the NVivo research database file to a password-protected secure (i.e., virus protection, file backup, firewall) FTP server stored in the HiRU at McMaster University.

Data analysis

I used NVivo qualitative data analysis software (QSR International; version 9 and 10) to facilitate management of text-based data, importing transcripts, PDFs of web sites, some memos and other elements not created within the NVivo software program. Using NVivo, all data entry and analytic actions were date-and-time-stamped—in addition to carefully dating data records and memo entries external to the NVivo file—providing a detailed audit trail.

Coding. The aim of the analytic process was to produce a substantive theory that fit the dataset. Codes are the labels given to analytic categories or concepts. In *open coding*, I derived codes from the data to open up all potential meanings and establish concepts to direct further analysis and data collection (Corbin & Strauss, 2008; Strauss, 1987) as follows: In reading interview transcripts or other text-based data records, I highlighted passages or sections that represented examples of new or existing codes, linking the data segment to the code label. In addition, I sometimes attached brief thoughts in the form of annotations to the data segment within NVivo (Richards, 2009). Reasons for selecting data segments and assigning codes derive from researchers' individual *theoretical sensitivity*—insights, curiosity or questions about the data arising from the researcher's prepared mind (Corbin & Strauss, 2008). In my case, theoretical sensitivity came from prior knowledge derived from ongoing exposure to the literature and parents' worlds. Elements of the coding and analytic process, described below, fostered further insight by forcing close interaction with the data (Strauss & Corbin, 1990).

Especially early on, prior to developing my own coding techniques and style, I selectively and purposefully employed analytic tools described by Corbin and Strauss, which included

asking questions of and making comparisons between data (Corbin & Strauss, 2008; Strauss & Corbin, 1998). In naming codes, I used the language or words of participants when possible (*in vivo codes*). For each code, I recorded a definition that was open to revision. Through a process of constant comparison I applied established codes to textual data. I also compared new or tentatively labeled codes with other codes to decide if they should be grouped or rearranged. A goal of coding is saturation of more centrally relevant categories, by finding enough examples to represent the range of its characteristics (properties and dimensions). By alternating between analysis and data collection, coding informed theoretical sampling and directed future data collection to meeting the emerging conceptual needs of the study.

Throughout the analysis I reviewed the code list to merge or remove codes that were redundant or unimportant to the developing theory, or to move and re-order codes to better reflect the emerging analytic structure. In the end, the code structure included slightly over one thousand codes—not an unusual number for a large PhD dissertation project per my experience with other grounded theorists participating in the Grounded Theory Club (Schreiber, 2001a).

Memos and diagrams. Memos record and extend analytic thinking (Corbin & Strauss, 2008). I used memos for descriptive summaries and interpretive thoughts about individual participants, codes, relationships between codes, questions for theoretical sampling, methodological thinking, reflexive thinking, and ideas relevant to the study or writing process. I often supported interpretations in participant and code memos with quotes or references to originating data. At the final analytic stages I reviewed and sorted memos as a means to integrate the theory (Corbin & Strauss, 2008). I also used code lists and developed diagrams to gain a more abstract perspective of important codes and their relationships, and integrate the theory.

Identifying context using the paradigm. Corbin and Strauss define context according to their philosophies of symbolic interactionism and pragmatism as, "the sets of conditions in which problems and/or situations arise and to which persons respond through some form of action/interaction and emotion (process), and in doing so it brings about consequences that in turn might go back and impact upon conditions" (Corbin & Strauss, 2008, p. 88). To help novice researchers identify context, they offer an optional analytic tool called the *paradigm* (referred to as the "axial coding paradigm" (Strauss & Corbin, 1990, 1998) or "the coding paradigm" (Strauss, 1987) in previous guides). I used this tool to consider relationships between contextual factors and process (inter/actional or emotional responses) by using it as a heuristic for thinking about data or codes in terms of the central problem, causal and contextual conditions, responses (inter/actions and emotions), and outcomes (consequences). It also adds value by providing a language familiar to researchers and follows the logic people use in their everyday descriptions (Corbin & Strauss, 2008, p. 89). I did not code according to the paradigm as a separate step (as was described in the first two editions of *Basics*, which described axial coding in a standalone chapter (Strauss & Corbin, 1990, 1998)). As the third edition states, any distinctions between open and axial coding are artificial since in reality they happen at the same time (i.e., codes are constantly related to one another throughout the coding process) (Corbin & Strauss, 2008).

Analyzing for process. Having a process as one's core category is a common, but not universal outcome of grounded theory, attributable to symbolic interactionist foundations of the method (Corbin & Strauss, 2008). The central category in this theory was the process of *making your own way*. Corbin (Corbin & Strauss, 2008) defines process in a specific grounded theory sense, as "the flow of action-interaction/emotions that occurs in response to events, situations, or problems. A change in structural conditions [i.e., context] may call for adjustments in activities,

interactions, and emotional responses" (p. 86; see also pp. 95-103). For example, "making friends" can be understood either as a singular one-time act, or as something that occurs in many variations under the many different conditions within a particular empirical setting—the latter representing process. Importantly, for a study involving developmental disorder, "Process is often described in developmental terms such as phases or stages, implying a linear or progressive nature to it. However, not all process is developmental or progressive" (p. 98). Alternatively, it can be described as sequences or series of action/interaction or emotion. I analyzed process by noting conditions that appeared to change with time, and how parents' responses changed as a result. I also sensitized myself to process by paying attention to how parents' evolving symbolic interactionist understandings influenced their responses differently over time.

Analysis of other data types. As Corbin (Corbin & Strauss, 2008) points out for other data types such as memoirs, "the analytic process is the same as it is with interview data" (p. 222). Thus for document data, I applied open coding and the other analytic methods described above.

Rigor

I use Guba's (1981) four generic criteria for trustworthiness here as a framework for summarizing the strategies and procedures that were used to ensure rigor, because they continue to be so highly influential in qualitative research. First, strategies to meet the criterion of *credibility* (that truth value is established, in terms of participants' perspectives) included reflexivity (see *Role of the researcher*), triangulation by data type (see *Data collection*), member checking (Appendix G), and peer review (Lincoln & Guba, 1985) (in which I checked the plausibility of my ongoing analysis with committee members). Second, the criterion of *transferability* (the extent to which findings can be applied to other contexts) was addressed by providing thick description of parents' shared situation in this report so that readers can judge for

themselves how comparable the setting is to theirs. Third, *dependability* (evidence that repeating the study can lead to the same findings) was promoted by following the methods of Corbin and Strauss closely to link interpretations back to the original data (see *Analysis*), maintaining a detailed audit trail, and providing detailed rationales for methodological decisions (see Appendices C through G). Fourth, *confirmability* (neutrality, where findings are not influenced by researcher biases) was achieved by self-awareness and reflexivity (see Appendix C).

To further ensure rigor, the grounded theory methods of Corbin and Strauss (2008) were adhered to closely. This includes verifying the consistency of the analysis and interpretations with the original data throughout the research and writing process, even as it progressed to higher levels of abstraction. I have suggested the optimal criteria for judging quality of this study in Appendix M (*Appropriate criteria for evaluating grounded theory*).

Ethics

This study was reviewed and approved by the Hamilton Health Sciences/Faculty of Health Science (HHS/FHS) research ethics board (REB) at McMaster University, and subsequently by the REB of an anonymous participating board of education. I have described the specific measures taken to ensure respect for persons and the other overriding principles of ethical research elsewhere in this chapter (Methods) and at the beginning of Chapter 4 (Findings).

CHAPTER 4: FINDINGS

This chapter presents the complete findings of this grounded theory study, which was aimed at developing a substantive theory of how parents of children with autism make their own way to intervention. It is divided into three sections. Section 4.1 provides a description of the sample of interview participants and documents whose data were analyzed. Section 4.2 provides a descriptive account of primarily external elements that parents commonly described contributing to their problematic situation of having to navigate autism-related intervention. Section 4.3 provides the core theoretical explanation from a symbolic interactionist perspective of the central social psychological[2] process that accounts for how parents navigate intervention aimed at resolving autism-related concerns—which I have labeled *making your own way*. Two appendices contain supplemental analyses that build on the theory of *making your own way*, but do not fit within a symbolic interactionist framework. These include an explanatory account of situations where parents seemingly neglect to take action (Appendix K), and a framework for involving parents in intervention according to their stages of readiness (Appendix L).

I have taken measures in this report to protect the privacy and confidentiality of participants and organizations. In referring to participants I either use descriptors (e.g., "one mother who had immigrated to Canada in the last ten years"), or pseudonyms (false first names, e.g., "Sarah"). To reduce the potential of identifying participants through multiple attributions leading to deductive disclosure (Kaiser, 2009), in some cases I used mixed pseudonyms to refer to the same participant with multiple instances of data. Likewise, I refrain from identifying organizations, agencies, or school boards where they have been identified by name or

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[2] As the grounded theory approach and the theory of symbolic interactionism used in this study are rooted in sociology, *social psychological* here implies an effort to explain and understand human processes from a sociological rather than a psychological perspective.

implication in participant quotes. I have referred to several specific organizations, agencies, government ministries, and web sites in referring to publicly available information when describing context. Codes (labels for concepts derived from the data) are indicated in the text by italics; wording of some codes varies slightly to ensure agreement with the subject of the sentence (e.g., *making your own way* also appears as *making their/her own way*).

SECTION 4.1. Description of the sample

The data sources for this study include interview participants and documents. Here I describe the attributes and characteristics of both the parents and professionals who make up the final sample of participants interviewed, and the more influential documents that were used.

In the case of parent participants, I collected most attribute information in the pre-interview phone survey, which includes information about their children with autism. In the case of professionals, I collected all attribute information in the primary interview. The purpose of presenting this information is to portray the range and variability of select characteristics relevant to the parent experience and action that are represented in the sample—specifically, what numeric locations or categorical points along a range of possible variation for each characteristic (e.g., which child ages, which ethnicities). This may help in making interpretive judgments about what conditions or situations the findings presented in subsequent sections are transferrable or relevant to. In addition, since all the attributes described here have an influence how parents' experience the central process of *making their own way*, their summary provides insight into the variation in experience that was captured, including outliers or extreme cases of interest.

Parent participants

The primary parent data comprise 35 transcribed interviews averaging 90 minutes duration with 32 parents, three of whom participated in a second full duration interview. These mutually

agreed supplemental interviews provided opportunities for answering further questions and providing some longitudinal follow-up on relevant life events. Several parents shared additional information outside the planned survey and interview interactions, usually by email.

There were 6 parent participants who consented to participate but never completed a primary interview. One of these opted not to participate because of a confidential conflict of interest. Two stopped responding to email or phone communications prior to completing the pre-interview phone survey, while three stopped responding after completing the survey. Although these parents never communicated their reasons for withdrawing, the lack of communication suggests it may not have been a black-and-white decision and that they wanted to keep their options open (during recruitment I requested participants to explicitly communicate their potential intention to withdrawal). Even among parents who ultimately participated in a primary interview, there were sometimes long delays before individuals would respond, which they usually explained was due to the chaos they faced in their lives. Thus in all of the latter 5 cases, it is plausible that the parents considered themselves too busy or experienced life events that interfered with their ability to participate further. All six parents were generally initially enthusiastic to participate and supportive of the study up to their withdrawal.

Excluded from the above count is one professional volunteer who was also the parent of a child with autism, and who shared extensive experiences as a parent in her interviews. She was not surveyed, and is therefore not included in the attribute data presented below.

Child characteristics

Number of children with autism per family. Four (12.5%) of the 32 parents interviewed had multiple children with autism—three families had two children with autism (two families had twins with autism), and one family had five children with autism (note, multiple families in

Ontario have 5 children with autism). In the case of the mother with five children with autism,

some data regarding a few of her children are missing; thus the totals in Figures 4.1.2 and 4.1.3

amount to less than 39.

Severity. Parents were asked to describe the severity of each child with autism regardless

of DSM-IV-TR subcategory (i.e., Asperger's syndrome, pervasive developmental disorder not

otherwise specified [PDD-NOS]), and to preferentially report what a diagnostician may have told

them. In a few cases where there was a clear discrepancy with information the parent provided

after the survey or when the parent indicated she was uncertain, I used details from the primary

interview to categorize severity. These numbers are summarized in Table 4.1.1.

Table 4.1.1. Numbers and proportions of 39 children with parent-reported severity of autism.

Severity of autism	Number (percent) of children
High-functioning (including Asperger's)	9 (23)
Mild-to-moderate	4 (10)
Moderate	6 (15)
Moderate-to-severe	12 (31)
Severe	8 (21)

Children's ages. The distribution of children's ages at the time their parent contributed to

the primary interview is shown in Figure 4.1.1, which illustrates a somewhat consistent

representation in this study of parents with children aged between 2.5 to 8.5 years, or 10.5 to 13

years. Owing to the varying severity of children's autism in this study, the developmental ages of

these children (and the corresponding parenting challenges experienced) would have a different

distribution. The age distribution in Figure 4.1.1 is partly influenced by the fact that more severe

autism is generally diagnosed at younger ages than high-functioning autism (i.e., the youngest ages were more predominantly children with moderate or severe autism).

The three oldest children (≥13 years) descend from the two most *seasoned* parents recruited in this study—defined according to the length of time a parent spends navigating autism intervention (see Figure 5, and *Interval between diagnosis and the primary interview*, below). Two of these were 13 years old while the oldest child was almost 18 years old.

Children's age at diagnosis. The distribution of children's ages at the time of diagnosis is shown in Figure 4.1.2. Since a diagnosis is necessary for parents to enroll their child to receive some types of funded services, earlier diagnosis is preferred because it allows parents to coordinate some forms of autism intervention to begin earlier. Age at diagnosis therefore provides an estimate of the efficiency of the diagnostic process experienced by different parents. Efficiency of the diagnostic process is determined by many upstream influences culminating in the final positive diagnostic assessment, including characteristics related to the parent's perceptiveness, which may depend for example on knowledge of red flags; characteristics of the child, including the severity of their autism and the signs they manifest; and characteristics of the elements in the system (structures, policies, professionals) positioned to detect autism (e.g., trained community-based professionals), refer appropriately, and conduct diagnostic assessments.

According to the standards of practice at the time of this study that are suggested from Figure 4.1.2, the Ontario system is capable of diagnosing many cases autism as early as age 24 months and occasionally slightly earlier. The median age at diagnosis was 36 months. High-functioning children, however, are known to be generally diagnosed older (Matson et al., 2008). Indeed 3 of the 4 oldest children in Figure 4.1.2 are high-functioning. But there is high variation

among high-functioning children, with diagnoses ranging from as early as 32 months, and 5 of 9

cases diagnosed before age 4.

Children's age when parents first perceived a developmental concern. The age when

parents first perceive a developmental concern in their child (Figure 4.1.3) marks the beginning

of the process of *making their own way* when they start constructing understandings of their

situation and navigating the system accordingly. It therefore defines the first point in the time

interval parents that parents spend navigating the system before successfully obtaining an official

diagnosis. It is influenced both by the parent's pre-existing knowledge of developmental

milestones and the signs of autism, interactions with people who may have this knowledge, and

by the nature and severity of the signs the child manifests. Among the parents interviewed, the

median age at first concern was 23 months, and ranged from 7 months to 6 years of age (73

months). Common times when parents first perceived concerns were at 11-13 months (19% of

cases) and 22-24 months (25% of cases); in 36% of cases, age at first concern was after age 2.

Interval between parents' first concern and age at diagnosis. The interval between

children's age at their parent's first concern and the age when they received a diagnosis of autism

(Figure 4.1.4) generally represents the time that parents spend navigating the system to

successfully obtain an official diagnosis. This was influenced by numerous factors such as the

seriousness of developmental concerns and parents' sense of urgency, life events that may affect

parents' time for pursuing action, parents' navigational skills and decision making (and

sometimes apparent luck), organizational aspects of the system in a parent's particular region,

parent capacity to pay for private assessment, the training and responses of professionals, and

behaviors or responses of the child during interactions with professionals. The process of

obtaining a diagnosis took a median of 12 months, including 1 year or less in 50% of cases, and

as short as 2 months in 11% of cases. In another 11% of cases, however, parents reported it taking longer than 3 or more years. The child for whom it took longest to obtain a diagnosis (6 years and 3 months) was also one of the two oldest children at the time of diagnosis (age 10 years and 4 months)—this parent described experiencing a highly frustrating fragmentation of services in seeking help for her son who had several comorbid conditions.

Interval between a first diagnosis and the primary interview. The interval between the first diagnosis of autism in a family (some families had multiple children diagnosed with autism) and the date of primary interview (Figure 4.1.5) provides one possible measure of the length of time a parent has spent navigating intervention, or *making her own way*. In other words, it represents the amount of experience a parent has had. This interval was primarily influenced by the recruitment materials, in which I specified that prospective parents' first child should be diagnosed in the preceding five years to be eligible. All parents except 4 met this criterion (2 additional children of qualifying parents aged past five years between recruitment and the primary interview). Figure 4.1.5 illustrates that parents across a spectrum of stages up to 6 years post-diagnosis were interviewed, the earliest being 5 months post-diagnosis.

I decided to interview 4 *seasoned* parents—defined as parents who had been navigating autism intervention post-diagnosis for over 6 years—in order to increase variation in the sample, which in turn made it possible to define the central process of *making your own way* more comprehensively. I interviewed these parents between 6.75 and 14.25 years post-diagnosis.

Interval between first concern and the primary interview. The interval between the parent perceiving the first concern (with her first-diagnosed child) and the primary interview (Figure 4.1.6) provides an alternative representation of the time parents spent *making her own way*—one which is perhaps more informative because it includes the important period spent navigating

prior to diagnosis. Similar to Figure 4.1.5, Figure 4.1.6 shows consistent coverage of parents at different stages, at least between earliest interval of 9 months and the interval of 6 years 7 months post-first–concern. For the 4 most seasoned parents (≥104 months), the post-first– concern interval ranged between 8 years 4 months and 15 years 11 months. The outlying parent at the 100-month interval had endured the longest delay between perceiving her first concern and obtaining a diagnosis for her child.

Parent characteristics

      Recruitment source. I recruited parents from numerous sources, listed in Table 4.1.2.

Table 4.1.2. Recruitment sources.

Recruitment source (demographic advantage provided)	Number of parents
Autism Treatment Network, Toronto Site (broad southern Ontario catchment, some rural coverage)	13
Autism Ontario, four regional Chapters (southern and northern Ontario coverage)	9
A regional Board of Education (increased socioeconomic coverage)	5
Response to news coverage of research in The Toronto Star (coverage of an additional Ontario region)	2
Response to handout left at private school for special needs	1
Response to poster presentation at international conference	1
Response to word-of-mouth from a personal mutual contact	1

      Geographic origin. Parents from 13 of Ontario's 51 regions participated fully in this study—listed roughly from west to east, and south-central to north (number of participants in

parentheses): City of Brant (1), City of Hamilton (6), Halton Region (2), Peel Region (8), City of Toronto (6), York Region (1), Durham Region (1), City of Kawartha Lakes (1), City of Ottawa (2), Grey County (1), Simcoe County (1), Muskoka (1), and Nipissing District (1).

Regarding urban-rural classification, 7 (22%) of the 32 parents lived in an area distant from (>50 km) major city centers (Hamilton, Mississauga, Toronto, or Ottawa) where a greater variety of specialty medical and developmental services could be accessed. Parents from these areas often described traveling to major centers to access one or more services. Four of 32 parents had relocated from another area in the 5 years prior to recruitment specifically to have better access to services, although none crossed the rural-urban divide.

Ethnicity and religion. For most participants I did not perceive an influence of ethnicity or religion. For 13 other participants, I noted their religion or ethnicity because it became explicitly apparent during the survey or interview, and because it seemed relevant to their experience and actions of navigating intervention. Religion (Christianity) was relevant for one participant who described her strong faith as a source of strength for coping. Ethnicity was relevant was relevant for 11 participants primarily because it because having a different cultural background or "being from somewhere else" influenced some participants' beliefs and understandings of child development, autism, or the Canadian system; limited or expanded their social networks; influenced their communication skills and strategies; or otherwise influenced their social responses and interactions. The study included participants who self-identified as Indian, Chinese, Filipino, Brazilian, Somali, Iraqi, Turkish, Serbian, and Italian.

Occupational status, education, and marital status. When asked about occupational status, 20 of 32 mothers reported they were a daytime caregiver for the child(ren). Of these, 5 were also part-time employed, 1 was full-time employed, and 1 was full-time employed and a part-time

student. Of the 12 non-daytime caregivers, 1 was part-time employed and 11 were full-time employed (one of whom was also a part-time student).

Participants reported their highest educational level achieved as follows (number of parent in parentheses): high school diploma (3), college diploma or certificate (9), university undergraduate degree (15), and university graduate degree (5).

The sample includes 4 single mothers.

Professional participants

The primary professional data comprise 10 transcribed interviews averaging 90 minutes duration with 9 professionals (8 female, 1 male) with substantial frontline experience supporting parents of children with autism. One professional offered to participate in a second full duration interview to answer further questions. Of the professional participants who consented, all subsequently participated in the primary interview.

Geographic origin. Professionals had worked in the following regions: City of Hamilton, City of Toronto, Peel Region, Peterborough County, Nipissing District, and Cochrane District.

Professional experience. Whether in a current or past role, participants shared insights and perspectives from their experience supporting parents of children with autism as the following types of professionals: autism agency manager, family support organization manager, special education teacher, educational director, social worker, behavior therapist/analyst, occupational therapist, speech and language pathologist, diagnostician, nurse practitioner, clinical psychologist, and psychiatrist.

Document sources

The main grounded theory developers all encourage researchers to rely on additional data types[3] beyond interviews, and describe the utility of documents in particular (Charmaz, 2006; Clarke, 2005; Corbin & Strauss, 2008; Glaser & Strauss, 1967; Glaser, 1978; Strauss & Corbin, 1998). The documents I used in this analysis were of five types: books that contained data analogous to parent or professional interviews, books that contained data about context, web sites that contained data about context, movies containing data underlying parent understandings, and national and local newspaper stories that contained both data analogous to parent interviews and data about context. The list below represents only a selection of the influential documents reviewed and analyzed. I reviewed many other web sites, for example, to understand specific regional services. I also subscribed to, or reviewed postings on, several parent list-serves.

I sampled documents about context selectively (i.e., sparingly): firstly, for their utility for illustrating characteristics of major concepts related to parents situation; and secondly, for their relevance to the experience of parents interviewed in this study—i.e., according to indications in participant data that the particular document source had influenced parents. I electronically captured the most relevant data from non-electronic document sources (including movies) by hand as summary notes and transcribed passages saved in NVivo. I saved relevant codable data from electronic documents in PDF format within NVivo.

I analyzed documents containing data analogous to interviews as I would analyze interview transcripts, with the exception that coding was done by underlining and making notes in the margins of the hardcopy. I analyzed documents containing relevant information about the

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[3] Glaser's (1998) phrase, 'all as data' p. 159, is perhaps the best known articulation of the practice of using a wide variety of data types for developing concepts.

context within which parents were situated according to guidance provided by Corbin (Corbin & Strauss, 2008) and by Clarke (2005, 2009), as outlined (see Appendix F, *Analyzing context*).

I used one book, *Carly's Voice* (Fleischmann & Fleischmann, 2012), which contained the account of an Ontario father's experience *making his own way* (analogous to a parent interview). I used another book, *A Mind Apart* (Szatmari, 2004), that contained the reflections and ideas of a professional with expertise supporting parents (analogous to a professional interview).

I used the following books for data about North American-level context relevant to the concepts of *information* (specifically information about autism) and *complexity*: the *Diagnostic and Statistical Manual of Mental Disorders (DSM), Fifth Edition* (American Psychiatric Association, 2013); *DSM-IV-TR* (American Psychiatric Association, 2000); *Autism's false prophets* (Offit, 2008); and *The Autism Book: What Every Parent Needs to Know About Early Detection, Treatment, Recovery, and Prevention* (Sears, 2010).

I used the following web sites that contained data about provincial-level policy context relevant to the concept of *intervention*: http://www.children.gov.on.ca (Ministry of Children and Youth Services); http://www.edu.gov.on.ca (Ministry of Education); and http://www.mcss.gov.on.ca/index.aspx (Ministry of Community and Social Services).

I used the following web sites that contained data about influential discourses, understandings, and philosophies about autism and disability: www.autism.com (Autism Research Institute); www.generationrescue.org (Generation Rescue); http://neurodiversity.com (Neurodiversity Weblog).

I viewed the movie *Rain Man* (released 1988) for data underlying parent understandings.

Figures

Figure 4.1.1. Distribution of children's ages at time of primary interview (39 children of 32 parents).
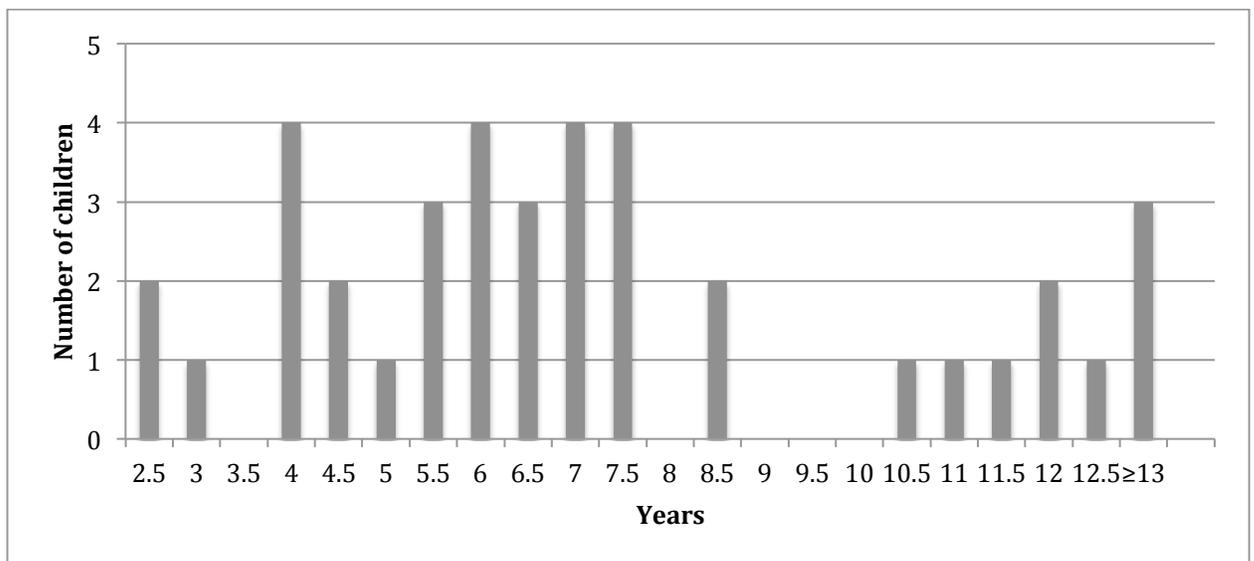
Figure 4.1.2. Distribution of children's ages at diagnosis (38 children of 32 parents).
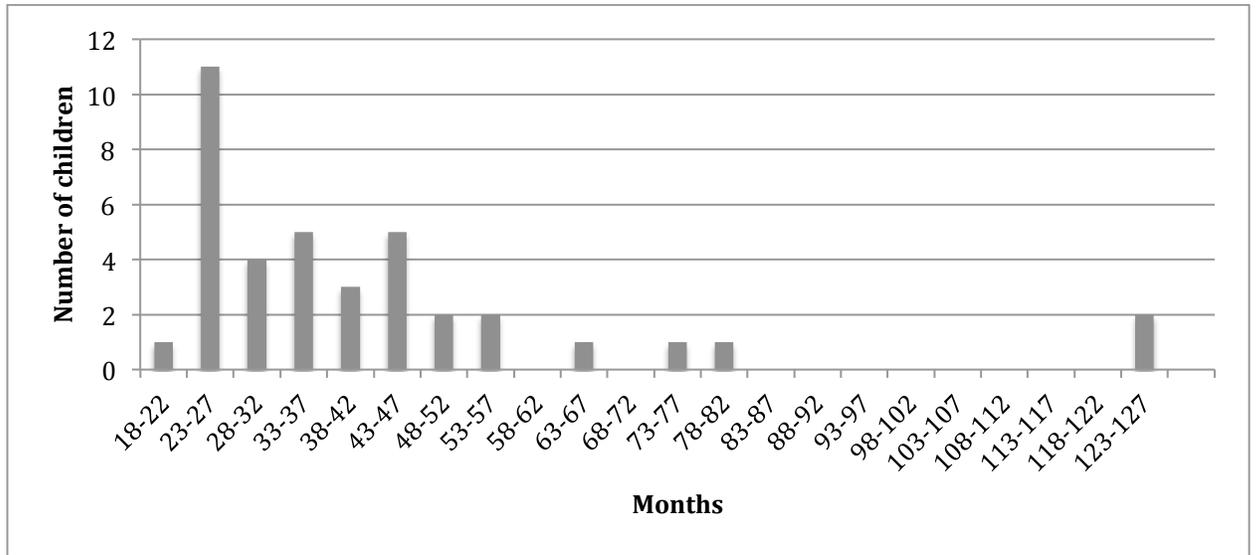
Figure 4.1.3. Distribution of children's ages at first concern (36 children of 32 parents).
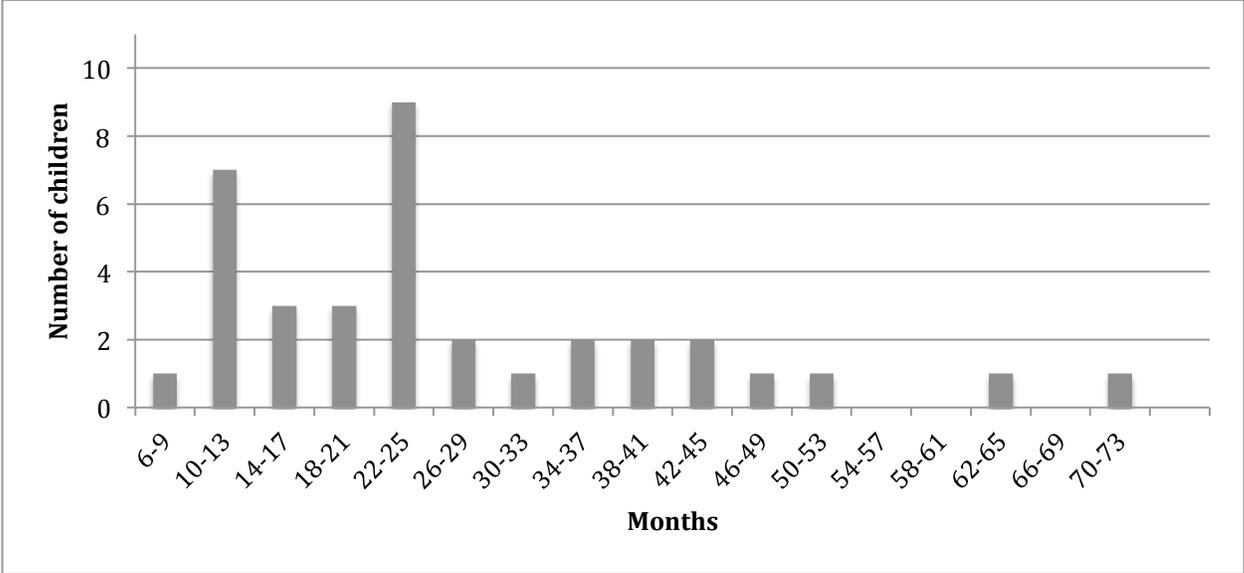
Figure 4.1.4. Distribution of intervals from first concern to diagnosis (36 children of 32 parents).
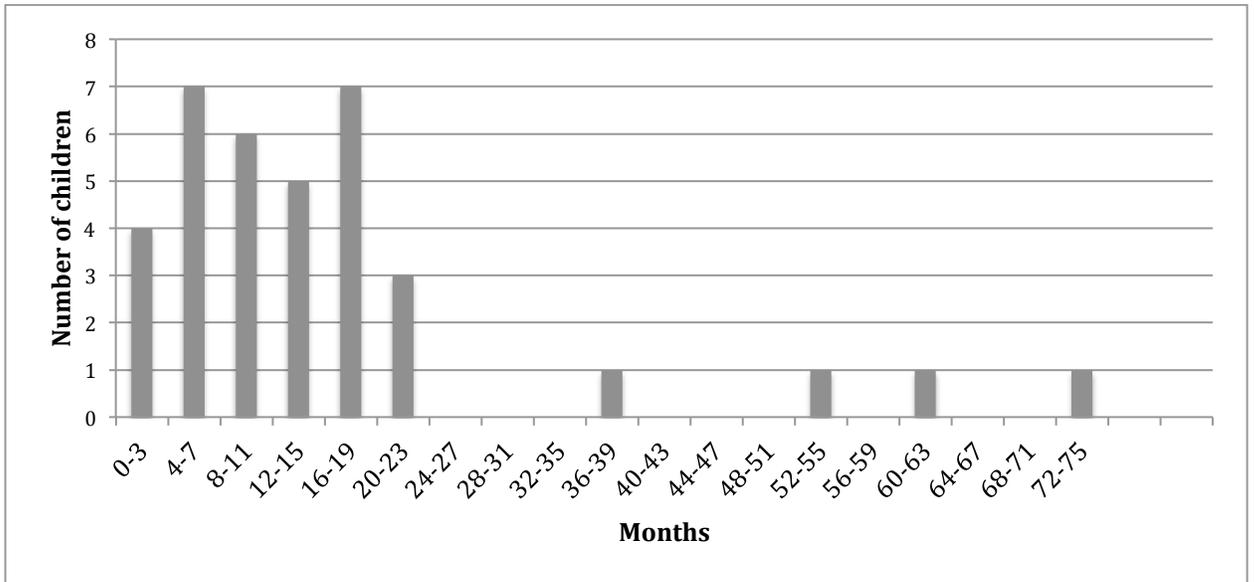
Figure 4.1.5. Distribution of intervals from first diagnosis to primary interview (32 parents).
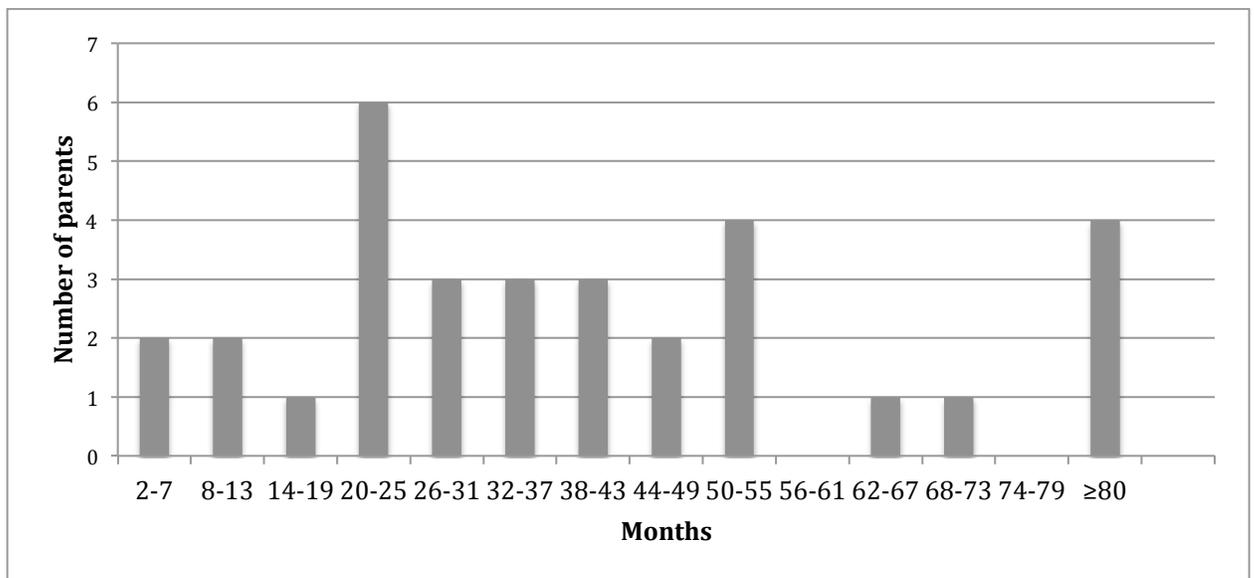
Figure 4.1.6. Distribution of intervals from first concern (for first diagnosed child) to primary interview (32 parents).
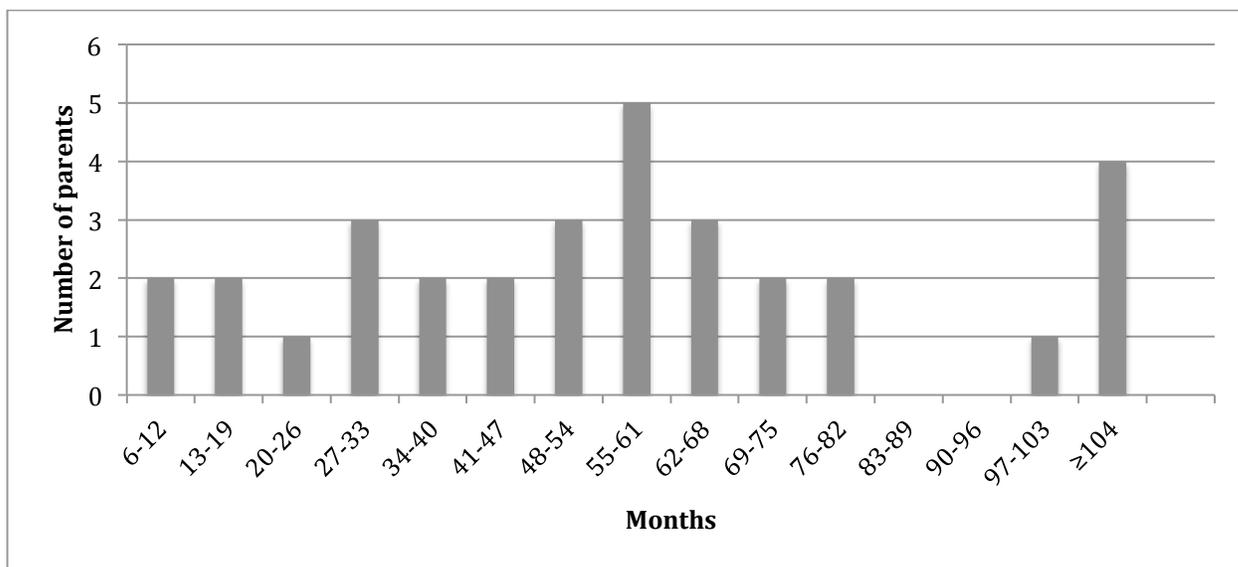
SECTION 4.2. Description of key elements in parents' shared situation

For those who are neither parents of children with autism nor autism specialist professionals, Section 4.2 provides an educational introduction to the autism setting that parents find themselves in as they respond to the challenges of navigating intervention. Here, I descriptively account for the key elements that parents described contending with in this setting. Participating mothers characterized most of these elements as *external*— things outside themselves with which they interact.[4] In describing these elements, I aim to partially[5] portray the common problematic situation (or central social psychological problem) that parents universally described responding to. I have named this situation (the central problem) using words several parents repeated in one form or another, as *having to make your own way*[6]. This label reflects parents' common sense that they have no choice but to draw upon personal resources and initiative to navigate intervention for addressing the autism-related concerns they have defined. I

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[4] An exception is *stress* (under *External obstacles, Burdens*), the only element in this section I define as internal. I account for *stress* in Section 4.2 because of its importance to the situation of *having to make your own way*—it is the most commonly described consequence and the primary reason the situation is harmful for parents.

[5] The broader portrait of the central social-psychological problem, *having to make your own way*, is further developed in Section 4.3, where the personal meanings that parents construct regarding their situation, and the paths of action they take in response to it, are addressed.

[6] It is important to stress up front that the central social psychological problem of *having to make your own way* is problematic in a symbolic interactionist sense—i.e., it is dominated by a perceived need for action motivated by the autism-related concerns the parent has defined as requiring a response. The adequacy of funded support services for addressing these concerns varied from parent to parent, and perceived lack of support certainly adds to the problematic nature of this central situation. But, as outlined in Section 4.3, it is a situation that ultimately requires the parent's involvement and action, regardless of what services are available. The name is not intended to imply a problematic universal lack of case management or other support services for parents; indeed some parents benefited from excellent support services as they navigated care.

have for the most part played down parents' more personal or internal responses to these elements, since I elaborate on this in the symbolic interactionist theory of Section 4.3.

Sandelowski (2000) makes a useful distinction in which the goals of qualitative research can be located along a dimension ranging from predominantly descriptive (where "there is no mandate to re-present the data in any other terms but their own") to more highly interpretive (where "a researcher deliberately chooses to describe an event in terms of a conceptual, philosophical, or other highly abstract framework or system"). Similarly, Strauss and Corbin (1998; Corbin & Strauss, 2008) distinguish between descriptive and theoretical aims for qualitative research. For them, description involves communicating ideas using ordinary everyday language, is more immediately accessible, corresponds more directly to individual experience, and is less abstract, although it still embodies concepts. Description is also the basis for developing theory. Theory, meanwhile, is more interpretive, and extends past description by involving more highly abstracted concepts "that are systematically interrelated thorough statements of relationship to form a theoretical framework that explains some phenomenon" (Corbin & Strauss, 2008, p. 55). Corbin and Strauss (2008) make the point that grounded theory methods can be used to produce either description or theory, with the analysis being cut short when only description is required.

To explain the rationale for presenting the substantive findings first at a descriptive level in this section, and then at a more abstract theoretical level in Section 4.3, I use an analogy of the relationship between the fields of anatomy (the study of body parts or structure) and physiology (the study of body function). Like anatomy, the descriptive account in this section provides an understanding some of the parts, whereas the theory to be developed in the following two sections compares to physiology by providing an understanding of the function and interaction of

those parts. The current anatomy-like section therefore focuses primarily on establishing some of the important concepts and their properties (conceptual characteristics of the concept) that allow a surface-level understanding of the central social psychological situation and why it is problematic for parents of children with autism. Because the aim is to describe the problematic situation, many of the concepts derive from of structural conditions that make up the context within which parents respond. This treatment of context involves an approach to analysis described in Appendix F (*Analyzing context: Situating the study*). Three supplemental analyses involving context are reported in Appendices H through J.

While many grounded theory accounts start off by integrating the theory right from the beginning, I believe a more stepwise development is justified in this case because the world of autism is so complex that it needs introduction. Readers unfamiliar with this world and what is involved for parents navigating autism-related intervention will therefore learn enough about this unique context to better appreciate the theoretical discussion in Section 4.3. I had to learn much of the descriptive story myself through early interviews and documents before building a theoretical understanding.

Sections 4.3 differs in several ways. First, rather than focusing heavily on context, I organize and interpret concepts and their relationships at the person level using the sociological theory of symbolic interactionism, which holds that people act towards things on the basis of the meanings that the things have for them (Blumer, 1969; see also Appendix D, *Revising the research question*). Thus, I introduce and develop several new concepts pertaining to how parents construct various understandings or meanings (within the sub-process of *adjusting to the need to navigate intervention*) and other concepts pertaining to parents' responses or actions (the sub-process of *taking action to pursue intervention*). Finally, there is more emphasis in the next

section on providing theoretical statements about the relationships between concepts, including between structural conditions described in Section 4.2 and the meanings and responses of parents.

The description of structural conditions in Section 4.2 is not, however, without any reference to the meanings parents construct of them or the ways they respond. Returning to the previous analogy, just as with an anatomy textbook whose primary objective is discussing structure, it is impossible to avoid any mention of function, or in this case theoretical statements about relationships. Thus, the line between descriptive content and theoretical content is arbitrary and imperfect in places. For example, in a few instances I have theoretically integrated some of the different elements of context with each other within this section. The predominant emphasis on description, however, is useful because it establishes valuable structure and allows readers to gain basic familiarity with the substantive area, which can serve as a frame of reference for the more abstract theoretical discussion presented later.

The problematic external elements of parents' shared situation that are described include the different forms of *complexity* that complicate parents' paths, the numerous specific autism-related *concerns* that parents interpret to be problems they need to respond to, characteristics of the many available *interventions* including aspects of *information about intervention*, the forms of *external obstacles* that parents encounter in pursuing interventions, and ways of conceiving of the *burdens* imposed on parents. Some of these concepts will be further developed in the later sections as they are related to parents' meaning-making and responses. The concepts themselves are not new. The way I define them (often informed by participants' words) and describe how each manifests in the situation of parents of children with autism, however, provides some new ideas and perspectives. The aim of this section is to introduce the language used in later sections to refer to the salient structural conditions and other aspects of parents' problematic situation.

Complexity

Complexity is a concept that has different meanings in different contexts. In the case of parents of children with autism, complexity is a pervasive characteristic of numerous elements parents interact with (e.g., the disorder, intervention, information) that substantially complicates the situation of *having to make their own way*. By complicating their understanding and action, complexity leads to added work, delay, anguish, and ultimately burden for parents navigating intervention. It is therefore one of the problematizing aspects of *having to make your own way*.

The elements of parents' shared situation characterized by substantial complexity (i.e., main sources of complexity) invariably include the following:

- Information (about autism, about intervention)

- Concerns parents define and respond to (autism itself, specific related concerns)

- Intervention (health and other systems; public or private)

- Skills required to respond (role requirements; for pursuing information or intervention)

- Interactions between any of the above

To illustrate the pervasiveness of complexity, I will briefly outline the multiple elements of parents situation that they experience as complex. First, parents usually experience the complexity of *autism* itself, as they struggle to develop their understanding of the disorder. This includes complexity that is fundamental to the disorder itself (i.e., independent of information about autism), and complexity of the information parents use to develop their knowledge of it. Second, there is complexity associated with the numerous specific autism-related *concerns*, or problems, that each parent must work to understand and struggle to respond to through intervention. Third, parents must learn about an assortment of complex *interventions* for addressing each concern, and navigate complex systems of care to obtain or implement them.

Fourth, in seeking interventions, parents often encounter multiple *external obstacles* that they must overcome. Finally, from beginning to end, parents' job requires a wide range of complex and demanding *skills*, many of which they must learn or develop in very little time.

The rest of this subsection on complexity portrays the complexity of autism itself. The other sources of complexity are described further in the subsequent subsections.

Complexity of autism itself

Autism (also known as autism spectrum disorder, or ASD) is a condition that has been defined and delimited in many ways since it was first described. A current concise definition that may be more stable than earlier definitions describes it as "a neurodevelopmental disorder with impairments in social communication and a pattern of repetitive stereotyped behaviors. Onset is early in childhood and the presentation changes with development over the lifespan" (Stelios Georgiades and Peter Szatmari, personal communication, September 14, 2013). Indeed, parents interviewed for the study reported seeing signs of autism in their child as early as 7 months (Figure 4.1.3: *Distribution of children's ages at first concern*). What this definition does not convey is the complexity of autism, partly due to the subtle and variable ways it manifests across children and across the lifespan. As a result, a more advanced level of understanding of the disorder is necessary for a parent to sufficiently comprehend their child's situation compared to parents of children with most other health conditions.

Parents rapidly expand their understanding of the disorder as part of an important process of adjusting to their situation, which in turn helps ready them for pursuing action, as is outlined in Section 4.3. Understanding autism is such an important early priority for parents beginning on their journey because it refines their subsequent response, helping them to focus their energies productively and efficiently. Ultimately, and regardless of their philosophies on autism, most

parents develop a deep enough understanding to be able to see the world through their child's eyes, at least to some extent. As one professional reflected, for parents to be in the best position to interpret or use information about intervention "it's also important to understand context, which in this instance is the inner world of the child with ASD, so mysterious yet so familiar at the same time" (Szatmari, 2004, p. 136). Some parent support agencies are aware of this and offer workshops for new parents that introduce them to important information about the disorder before covering information on how to intervene.

The aspects parents describe learning about or knowing with respect to autism include the developmental cues or red flags that signal the possible presence of autism, the definitions for and differences between the various forms or classifications of autism, the many different behaviors that are characteristic of autism at different stages of development, how autism can affect the child's processing of sensory information and in turn how this may explain specific behaviors, how autism can affect the child's cognitive processing of information and how this may explain behaviors or experiences for the child. Often parents also learn something about the neurology or neurobiology of autism and how it explains children's psychological processing. In some cases, parents familiarize themselves with the additional fields of epidemiology, genetics, imaging, pharmacology, and so forth. And each field has its own set of basic principles that parents can, and sometimes do, learn something about to give themselves better foundations on which to build their understandings. The complexity of autism knowledge is thus partly characterized by the considerable volume of information that parents must assimilate to form a coherent understanding. This information is used to grasp a situation that has profound implications not just for their child but for them as parents. Meanwhile, the early period when

parents' learning needs are greatest is usually when they are withstanding the most severe emotional demands and psychological adjustment.

Learning about autism involves a complex process of integrating multiple forms of learning from multiple information sources. Peter Szatmari (2004) illustrates this in the context of explaining how important it is that parents first learn about the disorder because understanding the child's perspective is key to their implementing treatment programs and sifting through further information; such understanding ideally includes the principles and theories that have been used to explain autism (pp. 136-137):

> *The first thing we needed to do for Alice [a mother named in Szatmari's book] was to help her enter Trevor's [her son's] world at his own level. Alice needed to understand what went on in Trevor's mind, how he saw the world and experienced all its vicissitudes of change and challenge, the constant swarm of sensations and chaos and the patterns seen in the most unlikely places. Over time, Alice watched Trevor very closely, especially in his play activities and how he spent his time. She also watched him in his playgroup at the library, where she took him once a week to interact with other children. She talked to team members about the meaning of certain behaviors. She learned that Trevor had a different set of priorities, a different set of values from the rest of us.*

As with many parents interviewed, Alice's learning (she also read about autism) involved close observation of her child and a two-way checking in with professionals. This was key to her piecing together how autism's noted strengths and deficits, learned at an abstract level, came together in her individual child. Parents thus integrate varied information to create intense and concrete personal meanings of autism.

Numerous parents (and even several professionals) made a spontaneous metaphorical comparison between the sophisticated intellectual work involved in understanding the disorder and the work of earning an undergraduate or graduate university degree. One mother referred to what it feels like processing her child's transitions:

> *"You know what, it evolves on it's own. You never know what's going to happen. The child is teaching you. You see it in your kid—I see it in my son now. It's like I'm in a*

> *university and I don't know when I'm going to be graduating. I'm telling you, that's how I feel—every day I'm in a classroom. He's teaching me something every day."*

Thus, learning about the disorder never stops because every developmental or externally imposed transition the child passes through elicits more sides of autism, each requiring additional efforts to make sense of in the context of autism.

The ongoing learning involved in developing one's understanding of autism for parents contributes to its complexity. Learning is ongoing for several reasons: First, research knowledge about autism evolves so rapidly that ways of understanding and even defining the disorder has historically changed substantially over periods of every 15 years or so, the time over which most parents witness their child transition from diagnosis to early adulthood. Second, every transition that a parent's child passes through, whether due to physiological development (internal) or to external change (e.g., entering the school system), has the potential to trigger new problems (or non-problematic idiosyncrasies) that the parent uses to refine her image of the disorder. A third, less important reason for parents' understanding to continually evolve is the variation with which autism manifests itself—every child with autism is unique and there is no universal or common behavioral presentation—something that parents soon come to understand contributes to its complexity as they eventually observe how other children manifest differently.

To further characterize how the complexity of autism (and of the process of understanding it) is partly attributable to rapidly evolving research knowledge, I present in Appendix H (*Analysis of context: Evolution and translation of autism research knowledge*) an analysis of the rapid historical evolution of our collective understanding of autism and how its constantly changing nature is fuelled by the gradual translation of the ever-expanding base of research knowledge, referring to the case of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM) as a partial but representative illustration.

Concerns

Concerns refer to any circumstance attributable to a child's autism that the parent subjectively defines or perceives to be sufficiently problematic for her to want to take action to address—whether it affects the child, parent, or family. Concerns, which can invariably be traced to one or a series of triggering events or signs of a problem, often start as nagging suspicions that something might be wrong, but ultimately cross a threshold of certainty and seriousness that motivates the parent to pursue action. Consider, for example, any parent's threshold to seek a formal medical opinion on behalf of her child. Concerns are also the logical targets that any intervention or action is directed at resolving. They can be general (e.g., autism itself) or specific (e.g., need for toileting skills). Some autism-related concerns, such as parental depression or marital breakdown, can be partly attributed to influences beyond or preceding the child's autism, which then become exacerbated by it (e.g., pre-existing depression, or marital differences that the mother felt existed prior to the child's autism, but which became magnified by stresses of autism). While parents often described specific concerns in limited functional terms, they also talked about the more profound implications that general and specific concerns could have. In this section, I describe *concerns* as parents often portrayed them descriptively (i.e., as external realities), rather than from a symbolic interactionist perspective (i.e., as internal constructions).

Overall, the seriousness of the *concerns* that most parents of a child with autism experience across their child's lifetime is, as some parents described, an order of magnitude greater than what parents of typically developing (non-autistic) children experience. Stories of exceptionally difficult situations were common. Some concerns are serious because of their potential for devastating outcomes, such as the parent who recounted her very real fear for the lives of her other children during a stage when one of her sons with autism was particularly depressed and

violent. Other concerns are serious because they are more immediately troubling, such as one mother's anguish at the fact that her son's lack of language meant he could never communicate to his mother about his suffering and unmet needs, which she experienced through inconsolable screaming tantrums that could exceed two hours. Sometimes there is a chain of concerns that ultimately affects the family and parent. One mother described how autism led early on to marital concerns that soon resulted in divorce, which led a loss of income and serious financial concerns that reached the point of bankruptcy; meanwhile, all her burdens combined had contributed more recently to deterioration in her health including hypertension and heart problems. Often, concerns have potential future consequences that are ill-defined or hard to predict. Some parents articulated their anguish and fear about the potential distant outcome of their child's social disability and lack of autonomy, which they saw could lead them to live in isolation or be victimized as an adult after the parent is no longer around. The remainder of the chapter provides many more examples of concerns and of how parents respond to them.

The term *concern* was chosen in preference to the term *problem* because the former implies a subjective perspective (i.e., the parent's perception) of a sufficiently serious problem that calls for personal response (even if just alerting someone else to intervene). One can thus be concerned for others' health, for one's own wellbeing, or for important relationships. *Concern* was also the word that parents used most frequently, without prompting in phone surveys and interviews. The remainder of this subsection simply describes further what characterizes autism-related *concerns*, while Section 4.3 explains how the parent comes to formulate them.

Breadth of parents' perspective. Importantly, *concerns* are defined from the parent's perspective in the theory of *making your own way*. This differs from the typical clinical perspective, which tends to define concerns in terms of impaired function that needs restoring.

While restoration of function is generally assumed to be highly important to individual patients, parent caregivers are concerned with a much broader set of implications with respect to autism. These include many considerations such as the child's social deficiencies, proclivities, and abilities that affect his or her prospects for long-term happiness; child behaviors that affect family wellbeing; threats to parent marital health; financial burden; the parent's ability to work or otherwise define her identity apart from special needs; and other concrete hazards to parent psychological and physical health. From the parent's perspective, *it is not just the child who has autism*. This was reflected in interviews, where mothers tended to use the first person singular (I) or plural (we) when describing events or experiences, such as receiving the diagnosis, where one might expect to designate the child as the subject.

On the one hand, parents did articulate concerns for those aspects of their child's functioning that clinicians typically value, including the child's ability to attend and succeed in school, self-care skills, communication skills, and immediate social functioning skills. But parents often further articulated how such functional concerns were in the service higher order concerns that reflected a more compassionate parental perspective. These more abstract concerns included the desire that their children live a socially fulfilling life, or have the capacity to autonomously advocate for themselves and avoid victimization once the parent is no longer able to advocate on their behalf. These are the problems that parents ultimately seek intervention to resolve. The goals of intervention that parents described therefore ranged from solving very particular problems to answering more abstract or distant ones.

Because parents' experience corresponds to a broader set of concerns related to autism, their perspective more closely reflects an interdependent systems perspective, which clinicians can learn from. As one of the most highly experienced professionals interviewed observed:

> *"We tend to think of the kid, and what the kid's strengths and difficulties are. But really we need to see an entire system, and the family's interaction, and the quality of their life, etcetera. It's a really important part of it."*

Aiming to target the breadth of the concerns listed here, therefore, may have greater promise for improving outcomes for each individual element of an interdependent system affected by autism—the family, the parent, and certainly the child.

Multiplicity of concerns. For any child with autism, the concerns were generally numerous and varied widely. The array of concerns that parents had to contend with were even greater when families had multiple children on the spectrum—13% of the 32 families in this study had two or more children with autism; the greatest number was five children with a confirmed diagnosis. Considering that each concern usually calls for its own set of actions to find a solution, the multiplicity of concerns represents a centrally important source of *complexity* for parents. The different categories of concerns that interview participants discussed at any length are listed in Table 4.2.1, which is intended to illustrate the diversity of problems parents direct their energies at resolving. Note that while a distinction is made between concerns that affect primarily the child and those that affect primarily the parent and family, child-specific concerns generally also affect the parent and family in profound ways (for example, consider the effects of a child's sleep disturbance).

Table 4.2.1. Categories of autism-related concerns defined by parents

Concerns primarily affecting the child	• Social
	• Communication
	• Sensory
	• Comorbidities (e.g., seizures, infection)
	• Motor

	• Sleep
	• Problem behavior
	• Nutritional; digestive
	• Non-functional symptoms (e.g., hand-flapping)
	• Fundamental presence of autism
	• Self-care; toileting
	• Peer – community integration
	• Child mental health (anxiety, depression; happiness)
	• Academic
	• Vocational; life success; fulfilled potential
	• Autonomy; self-advocacy; independence in adult life
Concerns primarily affecting the parent or family	• Parent mental health
	• Financial: family finances, funding eligibility
	• Marital health
	• Family function, crisis

For each specific concern, the parent must first detect or perceive it, then define it, which often involves further research to develop sufficient understanding to know how to respond; in turn, responding to each concern can entail finding and implementing multiple interventions. Each concern therefore often requires substantial time and resources to resolve. Moreover, new concerns constantly arise over the development and life-course of the child, right into adulthood. The trajectory of the parent's own life is therefore transformed to varying degrees by the multiple calls for them to respond.

Early concerns. Parents almost invariably defined their earliest specific autism-related concerns before the child's diagnosis, even prior to being aware their child had autism. Initial pre-diagnosis concerns most often involved delays in speech or language. But numerous other problems—commonly arising between the ages of one and three—also led parents to seek a professional opinion, including lack of social interest (sometimes first appearing as a hearing problem because the child would not respond), behavioral problems (e.g., severe tantrums, resistance to switching activities), sensory issues (e.g., "difficulty with clothing"), delays in motor or other developmental milestones (e.g., not progressing to walking despite eight months cruising), or the worrying loss of social interest or speech (i.e., regression). In other cases, initial concerns were related to comorbid conditions related to the child's autism such as seizures, depression or anxiety (especially for children later diagnosed as high-functioning or with Asperger's syndrome). Some concerns started at birth, such as premature birth, for which the child was clinically monitored over the early years and the parent was warned about the possibility of developmental delays including autism.

These initial autism-related concerns are generally what lead parents to first seek interventional help. Occasionally parents immediately recognize that initial specific concerns indicate the more general concern of autism (e.g., those who noticed red flags which they could match to a checklist for autism), but for many this is not the case and they remain blind to their child's autism. For these parents, seeking help for initial specific concerns brings them to interact with professionals or social contacts who may provide them with the first suggestions that her child has a general developmental disorder such as autism. Parents thus generally formulate their early concerns as part of another process of *coming to understand their child has autism* within the initial stage of the process of *adjusting* (explained in more detail in Section 4.3).

Once parents come to understand their child has autism, they are generally in a position to perceive and define many new concerns requiring intervention (see Section 4.3). The early period, therefore, quickly becomes a time when parents experience the most numerous concerns.

Long-term concerns. When parents who had adapted to the reality of their child's autism were pressed about their long-term concerns (sometimes framed as the ultimate goals for intervention, or long-term fears), they most commonly articulated that it was for their child to be happy, both now and into the future. Some parents further described their child's happiness as depending on both social connectedness (e.g., the adult child having friends who take an interest in and look out for him or her), and autonomy (i.e., the adult child having self-awareness of, and an ability to communicate and defend his or her own interests). One parent of twins with autism described the concern she had for meeting the needs and abilities of the more socially-inclined twin, which entailed considering intervention that would best foster his social abilities to ensure his continued happiness through to adulthood. Another parent, Dawn shared one example of how concern for a child's long-term happiness can sometimes be acutely painful:

> *"It was my husband, came downstairs one night and he was crying. And he said our son had said his prayers that night and prayed for friends. And, he said that hurt more than hearing him say, 'I wish I was dead.' Because there's nothing worse in the world than wanting your kid…[knowing that] your kid wants to have friend.' "*

The general long-term concern of the child's happiness resembles what most parents would wish for a typically developing child. Similarly, because autism is a developmental disorder, many of the specific concerns such as toileting or speech, are also functions that parents of typically developing children wish to see at a certain point for their child—although because these functions usually develop reliably with normal parenting through typical development, they never truly qualify as concerns. It became distinctly apparent from talking to parents interviewed that many of the autism-related concerns they defined are also fundamentally connected to the

process and experience of parenting. There are therefore aspects of the parent's interventional *response* to concerns (i.e., pursuing or implementing intervention) that parallel the process of parenting, especially when addressing a child's social connectedness and autonomy.

Ontario parents interviewed generally understood that their best chance of achieving both short- and long-term goals was to direct intervention at the immediately-concerning and specific aspects of their child's function early on. This was the case for one mother whose approach to addressing the major concern of her daughter's social connectedness was, "getting her as much help as we can, early on, so that she's more equipped to be in that environment." This focus on intervening to address specific functional concerns was even true for many parents who held pro-biomedical beliefs or used biomedical therapies (discussed further below under *Information, Complexity of intervention-related information*). Most of these parents came to understand through the process of *adjusting* (Section 4.3) that intervening to eliminate autism (i.e., a more general concern, and a goal of some forms of biomedical therapy) was unrealistic. The more commonly sought forms of *intervention*, described below, further reflect the fact that parents predominantly focus on specific functional concerns over concerns about autism globally.

Intervention

Intervention is used here to refer to any therapy or modification the parent or other agent (such as a professional) may consider to address an autism-related concern. While most interventions parents pursue target the child, they may also target parent or family concerns either directly or indirectly. *Intervention* includes therapies that modify the individual (child or parent), or accommodations modifying the environment. While child diagnoses or assessments are not interventions themselves, they are often needed to obtain or plan certain interventions. Therefore pursuing such assessments is considered a step along the way in pursuing intervention.

As mentioned previously, parents' long-term concerns related to their child's happiness are often connected to the process and experience of parenting. Similarly, some solutions that parents in this study described pursuing to address their fundamental concerns blur the lines between intervention and acts of typical parenting. As an example, one parent explained why community sport was an intervention: "We consider, as strange as it sounds, hockey to us is a therapy," because this gave her sons with autism a means to develop social "allies" within their small rural community who would look out for them. What can qualify as an autism-related intervention is therefore potentially very broad, and is defined flexibly by the parent.

Multiplicity of interventions. As described above, parents must contend with a multiplicity of concerns surrounding a single child with autism. Each specific concern, meanwhile, can require one or multiple interventions. Navigating each intervention usually requires a substantial amount of *work* (see *Burdens*, below) from the parent. The total time, energy, and other resources that most parents dedicate to navigating and implementing intervention can therefore be a significant burden. Some of the wide-ranging categories of interventions that Ontario parents in this study commonly discussed navigating include the following:

- Behavioral and educational therapy (e.g., applied behavior analysis [ABA], intensive behavioral intervention [IBI])

- Medical (medications, specialist care)

- Speech and language therapy

- Occupational therapy (including sensory therapy)

- Social opportunities, community activities

- Screening, assessment, testing

- Diet, nutrition, digestive (e.g., Gluten-free, casein-free, soy-free [GFCFSF] diet)

- Biomedical (e.g., Hyperbaric oxygen therapy, chelation, antimicrobial)

- Alternative therapy (e.g., horseback riding, music)

- Technology (e.g., iPad, communication device, social learning software)

- Academic

- Respite (funding, care options, camps)

- Financial relief

- Parenting strategies, approaches

- Parent training (courses, books, therapist interactions)

- Marital therapy

The list of professionals with whom parents must interact to access the many interventions their child needs is also extensive. It is not uncommon, for example, for a parent to have to coordinate the services of nine or more different professionals within a given year (e.g., a clinical psychologist, developmental pediatrician, speech and language pathologist, occupational therapist, behavior therapist, psychiatrist, naturopath, gastroenterologist or other specialist, and multiple educators). Most parents reported very little in the way of case management to help them with this task. Travel to the many appointments generally consumes substantial amounts of time, especially when even preparing to leave the house can be a challenge.

Public vs. private intervention

It is important to distinguish between interventions that are publicly-funded versus interventions accessed and paid for privately, because each of these two categories has its characteristic set of challenges related to accessing or pursuing intervention. Briefly, *publicly-funded* intervention options are pursued by virtually all parents of children with autism, resulting in inadequate supply-and-demand due to inevitably limited funding. This in turn underlies

problems of access such as difficult qualification criteria and notoriously long waitlists. Many *private* intervention options, meanwhile, are either not an option for those parents with less access to financial capital, or they are extremely expensive and involve significant financial sacrifice for the families that find a way to pay for them. *Going private* therefore often involves difficult decisions or resourceful efforts to obtain financing.

Both the problems are due to the fact that the most sought after forms of intervention, whether public or private, are extremely resource-intensive and expensive—in the case of publicly-funded intervention, provincial ministries are challenged to allocate sufficient funds to support quality intervention for the number of families who need it. A problematic characteristic shared by publicly-funded and private intervention is the regional variation in the availability and quality-related aspects of different intervention options.

Readers unfamiliar with autism intervention or the Ontario context can consult Appendix J for a summary of the prominent forms of public and private intervention parents navigate.

Information

Information is an important concept that, like *intervention*, is conceived of broadly within the theory of *making your own way*. Parents can interact with information in many basic ways such as seeking, attending, ignoring, miscomprehending, appraising, filtering, dismissing, misinterpreting, understanding, or internalizing. While experience itself is not considered information because it is internal, observable aspects of things or people in one's environment do qualify as information for purposes of this study. Many parents, for example, described the observations they made of their child in terms of *information* they gathered from the child.

Parents internalize a selection of the information they interact with to form *knowledge*. Three basic information topics (and knowledge) are relevant to parents *making their own way*:

- **Information about the child** (relevant for the process of *adjusting to the need to navigate intervention*, including *defining concerns*, addressed in Section 4.3)

- **Information about autism** (described primarily within the Complexity subsection, above)

- **Information about intervention** (described below)

  Sarah's comment reflects the expansiveness of these topics:

  > *"I've said to people before: navigating this world of autism—in order to learn about IBI, learn about the biomedical [interventions]; learn about autism in general; live; you know, try to figure out your own child—all of that can be so completely overwhelming."*

Note that these topics are not strictly exclusive of each other. Parents learn about autism, for example, by observing aspects of if from their child. And an understanding of many interventions depends on developing a certain level of knowledge of autism. And, to some extent, the information that a parent seeks (or the knowledge she develops) regarding both autism and intervention is specific to the child.

Information sources. Information always has a *source* that is external to the parent, and each major topic has its own characteristic set of information sources. Information sources can be inanimate or living and, like information itself, parents interact with them in numerous different ways. Sources of information about the child commonly include the child him/herself (whose behaviors, characteristics, or communication the parent observes), professionals (who often share verbal or written information, formally or informally), and reports (including assessment scores, copies of referrals, etc.). Sources of information on the two topics, autism and intervention, are more diverse. For both autism and intervention, they include web sites, list-serves, books, other parents, professionals, autism agencies and other organizations, autism conferences, and to a lesser extent, popular media, including TV, newspapers, and magazines.

Arguably the most influential information sources specifically about intervention are clinicians. Clinician-provided information about intervention includes three types: information about options, recommendations, and referrals to interventions or services the parent was not explicitly seeking. These categories of clinician-provided information about intervention vary by the extent to which they are directive to the parent about the best path of action—information about options is the least directive and most neutral, while recommendations convey varying degrees of professional opinion or judgment about what the parent should do, and referrals are generally most directive. Although recommendations and referrals have additional purposes, these categories qualify as informational from the parent's perspective because they usually help her construct ideas or knowledge about the next actions to take in addressing autism-related concerns (specific referrals that parents actively request may not qualify as information).

Complexity of intervention-related information

Information about intervention represents a major informational topic that parents must spend substantial amounts of time interacting with—in addition to information about the child and about autism. This includes any information that leads the parent to know what to do next to address a concern. Thus, *intervention-related information* includes much more than information about specific treatments, and is often used for processes other than decision making.

As Appendix H (*Evolution and translation of autism research knowledge*) demonstrates, *autism*-related information is derived mainly from the translation of research evidence and is both expansive and complex. *Intervention*-related information is also expansive and complex for similar reasons: a proportion of it is derived from rapidly evolving research knowledge from multiple fields, which is translated at varying rates and through varying channels to changes in professional practice and system policy. But intervention-related information is even more

complex than autism-related information for several reasons. First, its content is broad and diverse—it can convey not just knowledge for understanding intervention itself, but for how and where to get it, how to implement it, and other considerations the parents incorporate into their plans for responding appropriately to address concerns. Information about how to implement intervention includes *parent training* (through courses offered by agencies, advice from individual professionals, or guidance from books), which provides interventional strategies that parents can use to address concerns (such as toileting or communication) directly themselves.

The sources of intervention-related information and ways of interacting with it are also diverse. The most important reason for complexity of intervention-related information, however, is that much of it is not based on traditional research evidence, which has resulted in varying perceptions of its credibility (see Appendix I: *Analysis of context: Credibility of information about intervention)*. I describe parents' positions regarding credibility issues, next.

Ontario parents' positions regarding credibility of intervention-related information

Parents ultimately occupy positions regarding the credibility of information throughout the process of *making their own way*—just as we all have some sense, however vague, of whether or not to believe any information presented to us. In this study, parents' positions regarding information varied in several ways—by being ambiguous or clear, naïve or informed, and trusting or critical. Also, their positions regarding the credibility of information about biomedical interventions supported by nontraditional forms of evidence generally changed over time, as parents learned to be less trusting and more critical of information and information sources after *seeing what is involved* (see Section 4.3, *Adjusting to the need to navigate intervention*). Of the 25 parents who discussed biomedical information and intervention, six expressed highly critical positions that I will refer to as anti-biomedical, six communicated neutral or apparently

ambiguous positions, twelve parents who had had time to adjust to the demands of navigating

retained favorable positions towards information about biomedical options that I will refer to as

pro-biomedical (although there were varying tendencies among them to be critical of such

information), and only one parent seemed uninformed about what *biomedical* meant. Each of

these positions will be described further, starting with the anti-biomedical position.

Terri, who never used biomedical treatments, eloquently summarizes the frustrations

generally shared by the six anti-biomedical parents regarding how the flawed credibility of

biomedical information was problematic for parents:

> *"The one thing about reading was, I had to stop. It got overwhelming. One, a lot of it is outdated. And two, I get frustrated by people that can write stuff that isn't scientifically proven, like the vaccination theory, the gluten-free-casein-free diet. You know, all these biomedical things. As a parent, you'll try anything, and you'll grasp at any straw. And I get frustrated reading this stuff not knowing that there's any true outcome and that parents are willing to spend money to buy the books to try these things, to do anything to help their child. And I don't like people that write books that say that they think they can cure autism. It's very misleading and it's misguiding. And I was getting overwhelmed. And I just said to my husband, 'I can't do any more reading. I'll be very selective in what I do read and what I believe. And I'm not going to get caught up in all this,' because there's so much out there."*

Terri became overwhelmed by the complexity that the existence of biomedical information

introduced to the informational landscape, because this added further demands for navigating

intervention—i.e., the necessary skills and the time for filtering and appraising expansive and

conflicting information about intervention—which she did not feel equipped to meet at the time.

Another parent expressed several times how upsetting such information was, not just for how it

had affected her, but for how it complicated the lives of parents of children with autism generally.

Several anti-biomedical parents also described another problem, caused specifically by the

biomedical narrative that vaccines cause autism. These parents found themselves in a position of

having to defend themselves against implicit or explicit accusations of negligence for having

vaccinated their child. In doing so, they used arguments about the lack of credibility of anti-

vaccine information to do so. At least one parent described how the need to defend herself from family was a subtle source of guilt and pain.

Three of the anti-biomedical parents came to their more evidence-based position only after having earlier embraced biomedical intervention at a time when, in the words of a parent, they were "desperate for a panacea." Each of these parents described feeling misled. Basra provided frank insight about her early inclination to be uncritical of information:

> *"You see, at that time, I was in a very tough position. I was gullible. I was a mother who was confused. Like, if anybody came to me and told me they had a cure for my son, I would just believe it and pay for that person. Because I was in a desperate position, not realizing what I was getting myself into. Because, I don't know, my mind was just not working properly, I guess. I don't know. Because if some doctor just posted some information online telling me he can do this, or he can fix that, probably the next day, he would see me at his doorstep, you know. That was me. And I think that's why some doctors are taking advantage of someone like me."*

Another mother who never used biomedical interventions herself lamented the vulnerability of parents, "we're desperate, and we will jump on any bandwagon."

Ambiguous or neutral positions held by parents took more varied and often subtle forms. Some parents' positions were apparently ambiguous simply because they were less informed or reflective about the controversial nature of intervention-related information, and generally less critical of the information they encountered as a result. Other parents whose positions were ambiguous, however, were better informed about biomedical information and associated credibility problems. One such parent had never adopted any biomedical options, but "wouldn't rule out doing them" if they felt a treatment applied to their child's specific case. Another mother was warned by a family member about the lack of scientific evidence for the biomedical approach, but felt she was "smart enough to take it for what it's worth and evaluate the information that [her naturopath] is giving me," and refused, for example, chelation therapy.

Pro-biomedical positions were also varied. Four of the twelve parents in this category were

highly trusting and much less critical of biomedical messages, including explanations about the causes for autism and the logic of targeting pathophysiology to "cure" or "recover" the child with autism. One such parent, for example, discontinued vaccinations for her children once she learned about their role in causing autism from biomedical information. Another mother described how her husband, who was still less accepting of their son's autism, was *willing to try anything*: "So anything that says it's biomedical, he just wants to try it…And there's so many people saying that this treatment has worked for them. But that's what I try to tell him, that we can't do *all* the treatments…maybe it's not going to work for us. But then his point is, 'What if it does? We still need to try it.' "

Other pro-biomedical parents, who described refining their ideas about biomedical information as they gained greater awareness and knowledge of the contextual influences described above, arrived at a position that was conflicted by two opposing tensions. The first tension derives from the fact that, as one parent observed, there are so many challenges in conducting any "clinical trial that involves children with autism where you can control all of the variables," which underlies the general lack of traditional research evidence about most interventions. But, as the same parent reasoned, "Does that mean we ignore all of the anecdotal evidence that's, you know, coming from parents where they say, 'Oh, it made a difference.' And what's the harm if you can replace it with whole foods, and supplements, and all good stuff. So you don't know. I don't know. I still don't know, but we're doing it." In summary, even informed parents are motivated by the need to take action and proceed with decisions—often to address functional concerns, while considering the potential for harm—and in the absence of sufficient tradition research evidence, they will resort to nontraditional evidence.

The opposing tension involves informed pro-biomedical parents' awareness of flaws in the

credibility of some biomedical information. For example, numerous of the generally pro-biomedical parents described critically appraising biomedical information, and sometimes expressed skepticism about traditional biomedical messages—especially about the possibility of curing autism. Sarah, who paid out of pocket for the services of a biomedical practitioner, was direct about not believing there was a cure for autism. She recalled two reasons for not following her practitioner's recommendation that her son try hyperbaric oxygen therapy: "the cost was the big one on that. And I think my skepticism on that treatment kicked in there too."

Other parents besides Sarah reported vacillating between skepticism and adoption of biomedical interventions, making their final decision by considering the financial cost and the potential for harm; if these were minimal, they would "give it a try." One can compare this, by analogy, to the high-level sports coach who prescribes multiple changes (e.g., dietary changes, use of supplements) in an attempt to gain whatever advantage they can for an individual athlete, prioritizing the most credible information but still making numerous decisions in the absence of conclusive traditional research evidence. One parent expressed her skeptical information-centered approach as follows: "I need to be fully versed in what it is I'm going to do to my son or offer my son. So when I went for biomedical treatments I knew exactly what to ask for."

For the most part, pro-biomedical parents seemed non-hostile towards mainstream intervention or information supported by traditional research evidence—although some expressed resentment towards traditional professionals or agencies for leaving them uninformed about biomedical options. As one indication of the reliance and faith that most such parents had for mainstream intervention, some described using biomedical treatments to treat functional concerns (rather than to treat causes), positioning their biomedical approach as compatible and supportive of traditional behavioral intervention such as IBI. For example, Linda—whose son

was diagnosed by a DAN[7] naturopath as allergic (not just sensitive) to milk, gluten and soy—

reflected on what she saw as the main benefit of the GFCFSF diet:

> *"After seeing the improvement that taking out the gluten, taking out the dairy, taking out the soy, our logic was thinking, 'OK, if you're not physically feeling well, then you're not ready to learn. You are not ready to do anything. You just want to curl in a ball and not do anything.' So if we can combine his biomedical part of it—make him physically feel better—then the IBI therapy that we are working on has a better chance of succeeding because he's feeling well, and he's good to learn."*

Even the most faithfully pro-biomedical parents felt the need to be at least somewhat

selective about what biomedical options to trust. Colleen, for example, described the need to be

critical in choosing a biomedical practitioner: "You go off the mainstream to DAN, and then

within DAN there's also differences too. So it's kind of like you have to keep filtering. It never

stops…because it's not mainstream they [DAN practitioners] can kind of go their own way."

By appreciating the range and complexity of parents' positions, readers may avoid overly

simplistic judgments about parents' reasons for adopting biomedical or other non-mainstream

options. In Section 4.3, I provide further understanding of how parents make sense of and

respond to their complex informational landscape as they seek to address autism-related concerns.

External obstacles

External obstacles threaten the success of parents' efforts to navigate intervention and

address autism-related concerns. They are impediments that delay or reduce the efficiency of

intervention, slow its implementation, or altogether block access to partial solutions a parent may

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[7] DAN (Defeat Autism Now) practitioners offer and promote biomedical intervention. A list of DAN practitioners was previously available on the Autism Research Institute (ARI) web site, but was removed in 2011 for liability reasons because the ARI could not guarantee the quality of recommended practitioners (see http://www.autism.com/treating_finding). While most parents who identified DAN practitioners in this study would have accessed the ARI web site before this date, this list has been propagated by some local information sources.

be seeking. They are another set of challenges—in addition to the numerous sources of complexity already discussed—that the parent must overcome in *making her own way*.

Multiple parents likened the problematic situation of *having to make their own way* to struggling to stay afloat in a large body of water (see *Stress, Causes, Obstacles leaving parents feeling helpless*, below). Thus, obstacles sometimes feel like unexpected waves large enough to overwhelm or swamp parents already struggling. One parent described them as "blows" to be absorbed. They are unexpected setbacks of varying significance that differ in how they affect parents' level of morale, stress, depression, hope, or resolve. And obstacles can be highly frustrating, because the self-sacrificing responses they require seem so unnecessary.

Some obstacles (e.g., waitlists) prompt parents to be proactive, innovative, or persistent (e.g., by designing home IBI programs, persistently following up regarding a waitlist position). This is because the potential consequences of obstacles are so undesirable, including failure to secure a desired intervention altogether, reduced effectiveness or efficiency of an intervention program, ultimate failure in satisfactorily addressing short- and long-term concerns, and exacerbations of the stresses parents endure that may also harm their mental health. Invariably, obstacles increase parents' already high workload as they struggle to overcome them. These extra responses involve sacrificing what are often significant resources—including scarce time, financial resources, and physiological reserves used for coping physically, emotionally, and cognitively—adding substantially to the already high burdens of *making your own way*.

Parents attributed obstacles to two main types of causes, elaborated in the next subsections:

- Limitations imposed by system organization
- Obstructive responses of individual actors within the system

Limitations imposed by system organization

Inadequate supply of funded intervention. Parents attribute some obstacles to how they see the system organized, including rigid policies. The most concrete examples are limitations due to finite provincial budgetary funding for autism intervention programs, making services scarcer than demand. Most parents first experience this upon learning their child needs to first qualify to be eligible for funded IBI, the most demanded form of therapy. This entails assessment in which the child must be "towards the severe end" to qualify (Ontario Ministry of Children and Youth Services, 2006). Several parents described how their child's arbitrarily poor behavior on the day of the assessment was the deciding factor in qualifying. Thus, in addition to provincial policy, access to funded IBI seems to also be limited both by the interpretation and judgment of clinical assessors and how their child happens to respond in the moment. Thus, limited availability of funded intervention leads the system to limit access by setting requirements that are obstacles for parents, including narrow qualifying criteria, proof and documentation requirements, long time-consuming application forms to complete, and long waitlists.

Lack of diversity in intervention options. Another limitation imposed by the system, perceived by some parents, is the narrow range of intervention options that Ontario offers. Due to high variability from child to child in the concerns that may need to be addressed, multiple approaches are needed in autism and no one form of therapy can be appropriate for all children. As a result, several parents commented how certain available options were simply not suitable for their child. Moreover, the narrow selection of available options left some parents feeling unable—unless they could afford private options—to construct a comprehensive treatment plan suited to the unique needs of their child. The lack of variety in officially-funded options is primarily driven by Ontario's policy of using scarce budgetary resources only to fund evidence-

based interventions. There were examples from parents of children with autism from less researched subgroups, such as girls or higher-functioning individuals (including children with Asperger's syndrome), for whom it was especially challenging to find appropriate therapy options (especially social skills groups) matched to the child's needs.

Several parents, however, described an agency- or region-specific lack of choice. For some, the lack of options was attributable to the perceived limitations in the training of the professionals at their agency. Corroborating this, some participating professionals acknowledged that there could be prominent variation in the training or knowledge of professionals from agency to agency, which would lead to differing experiences of certain services according to where parents took their child. For example, one parent described how the therapists from her local agency were apparently trained to use only a limited approach to therapy, which they used from session to session regardless of the fact that it was not ideal or even appropriate for her particular child. Other parents for whose child such therapy might be an appropriate match would likely experience intervention from this agency quite positively. Further contributing to these inconsistent experiences, according to one professional interviewed, is the fact that some regions in Ontario simply do not offer as many services as others. One parent hypothesized that the professionals in her area were less knowledgeable about diverse approaches because their distance from a major urban center limited professional exposure to new ideas and knowledge. Whether agency-specific or region-specific, parents experience these limitations to available intervention options as barriers to realizing their child's potential. As one parent who migrated to a different city to access different school services expressed, "the sky is *not* the limit when you're limited by a school board."

Organizational limits to intervention effectiveness. Some limitations imposed by the system were obstructive in the sense that parents perceived certain aspects in the way a funded therapy program was organized as flawed to the point of undermining its effectiveness, imposing frustrating limits on the possible benefits for their child. In other words they reduced the efficiency of intervention—indeed, many parents used the words "not efficient" to describe the undermining aspects of funded intervention. The most universally experienced causes of inefficiency attributable to the way the system is organized are waitlists. Parents frequently commented, "everything has a waitlist." This is a problem because, as most parents in this study were aware, starting intervention early is known to be important for maximizing effectiveness. For this reason, parents complained that the invariably long two- to four-year waitlists for funded IBI sabotage both the benefits that can be achieved with the collective public resources directed towards this therapy, and parents' desire to improve their child's trajectory as early as possible.

Other parents perceived that the high demand for non-IBI services—such as preschool speech and language or Ontario ABA programs—led some agencies to organize their therapy into blocks of 6, 8, or 10 weekly sessions. As these parents observed, agencies discontinue therapy in between sessions (sometimes for durations equal to the blocks of therapy they provide) as a deliberate strategy to free up spots, allowing more parents to get their children into the system and effectively keep waitlists down. The disadvantages of what these parents viewed as a rationing system, however, were significant. Parents experienced the interruptions to therapy as interfering with their child's bonding with therapists—necessary and time-consuming process for many children with autism favor routine. Thus, some children did not develop the bonds necessary to participate attentively and meaningfully in therapy until a block of sessions was almost over. Parents observed their child needing to restart the bonding process in the next block,

sometimes with a new therapist, rather than capitalizing on the rapport and ability to focus they had developed in the first block. This was especially problematic for skills that could only be transferred and retained by a child through long-term consistent and uninterrupted exposure. One parent who had the luxury of paying for private speech therapy between blocks lamented that this was still inefficient because, "they [the private therapists] kind of don't know where the other person left off, or he has a hard time getting used to their technique again." Some agencies try to address this interruption by providing parents with materials and encouragement to continue working with their child at home between blocks; but this assumes the parent has the time, energy and willingness to follow through, which may not be the case (see Appendix K, *Supplemental analysis: Staying*).

   Fragmentation (lack of integration) of services. Several professionals described how the fragmented nature of Ontario's system poses fundamental obstacles to accessing ideal care. Partly owing to the complexity of autism-related concerns, there are at least four provincial ministries in Ontario that provide services and care for individuals and families affected by autism: the Ministries of Child and Youth Services, of Health and Long-Term Care, of Education, and of Community and Social Services. One professional observed that this has resulted in a degree of overlap, competition, and lack of coordination between organizations and professionals from different parts of the provincial system. Depending on the region, parents often experience services as disjointed as a result. The most prominent example is the gap between diagnostic services and intervention services. As a second professional pointed out, the main funding for each of these two services is assigned to designated organizations in each region, so that organizations providing diagnostic services may not have a mandate to provide intervention services even if they have the expertise. While in some regions both services are accessed in the

same place, numerous parent participants from other regions described experiencing a chasm-like gap after diagnosis. As the following quote illustrates, this gap leaves parents to fend for themselves in coordinating or implementing their own intervention according to the resources available: "And *everything* I read said you have to do something now. So there was this two-year gap. And so the only person that could fill it was me. There was no therapy that we could pay for." The main consequence, therefore, is a substantial increase in the navigational challenges that parents face, which in turn contributes substantially to their high levels of stress—a central problematic experience that is elaborated on further in subsequent sections.

A third professional highlighted how the lack of integration results in less efficient and less effective intervention because the system "takes an acute care model, rather than a chronic model," which is what is really needed to address the lifelong condition of autism. Thus, "people are taking an episode in the autism trajectory and treating that, and then once that's done, they then pass them on to the next service or agency." As a result, it is up to parents to learn about, navigate, and often finance, a complexly fragmented *sequential* web of services as they struggle to maintain some continuity in the intervention and support their child receives.

In addition, fragmentation results in logistical obstacles that parents experience more concretely. One professional quoted a single mother to illustrate:

> *"Why isn't everything in the same place? You know, I take the TTC [public transit in Toronto]. I have to come here for the assessment. I have to go to another place for my speech and language. I have to go to another place for my medical care. I have to go to another place for my hearing test. It's really difficult for me as a single mum."*

By "really difficult," she was referring to the time and energy it takes to dress a sensory- and transition-averse child with autism to leave the house, and perhaps line up to wait for a bus, for each and every appointment. More fortunate two-parent families described coordinating each others' schedules with iPhones and taking substantial time off work to shuttle their child(ren) to

appointments, or, more commonly, deciding that one parent needed to give up employment altogether to take on this task. As well as travel, some parents complained that for every agency or organization there can be a four- or five-page intake form to complete, where often they ask for the same information. Another parent complained about the incomplete and sometimes inconsistent information she received from different professionals who did not communicate or collaborate with each other. In the end, the dealing with fragmented services can wear the parent down, as the following parent recalls, "I was exhausted, sort of emotionally and mentally just trying to keep up with all the different things to do for him, and thinking, I don't even know if I'm doing the right thing at the right time."

As one professional noted, autism is a condition where integrated care is especially needed. Not only are parents and professionals acutely aware of the ways that fragmentation make intervention less efficient and effective, but there are stories of how more highly integrated care improves intervention efficiency and effectiveness. For example, one parent who witnessed an OT and SLP work together on her child's apraxia-related speech problem was amazed at the concrete progress they made in a short time.

Censored information due to liability concerns. Parents experienced barriers to obtaining valuable information when organizations or professionals acted to reduce their liability risk. This occurred in several types of situations. The first concerns those parents who are in the early stages of *making their own way,* and still coming to understand their child had autism. Several such parents recalled interacting with various professionals who they believed in retrospect were aware that their child likely had autism but who never explicitly communicated this knowledge. This generally delayed parents' awareness, and sometimes also their initiation of action. Some parents, however, came to appreciate that the reason for professionals not informing them of the

likelihood of their child's autism was that they were not qualified to give a diagnosis and were therefore restrained from making pronouncements. At least one parent reported the professional providing oblique hints, such as by mentioning that their child had developmental "red flags," referring to telltale symptoms of autism. But, as one non-diagnosing professional put it, professionals such as SLPs and educators are not allowed to mention autism because it would be violating a protected medical act for which they could receive a complaint or be sanctioned by their profession's governing body.

Parents or professionals also described liability concerns as impeding the following:

- An organization from avoiding extensive restrictions on a new program for connecting parents of newly diagnosed children with parent mentors, which would prevent paired parents from communicating with each other offsite

- An agency from allowing parents to post answers to each others' questions publicly on the agency's web site

- A school from sharing parent contact information with an inquiring mother who wanted to learn from other parents in her daughter's Section 23 class about the interventions they were using—note, if the mother's daughter had been verbal, this would have been easier to request directly (for example, this mother's typically developing son had previously provided her with his friends' parents' phone numbers)

- A professional from stepping out of her role by communicating or collaborating with other professionals who she knows are part of the family's intervention team (e.g., educators at the child's school)

- Various agencies from providing information about biomedical options, or even that biomedical intervention exists

- An agency from providing information about professionals in a person's area because it cannot guarantee the service they will provide

- The Autism Research Institute from continuing to publicly provide its list of Defeat Autism Now doctors on its web site because it cannot guarantee the service they will provide

The main consequence of censorship in parents' eyes is delay in learning certain facts, which may in turn delay action and the initiation of an intervention, potentially setting back the child's trajectory. Another consequence is that parents must be more resourceful to find needed information. This means turning away from mainstream sources, which can be problematic as one parent attested: "But as a parent you feel like you're getting your information from back alleys, practically, because no official channel wants to tell you anything other than the official line." Thus, the system's failure to provide non-official or non-mainstream information—or even advice on where and how to look for it—contributes to parents' sense of being on their own in *having to make their own way*. A metaphor multiple parents used to describe this aspect of their situation is that of blindly feeling one's way through a maze in the dark.

Obstructive responses of individual actors within the system

Most parents described having access to an intervention they were in the process of seeking blocked by individual actors within the system who acted as gatekeepers—including professionals, agencies, schools, and school boards. Interactions with these actors could be brief single encounters (usually where the parent felt powerless in the face of the actor's authority), or consist of longer negotiations often involving confrontation or conflict. Actors could deny whole requested services or parent-proposed modifications to existing services.

Explanation of how parents respond to the obstructive responses of individual actors within the system are an important aspect of the central process of *making your own way*, and this form

of obstacle is therefore addressed again in Section 4.3. Briefly, parents' ability to overcome

actors' denying them access depends in many cases on having or acquiring perhaps the most

challenging of the many skills required for *making their own way*—the ability to negotiate

effectively. Some parents perceived the prospect of negotiating itself as a formidable obstacle to

overcome, requiring too much time and energy, and leading them to give up or seek other

alternatives. As a consequence of obstructive responses to their requests, parents described

experiencing both stress with the process of struggling to get what they wanted, and exasperation

at the lost solution they had felt was so important for their child.

While there are numerous types of situations where parents encounter individual actors

who deny access to the solutions they seek, there were two general scenarios parents most

commonly described in this study. The first involves physicians whom parents perceive to hinder

rather than help them obtain a timely diagnosis—either by neglecting to take immediate action

on the parent's concerns such as by referring them for further assessment, or by neglecting to

diagnose the child who indeed has autism. The second scenario is where educators, schools or

school boards respond, from the parent's perspective, by opposing their input, recommendations,

or requests for accommodation. Each of these two scenarios is considered in more detail below

to reveal some of the common conditions, characteristics, and consequences that can be useful

for understanding obstructive responses of individual actors in other situations.

Physicians not supporting timely diagnosis

Timely diagnosis is important because it gives the parent access to some forms of

intervention earlier, for example, by allowing the parent to get her child on the waitlist for IBI as

soon as possible. The various paths the parent can take to diagnosis are described in Section 4.3

(*Pursuing a diagnosis*). Different types of physicians may be involved at several points. Family

physicians can be the first point of contact for parents who initially decide they need to take action on concerns about their child's development; family physicians can then decide whether or not to refer the child for a diagnostic assessment. Pediatricians were a second point of contact for some parents, usually after referral from a community-based professional; pediatricians that parents in this study encountered often offered a diagnostic opinion (positive or negative) although this was not always in the context a formal diagnostic assessment. Developmental pediatricians are positioned at or near the end of the diagnostic path for most parents; they generally provide formal diagnostic assessment services in one of the province's designated regional centers. Over half of the 32 parents in this study shared accounts of physicians failing to believe or respond to their initial concerns, and refusing or delaying a positive diagnosis or referral for further assessment as a result.

As an explanation for why physicians tend to arrive at falsely-negative diagnostic opinions as often as they do, one diagnosing professional and at least one parent suggested it could be because physicians' training encourages them to come to black-and-white conclusions based on rigid criteria consisting of yes-or-no checkboxes or ranges on test scores. This in turn prevents some physicians from considering alternative possibilities beyond what test scores tell them, such as by investigating how the child's behavior might be influenced by different contexts. The diagnostic tests themselves, including the Autism Diagnostic Observation Scale (ADOS), are susceptible to false-negatives, especially when the child has benefited from therapy (including the parent's own informal efforts early on!)—as one diagnostic professional noted and another parent experienced firsthand. There were multiple parents who described difficulty getting a diagnosis or referral for assessment because their child did not display some of the traditional signs of autism, especially if their child had high-functioning autism or Asperger's syndrome.

Some of these parents pointed to their physician's likely out-moded training or knowledge as an explanation for why they did not understand that such children could still have autism, especially if they were generalists (family physicians).

Another factor in the resistance to diagnose or refer children for assessment may be a clinical belief that it is not possible to diagnose autism before a certain age. One parent described overcoming one developmental pediatrician's policy of not scheduling diagnostic assessments with children younger than 24 months. Her child was diagnosed at 20 months as a result, one of only three of participants' children diagnosed before age two. Many participating parents, meanwhile, described being aware of, and often seeking medical help for, their child's autism earlier than 24 months, several as early as 12 months (see Figures 4.1.2: *Distribution of children's ages at diagnosis*, and 4.1.3: *Distribution of children's ages at first concern*).

Finally, another possible explanation for refusal to diagnose or refer for assessment, which was described in a minority of parents' accounts, is a phenomenon of *competing to be the expert* in which the professional and parent engaged in a power struggle over who understands the child with the disorder best—something parents experienced with several different types of professionals, and elaborated further under *Facing opposition within the school system*.

One mother, Mariana, described struggling with her family physician. He first dismissed her when she brought her son to him at age 10 months with concerns about his development. At the 12-month check-up the doctor acknowledged there was "a bit of concern" after witnessing one of his tantrums. She recalls:

> *"The doctor said to me, 'Is he always like this?' I said, 'Well not always, but most of the time.' 'Well, maybe he's having a bad day. Bring him back in three months.' It was a lot of that, you know, 'Bring him back. Bring him back,' kind of thing. So finally [at the appointment three months later] I said to the doctor, 'Can you just send me to see somebody because I'm convinced he has autism and I need that diagnosis to get him the help that he needs?' And he again told me I was paranoid. And by this time I was*

> *pregnant again, and he said, 'You know maybe it's just your hormones, and that's why you're so upset,' and all of that stuff. So I then started my quest to find another doctor. And that didn't go too well [despite consuming much time and energy in the later stage of her pregnancy]. So then I finally had the girls, and I was assigned a pediatrician because they were twins. And I asked the pediatrician in the hospital, 'Can I bring my son to you?' And she said, 'Yes.' And the minute I brought him in, she said, 'We've got to send him to a developmental pediatrician because I think that he has autism.'*

> *"...when I did get the diagnosis, I brought him [her family physician] a copy, and I said, 'Here is my diagnosis from a developmental pediatrician that knows what he's talking about.' And he still said to me, 'But he's only two [he was diagnosed at 29 months]. How can he already know that he has autism?'!"*

Mariana's physician not only refused to provide her with a referral after multiple requests, but remained steadfast in dismissing her concerns, which contributed significantly to her sense of isolation. She also complained of not knowing what alternatives she had in the face of this barrier, especially after the frustrating and fruitless search for another family physician. Mariana's ultimate regret, however, was that "if he [physician] would have given me the referral sooner, he [son] would have gotten the diagnosis sooner, and he would have gotten the help that he needed sooner."

Julia described what it felt like to ultimately be refused the diagnosis after making it to the point of a formal assessment:

> *"And everywhere I turned, honestly, I did run into roadblocks. Like the whole [interaction with the regional diagnostic center] thing. I mean, I was so hopeful going there and thinking, "I'm going to get some help for this kid. I'm not going to have to deal with this anymore." And then to be turned away and say, "Oh no, he's a typical child." I was like, "What? If he's really typical, then what's wrong with me? Like, why can't I handle this?" So, it really did a lot of damage to me as a person. Um, I haven't really recovered from it. Like, I don't know if you ever can."*

Elsewhere in the interview, Julia explicitly linked being refused the diagnosis and having nowhere to turn for help with the onset of her clinical depression.

Other parents used words like "downtrodden" or "really shut down" to describe their feelings after false-negative diagnoses. Together, these quotes point to some of the numerous

consequences repeated by many parents who indicated how the denial or delay of the diagnosis affected them:

- Exasperation at being left unable to qualify for intervention

- Burdens of having to cope with their child's problems on their own without help

- Delays to effective intervention, which parents understood reduced the chances of an optimal developmental trajectory or outcome

- Burden of extra work navigating the system to finally arrive at a positive diagnosis

- Harm to parents' mental health in the form of self-doubt, despair, dejection, or aggravation of clinical depression.

Experiencing obstacles when pursuing diagnosis has some similarities and differences to experiencing obstacles in the education system, described next. One key difference to bear in mind is the timing of these two events. Obstacles to diagnosis are generally experienced early on in parents' journey pursuing intervention when they are still learning some of the fundamental realities of autism and the system. By the time parents begin navigating the education system, however, most have had the opportunity to better understand through experience the situation of *having to make their own way*—compare Figure 4.1.2, *Distribution of children's ages at diagnosis*, to the typical age at school entry (57-69 months).

Facing opposition within the school system

Most children with autism first enter school around the same age as typically developing children. Thus for many parents in this study their children started senior kindergarten in the year they turned 5 years old (a few parents reported their child starting junior kindergarten in the year their child turned 4 years old). While often an exciting time, it is also a significant transition for both the child and the parent navigating special needs services in the school system on the child's

behalf. Many parents adapt to this new situation without serious difficulties and come to experience positive constructive relationships with the educators they rely on to promote their child's development. While the aim in this section is to illustrate the nature of obstacles, it is important for readers to bear in mind that there were numerous accounts from the parents interviewed in this study of highly supportive schools and educators, "going above and beyond and meeting the needs of my family," to use one parent's words. In the paragraphs below, I focus on key characteristics of the many parent accounts of their interactions with educators in which they felt they were treated insensitively or that school staff were unresponsive to their concerns.

Conditions contributing to the potential for conflict. Several conditions contribute to the potential for parent-educator confrontation and conflict as the parent seeks accommodations or solutions for her concerns within the school system. Some of these conditions derive from the parent. Most parents of children with autism have an underlying high level of stress from various sources, which often include adapting to existence of their child's disorder, managing child behaviors, and navigating the system. Now with the transition to school, the parent must learn to accept and interact with a new set of professionals who will care for her child for main part of the day. Moreover she knows her child, who in many cases of autism has an aversion to transitions, will be immersed in a completely new context. In addition, she may equate the shift from preschool services to school services with a sharp drop in the intensity of their child's intervention. (Note, while the parent and child must give up types of preschool programming, parents can sometimes rearrange the child's pre-existing IBI or other therapy to take place on evenings and weekends.) Finally, some parents experience distress at the sudden lack of control over and ability to monitor their child's intervention once they enter the much more closed school setting. Overall, the potential for difficulties with this transition, and the fear it will

damage the child's wellbeing or aggravate behavioral problems, can contribute substantially to the parent's already high levels of anxiety and stress. As one parent put it, these high levels of stress predispose many parents to "naturally feel defensive and over-protective," which in turn can lead some parents to getting angry and responding confrontationally more easily.

Other important conditions involve structural realities constraining the school system, which has variable influence on how some individual educators respond. As one professional pointed out, despite the obstacles parents experience, the education system is trying very hard to provide for them. Another educational professional summarized a crucial structural source of the problem: the system simply does not have the resources to develop sufficient capacity—by training or hiring people with the necessary autism skills or experience in every school—to provide consistent and high-quality service to children with autism and their families. As a result, she noted, the transition to school can seem stark: "In preschool, only professionals who are expert in autism are working with you and your kid. Once you hit school, there are people that may or may not have any expertise in autism." In other words, parents' experience of school can vary substantially: some parents will inevitably end up with worse schools or with worse teachers, while others will encounter supportive schools or brilliant educators who seem gifted in working with their child. Experiences can vary even within the same school, both because individual teachers can make a huge difference, and because variation in the needs of individual children result in better or worse matches with the educator or school. For example, among two sets of parents in this study whose children attended the same school, one described being very happy with services and had praise for how welcoming the principal was, while the other couple described experiencing obstructions and unwillingness to include them as partners, primarily

based on their interactions with their son's teacher: "The teacher is very reluctant to modify anything in class because I feel that it means extra work for her."

Competing to be the expert. Multiple professional participants pointed to the resource-constraints of the education system, and the resulting lack of autism expertise in some schools, as an important factor in educators sometimes responding to parents insensitively and apparently obstructing the path to solving their concerns. From the parent's perspective, the problem with lack of expertise is not only that a professional is more likely to make decisions or intervene in ways that they perceive as inappropriate for the child. Rather, lacking expertise is particularly problematic when it also includes a lack of appreciation for the expertise that parents bring to the table. Given that the caregiving parent has usually observed the child more than anyone else and knows their whole interventional history, as many parents reasoned, they were best positioned to define the unique needs of a highly unique child for any previously unfamiliar professional.

Professionals lacking appreciation for their expertise was something parents repeatedly said made them feel disrespected. In the experience of one parent, "They treated us like we were teeny-bopper parents—let me put it to you that way. They were really condescending. It was very bizarre. Because [my husband] and I are educated." But *competing to be the expert* works both ways, and a lack of appreciation for expertise by either side can undermine the potential for positive and collaborative relationships. The same parent reflected on how her and her husband's approach to interactions with educators may have been naïve and undiplomatic, which ultimately contributed to the "unhelpful" relationship with their children's school:

> *"Maybe we could have gone in and faked less knowledge at that time…Maybe if we had gone in and changed the wording, or changed our attitude about it, and said to them, 'It's really important to us that the boys continue to have the opportunity to go [to their IBI program], but that we're open to discussions with you guys of what you feel could help them in their school setting.' Maybe that would have helped."*

By contrast with less expert professionals (including educators, physicians, or other clinicians) who show less appreciation for parent expertise, parents often experienced expert professionals—one's who in their words "get it"— as appreciating the value of parent knowledge and sensitive to the validity of their concerns.

Experiencing opposition when resources and solutions seem accessible. Numerous parents described struggling at various levels against opposition to the solutions they sought for their concerns. Sometimes conflicts arose at the teacher level when the accommodations seemed readily accessible. Maria described how her daughter's Grade 1 teacher responded to her daughter's loss of bladder control at the beginning of school by insisting that she be sent to school in diapers, something Maria found unacceptable. Earlier, Maria had even discussed with the teacher and her daughter's EA the options of either working with her daughter to overcome her fear of the hand dryers in the typically developing children's washroom, or taking her to the designated special needs washroom. Fortunately, after "politely" asserting herself in the office, the principal responded by asking Maria about her concerns. She was able to explain that her daughter had not worn diapers in two years and she did not want her to regress and lose her toilet-training, and that she did not want her to be humiliated when her classmates inevitably found out. In this case, the problem was solved cooperatively. As Maria reflected, however, "Everybody has different needs. And I don't think our school system still adapts to that."

Contradictions to special needs policies. Multiple parents described situations where individual educators appeared resistant to accommodate for special needs, despite such accommodation being explicitly emphasized as a priority within various Ministry of Education, Board of Education, or school-level policies, documents, or verbal assurances. Parents experienced this as a form of betrayal, "I just felt like that wasn't how we were treated in the

beginning at our case conference. Like, we sat at a table: 'Everybody's a team. We're going to work as a team. We respect you.'" Some reflective participants hypothesized that time pressures on teachers or budget constraints at school and board levels contributed to the inconsistencies they experienced between individual educators' responses and the special needs policies.

Experiencing inflexibility, lack of support, and power imbalance. An example illustrates the lack of power one mother experienced when a school principal responded inflexibly and unsupportively on multiple occasions. Kathy, experienced particular difficulty getting her daughter to school every morning during her Grade 1 year. Because of severe sensory issues, she would not wear socks and wore the same set of clothes every day, which her mother washed nightly. Getting her daughter dressed and out the door was therefore always a struggle, and Kathy often had to physically drag her into the van screaming. Aware of her difficulties, a kind EA from the school (and on one occasion the vice-principal) had occasionally helped Kathy's daughter from the van. When the principal discovered this, however, she objected unsympathetically and told Kathy, "You're not going to get any help any more getting your child out. She's not our responsibility until she walks through the front door." Despite her frustration, Kathy responded by avoiding the principal to minimize confrontation. In a separate incident, the principal bluntly refused Kathy's request for an IPRC meeting at a time when she was desperate to find out what was wrong with her daughter—who was only later diagnosed with Asperger's syndrome. This reduced Kathy's general ability to cope, pushing her stress level dangerously high because the principal left her feeling unsupported and powerless at the "lowest point" in dealing with her daughter's problems. It was a time when "there was no way we could go on like that. It was like living in a war zone." In characterizing the unusual severity of her stress, she noted, "I've read that special needs parents [can] have post-traumatic stress disorder."

The added barrier of a non-user–friendly system. Another mother, who described herself

as better equipped than most parents to advocate for educational services because she and her

husband were both teachers, portrayed the potential for encountering substantial obstacles in a

system that was so difficult to navigate: "The school system is crazy…It's not transparent. Not at

all. And this is why we were so motivated to get a diagnosis for [our son], because we knew that

without it we would just get stonewalled all the way. I mean, look how much stonewalling we

get from her [the principal] now. And imagine if he [our son] didn't have anything [as a

diagnosis]. It would be horrific trying to deal with this principal." Related to this, a professional

interviewed described observing how parents with low literacy or English language skills often

experienced greater challenges to overcoming obstacles in the school system, partly because they

seemed to receive less of the information needed to advocate effectively.

Not only do parents need sophisticated knowledge and navigating skills to inform

themselves of the services and processes for accessing them in an unusually complex system, but

they must learn how to adapt their social behavior to match the unique negotiating environment

that special needs parents encounter within the education system.

Confrontation and anguished decisions. As a result of obstructiveness, several parents

recounted how they became torn by the decision to delay or find alternatives to sending their

child to the school in question after interactions with educators led them to perceive the school

environment as too uncaring, or school staff as unlikely to look out for their child's best interests.

Jennifer's son had severe autism and was scheduled to transition from his IBI program run out of

a private school to a kindergarten class at their local Catholic school in September. She described

her concerns about the transition her son faced without an adequate plan:

> *"Basically if I were to just send him to the school, on the first day of school I'd drop*
> *him off to a teacher and an EA that he doesn't even know, with a class of twenty kids.*

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> *And he's used to one-on-one. I don't know how he's going to react. He's nonverbal. He's not going to ask for anything. He's going to probably sit under the table the whole day. I don't want that."*

As her preferred solution, she "thought if I sent one of his [IBI] workers with him for a few days, because he knows them, they can engage him in activities and be that go-between for the EA and [son], make that relationship stronger, faster." The school opposed her idea, although inconsistent information from various sources left her with an unclear idea about what the real reason was. She recalled school staff telling her that "it's a Ministry policy that no IBI staff are allowed on the school grounds." But when she called the Ministry of Education to investigate, she found "no such policy exists." She next asked the school's special education teacher, who deferred talking to her. Her son's assigned teacher was more helpful and offered to consult the principal, but instead the teacher came back with a message relayed from a director at their Board of Education saying simply that it was "not allowed." When she called the Board, they told her "it must be a Ministry policy." Still unclear about what the reason was, she speculated at one point that "it's a union thing" since another professional at her son's IBI program had mentioned this. Yet, Jennifer was also led to believe that some of her non-IBI professionals would be allowed to come to facilitate with the transition (but they were not familiar enough with her son for Jennifer to see this as helpful). Without a definitive answer, and motivated by the strength of her concerns, she continued to pursue her preferred solution by emailing the superintendent at her Board of Education requesting a meeting. "And we got an email back saying that Bennett's therapists were not allowed in the school. And he sent it to all the other Special Education teachers in the Board to let them know that none of these people are allowed at any of the schools."

Without a sufficiently clear reason for their refusal of her request, Jennifer perceived the school system's response as stonewalling and non-transparent, inflexible, and disrespectful. In

addition, she noted, they seemed unable to sufficiently empathize and reassure her about the basic concerns she had for her son's transition from one-on-one therapy to the large class, "I don't know what to anticipate and they don't seem to understand." She contrasted this with the treatment she receives at her son's specialized IBI provider where she feels "well respected," and "even though they're professionals, they totally get it from our point as parents. They respect the fact that we live with it twenty-four–seven."

The consequences of Jennifer's conflict with an oppositional school board included high stress during the negotiating process, followed by an anguished decision not to send her son to the school. Something Jennifer found painful about the confrontational negotiating process was feeling like she was behaving like a "nasty" person, because it was so incompatible with her self-identity. She also described how the process contributed to her stress: "I was a nervous wreck. August was the worst month. I was dreading school…I was physically throwing up, because I was so nervous and so frustrated with trying to get answers and getting people to listen to me." The stress of the conflict with the school board also contributed to an "intense" worsening of her depression, which left her feeling, "really sad and very overwhelmed all summer."

Deciding not to send her son to the school, at least for kindergarten, was difficult because Jennifer had felt it was important to integrate her son with his future classmates in the first year because, "kids are more accepting if they all start together." But the school board had acted as if, "we were just supposed to trust them and just let them do whatever they felt like with our child." But Jennifer and her husband felt the School Board did not have their son's "best interests in mind" because their actions "made me feel like my child's not important." In the end,

> *"The way we were being talked to and responded to, that I just didn't feel like they cared. I just wasn't going to throw him into an environment without any plan put into place. So it was actually a fairly easy decision."*

Although Jennifer had an ongoing relationship with the school, she experienced a disappointing lack of concern after her decision, even from some of the more supportive educators she had interacted with. Despite sending them each an email, "I haven't gotten one phone call, I haven't had one person ask me why I had pulled him out of school."

The need for negotiating skills. Interactions with schools and educators often involve the highly social process of *negotiating*, which transpires in the context of team meetings or individual interactions. The negotiating process itself is highly complex and outside the focus of this study. I discuss it here only to illustrate that while *negotiating skills* are highly important for parents striving to overcome opposition to acting on their concerns within the school system, they are difficult to acquire. Indeed, having the knowledge and experience to negotiate effectively represents a highly sophisticated skill needed by parents in the greater process of *making their own way*.

One source of negotiating skills includes the parent's own pre-existing knowledge or expertise. As mentioned above, the high stress that many parents experience in their respective situations generally increases their predisposition for confrontational conflict when they experience resistance to the solutions they define as necessary for their child. Nevertheless, several parents facing potentially confrontational situations described responding with surprising restraint or diplomacy. Some expressed a belief that confrontation is usually counter-productive when negotiating for something one wants, and understanding this helped them restrain combative impulses evoked by opposition from educators. One parent strategically responded by avoiding confrontation to "not burn bridges" with professionals who were in a position to help her child later. Another highly sociable participant used her understanding of "human nature," while another drew on previous professional experience in a high-powered job. Many parents

lack the social and professional understanding or experience that these participants drew on.

It is also possible to find useful information about how to negotiate in published materials including the internet and books. In response to the recognized potential for conflict between educators and parents when negotiating accommodations for students with special needs, for example, the Ontario Ministry of Education (2007) offers a highly relevant 55-page guide called *Shared Solutions*. It provides concrete advice to parents and educators promoting collaboration to achieve mutually agreeable solutions. No parent indicated that they had read this or other published resources on negotiating skills, although I only questioned participants generally about the information sources they used for navigating autism intervention.

Knowledgeable professionals are also well positioned to provide guidance on negotiating skills. Several of the expert professionals interviewed described supporting parents by sharing their insights on the negotiating process. Similar to key messages in the *Shared Solutions* guide, some of these professionals emphasized how important it is for parents to strive to establish positive relationships with their educational negotiating partners, positioning it as the best strategy to ensure their child receives better treatment within the school system.

Another source for developing negotiating skills is provided by the various family support organizations who have recognized how valuable and important these skills are for parents of children with autism. Such organizations offer training workshops that can highly effective. Ilona, a single mother, described how one such workshop helped her. It taught her to be assertive and negotiate effectively an Identification, Placement, and Review (IPRC) meeting. Facilitators coached her to understand that "Whatever it is that you need help with, make sure you bring it up right there and then." After overcoming initial opposition, Ilona succeeded in request to having an educational assistant (EA) assigned to her son. In addition, she raised her concern that the

existing EA in place at the time was not a good match for her son's needs. As a result, "they actually brought in a new TA because of that meeting. So I was very happy for the workshop." Not only did this outcome address her concerns, but it had the surprising effect of improving her previously rocky relationship with the school: "And the next year things absolutely changed, like, one hundred percent. And I can say right now I'm very happy with the school. You know, even his Grade 1 teacher absolutely understands him." Since the availability of such courses vary by region, it is possible that relatively few Ontario parents acquire negotiating skills this way.

In conclusion, while negotiating skills are highly important for overcoming obstacles to addressing concerns in the education system and other settings, they are not intuitive or straightforward for most parents. Meanwhile, developing effective negotiating skills can require specific information gathering work that many parents do not have the time for considering the many other tasks competing for their time.

The difficulty of choosing a school to avoid problems. Negotiating skills are most effective in contexts where educators are also equipped with the expertise and disposition to work collaboratively and constructively with the special needs parent, which is not always the case. Another possible strategy for overcoming opposition in the school system is for parents to avoid such problems altogether by choosing schools where confrontation is less likely. Aware of the conditions that can lead to experiencing opposition in the education system, Peter Szatmari (2004), in his book *A Mind Apart*, suggests characteristics parents can look for when selecting a school—which also apply to individual educators the parent would have to interact with including the principal, special education professional, or teacher (pp. 163-164):

- Previous experience with autism

- Willingness to be flexible and accommodating

- Tendency to treat parents as part of the child's team and work collaboratively

- Willingness to use the consultants and experts their board of education makes available

- Enjoyment working with children with ASD

Such characteristics, however, are usually not readily apparent since a school's or educator's practices often do not precisely match their school's or school board's stated policies. Parents must therefore rely on a school's reputation, which can sometimes be constructed by word-of-mouth reports form the other parents or in online listservs. For most parents, however, it is not possible to research a school's reputation in advance, and the presence or absence of the above characteristics become apparent only through direct experience interacting with their local school. Some parents do not have the luxury of choosing between public schools because they live in the catchment of only one school. Others struggle with the choice between their uncooperative local public school and a financially harmful but more responsive option—a private school specializing in children with developmental needs.

Burdens

Each of the external aspects of *having to make your own* described so far in Section 4.2—complexity in its many forms, the multiple autism-related concerns to respond to, the many and often difficult-to-access interventions to access, the expansive information to interact with and internalize, and the external obstacles that lie in parents' path once they have committed to act—are problematic for the common reason that they contribute to the burden parents experience as a result of navigating intervention. The burdens I discuss here primarily result from the process of *making your own way*, although other non-intervention–related burdens such as parenting and coping with challenging aspects a child's autism-related behavior often interact with this process and are therefore also relevant.

Below, I descriptively characterize two forms of burdens: the substantial *work* that parents must do navigating intervention, which results in expendable personal *resource loss* by costing parents finite time, financial resources, and physiological reserves (energy) for functioning and coping physically, emotionally, and cognitively; and the *stress* and related consequences that invariably impact parents and their families in various negative ways. Along with this description, I outline some theoretical elements that explain the relationship between *making your own way* and *stress* and its consequences as parents of children with autism experience them.

Work

As described previously, parents must contend with a multiplicity of concerns for each child with autism, with each concern requiring one or multiple interventions. Navigating (pursuing and implementing) each intervention generally entails many *tasks*—common ones include researching, gaining access, planning, completing forms, coordinating and traveling to appointments, managing financial and human resources, negotiating obstacles, engaging in personal development to develop skills, implementing treatments or modifications, monitoring implementation, and evaluating effectiveness. In turn, each of these tasks can entail substantial *work* for the parent. When considering the sum of tasks across all interventions together, the total time and energy that most parents dedicate to *making their own way* represents a significant burden of sometimes overwhelming proportions. Several of the many parents whose primary occupation was fulltime caregiver compared their workload navigating intervention and caring for the child with autism to holding several fulltime jobs.

While the work of navigating intervention requires time and energy, each task also requires varying skills. If one listed all the skills needed for all tasks, the skillset most parents need to

accomplish their work is daunting. The demands of work in terms of these skills, and of expendable resources are expanded on in turn below.

Skills

A skill is defined here as the ability or expertise that allows a parent to complete a certain kind of work or task more efficiently. The improved efficiency that comes with more skill usually means that a parent can accomplish a certain task with less loss of expendable resources. Importantly, one skill includes knowledge, since knowing—for example, how to do something, what one's options are, or where to access something—on its own, can greatly increase the efficiency of action. Learning and knowledge development, which are so important for navigating autism-related intervention, therefore, are not only examples of centrally relevant skills but are also critical means for parents to develop other skills in making their own way.

Parents generally start out in the situation of having to make their own way with a partial repertoire of the skills they will need to navigate intervention. Indeed, it is partly because of the vast skillset that their new role requires, that parents generally find initial adjustment to this situation so challenging that they often feel overwhelmed (see Section 4.3, *Adjusting*). Relevant skills, as are illustrated in the examples throughout this chapter, can include research skills, information appraisal skills, information management skills, organizational skills, effective written and verbal communication skills, negotiation skills, social networking skills, resource management skills, and many others. Many of these skills are required at a sophisticated level, compared to many other health conditions, due to substantial complexity of the various elements in parents' situations, discussed previously. Two parents, for example, compared the information-related workload and skills requirements for navigating intervention to the work and skills required for completing a university degree.

Parents develop skills they need by several means: by quickly learning through repeated experience, by engaging in personal development activities (training, consulting how-to information), or by turning to people in their social networks who are more expert than them for help or information. Engaging in personal development activities and other efforts require commitments of time and energy, and therefore represent another category of task, adding to the work already draining parents' expendable resources. Parents interviewed were generally enthusiastic about work that developed their skills, as the following quote illustrates: "Because if the speech-and-language pathologist can't come and do one-on-one therapy, then she's going to teach me. It was a lot of going to parent workshops and training yourself, which is great and I was very gung-ho about."

The case of negotiating skills. As already described above (see *Obstacles*), negotiating skills are particularly elusive and challenging to develop for parents who lack them. Negotiating skills are important whenever parents have their own ideas for interventions or accommodations that depend on the actions of others to be implemented. In other words, they are needed in many situations where parents must interact with professionals who are in a position to help them. As multiple professionals in this study observed, however, stress (described further below) appeared to make some parents more prone interacting in confrontational, angry, or "quite hurtful" ways (a senior professional's words) with the professionals who are positioned to help. Indeed, throughout parent interviews there were abundant examples of parents *feeling angry* at being treated with perceived disrespect or lack of understanding (as well as other examples of surprisingly controlled emotional responses). Some parents described *acting* on their angry impulses to varying degrees. One parent, who reported expressing her anger to her son's teacher, revealed the explanation for her behavior as follows: "And the protectiveness, right. And the

doubt that other people know what your child's going through or what you are going through."
She regretted not controlling her anger and apologized to the teacher afterwards. Several other parents described explicitly recognizing the need to preserve, or avoid damaging, relationships with professionals precisely to avoid alienating those who were positioned to help—even when the professional apparently treated them with disrespect.

In addition to seeing the need to preserve relationships in confrontational situations, two other negotiating-related aspects that parents described as important included being assertive about what it is you want even in the face of authority, and of understanding human nature. These aspects are far from straightforward for many people partly because they require a level of social expertise that some may lack. In conclusion, while negotiating skills represent perhaps the most difficult of skills to develop, numerous of the other skills parents require to *make their own way* are also sophisticated and challenging. From a health literacy perspective therefore—in which skills of the healthcare consumer are conceived as having to match the demands of the systems providing care (see Appendix L, *Framework for involving parents in intervention*)— autism represents an extremely demanding health condition for a consumer to navigate care for.

Expendable personal resource loss

Parents draw on various types of personal resources in their efforts to navigate intervention and handle autism-related demands more generally. These resources are required to accomplish any of the work involved, to pay any financial costs, and to cope physically and emotionally in the face of stress. I divide personal resources here into two general categories: non-expendable skills, which are never consumed although they can fade over time; and expendable resources, which are available in finite supply to be consumed. Expendable personal resources used for navigating intervention and parenting the child with autism include time (i.e., the 24 hours

potentially available in a day for work), financial resources (to pay for private intervention), and physiological reserves (i.e., energy) for functioning and coping physically, emotionally, and cognitively. While these can be depleted, they are also usually eventually replenished again through different processes that restore equilibrium (to varying degrees, and at different rates)—for example, even the time someone has available each day can be freed up by discontinuing less essential routine tasks.

Motivations driving continued resource use. Parents commonly responded at some point (usually in the earlier stages of *making their own way*) to certain aspects of their situation with intense feelings related to urgency (see Section 4.3, *Urgency*), which motivated them to invest ever-greater amounts of their expendable personal resources. For example, parents were generally aware of and highly motivated by the research evidence suggesting it was important to start intervention as early as possible to optimize outcomes: "So I learned a lot there about intervening and not taking this wait-and-see approach—because that was the worst thing you could do. So I was online 24-7. I became an insomniac because I was obsessed with fixing him." In addition, parents commonly felt pushed by guilt stemming from the finite limits to their time, or money. As one parent expressed: "I always feel like I'm never doing enough."

Sometimes parents can drive the rate of their personal resource use to a point that most observers would expect is beyond sustainable limits to allow continued functioning (see Section 4.3, *Going into high gear*, *Resource-intensive action*). As one professional remarked, "And the parents that are giving as much as they can…I don't even know how they are still operating. They're, to me, burning out. Or they're coming close to burnout, but they just don't stop." One thing that keeps many parents going through the most demanding of times is the knowledge that if they stop, everything will break down and their dependent child(ren) will have nothing. Kim

described the logic that kept her going in the midst of a depressive episode:

> *"Because you're thinking, 'If I fall apart, everything falls apart. I've got to hold it together.'...And I remember being mad and angry and thinking, you know, 'I don't even have the option of having a nervous breakdown. Like, what a luxury to have a nervous breakdown, but I don't have time!'"*

Depletion of time and physiological reserves for coping. One parent of a higher-functioning child summarized the *time* requirement to accomplish all the tasks she undertook to navigate intervention, "It takes, like, every minute of our lives—seriously." For another mother of a 5-year-old boy with severe autism, the demands of caring for her son had profound effects on her time, leading to sleep deprivation. She described the moment-to-moment attention this required by saying "I'm watching him by seconds, not by minutes…I don't know if you will believe me, but by *milliseconds*, just trying to watch him, or playing with him, or teaching him anything." Indeed, this was very evident as she followed her son from room to room around their home throughout the phone interview; and on two occasions when the needs for her attention grew noticeably, we agreed to stop the interview and continue another day. For several years, she recalled, she could get no more than one or two hours sleep at a time because of the need to be present when he was awake. While she reported that things were much improved now that her son was on medication for his severe sleep problems, she still needed to take advantage of any opportunity to recover from her constant sleep deficit, sometimes napping during the day and therefore preferring not to schedule commitments in advance if it could be avoided. (Despite these demands and my concerns about burdening her, she insisted on continued participation.)

There were numerous examples of parents experiencing prolonged phases of inadequate sleep sometimes lasting years, usually in cases where the child with autism had sleep problems. One mother was most sleep-deprived for several months after she gave birth to typically developing twins at a point when her son with autism was aged 21 months. She slept "at best, a

couple of hours a day" since nights consisted of nursing her twins which required first soothing them back to sleep, and subsequently tending to her sleep-challenged and difficult-to-settle son who inevitably woke up because he shared a bed with them. "The only time I really got to sleep," was during the day on the three weekdays her son was in preschool, and only when both twins were asleep simultaneously. Lack of sleep was highly stressful, commonly affecting capacity to carry out cognitive tasks and get along with spouses, (discussed further under *Stress*, below).

Several parents described how work contributed to depleting not only time for sleep, but draining their other *physiological reserves for coping*, particularly after extended periods of functioning at a very high levels, such as the following mother:

> "Like, I went to his daycare. And I did playgroups with the other kids to teach him how to interact. I sat down and did play therapy with him. I did speech and language strategies with him. I learned sign language. Like, I jumped in with both feet. But what it did was, it exhausted me, mentally."

Depletion of financial resources. The amount of financial resources a parent has available to dedicate to intervention depends on her broadly-defined personal and family financial situation. In this study, it was clear that available financial resources were determined not only by income, but also by access to financial capital within and beyond the nuclear family. Parents interviewed described financing intervention through a variety of sources: personal savings, retirement savings, lines of credit, straight bank loans, home mortgage refinancing, loans from extended family, employee health insurance coverage, government assistance, and even fundraising to pay for a child's private school tuition. Parents' backgrounds influenced access to certain sources of finances. For example, some new Canadians had less access to loans from extended family because their relatives still resided in less developed home countries and were significantly poorer. Meanwhile, parents with low family incomes may have been more likely to qualify for government assistance, but they lacked access to more substantial bank loans. Family

income levels, meanwhile, depended on key circumstances besides salary, including whether the

main caregiver (usually the mother) is working or not, whether she was single, and if single,

whether the ex-partner provided support. Among the parents who participated in this study, a

high proportion of mothers had decided and forego employment to stay home and take care of

the affected child(ren) for several years or sometimes indefinitely (in at least one case, the

husband had foregone employment to stay home instead). Thus only 13 mothers were full-time

employed, while 6 were part-time employed, and 13 financially unemployed (see Section 4.1,

Description of the sample). Four of 32 mothers were single, one of whom was also unemployed.

Although I did not collect financial information, it appeared that only a few parents in the sample

were in the position of having both low family income and limited access to financial capital.

In extreme cases autism can quickly lead to serious financial insecurity. One mother, who

decided not to return to work in order to take care of her son after learning he had autism,

described how the shared decision with her husband to refinance their mortgage to pay for

intervention contributed to her financial vulnerability. Two-and-a-half years after the diagnosis,

autism had taken so much toll on her marriage that she and her husband separated. He had

supported the family with his generous income up to that point. But even at the time of the

interview, almost two years after leaving, he had neglected to provide any financial support—in

her words, "*Zero*." This brought her to a position of having to cash in her RSPs and borrow from

family, not to pay for intervention, but "to put food on the table for the children." She had turned

to food banks, and described her situation as "at the point of personal bankruptcy."

For most parents interviewed, the short-term consequences of financial sacrifice were less

serious. But as one professional noted, for parents who "get far in debt, it's going to be very hard

to get out long-term." One parent described her awareness of potential expenses in the distant

future considering the capacity of her son with autism to financially support himself. Meanwhile, she acknowledged, "We're behind on our savings, for sure." When parents consider implications for the future, such as the prospects for recovering enough wealth to retire comfortably, the difficult financial decisions they face become all the more stressful.

While parents commonly experienced substantial financial sacrifice and other forms of resource loss as highly stressful, those who had seen their child develop for a number of years expressed having no regret for making these sacrifices in light of the benefits that they perceived it brought their child. Nevertheless, for some parents resource loss was a source of stress that in turn led to further damaging consequences, as we shall see.

Stress

Stress is defined here as an individual's internal emotional, psychophysiological, and physiological response to a triggering object or event that the individual experiences or perceives as an imminent threat to his or her wellbeing (or the wellbeing of a child or loved one) or continued ability to function. Being an emotional or psychophysiological response, individuals also experience stress as a subjective sense or feeling. The word *stress* resonated with parents interviewed who invariably responded whenever I mentioned it, whether as part of a question or as an observational comment, by affirming its profound relevance to their experience through words or emphatic body language. Stress featured naturally and prominently in the majority of participant interviews and stands out in the analysis as a dominant feature of parents' experience and a fundamental problematic consequence of the process of *making your own way*. The definition above was carefully developed both to match parents' use of the word, and to have the theoretical power for explaining the numerous relationships with varied problems and actions that parents linked to it.

A branch of biological human science is dedicated to studying the physiological mechanisms and consequences of stress. The well recognized mechanisms include the short-lived *fight-or-flight response*, with the release of epinephrine and norepinephrine that quickly mobilize the brain and body for immediate activity; and the longer-lasting *resistance reaction*, with the release of cortisol, human growth factor and thyroid hormones that increase metabolism of the body's energy stores to feed more prolonged activity to counter the stressors that triggered the response. The primary recognized consequence of long-term exposure to stress and high levels of cortisol is physiological *exhaustion*, which can manifest as stress-related disorders that include varied immune-related, cardiovascular, mood disorder-related, and other health problems. In summary, stress mobilizes greater cognitive and physical energy for responding to threatening situations in both the short term and the medium term, but it leads to negative consequences when stress is overly prolonged. This physiological conception provides a useful analogy for considering parents' stress in its many forms, and it partly informed the definition above.

As parents repeatedly described stress, including its causes and consequences, I slowly began interpreting it at least partly through this physiologic lens for two reasons: first, because it was consistent with the growing body of interview data, and second, it allowed me to see and construct several incisive explanations that I otherwise would likely have missed. I already described previously, for example, how Jennifer was a nervous wreck and physically throwing up due to her stress navigating opposition from the school system (see *Obstacles*). Some professionals interviewed, meanwhile, communicated their empathy towards parents who they experienced lashing out angrily at those helping them, attributing their confrontational behavior to unusually high levels of stress. Not only does a physiologic lens help account for some of the physical consequences or immediate and longer-term reactions to stress that parents and

professionals described, but it led to an explicit appreciation of the importance of bodily influence on cognitive processing that parents use to construct their lines of action from a symbolic interactionist perspective (see Section 4.3, *Going into high gear*). Note, the apparently stress-related process of *going into high gear*, described later in Section 4.3, was named and conceptualized *before* interpreting the relevant data through a physiological lens.

While the definition above makes stress appear like a unified phenomenon, empirically I encountered that parents experienced, and were affected by, quite different forms of stress (or stress responses). In the following discussion, I outline how different categories of causes underlie some of these different forms of stress. Later, in describing the common consequences of stress, I attempt trace the ways in which certain consequences appeared to be characteristic of the different forms of stress, as defined by their causes. Note that careful analytic attention to the specific empirical case is necessary to make the distinction between a cause and a consequence, since some common causes (e.g., sleep deprivation, marital problems) also operate as consequences of stress in different circumstances. Adding to this complexity, even in specific empirical cases, certain consequences of stress appeared to have a feed-forward influence by contributing to further stress as causes.

Nevertheless, it was possible to separate out characterize some of the more common distinct forms of stress and link each to certain types of consequences specific to parents of children with autism. As a broad observation, the association between forms of stress and their consequences varies depending on what stage of *making her own way* the parent is at, with earlier forms generally associated with increased motivation for action and later forms associated with exhaustion. Readers should note that the following preliminary typology showed good fit with a particularly substantial body of stress-related incidents available in the dataset (and was

tested partly by selectively coding over 50 previously incompletely-coded segments), suggesting its potential generic usefulness.

Causes

Parents described a diversity of *stressors*—objects or events they characterized as sources, triggers, or causes of stress (including the psychophysiological response or emotional experience of stress). The specific forms that stress took generally varied according to the generic source or *type* of stressor. To make sense of their diversity, I organize and discuss stressors and the characteristic forms of stress they produce under the following general categories:

- The combination of multiple stressors

- Circumstances underlying urgency of the situation

- Obstacles leaving parents feeling helpless

- Work-related resource loss reducing capacity to cope

Note this list of general types of stressor only includes larger categories that together cover most causes of stress, but it is not exhaustive. For example, shock of the diagnosis, marital problems caused by differences of opinion regarding intervention, losing friends as a result of autism, and guilt for not doing enough are other causes of stress that do not fit in the large categories listed.

The combination of multiple stressors. Since this study centers on how parents *make their own way*, in some interviews I asked participants to specifically trace how stress was attributable to their experiences navigating intervention. In some cases it was possible to isolate the *work* involved in navigating intervention or the *obstacles* parents encountered as unique causes of stress. In numerous other cases, however (including interviews where I did not ask participants to specifically trace the connection with navigating intervention), the particular instance or manifestation of stress was clearly due to a combination of causes or stressors, some of which

were not directly attributable to navigating intervention but rather interacted with it. Sometimes, for example, stress specifically attributable to the work of navigating intervention combined with substantial stress due to problematic child behaviors. In addition, stress caused by other significant challenges in areas of life not necessarily related to autism (e.g., the deteriorating health or death of another family member, or the recent birth of a child) could coincide in time with major autism-related challenges. In numerous cases, the challenges of normal parenting of typically developing siblings combined to increase stress.

Aspects of parents' daily environment are likely common contributors to stress, although they are perhaps overlooked since few parents commented on them with the exception of the following mother: "Another stressor was the space. We had a two-bedroom [making her son's wakefulness at night a particular problem, especially for his typically developing sibling]. And me stuck in that 24-7 wasn't helpful." Other non-declared aspects of the environment, of which neither the observer nor the parent is aware, represent potentially hidden sources stress.

It therefore becomes important to consider how stress from multiple, and sometimes difficult-to-identify sources can combine in the same individual, when considering the various stress-related consequences seen in parents such as fatigue, anxiety, depression, or marital problems. Nevertheless, based on the accounts of parents in this study, stress specifically and directly attributable to the work of navigating intervention is clearly a substantial and important (and often highly under-appreciated) contributor to parents' combined stress level, and in several cases it was uniquely attributed to substantial stress-related harms.

Circumstances underlying urgency of the situation. Parents perceive certain worrying aspects of their situation as reasons for acute urgency, which push them into a mode of pronounced motivation to take action to intervention. These motivating aspects—or sources of

urgency—include anxieties related to coming to understand the child has autism, seeing one's child struggle, knowing about the research evidence about the importance of intervening early to achieve optimal outcomes, and seeing a gap in services created by the long waitlist for IBI that requires attempts to find other forms of intervention (see Section 4.3, *Going into high gear*). The stressors in this category therefore, while anxiety-producing, generally have positive consequences for the parent's ability to pursue intervention (when they are not combined with stress due to obstacles leaving the parent feeling helpless, described below). This constructive effect of stress (analogous to the first two physiological stages of stress—the fight-or-flight response and resistance reaction), contrasts with the stress attributable to the other types of causes whose effects are generally to reduce parents' capacity to cope or function.

Obstacles leaving parents feeling helpless. Setbacks due to the *obstacles* described in the previous subsection often buffeted parents emotionally, leading to varying degrees of despair and reducing their capacity to cope. Parents sometimes became profoundly distressed at the prospect of not being able to begin the intervention they felt their child would benefit substantially from, their stress manifesting as feelings of helplessness and exasperation. A common example of such a stressor was the long waitlist for IBI. Although some parents experienced this as a reason for urgency and motivation to act as described above, others experienced helplessness and anxiety, which was severe enough in at least one case to trigger a depressive episode. One parent equated the impact of learning about the IBI waitlist length to the stressful emotions some parents experience after discovering their child has autism: "When you find that out, then you're back to square one, where you're grieving all over again." Another parent described how having funded IBI suddenly cut off when her son was six and still benefitting as a "return of darkness."

Obstacles are stressful partly because they lead to a sense of loss of control. When it was

profound, some parents described the sequelae of profound emotional loss, such as denial. Thus, for parents who still hoped to achieve a close-to-perfect outcome through intervention, the feelings of loss that obstacles trigger can be highly stressful.

One participant described the stress of her anguish and fears as a result of not being able to access speech and other therapy for financial reasons after seeing how "tremendously" it had benefited another boy from a more well-off family who "had lots in common with my son":

> *"It's really a very stressful feeling, to be honest with you. You feel like you're helpless. You cannot do much. You love your child, and you want to make the sacrifice. And you want to see your child functioning normally. The future—and I've felt worried—I've thought, 'My God, if I die, what will happen to my son? Who will do all this [since] he can't function normally?' It's really hard. It's very, very tough. Every day that passes I think about that."*

Lack of support at the time when many parents needed and expected it the most—i.e., soon after the diagnosis—had the same stress-inducing effects as later obstacles to intervention. This gap in support post-diagnosis was partly attributable to an external obstacle described previously: fragmentation of services. One parent expressed her sense of helpless, exasperation, and desperation at this time as follows:

> *"So I felt, like, a huge burden, huge burden with no guidance again. And it kind of felt like…it was like [my son] was drowning. And I couldn't find the life raft. And nobody was showing me where the life raft was."*

Other parents echoed the same sentiment with comments such as this: "And the thing that we both felt at that point—you're lost in this world! All of a sudden you get a diagnosis, you have no idea where to go next." Three additional parents and one professional used a remarkably similar metaphor of struggling to stay afloat in water to convey the overwhelming helplessness and stress parents experience soon after diagnosis.[8]

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[8] I include the quotes to illustrate how remarkably similarly these four additional participants reproduced the metaphor, in all cases without prompting. Second parent: "So yeah,

Problems with information—its insufficiency when parents felt it was needed most, its excess when parents felt overwhelmed, and contradictions or inconsistency when parents needed clear direction—left parents feeling further helplessness and uncertainty about what to do next.

Work-related resource loss reducing capacity to cope. Stressors sometimes take the form of a progressing deficit in expendable personal resources that has resulted from doing the vast amounts of work to meet the demands of autism. As outlined previously, the expendable personal resources used for this work—the work of both navigating intervention and parenting the child with autism—include time, financial resources, and physiological reserves for functioning and coping physically, emotionally, and cognitively. A deficit forms when these resources are depleted faster than they can be replaced. As the resource becomes more deficient, the parent progressively loses her capacity to handle further challenges. Invariably the parent perceives, either cognitively or physiologically, the progressing deficiency as a threat to her wellbeing and ability to function and adjusts by shutting down further resource use and sometimes relying on other less efficient systems to cope. This shutting down is analogous the final physiological stage of stress, *exhaustion*.

While resource loss attributable to navigating intervention was the more central interest in this study, resource loss attributable to daily parenting work that includes the need to manage and cope with severe child behaviors is also highly relevant to understanding parents' stressful

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it's like you've been thrown into the ocean with maybe a life preserver, in terms of the life preserver being a 3-page report, and then it's like 'OK swim...go!' And land is a really far off place." Third parent: "I was drowning in it, and I didn't know where to turn, how to find help. I just remember feeling like I was drowning in the beginning, and then finally bit-by-piece kind of getting my way through it." Fourth parent: "It was kind of a sink or swim feeling, I guess. You know, I just had to be as strong as I can." Professional: "Every time I see it [a parent who is overwhelmed by the diagnosis], I just think about someone swimming, like, someone that was dropped in a pool that can't swim."

situations. Sleep loss due to child wakefulness, mentioned earlier, is a common source of such stress. One mother (different from the two sleep-deprived parents referenced under *Resource loss*) summarized the generic stressful effects of sleep loss: "When you take [sleeplessness] to an extreme, you can't function. Everything is a problem. You can't do anything when you're going on two hours sleep and you have to get up with a child." For this mother, as with other parents, the inability to function manifested as difficulty carrying out tasks, family conflict, and marital problems. Other problematic child behaviors that often consume parents' energy (i.e., physiological reserves for functioning and coping physically, emotionally, and cognitively) include tantrums triggered by child frustration or transitions, sensory problems that make dressing or feeding the child difficult, and toileting problems. Sometimes the parent must deal with a combination of challenging and stressful behavior, as the following example illustrates:

> *"Last summer [my son] went through a jag where he stopped eating for six weeks. He was drinking milk and eating Cheezies and that was it. And he lost five pounds. It didn't matter what we did. So we stopped all programs. Like he stopped sleeping, the meltdowns were bad, the self-stimulation was intense. Everything was falling apart. I thought we were losing him again. I thought he was going back into this dark, deep place that we weren't ever going to get him out of again. He was throwing things. My house was a disaster—he broke two sets of kitchen chairs. I mean he was just over three at this time. He's not big. But he'd bite me when he was mad…"*

The work of navigating intervention (summarized previously) is the other major cause of resource loss, and a major stressor, as the following story illustrates. Cheryl, who lived in a small rural town, found out from her regional autism intervention center that one of her twins with autism had reached the end of the waitlist and was eligible to start IBI. But this left the other twin with a further wait of unknown duration. Moreover, the only option was to receive therapy at the center, located in a small city 40 km away. Since Cheryl's husband needed a car for work, they decided to sell their only vehicle to offset the costs of purchasing and running two "pieces of crap cars." Three days a week, Cheryl would wake at 6:00AM to get both twins ready and out

the door, make the 40-kilometre commute, and return with the children around 6:30PM,

sometimes later in winter because of frequently snowy weather. During the day, however, she

remained in the small city with her second son, all the while trying to advocate for emergency

funds so he could join his brother in the IBI program:

> *"I used to call [the center] on a daily basis and let them listen to [our second son] screaming and crying in the back seat of my car because I had to sit there for eight hours with him because I couldn't afford to drive home. And we had a DVD player and we had snacks and food. But he couldn't go into a mall—he would have a nervous breakdown [due to sensory problems]." [After three months her second son was finally accepted, which freed up her time.] "So I got a job, which made things very much easier for us because then I could travel to [the small city], drop them off, go to work for five hours, go back, pick them up and go home. And then I had an income to pay for the gas and [insurance] for the car."*

Cheryl reflected how, "that [three months when only one twin was receiving therapy] nearly

broke us. I mean it was very, very hard, not just financially, but just physically."

Several other parents described reaching a point of burnout after investing unsustainable

levels of energy in pursuing intervention for longer periods, sometimes lasting a year or more.

One mother, Dilin, described her experience of burnout as follows:

> *"Eventually everything that's in high gear has to stop, or come down, or put the parking brake on for a while, or else it's just going to explode. And that's what started happening. It started taking a toll on me mentally, physically, emotionally —like, everything. Because I wasn't sleeping properly. I wasn't eating properly."*

Thus stress for these parents manifests as the prolonged investment of expendable personal

resources and ultimately *exhaustion* when depletion of those resources continues for too long.

Stress involving exhaustion (the depletion of resources) can have potentially serious

consequences, often feeding forward to fuel new forms of stress, with one or more breakdowns

in function and the capacity to cope—as will be illustrated below.

Consequences

The types of consequences I consider below correspond to the stress-related effects participants discussed most. They vary in how proximal they are to the stress response. Thus the reader may consider some of these consequences to be mechanistic or stress process-related (e.g., neglecting aspects of self) and others to be more terminal or outcome-related (e.g., divorce). Likewise, the consequences discussed below vary in when parents tend to experience them during the process of *making their own way* (the stages of which are outlined in Section 4.3). Thus, parents can experience some consequences early, prior to diagnosis after they first perceive their child's autism (e.g., being overwhelmed in terms of one's ability to function), while other types of consequences can be experienced at multiple points throughout the process—the timing of consequences roughly corresponding to what causes of stress (outlined above) they originate from.

An important aim in this subsection is to provide a somewhat detailed and precise account of the links or relationships between the types of consequences of stress and their originating causes, specifically in the case parents of children with autism navigating intervention—precise accounts being more useful, for example, than stating simply and imprecisely that "marital conflict is both a cause and consequence of stress." For each type of consequence, therefore, I use participant examples primarily to illustrate which types of stressors most generally tended to underlie, or trace forward to, what type of consequence.

Going into high gear. *Going into high gear*, where parents enter a prolonged mode of high motivation for *taking action to pursue intervention* and expend personal resources at a high rate, is often attributable to *circumstances underlying urgency of the situation* (one of the categories of causes of stress). This consequence is discussed in Section 4.3 (*Going into high gear*).

Being overwhelmed. The stress-attributable consequence of being overwhelmed and temporarily unable to pursue action is something parents most commonly experienced early on, after learning their child had autism, although it also sometimes affected parents at later points in the navigating process. Note that being overwhelmed in this sense is distinct from exhaustion due to prolonged resource loss described above.

Being overwhelmed commonly manifests itself as denial or avoidance, which both delay parents from taking action to pursue intervention. Denial, which affected numerous parents interviewed, was a preconscious coping strategy that protected parents' psychological wellbeing when news of a child's autism was too big a threat to their picture of their self or the world. As a result, such parents integrated news about the need to intervene much more slowly, or only partially. Several parents described "not hearing anything" after first receiving the diagnosis while professionals tried to communicate various details to them. Multiple other parents described periods of weeks to months after learning their child had autism, during which they were overwhelmed by a combination of their lack of knowledge about autism and a grieving process characterized by worry and uncertainty about their child's future. While grieving, some parents commented they were too overwhelmed to support or communicate with their spouse.

Stressful events or thoughts also elicited protective avoidance strategies at later points in the process of *making your own way* in various circumstances or conditions, such as with the onset of depression or anxiety. For one mother, clinical depression and anxiety overwhelmed her capacity to consider planning intervention or accommodations for her son's distant future:

> *"I can't think about whether [my son] will have babies or not, or whether he'll go to university, or whether he'll get married. And I can't think of what will happen when [my husband] and I are gone because that is just…like, it's consuming, and it'll just eat you alive…So I just focus on the daily stresses…We don't have long-term goals or long-term plans. We just kind of go day-by-day."*

Being overwhelmed is discussed further in Appendix K, *Supplemental analysis: Staying*.

Disrupting sleep, eating habits, and self care. Stress had various physiological effects, but parents often answered questioning about how stress affected them with a comment such as the following: "Oh, a lack of sleep! I didn't get hungry, I wouldn't eat." In total, at least five of the ten parent participants with depression described stress depriving them of sleep and interfering with their appetite. According to one mother who suffered from clinical depression and anxiety: "Yeah, like I want junk all the time now when I'm stressed. I was never like that. I never needed food to comfort me. And I've put on weight. Like, I've definitely put on weight. So sleeping—I don't sleep, I don't eat, or I eat too much of bad things. And you know, I cry. I tend to cry a lot more than I would like to."

Another mother with depression reflected on how, for her, it was thoughts about navigating intervention that caused her to lose sleep at night:

> *"The lack of sleep [began] when I started sort of becoming more aware of what could be done potentially, and how much there was to do, and resources—that's when I used to lie awake at night and think, 'Oh my goodness, you know. I should call so-and-so and ask about this.' And that's when my best thinking would happen was at three in the morning.*

> *"...Because it was during the day that you're running, running, running. And you're doing one thing to another, to another, to another. And you don't really have time to stop. So you go to sleep. And then when you wake up in the middle of the night you're thinking, 'OK, I have to think about…OK, so now I've got to do this tomorrow. I should do this tomorrow. I've got to call so-and-so. And, oh yeah, this never came to my mind before. Yeah, that's a question too.' And 'Oh, this is a game that I should play with him because it's going to teach him this skill.' So, you know, all these thoughts. And I got to the point where I would sleep with a note pad beside my bed just so I could write everything down and then get back to sleep. And that lasted, like I said, for the six months during the depression."*

For several of these parents, periods sleep and appetite loss were accompanied by more psychological (less physiological) failures to care for themselves, such as by neglecting to get exercise. These times generally culminated in the exhaustion that results from prolonged stress (described previously). Parents' denial of their body's physiological needs was the concrete

manifestation of the unsustainable pace at which many parents drove themselves (see Section 4.3, *Going into high gear*), and a readily apparent reason for their ultimate exhaustion and breakdown.

   Clinical depression and anxiety. *Clinical depression* and anxiety are known to affect a high proportion of parents of children with autism (Bitsika & Sharpley, 2004; Davis & Carter, 2008; Giallo et al., 2013). However, I did not systematically probe parents about their clinically significant mental health problems in interviews, although as the study progressed I gave participants the option of expanding on this topic if it was relevant. Overall, six parents offered to discuss personal depression they had received clinical treatment for, an additional four participants discussed depression that they did not receive clinical treatment for, and four participants discussed their clinical anxiety (two of whom also experienced clinical depression). One parent suggested depression among mothers of children with autism was more prevalent than conventionally thought, referring to the evidence of it in her online parent support group: "You'll find a lot of moms won't admit that [they have depression]. [But] I can tell you all my autism mommies, they're *all* on some form of antidepressant—most of them."

   For some parents their depression or anxiety was triggered by autism (including navigating intervention), while other parents had pre-existing conditions that were aggravated by autism. The examples that follow illustrate the types of stressors that led to the onset or aggravation of these conditions among the parents. For Martha, who had pre-existing depression, the stress related to autism magnified the intensity of her depression: "It's another layer of the depression that needs different tools to cope with it. It's not the regular depression that I deal with in the everyday stuff. This is a whole other level." As a result she had to find different coping strategies and change her medication to manage her depression. The worst wave of depression came with the diagnosis, which Martha described "was like a tsunami of depression." She compared her

struggles navigating *obstacles* to "riding the waves of the diagnosis." Regarding her recent

struggle with the school system, she remarked:

> *"I would say this is definitely a bigger wave than I've had to deal with in a long time…*
> *I'm not used to how the game's played, and I'm not treated as an equal player. So I*
> *mean the depression and the stress from that, was intense."*

Although grieving is typically not a clinical form of depression, some parents reported

passing through an intensely depressive period after discovering their child had autism—the

sadness that followed the shock or denial, described above under *Being overwhelmed*. One

mother who never characterized herself as clinically depressed described her pain during this

grieving period: "I wanted to die, initially. And I'm saying it very neutrally right now. Initially, I

walked the streets [while my husband was at home with our son at night] wanting to die. But I

couldn't, because he [my son] needed me." Another mother who had put her daughter "on a

pedestal" before discovering autism described her grieving period as follows: "I spent about a

week or ten days feeling like she had died. It was really, really overwhelming. And I was just *so*

sad." She ultimately consulted a clinical psychologist for help dealing with these emotions.

Guilt—caused by feeling responsible for the child's autism, neglecting one's other children,

or not being a good parent—was a prominent stress-related emotion reciprocally related to

depression. While thoughts of inadequacy and failure for not doing enough were stimulated by

the impossible demands parents faced in the absence of adequate support, such thoughts were

also likely to be fuelled by depression itself. The powerful sense of guilt stimulated by such

thoughts, meanwhile, could be "very very hard to deal with," and inevitably contributed further

to parents' depression.

For one mother who previously experienced a severe post-partum depression unrelated to

autism, the combination of her son's autistic behaviors, concerns about his delayed speech, and

being ostracized by other children and parents were challenges that required a doubling of the

dosage of her antidepressants. Now, "Sometimes I miss my pill for three days—it's *disaster*! I seem like I can't handle any outbursts that he has, or stuff like that, you know. So the antidepressants definitely give me like a stability bar." Yet another mother attributed the onset of her depression to the obstacles she encountered pursuing solutions for one of her sons with autism, seeing him ostracized, and then losing contact with her adult friends, which she felt affected her irreversibly as a person:

> *"I don't really have friends anymore. I'd love to, but the ones that I did have don't really want to hang out with me, and I don't really have time to find new ones. So it's kind of a…there's a lot of aspects of my life that have been damaged, or destroyed even, through the whole process."*

In summary, depression among the parents interviewed appeared to be recurrently triggered or aggravated by the emotional stresses of initially learning of a child's autism, stressful child behaviors, facing obstacles to one's efforts, guilt for not doing enough, or social isolation.

Anxiety refers both to the feelings of worry, nervousness, and unease that everyone experiences at some point; and to the set of related clinical psychiatric disorders including phobias, panic disorder, agoraphobia, social anxiety disorder, obsessive compulsive disorder, post-traumatic stress disorder, and generalized anxiety disorder. While four participants declared having clinical anxiety, the accounts of other parents interviewed suggest that as a population they experienced anxiety on a continuum ranging from normal transient feelings of anxiety, to more prolonged and severe levels of anxiety that may impact other areas of life, to likely clinical levels of anxiety that in some cases remained undiagnosed.

While anxiety is provoked by stress itself, it also reduces the threshold for experiencing stress in future responses to events that might not otherwise be stressful. Anxiety and depression are also closely related. Some of the sources of depression described above were also triggers for anxiety. In some cases, I had difficulty categorizing parents' feelings or responses as anxiety- or

depression-related because they seemed like an inseparable mix of both. Likewise, it was sometimes impossible to tell whether some consequences such as insomnia or appetite loss were attributable to a parent's depression, anxiety, or directly to their prolonged level of stress.

Parents described many panic-inducing situations or experiences that increased their fears for the future that triggered anxiety to varying degrees. One woman described what happened when she visited a parent support group attended by another inexperienced couple with a newly diagnosed child like herself and two sets of more seasoned parents with late adolescent children:

> *"And we did not understand what we were in for, what we were headed for…And there were these other parents with older children with autism. And it* terrified *me to hear their stories…And I was sitting there going, 'I can't handle…I'm not going to be able to handle this, if that's where I'm headed.' And it was at that point that I also knew that [my son] was severe on the spectrum. So I was very, very worried. And that's when my anxiety started to happen. I developed a really bad anxiety disorder.*
>
> *"…[later] I had to sort of trial and error with different [anxiety] medications. Because I would…I thought I was having heart attacks, but I found out that they were panic attacks, where I was, like, shortness of breath, and all kinds of stuff started happening, as a result of my stress with the situation."*

Another more seasoned parent recalled the confluence of two events that preceded her diagnosis with generalized anxiety disorder: her eldest son being cut off from funded IBI "despite the fact that he has shown remarkable progress," and the birth of their third child which was accompanied by post-partum depression. She experienced the panic-inducing loss of her son's IBI as "a return of darkness" since the pressing demands of caring for a newborn while finding an alternative solution that would maintain her eldest son's progress at his crucially young age were so overwhelming.

Guilt, which parents often experienced as related to their depression, also contributed to their anxiety. One mother reported seeking counseling to address the guilt she experienced because it was feeding her clinical anxiety. Such guilt was closely linked with worry about not doing enough, and an often-unhealthy drive to do more.

Another aspect of anxiety is obsessive thinking or behavior. Thus, anxiety commonly manifested as obsessively pursuing intervention, as a representative quote illustrates: "I became an insomniac because I was obsessed with fixing him." Additionally, the extreme information-seeking efforts that were almost characteristic of the parents of children with autism in this study could be considered obsessive in many cases. The clearest signs of obsessiveness, and therefore anxiety, were apparent when parents were in *high gear* (see Section 4.3). Obsession often led to neglecting other children, spouses, and other aspects of the parents' health and self.

Mental health problems caused by stress had their own consequences for parents capacity to *make their own way*. As mentioned above, depression and anxiety contributed to parents' sense of being overwhelmed (see *Being overwhelmed*), which led to avoidance behaviors that interfered with planning for the future or parenting assertively. Both conditions were also associated with disruptions to sleep and eating habits described above, which sometimes in turn interfered with cognitive energy and alertness needed to participate in implementing some forms of parent-administered intervention. It also led to shutting the world out, which increased parents' social isolation and further reduced their ability to cope or seek solutions. Finally, parents' clinical depression and anxiety were additional autism-related concerns that consumed more of their scarce energy and time to inform themselves about and pursue intervention for by seeking both professional and informal help, implementing structured coping strategies, and managing medication. Multiple professionals reported observing and worrying about parents' mental health problems, citing this as a key impediment to their ability to cope and engage fully in parenting and implementing intervention.

Family dysfunction. Many parents reported stress related to autism causing disruption of family function and wellbeing, and marital dysfunction sometimes ending in separation or

divorce. Participants generally attributed stress-related disruption to family function and wellbeing to three causes: disruptive behavior of the child with autism, parental neglect of other family members (one's spouse, the child's siblings) due to time spent on managing the child and navigating intervention, and financial stress.

Whether high- or low-functioning, parents' accounts of their child's stressful and disruptive behavior and its effects on family were similar. One mother described how the behavior of her high-functioning son—who at the worst point was depressed, had been "talking suicide," and was violent to the point of being a potentially mortal threat to his siblings— significantly disrupted family dynamics by causing constant tension, chaos, and yelling. Another parent shared further insight into how the stress of her son's behavior affected her family:

> *"It comes out in being short-fused as a family. So you're short-fused with your kids—so both the ASD one, and the neurotypical one. You can be short-fused together as a couple. So there's…it creates a lot of impatience sometimes for one spouse or both spouses."*

Other parents used words like *disaster* or *crisis* to describe the state of their family in the face of a child's extreme and disruptive behavior. Disruptive child behaviors included night-time wakefulness, which in some cases deprived multiple family members of sleep and invariably contributed to reducing parents' capacity to function emotionally, resulting in more anger, blame, and conflict with other family members. Some parents described how extended family members lacked understanding and empathy regarding disruptive child behaviors, something that reduced contact or weakened relationships with extended family.

In addition to disruptive child behavior, a mother's neglect of her family—something that is usually unavoidable as the mothers are commonly the parents who spend most time caring for the high-needs child with autism, and often also the person who does most navigating of

intervention—is a common stressor contributing to family dysfunction. As one mother acknowledged:

> *"I did neglect my other children to a certain degree—not knowingly, but just because I thought, 'This is the one that needs the most help.' So all these little dynamics started coming into play."*

Neglect of other family members inevitably caused guilt. For one mother, the pain associated with this was inescapable and quite distressful because she perceived that it had affected her other child:

> *"Well, I spend less time with [my typically developing son] than I do with [my son with autism]. And that's…that's hard [emotional pause]—sorry…I see it in [my typically developing son's] behavior. [He] is a big attention seeker, and…[struggling to control emotions] and that's* hard*. That's hard, seeing your relationship with one child suffer because you know that eighty percent of your focus on your family is on your other child…the evidence is in how [my typically developing son] behaves. And you know, [he] has pushed and hit some of the other kids at school, and throws temper tantrums quite often at home."*

Finally, financial stress clearly disrupted some families, particularly those who, as one professional observed, ended up "rearranging their entire goals of their life around trying to accommodate the child, because the services are not there for them." Some difficult financial decisions had potential implications for future financial stability and long-term family wellbeing (for example, by changing retirement plans). Financial instability inevitably affected not only the family, but also wellbeing of the child with autism when this prevented families from being able to afford private intervention that was clearly beneficial. Indeed, all stress-related causes disrupting family function are significant because of their potential effects on the child with autism. Multiple professionals emphasized the importance of seeing the child and family with autism as part of the same system—the autism unit—because family function and family relationships are so closely tied with the child's wellbeing.

Marital dysfunction. Marital dysfunction including separation or divorce, was attributed to many of the same causes that disrupted family wellbeing, but was also influenced by several other aspects. While most participants in the sample had intact marriages, three of the four single mothers interviewed provided insights into how autism-related stress at least partly contributed to the breakdown of their marriages—one parent attributed autism as the main cause. At least one professional observed the prevalence of separation and divorce to be high among the parents she saw, noting that in many but not all cases it was the father who became overwhelmed and left the family, "so one parent is stuck raising their child with high needs." Another professional theorized that the prolonged stress parents of children with autism experience contributed to changing their personalities from the person their spouse felt they knew.

Disruptive child behavior that affected families inevitably also strained the parents' marital bonds. One mother who had coped with a child's sleep problems for three years noted, "It's a testament to [my husband] that he's still here because I was so tired and cranky sometimes." In situations like this, some mothers perceived unfairness in assuming a disproportionate burden of managing the child—sometimes she was the only parent the child would turn to—causing anger and reactiveness. Another mother recalled the effects of disruptive behavior:

> *"It was so tumultuous in this household that we couldn't even be a couple. And so we ended up just being, like, fighting and just angry at each other. [Our son] would have a fit where he would hurt somebody, and we would disagree over how to handle it…That's all come full circle though. We're strong again. But that almost destroyed us."*

Disagreeing, not about parenting the child, but rather about intervention and how to handle autism, strained the marital bonds for several other parents, including Karen whose marriage did not survive: "That was one of the main sources of friction with the husband. I think I was getting to the place of accepting [autism's permanence], whereas he was still stuck on this, 'We can fix him. And you're not doing your job.'" In this and several other cases, disagreement was related

to a trend for fathers to be at different points than (usually lagging) their spouses in the process of accepting their child's diagnosis. Some mothers described how their husbands, when still in denial, refused to cooperate in seeking a diagnosis or implementing early forms of intervention.

Parents whose time was consumed by navigating autism intervention neglected not only their wider family, but also their spouses. The same single mother, Karen, acknowledged this as another important factor that contributed to her marriage breakup. While she and her husband were together, the combination of financial strain from refinancing their house and her intense focus on pursuing intervention "lent itself to the stress, which created friction between my husband and I, because I was no longer focusing on him. All I lived and breathed was autism morning, noon, and night."

Neglecting one's spouse was sometimes worst during the grieving process. Several parents described how they were too overwhelmed at this time to comfort or communicate with their spouse, leaving each partner to cope in his or her own way. As one mother recalled: "[My husband] and I were unable to support each other. Because I think we were both so far into grieving that we didn't know how to find each other." Whenever the same mother was not working or spending time with her son, "I would be online looking [for information]." Some parents described how, after recognizing the need to provide support, they went outside the marriage to find it—to male friends in the case of one father; to religion in the case of one mother; or, in numerous cases, to communities of other mothers of children with autism.

Not only did divorce increase the burden on the main caregiving parent who now had to spend even more time and energy caring for the child and navigating intervention unsupported, but it had further repercussions for her exhaustible resources. Two participants described how the divorce process added considerable new demands. The inflexible timelines of legal processes

created a crisis situation forcing these parents to divert the full capacity of their resources (time and energy) away from caring for their children and the urgent pursuit of intervention. In addition, their estranged husbands' maneuvering led to substantial financial uncertainty and stress. In both cases, this maneuvering undermined the mothers' ability to continue to afford intervention that had been in place before the separation.

While at least two parent participants reported seeking counseling to help preserve their marital relationship, this was private therapy that consumed scarce financial resources. Multiple parents emphasized that funded marriage support or family counseling at the point of diagnosis are much needed services that would go a long way to preserving marital bonds, family function, and a healthier supportive environment for the child with autism. As one divorcee who had never received private counseling reflected,

> *"The whole way we operated changed. Everything just felt so different that nobody knew what to do…The day that a child gets diagnosed with autism, the whole family is diagnosed with it, in my opinion. And the first thing that should be offered is a family counsellor, to help guide the family through what to expect emotionally, what kind of changes this could bring up, and that that's normal, and that this is how you may get through that. Because I was…I was driving a boat and I didn't know where I was going."*

Crisis. At its simplest, crisis is a situation of overwhelming stress. I define *crisis* more specifically here as a situation in which a parent's psychological self, physical self, family, or relationship (i.e., any functioning system in which the parent is involved) is subjected to a substantial level of stress that disrupts homeostasis of the affected system, resulting in a sudden or progressive loss of function and sometimes a sense that a catastrophic failure is imminent— i.e., the current situation is experienced as unsustainable. Crisis is usually triggered when the level stress exceeds a threshold or psychological breaking point, beyond which one of two things can occur: the affected parent desperately seeks resolution and change from the status quo, or, rarely, there is catastrophic failure of the system in question (e.g., end of a marital relationship).

This definition was partly informed by the following definition of *crisis* found in the literature on stress in parents of children with autism (see Weiss & Lunsky, 2010, p. 522):

> *"An acute disruption of psychological homeostasis in which one's usual coping mechanisms fail and there exists evidence of distress and functional impairment. The subjective reaction to a stressful life experience that comprises the individual's stability and ability to cope or function. The main cause of a crisis is an intensely stressful, traumatic, or hazardous event..."* (Roberts, 2000, p. 516).

I further tailored the specific definition used here, however, to parents' responses to questions about what crisis meant to them, and to iterative interpretation of examples coded as crisis in the data. Thus, there are several relevant differences from the definition taken from the literature, which I discuss in expanding on the different aspects of crisis on below.

The first difference from the cited definition is an explicit acknowledgement that different functioning systems that can be in crisis. Thus, for any example of crisis in the data, it was important to identify what functioning system the crisis primarily centered around. Most commonly, parents described their personal *self* in crisis. The individual parent's self comprises multiple interrelated aspects of functioning, including the emotional and psychological, the physical, and even the financial (although financial function can also be an aspect of the family and of some relationships). Parents also commonly talked about their *families* and marital *relationships* being in crisis. Crises centering on the *child* with autism, meanwhile, were considered to involve the parent in cases where she truly shared in the child's distress.

Another important aspect of crisis to recognize is the stress-related *trigger*. Unlike the definition cited from the literature, crisis here can either be caused by a single acute and intensely stressful event, or—more commonly for parents of children with autism—a historic or progressive buildup of stress from a combination of multiple stressors or sometimes a single stressor that has been ongoing. In the case of a historic buildup, the final stressful event triggering the crisis can seem relatively benign. As one parent put it,

> *"I would say the crisis then for us was several peaks like that where they were just too close…I don't think there's ever been a time where it's been one specific [trigger of] crisis. It's always been too many things. When it rains, it pours."*

Thus, it is important to consider that a combination of stressors usually accounts for the full load of stress burdening a parent at any given time.

In a majority of the examples from the data, parents clearly and explicitly attributed multiple *stress-related precursors* to crisis. Parents also described numerous cases of approaching but not crossing the threshold or breaking point for crisis due to the characteristic buildup of stressors, such as the following mother who offered her observation of a father she knew as an example:

> *"So he has two [children with autism]…I think they're maybe eight and ten. And he is* on the edge. *You can see. He is so stressed out, and he's so on the edge. And he hurt his back so he is not working. And it just seems like he's got a crap-load of bad, bad luck. And I keep saying to him, 'Just hang in there, man, because, you know…' And he keeps saying, 'Well, it can't get any worse.' And I keep saying to him, 'Well, yeah, it could. You could break your leg. You could get hit by a car. So it can get worse. Don't think that way, you know. I mean, yeah, be positive, but…,' you know. And his kids—he has no respite—and they're stressing the shit out of him, you know! And I know. I know. But that's the thing. I can say to other parents, 'I know exactly how you feel.' "*

By suggesting his situation could still get worse, this participant hinted that the father had not reached the point of full-blown crisis yet despite his seemingly unsustainable load of stress; she then alludes to her own experience of approaching the breaking point for crisis with, "I know."

Exhaustion as crisis. Exhaustion due to prolonged stress and the progressive depletion of expendable personal resources—generally associated with remaining in *high gear* for too long (see Section 4.3, *Going into high gear*, *Resource-intensive action*)—also qualifies as a source of crisis because it involves a breakdown in normal function. Kim described the crisis she experienced as a result of exhaustion due to the work of navigating intervention and other related stressors including disagreement with her spouse, guilt for not paying attention to her other typically developing children, the onset of depression and associated sleep deprivation:

"About a year into it [post-diagnosis] I think we hit the crisis point…at least I did. Because I was the one who was doing most of the research, most of the implementing of everything that we learned, most of the absorbing of the therapies, and trying to implement them at home, you know, the diet, everything. Running around taking him to all of his appointments. Doing all of the interviewing. And then you realize that it's just…you get overwhelmed. And you get exhausted. Because there's so much you can do. And you're running, running, running. And then at that point I think I sort of hit the top. And I got really, really exhausted. [My son was making only slow progress up to that point] and I think that's when it really hit me that, 'Oh my God, this is what autism means. Am I going to get through this? How am I going to get through this?'"

[During my six-month depression] "I was afraid that it [the work and stress] would just keep on going. And every day I felt like, 'OK, I need to get it together. Why can't I get it together? I need my energy back. I need to get something to snap me out of this.' And I knew, I was aware of what was going on, but I just couldn't…I couldn't do it, because I had no support."

Kim's description highlights the lack of function and unsustainability that were characteristic of other parents' accounts of being in crisis due to exhaustion. These aspects created a desperate need for resolution, which in this case pushed Kim to "reach out to other moms" despite her introverted nature. Thus she found support and met role models who showed her it was possible to get through this, which ultimately allowed her to move beyond her depression.

Acute crisis. Crisis can also be a consequence of acute events such as medical emergencies, although the numerous parents I asked about crisis only rarely provided examples of this type. One parent described a single mother she knew who had a young adult child with autism. She was running an errand with her daughter briefly alone at home when she had an episode of atrial fibrillation complicated by a seriously low heart rate for which she later required a pacemaker. When the ambulance arrived, she explained she could not go to hospital because her daughter was at home and could not care for herself for long periods. After signing a waiver with the ambulance attendant, she drove home despite the strain of her low heart rate, where she called the local autism service agency to arrange for emergency respite before finally admitting herself

to the emergency department. There was one other case in which respite represented the necessary solution to a potentially catastrophic medical emergency affecting the parent.

  Responses to resolve crisis. Finally, crisis (and sometimes sub-crisis levels of stress) forced parents to respond in different ways to find a resolution to their situation by restoring some kind of balance. For Kim, above, this meant turning to other mothers for psychological support for her depression when the necessary support was not available anywhere else. Dilin, provides a more extreme example how a progressing chain of stress-related events, which led to multiple crises, eventually force a psychological response that allowed her to continue functioning at a more normal level. As described above (see *Work-related resource loss reducing capacity to cope*), Dilin suffered from exhaustion due to prolonged resource loss (recall her quote about needing to "put the parking brake on for a while, or else it's just going to explode"). But a sequence of other aspects of her situation also contributed to her substantial stress. She suffered from generalized anxiety disorder triggered by navigating intervention, and depression due to overextending herself that led her to shut the world out. It was the combination of disagreement with her husband about approaches to intervention and her neglect of their relationship after dedicating most of her time to navigating that led to marital crisis ending in divorce. Her husband's subsequent unwillingness to provide any financial support, combined with the fact they had previously re-mortgaged the house to finance intervention, led Dilin to financial crisis in the form of personal bankruptcy where putting food on the table for her three children became a greater concern than her son's autism. The stress of these events, combined with the underlying autism-related stresses and the associated neglect of her self, finally took a toll on Dilin's physical health. She developed hypertension, and was even hospitalized for a "mild heart attack" while home alone caring for her children. This experience of physical crisis,

combined with her doctor's warnings that she "had to find ways to focus on [her]self," forced her to recognize the catastrophic possibility that her children could potentially be left with nothing if she continued at the same pace without tending to her health. This was the breaking point that pushed her to come to peace with her limits and seek balance both physically and emotionally with a new psychological strategy. "I gave myself permission basically to take some time off," she said, and further reflected that, "one of the things I *have learned* since then is that you need to change your expectation level when you're dealing with autism." Other parents also described a desperate need for "change in direction" that they achieved through psychological strategies or by changing their mode of functioning.

Summary of key elements and their basic relationships

I have described some of the major elements that make up parents' problematic situation of *having to make their own way* as they struggle to navigate intervention. In Figure 4.2.1 (*Elements in the situation of having to make your own way*) I illustrate the basic theoretical relationships between these elements and how they relate to the central process of *making your own way*. The most central relationship, illustrated by a wide arrow, is between *concerns* and *intervention*. By definition, *concerns* motivate parents to take action to pursue *interventions*. The process by which parents become motivated and follow through on this action is illustrated as a cycle inside the arrow, labeled *making your own way*—the two arrows of the cycle represent the mutually influencing component processes of *adjusting to the need to navigate intervention* and *taking action to navigate intervention*, described in Section 4.3. The elements of *information* and *obstacles* are positioned as ingredients feeding into the central process; and *burdens* are portrayed as the main problematic consequences of this process. *Complexity*, meanwhile, pervades all elements, complicating parents' understanding and action.

At a generic level, *having to make your own way* is about healthcare consumers contending with the need to independently navigate systems of care to find the interventions they feel will effectively address their concerns. In the next section, I provide more detail of how parents interact with and respond to the elements that define their situation by elaborating the central process of *making your own way*.

Figures

Figure 4.2.1. Key elements in the problematic situation of *having to make your own way*.
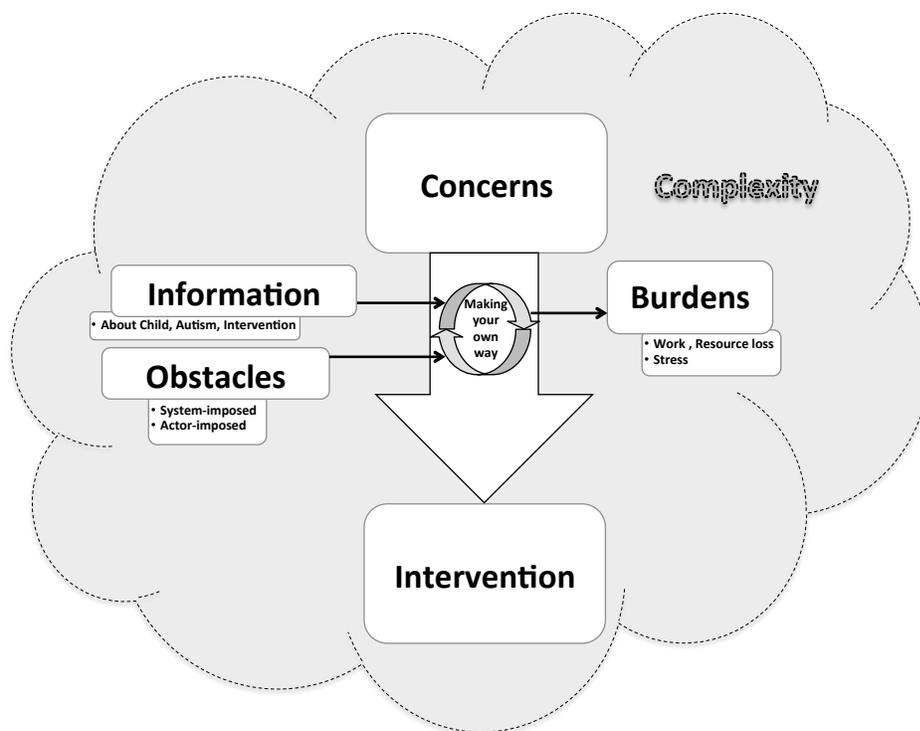
SECTION 4.3. The theory of 'making your own way'

In this section I present the symbolic interactionist theory of *making your own way*—the central explanatory process by which parents respond to the problematic situation of *having to make their own way*. Reflecting the symbolic interactionist perspective adopted (the premises of which are listed in Appendix D, *Revising the research question,* under *Methodological principles from symbolic interactionism*), this theory explains both the process by which parents form and revise the meanings they hold for the things around them as a result of varied social interactions, and the actions that parents take in response to those meanings.

Fundamental organizing elements of the theory. Even prior to using symbolic interactionism as a framework to guide ongoing analysis and interview questioning early in this study, I had observed several readily apparent examples of how parents' meaning-making preceded their action aimed at navigating intervention, both at the level of responding to autism generally and involving specific forms of action targeting more specific concerns. Thus I came to see parents' initial meaning-making as its own process, observing how it was a necessary step for parents to pass through to become ready, prepared, or motivated for the possibility of taking action to pursue intervention and information as a response. I have labeled the overarching meaning-making process in which parents understand and respond emotionally to the implications of their situation, which includes defining their options for action, as *adjusting to the need to navigate intervention* (hereafter, *adjusting*). Parents' subsequent process of acting on these meanings is labeled simply as *taking action to navigate intervention*.

These two processes, *adjusting* and *taking action*, are the overarching elements around which the theory is organized. Figure 4.3.1 represents the readily apparent feedback influence

between parents' meaning making and action, which unites these two processes in an inseparable cycle. Thus, while meaning-making is necessary for and precedes action, parents *take action* in some way throughout the course of *making their own way*, starting from the point they decide to act on the early concerns about their child's development.

Because autism is a lifelong disorder, there is an endless cycling between *adjusting* and *taking action*. Accordingly, the process of *making your own way* evolves and changes over time as the parent seeks to address quite different autism-related concerns at different points of development over the child's lifespan and the parent's own journey. I divide the social psychological process of *making your own way* into three chronological but heuristic and overlapping stages:

1) *Beginning the autism journey* is where parents respond to initial needs and realities of navigating intervention; *adjusting* begins with the parent defining the general developmental concern of autism and other early specific concerns; it is ongoing and continues indefinitely.

2) *Handling transitions* is where parents make sense of and respond to concerns arising from the various developmental and environmentally-imposed transitions that trigger or expose new autism-related problems.

3) *Easing off* is where the parent understands and responds to her situation less urgently in the context of her increasing awareness of the lifelong nature of the disorder and the implications this has for pursuing intervention as new concerns continue to arise over the child's lifespan; it is most apparent in seasoned parents whose children have reached adolescence or young adulthood, but it can be present at earlier stages provided the parent has experienced multiple cycles of *adjusting* and *taking action to pursue intervention*.

Although they can be chronologically ordered, none of the stages is defined as having any ending, as we shall see. Similarly, these stages are not conceived as distinct from each other. There is considerable overlap between them, so that each parent's story can include several incidents identified as examples of a later stage (e.g., *easing off*) occurring prior to incidents from an earlier stage (e.g. *handling transitions*). I relate each stage to its neighbouring stages more specifically within their respective subsections, below.

As mentioned above, *making your own way* consists of repeating cycles of the two reciprocal processes, *adjusting* and *taking action*. Within each cycle, the meaning-making of *adjusting* informs the subsequent response of *taking action*; meanwhile, the experience and interactions of *taking action* feed back to the parent's understanding of her situation via the process of *adjusting*. Furthermore, cycles of *making your own way* can be conceived as occurring at different levels of abstraction. At the most basic level, each cycle corresponds to the pursuit of intervention aimed at any single concern; at a more abstract level, cycles of *adjusting* and *taking action* can apply more generally to the parent *making her own way* as a whole over the lifetime of the child, or alternatively at the level of any of the three stages.

Adjusting and its sub-processes. At any stage or level of generality, parents engage in *adjusting to the need to navigate intervention* by constructing meanings of the external elements in their situation—including concerns, intervention, information, obstacles; and sometimes the burdens of work, resource loss, and stress. It is a cognitive and emotional process that invariably involves several interrelated sub-processes: *defining concerns* related to the disorder, *informing oneself* through active and passive interactions with varied information sources, *seeing what is involved* in taking action to resolve concerns, and *emotionally adapting* to implications parents see for themselves and their child after reflecting on aspects of their situation and the process

they are engaged in (Figure 4.3.1). Thus, through all the sub-processes of *adjusting* the parent progressively becomes prepared and motivated for *taking action* to address her concerns.

Taking action and its three main categories. *Taking action* refers to anything the parent does actively or willfully in response to her understanding of the situation. Parents feel motivated to take action when, according to their understanding, they perceive something about their situation to be problematic or unresolved and conceivably within their power to affect. While action is often motivated by the problematic aspects related to concerns, it can also be motivated by positive aspects including concerns for the happiness of one's child (Section 4.2, *Concerns*, *Long-term concerns*), or by the hope for better outcomes that gets kindled after the parent sees progress in her child (see below, *Urgency*, *Hopeful child outcomes*). I define three categories of action (Figure 4.3.1). The primary target of action when *making your own way* is intervention, the pursuit of which I label *taking action to pursue intervention*. Parents, however, recurrently described a second major target for their action—information, be it about autism, other specific concerns, or about intervention. I label this similarly, *taking action to pursue information*. There was also evidence of a third category of *taking action*—the subtler forms of action that are laced throughout discussion of the sub-processes of *adjusting*. For example, as we shall see, the sub-process of *coming to understand the child has autism* (a form of *defining concerns*) comprises steps (such as *starting to question the signs*) that involve parents' motivation and action. I label such instances of action generically, *taking action within sub-processes of adjusting*. *Navigating intervention* comprises *taking action* both *to pursue information* and *to pursue intervention*.

Organization of the section according to stages. The first subsection of Section 4.3 provides an extensive account of the first stage of *making your own way*: *beginning the autism journey*. Although I account for the cyclic processes of *adjusting* and *taking action* within each

of the three stages of making your own way, I describe and develop their central characteristics and properties most fully within this first subsection. In particular, I develop the process of *adjusting* in greater detail here since it is most intense when *beginning the autism journey* and that challenge to parents' understanding of their situation and their self is most wrenching. Also within the first subsection, I discuss the process of *going into high gear*, an urgent and intense mode of *taking action* that is almost a hallmark of the experience of parents of children with autism; although most characteristic of the first stage, I also observed parents *going into high gear* in the latter stages. The final two subsections, account for how *making your own way* evolves in the subsequent stages of *handling transitions* and *easing off,* respectively.

Beginning the autism journey: Stage of defining and responding to initial concerns

Beginning the autism journey represents the first stage of making your own way. As will be discussed in more detail, both adjusting to the need to navigate intervention and taking action to pursue intervention typically begin before the time of diagnosis, as parents start to make sense of the signs that lead to the recognition of autism. This stage can be compared to other health disorders whose onset is difficult to determine and where signs are often noticed gradually over time before the patient or caregiver develops an understanding of what the underlying problem is. What sets this first stage of making your own way apart from the others is the fact almost everything related to the child's autism—ideas about the child and about parent's own future, the parent's social world, and the expansive knowledge, actions and skillset required of her—is new for the parent, representing a enormous task of adjusting.

As with later stages, while *beginning the autism journey* has an identifiable starting point, it has no identifiable finish. This is because is because the parent's *adjusting* to the need to respond to the initial central concern of autism never has a defined end, as new aspects that

expand the parent's understanding of this lifelong disorder constantly have the potential to arise throughout the child's development. Since this stage is concerned with adjusting to autism generally, it not only overlaps, but encompasses, the other two stages, which are concerned with different *aspects of autism* that can be experienced as *new*—the second stage, *handling transitions*, is concerned with transitions in autism, while the third stage, *easing off*, is concerned with its lifelong nature.

Adjusting and taking action within the first stage of making your own way

Recall that each cycle of *adjusting* and *taking action* generally centers on understanding and resolving a single autism-related concern. Concerns, meanwhile—and the corresponding cycles of *adjusting* and *taking action*—can range from the concrete and specific to the abstract and general. What parents predominantly emphasize *adjusting* to and *taking action* towards within the stage of *beginning the autism journey* is the general developmental concern of autism, although they also generally describe *adjusting* and *taking action* with respect to various specific early-stage concerns. As we shall see, *adjusting* at the very general level of autism is ongoing as the parent begins and continues through her journey through her child's disorder, which is lifelong. Many of the characteristics of *adjusting* and *taking action* illustrated specifically at this stage are also seen at other levels and stages, making them foundational for understanding these processes in the later subsections of *Handling transitions* and *Easing off*.

The process of *adjusting* and *taking action* to the new needs and realities encountered while *beginning the autism journey* comprises several interrelated sub-processes within *adjusting* and categories of *taking action* that parallel both the generic sub-processes of *adjusting* and the categories of *taking action* outlined previously in Figure 4.3.1 (see Table 4.3.1). I briefly introduce these in the order they will be discussed in the remainder of the subsection.

For the parent who is *beginning the autism journey,* the process of *adjusting* commonly starts as the parent begins a sub-process of *coming to understand her child has autism*—the stage-specific manifestation of the generic sub-process of *defining concerns*—which involves defining the general developmental concern of the disorder itself with its lifelong implications for the child and the parent; as mentioned, more specific (often functional) concerns within the disorder must also be defined. Conviction of the child's autism is what triggers many parents to begin *pursuing a diagnosis*, the first manifestation of *taking action to pursue intervention* directed at the general concern of autism; the parent may, however, begin *taking action to pursue intervention* directed at more specific concerns before *pursuing a diagnosis*.

While *coming to understand the child has autism*, parents engage in progressively *informing the self* (both actively and passively), developing knowledge about autism (the concern) which they usually had little prior knowledge of, understanding what to do about it (intervention), and learning how to interact with the systems they will first try to access intervention and services from.

In beginning to interact with systems of care (e.g., consulting clinicians in *coming to understand the child has autism*) and information sources (e.g., researching red flags for autism), parents begin *seeing what is involved*. This involves learning, both from these early interactions and by *informing the self* about potential intervention, and about the requirements and realities of their situation—such as the need to take personal responsibility for navigating intervention (see Section 4.3, *Urgency*, *Learning it is up to parents to take action*), or the nature of the obstacles and burdens they will encounter. Along the way, parents reflect on the implications that these requirements and realities have for their child and the parent's self, responding by *emotionally adapting* to their new situation and the need to navigate intervention.

By means of the above sub-processes of *adjusting,* parents progressively prepare and ready themselves for *taking action to pursue intervention* to address the concern in question. Finally, a majority of parents *beginning the autism journey* (and sometimes at later stages as well) enter a distinctly urgent and intense mode of action by *going into high gear*, in which they devote substantial expendable personal resources to pursuing solutions for their child and seem to function at an unsustainable pace.

Table 4.3.1: The generic sub-processes within *adjusting* and categories of *taking action*, and corresponding manifestations of each discussed within the stage, *beginning the autism journey.*

Generic sub-processes of *adjusting*, and generic categories of *taking action*	Stage-specific manifestations of each sub-process or category discussed within *Beginning the autism journey*
Adjusting	
Defining concerns	Coming to understand the child has autism
Informing the self	Initially informing oneself about autism
Seeing what is involved	Experiencing the work of pursuing a diagnosis
Emotionally adapting	Accept the possibility of autism, Release culturally-based hopes and expectations for the child's future, Accept an uncertain and fearful future for the child, Surviving the emotional strains of making your own way, and Redefine one's role and self according to new occupational requirements as the parent of a child

	with autism
Taking action	
Taking action to pursue information	Sharing (with other parents)
Taking action to pursue intervention	Pursuing diagnosis Going into high gear*
Taking action within sub-processes of adjusting	Starting to question the signs Knowing something is wrong

*Note: *Going into high gear* is highly characteristic of *beginning the autism journey*, but also happens in the other two stages.

Coming to understand the child has autism: Defining the broad developmental concern

As mentioned, *adjusting* starts with the parent realizing the problem(s) she initially perceives are indicators of a greater issue that she defines as a concern. The most prominent example of *defining concerns* occurs in the first stage, with parents *coming to understand their child has autism*. When parents pass through this process, they usually only reach full certainty of their child's autism (the overarching concern) after gradual increases to their awareness— unlike many other child conditions, which parents may become aware of after perceiving clear signs that may be quickly and straightforwardly confirmed upon engaging with the healthcare system. Parents of children with autism follow many highly variable paths to their awareness. Most, however, become aware their child has autism well before any diagnosis, leading them to respond by taking action to pursue the diagnostic assessment. The less common situation, in which parents initially become aware of autism at the point of diagnosis, was experienced by a minority of participants in this study and will be also described—for example, in the course of consulting a qualified clinician regarding isolated concerns who then diagnosed autism.

Below, I start by establishing some characteristics of the generic process of *defining concerns*, of which *coming to understand the child has autism* is an example. Next, I discuss the relevance of parents' prior images and future expectations. I then outline a progression of four common steps that parents described passing through before reaching the awareness and, ultimately, certainty that their child had autism. These steps involve interacting with both the self and with information sources (i.e., by communicating with professionals, conversing with family and acquaintances, consulting web sites and other text-based information sources, observing of the child, etc.). I also review parents' process of *emotionally adapting* to their first understanding that a child has autism. The progression of steps leading to awareness of autism begins, prior to noticing any suggestive problems, with the parent's initial image or understanding of her child and of her own role and parental relationship with respect to that image. As we shall see, parents transform this initial image of their child as they cross progressively certain thresholds of understanding that their child has autism. As certainty about the presence of a developmental concern grows, parents become motivated to pursue more types of action.

Defining concerns: Some characteristics of the generic process

Defining concerns is a process by which parents (or any healthcare consumer) come to perceive and ascribe deep personal meanings to an autism-related problem that is facing them, meanings that necessarily motivate them to take action to address or resolve it. Recall, concerns may be general (e.g., the general developmental concern of autism) or specific (e.g., toileting, apraxic speech). Distinct from concerns, problems are the initially perceived signs of what parents ultimately identify with an underlying issue, or concern, to be addressed. In defining concerns, parents construct understandings about the implications the concern has for things that matter to them (most often, their self or the child's wellbeing). The problematic nature of these

implications motivates parents to act to resolve concerns. The implications of concerns may be unclear or uncertain.

Importantly, the process of *defining concerns* is interrelated with some of the other sub-processes that make up *adjusting*. *Defining concerns* involves *informing the self* by interacting with various information sources to develop knowledge and refine one's understanding of the issue underlying *problems* encountered—especially those that parents commonly first perceive and later attribute to autism. As the parent develops progressive information-supported understanding of the core developmental concern (autism) and reflects on its implications for the child and her self, she also attributes emotional meaning to autism by *emotionally adapting*. The meaning thus constructed of autism is itself motivation to take action.

Integrating multiple understandings. *Defining concerns* usually requires parents to integrate multiple understandings and knowledge. For example, parents may integrate the knowledge that autism is a spectrum, which has the same central deficits across the spectrum, with knowledge since their child has Asperger's syndrome they should show some of these central deficits, but in a milder more subtle form; this provides a basis to perceive the idiosyncratic signs they witness in their child more deeply, seeing them as manifestations of a specific underlying core deficit specific to autism. By defining this underlying deficit as the central concern, they define it as the relevant target intervention rather than the outward signs. Thus when parents integrate knowledge effectively, they are better able to define more relevant concerns, and identify with greater certainty what interventions are appropriate.

The importance integrating multiple understandings became apparent in this study after witnessing parents who described struggling to define concerns. Several of these parents had children with more complicated presentations of autism—usually due to the presence of high-

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functioning autism, or other significant diagnoses such as epilepsy—where the underlying concerns related to autism were less straightforward to define. In high-functioning autism, for example, core deficits can be buried or masked by the child who is intelligent enough to compensate for social function deficits.

As a result, some such parents described their frustration after losing time and energy pursuing solutions in areas of the system that were unable to help, such as Maya whose daughter had high-functioning autism: "Yeah. I phoned everywhere. I was phoning mental health associations. I was phoning everything that I could find. Anything. Nothing." Maya had identified her daughter as needing help for anxiety-related behaviors, which she sought in general mental health settings because her daughter did not qualify for autism-specific services. Because she had had little opportunity to witness her daughter's social functioning with other children, Maya was not in a position to articulate how any social deficits might underlie her daughter's anxiety-related problems to the professionals she interacted with.

The influence of philosophies and beliefs about autism on defining concerns. An important influence on how parents define specific concerns (i.e., more specific than the broad developmental concern of autism itself) is the different philosophies or beliefs about the causes and nature of autism that parents can hold. Parents generally develop meaningful beliefs and positions about autism only after becoming aware their child has the disorder, which triggers them to pursue information about autism. As parents' knowledge of autism continues to deepen with years of experience, their philosophies about autism and disability become more reflective, and are therefore subject to revision. Parents generally construct their beliefs and positions independently after reflecting on both their experiences and the external information they process.

These philosophies or beliefs can be differentiated by the extent to which they view autism

as desirable or undesirable and, similarly, the extent to which they view autism as inevitable and irreversible or potentially reversible. While participants usually did not explicitly reference any specific ideologies that informed their views, two opposing movements have influenced the discourse and basis for parents' beliefs and attitudes about autism: the *neurodiversity movement*, which values autism and sees no point in reversing it; and the classical *biomedical movement* (or *recovery movement*), which sees autism as undesirable and proposes various biological causes that are theoretically reversible. Similar to the effects of research evidence (see Section 4.2, Complexity), there were indications in the data that the discourses corresponding to these philosophical movements percolated down and influenced parents' views—sometimes indirectly through parent interactions with professionals more directly familiar with these movements, and sometimes directly through popular books or web sites. Table 4.3.2 lists examples of some of the popular media that partially represents the discourses of each movement. Media promoting the classic biomedical perspective are generally more prevalent and forceful. Much of this media originates in the United States, and some parents commented on its cross-border origins.

Table 4.3.2. Examples of media promoting two opposing philosophical movements in autism—the neurodiversity and biomedical movements—whose language and ideas are an important influence on parents' beliefs and positions about autism.

Philosophical movement	Media sources
Neurodiversity	• Web site: Neurodiversity.com • Movie: *Loving Lampposts* (lovinglamppostsmovie.com) • Book: *Neurodiversity: Discovering the extraordinary gifts of autism, ADHD, dyslexia, and other brain differences,* by Thomas Armstrong

Biomedical	• Web site: Autism Research Institute (www.autism.com)
	• Web site: Generation Rescue (www.generationrescue.org)
	• Movie: *Finding the Words* (www.findingthewords.org)
	• Book: *The autism book: What every parent needs to know about early detection, treatment, recovery, and prevention*, by Robert Sears
	• Book: *The Autism Revolution: Whole-body strategies for making life all at can be*, by Martha Herbert

Not included in Table 4.3.2 are information sources that promote a biomedical perspective that is more progressive than the classic biomedical version because it endorses a more mainstream empirical approach to science that relies on direct clinical research evidence to support claims. This contrasts with the classic biomedical perspective, which relies on mechanistic research (for example, from animal research) and takes an indirect deductive approach to support its claims. The Autism Treatment Network funded through Autism Speaks is an organization that promotes a more progressive biomedical perspective.

Notably, most of the Ontario parents interviewed communicated skepticism regarding the classic biomedical perspective. Some even expressed indignation and anger over what they felt was misinformation spread by the biomedical movement, which had misled them in the early stages and continued to confuse the informational landscape for new parents, wasting their time and precious resources. The classic biomedical philosophy may also be problematic for professionals positioned to help the child or family with autism. A clinician may therefore not be sympathetic to the concerns of a parent who sees the root problems according to this philosophy.

Parents could define the specific signs they observe in their child as problematic enough to require intervention for two separate reasons: because they interfere with child or family functioning (e.g., inability to communicate), or because they are perceived to indicate severity of the child's autism (e.g., hand flapping). The majority of Ontario parents interviewed were not primarily concerned with eliminating these latter non-functional signs. This was because most parents had chosen not to direct their energies to eliminating autism itself. This was even true for several parents holding biomedical or recovery beliefs about autism (see Section 4.2, Information). Parents who held classical biomedical beliefs understood some signs (e.g., lack of eye contact, gastrointestinal problems causing discomfort) as both pathological indicators of the fundamental severity of autism, and as pragmatic functional problems because they interfered with the child's ability to fully participate socially or be attentive during behavioral therapy.

Although parents' specific positions were nuanced, as a generalization those who adopted the classical biomedical philosophy tended to define some of their concerns and goals for intervention at a non-specific and general level, reflecting their desire to eliminate their child's autism to the whatever extent was possible. Even pro-biomedical parents, however, generally admitted they understood it was very rare for children to 'lose' their autism completely. Sometimes parents described abandoned their desire to eliminate autism after coming to terms with it in their child; other parents sometimes abandoned this desire after being convinced by information presenting research evidence that autism is not reversible. Parents tend to hold and be influenced by the classic biomedical philosophy, therefore, more often during the period they are struggling to integrate a coherent picture of autism, and before they have learned to accept it.

Similarly, there are philosophies about disability more generally, which range in terms of their acceptance of or desire to eliminate disability. Discourses related to these more general

philosophies are equally likely to have direct and indirect influences on parents and how they define concerns. In turn, parents' advancement through progressive stages of accepting their child's autism in some cases coincides with rejection of previously held philosophies in favor of new more consistent ones. Conversely, the power of highly publicized anti-disability discourses such as the biomedical movement may slow or obstruct some parents from advancing to more progressive stages of acceptance. A proportion of parents thus continue problematizing non-functional aspects of autism and retain unrealistic hopes for eliminating the disorder. This may be harmful because dedicating family resources (time, energy, or finances) to such concerns may be later perceived as misguided and wasteful when parents progress to later stages of acceptance.

Role of prior images of the child and future expectations

To appreciate how parents *come to understand their child has autism*, it is important to be cognizant of how they start off, prior to any awareness of autism. Even from birth, parents invariably carry prior understandings or images of their child, which they inevitably modify as they continue to observe and learn more about his or her character. They also make predictions and form vague expectations about what he or she will be like in the future. Lastly, parents also maintain understandings and anticipations about their own relationship with the child, and their identity and future as a parent.

In most cases, parents start out generally naïve about the possibility of autism in their child. (Parents who may have encountered autism in a previous child represent one exception to this.) Moreover, most parents are prepared to have to modify the initial images of the child and their parental relationship only slightly, as more features gradually emerge with the child's development. In some cases, parents may also be unaware of what qualifies as a deviation from typical development as they watch their baby age through the different stages. In addition to this

naïve lack of readiness to perceive autism, the variable strength of parents' attachment to initial understandings of their child and their parenting identity has extensive influence on their responses to the emerging signs and indications that their child has autism.

Parents vary in the strength of their attachment to initial understandings of their child and parenting roles. At one extreme, parents develop powerful attachments to images of their child as typically developing baby with a "normal" future unaffected by disability. In one mother's case, attachment to the image of her child's perfection was particularly strong due to personal perceptions of limited fertility that made her only child especially precious:

> *"Well, we had really put her on a pedestal before that because…I mean, probably even more so than other parents. I was…I thought I might never have a baby. I don't know why I thought that—just things didn't happen for me. And the way I planned my life, or whatever. So when she was born, and the pregnancy was wonderful, and she was a good sleeper, like, everything was just so perfect. I used to say, "We're so lucky. We have the most perfect little baby." And so we had never ever had anything except a hundred percent positivity. So it was really hard. It was the first time that the perfection disappeared."*

This mother, who had virtually no prior knowledge of autism, was faced with drastically revising her images of her daughter when she eventually discovered her autism. Doing so was "really hard," involving a gradual process of emotionally adapting (see subsection below). She described having to release her hold on dreams she had for her daughter's future such as getting married and having children, which was highly distressing and led to consulting a psychologist for feelings of depression: "I spent about a week or ten days feeling like she had died. It was…yeah, it was really, really overwhelming. And I was just *so* sad."

By contrast, another mother, who had developed a positive image of autism from growing up with a brother who had Asperger's disorder, showed remarkable emotional readiness to revise the image she had of her son by accepting the possibility of autism. She described her initial feeling after discovering her son had autism quite differently:

> *"It was joy. And I know that that's very backward for a lot of people. But I absolutely adore my brother [the first person I knew with autism before my son]. I mean, he's at Queen's doing his Master's right now, and was accepted to the doctorate program for engineering. But he's decided not to do it. But he's a very intelligent man and surpassed all kinds of barriers that service providers and doctors had sort of said would be in place. So right away my view of autism is very different than a lot of people's. I've talked to friends who would say, 'I would be devastated if my child had autism.' And I'm like, 'Why!?' Because to me, it's not as much of a barrier as it is to others. So it was joy, because I absolutely delight in my brother. He's an absolutely amazing person and makes me laugh left, right, and center. And so I thought, 'I'm going to have one of those. I'm going to have a boy like that. This is awesome.'"*

Note that both types of parents—one uninformed and holding a more fearful picture of autism, and the other more familiar and holding a positive image of it—refer to how autism affected the image they held of their child's future. The latter parent, however, was much more flexible and ready to revise her prior image. Such receptivity to autism though, is uncommon. The majority of parents in this study tended to start out unfamiliar with autism, and initially associate it with uncertain and negative expectations for the future. Consequently, many parents described reacting strongly to the discovery of autism in their child with feelings of fear and sadness. And when this discovery was sudden and unexpected—true for a smaller proportion of parents—they also commonly described feelings of shock.

Parents who were strongly attached to the prior images they held of their child (illustrated by the first parent quoted above) generally described having more difficulty in *adapting emotionally* to eventual awareness of autism in their child. For numerous of these parents, the process of adapting emotionally included resistance to fully accepting autism, and passing through a transient phase of mourning or grieving loss of the child. One such mother, Rosa, reflected on the reasons for her and her husband's grieving as follows:

> *"But for [my husband and me], when we've talked about it since, we grieved for the kids we thought we were getting. You know, you think you're getting your neurotypical, normal children that are going to run and play. You have this idea in your head of how they're going to grow up, and the things that you're going to do with them. And when somebody tells you, "Oh, they might have autism…" all those things are sort of ripped*

> *away from you. And you have to grieve those pictures in your head that you're never going to be able to do with them. Or, that's what we thought then. I mean, that's not really the reality of it. So we went through this starting of a grieving process. And preparation, sort of preparing yourself for what's going to happen when somebody says "Yes," you know [confirming he has autism]."*

Notably, Rosa described grieving as "preparation" for accepting more certain indications that her child had autism. For some parents, grieving and resistance to fully accepting autism slows the process of *adjusting* by delaying readiness to seek or accept further more certain information about the possibility of autism, and accept the need to pursue intervention, as we shall see.

In summary, prior images of the child and parenting expectations have an important influence on aspects of parents' process of emotionally adapting to autism. The influence of these prior images is first apparent as the parent struggles with accepting the possibility of autism within the process of coming to understand her child has autism. Their further influence on releasing culturally-based hopes for the child's future, and accepting an uncertain and potentially fearful future for the child will be discussed later (see Emotionally adapting).

I now describe the first in a series of steps that many parents described passing through in coming to understand their child has autism.

Forming an image of difference.

Some, but not all, parents began the process of *coming to understand their child has autism* by noticing what initially seem like minor signs in their child. Parents commonly described responding to initial perceptions of these signs either by starting to see their child as slightly different in some respect but not in a seriously problematic way, or else by *thinking nothing of it*. Importantly, parents did not view what they perceived as worrisome or problematic enough to define it as a concern worth taking action on. Parents thus would not even take the action to investigating or seeking further information about the sign, at least at this stage. Rather, the only action taken at this step is to observe the child, and perhaps observe cues (usually other children)

in the parent's social surroundings that allow her to understand simply that an aspect of her child is different.

> One mother reported noticing difference in her son in the first year of life:

>> *"When he was born, when we took him home, one thing that I noticed about him right away was that he preferred to be alone…If he was crying and he was having a difficult time settling, if you would just put him in his crib and close the door and walk out, that's what would make him happy. And I always thought that was a little bit strange, because I do have nieces and nephews and none of them were like that. People would tell me he's just one of those babies. Some babies get over-stimulated."*

In this, and many other cases, the mother forms her image of difference based on comparison with other children. She also comes to understand that it is not a reason for concern at least partly from interacting with others who tell her not to worry.

Parents sometimes described their internal rationales for why the differences they saw in their child should be expected or made sense. For example, one mother, who was particularly unsuspecting of autism, explained her initial observations that her son was extremely clingy and unable to detach from her as follows: "Both my husband and I were very shy children. So we weren't surprised when [our son] seemed to shy away from other people…because we had both been, not quite that shy, but we had both been shy children."

When parents responded to early signs by *thinking nothing of it*, they usually later reflected regretfully that this had delayed them from *coming to understand their child had autism* and taking action to pursue intervention earlier. One mother, who had thought nothing of her son's delayed speech at age two because her peers' sons were also delayed speaking at that age, remarked on the common language that sometimes influence parents to respond nonchalantly this way, " 'Boys will be boys." That's my other least favourite expression next to 'all kids do that'—'boys will be boys.' " Or, as another parent was told, "He's just a late bloomer." These social explanations for why the parent should not worry sometimes also pressured them to ignore

their own instincts regarding possible problems. Parents in this situation therefore commonly regretted failing to question others' reassurances and take action sooner.

Another parent reflected on her inclination to believe external messages that nothing was wrong and suppress her more worrisome intuitions: "So you have a tendency to trust your doctor and go, 'OK, everything's fine.' Because you want everything to be fine. So you kind of push your own doubts away. If the doctor thinks everything's fine, surely everything must be fine and we're just seeing things that aren't there. In hindsight, I wish I had listened to myself more." Instead, parents such as this often described persisting in this phase of simply observing their child, and delayed further defining and refining their image of difference until something convinced them to see it as potentially problematic and take action to investigate things further. Parents who "want everything to be fine" at the step of *forming an image of difference* is thus one of the explanations for denial, which delays not only *coming to understand the child has autism*, but also diagnosis and intervention.

There is another explanation for delays in parents' progression through the steps of *coming to understand the child has autism*. Many parents lacked previous experience with young children, usually because they were raising their first child. Such parents generally had more difficulty in *forming an image of difference*, which they commonly attributed to their ignorance of typical development and the normal age ranges for reaching specific milestones. Parents frequently shared comments like, "He was my first baby, so I had no clue about how things were supposed to go." Sometimes they informed themselves what to look for after consulting parenting reference books or, rarely, being informed about developmental checklists such as the Nipissing District Developmental Screen. Other times, however, it wasn't until they interacted with an observant professional who informed them that some aspect their child's development

was delayed or abnormal. At the point when parents realized a difference was potentially problematic, most would typically respond according to subsequent steps of *coming to understand their child had autism*—more commonly by *starting to question the signs*, and sometimes by more anxiously *knowing something is wrong*.

Starting to question the signs

A parent starts to question the signs when what she observes in her child triggers a vague suspicion that a sign might be something problematic, and is therefore merits investigating further. It is thus the first formulation by the parent that something is sufficiently out of the ordinary to warrant taking action. This is not action to intervene, however, but rather to assess and begin to define a potential problem that may be reason for concern. The kind of action the parent becomes motivated to engage in at this step of *coming to understand the child has autism* is therefore limited to information gathering and reflection, with the goal of developing a picture of what may be a concern requiring intervention. In this step, parents seek to develop an understanding of the problem that is just clear enough to indicate whether further action is called for and, if so, what their next action should be. (Parents in this step are thus engaging in both central symbolic interactionist processes described by Blumer [see Section 4.1, *Revising the research question*]: taking action based on prior understanding, and developing their understanding to inform further action.)

Perceiving mildly problematic signs. *Starting to question the signs* commonly begins with noticing one or more signs that she perceives to be mildly problematic. For many parents, some information about these signs came through other caregiving professionals positioned to observe the child in the parent's absence, such as a daycare provider reporting observations in a standard communication book or verbally at the end of the day. Often, parents gradually pieced together

multiple signs, from multiple settings, over a period of time that, together, suggested there was something at least mildly out of place with their child. One mother recalled how she slowly moved beyond seeing her son as just different:

> *"It wasn't until, I guess, just after he turned a year. He hated his first birthday party, which surprised me. He screamed through the whole thing. And Christmas that year was hard… I remember we'd gone to playgroup. He wasn't playing with the other kids. He would sit with me, which wasn't untypical because there were other kids that just sat with their parents. He wasn't interested in toys. He wasn't interested in venturing away from me. One of the other moms was saying the other day he was eating soup on his own and I was like, 'Wow!' So I just kept putting things in the back of head and thinking, 'Oh. Oh,' you know."*

Thus, questioning of early signs often leads to watching or monitoring the child for new signs, sometimes tracking things that emerge in written logs. Whether their awareness developed gradually or suddenly, parents' perceptions about the potentially problematic nature of the signs they witnessed led to internal conversations (with the self or with a spouse) that eventually crossed a threshold for *taking action to pursue information* to investigate things further.

    Questioning non-specific versus autism-specific signs. In *starting to question the signs*, parents generally approached their information-seeking actions differently depending on whether they were aware or naïve of the fact that autism could be a possibility. If they were aware of autism as one possibility, parents eventually proceeded to obtain information about the signs of autism—for example, by interacting with information about *red flags*, the commonly established indicators of the disorder—and continued to question whether the signs they observed in their child indeed suggested autism. Alternatively, if parents were naïve about the possibility of autism, they would instead proceed by seeking the root of problems that they perceived to be isolated and not necessarily related to autism—such as pursuing hearing tests for what they considered was a possible hearing problem, or arranging a speech and language assessment to investigate perceived speech delays.

For parents who were aware of autism as a possibility, questioning signs frequently led directly to understanding the child had autism. Parents who failed to connect the signs they observed to autism, on the other hand, sometimes had to first progress to the point of *knowing something was wrong* in a non-specific sense (i.e., unaware of autism as a possibility), which was more likely to motivate them to seek the help of professionals who were better equipped to help them consider autism as an underlying concern.

Asking professionals. In seeking information, many parents first consulted clinicians (often their family physician). The clinician consulted would respond in one of three ways: either to confirm the problematic nature of the sign, turning the parent's vague suspicion into a real concern for the parent (pushing her to either of the next two steps of *coming to understand the child has autism*; and in at least two cases, identifying autism for the parent); deny or play down significance of the suspicious sign (often leading to delay in the parent *coming to understand the child has autism*); or provide what the parent considered to be an unsatisfactory answer to her questioning, in which case she sometimes became motivated to seek further information elsewhere. Parents who consulted clinicians at the step of *starting to question the signs* were generally less seriously concerned than parents consulting clinicians at later steps in the process. As a result, they were less likely to insist their concerns be taken seriously after clinicians initially denied or played down their significance, and more often delayed taking further action to investigate the signs themselves as a result. These were therefore the earliest instances of obstacles to *making their own way* that parents described.

Being guided to awareness by professionals. In multiple cases, the parent reported being encouraged to *start questioning the signs* by a tactful professional, who they usually had consulted in the course of questioning a sign they were not yet aware necessarily involved autism.

Sarah, for example, described how she and her husband were prompted by the developmental worker providing follow-up services related to their twins' premature birth, "that actually said to us, 'At what point do you guys want to talk about the fact that these delays aren't…we're not seeing any catch-ups?' " Since some types of professionals are not qualified to diagnose autism, many took care to avoid using the label for the disorder and instead employed more tactful and roundabout ways to raise the parent's awareness (see Section 4.1, Obstacles, *Censored information due to liability concerns*). When professionals were qualified to offer diagnostic opinions, on the other hand, and proposed the possibility of autism more directly, parents were generally initially taken off guard by this new information. In either case, however, parents described how professionals' prompts raised questions in their own minds that led them to seek further text-based information (such as by looking up and comparing the red flags for autism) or begin new conversations that could increase their awareness.

Many parents described receiving such prompts and encouragement to question the signs, not just from professionals, but also relatives and acquaintances with some degree of expert knowledge. This ultimately had the effects of gently guiding parents past feelings of denial, facilitating earlier awareness of their child's autism, and helping them in *taking action to pursue intervention* earlier than they otherwise might have.

Asking other parents. Some parents *started questioning the signs* they saw by consulting non-professionals. This often included talking to other people in their social network, especially other parents of children around their own child's age. Parents compared their own child to the norms of others this way, developing further understandings of how the signs they had observed were abnormal.

Researching. *Starting to question the signs* is when parents start *informing the self*. They inform themselves about the child through observing and comparing signs to other knowledge, as we have seen. They also gain information about the child and sometimes about autism through interactions with professionals, relatives, other parents, and acquaintances. Finally, parents who were cognizant of autism as a possibility described *researching*, most often to follow up on information they had been guided to by a knowledgeable expert. When first researching autism, parents almost always began by consulting the internet via search engines such as Google. At this stage, researching consisted mostly of looking up unfamiliar names of specific disorders they had heard of (e.g., Fragile X syndrome, PDD-NOS) or finding checklists for autism. In other words, parents were first motivated to find answers to the more focused question of whether their child had a form of autism; they generally became increasingly motivated to pursue information the *meaning* of autism later, as they gradually became more convinced their child had autism.

Perceiving successive new signs. In some cases, additional new signs arose after the parent had begun questioning initial signs, forcing them to re-question the child's developmental status more seriously. This happened particularly, for example, among the few parents who described witnessing a child's sudden regression to autism. These newly arising signs not only motivated the parent to seek answers to her questions with greater urgency, but they led some parents to progress more quickly to the next step, *knowing something is wrong*. For other parents, new signs motivated them to research what they observed, which quickly resulted in *being convinced it's autism*. Some parents experienced a newly arising sign as directly problematic, motivating them to respond immediately by *taking action to pursue intervention*. This sometimes happened even if the parent had not yet perceived autism as a possible underlying concern. The action that parents pursued as a result, however, sometimes led to interactions with clinicians who guided

the parent to awareness of autism. Thus, newly arising signs generally hastened parents' progression through subsequent steps of *coming to understand the child has autism*.

In summary, *starting to question the signs* naturally leads the parent to either of the next two steps, *knowing something is wrong* or *being convinced it is autism*. Actively questioning the signs—by interacting with professionals, other parents, family members, or text-based information sources— is a form of *taking action to pursue information* that generally continues throughout the remainder of the process of *coming to understand the child has autism*.

Knowing something is wrong

Parents enter a new step in *coming to understand their child has autism* when they finally interpret that the signs they have observed indicate something sufficiently seriously wrong with their child to warrant their more urgent attention and action to address. For example, multiple parents progressed through thinking their child had a problem with speech or hearing, prompting hearing tests and other assessments; but at some point these parents came to understand these narrow functional problems were part of a broad impairment in social function, leading them to become worried and motivated to take action because of the certainty that something was more seriously wrong with their child. In many cases, parents reach the point of *knowing something was wrong* after interacting with others with expertise (professionals, or knowledgeable acquaintances or relatives), who in turn interpret the signs for them and guide them to see the more serious nature of the problem earlier than they otherwise would have.

The transition from the prior step of *starting to question the signs* to *knowing something is wrong* is sometimes gradual, particularly when parents are not ready to abandon the explanations they had used to rationalize signs previously perceived as only mildly problematic (see *Forming an image of difference*). Sandra recalled discarding prior excuses for delayed speech as follows:

> *"Actually, I worried for a long time because I was telling myself, 'No, it's going to happen next month. He'll talk next month. It's gonna be next month,' you know. I knew something was wrong. But then I was telling myself, 'You know what, maybe it's a little too early. You know, kids, sometimes they develop in different ways. So maybe he's taking a little longer. He will talk. He will talk.' That's what I was telling myself. But then I said, 'Uh-oh, that's it. We have to do something now.' "*

The distinction between the prior step, *starting to question the signs,* and *knowing something is wrong* can also be subtle because both are accompanied by motivation to question the signs by *taking action to pursue information* to understand the nature of the problem. Unlike the prior step, however, when parents reach the point of *knowing something is wrong* they generally become motivated to take action to intervene. Thus, the goal of understanding the problem here is not to determine *whether* intervention is necessary, but rather to more quickly understand the problem clearly enough to know *how* to intervene. Most parents begin to experience a pronounced sense of urgency regarding the need to take action, caused by feelings of fear and anxiety about their child's wellbeing and uncertainty about the future and the problem facing them. The action parents take as a result of *knowing something is wrong* is not limited to *pursuing information*, but also includes *pursuing intervention* to address the problem.

Beginning the process of emotionally adapting. Parents first enter the process of *emotionally adapting* to their situation as soon as they see their situation as serious enough to require a realignment of the expectations they have regarding their child and their self. This generally begins at the point of *knowing something is wrong*, as parents come to terms with their emerging understandings of the usually serious developmental problems facing their child—such as by partially releasing culturally-based hopes and expectations for the child's future, and by starting to accept an uncertain and fearful future for the child (see *Emotionally adapting*, below).

An important distinction was made previously between parents who have become aware of autism as a possibility for their child and parents who remain naïve of autism as a possibility (see

Starting to question the signs, *Questioning non-specific versus autism-specific signs*), which is also relevant at later steps of *coming to understand the child has autism*. At the point of *knowing something is wrong*, each of these two types of parent perceives different aspects of their child's condition to be a sufficiently real threat to the child's future that they experience the need to realign their expectations. Parents who are naïve of autism as a possibility usually perceive broad functional problems of unknown etiology (particularly social function) or other non-autism diagnoses (such as attention-deficit/hyperactivity disorder [ADHD]) as the cause for concern. Parents who are aware of autism as a possibility are distinguished at this step both by their drive to research autism more deeply to begin understanding its meaning and know how to intervene, and by their readiness to begin *emotionally adapting* to autism as a plausible eventuality.

Autism-aware parents begin *emotionally adapting* at the point of *knowing something is wrong* most evidently by researching information about autism more intensively, which at this stage typically consists of interactions with the internet. Numerous of these parents described strong emotional reactions to the online information they encountered, the most common response being fear. Passing through fear triggered by a combination of growing awareness one's child had autism and absorbing the all-too-prevalent information that painted a fearful picture of autism appeared to be an essential part of the process of *emotionally adapting* for many parents. One parent dyad described their early explorations of autism information as a hesitant process during which, according to the mother: "I think both of us were probably a little afraid of what we'd read. So we read sparingly. We'd see [something about autism], we'd read…and then we'd kind of back off." The father recounted how his enthusiasm for exploring autism information was influenced by his readiness to accept the possibility that their daughter had autism:

> *"I would convince myself that…I'd read something about autism that, you know, in retrospect, seemed to square exactly with her behavior. And then I would just sort of try*

> *and find those exceptions. And I'd think, 'Oh! But, you know, she laughed that one time. Kids with autism don't have a sense of humour.' Or, you know, 'She hugged me. So, kids with autism aren't affectionate. So it couldn't be autism.' [chuckles]"*

Their willingness to explore and accept autism information was also influenced by the frightening nature of this information. They, and numerous other parents, described information being frightening because it presented images of severe autism and its outcomes, which they did not yet understand might not necessarily apply to their child. Since the expected new realities such information presented could be so exaggerated, some parents found it more difficult to adapt emotionally. Eva described how frightening information interacted with her process of *emotionally adapting* to accept the possibility of autism:

> *"And that was about all I could handle. I couldn't go to any other websites at that point because I was still in shock, because I thought my whole life, or actually [our son's] whole life was over, at that point. I was positive. I said "We're going to have to institutionalize him," like, you know, all those horrible things from the fifties that you think about."*

Shock served as a protective response that prevented Eva from seeking and absorbing further information as she faced the highly emotional struggle of realigning her future expectations for her child and her self. Several other parents reflected resentfully on the frightening information they encountered in their early research as contributing needlessly to their stress at this time.

Denial: An obstacle to knowing something is wrong. Images of severe autism and negative prognoses (often presented in online information sources) represented only one possible reason behind autism-aware parents' hesitancy to accept autism as a possibility in their child. The process of *emotionally adapting* to accept the possibility of autism was also slowed for many other reasons underlying what parents later reflected on as their (or their spouse's) state of *denial*. A common reason cited for denial was the fear of labeling and therefore isolating or stigmatizing the child, parent, or family—particularly among parents familiar with foreign systems of care from their home countries. As one mother explained, "Because you don't know

where [the label is] going to take them…You just want your child to fit in, right?" Understanding what could be gained in terms of helpful services after acknowledging a child's autism helped at least one parent overcome this form of denial. Understanding that some Ontario services promoted integration rather than allowing isolation of children with special needs further counterbalanced fears of stigma. Understanding the importance of intervening early (see Section 4.3, *Urgency*) also motivated some parents to overcome denial.

Denial provides the most powerful explanation for variation in how quickly and completely parents pass through the process of *emotionally adapting* to accept the possibility of autism, as signs of problems with a child's development continue to emerge. Often, denial prevents parents from even reaching the point of *knowing something is wrong*. In some cases, for example, the father remained resistant to accepting that something was wrong even after the child had received a positive diagnosis of autism, the mother meanwhile having long since progressed to pursuing intervention. One mother offered the following insight into why husbands such as hers were slow to accept the idea that something was wrong:

> *"I was the one that spent most time with him. My husband worked shift work. So he would only see [our son] in the morning. And then at the end of the day when he'd get home, [our son] would be in bed. So when I would say, '[Our son] had a tough night," or 'He had a tough day,' he would say, 'It's because you're here by yourself. And I'm sorry I can't help you.' He didn't see everything that I saw because he didn't spend as much time with him as I did."*

Another mother expressed, in her husband's presence, how denial could have been a necessary part of his process of emotionally adapting to accept the possibility of autism:

> *"I didn't know if [being in denial] was because that's what was easier for him, because he found it hard emotionally to face the fact that that's what was wrong with [our son]. Or, you know, it just took him time. That's all. It took him more time than it took me."*

In other cases, denial in a spouse (more commonly the father) represented an obstacle to the mother's motivation or ability to *take action* in response to *knowing something is wrong*.

Some fathers were in such denial that their resistant responses sometimes delayed or even blocked the mother's pursuit of a diagnosis or intervention—for example, by limiting access to financial or other resources. Fathers' delays in accepting were also acknowledged as an important source of marital friction.

Being doubted by others. Parents also commonly described *being doubted by others* at this step, including spouses who may have been in denial, other relatives, and professionals (most commonly, family physicians). Several mothers reported being treated or labeled by those around them as if they were "crazy" for thinking their child had autism or autism-related problems. Being doubted by these different actors had various effects that impeded their motivation or ability to pursue action to address what they perceived was a problem, such as by causing a lack of confidence (see Section 4.2, Obstacles). Caroline, who progressed from researching signs to suspecting her child had sensory processing disorder or autism, summarized the emotional effect this had for her: "Then it makes you feel like crap, because you're thinking, 'Nobody else sees this? What's wrong with me that I think there's something wrong with my kid? Maybe it's not my kid. Maybe it's me.' " Numerous other parents reported having highly self-critical thoughts after being doubted.

Seeking help from professionals. When *starting to question the signs*, parents' predominantly sought professionals' help for answering questions about what they were witnessing in the child. At the point of *knowing something was wrong*, however, clinical interactions involved requests for more direct and specific help, either in the form of intervention to address the problems that had become a reason for concern, or in the form of referrals to the appropriate specialists who could definitively identify the source of the problem. Seeking help from professionals (usually within publicly funded agencies) was the most common form of

action to pursue intervention parents described prior to the diagnosis, where intervention could include diagnostic services to reveal what needed to be done. Parents sought referrals from family physicians, followed referrals or recommendations from community-based professionals, or self-referred to community or regional child services—in many cases without an inkling the problems they were seeking intervention for had anything to do with autism.

Parents were also more insistent when interacting with professionals at this stage, motivated both by their certainty that something was wrong and by their mounting sense of urgency. They therefore became frustrated when access to intervention (including further assessment) was blocked by obstacles such as dismissive responses from professionals. Because parents were more certain about the existence of problems requiring intervention, they often expended additional personal resources to pursue alternative solutions when these obstacles promised to block or delay getting needed help.

Being convinced it's autism

Parents usually reach the point of *being convinced it's autism* by one of two routes: reaching certainty on their own after integrating the signs observed in their child and information about the indicators for autism; or after being informed by others with expertise that their child has autism and subsequently *emotionally adapting* to this information and its implications before accepting it as credible and internalizing it as certain knowledge themselves.

Reaching certainty on one's own. While many parents reach certainty on their own after passing through previous steps of *coming to understand the child has autism*, some parents may have skipped past some or all prior steps at the point of *being convinced it's autism*. The following mother responded immediately to the signs she observed in her child by *being*

convinced it was autism, primarily because she had been sensitized to the significance of those

signs from prior experiential learning about autism:

> *"Up to [age one] we didn't have any concerns. She was saying the typical words that a child that age would say, like, baa, and ma-ma, and all that stuff. And she was friendly and everything. And then sometime, I'm thinking early [fall], I was feeding her day after day, and I just started noticing that she wasn't looking at me. And then I started doing a few tests by calling out her name. And it was like she was* gone. *So I called our doctor right away because I knew exactly what I was dealing with. And I went down there and basically said, 'She has autism. Send us to the right people, please, and hurry.' "*

She credits her early response and the expertise of the physicians who helped her for the fact that

her daughter was diagnosed as young as 20 months. Other parents skipped previous steps before

being convinced it was autism because they were previously unaware of anything wrong before a

physician informed them their child had autism, sometimes in the context of a diagnosis.

In most other cases, however, parents who reached certainty on their own had *started to*

question the signs in their child earlier and subsequently first became aware of autism as a

possibility rather than a certainty. This led them to research autism further to acquire sufficient

knowledge of it—which they sometimes integrated with existing knowledge from prior

professional, educational, or experiential learning—to be confident their child had the disorder.

Most of the parents who described becoming certain about their child's autism on their

own recalled checking off a high proportion of the red flags for autism, or noticing what they

understood to be distinct signs of "classic autism." Parents who described observing exceptions

to the classic presentation of autism, however, more frequently described delays to recognizing

autism due to simple confusion or to their making of excuses to resist being convinced their child

had autism—at least one such parent referred to herself as in denial. As a result, some of these

parents described following extended paths, sometimes involving interactions with numerous

professionals or additional research, before being convinced their child had autism.

Emotionally adapting after being informed by others. Numerous parents *come to understand their child had autism* after being informed by others with expertise in autism—either clinicians, or trusted acquaintances or relatives perceived to have the necessary knowledge or training—who themselves are certain the child has autism and communicate this in a factual manner to the parent. Among the parents who learn their child has autism after being informed this way, there is variation in the time required for *emotionally adapting* to the information being communicated before accepting it as credible and internalizing it as certain knowledge, particularly when the news triggers initial responses of denial and shock (see also similar descriptions of *emotionally adapting* and *denial* in the step of *Knowing something is wrong*).

Parents who were still naïve about autism as a possibility at the point of being informed by others about the certainty of their child's autism[9] more frequently responded to the news of autism with shock and denial. As an example, while Alyssa had reached the point of *knowing something was wrong* with her son, she thought he had ADHD and was shocked to find out the signs she had observed indicated autism:

> *"I knew nothing about autism. I thought autism, you're sitting in the corner banging your head against the wall and you're lining things up. But it's funny, because he did line things up. Like he did have some certain things. But I thought, 'No, no, no.' Because he has that [ADHD], he can't have that [autism], you know. So it hit us like a...we hit a brick wall when we sat there and we actually received the diagnosis. I was almost in disbelief."*

Another autism-naïve mother recalled the emotion that accompanied her relatively quick transition from *knowing something is wrong* to *being convinced it was autism*:

> *"I figured, you know, it's many things that could be serious—and in a million years I never could have imagined that I could have a child that was less than perfect. [After witnessing our son's behavior at his second birthday party, my mother-in-law with*

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[9]The majority of parents in this study had become aware of autism as a possibility (i.e., were not autism-naïve) prior to the step of *being certain its autism*, whether they reached such certainty on their own or from being informed by others with expertise.

> *expertise told us he had autism.] I wasn't even sure what that meant at the time. So we ran down to the internet, and looked at various assessments we could find. I remember looking at a chart of eighty-five things that a child might do if he had autism. And [our son] was scoring eighty-five out of eighty-five! It was the most unreal, anxiety-provoking, nightmarish feeling."*

Indeed, many parents described confusion at first being told their child had autism, commonly independently seeking further information for clarification, usually by consulting the internet.

Genuine disbelief in the form of outright denial was a common response among previously autism-naïve parents (particularly those who may have skipped the prior step of *knowing something is wrong*) after first being informed in diagnostic or other clinical contexts about the certainty of their child's autism. One mother recalled her initial resistance to her son's quick diagnosis: "I thought, 'Well how can you have an accurate diagnosis? You've looked at my kid for twenty minutes.' " Multiple parents who entered a state of shock after being informed their child had autism described closing themselves off to what professionals around them were saying, as the following mother recounted:

> *"The very last part of the meeting that we had, they told us 'He is on the spectrum.' And I said, 'What do you mean? Are you sure?' you know. And that's when she tried to tell me about this spectrum, like 'it's a spectrum, it's an umbrella, you know?' I was not hearing anything. I was totally, like, 'What?' My husband was with me, and I mean I didn't cry or anything because I thought she was completely wrong. I said that. I said, 'I think you're wrong. I mean, he does not have autism.' But then she was just really trying to explain it to me, and I just really wouldn't hear it at that point. And I remember they gave us a package of 'Your Child has Autism' and then said, 'Here you go. Give us a call next week and we'll make an appointment with the social worker.' And that was it. And I remember, we went home and I did not talk about it for…I think for that whole week I was in a daze."*

Multiple professionals described how some parents' outward expressions of denial could be confrontational and heated, reflecting the threat that this information posed.

Sometimes the parent who was convinced about autism had to contend with the denial and doubt of others. This usually left the parent who was convinced of certain feeling isolated and alone, unable to share their grief or communicate with others to process their emotional

responses. As one mother recalled: "I remember there was that timeframe of, you know, six months where I felt really alone and didn't want to say the 'A'-word and figure that people would think I was totally crazy. But I knew."

Upon becoming certain their child had autism—whether reaching certainty on their own or after being informed by others—parents became highly motivated to take action to pursue intervention. Predominantly[10], parents first engaged (or continued to engage) in *pursuing a diagnosis*, outlined after the *Summary of coming to understand the child has autism*.

Summary of coming to understand the child has autism

The four steps described above highlight several relevant characteristics of the general process of *adjusting to the need to navigate intervention*. Specifically, as they pass through the steps, parents become progressively more *certain* about the presence of a serious problem that warrants concern; their certainty increases as a result various interactions: interactions with the child, others with expertise, the self, and with mostly online forms of textual information. With progressing certainty, the parent's sense of *urgency* also grows, increasing her motivation to take stronger and more energetic forms of action—both to pursue information that helps define the problem as a concern (i.e., about autism), and to pursue intervention (including diagnosis)—see *Going into high gear, Urgency*.

Parents vary in the *speed* with which they define the central concern (i.e., come to understand the child has autism), for three reasons: first, is the constellation of fixed conditions that define the parent's situation, such as the nature of the signs the child displays, the parent's opportunity and position to observe the child, or the availability of others with expertise to

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[10] With the exception of parents for whom the diagnostic assessment was the means to *being certain its autism*.

inform the parent of the possibility of autism; second, are what the parent retrospectively defines as obstacles to her attempts to get help, such professionals who dismiss their early suspicions; third, is variability in the process of *emotionally adapting* to information from others about the possibility or certainty of autism, which can be slowed by the self-protective responses of shock and denial. It is partly by *coming to understand the child has autism* that the parent becomes *ready* to take action to address it by *taking action to pursue intervention*.

Coming to understand the child has autism is the means by which parents perceive with certainty the presence of the general developmental concern, autism. Thus it is a stage-specific example of part of what is involved in the generic process of *defining concerns*—in which parents ascribe meanings that motivate or prepare them for taking action to pursue information and intervention. *Defining the general developmental concern of autism* further involves other sub-processes of *adjusting*, including *informing the self* about autism; additional aspects of *emotionally adapting* (beyond *accepting autism*), such as *releasing culturally-based hopes and expectations* for the child, and *accepting an uncertain and fearful future*; and *seeing what is involved*—all described below.

Pursuing a diagnosis: Taking action on initial awareness of autism

Parents obtain an official written diagnosis for their child after a positive diagnostic assessment conducted by one or more qualified professionals, which may be publicly-funded (generally involving a waitlist) or paid for privately (to obtain an earlier assessment). A substantial proportion parents interviewed articulated that a prior motivation for pursuing a diagnosis was to hopefully qualify for the funded autism services available in Ontario (including educational supports; see Section 4.2, Interventions). Thus, just as *coming to understand the child has autism* is the first common manifestation of *defining concerns* as part of a greater

process of *adjusting to the need to navigate intervention*, *pursuing a diagnosis* is the earliest common example of *taking action* to address the broad developmental concern of autism. (Note, that by this stage many parents have already taken action to pursue intervention, but this is intervention to address the *specific* initial concerns, such as delayed speech, that may have led to *understanding the child has autism*.)

Parents in this study followed diverse routes before obtaining a positive diagnostic assessment for their child. While a few parents (<5) described being guided by professionals to a publicly-funded assessment efficiently and with reasonable wait-times, multiple others were guided but less efficiently, while the majority had to use their own initiative both to make sense of the complex signs they observed and navigate complexity of a system that was ill-equipped to understand less conventional presentations of autism. Thus, it was through *pursuing a diagnosis* that many parents first learned what is required in their new role, navigating some of the complexity and obstacles that are characteristic of *taking action to pursue intervention* throughout the process of *making their own way*.

It was not uncommon for a parent to pursue multiple routes to get a diagnostic assessment, sometimes simultaneously. Parents generally started off with little or no knowledge of where or how to go about pursuing a diagnosis, and so some would reach dead ends after their initial attempts. One parent, for example, who was having extreme difficulty coping with her daughter's behavior but who was still naïve of the possibility of autism, sought to start the diagnostic process in the school system by requesting an IPRC, based on her understanding that "if the school sees anything, they are legally obligated to come forth with any information that they feel [indicates the child has a diagnosable problem]." But she was doubted and made to feel paranoid by an unsupportive principal who stopped the process abruptly, failing to acknowledge

her concerns or share any information about where else she could go to investigate them.

The obstacle of wait times and responding proactively. One of the most common obstacles parents encountered was the long wait-time to receive a publicly-funded diagnosis at their regional diagnostic center—which could easily be up to a year or more in many regions. The prospect of having to wait for a diagnosis was generally experienced by parents as intensely discouraging. This was because by the time they were convinced it was autism, most parents had learned from the information around them that is was important to start intervention as early as possible. Consequently they urgently felt a need to start intervention with as little delay as possible. Parents responded innovatively to get around wait times, either by pursuing a private diagnosis if they had the financial means, some found a means to obtain a diagnosis quickly by participating in autism research they learned about, while others pushed for faster access through the public system (in two cases by pursuing an assessment in a different city). A minority endured the frustration of a long wait time because they did not see any other options.

Parents' tendency to respond proactively in the face of obstacles at this early stage is highly characteristic of the action of parents of children with autism more generally throughout the process of _making their own way_, as we will see. Yet parents responded proactively while _pursuing a diagnosis_ not just by finding alternative routes to obtain an assessment, but sometimes also in how they interacted with professionals: some parents—of varying socioeconomic and cultural backgrounds, but usually with strong social skills–could be assertive. One mother recalled pushing for a faster way around the usual public assessment as follows:

> _"What happened was when I had the appointment for the [community] pediatrician, I went in with all the evaluation that I had done, and all the research I had done. And I said to him, 'Look, my daughter has autism. I know she has autism. She does this, this, this and that. Look, she had this evaluation, that evaluation. And nobody wants to say the word autism, but we know it's autism.' I said, 'You can give me a referral to put her in [the regional assessment center to follow the usual publicly-funded diagnostic_

> *process]. If you send me to a developmental pediatrician, I'm going to wait another year, or year-and-a-half—because that's the waitlist for the developmental pediatrician. That's only going to put her on a list of two to three years for [IBI at the same center]. That's going to be too late.' So he said, 'OK, I'm going to see what I can do.' And he, himself, forwarded a diagnosis from [my daughter to the regional center 9 days later]."*

The obstacle of being doubted by professionals. Numerous parents went to their family physician (or sometimes a pediatrician) to seek referral for a diagnostic assessment, usually at the point of being convinced it's autism. While there were many reports of physicians seeing the need for a diagnosis and responding supportively, numerous other parents reported their physician doubting them and resisting requests for action—being doubted was an especially common experience when the child was younger than 24 months old. Since parents were usually more certain and felt more urgent about the need for help at this stage, they commonly responded by becoming more insistent or, failing this, seeking alternative avenues to a diagnostic assessment, as the following mother did:

> *"I remember that day actually in the doctor's office—the minute the door closed behind us and the doctor walked in, [our son] went off and there was no calming him down. Nothing any of us did calmed him down. The doctor said to me, 'Is he always like this?' I said, 'Well not always, but most of the time.' 'Well, maybe he's having a bad day. Bring him back in three months.' It was a lot of that, you know, 'Bring him back. Bring him back,' kind of thing. So finally I said to the doctor, 'Can you just send me to see somebody because I'm convinced he has autism and I need that diagnosis to get him the help that he needs?' And he again told me I was paranoid. And by this time I was pregnant again, and he said, 'You know maybe it's just your hormones, and that's why you're so upset.' And all of that stuff. So I then started my quest to find another doctor."*

Other parents encountered obstacles at the point of diagnostic assessment. Reasons parents perceived or described for the failure of diagnosing professionals to grant a diagnosis of autism included the following: young age of the child leading professionals to opt to delay pronouncing a diagnosis, the presence of other diagnoses that confound the professional's ability to confirm autism as being responsible for the child's presentation, rigid checkbox-style adherence to the presence of certain signs of autism, the child' high-functioning presentation of autism in which

the signs are not obvious, and performance of the child on the day of the assessment. The following mother believed that a developmental pediatrician failed to deliver a positive diagnosis because she had over-prepared her high-functioning son for the social interaction beforehand to avoid a meltdown, as a result of which, "He was very cooperative," on the day:

> *"During the assessment I'd spoken to her [the developmental pediatrician] in detail about all the family history and all of, you know, everything I've told you. I told her in really great detail. "Oh, he's fine. He's gifted" [was the final opinion she delivered in a later appointment]. And we just, like…I actually started to cry because, like, "No! You don't know what it's like living with…like, he is so…there are so many challenging behaviors! And there are so many signs that we're seeing! And I'm sorry that you didn't see them, but they're there." So she actually scheduled…she said, "Well, I don't usually do this, but we'll do a follow-up visit six months from now." So we had the follow-up visit [when] he was six years old, in grade one. Normally she wouldn't see him anymore because he was six. But she said, "Well, we'll do this follow-up visit." And then at the follow-up visit his Asperger's side…He was uncooperative. He was defiant. Like all those things all came out. And it's like, "Yes! Thank you, thank you!" And she said, "Ok, now I see it." And she agreed that [he should be diagnosed with Asperger's syndrome]."*

In this case, as in several others where the parent was convinced about her child's autism, the parent's insistence seemed to win the professional's cooperation to facilitate the diagnosis. In some cases, however, the parent had to find someone else willing to do a new assessment.

Informing the self: Using information to guide intervention

Informing the self is both an important part of the meaning-making process of *adjusting to the need to navigate intervention*, and is a key form of *taking action* (i.e., by *taking action pursue information*). Actively *pursuing information* involves *researching* (see below)*,* seeking appointments or referrals to professionals who they feel can provide further information, and intentionally observing the child for signs. To *inform the self*, parents process considerable volumes of information from multiple sources and fields to develop expansive knowledge about the broad topics of autism and related concerns (see Section 4.2, *Complexity of autism*) and intervention (see Section 4.2, Complexity of Intervention-related information). *Informing the self*

about concerns and intervention is done as part of *defining concerns* and *taking action to pursue intervention*, respectively.

Parents gain knowledge about both topics through diverse information sources—namely professionals, organizations, other parents, family and other personal contacts, the child, clinical reports, autism agencies and other organizations, autism conferences, web sites, list-serves, books, and other popular media (see Section 4.2, Information). While the information source (with its unique formats) partly determines the kinds of interactions parents have with the associated information (e.g., searching, appraising, rejecting, recording, organizing), parents often interact with information from a given source in diverse ways. Parents also develop instrumental understandings of the very information they have to navigate—both from informational sources and from the experience of interacting with information—which informs and transforms how they interact with information going forward.

Because *informing the self* is largely up to parents to do themselves, and the information and its sources are so problematic, the struggles of *pursuing information* contribute importantly to their emotional burden (see *Weathering the problems of having to do it on your own*).

Timing of readiness and motivation for informing the self. Timing of parents' readiness and motivation to develop certain types of knowledge is an important aspect of *informing the self*. Parents take action to pursue information about different topics as they become relevant at different points along the process of *adjusting*. For example, parents generally become interested in information about the red flags or signs of autism as soon as they see it as a possibility in their child, but later take in broader information about autism that will give them an idea of what to expect once they have become certain their child has autism. While parents seek and interact with information about autism most intensively at the early stages, learning about this topic

continues for a long time as parents continue to understand its vast complexity. Several parents commented how their learning about autism continued for a lifetime, as they informed themselves about new aspects of the disorder whenever their child transitioned to new stages.

Parents generally begin to feel motivated to pursue (and ready to receive) information about intervention after undergoing aspects of *emotionally adapting*. Not only must parents have passed through any denial that their child has autism, but numerous parents must pass through an early period of intense *grieving* (see *Emotionally adapting*, below) before feeling a need to inform themselves (or listen to others around them) about how to intervene. Thus, parents inform themselves about intervention with a slight lag compared to informing themselves about autism. Many parents soon dedicate substantial amounts of time and energy learning about the many things they can do to address both the general and specific concerns that arise. Information about intervention remains important to parents throughout all stages of *making your own way* as new concerns arise with new transitions, although parents generally reduce time spent informing the self over the years as a result of *easing off*.

The burden of pursuing information. Discussed previously (Section 4.2), the information parents must interact with is highly complex for multiple reasons. Parents meet the challenge of navigating this informational complexity by committing substantial effort and work to building the knowledge and understanding they feel is necessary for taking action. This makes *informing the self* a significant burden for many parents, often involving significant personal resource loss. Potentially burdensome tasks include researching, personal development (attending parent training, consulting how-to information), interacting with others who can share information, and others. The amount of effort parents feel they must dedicate to such work is sometimes reduced when local and regional services successfully provide efficient and high quality informational

support—the right information, at the right time, in the right format—in the form of communication from professionals, handout materials, online and list-serve information.

Work and resource loss are not the only information-associated burdens parents experience. Additionally, various problems with information—its insufficiency, its potential to overwhelm, or its inconsistency and lack of clarity—contribute to parents' sense of helplessness and uncertainty about their situation, making it an important source of stress (Section 4.2, Stress).

Information feeding the sense of urgency. A key piece of information parents commonly use for *defining the central concern of autism* is the well circulated research evidence about the importance of intervening at younger ages to achieve better long-term outcomes or developmental trajectories for the child. The resulting knowledge, which many parents gain early on (often pre-diagnosis), has a powerful effect leading parents to see their situation as urgent and requiring quick action to obtain intervention early as possible. Parents' fears for the future become a greater source of anxiety, and obstacles that delay intervention become intolerable and exasperating as a result.

One professional, reflecting on the parents in her practice, observed that informing the self is ideally done *before* taking action, because it equips parents with the knowledge and understandings to take action with more confidence. But, as the same professional pointed out, parents often feel urgency and pressure to act quickly, without allowing themselves time to finish the self-informing themselves adequately about the situation they are faced with:

> *"Everybody talks about early intervention and the importance of getting in there and don't hesitate. But the families are still learning about 'What is this?' And 'How is it being expressed in my child?' And, you know, they're learning. And it's very difficult to make decisions while you're learning about something. And there's no luxury of time because of the urgency. So they're in a tough place."*

Integrating information. Often, information is converted to knowledge after integrating it with either information from other sources, or with pre-existing knowledge (see also *Defining*

concerns, Integrating multiple understandings, above). The following mother describes having

to integrate information from a range of sources, including knowledge about her son, as she tries

to make sense of everything at an early stage of navigating intervention:

> *"So a large part of this journey, it's constantly educating myself. I'm constantly reading, whether it's books or it's Internet research. I just feel like I'm constantly trying to understand all the different acronyms, what they mean, and what the programs and the services are all about in order to try and put together the best program for [our son]. And it's hard because I don't have anyone guiding me, except myself...and in conversation with other mums, and my husband, trying to put it together. But there isn't one person saying, who's looked at [our son], who understands [our son],and says, 'OK, here's [son's name]. This is what he needs.' "*

Information for understanding autism

Parents almost invariably arrive to the situation of *having to make their own way* with prior

images of autism, however incomplete and unclear. Rather than construct new images of it, they

absorb vast new information to substantially revise these images—often completely rewriting

what little they knew before. Below, I describe the relevance of prior images and how they were

formed, and next address the more action-oriented process of revising them. In addressing how

parents revise their images of autism I introduce many of the interactions with information.

Parents' prior image of autism. As mentioned, parents' initial emotional and action-

oriented responses to learning the possibility or certainty that their child had autism was strongly

influenced by their prior image, or understanding, of the disorder. Most parents fell into one of

two categories with respect to prior knowledge: knowing very little, or having some background

in the form of educational, professional, or experiential knowledge.

A majority of parents were of the former category, making claims such as knowing

"nothing" or "very little" about autism prior to encountering it in their child. Five parents

claimed their only knowledge was from the movie *Rain Man*—the blockbuster movie set in 1988

with Dustin Hoffman playing the protagonist with autism, Raymond Babbitt. Raymond is

ultimately institutionalized, and the psychiatrist charged with his care at one point indicates that most people with autism are non-verbal. This influential but dated portrayal of autism undoubtedly contributed to outdated understandings and fears among parents—two of the same parents described initial fears of institutionalization. Parents may have also constructed a preconscious image of autism from sources and secondary interactions they could not recall. The most relevant aspect of any image of autism at these early stages, however vague, seemed to be its outcome. At the time of this study, news stories of autism crises were common in local and national newspapers, such as reports of parents who, after exhausting *all* other options for managing their young-adult-child, were faced with abandoning him or her to a homeless shelter because no local program was equipped to step in. Such stories and other media portrayals likely had subconscious or undisclosed effects on parents' prior images of autism. One parent described her incomplete but very fearful sense of autism as follows:

> *"I think whether it was in movies or books or whatever, I had this picture of a child being frustrated and banging his head against a wall in his room, his or her room, and being very non-verbal and violent, and biting and spitting when they were having a tantrum. Like, that was my snapshot of what I thought autism was."*

A smaller proportion of parents described how their previous knowledge partially equipped them to know what signs to look for, or what outcome might be associated with autism. Several parents described educational knowledge such as courses in developmental psychology, sometimes returning to consult their old books as this information suddenly became highly relevant. Other parents described professional experience from working at summer camps with special needs children, or as educators. And a small number of parents described personal experience with autism, having relatives affected by the disorder. One mother's experience with a brother who had autism led her to hold a highly positive prior image of autism and its outcomes.

Revising one's image of autism. It is largely because of parents' ongoing pursuit of information that their image of autism is not static and is continually evolving. Refining this image involves continued researching or otherwise encountering new information. Since information varies in comprehensiveness, clarity, and credibility, the parent must then sort, filter, appraise, reject, accept, decipher, and integrate the new information with prior knowledge and information from other sources. Refining one's picture of autism also involves reacting emotionally to new information giving this information deeper meaning, and influencing perceptions of the information source, such as its credibility. This all involves a communicating with the self through continued interpretation and reflection on the implications, as the parent's knowledge of autism and how it applies to her child evolves. (Note, this list of interactions only includes what I observed, and excludes any other interactions one might possibly conceive parents engaging in.)

Early interactions with information lead most parents to form an unsettling picture of autism early on that calls urgently for a strong response by taking some form of action; although other parents, such as those who frame autism positively, may feel a less urgent response is necessary. As a result parents construct lines of action for responding to these unsettling aspects of their picture of autism. According to a symbolic interactionist perspective, in constructing these lines of action, parents would also be influenced by other conscious and subconscious considerations, including personal goals, perceptions of what lines of action are realistic and available to them, the anticipated actions of others, self-image, and perceptions of the likely results (see Blumer, 1969, p. 15).

Some parents at the early stages described defining a vague and fearful picture of autism for themselves based on partial information, seeing it as something they felt powerfully

motivated to try to reverse or eliminate. Later, with more information, these parents described their image of autism becoming more comprehensive and clear, most understanding autism as something that cannot be cured. This led them to revising their expectations, goals, and what kind of action was necessary. Thus *defining concerns* (in this case the general developmental concern of autism) can be a long-term or ongoing process as parents redefine the concern in the face of new information.

Parents also revise their image of autism to see a more hopeful trajectory, specifically because more hopeful outcomes are possible with the appropriate intervention. One mother described learning this through information she gained form observation. After noticing how quickly her son could learn to use a mouse, simply from watching his mother, she described reaching a new understanding of autism in which she considered affected individuals capable of learning or knowing essentially anything. Suddenly seeing this expanded potential for her own child, she reflected, relieved her own stress about expectations for the future, which had been dominated by an image of autism as un-curable disorder with much less hopeful outcomes. It also motivated her to want to do more for her son so that he could reach his potential. Another parent who revised her image after observing breakthrough abilities of her child referred to is as a "burst of sunshine." For another mother, reading the book *Carly's Voice* created a motivating image of a much more hopeful trajectory.

In revising their image of autism through new information, parents additionally learn about other aspects, such as what some of their important new parenting requirements are and how to meet them. Parenting requirements is one of many aspects of autism that parents also revise their image of through *experience*. For these aspects, as we shall see, experience can become a greater source of knowledge and ideas for lines of action (to pursue intervention) than information.

Researching

Researching is the word parents commonly used to describe their information-seeking activities, generally involving text-based information sources. It is the most common proactive means by which parents described *informing the self*. *Researching* encompasses numerous other informational interactions such as searching text-based sources, filtering, appraising, rejecting, recording, and organizing, some of which will be described below.

Researching served several different purposes. The most straightforward and common purpose was to prepare, in various ways, for the general process of *taking action to pursue intervention*. A somewhat uncommon use of information gained through researching was to facilitate communication with people unfamiliar with autism. One parent, for example, described finding a very helpful video she used to educate family members about autism. In some cases, parents found books through researching that contained the stories of other parents, which helped reduce their stress or cope emotionally, functioning as intervention for their mental health. As one mother described,

> *"When I have some kind of situation, I go to the library. I always look for information, such as something that someone might share about what they experienced in the past. And I always use their suggestions—like when someone says 'This happened to me, and I used to do that.' "*

Parents also used researching to gain power, described next.

Seeking information to gain power. Parents sometimes used descriptors like "arming myself with information," to emphasize the self-empowering purposes that *informing the self* could serve. Parents sought and used often-detailed information to develop deep knowledge of the options available and to support their decisions. For example, one parent used a staffing report from her local board of education that she found buried online to identify which primary school had the most resources for special needs. Additionally, many parents used information to

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prepare themselves for communicating more proactively with professionals—such as by printing off a list of questions to ask, or by completing a screening tool for autism and bringing it to a doctor's appointment. One mother described how knowledge was necessary to interact on a more even footing with physicians: "If I'm speaking to a doctor about it, I want to have enough knowledge that I can engage in that conversation, as fully as possible, without just being *told* information." Other parents described how *informing the self* better prepared them to respond and advocate appropriately in cases where they received partial, conflicting, or misleading information from professionals.

Parents also sought and used information to learn about or equip themselves with various skills. Workshops and other training activities helped parents learn everything from how to participate in implementing intervention, to advocating more effectively for their child within the education system. Books or internet sources provided information not only about how to deliver behavioral and other interventions, but about parenting approaches that also qualified for purposes of this study as a form of intervention.

At a more abstract level, *informing the self* by actively *researching* was a means for parents to try to regain control of their problematic situation. Numerous parents described how they responded at the most stressful and out-of-control points in their journey by aggressively, and sometimes obsessively, pursuing information through *researching*. This more frenetic activity to *inform the self* was usually part of a distinctly energetic phase of pursuing intervention, discussed later (see *Going into high gear*).

Sharing: Exchanging information and support with other parents

Some informational interactions are source-specific. Informational interactions with professionals, for example, include receiving referrals, recommendations, and non-judgmental

information about options (see Section 4.2, Information). In this subsection I characterize

sharing, the word parents used frequently in interviews to refer to their informational interaction

with other parents. For many parents, *sharing* is one of the most important means for obtaining

information for navigating intervention—many mothers in this study credited other parents as

their most important and trusted information source. *Sharing* also helps parents cope emotionally.

The different modes of *sharing* range from face-to-face parent support groups, parent-only

email groups or listservs, blogs, and casual advice. These formats are characterized by the same

elements of cooperativeness, belonging, rapport, empathy, mentorship, and responsiveness to

each other's specific needs. Kayla describes a typical support group and how it benefits her:

> *"What happened was a number of mums in the area all with kids on the spectrum*
> *formed a support group, and we literally just meet every other week at one of our*
> *houses. And we just talk and we support each other. We trade information, and ideas,*
> *and resources, and just stories and strategies, and that sort of thing. And because I was*
> *in this group for about 2 months, even before I had a diagnosis--like they did encourage*
> *me to come even though I didn't have a diagnosis, because I kind of knew--it was*
> *because of them that...you know, when I did get my report, they had very clear opinions*
> *and ideas around some of the services. And so some of them had mixed things to say*
> *about [our local support agency]. But they did explain that, 'Yes, you do want to at*
> *least start there.' So I feel sometimes without their guidance, without their information,*
> *I wouldn't have necessarily known what to do to begin. So having this local group of*
> *other mums has been really, I find, critical to my overall coping and my ability to access*
> *resources. And we all share. We started to share names, and who to call, and that sort*
> *of thing, and different types of programs."*

Sharing was a well-suited means for parents to gain several specific kinds of information.

One of the key ways parent-provided information helps other parents is by promoting the skill of

advocating, often by raising awareness about what services they have a right to try to access. As

one parent recalled of her support group, "They gave me questions to ask. They said, 'Make sure

you ask this. Make sure you ask that.' And I wouldn't have known what to ask if I didn't have

this group of mums." Parents are also highly useful as a source of detailed answers to specific

questions that professionals or support agencies are unlikely to have answers for. For example, it

is through *sharing* that parents form reputations of the professionals, schools, and organizations that are available to provide services. Parents also learn where they can find a dentist or swim instructor in their area who is good with children with autism; or where they can find local biomedical practitioners, lists of whom are generally unavailable on from any support organization (even the Autism Research Institute, in 2011 replaced its famous online list of Defeat Autism Now [DAN] doctors with advice to consult one's local parent group).

   Cooperativeness. As the term implies, *sharing* is often a two-way exchange. Because it is a highly social act, *sharing* provides parents not just with information but important psychological and emotional benefits that increase their resilience and strength for coping. One of these benefits is participating and feeling more connected with not just a new social group, but with the greater collective of parents of children with autism—a group defined by the common intense experience and shared culture of its members. Contributing information (and advocating the system), for numerous parents, was a communal or cooperative act that improved the situation of the group to which they belong. As one parent remarked, "I think strength in numbers. I mean, the more of us that go through it…I think sometimes we're better than therapists and clinicians at these facilities because we live it day-in and day-out."

   Some parents belonged to even more culturally specialized groups comprising parents of children with autism from their particular ethno-cultural community (e.g., Somali, East Indian, Mexican), where the *cooperative* aspect of *sharing* could be intense. In one example, a professional remarked how a group of immigrant mothers she knew benefited from *sharing* information and supporting each other in such a communal manner:

> *"I'm always surprised by how people of the same culture—there are lots of kind of underground networks that happen. Like, I just am thinking about one group of women, they came from Mexico [a number of whom did not speak English]…[Listing several*

> *specific services they accessed] They've accessed more than most families that are Canadian have accessed!"*

Unique rapport. Many experiences contribute to parents' sense that they are distinct from the rest of the world. As one example, several parents shared in interviews how a mundane outing such as a trip to the supermarket quickly turned into an intensely humiliating event after their child's behavior led ignorant onlookers' to publicly ridicule and accuse them of being bad parents. Through interacting with other parents in the same situation, there is a sharing and validation of identity that parents can find nowhere else. By pulling together, parents increase resilience of everyone in the group.

Numerous parents voiced how they felt there to be an inevitable line between parents of children with autism and outsiders who do not share their identity, such as the following mother:

> *"Because again, it's nice to talk to somebody who gets it. Because I have other friends, and sure they can be really understanding, but they don't get it. They just don't have a clue. A lot of the times that can be really frustrating. So to have somebody who, just, I can vent to her and she completely understands because she goes through a lot of, even if it's not the same situation, very similar. She just gets it."*

One professional remarked how her identity as parent of a child with autism improves her ability to help parents: "I find the families who know that I am also a parent of a child with ASD seems to be more relaxed and trusting of my advice."

The rapport that comes from this shared identity facilitates information exchange and uptake in ways that can't be reproduced with other information sources. The information that parents share is imbued with a level empathy and credibility that is irreproducible. It is usually uncensored, unconstrained by concerns for liability; and at a level of specificity or detail that makes it relevant to the other parent's needs. All these characteristics make many parents highly receptive to information from other parents—sometimes more than from trusted professionals.

The high level of trust and comfort that comes with unique rapport also lowers the threshold for asking questions or seeking specific information, compared to other human sources such as professionals. Parents who enjoy close relationships with other parents can often simply pick up the phone to get a response to their concerns right away. As one mother remarked: "if there's something I can't find or I'm just basically lazy and want to know if she knows about it first, I'll check with her. She's almost like a starting point." In other settings such as online list-serves, empathetic parents are often similarly on hand and available to respond quickly to a parent's information needs, although the types of information requested might differ.

Mentorship. Parents feel motivated to contribute to less experienced parents' knowledge not only by a sense of cooperativeness and commitment to those who share their identity, but also by a desire to share the vast knowledge and expertise they often gain. Parents choose to share valuable knowledge and expertise in different ways. One parent of two boys with autism had previously agreed to her principal's request to be a resource within her school's community, which motivated a desire to start her own parent support group. Other parents found scarce time to maintain blogs where they shared their evolving experience and carefully posted informational resources for others to access. Some parents even found ways to remunerate themselves to partially justify dedicating the extra effort of *sharing* their valuable expertise—for example, by offering professional consultation services, or by writing and publishing books. Both professionals and parents shared several comments to suggest that parents' expertise positions them for an almost professional role supporting other parents.

Further motivation for sharing knowledge and expertise is the perceiving that they are actually helping other parents. Some parents described receiving concrete feedback that they were helping, as one seasoned parent did after blogging about a specific experience: "But what

was really neat was I posted it, and the onslaught of people who commented. And I had no idea

of what it would for people. And they all, every single one of the posts, mentioned hope."

Not fitting in. While sharing was a common informational interaction, there were some

parents who engaged only modestly or not at all in *sharing* with other parents. In light of the

substantial informational and psychological benefits of *sharing* that many parents described, it is

important to consider some of the explanations that these parents gave for not participating (or

benefiting) from this type of interaction. Common differences among parents of children with

autism can create divisions that keep some from fitting in with parents of a particular group.

One such division is between parents who are favor biomedical interventions and those

who do not. Harriet, for example, had been criticized for not implementing the GFCF diet by

> *"...Other parents who have autistic children on gluten-free-casein-free diets. You know, 'Why wouldn't you do everything to help your child? I'd do anything to help my child.' But they also believe they're gonna cure their child. And I don't believe there's a cure."*

One professional perceived that parents of higher-functioning kids can, as a group, have

elitist and exclusionary attitudes towards parents of children with lower-functioning autism.

While I did not see evidence of this among the individual parents I interviewed, one mother

described being rejected by other parents whose children were *lower-functioning* than hers:

> *"I did try to go to a parent workshop, and the parents were mad at me. Huh! Because they were talking about situations, you know, things like their children not wanting to get on the bus. And I'm like, "Oh, my son just gets on the bus," you know. And so whatever the situation had come up during the discussion, [my son] didn't apply to that. He looked like the golden child. And finally the parents are like, 'Well, why are you here?' So I got discouraged and left."*

Another parent reflected on how anticipated division between subgroups of parents may

have motivated her son's special needs private school not to operate a parent peer support group:

> *"So [one mother's] belief is that you can't really get a group of parents together because there's so many differences within the children's functioning levels that it's not really like a cohesive group. There would be conflict. Jealousy. Because especially for services. Like, I know because of the waitlist in [my region]—and even when you get off*

> *the waitlist, the amount of support you get—a lot of parents don't think it's enough. So when you see a child and—I'm being honest, I've been guilty of this too—when I see a child who can speak, can walk alongside his mommy, and do everything else, and they are getting the funding, you feel like, 'But my child needs that.' "*

Another parent who was spurned by a parent with whom she had had an email relationship revealed how her written *social skills* were an obstacle to *sharing* in writing-dependent settings:

> *"Because words can, when they're read, you can take them a certain way as opposed to when they're being said. I'm not really pro-writing. I'm quite awkward at socializing most times, so I try not to venture into it. But if I'm somewhere, I'll get verbally involved. I like to talk, you know."*

Other parents' broader lack of social skills similarly restrained them from sharing with parents.

A subtle obstacle for some parents to benefit from *sharing* was *discrimination*, which several new-Canadian parents who perceived themselves as not fully assimilated described experiencing in indirect ways. Although overt instances of discrimination were rare, one mother had the courage to draw explicit attention to this problem: "Frankly, I feel that there is, you can say, kind of discrimination in Canada against international people." Two such participants (who did not have a parent group of their own ethnic culture to participate in) described their lack of success in connecting with other fully assimilated Canadian parents after making concrete efforts to do so. This disappointed them because they perceived how other parents clearly knew more than them. One mother (M, below) described how a briefly helpful interaction with another mother with superior knowledge never evolved into a long-term *sharing* relationship:

> M: *"Because maybe there are things in Canada I don't know about it, as you say, because I'm not originally born in Canada, but…maybe. As I say, in the workshop I have attended there was a nice Canadian lady. And she told me, for example, about some charity organization that I could apply for. I could get some money to help my child. Because, as I said, the waiting list for his treatment takes more than three years in Canada. She knew about this charitable organization—I don't know from what. I felt at that time that this Canadian lady, she knows about many things I don't know about it. And she has a lot of information better than me. And I was surprised."*
>
> Gentles: *"So you saw how she had all this information, and you wondered how was it that she got all that information?"*

> M: *"Yes. But she didn't tell me. At that time, she just told me to apply for this organization to get some money to bring private occupational therapy for my son."*

Summary of informing the self

Informing the self is an important means by which parents construct their ever-expanding understandings of the autism-related problems they need to respond to (i.e., concerns), and the means they have for addressing them (i.e., intervention). But it is not the only means by which parents construct these understandings, parents also internalize important meanings through the experience of taking action that leads to *seeing what is involved*, and through the emotional meaning-making that is achieved by *emotionally adapting. Informing the self* is therefore a key means by which parents continually prepare themselves for action as part of the process of *adjusting to the need to navigate intervention. Informing the self* is also a form of *taking action*, and a necessary step on the way to obtaining intervention. But because of the many other forms of action that are involved in pursuing intervention and overcoming obstacles, *informing the self* occupies a less-than-central position in the over-arching process of *making your own way*.

Parents inform themselves about the two major topics—concerns (including autism) and intervention—as different aspects of those topics take on importance and relevance at different points along the path of *beginning the autism journey*. The types of informational interactions parents draw on for *informing the self* are numerous and complex, and partly determined by what information source the parent is engaged with. Different information sources vary in importance and influence on parents' knowledge and action, with professionals and other parents being the most importance—a finding that has implications for where to focus efforts on providing informational support to parents. Nevertheless, parents can spend substantial amounts of time and energy on *researching* and otherwise interacting with text-based information.

Seeing what is involved in pursuing intervention

Seeing what is involved is a process by which parents construct their understandings about the requirements of *pursuing intervention*. Parents do this in two ways: primarily after gaining their own experience *taking action to pursue intervention*, and by *informing the self* with external information sources that can tell them about what is required. By developing and refining their understandings of what is involved, parents inform their expectations and subsequent approach to *taking action to pursue intervention*. Parents develop more informed understandings of what is involved in pursuing intervention in two general ways: by *learning that it is up to parents to take action* in the first place (see *Going into high gear, Urgency*, below); and after learning about the obstacles that potentially lie ahead, later on. In both cases, parents respond by psychologically preparing to invest commensurate resources in future efforts to pursue intervention. As an arbitrary example, in *learning that it is up to parents*, the following mother decided to involve herself in delivering intervention after seeing how little is offered by the publicly funded system:

> *"So what ended up happening, what a lot of parents realize as you're going through this journey, is it's not that your son's going to get one-to-one help, it's that you're going to educate yourself how to help them yourself. Because, you know, if the speech and language pathologist can't come and do one-on-one therapy then she's going to teach me how to do it. And it was a lot of going to parent workshops and training yourself, which is great and I was very gung-ho about."*

It is easier to appreciate how significantly learning the lessons about what is involved in pursuing intervention influences parents' subsequent approach to *taking action* by considering what parents' prior expectations of what seeking care for a child with autism might be like. Many parents repeatedly described how, prior to gaining any significant experience navigating the system, they expected that they and their child would be generally well taken care of, as Canadians generally are for many mainstream health problems. One mother described how she, "had expectations that once [my daughter] was diagnosed she would get all these services, and

that didn't happen." Another mother emphasized how she had been disappointed not only by the system doing so little to connect her to intervention, but by the fact that she had to find out slowly through personal experience of the need to do so much of what was required by herself. Disappointment, after their prior expectations were not met, spurred many parents to become more proactively involved in taking action.

Learning from experience. The actions that parents take to pursue intervention—through which they gain experience that informs their understandings of what is involved—vary depending on what stage they have progressed to in the process of *making their own way*. Parents frequently gain their earliest experiences when they navigate the system in pursuit of diagnosis for their child. As described (see *Pursuing a diagnosis*, above), parents often encounter obstacles at this stage, forcing them to do unexpected work and to experience emotional and other burdens as a direct result of navigating intervention. This experience leads them to form some of their first ideas about what may be involved in the general project of *taking action to pursue intervention*. As a result of these preliminary and often ill-focused expectations of the future, parents start to see implications for how they should subsequently approach interacting with the system. Thus parents begin to see the need to do things for themselves, to push hard to advocate for your child, and to prepare to commit substantial energy to proactively taking action. Many mothers, for example, explicitly decided at some point (generally after their child was 2 years old) to stay home as a fulltime caregiver instead of being employed so they could dedicate themselves and their energies to pursuing intervention for their child.

Many of the actions that parents take to pursue intervention at later stages are summarized at a descriptive level in Section 4.2 (see Intervention, Obstacles, and Burdens). Some parents find that pursuing intervention not only requires more of them than they expected, but that at

least some of what is involved is unpleasant. Dilin particularly disliked always having to fight:

> *"I said to my husband, 'You know, I thought the hardest part would have been the diagnosis part and getting used to that. And that seems like a breeze now compared to what I'm having to go through lately.' I feel like I'm jumping through more hoops and everything. It just seems like everything's an issue, and I'm tired of it. I'm getting very tired of fighting. I said to my husband, 'I don't know how much fight I've got left in me. I know I'll fight until the death, but I just…there's more to life too.' "*

Several parent learned it was like having multiple fulltime jobs. As a result of this later-stage learning, these and other parents came to see a need to scale back their energies and seek balance.

 Learning from information. In addition to learning through experience, parents also develop understandings of what is required by reading or hearing about it. Other parents are an important source of such information. Elise had recently experienced pursuing a diagnosis, but had also talked to enough parents from her parent support group to rapidly understand the implications of *having to make your own way* for her life in terms of the work that would be required. Hearing how fearfully hard this work is, she has braced herself emotionally for how uncomfortable and draining certain aspects of her future could be:

> *"What I'm dreading is the fact that, if [my daughter] remains moderate-to-severe on the spectrum, then fine. I'll continue going at this rate that I'm going to make sure she gets everything that she needs and her life is the best. But I'm not looking forward to, you know, fighting with school systems and, you know, continuing advocating year after year after year after year because I feel like I'm going to, like, have some kind of a breakdown from just fatigue."*

Emotionally adapting

 Parents generally experience *emotionally adapting* to a common set of problematic aspects of their situation at the stage of *beginning the autism journey* (and often later). Thus *emotionally adapting* involves

- Accepting the possibility of autism,

- Releasing culturally-based hopes and expectations for the child's future,

- Accepting an uncertain and fearful future for the child,

- Enduring the strains (i.e., coping successfully with challenges to one's emotional, physical, and financial capacity to function), and

- Redefining one's roles and self according to new occupational requirements (i.e., as parent of a child with autism).

Each of these sub-processes, as we shall see, is an important and necessary means by which parents become prepared and motivated for *taking action*. Alternatively, parents can become overwhelmed as they struggle emotionally with any of these aspects. When this happens, they generally need more time for *emotionally adapting* before being ready to engage in *taking action*.

We have already seen how parents first engage in *emotionally adapting* by overcoming internal resistance to *accepting the possibility of autism* (i.e., overcoming denial), which can hold them back from *coming to understand their child has autism* at any of the four steps described previously. *Accepting the possibility of autism* and overcoming the emotional obstacle of denial is generally necessary before engaging in the other aspects of *emotionally adapting*, below.

Releasing culturally-based hopes and expectations for the child's future: Grieving

Inevitably, at various points even before their child is born, parents construct prior images about their child's future and about what parenting will be like, some of which they hold and develop attachments to as hopes. It is these culturally-derived images—whatever they are and whenever in the parent's own development they are constructed—that the parent must release in order to accept a different future for her child (described next). As previously mentioned, parents sometimes begin the process of *releasing culturally-based hopes and expectations for the child's future* as soon as they come to understand and accept that their child had serious developmental problems that will likely affect their future (see *Coming to understand the child has autism, Knowing something is wrong*). While many parents experience the initial release of hopes and

expectations as a sudden and painful event, parents can also let go of some of their prior images

later, at any point in the process of *making their own way*, as will be described.

    Releasing prior hopes and expectations after initially perceiving the child's autism. The

process of letting go of hopes and expectations as a part of *coming to understand the child has*

autism can be extremely painful depending on two things: how strongly parents are attached to

their prior images; and how vastly different these expectations are from the new (fearful) images

parents initially have to replace them with as they perceive their child's autism. In some cases in

this study, parents had defined their child according to prior images so completely that they

experienced losing the idea of who they thought their child should as tantamount to losing their

child entirely. Thus, several parents described feeling like their child had died. Even when the

loss was not experienced to be quite this great, parents frequently described having to mourn or

grieve the parts of their child they felt they had lost. This made *releasing culturally-based hopes*

and expectations for a child's future one of the most emotionally depleting times in *adjusting to*

the need to navigate intervention for some parents. The following mother's description of

grieving, including the prior expectations she faced losing, was typical for many parents:

> *"For about two weeks, I was so depressed and I was so worried, and I was so upset and everything, because I didn't know what autism was, really—like how it affected him, if he was going to be able to have a life where he was going to be able to live on his own and have a job and a family and everything. At that point I didn't know that that would be possible for him. So it broke my heart as a mother to think that, you know."*

Multiple parents described how grieving effectively paralyzed them, preventing them from

seeking or even hearing professionals tell them new information that would help them.

    Some parents, however, experience less emotional difficulty letting go of their prior

images than others. In this study for example, certain parents were somewhat flexible both in the

attachment they had to their prior images, and in how concretely they defined prior images or

expectations for their child in the first place. Other parents seemed to release their prior images

more gradually than others, for example, by beginning to change their expectations in small ways as soon as they first noticed the signs of a developmental problem, so that overall shock of the eventual certainty about their child's autism was not as great or abrupt.

  Releasing prior hopes and expectations at later stages. While parents generally experience the greatest and most sudden loss of prior culturally-based expectations during the process of *coming to understand the child has autism*, they may retain or revive some prior expectations at later points in time, only to release them again after observing their child's development over time and perceiving less hopeful outcomes to be more certain—sometimes repeatedly shifting the balance between maintaining hopes and releasing them this way. Parents can thus sometimes continue holding strong attachments to prior expectations for their child while *taking action to pursue intervention*. Needing to fulfill prior expectations partly explains some parents' sense of urgency to intervene as they seek to eliminate their child's autism.

  Several parents who maintained prior culturally-based expectations until later stages described a "need for normalcy" (the words of one such parent, Natalie) in which they hoped to make at least some of the dreams they held for their child come true—such as going to university, living independently, finding employment, getting married, or having children. As Natalie reflected, the urgency that can be fueled by holding out such hopes can lead parents to pursue intervention at an unsustainable pace, consuming expendable personal resources too quickly, and making burnout inevitable. Another such parent, Dilin, who experienced severe personal loss after neglecting herself by directed excessive energy on trying to "fix" her son, reached the counter-intuitive but profound realization that it became easier to take effective action to help after she finally released her prior culturally-based images and hopes for her son:

   "I kept my expectation level where it would have been with typical kids. And that's the mistake we all make at first, is that we're like, 'OK, how do we fix him? How do we get

> *him normal, basically? What can we do?' And eventually you come to the understanding that it doesn't matter how much money you throw at it. It doesn't matter—you know, autism is still going to be there. It's just how much can you help him function within his autism. And once you kind of accept that, it becomes a lot easier to help...So it's changing your expectations that makes you cope."*

This realization was key for Dilin to begin directing more energy to care of herself by pursuing intervention at a more sustainable pace, so she could better support her children in the long term.

Accepting an uncertain and potentially fearful future for the child

As described, *adapting emotionally* specifically to one's awareness that one's child has autism involves releasing prior culturally-based hopes and expectations. Here I discuss the closely-related sub-process by which parents accept the new images or expectations that replace the expectations they let go of. Whereas releasing prior expectations often led to emotions of grief, the new images and expectations of autism parents accepted in replacement often led to emotions of fear—many parents experienced simultaneous grief (for a future lost) and fear (of the future their child faced), after learning their child had autism. Parents especially experienced fear early on when their understanding of autism was so incomplete and unclear, and expectations of the future were at their most uncertain. For example, one parent described being "*terrified*" to hear the stories about what autism might be like from more experienced parents at a parent support group she attended as a new parent. She attributed that event to causing her first panic attacks, which led to her be diagnosed with generalized anxiety disorder. Usually, the earliest images parents use to replace the expectations they have for their child are their prior understandings of autism, which are often the least accurate and most fearful (see *Informing the self, Information for understanding autism*).

One parent articulated in detail her fears for the future, which resembled other parents':

> M: *"The hardest part has always been fear for his future. That's always been—"*
>
> S: *"OK. So it's an ongoing thing."*

> *M: "It's an ongoing thing. And that is the hardest part for me is, what's going to happen to him when I can't be there anymore."*
>
> *S: "And why is that so worrisome? What is it that you're wishing for or fearing most?"*
>
> *M: "Fearing that nobody can give him what he needs if I'm not there to advocate for him and be his voice, because he's non-verbal. So that's a huge fear. Fear of him possibly being abused, or put into a situation where he can't speak for himself, and something happening, and how would anybody ever know. That's a huge fear. Because he can't, you know. And—"*
>
> *S: "Of him being victimized, kind of."*
>
> *M: "Yeah. It's a very big fear. It's like, I would imagine it to be what families face when they have to put their elderly parent with, like, Alzheimer's or something, somewhere. That they must have this fear of that, because they can't vocalize for themselves properly because there's confusion going on. And, you know, you're putting your most precious thing into the hands of someone else and praying and hoping that he gets what he needs, you know. It's very, very frightening. Because I know that the general course of life is that parents die before their children. And so it makes you come to terms with your own mortality. It makes you come to terms with the fact that he is going to have to live in this world without me, at some point."*

Accepting an uncertain and potentially fearful future for the child therefore requires not just replacing old images with new ones, but managing the fears that the new images cause. Most parents seemed to absorb or endure these fears. The following mother explains how it can be such a difficult struggle to come to terms with fears for one's child's future, in this case the prospect that her child may never talk:

> *"He doesn't have to use a voice. But that's really hard to accept as a parent, because it means that he's going to struggle. And as a parent you don't want that for your child. …I can at least talk about it now. Before it was like, 'No, no. That's not going to happen [i.e., the outcome of lacking speech as an adult]. He's going to be OK. He's going to…[improve]' You almost deny it to yourself."*

The above quote illustrates an important strategy many parents used for coping with their fears: to hope for positive outcomes, essentially denying that one's more fearful expectations will come to pass. One parent even characterized her denial about the very possibility of autism as a form of hope: "So ultimately, yes, there was lots of denial. I mean as a parent you always hope

for the best, right?" Another parent interpreted her use of the word "hope" regarding long-term outcomes for her adolescent son to mean hope "for that normal development" that she described is culturally defined. Other parents described hoping that their child would be happy and socially accepted for who they are in the long-term future.

But deciding where to set one's hopes for positive outcomes—particularly after learning about the highly variable outcomes one can expect from autism—can be a highly uncertain task. As Cynthia noted,

> *"I don't even think any parent with a kid on the spectrum can answer that question— like, 'Where is he going to end up?' I hope he's going to end up somewhere where he's well equipped to be in the world on his own."*

Another parent describes how she is able to temper her hopes for positive outcomes as certainty about the more fearful expectations increases with time and child development: "Because I think as time goes on and you see how it is. I mean, you can hope for a miracle. But aside from that, you start to understand that this is probably the way it is."

In summary, as part of *emotionally adapting*, parents repeatedly struggle with how and where to shift their expectations between hope for better outcomes, and acceptance of worse outcomes. What kind of outcomes they hope for, and those they come to accept, shift at different stages of *making your own way* as the kinds of expectations and level of certainty they hold about the future change with time. Thus, the overly optimistic hopes some parents hold while still in denial about the possibility their child has autism eventually become replaced with expectations of highly fearful outcomes that are informed only by their inaccurate and incomplete pictures of autism. Some of the kinds of outcomes parents come to expect usually become at least slightly more hopeful after *coming to understand the child has autism*, as parents *inform themselves* and develop a clearer, more accurate picture of autism; similarly, they come to accept certain other outcomes with greater certainty due to the fact their understanding of autism

is more informed. (A minority of parents may understand autism to be reversible for some children under some conditions, and hold out hopes that their child may *recover* or lose the diagnosis completely; most parents who held this understanding in this study admitted that they lacked any certainty about the odds of this happening in their child.) Parents' expectations can, and often do, shift again to be both more hopeful and much more certain as they observe their child's developmental progress over time. At any point, when the images of potentially worse outcomes are too painful, parents often resort to the strategy of shifting their expectations, maintaining hopes for better outcomes and avoiding accepting the possibility of fearful outcomes.

As we shall see, parents' fears for the future at the early stages of *making their own way* often lead to a sense of urgency and motivation for *taking action* (see *Going into high gear*).

Surviving the emotional strains of making your own way: Responses and strategies

Surviving the emotional strains of making your own way involves parents successfully enduring or coping with the various challenges and threats to their emotional functioning that they encounter throughout the process of *making their own way*. Emotional strains generally arise from the obstacles and burdens described in section 4.2, and usually involve stress of some kind. Parents must successfully endure these strains to avoid being overwhelmed and remain in a position to proceed with *adjusting* and *taking action*. Surviving emotional strains can involve either absorbing them and moving on, or finding responses and strategies to ease or get around them. For example, above, I discussed some of the potentially overwhelming emotional strains involved in releasing prior expectations and accepting a new potentially fearful expectations for the child's future—i.e., grief and fear (anxiety). Parents either absorb these strains or, when they threaten to overwhelm their emotional capacity, parents may resort to a strategy of shifting their

expectations, maintaining hopes for better outcomes and avoiding accepting the possibility of fearful outcomes.

In this subsection I outline some of the additional responses and strategies parents use for surviving the emotional strains of *making their own way*. Parents experience a majority of emotional strains at the stage of *beginning the autism journey*, but continue to experience them as serious problems arise at later stages. The strategies and responses below are organized in rough order of when in their journey I observed parents to use them.

Not talking about it with one's spouse. Among parents who found the period after learning their child had autism intensely difficult, several described *not talking about it* with their spouse for varying periods of time. This response was even used by parents who described having otherwise strong, positive, and mutually supportive relationships with their spouses. Some mothers suggested that this often mutual response of *not talking about it* may have arisen for shared reasons, including an unspoken perception that the other spouse needed to cope with the emotions of the situation differently, or the fact that both spouses were so overwhelmed dealing with their own emotions that each lacked the capacity to support the other emotionally at that time, or a desire not to burden the other spouse. As one mother recalled, "Neither one of us wanted the other one to know that we were traumatized. I talked to my sister. And he said he talked to his friends. And we didn't really discuss our trauma and sadness with each other."

Instead of talking to their spouse, many mothers spent time mourning on their own. One mother described how her need to break the silence and move on with pursuing intervention as a couple led to an emotional event in which she reconnected with her husband:

> *"And I just kind of grabbed him, and I was just kind of all ready to, you know, just shake him or whatever. And I saw tears in his eyes. And then I went and I started crying. And then I said, 'We have to talk about this.' I said, 'We don't…we both are dealing with our things separately. We have to talk about it.' "*

Not talking about it seemed like an unconscious response that may have served to insulate parents from each other's powerful and complex emotions while grieving was at its most intense.

Turning to outside sources of support. In addition to grieving in silence, many mothers also found other sources of support beyond their spouse. One mother described how her Christian faith, and the spiritual and social benefits of belonging to a church, was an important source of strength for her because, "that really helped me kind of realize not to give into despair, and not to become overwhelmed." Many other mothers connected with other parents of children with autism (see *Sharing*, above) or empathetic relatives. Numerous parents described how talking to or simply receiving information from others who understood was often powerfully therapeutic. One mother recalled how effectively a temporary support group provided for her emotional needs: "And that's when I knew I needed a [long-term] support group because I did feel better after I talked to other people about my feelings—that what I was feeling was OK." Another parent attributed outside support for improving her depression and fear:

> *"A lot of my focus ended up being on, you know, other parents with children with autism, which is where I drew my support and my strength. So when I started reaching out to them I think I got a little bit over my panic and my depression."*

Some parents described how seeking support beyond their spouse led not only to their own ability to cope, but also contributed to resilience in their marriage and the family unit. Parents generally returned to spouses again for support and communication after the grieving period.

Prioritizing one's own ability to function for the sake of one's child. Numerous parents in this study were strained by overwhelming sadness, despair, fear, or anxiety—sometimes upon learning their child had autism, and sometimes at later points in the process of *making their own way*. As described earlier (see Section 4.2, *Concerns*), parents' overall greatest concern was generally for their child's present and long-term wellbeing (such as happiness, autonomy, social connectedness). This was such a priority in some cases that it led parents see their sadness and

despair from a different perspective. When, at some point, parents realized that their child's

wellbeing depended on the their own ability to function, parents became motivated (sometimes

suddenly) to move past their own immobilizing despair. Consequently, multiple parents such as

the following mother described wanting to "snap out of it," and break free of their sadness:

> *"I'd say to myself, 'Oh my gosh, I need to get my act together, because my son needs me.' You know, if I don't take care of myself, then who's going to take care of him? So I have to help myself in order to be strong for my son…The other questions I would ask, is, 'What if something happened to me? How would he survive?' Because he's so attached to me. I'm really the only one he has. And how would he cope? Who would be there to take care of him the way that I take care of him? Will he ever function normally? If he has to face challenges, how will he be able to survive? These are things that I always ask myself."*

As part of this quote suggests, parents sometimes also used their child's dependence on their

ability to function as a rationale for needing to take care of themselves—see *Restoring balance*,

below. Another mother used the logic of *prioritizing her own ability to function for the sake of*

her child as reason why she did not even have the option of having a nervous breakdown in the

midst of a period of depression that was draining all her energy; consequently, she pushed herself

to soldier on, daily navigating intervention despite the difficulty getting up every morning.

Restoring balance. Some parents described responding to the emotional strains of

pursuing intervention (particularly after *going into high gear*—described below) with personal

psychological strategies for *restoring balance*. A common strategy for achieving this is by

reducing one's expectations of what one can accomplish after coming to terms with the limits to

one's expendable personal resources, as the following mother did:

> *"If I do the best I can, at the end of the day I just have to be at peace with that. Because if I don't take care of myself, they've got nothing, because I'm all they've got. So I have to be at peace with what I'm able to do. And if I have a bad day where I don't do much—oh well, so does everybody!...I give myself permission to not be perfect, I guess."*

Restoring balance is a characteristic of the third stage of *making your own way* (see *Easing off*).

In summary, parents' responses and strategies contributed to their remarkable resilience, helping them to endure, move past, or recover from the severe emotional strains they endured. This ultimately allowed parents to continue functioning and move forward in the process of *making their own way* despite formidable obstacles and burdens (see Section 4.2).

Redefining one's roles and self[11] according to new occupational requirements

Redefining one's roles and self according to new occupational requirements is a process by parents communicate meanings about the self to themselves in order to define how to modify or adapt aspects of their self (including non-autism–related roles and identities) in light of their new roles as parents of children with autism pursuing intervention. It often involves expanding one's skillset and comfort level in performing certain activities required for *making your own way*. *Redefining one's roles and self* ultimately has an important influence on the degree to which, and the situations in which, the parent is more or less likely to be proactive. If a person is not comfortable, they will be more hesitant, seek indirect lines of action, or otherwise delay meeting what they see as the requirements of their new role.

Parents therefore struggle emotionally to *redefine their roles and self according to new occupational requirements*. The occupational requirements of parenting the child with special needs and of pursuing intervention have substantial implications for how parents spend much of their time, changes brought by a new role most parents never anticipated before coming to understand their child had autism. Parents have multiple roles and identities that they must rearrange in order to make way for their time- and energy-consuming roles as parents of children

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[11] I refer to *self*, *identity* and *role* defined according to a symbolic interactionist perspective, summarized by Stets and Burke (2003). Briefly, the *self* is organized into multiple parts or *identities* that are tied to the aspects of social structure an individual interacts with, which correspond in turn to the various *roles* or relational positions they hold in society (p. 131).

with autism and pursuers of intervention. Redefining these identities entails changes to who they perceive themselves to be, or a redefining the overall concept of their *self*.

Resolving dilemmas of conflicting roles and identities. One role or identity that many parents described struggling with after their time was significantly rearranged by autism is their role as the parent of *typically* developing children (in cases where their child with autism had typical siblings). One mother to first respond to her inability to parent her son with autism as capably as she had parented her typical sons by overcompensating for this short-coming:

> *"It was the first time I ever felt like I couldn't do my job as a mom. Because I was a natural mom with my other boys. It came very naturally to me. I could always meet their needs. And this was the first time I was not able to meet a child's needs. So I felt inadequate, almost. And I...so I obsessed about this. And so the husband got neglected. The other two kids got neglected."*

Often, the extra time required for parenting a child with autism and pursuing intervention also led parents to experience painful guilt and inadequacy for neglecting their other children. One way parents came to terms with such dilemmas posed by their new roles was by making peace with the fact that they could only do so much in the time they had each day—letting go of some of their identity as a capable parent and accepting the identity of the busier parent of a child with autism. Parents' situations posed other conflicting dilemmas for the roles, identities and sense of self they held, which they had to come to terms with in similar ways. Parents gave up numerous social identities, actual and hoped-for, to make room for the new ways they occupied their time.

An important part of *redefining one's role and self* involves revising one's expectations about one's own future role as a parent and coming to terms with the implications of this for one's overall self. Elizabeth described how emotionally difficult this was:

> *"We have sort of come to this realization that [our son] may not ever be to a point where he can be independent. I mean that's a reality, which means I'm a caregiver until I can't be a caregiver anymore—physically, mentally—whatever that may mean. So that puts added stress on me knowing that I'll never be able to do the...like, it changes the direction of what your life was supposed to be, or what you thought it was supposed to*

> *be. Because I will have an adult child with me until I can no longer take care of him.*
> *And that's very difficult to come to terms with."*

This process of resolving dilemmas posed by new roles is comparable to the dual process of

releasing culturally based hopes and *accepting an uncertain and potentially fearful future for*

one's child (see above), which involves a shifting of the balance between maintaining hopes for

more positive outcomes and accepting more negative expectations about their roles and

associated role requirements; meanwhile, accepting more negative aspects about their roles can

require overcoming denial. Elizabeth further illustrates this:

> *"I still feel that those [more hopeful] things may be possible, because we don't know*
> *what the future holds. But at the same time I have a realistic look on it now, where, you*
> *know what, I can accept that that may likely be the course of our life. Whereas before it*
> *was like, 'Absolutely not—that is not a possibility. Failure is not an option,' "*

Acting against one's nature. Another dilemma posed by parents' new role pursuing

intervention was how it sometimes forced them into *acting against their nature*—threatening the

integrity of some ideas they held about their self. Some tasks involved in meeting the

requirements of their role, such as *having to fight* were experienced as particularly unpleasant

because they were out of character for the parent. Multiple parents, such Marie, saw *having to*

fight as an unpleasant requirement of their role:

> *"You know, they say you can advocate for your child—you're your child's best*
> *advocate. Well to me, advocate just is another word for bitch. Because as soon as you*
> *start advocating for your child, well then you're seen as that parent: 'Oh, here comes*
> *that parent again.' You know, 'She's going to bitch about this, she's going to bitch*
> *about that.' "*

Marie later complained that the worst part of *having to fight* is coming across as "nasty," because,

"I'm not. And, you know, I don't want to be." In a subsequent interview, the she described

making a decision that avoided continuing the conflict in question:

> *"When we finally made the decision, and we decided not to, I felt a lot better. I felt I*
> *didn't…l was turning into somebody I didn't like near the end, because I was getting so*

> *frustrated and, you know, I was crying all the time...I mean, I'm still going to fight for [my son] and his rights. But I'm just doing it in a more positive way I would say."*

Numerous other parents described similarly *feeling discomfort assuming their new role*, sometimes referring to the activities they had to engage in as being outside their *comfort zone*. Comfort zones here corresponded to perceived limits to activities the parent willingly engaged in, beyond which she feared there was potential for damaging or losing an aspect of the self. Parents appeared particularly to fear damaging or losing aspects that they felt they had greater stake in maintaining, either because of the time and energy they cost to construct or because they would be difficult to reconstruct if lost. As a consequence, Marie and other parents pulled back from the problematic activities and often found alternative means to meet their objectives.

   Capacity and motivation for accepting new role responsibilities. The demands of parenting a child with special needs and pursuing intervention, which define how parents' spend their time and energy, require them to invest aspects of themselves in ways they never expected prior to learning their child had autism. Parents often lack capacity and feel unprepared for the requirements of *making their own way* and pursuing intervention, both because they lack the time and energy (physical and emotional energy), and because they lack the requisite skills and abilities. For example, multiple parents described feeling underprepared (and under-supported) for the onslaught of information they had to assimilate at the early stages of *making their own way*, leading in turn to feeling overwhelmed. Also, as multiple professionals observed, many parents are unprepared to participate fully in implementing intervention when they have too much else going on in their lives. Parents' capacity for meeting these and other requirements is an important indicator of the extent to which they accept their new role. In a supplemental analysis (see Appendix L: *Framework for involving parents in intervention, Stages of making your own way and implications for involving parents*), I discuss how parents' readiness to accept

the requirements of their new role varies according to what stage they are at in the process of *making their own way*. Thus, at earliest stages, when they are more pre-occupied with difficult aspects of *emotionally adapting* such as *grieving*, parents have less capacity to participate in *pursuing intervention* than they do later on. This capacity—and parents seeming acceptance of their new role pursuing intervention—generally increases as parents' motivation and sense of urgency increases (see *Going into high gear*). This supplemental analysis gives a general-level idea of how *redefining one's role and self* is related both to parents' capacity and their level of motivation for taking action. As described, the various sub-processes of *emotionally adapting* contribute to increasing their emotional capacity, sense of urgency and level of motivation for *taking action*. Thus, *redefining one's role and self* is partly achieved through the other aspects of *emotionally adapting* described above.

Parents partly define their role of *pursuing intervention* in advance, by *seeing what is involved* (described above, prior to *Emotionally adapting*). I described above, for example, how Elise learned about the kinds of work that would likely be required after talking to other parents. She was emotionally unprepared, however, for the idea of having to "fight with school systems" or "advocating year after year" because at that particular time she had already exerted herself to the point where she felt she "could use a week off work or something just to, you know, relax." Thus *seeing what is involved* in advance of experiencing the requirements of *taking action* firsthand may unnecessarily increase parents' stress and fear of the future if it happens when parents already feel strained by the temporary early-stage aspects of *emotionally adapting*. In addition, parents may not yet feel the same level of urgency and motivation that later drives them to pursuing intervention in those ways. Both explanations were at play for this mother:

> *"What I'm dreading is the fact that, if [my daughter] remains moderate-to-severe on the spectrum, then fine. I'll continue going at this rate that I'm going to make sure she*

> *gets everything that she needs and her life is the best. But I'm not looking forward to, you know, fighting with school systems and, you know, continuing advocating year after year after year after year because I feel like I'm going to, like, have some kind of a breakdown from just fatigue."*

Experiencing personal growth: Expanding comfort zones. *Redefining one's role and self according to new occupational requirements* can have some positive consequences. Namely, several parents commented on *expanding their comfort zones* and, consequently, *experiencing personal growth* in terms of the knowledge and expertise they had gained. As one seasoned parent reflected, "You're out of your comfort zone, and yet that's what makes you grow. Because you don't grow in your comfort zone. It's never comfortable when you're growing. It doesn't feel very good, but you do it anyway." And, noting one area of personal growth: "I definitely would never have called myself tenacious." Another parent described overcoming her unsocial nature, forcing herself to be outgoing enough to interact and make connections with other parents—something which allowed her to develop a critical support network.

Generally speaking, as parents overcome their discomfort (often motivated by their sense of *urgency*; see *Going into high gear*) and gain more experience in their new roles, they become valuable experts in many ways—experts in their child, experts in their knowledge of autism, experts in how to navigate the available services, and even experts in what interventions or approaches work in certain conditions. The knowledge and skill they gain in turn gives parents power, which equips them to help themselves and other parents facing similar challenges. Numerous parents described "always getting called for information," while others assumed leadership positions in parent support roles. Some parents even managed to take their skills and expertise to a quasi-professional level, for example, selling books or offering consultation services. The expertise of parents who have accepted their new roles has substantial (and under-recognized) value for solving the problems of other parents *having to make their own way*.

Going into high gear: The role of urgency

Going into high gear refers to a process in which parents respond to their own sense of urgency about their child's autism by entering a chronic or somewhat prolonged mode of high motivation for *taking action to pursue intervention* in which they expend personal resources (time, energy, and financial resources; see Section 4.2, *Burdens*, *Expendable personal resources*) at a rate that is unsustainable in the long term. Parents can continue operating in this mode for surprisingly long periods, commonly for two or more years. Numerous parents in this study described experiencing stress, fatigue, and exhaustion as a result of the resource loss caused by *going into high gear*. Many parents who were in a position to reflect back on being in high gear, however, felt it benefitted their child and did not regret the sacrifices they made; although some parents acknowledged losing balance in their life.

Urgency (described further below) is a key ingredient of *going into high gear*, but the two phenomena are separate. One distinguishing feature is that parents' sense of *urgency* usually precedes *going into high gear*. Most commonly, parents start feeling urgency as soon as *knowing something is wrong* (the third step of *coming to understand the child has autism*) when it drives early action in the form of pursuing information to develop a better picture of autism (i.e., *defining concerns*) and develop possible lines of action for responding. (Note, this action usually consumes expendable personal resources more slowly than *going into high gear*.) This sense of urgency remains, and may even grow, as parents reach a point of readiness and motivation for *taking action to pursue intervention*. Thus, g*oing into high gear* refers specifically to parents translating *urgency* into a high-energy mode of action at the point when they are prepared or ready to more fully engage in *pursuing intervention*—something which happens through the sub-processes of *adjusting*, generally after *coming to understand the child has autism*.

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Timing of going into high gear. An important characteristic of *going into high gear* is its timing. Parents go into high gear in response to three main types of urgency-inducing events:

1) Coming to understand the child has autism

2) Encountering obstacles to publicly-funded intervention

3) Autism-related crises

Parents most commonly *go into high gear* in response to the urgency of *coming to understand their child has autism*, and most of the discussion and examples in the remainder of this subsection pertain to it as the triggering event. *Going into high gear* in response to the latter two urgency-inducing events are addressed next.

Encountering obstacles to publicly-funded intervention. While parents most commonly *go into high gear* in response to the urgency of *coming to understand their child has autism*, it also frequently happens later, when parents encounter significant obstacles to obtaining or retaining publicly-funded IBI—an event that can cause acute stress when parents feel it endangers their child's developmental progress or trajectory. As one example, Elsa's most stressful and urgent time was after learning that the wait-time for her daughter to start IBI would be 18-24 months. After an initial phase of denial, she responded by *going into high gear*:

> *"When it finally came down to it, I freaked out. And I just started* going*, on creating this home program for her here at the house. And it was a lot to undertake, because I didn't know anything about it. So I was gathering information left, right, and center. And of course we had to go and get the money for that. And that was very stressful."*

Another parent, Dawn recounted how her son was discharged from IBI at age six, after having received one year of therapy, "arbitrarily," and "despite the fact that he had shown remarkable progress." This was traumatic and distressing: "You talk about a return of darkness. It was indescribable how dark it was." To avert the loss of momentum this would cause to her son's development, Dawn embarked on developing her own in-home behavioral intervention

program—a considerably burdensome undertaking (see Section 4.2, *Intervention, Private intervention*)—in addition to the demands of her newly born third child and working half-time.

Crisis. Autism-related *crisis* can cause a special case of *going into high gear*, one that can happen later in the child's development and is usually less chronic. I earlier outlined multiple forms of *crisis*, which was discussed generally as a consequence of stress (see Section 4.2, *Burdens, Stress, Consequences*). The relevant form of *crisis* that leads to urgency and motivation for *going into high gear* is that which centers primarily on the child, caused by a *specific* parent-defined concern usually related to child behavior that is responsible for an intolerable situation or problem. As an extreme example, at the time of this study, there were recurring news reports in local and national news media of autism crises where Ontario parents had struggled unsuccessfully in managing their young-adult-child—sometimes, for example, involving behavior that was a threat to other siblings in the family. After exhausting all other options to care for the child outside the home, his or her situation often progressed from frequent admissions to hospital emergency departments to the prospect of living in homeless shelters.

Unmanageable child behavior problems occurring at varying stages of development were a source of urgency that drove *going into high gear* for several parents in this study. Kathy communicated the intolerable situation created by early-stage behavior stemming from her daughter's sensory problems, "there was no way we could go on like that. Like, it was like living in a war zone." This led her to *going into high gear* to obtain a diagnosis and get the needed help.

Meredith, who was raising several children with low- and high-functioning autism, identified the point when she experienced her greatest level of stress and sense of urgency:

> *"It was when my oldest [and highest-functioning, latest-to-be-diagnosed] son was depressed, because he was talking suicide. And a second cousin of his actually did commit suicide at the same age…he was nine years old. And my son was nine years old, at the time when he was extremely depressed."*

> *"…When he started talking suicide and I realized how real it could be—that it could really happen—I…it was a fire under my butt, basically. I got off my…I took off, and did something. That was when I started really pushing and saying, you know, 'I don't care whether you think he has autism or not. I want that referral.' "*

After a chain of referrals and lobbying, Meredith secured a diagnosis of Asperger's for her son within a few months, at age 10. At the same time, she moved him from his public school environment to a private school (for typically developing children) that provided the outlets and accommodations he needed, which improved his psychiatric problems and resolved the crisis.

As a final example, Dawn's son had a hard time adapting to the move from their small northern Ontario village to a mid-sized city further south in Grade 4. He became apparently depressed, and at times talked about killing himself. This problem peaked when he responded to a bullying incident with a violent outburst in which he hit one of his own friends, and was suspended as a result. Dawn, however, experienced the crisis as an ongoing problem with lots of incidents that left her and her husband anxious and worried for a prolonged period, requiring over a year of intense effort before their son's issues resolved.

The transition to high gear. In addition to its varying time of onset, multiple parents described the transition of *going into high gear* itself as sudden or rapid, following the urgency-inducing event that triggered it. As one parent described her response to learning her child had autism, "You jump right in, you know…I went full speed." Another parent recalled,

> *"I automatically went into the 'fix' mode, you know, got to do something now…He needs therapy right* now. *I can't just sit there and let him go down this path…I clicked…The next part was finding out what I had to do, and finding that information."*

Another parent described the immediate survival response to her son's autism that sent her into high gear: "It was kind of a sink or swim feeling. You know, I just had to be as strong as I can…I was more driven by the idea of, 'OK, what do I need to do? And let me do that right away.' "

To elaborate *going into high gear*, I next address what drives this process: *urgency* and its various causes. After that, I discuss aspects of the *resource-intensive action* that results from being in high gear. Finally, I discuss implications of *urgency* and *going into high gear* for the speed of information processing and decision making, and transcending personal limitations.

Urgency

I consider *urgency* here not as an external characteristic that people objectively ascribe to a situation, nor as a characteristic of response or action, but as a subjective sense or feeling. Thus, one's sense of urgency has personal subjective causes or sources, and consequences or implications for one's approach to action. For parents of children with autism, *urgency* is thus an experiential state comprising a sense of stress or tension that is both cognitive and emotional, psychophysiological, or physiological, similar to *stress* (see Section 4.2, *Burdens*, *Stress*); additionally it involves a sense of imperativeness, or intense motivation, for *taking action* quickly to resolve the source of stress or tension that threatens something they have developed a high stake in (usually the child, or the self). Importantly, there is a time-pressure associated with the need to action, which logically implies a need to avoid or achieve some outcome quickly, before time runs out. While urgency involves a powerful desire for action, action itself is not required as a consequence since action can sometimes be blocked by constraints the individual can do nothing to overcome. Parents and professionals commonly referred by word to the *urgency* of parents' feelings and action, particularly related to *going into high gear*.[12]

The degree of urgency parents feel varies according to different conditions. There are two relevant dimensional aspects of urgency in autism: the amount of time-pressure, which consists

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[12] Note the discussion of *urgency* here primarily applies to parents' response to *coming to understand their child has autism*, although several aspects also apply to the other events that trigger *going into high gear*—encountering obstacles to publicly-funded intervention, and crisis.

of an intuitive perception of the time available before the outcome one wants to avoid or achieve occurs relative to the time necessary for taking action to avoid or achieve it; and, secondly, how intensely one feels one has a stake in the outcome.

An implication of the increase in motivation is that parents have a lower threshold for *taking action*. That is, the expected chance of success can be much lower before a parent is willing to invest personal resources (i.e., energy, time, or financial resources) in *taking action*. Sometime the only requirement is a basic capacity for action, even when hope for success is almost negligible. This reduced threshold for action allows parents to transcend self-perceived limitations, and increase their power for action (see *Transcending personal limitations*, below).

Finally, *urgency* has important similarities and overlap with *stress*. *Urgency* is one possible manifestation of stress and therefore shares some of the same causes—recall, one of four categories of causes that I defined for *stress* was *circumstances underlying urgency of the situation* (see Section 4.2, *Stress*). These causes are described in more detail next, as the *Sources of urgency*. Aspects of the physiological mechanism of stress I used earlier as an analogy to account for its physical and behavioral manifestations also apply to urgency. Thus there is a shorter-lived response that mobilizes energy stores to prepare the brain and body both for rapid action, and a longer-lasting response that maintains energy-intensive levels of functioning for prolonged periods; additionally, physiological exhaustion can result from responding to urgency for excessively long periods. Thus, one of the outcomes of both *urgency* and *stress* is *going into high gear* with its similarly physiological manifestations and consequences.

Sources of urgency. The sources of urgency generally include fear-related aspects (i.e., framed as negative outcomes parents want to avoid) and hope-related aspects (i.e., framed as positive outcomes parents want to succeed in achieving) of the outcomes parents feel a high

stake in. As discussed, the each of the sub-processes of *adjusting to the need to navigate intervention* (i.e., *coming to understand the child has autism* or *defining the concern*, *informing the self*, *seeing what is involved*, and *emotionally adapting* to various aspects of the situation) prepares and motivates parents in many ways for *taking action* both *to pursue information* and *to pursue intervention*. Together, the meanings that parents construct for themselves through these sub-processes of *adjusting* combine and interact to feed a more pronounced sense of *urgency*, which in turn predispose them for *going into high gear* by super-charging their motivation for action. The following fear-related meanings, or *sources* of urgency, can interact in complex ways to influence parents' action:

- Feelings of anxiety about possible future outcomes of autism

- Seeing one's child struggle

- Knowing the importance of intervening early

- Learning it is up to parents to take action

- Guilt for not doing enough

The following hope-related source of *urgency*, meanwhile, usually affects parents' motivation for action independently of the fear-related sources above:

- Hopeful child outcomes

I discuss each of these sources in turn, next.

> **Feeling anxiety about possible future outcomes.** Parents commonly develop feelings of anxiety and fear about the possible future autism-related outcomes through the expectations they develop for their child—images of the future that the parent continually revises as she comes to accept more negative outcomes or revives more hopeful ones (see *Emotionally adapting,*

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Accepting an uncertain and potentially fearful future for the child, above). Two kinds of events shift parents' hopes downward and trigger feelings of anxiety and fear:

1) Coming to understand their child has autism, and

2) Encountering significant obstacles to obtaining or retaining publicly-funded intervention (see *Timing of going into high gear*, above).

Described previously, parents begin developing a sense of urgency in response to the first of these events, *coming to understand their child has autism*, at the third step of this process: *knowing something is wrong* (see that earlier subsection, where early forms *urgency* motivating quick action are discussed). While all parents in this study experienced anxiety at this stage, the urgency and rush of *going into high gear* was commonly more pronounced among parents who had difficulty with aspects of *releasing culturally-based hopes* and *accepting an uncertain and potentially fearful future* (see *Emotionally adjusting*). Such parents described, for example, being motivated by a desire to 'fix' their child, or a need for normalcy, at this stage. In addition, the act of *informing themselves* about autism sometimes played an important role in forming early images of autism that were anxiety-provoking (see *Information for understanding autism*).

In communicating such anxiety-related urgency parents used language that was suggestive of a physiological stress response. Laura, for example, described feeling a combined physical sense of panic and sense of urgency after realizing her daughter had autism: "For me it was like, you get that cold thing in your chest, like, [inhaling] 'Oh my God!' right. But I was also like, 'I have to do something.' And I didn't know what to do." Rosa mentioned *panic* several times before the following quote in describing her sense of urgency, which was directed at restoring the initial culturally-based hopes she had for her child:

> "Well then I understood that we could get some help and some early intervention, right. That came up very quickly—how important that is. And so I was in a panic to make sure

> *that we moved quickly now. Because I believed that if we could get her the help early enough that it could all go away."*

Dawn's description of *going into high gear* in response to *coming to understand one's child has autism* implies the long-term nature of this response: "It's like you get stuck on a panic button."

Examples of urgency and going into high gear in response to the second type of event that commonly triggers feelings of anxiety and fear—encountering obstacles to publicly-funded interventions—were presented previously (see Timing of going into high gear; Section 4.2, Stress, Causes, Obstacles leaving parents feeling helpless).

Seeing one's child struggle. Seeing one's child struggle—whether suffering in some way, or having difficulty keeping up or fitting in with peers—is difficult for virtually all parents because they care and feel a deep emotional stake in seeing their child flourish. This stake comes partly from prolonged and close contact and involvement with the child, through which parents develop expert knowledge that positions them to be intuitively aware of the child's needs. Parents of children with autism see their child struggle in many ways. It is an experience that adds anguished emotional meanings to many of the concerns parents define for their child, and contributes urgency and motivation for greater involvement and action to resolve the problem. Carol, for example, described feeling urgency to act after seeing her son struggle academically:

> *"I guess the need to take action is when you watch your child, and you see him struggle. And you realize that he's not keeping up with his peers. So, for example…if I look at him overall in relation to the other peers in his class, he's in my bottom three. And that made us act pretty fast."*

Another parent commented on the anguish she feels whenever she receives information showing that her son compares poorly with typically developing peers:

> *"I'm always stressed when they do assessments and I get the results because all they do is focus on the negative. It's never the positive. It's not what he's doing, it's always what he can't do and how different he is from all the other kids. And I just really have a hard time with that."*

Parents' commonly experienced anguish and urgency when they observed how autism threatened their child's happiness and social connectedness. Terry's anguish about her child's inability to speak involved anxiety about possible future outcomes: "He doesn't have to use a voice. But that's really hard to accept as a parent, because it means that he's going to struggle. And as a parent you don't want that for your child." While Sofia described numerous fears for her son's future that motivated her urgency, these were rooted in direct observations of how he was struggling: "So I saw, OK, my son can't communicate to get his needs met, or to ask questions—to be curious, you know. So he can't have friendships. And I couldn't imagine him not being able to have *friends*." She emphasized that she was motivated by concerns about, "not just his future, but his day-to-day."

Feelings of anguish and urgency were particularly acute among parents who witnessed their child suffer emotional distress. Meredith, whose family experienced a financial setback when her husband's pay was cut back, had witnessed her children's mental health suffer in a public school setting and was particularly worried about one son's risk of suicide (see *Going into high gear, Crisis*, above). This inspired a powerful urgency to improve his psychiatric wellbeing, one in which, "We were more motivated to deal with the financial burdens…we said, 'I don't care if it means we have to sell our house. These kids need to be in the private school,' " which she knew could better accommodate their needs.

Maria recalled how, after already suspecting her daughter had autism, she responded with an emotional sense of urgency to witnessing her daughter's performance during an assessment evaluating her eligibility for a resource consultant:

> *"And she wasn't doing what they were asking. She was getting frustrated and she started throwing herself on the floor—things that she would never do, because she was always in a good mood, right. But I realized that when you pushed her, she started getting frustrated. And that day, I came home. I parked in my driveway. I remember so*

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clearly. She's in the back. My mom was in the house with my little one, who at the time was not even a year, and I called my husband. And I said to him, I go, "Look, she has autism. This is real. We have to move." And then we were crying on the phone."

The response to *seeing one's child struggle* can be primal and protective—as one mother put it, "I do believe very much that the mother bear kicks in." Thus, threats to a child's wellbeing evoked a stress response for many parents in which it seemed their physiology became involved in mobilizing energy for rapid, focused action to resolve the concern (see Section 4.2, *Stress*). Because this protective response applies to other caregiver contexts besides parents of children with autism, the stress-related urgency that comes from *seeing one's child struggle* is perhaps the most generic ingredient of the process of *going into high gear*.

Knowing the importance of intervening early. A majority of parents in this study indicated their direct or indirect awareness of research evidence about the importance of intervening at younger ages for achieving better outcomes in autism as a key reason behind their sense of urgency to take action quickly. Thus, parents frequently offered comments reflecting their exasperated desire to begin intervention, such as, "I was consistently reading how important early intervention is." One mother provided detail about specific information promoting earlier intervention:

> *"When we looked at some of the research that we had already read about, they were saying that the optimal time for the IBI to work is before the age of six because of the way the brain develops, and the way that people develop habits. And if you get children early enough you don't have to un-teach a skill that they have already learned, and then reteach it."*

The following exchanges illustrates how parents' knowledge of such research interacts with their anxiety about possible future outcomes to increase parents' sense of urgency:

> *M: "Well all of the articles about early intervention—that scared the crap out of me. If your child doesn't get therapy in the first couple of years that they're diagnosed, their prognosis in life or their outcome in life is not reaching their full potential. That scared the crap out of me."*

> S: "So kind of a lost opportunity."
>
> M: "Yeah, absolutely. I just felt like all the dreams I had for him, university, living by himself, or getting married, were totally out the window if I didn't fix this. Yes, I guess a need for normalcy in his life, right."

Awareness of the importance of intervening early is one possible reason parents push for an early diagnosis after becoming aware their child has autism, sometimes paying for it privately so they can get on the IBI waitlist earlier. The same knowledge also increases pressure to find ways of making up for the absence of publicly-funded services that many parents experience after diagnosis while on the waitlist for IBI. As one parent lamented, "So there was this two-year gap. And so the only person that could fill it was me. There was no therapy that we could pay for."

Importantly, the pressure to intervene early leads parents to change how they weigh the trade-offs of taking resource-intensive action, as the following mother illustrates:

> "How we look at it is, 'What can wait? Can treating him now wait, or paying off debts wait? Which is something that you can do later?' And we realized we can't wait until later to help him…We're always, like, 'We have our whole life to pay off debts.' But when he's older, it's going to be harder to help him. We have to do it now."

As another parent remarked, "This is precious time in the child's early years."

Learning it is up to parents to take action. I have already partially described *learning that it is up to parents to take action* as one of the two means of more broadly *seeing what is involved in pursuing intervention* (see that subsection, prior to *Emotionally adapting*). Many parents in this study communicated how, at some point, they realized it was up to them to be proactive in *taking action* themselves if they hoped to achieve better outcomes for their child; this was primarily because they had learned the system was unlikely or incapable of providing the intervention that they clearly understood their child needed. This learning represented a shift from prior understandings or assumptions of what the system could provide. As one parent described her prior understanding, "When I finally got the diagnosis, I remember thinking,

'Thank God I'm in Canada.' Because Canada is way better in the health system, in the school system, than [my home country]." The same mother describes how she felt after gaining a more informed understanding: "I was very disappointed, because I had this other image." She believed instead that the system works well only for those with standard health problems, and not for non-standard problems like autism.

Some parents demonstrated how their prior expectations limited their actions early on, leading them to naively trust the system to guide and take care of them instead of more proactively taking things into their own hands. One couple, for example, knew their daughter had autism but put off pursuing any intervention until after securing a diagnosis, assuming the system would do what was most appropriate at the right time. In hindsight, they realized they did not need to have waited for a diagnosis before taking action themselves to pursue intervention that would have been appropriate for a child with autism.

Parents' begin to change their naïve prior understandings as they start gaining experience with the system, often first interacting with it through *pursuing a diagnosis* when they may experience multiple obstacles and inefficiencies that delay the process, such as one parent:

> *"I think that when the principal shut us down from getting a diagnosis and any help that way. I think that really kind of said it. We weren't going to be getting any help from them, so I didn't have any choice but to try to find it on my own. So I think that would have been the lowest."*

Some parents described such learning as slow: "But then slowly we learned that we're not going to get anything out of the system. We know it. What we have to do is we have to do it ourselves."

One mother framed her learning about the importance of proactively informing oneself as advice she would give new parents: "Don't wait for other people to do the work for you, because then you'll be missing out on services or funding. *You* have to be knowledgeable." Another father described the implications of this learning:

> *"As a parent, you're in other people's faces, because you want what's best for your child. Because if you don't, your kid will fall through the cracks. They won't get the best service. Because the way the system works—it doesn't work—you've got to be your kid's biggest advocate because there's nobody else going to advocate for your child."*

Many parents described a desire to overcome limitations in the available publicly-funded therapy by empowering themselves to deliver it on their own. One mother was motivated by knowing her daughter would lose her funded IBI: "I decided to start doing the training because I figured, you know what, I need to be ready for her. I can't wait for anybody else. The authorities can't do…are not, you know…I can't wait." For another parent, training was a cost issue: "I can't afford therapists. It's easier for me to train myself than to pay for a private therapist. And I'm with her a lot more time, right."

Indeed, multiple parents realized that the time they spent and their unique familiarity with the child obligated them to be more involved in intervention, such as the following mother:

> *"As much as we don't want to be the ones to do it, we've slowly realized that we're her parents. We're the ones who spend the most time with her. So, unfortunately, it's our obligation to be her main therapists. That was a harsh realization actually."*

One professional similarly expressed how parents are uniquely positioned to be involved in advocating to help their child: "It's sad to say, but a lot of the times the parents, or the main advocate, they know their kids, and they're the one who have to do most of the work, educate themselves, and help their child. Because they're with them most of the time."

In summary, parents learn it is up to them to take action by becoming aware of the limitations of the system and realizing they have a responsibility to be involved as parents whose familiarity with their child best positions them to help. This learning in turn empowers and motivates parents to be highly proactive in how they take action.

Guilt for not doing enough. Contributing to their sense of urgency, many parents often feel guilt for not doing enough, putting pressure on themselves to expend more personal

resources. One mother, who sought psychological counseling for her guilt, expressed how

feelings of inadequacy and anguish were connected to the impossible pressure she felt from this:

> *"Lots of guilt. Guilt about if I had done something differently maybe he wouldn't have autism. Guilt about how can I spend proper time with my other kids. But yet how do I neglect [son] to give them what they need. I can't. Like, I needed to split myself into four people it felt like. And it still feels that way. I still feel like I cannot do all I should be doing as a mother. I don't feel like I'm doing my job. And yet I know I'm trying hard, so. The guilt is a very big part of it. It's hard. It's very, very hard to deal with the guilt."*

Any information about additional possible intervention-related actions parents could take

to further help their child had potential to evoke feelings of guilt. For example, Ilona recalled

being told by an instructor teaching her to deliver behavioral therapy that, "There's no limit to

what kids with autism can grow up to [do]. So then there is no limit to how much you [can] treat

them, right?" In describing the effect this information had on her, Ilona remarked, "I am a very

responsible person. So how [my children] turn out with their autism is on me." Indeed, she was

dedicated to delivering as much therapy as possible, working at it 80 hours per week and

assigning housework to grandparents and a nanny so she could fit more in. But, she noted,

> *"I started getting drained, tired. And then, like, you can only do so much…there was always something to do on my list of things, and then there wasn't enough time to do all that. And it creates a, like, 'I'm not doing enough. I'm not doing enough to keep up.' "*

Another mother summarized the pressure to try or add new things, "Like, you can't just try

one thing and say, 'Well, it didn't work,' you know. With an autistic child, you've got to try it

twenty different ways. It's exhausting. It's physically, mentally, and emotionally exhausting."

Guilt for not doing enough to address a child's autism is another motivator underlying parents'

neglect of other aspects of their lives such as personal health, marital relationships, or other

typically developing children in the family. Doing more is the antidote to guilt because, as one

parent reflected, it helps her feel "absolved." Thus, guilt for not doing enough exacerbates the

loss of balance and deficit of expendable resources that define *going into high gear*.

Hopeful child outcomes. Several parents and professionals highlighted an alternative form of *going into high gear* in which parents' urgency was fuelled by the success of seeing hopeful child outcomes rather than by fears of more negative ones. Parents had often already operating in high gear for some period of time before they started to notice their efforts paying off in the form of positive outcomes in the child. Seeing these positive outcomes usually led such parents to feel excited about what was possible and restored their hopes and expectations to higher levels. It also increased confidence that they could achieve more success by investing additional personal resources in further action to pursue intervention. As one experienced parent, reflected, "High gear comes, I think, from hope and a feeling that all is worth it." Seeing a hopeful trajectory leads parents "to keep really pushing hard to not give up on [their child]."

Kim described how seeing progress increased her capacity to do more:

> *"But because he's made so much progress, you know, you just feel so energized and you feel like everything's been worth it. It's just a completely different feeling now from where I was a year ago. Because now I see…it's almost like all of it is coming together now. All of the therapies, everything that we've done is now starting to benefit him.*

> *"So now there's like a renewed energy where—like, look at the outcome! I mean if he can do this in such a short period of time, you know, he's going to do so much more. And that's why now I want more information, more sophisticated information, more detailed information about next steps, and to push even harder. So we're thinking of doing more ABA. You know, I was thinking of sending therapists into the daycare. So, like, more intervention than ever before. Because now he's got the base. I think, before, you couldn't do a lot of it because he was non-verbal. He didn't have a base. He was so young. He was exhausted. Now he's got a good foundation of language, so you can teach him so much more. And he's so ready now for even more intervention, I think."*

Kim further commented in a later communication how, had they not seen progress, they might have given up and denied their son many opportunities to develop. A professional shared a similar corroborating observation of the many parents in her practice:

> *"If the parents see a glimmer of personality, if they see change—that gives them a great deal of hope…And that really drives parents to invest a lot of their time and invest in a lot of therapies as well…Because it's momentum, right."*

Resource-intensive action

Urgency motivates parents to *go into high gear*, and equips them with determination and power to meet the often-substantial obstacles and burdens that parents of children with autism generally encounter in the course of *taking action to pursue intervention* (see Section 4.2, *External obstacles; Burdens*). Here, I first discuss how the resource-intensive action that defines *going into high gear* is ultimately a stress-driven attempt by parents to restore control of the fearful and uncertain aspects of their situation. I next summarize how, for many parents, this action is characterized by a desire to try everything and anything they can find to address their main concerns. Finally, I address how the time that parents spend in high gear is self-limited by the unsustainable rate at which parents expend personal resources in pursuit of intervention.

Restoring control. *Going into high gear* in response to anxiety-related *urgency* can partly benefit parents by *restoring a sense of control* over the fearful and uncertain aspects of their situation and thereby reduce their stress. For example, the reason Marsha went to the extent of training herself to become a therapist was because she couldn't stand the panicked, insecure feeling of not having a behavioral therapy team in place for her son whenever they had to part ways with their latest provider: "I was petrified not to have a team." She confirmed that becoming a therapist increased her sense of control, because it equipped her to step in to deliver high quality therapy herself if individual therapists turned out to be unsatisfactory, or they risked losing his team again altogether. It also gave her more financial control in managing her son's therapy. Another parent increased her sense of control by putting considerable work into organizing the information she collected so that it would be readily available to guide her when new needs arose as her son transitioned to new stages. Parents often portrayed their act of *researching* as a scrambled effort, or longer-term obsession, with controlling some aspect of

their situation. Much of the action parents engage in as a result of *going into high gear* can be regarded as a means of restoring control, and thus parents' sense of power over their situation.

Wanting to try everything. For many parents, the action that results form *going into high gear* is especially resource-intensive because it involves a desire to try everything and anything they can find to address their main concerns. *Wanting to try everything* is something that happens to parents early on, usually as soon as they have learned their child has autism. The types of parents who most commonly described *wanting to try everything* were those who also had difficulty with aspects of *releasing culturally-based hopes* and *accepting an uncertain and potentially fearful future*, wanting to "fix" or reverse their child's autism.

Such parents sometimes appeared to desperately grasp for solutions anywhere they could find them. As one professional observed, "Some of [the driven parents] will search and search and search for any treatment across the world that might kind of help or cure." As one mother described, it was her husband who pushed urgently to try everything to fix their son's autism:

> *"He always looks for information. And if he finds a link anywhere which says, you know, that this is something that has worked for somebody in the world somewhere, right. I'm not talking about Canada. I'm talking about the world. Somebody tells him that this is something in the world that has worked for even one person, you know, he doesn't mind trying…his point is, 'It worked for one out of ten thousand. Maybe we could be that one.'…He wants to do all the different kind of treatments that are possible all together: 'Since we don't know which one is going to work, why don't we try everything.' "*

For many parents like the father above, *wanting to try everything* meant trying unproven biomedical or other alternative treatments. Some professionals, such as the following diagnostician, encourage the parents they support to be critical of the information about such treatments: "I try and teach my parents to be smart shoppers and consumers. Because they're all over the internet. One of my hard-and-fast rules is if something costs a lot of money and says it's going to cure it, walk away." But as another professional noted, getting parents to process information they may encounter on the internet or elsewhere critically, "is really challenging

because parents are searching for everything. And, you know, we haven't done the studies on the interventions." Empathetically, she admits, "if I was a parent in that position I would probably explore all my options as well." Basra provided frank insight about her early inclination to be uncritical of information early on, when she felt the greatest urgency to act (see also Section 4.2, *Information, Ontario parents' positions regarding intervention-related information*):

> "You see, at that time, I was in a very tough position. I was gullible. I was a mother who was confused. Like, if anybody came to me and told me they had a cure for my son, I would just believe it and pay for that person. Because I was in a desperate position, not realizing what I was getting myself into."

Other parents described an early gullible phase, which they outgrew as they informed themselves.

The biomedical movement is known for historically relying on different, lower standards of evidence in the information it uses to promote biomedical interventions (see Appendix I: *Credibility of information, Case of the biomedical movement*). Parents held a variety of different and sometimes nuanced positions towards biomedical ideas, which influenced both their disposition to appraise information critically and adopt biomedical interventions (see Section 4.2, *Information, Ontario parents' positions regarding intervention-related information*)—positions that sometimes evolved as it did for parents who referred to themselves as previously gullible.

Urgency, however, led even parents who were unsympathetic to biomedical ideas to want to try biomedical interventions, such as the following mother: "I guess I've never really been a huge into this alternative medicine…so it's hard for me to buy it, to agree with it. But I'll try anything, basically—whatever. When it comes to [my son], I'll try anything." Some parents were critically aware of the lack of evidence to support many treatments, but felt they had little choice but to adopt them. One mother, Kim, acknowledged being aware that the quality of the science

was very poor for biomedical interventions, but said she had to take a chance in the interest of moving forward towards a solution.

Parents' urgency, and consequently the desire by some to try any interventions available, may be motivated in part by *guilt for not doing enough* (see *Sources of urgency*, above). One parent, who simply wanted her daughter to become more autonomous, described her reasoning for the sacrifices her family made as follows:

> *"I wanted to try everything. Because there are a lot of things that are not proven. We also did the diet. And that costs a lot of money because you're doing all organic. We're paying for the naturopath, etc. You just want to have a feeling that 'I tried everything.' You don't want twenty years from now to think [you didn't do everything possible]."*

But there are several disadvantages of following through on the desire to try everything. First, by *going into high gear*, non-autism priorities generally fall down on the list and many aspects of life get neglected, including the parent's own health. Second, as multiple professionals remarked, the time spent engaged in numerous interventions can be hard on the child. As one professional put it, "the child has no time to be a child. They're just totally programmed." Third, as will be discussed next, implementing every possible intervention is not sustainable for the parent because this generally entails growing deficit of personal resources. As one professional observed, some parents who, "go into overdrive…[have engaged] with every service, and they're almost on the verge of exhaustion…so my job is to help them find a happy balance."

Unsustainability of expending personal resources at sprint pace. As described previously, parents usually contend multiple autism-related concerns, each usually requiring multiple interventions, with each intervention generally entailing many possible tasks (related to navigating and implementing), each of which can involve substantial work (Section 4.2, *Burdens*, *Work*). Parents' workload from both navigating intervention and parenting the child with autism can therefore be considerable, even without *going into high gear*. In addition to parents'

workload, the financial costs associated with intervention, and coping with physical and emotional autism-related stresses drain parents' expendable personal resources—including time, financial resources, and energy (physiological reserves for physical, emotional, and cognitive functioning)—resulting in burdens that sometimes overwhelm parents.

Parents who continued operating in *high gear* for extended periods of a year or more often described signs of chronic stress—namely *exhaustion* caused by a depletion of expendable personal resources. I previously illustrated with examples how the sacrifices parents make as a result of *going into high gear* often lead to the depletion of personal resources faster than they can be replenished resulting in a disequilibrium or deficit that progresses over time—such as time demands causing sleep deprivation that in turn reduces cognitive and emotional coping capacity (see Section 4.2, *Work*, *Expendable personal resource loss*). I also illustrated with additional examples how a chronically progressing deficit in expendable personal resources can ultimately result in a loss of function that is characteristic of chronic stress-related *exhaustion*, which further reduces the parent's capacity to cope with challenges and creates a risk of breakdown if there is no change in the situation—such as descriptions of debilitating depression, "burnout," experiences that "nearly broke us," or marital breakdown (see Section 4.2, *Stress*, *Work-related resource loss reducing capacity to copy*; and *Exhaustion as crisis*).

Dilin, whose health ultimately broke down as a result of being in high gear for so long described the onset of this *exhaustion* as gradual:

> *"But as I started, you know, getting into the thick of that [navigating intervention], and dealing with [my son with autism] not sleeping, and starting to self-injure, and then having a son almost in high school at this time, and then another one just a year older than [my son with autism]—just keeping up with the day-to-day stuff that a normal parent goes through, and then having this on top of it, it was like having three fulltime jobs, is what it felt like. And it started to take a toll on me—slowly at first."*

In summary, *going into high gear* often turns out to be unsustainable. One seasoned parent

used the analogy of going at sprint pace, when at some point parents need to learn to go at marathon pace. This analogy is fitting. Elite marathon runners may go about half as fast as elite 100-metre sprinters, but they manage their energy resources within sustainable limits that allow for an effort that is 420 times longer.

Not all parents continue in *high gear* until exhaustion. But decisions to go slower along the way can be very difficult when they involve a sense of urgency to pursue intervention at what might be a critical point in a child's development on the one hand, and the desire to maintain balance in other important aspects of life on the other. Juliana described her decision between moving to a small city where it would be possible for her son with autism receive therapy but where she and her husband would have such a long commute they would have few waking hours to spend with their children, or continuing to live where they did without the option of therapy:

> *"And we sat down and thought, well, my aunt lives in [small city]. And she's offered us to move in with her so that we can work and [my son with autism] can get his therapy, and she can watch the girls for us during the day. You know, we thought about all that. But then we thought, we love him, and we'll do anything for him, but we also have two other children. So sometimes we need to do what's best for them too. It can't always be what's best for him. So we always go back…and I mean, the guilt sometimes gets us. But we have to remember that he's not the only person in this family. He's the one that needs the most help right now, but he's not the only one here…It was a very hard decision, and we went back and forth on it forever…I hope we made the right decision."*

Often, balance is something parents realize they must restore after a period of imbalance that pushes them close to or beyond the point of *exhaustion*. One seasoned parent reflected on deciding to work as her son's therapist, which was hard on her son and wore her out, as follows: "That would be my regret. You need to get away from autism for a while, so that you can recharge." And later she added, "It's not all about special needs. It's about life." This realization of the need to restore balance and go at a more sustainable pace is a central feature of the final stage of *making your own way* (see *Easing off*, below).

Transcending personal limitations

Stress is an important element of *urgency*, and aspects of the physiological stress response were apparent in parents as they developed and responded to a sense of *urgency*. The two sources of *urgency* described previously that were explicitly associated with a physiological stress response related to fear (in contrast to the more cognitive learning that characterized some of the other sources of urgency described) include *feelings of anxiety about possible future outcomes of autism* (where stress manifests as panic and panicked action), and *seeing one's child struggle* (where the stress response manifests as a natural parental protective response to threats endangering one's child).

The stress associated with these sources of *urgency* underlies the more instinctive and less deliberative aspects of parents' responses to urgency when *going into high gear*. One aspect is parents' emotive (or psychophysiological) eagerness to embark on action. There was abundant evidence in parent interviews suggesting that this unhesitating eagerness involved a disregard for personal limitations that might otherwise hold them back from initiating the kind of action involved in *going into high gear*. This disregard involved a seemingly subconscious suppression of the cognitive awareness of personal limitations that parents may have let influence their action in less urgent times, and a disregard for the costs of action.

A helpful analogy of how fear-related stress can lead people to respond by disregarding and transcending personal limitations—apparently becoming superhuman—is the popular anecdotal phenomenon of adults lifting cars out of panic to free trapped children. In his book *Extreme Fear*, Jeff Wise (2009) evokes a true account of this anecdote to help illustrate the physiological mechanisms that explain how fear-related stress removes limitations that normally restrain performance and "unleashes reserves of energy that normally remain inaccessible" (p.

27). While some of the mechanisms remain unknown, he points to research that they partly involve analgesia, so that "under intense pressure…you just won't feel that pain" (p. 36).

Parents of children with autism similarly can take on seeming supra-normal capacity to act and to cope with the sources of urgency that characterize their situation. There are some notable differences, however, from the car-lifting analogy. While the cause of stress and urgency is similar (i.e., *seeing one's child struggle*), the timescale and actions that parents of children with autism take in responding differ—for example, the actions being less physical. Thus, the limitations to action that parents overcome in *going into high gear* also vary. The more psychological limitations that under normal circumstances otherwise logically constrain the kinds of action that parents typically embark on when *going into high gear* include,

- Perceptions of limited personal skills or abilities,

- Comfort zones, or the set of activities an individual associates with a low risk of damaging or destroying any aspect of the self (see *Emotionally adapting*, *Redefining one's roles and self according to new occupational requirements*), and

- The high cost of personal expendable resources (particularly relative to the chance that the associated action will succeed in producing the outcome pursued).

I have provided many examples earlier in this subsection (and elsewhere in this dissertation) of parents overcoming the above limitations by recruiting or acquiring remarkable skills and personal resources to pursue intervention—skills and resources they would almost certainly not draw on in non-urgent situations. Here I review some aspects of prior examples, and consider some new ones, to further illustrate how *urgency* leads parents to *transcend personal limitations* and increase their own capacity (power and resourcefulness) for action.

The strongest, most obvious examples of *transcending personal limitations* are the instances where parents have sustained the high rate expending personal resources to the point of reaching physical, emotional, or psychological exhaustion (see *Resource-intensive action*). Parents who have taken their action as a result of *going into high gear* this far have clearly disregarded the limitation of the *high cost of personal expendable resources*. Dilin, in describing what led to her eventual exhaustion, recalled her initial eagerness, "It started off with, 'OK, I have this…I have lots of energy to jump in here and intervene, and help, and learn, and educate myself.' " Later, she indicated her continuing disregard for the toll that being in high gear was taking on her family and her own emotional reserves: "I was, you know, like a steamroller with this whole autism thing."

Further examples can be gleaned by examining the wording of other examples in this subsection, which contain numerous indications of how parents transcended personal limitations. Recall the first quotation used to illustrate *going into high gear* in which Elsa described how she "freaked out" and embarked on developing an in-home behavioral intervention program for her daughter. She indicated how she overcame the limitation of *personal skills* by doing the extra work of researching to develop the required knowledge: "And it was a lot to undertake, because I didn't know anything about it. So I was gathering information left, right, and center." Further, she suggests how she disregarded the limitations of her *comfort zone* by negotiating for a bank loan: "And of course we had to go and get the money for that. And that was very stressful."

Another mother, despite being keenly aware that she and her husband could not afford behavioral intervention for their son who was ineligible for funded IBI (i.e., her personal financial resources were a very apparent limitation), nevertheless considered it possible that they might somehow find a way to afford it and researched specialized private schools that offered

such intervention. When asked why she originally considered such private schools as an option despite not yet knowing how they could cover the exorbitant yearly fees, she explained that when you discover your child has autism, "what I've observed from talking to people, you go one of two ways. You either go fully into it and you want to do everything for your child, or you become overwhelmed." Ultimately, she found the means to finance the tuition thanks to the generosity of parents-in-law.

These examples all illustrate how the various limitations—of limited personal skills and abilities, comfort zones, and costs to personal expendable resources—represent another type of obstacle that parents overcome in *making their own way* to intervention. Parents, however, do not always perceive these obstacles as they instinctively take action. Rather it is observers, such as support professionals, who are more likely to perceive a discrepancy between what parents are equipped to achieve comfortably, and what they are motivated by their sense of urgency to try to accomplish. It is this sometimes formidable discrepancy that parents are empowered by their sense of urgency to disregard and frequently overcome. When *transcending personal limitations* results in the acquisition of new skills, parents can experience personal growth as a result of their unhesitating action.

Fast intuitive vs. slow deliberative thinking in choosing lines of action

Parents' sense of urgency that motivated *going into high gear* appeared to also have stress-related effects on how they responded cognitively to formulate lines of action and make decisions about what action to pursue. As described previously, the physiological stress response mobilizes energy stores to prepare the brain and body both for rapid action, and maintain energy-intensive levels of functioning for prolonged periods. Thus, stress leads partly to mental arousal in which the individual becomes more alert and perceptive of her surroundings or situation, and

engages in rapid intuitive thinking and problem-solving directed at the source of stress. Reflecting the effects of stress and urgency on cognitive processing, parents in high gear commonly indicated that they came to conclusions about what lines of action to follow in a rapid and intuitive manner—sometimes as if no conscious decision making were taking place at all. Slower deliberative decision making about what intervention to pursue, by contrast, was rarely described in association with *going into high gear*.

 Intuition. For purposes here, I define intuitive thinking (*intuition*) as a rapid, non-deliberative form of cognitive processing that draws on and integrates existing knowledge in ways that are initially not explicitly conscious because it does not involve a deliberative interactive conversation with the self or others. *Intuition* often produces in parents the understanding of a defined concern, or a decisive idea of the best line of action to follow in addressing a concern. Decisions about action do not resemble a deliberative choice between options, but usually a unified idea about what is the best action to take, one that can be hard to justify. The logic of intuitive thinking can be difficult or impossible to trace because it is not initially made explicit with language. It therefore requires effort to articulate one's reasoning to be accountable for its logic. While intuitive thinking is often informed by the holistic integration of a broad range of considerations and knowledge, it is still susceptible to mistakes as the individual fails to consider information that takes more time to gather or neglects analyses that require slower deliberative thought.

 In the case of parents of young children with autism, intuitive thinking and the action it directs are often based on extensive knowledge of the child, informed by prolonged close contact throughout development (i.e., information, in the form of observations of the child). Parents thus attributed meanings and instinctively recognized the implications of signs and behaviors that

others might not notice. Substantial intimate knowledge of the child thus made parents experts, so that the intuitive thinking based on such knowledge was usually well founded and sound. This expertise was especially apparent and consequential in interactions with non-expert professionals whose advice sometimes appeared clearly off-base to parents. In such situations, parents typically *questioned* the uninformed advice, putting more stake in their own ideas for action (see Appendix K, *Supplemental analysis: Staying*, *Questioning*).

The advantage of expert intuition: Hershel's mother. The book *A Mind Apart* (Szatmari, 2004) includes examples of real individuals with autism that illustrate the disorder's many aspects. The example of Hershel (Chapter 7) illustrates the real case of an urgent and determined mother who disregarded the advice a specialist whom she had recruited to diagnose her son. This was sometime in the 1950's, and the specialist had recommended she educate her son separately from typically developing children and eventually institutionalize him. Instead, based on her own intimate knowledge of her son, she intuitively decided it was better to integrate him as much as possible. Doing so entailed taking action involving substantial work—characteristic of *going into high gear*—including enrolling him several community activities, and in regular kindergarten despite "having to fight" with the school, the school board, and administrators to do so. It later turned out that her intuitive actions were probably the best thing she could have done. But she made these decisions on her own, remarkably, prior the existence of any research evidence "that mainstreaming children with autism was more beneficial in most circumstances than setting up special schools and segregating them from their peers" (p. 110). The author of the book, an expert with over 30 years supporting families with autism, attributed Hershel's positive adult outcome—he was in university at the time—to his mother's forceful actions.

The real case of Hershel's mother is a powerful example because it illustrates how a parent's *questioning*—based on intuition informed by extensive familiarity and knowledge of the child—can potentially lead to urgency-motivated decisions that are superior not only to a professional's recommendations, but also to the prevailing wisdom and science of the time.

An example of complementary thinking styles. One mother-father dyad, who discussed at length the differences between their respective approaches to developing and choosing between different lines of action, provides an instructive example of the differences between rapid intuitive thinking and slower deliberative thinking. The following exchanges between Melanie and her husband come from a part of the interview where they discuss their shared decision about what school to move their high-functioning son to after concluding that the public school he attended was not the best environment. Melanie contrasts her more urgent thinking approach to this decision to that of her husband:

> *"I'm the one who said, the minute I saw him struggling in school, 'Get him out of there. Get him out of there now, and put him in private school. I don't care.'…I think it's an instinct, when I feel like a place is not safe enough, not supported enough, not…And so I do tend to be more rash, and say 'We've got to get him out.'*
>
> *"And [my husband] is more methodical about it, and more political, and more strategic. I would say that that's sort of the way it goes."*

(Note, parents' cognitive responses are not necessarily stereotypically gendered as this couple manifested them to be. For example, there were important examples in other participant accounts of fathers becoming more affected by urgency than mothers, leading to greater paternal involvement with the child and *going into high gear* than the mother.)

When her husband added that his approach was, "Less irrational," Melanie countered with "I don't think I'm irrational," perhaps reflecting her intuitive awareness that there must be some logic underlying her approach. But later, when she was unable to discern or articulate the logic underlying her intuitive "gut instinct feel that the school that [our older typically developing son

attends] is the right place [for our son with autism]," she conceded, "It's not logical, that's right. It's not logical."

Melanie outlined how her husband's approach is slower and less direct:

> *"[He's] always like, 'Well what are they going to do for him? I want to hear specifically what their plan is. Every minute of every day, what's the plan?' And I'm saying, I think that these people are right people to deal with him, period."*

She bemoaned his approach as "Slower! So slow—let me just say," which contrasted with the speed at which she made decisions: "I'm like this—[snapping fingers]."

Melanie's husband derided his wife, half-jokingly, for the weakness of her approach: "There were a lot of—[snapping fingers back at her]—mistakes in those decisions, those quick decisions." He later outlined the logic behind his desire to obtain more information, and how in his approach he deliberatively considered aspects that his wife neglected in hers:

> *"I'm not going to pull him just for the sake of pulling him, and put him somewhere else without [knowing] what is missing there…I want to make sure it's a 'better place'."*

> *"I do want to talk to them, to understand the type of support they can and can't provide. And then we need to process—'Is that going to be different than what he gets now?' "*

> [Also] *"We have another school that we've met with, and we had a good feeling about it too, that we want to try it as well. So I always believe that we should have options."*

In this case, Melanie ultimately accepted the value of her husband's slower approach to the decision. But it was partly due to the nature of this particular decision, which the husband noted:

> *"With big decisions like school…you want to try to make it the right school for the next seven years...We don't have a deadline [to choose a school] right now. I'm sure there is a deadline where we have to decide what school. But we'll use that time up to the deadline to make the right decision based on what we feel is right for him."*

In other words, for decisions where there is the luxury of time, a slower approach is appropriate.

For most of the other decisions that had to be made at the earlier stages of pursuing intervention, however, there was a greater necessity to act quickly. For these, Melanie's husband accepted his wife's approach. Melanie describes her dominance in such decisions:

> *"But the speed of all these decisions, always, to get the intervention as soon as possible, it's always been a driving factor. If we decide that he needs, you know, an OT to look at a particular issue, I always want it to be the next day."*

Her husband affirmed that he always supported her rapid decision making in such cases, and generally appreciated that it was better to do things fast as she did: "I'm good with that. I have no problem with the speed of things, and I don't prevent it." Melanie added, "He follows my lead."

Melanie and her husband's case illustrates how, when a couple has two different thinking styles—the rapid and intuitive thinking of a parent who has gone into high gear, and the slower and deliberative thinking of the other less anxious parent—this complementarity can be a strength because it allows for more balanced or appropriate responses in different situations. But it is because of the rapidness of intuitive thinking associated with stress and *going into high gear*, that the parent with the greater sense of urgency more often leads the charge in taking action.

In summary, most (but not all) parents who experience fear-related stress leading to a sense of urgency and *going into high gear* respond by shifting to a more rapid intuitive mode of thinking. This new mode of thinking has profound implications for the decision making and action that follows. In intuitive decision making, parents tend most often to implicitly form a unified idea about the best line of action to pursue, and only rarely make explicit deliberative choices between options. Intuitive action is usually informed by an extensive base of sound expert knowledge, but it can be rash if the parent postpones or disregards certain considerations.

Handling transitions: Defining and responding to newly arising concerns

Change can be problematic for children with autism, and thus for their parents, for multiple reasons. First, because it is a developmental disorder, the change that comes with simple child development is a common source of new autism-related problems that call for new solutions. Second—related to the fact that restrictive, repetitive patterns of behavior, interests, and activities a hallmark of the disorder—many children with autism experience difficulty or distress

with transitions involving their environment. *Handling transitions* refers to the process of parents *adjusting* and *taking action* in response to new specific concerns triggered by developmental (i.e., internal, with respect to the child) or environmental (i.e., externally imposed) transitions.

Internal developmental transitions that trigger new concerns independently of environmental changes can include major changes (such as puberty) or less significant ones (developing a new sensitivity, or physical or cognitive ability). Similarly, environmental transitions that a child must face throughout a lifetime can be major (school entry was most commonly described example of a transition; several parents also worried about the transition from school to adult life), moderate (such as changing teachers) or less significant (examples parents mentioned included daylight savings time, and Christmas holidays). Most environmental transitions represent changes to parents' routines too, beyond the new child concerns they trigger.

Adjusting and taking action within the stage of handling transitions

Handling transitions, the second phase of *making your own way* resembles the other stages by involving a reciprocal cycling between *adjusting* and *taking action* (see Section 4.3, *Introduction*). But unlike the first stage, *beginning the autism journey*, which consists of one large abstract cycle of *adjusting* and *taking action* in response to the overriding concern of autism, *handling transitions* consists of multiple smaller cycles, each centered on a newly arising concern. Moreover, as most specific concerns are not lifelong, their cycles are shorter-lived.

Additionally, I mentioned (see Section 4.3, *Introduction*) how there is theoretically no end to the larger cycle of *adjusting* and *taking action* that comprises *beginning the autism journey*. Consequently, *beginning the autism journey* theoretically encompasses the phase of *handling transitions* with its multiple smaller cycles of *adjusting* and *taking action*. Thus, *adjusting to the need to take action* to the more abstract overriding concern of autism (as part of *beginning the*

autism journey) encompasses learning that autism itself consists of newly arising concerns that the parent must respond to (Figure 4.3.1). *Adjusting* as a part of *handling transitions*, by contrast, is more concrete and limited to implications of the specific concerns triggered by transitions.

Many of the aspects of *adjusting* and *taking action* that were outlined for *beginning the autism journey* apply to each cycle within *handling transitions*, while several aspects do not. Consider what is involved *handling transitions* when, for example, parents decide their child is ready to learn a new life skill they are delayed in developing such as toileting, or the academically-important fine motor skill of handwriting (both described by parents in this study). These generally involve the generic sub-processes of *adjusting* and *taking action* listed in the left-hand column of Table 4.3.2, examples of which are outlined in the right-hand column.

Table 4.3.2: The generic sub-processes within *adjusting* and categories of *taking action*, and possible examples related to developing toileting or handwriting skills.

Generic sub-processes of *adjusting*, and generic categories of *taking action*	Possible examples of each sub-process related to delayed toileting or handwriting skills
Adjusting	
Defining concerns	Coming to understand delays in these skills, including causes and implications
Informing the self	Learning about what explains these problems, what professionals or interventions are available, and how to obtain them
Seeing what is involved	Experiencing the work of recruiting the necessary professionals, training oneself to train the child directly, requesting accommodations for delayed

	abilities (e.g., at school)
Emotionally adapting	Surviving the emotional strains of adjusting and taking action (i.e., related to the obstacles and burdens involved)
Taking action	
Taking action to pursue information	Researching the specific problem and possible solutions; sharing (with other parents)
Taking action to pursue intervention	Recruiting professionals; implementing intervention by training the child directly; negotiating with the school; paying privately for professional services

Additionally, for some newly arising concerns, *handling transitions* may involve *going into high gear*, particularly if concerns lead to crisis.

Importantly, *adjusting* in the case of *handling transitions* is emotionally simpler and involves a more finite amount of work than it does for *beginning the autism journey*. Thus, *handling transitions* usually does not entail many of the aspects of emotionally adjusting described previously, such as accepting the possibility of autism, releasing culturally-based hopes and expectations for the child's future, accepting an uncertain and fearful future for the child, or redefining one's role and self according to new occupational requirements as the parent of a child with autism. Additionally, the parent is not faced with the daunting work of *informing the self* about autism in all its complexity, nor taking action to pursue the major forms of intervention that address the disorder as a whole.

Starting all over again. *Handling transitions* can be frustrating for parents because it can feel like starting all over again, when one starts to navigate intervention for a new concern. This is because preparing to address new concerns often requires developing new skills, and acquiring new information and knowledge. Major transitions can require acquainting oneself with entirely new systems run by different provincial ministries: the education system (Ministry of Education) as the child transitions to school, or the social services system (Ministry of Community and Social Services) when transitioning from high school to adult life.

One educational professional commented on the structural roots underlying the challenges parents experience when transitioning their child to school, considering how attached they often become to the attentive providers and supportive services they acquired for their child at the preschool stage:

> *"you're leaving that and moving into a whole new system. You're crazy as a system [i.e. the educational system] that we change all the people that are involved with the family at the same time as we're changing the context [the child is in]. Why we don't have, you know, people [i.e., professionals from the preschool stage] continue on into grade one, and* then *shift, and* then *shift. That we don't overlap the providers so that parents aren't losing all of their relationships, as well as, a kid who hates transitions, also. It's tough."*

She also acknowledged that the school system does not have the resources to equip all educators with the expertise to consistently support all children with autism to the same high degree:

> *"And so for families, how scary to think that my vulnerable child who maybe can't talk and communicate, can't tell people when he's been hurt, can't say when he's hungry, is going into a place where they don't necessarily know how to support him."*

Parents must therefore start all over, repeating all the work they did to guide and educate a set of professionals how to best support their child at the preschool-stage again with a new set of educational professionals. This is made more challenging by the fact that parents generally need to draw on more advanced negotiating skills and learn more complex negotiating rules when dealing with the school system. While most parents recalled being excited about the prospect of

their child with autism starting school—even if they later experienced sometimes difficult

negotiations—some parents about to start this transition, such as Kim, expressed apprehension:

"And I'm just really afraid now that once he hits school that's going to be a whole other battle

that I know nothing about."

    The need for consistent support to plan for transitions. The transition of *coming to*

understand their child had autism was something that many parents wished they had someone to

help guide them through (take, for example, the parent who felt that counselling to prepare her

for the effects on her marital relationship could have helped her marriage). Similarly, as one

professional noted,

> *"There's key transition points where parents need more information. They need*
> *somebody who has experience to help. And there's not steady trajectory of follow-up to*
> *deal with those issues for parents.*
>
> *"Because they're going to have to deal with the school system, and they're going to*
> *have to deal with the developmental system, pretty well the entire child's life, and adult*
> *life too. So, at every stage we have to kind of change and give them skills that can get*
> *them to the next stage."*

In other words, because autism is a lifelong ever-changing disorder there is a strong need for

ongoing case management to help parents navigate and coordinate services over the lifetime.

Easing off: Defining and responding to the implications of a lifelong process

    Most individuals with autism never lose their diagnosis and continue to need support.

Many parents thus continue *making your own way* past their child's transition from high school

to adulthood, as developmental transitions continue to trigger new concerns requiring the parent

to adjust and take action to address. The third and chronologically latest stage of *making your*

own way—easing off—starts as soon as the parent begins developing her own understandings of

the implications of the fact that autism is lifelong and involves the constant change of repeated

transitions. As part of this process, parents define the need for their continued long-term

involvement as a personal concern that calls for *taking action*—namely, by restoring balance by modifying one's overall approach to *making your own way*, and by continuing to respond to often serious autism-related concerns.

Easing off involves *adjusting to the need to take action* for addressing concerns related to the continuing need for parents' long-term involvement in *pursuing intervention*, including implications they perceive for the self. As a part of this *adjusting*, parents progressively perceive implications of the long-term requirement for their involvement as they make sense of their experience of repeated cycles of *adjusting* and *taking action* to address specific concerns. Sometimes parents are in a position to also observe and consider the implications of outcomes they perceive to result from their action—and they may be less likely to reduce their efforts (*ease off*) when they see encouraging progress in their child (see *Urgency, Hopeful child outcomes*). Because it requires prolonged or repeated experience, *adjusting* within the process of *easing off* entails progressively *becoming seasoned* as a parent. Seasoned parents come to define the process in which they see themselves engaged (*making their own way*) in new ways. This generally involves the desire to *ease off* on the intensity of pursuing intervention, by expending personal resources at a more sustainable pace, to restore balance in their lives, described next.

Defining and responding to the need for restoring balance

Parents perceive and respond to the need for restoring balance in their lives after experiencing exhaustion, guilt, the threat of losing important aspects of the self, or other concerning consequences related to neglecting aspects or life or family unrelated to their child's special needs. Parents commonly first experience a problematic imbalance as a result of going into high gear. In these cases, the intense workload, financial costs, and other stresses drain parents' expendable personal resources and lead to a deficit that can end in exhaustion. The loss

of function that comes with exhaustion puts parents at risk of breakdown if there is no change to the situation. Parents who have reached this stage thus feel an often-powerful need to modify their approach to making their own way to restore balance to their lives (see *Going into high gear*, *Resource-intensive action*, *Unsustainability of expending personal resources at sprint pace*). Reducing one's expectations of what one can accomplish, after coming to terms with the limits to one's expendable personal resources, is one important and common strategy used by parents for restoring balance and coping with the excessive demands of going into high gear (see Emotionally adapting, Surviving the emotional strains of making your own way).

One parent recalled realizing the need to restore balance during her time in high gear:

> *"Not taking care of our own health is a huge one. I think that somewhere along the line, and I couldn't tell you where, I started going to the gym in between IBI and work. I look back now and think, how the hell did I do that? But I remember it made a big difference. And so somewhere along the way my husband and I both thought, we can't keep putting off taking care of ourselves, and our marriage. I think that would be another cost. So your physical health, your marital health—the high gear takes a huge toll."*

Another parent recalled the reasoning behind the conscious decision to stop the long commute for therapy that "nearly broke" their family:

> *"It was like, OK, we've been doing this for a really long time. We've done the very best that we can for our kids and we're tired. And it would be nice to take some time off— like a real weekend, like other people have where we're not running around like maniacs getting up at 5:00 in the morning...And so we had made all of the conscious decisions that we were ready to start slowing down with the services that were provided to us, and that we were ready to take a break."*

Life shifting away from special needs, centering more on the parent. While parents may initially perceive a need for restoring balance as a result of *going into high gear*, they continue to perceive and respond to this need for restoring balance indefinitely as they become more seasoned—experiencing more cycles of *adjusting* and *taking action*. In this study, I interviewed 5 seasoned parents (4 parent participants and 1 professional participant who also shared her experience as a parent)—defined as parents who had navigated autism intervention post-

diagnosis for at least 6 years (range 6 to 14 years post-diagnosis), and had therefore experienced

multiple cycles of *adjusting* and *taking action*. These parents had children who were either soon

to enter, or soon to graduate, from high school (child age range 12 to 18). The following quote

represents the perception of needing to restore balance from a seasoned parent's perspective:

> *"...you lose balance. And that's not...I think it's OK...I say this to parents, if your child was diagnosed with cancer, of course, for a while, cancer becomes everything, like, the center of your world. But eventually you...I've seen parents go through it. They find a new kind of normal and a new kind of balance. And I think that the danger is when people stay hyper-focused on that panic button and autism.*

> *"I agree...it's not all about special needs. It's about life. I have a word that I think that...sometimes mums play martyrs. And I think it can have a lot to do with you...it almost can become a sickness in itself. Like, somehow if you stop playing martyr...you know, and I think we have to be careful. We have our own lives that we have to be very careful of and tend to."*

The seasoned mother's perspective is different because she has experienced not only being in

high gear (many participants I interviewed indicated they were still in high gear), but also

coming out of it. She had therefore experienced the importance (mentioned earlier in the

interview) of "get[ting] away from autism for a while" to regain perspective. Gaining perspective,

in turn, allowed her to see how easy it is for one's child's special needs to become the "center of

your world" and a "new kind of normal," and the need to eventually break away from it to

restore focus on one's own self.

Another seasoned parent, whose 12-year-old son was diagnosed 10 years prior, referred to

the deliberate shift away from special needs that she and her husband had started to achieve:

> *"My husband and I moved here and we're trying...we've been sort of leading a little more normal [life]—a little less in the world of autism. I mean we get called back quite regularly, when the teachers call and the principal calls, and things happen at school constantly, but..."*

Yet another seasoned mother, whose two 13-year-old sons were diagnosed almost 11 years prior,

described her perspective on *easing off*, which she framed as a hopeful message for new parents:

> *"For a while [my husband] and I were mentoring, and the number one thing we used to say to them was, you have to allow yourself to grieve, that's true—you can't take that away from yourself. But, if we had known back then what we know now, I don't think we would have been so upset, because our lives are very full. Our kids are very happy. We do lots of things. We leave the house all the time. We have respite workers who come and help us, just like a babysitter comes to other families. And yes, it gets a little more complicated as our kids get older. But we just have to have different plans in place for their future. It's just different planning, it's not the end of planning."*

Notice, however, that both parents temper their message about the shift away from special needs by acknowledging the reality of still having to focus some attention on autism-related concerns, addressed further below (*Continuing to define and respond to serious autism-related concerns*).

The same mother of 13-year-old sons drew attention to another important reason for the shift in parents' lives away from special needs: that services "start to phase out." While this opens up some parents' time, they also usually experience it as a serious concern in itself.

Marathon vs. sprint pace. For most parents, *going into high gear* was motivated by their urgent desire to seize the window of opportunity for intervening early that they perceived to be quickly closing as their child aged, which they understood to be necessary for achieving the best outcomes. As parents become seasoned, however, their child ages and so many become less motivated by this source of urgency. At the same time, they start seeing the need for balance in order to address concerns arising from repeated transitions and the lifelong nature autism. This involves a shift in pacing—to repeat the analogy a seasoned parent provided—from an unsustainable sprint pace to a more sustainable marathon pace (see also *Going into high gear*, *Resource-intensive action*, *Unsustainability of expending personal resources at sprint pace*). According to the same parent who shared the analogy, however, "It takes a while to learn that though." And later, in referring to the need to continue responding to autism-related concerns even after *easing off*, she remarked, "Make sure you take your water breaks, and make sure you do whatever you need to keep running because you will have to sprint again."

Continuing to define and respond to autism-related concerns

Despite parents' focus shifting away from special needs, another characteristic of the stage of *easing off* is the continued need to define and respond to autism-related concerns. I divide the concerns at this stage into two categories: service availability-related concerns, and new but serious autism-related concerns.

Service availability as a concern. A central concern for many parents as their child approaches graduation from high school becomes the drop-off in available services. After age 21 the child is no longer eligible for Autism Services through the Ontario MCYS or services through school. The services and funding that become available to parents through the Ministry of Community and Social Services, meanwhile, are more limited (see Section 4.2, *Intervention*). Parents expressed concerns over the availability, for example, of day programs and respite. One mother expressed concern for the loss of social connection for her son:

> *"Because once they've finished high school, there's really not a whole lot for them. It's sort of the end of the road, you know. No more social…Because even though we'll say Devlin has a ton of people who say hi to him in the halls at school—because he's a very popular kid there—but they don't come to our house, they don't call him to play. So it's going to be very hard for him to adjust to not having that social aspect. And we're going to have to try and find bowling groups, movie groups, golf groups, that kind of stuff, that he can go and see other people, other than us."*

One of the most worrisome service availability-related concerns for parents with children who are unlikely to be able to live independently is the lack of group homes, or other housing options, which started to come more clearly into focus for some parents in this study even before their children entered high school. As one such parent put it,

> *"They've kind of left a lot of us parents sort of high-and-dry for when we die. I don't know what's going to happen with this generation. Because there used to be group homes, and I know that. But all of them have closed here. There's no such thing any more. So we don't know what's going to happen. We don't want them to have to move away from the community where they are going to be comfortable, where their peers are going to be and where their family is."*

Another seasoned parent estimated the waitlist for her daughter, who was 18 at the time, to enter a group home in the urban area where they lived to be at least 30 years.

Responding to serious autism-related concerns. Parents still develop a sense of urgency when more serious concerns arise. Multiple parents in this study, for example, had to respond to the serious concern of their high-functioning child's suicide risk as an older child. Sources of urgency at this stage therefore usually represent crises that must be responded to more quickly and have a shorter time time-course than the more general concern of autism itself. One seasoned parent summarized the experience of encountering serious concerns after *easing off* as follows:

> *"I do have an analogy that was given to me once, that I think fits really well. Someone was telling me once that, raising a child with autism is like riding a horse. And you'll be going along and you'll just come in to a comfortable ride [analogous to 'easing off'], and then something will spook the horse. And the next thing you know you're galloping and holding on for dear life. And that has been, for seventeen years, exactly what it's been like. And it's huge. Because you just know [things won't remain calm indefinitely]."*

In other words, there will always be an intermittent need to pursue intervention, perhaps even *going into high gear*, to resolve a new serious concern because, "Something—whether it's a new developmental milestone, or whether it's a new change—something will come along, and the autism will become forefront again." But the parent who has eased off has usually already learned that she must ideally maintain a balanced approach and expend her resources sustainably.

Finally, regarding the stress attributable to *taking action to pursue intervention* after *easing off* (an autism-related concern affecting most parents in the earlier stages), one seasoned parent said it was just as high as it was at the beginning of her journey and lamented the lack of navigational and case management support, while another such parent reported, "It's different. I mean I don't feel as urgent, I don't feel as desperate, I don't feel as useless as I did back then."

Figures

Figure 4.3.1. The cyclic social psychological process of *making your own way*.
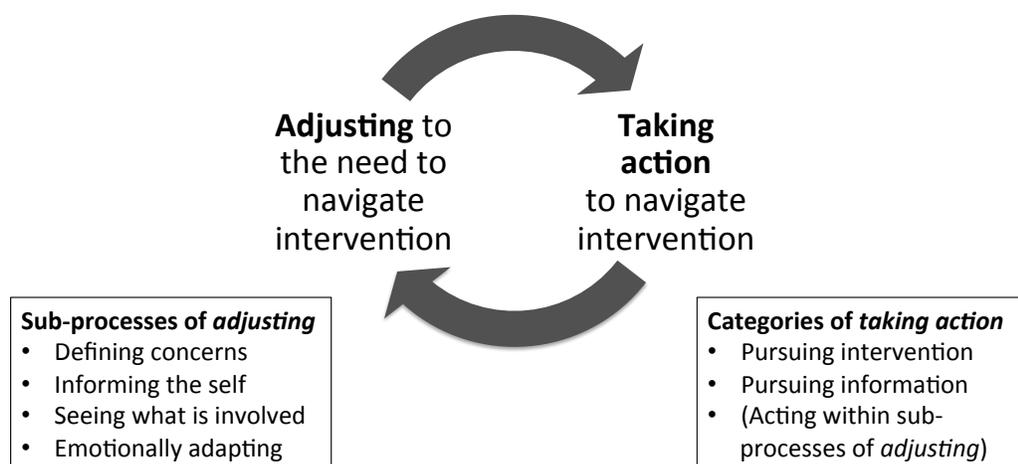
CHAPTER 5: DISCUSSION AND CONCLUSION

In this chapter I describe various contributions this work makes to knowledge in different fields. I also address how some findings are relevant to understanding and improving one of the first aspects that parents navigate, early diagnosis. Finally, I discuss strengths and limitations and opportunities for further research.

Contributions to knowledge

This research addresses numerous conceptual domains relevant to many different fields. First, I discuss the utility of *making your own way* as a generic process that is potentially transferrable to individuals in other healthcare consumer populations that must navigate one or more systems of care. Second, I discuss how the findings contribute to the literature regarding *system navigation*, which emerged as a central topic in this study. Third, since the original motivation for this study was to improve understanding of healthcare consumer behavior within the field of knowledge translation, I discuss the findings in the context of relevant conceptual and other literature from that field. Thus, I propose some practice implications and relevance this theory has for the areas of patient-centered care, shared decision making (SDM), and patient engagement. Finally, I relate the role of *urgency*—arguably the most distinguishing and interesting feature of the theory—to some of the theoretical behavior change literature that is often applied to developing and evaluating knowledge translation interventions, and propose implications for values clarification methods used in decision aids.

Generic transferability of the central process making your own way

Generic transferability is an agreed indicator of the utility and quality of a grounded theory, mentioned by the major developers of the method (Charmaz, 2006, 2014; Corbin & Strauss, 2008; Glaser & Strauss, 1967; Glaser, 1978; Strauss & Corbin, 1990, 1998). Here, I propose that

the central process that parents of children with autism engage in—*making your own way* to intervention—is transferrable to other healthcare consumer populations (patients or their informal caregivers) that must navigate one or more systems of care (health, educational, social, legal, funded or private, etc.) to address their health-related concerns. Whether the parent of a child with another developmental delay, a young adult with cancer, or a 75-year-old struggling to manage a growing number of health concerns, there are numerous other types of healthcare consumers that appear to share remarkably similar experiences, responses, and processes to those outlined for parents in this theory. Specifically, the theory accounts for domains of experience and processes that healthcare consumers pass through as they navigate systems of care that sometimes lack the capacity to provide comprehensive or sufficient guidance and support, or to successfully connect such consumers to interventions that optimally address their concerns.

Additionally, the theoretical process of *making your own way* has the advantage of being more holistic, consumer-relevant, and useful than some existing theories or models concerned with explaining consumer behaviors solely within the clinical encounter. This is because the theory considers both consumers' meaning-making, which resides predominantly outside clinical settings; and consumers' action as it takes place broadly *across* systems of care rather than, for example, only within the clinical settings of the publicly-funded health system.

Application to individual healthcare consumer situations

The central process laid out by this theory has elements (including its sub-processes) that can be applied or adapted to facilitate deeper understanding of individual situations where healthcare consumers become motivated to be self-reliant in navigating intervention. Consider, for example, the story of Julia Wolf (Knox, 2014)—a young woman who, after 6 years pursuing help within her local health system which failed to take her initial suspicions and health concerns

seriously, was confirmed to have advanced melanoma. By the time she was diagnosed, Julia was already pregnant and soon gave birth to her son. Her efforts then became an urgent quest to find intervention that might save her life. Later, after her cancer metastasized, her struggles turned into a search for clinical trials of investigational treatments that could prolong life so she could spend more time with her then 5-year-old son.

Most apparently, Wolf's case embodies the sub-process of *defining concerns*, as she likely passed through some the same steps parents in this study did in *coming to understand their child had autism*—namely *starting to question the signs*, *knowing something is wrong*, and upon her diagnosis, *being convinced it's melanoma*. She also certainly encountered obstacles in *pursuing a diagnosis*. In addition, she likely experienced similar aspects of *emotionally adapting* at different points of her journey, including *grieving*, *releasing hopes*, and *accepting a fearful future*. Her continued quest for intervention consumed significant personal resources such as time and money to pay for air travel to participate in the trials of investigational treatments she discovered. She likely endured a unique constellation of *burdens* (including work of navigating intervention and stress), which in turn were likely exacerbated by aspects of her condition. Thus, her case features clear examples of *adjusting to the need to navigate intervention* and *taking action* by proactively pursuing information and intervention. In the general case of young adults with cancer, there may even be different *stages* of *making your own way* as the patient's understandings of the central concern and their goals of action change. Finally, Wolf's story suggests that there can be tragic consequences when navigating systems of care is rendered unsuccessful by missteps caused by obstacles along the way.

Application to literature containing elements of the central process

In addition to facilitating sensitivity and understanding of situations where individual

healthcare consumers self-reliantly navigate intervention, this theory provides a means of interpreting reports in the literature that contain elements of the central process. Thus, a source of comparable research is literature from areas concerned with navigating systems of care.

Relevance to patient navigation. One such area is the literature regarding *patient navigation* (or, *peer navigation*), a patient support model first used in 1990 to help disadvantaged cancer patients (Hede, 2006), in which patients are paired with more experienced ex-patients who help them "find their way within a health care system ill-suited to meet multiple needs" (Bradford et al., 2007, p. 50). This role overlaps those of patient advocacy, case management or care coordination; and its popular application in cancer (Wells et al., 2008) has been extended to reduce disparities in other conditions known to frequently affect vulnerable populations, such as HIV (Bradford et al., 2007) and mental health (Corrigan et al., 2014). The term *patient (peer) navigation* had not been applied in the literature in reference to parents of children with autism. Parents in this study commonly described a need for greater guidance navigating systems of care, which they filled partly by turning to more experienced parents for navigation information. *Patient navigation* may therefore provide a naturally well-suited model to support parents' navigation needs, representing a novel consumer group for its application.

Fit with grounded theory studies involving navigation. Lastly, I compare the findings of this study with two other published grounded theory studies that address the concept of navigating systems of care as a primary focus. The purpose of comparison is simply to highlight the conceptual areas of overlap with those analyses involving other populations. The first is a recent grounded theory study of a remarkably comparable population—parents of children with cerebral palsy (Hayles et al., 2015). The focus of analysis in that study was slightly different: to account for how parents *experience* health care for their children with cerebral palsy. The core

category in that study, *making the most of their body and life*, in which parents defined the purpose of care as maximizing their child's life potential, corresponds to what I have described as *defining concerns* rather than a process by which parents both define and respond to them. This core category is surrounded by six other categories related to experience of the child's health care, which overlap with elements of the theory of *making your own way* as follows: *evolving needs*, in which the parent experiences care needs that are constantly changing or evolving, overlaps the autism-specific heuristic stage of *handling transitions*; *learning as you go*, where parents learn about the child's needs and learn to accept through a process that involves interaction with information from different sources, is most comparable to the process of *informing oneself* (a sub-process of *adjusting*); *navigating the systems*, in which parents either passively or actively engage in researching and pursuing services in the health and education systems, has most overlap with *taking action to navigate intervention* (one of the two overarching processes that comprise *making your own way*); *meeting needs through partnership*, which reflects parents' experience of the degree to which professionals and system organizations partnered with them in care and relates to the researchers' *a priori* theoretical interest in family-centered care, overlaps the conceptual elements of *external obstacles* and, partially, *stress; being empowered or disempowered*, which reflects how feelings of confidence parents had in meeting care needs depended on the helpfulness of professionals and systems of care, does not have apparent overlap and likely reflects differences with the cerebral palsy setting; and lastly, *finding a balance*, which involved a varying balance between prioritizing efforts related to meeting needs of the child and meeting needs in other aspects of life, has partial overlap with the concept of *restoring balance* (within the heuristic stage of *easing off*). An important distinction between the two studies is in the position of navigating systems of care. In my theory, I equate *navigating*

intervention with the central process of *making your own way*, which accounts not just for the action involved in navigating but also the meaning-making that motivates it. In Hayles and colleagues' theory, however, *navigating the systems* only accounts for the action involved in navigating systems of care (the meaning-making contained in other categories serves the primary analytic purpose of portraying the experience of parents rather than explaining action, reflecting a non-symbolic interactionist study framework). Thus, my autism-specific theory explains the mechanisms underlying the action of navigating systems of care, while Hayles and colleagues theory primarily accounts for the experience of this action.

The second grounded theory (Wuest, 2000) is a study of mothers of young children "caring for well, disabled, developmentally delayed, and chronically or acutely ill selves and others" (p. 53), which was expanded through the analytic process of emergent fit to incorporate the findings of Wuest's prior research and those of three qualitative syntheses from comparable populations. Its central process, *negotiating*, in which women interact with professionals and systems of care "to limit fraying connections [i.e., through adversity, disillusionment] and to facilitate caring in a manner acceptable to the woman" (p. 57), is comparable to the central process of *making your own way*. This process involves four categories, which overlap conceptually with elements of the theory of *making your own way* as follows: *reframing responsibility*, in which women reconsider who is responsible for certain aspects of care after experiencing disillusionment, has partial overlap with *seeing what is involved* (a sub-process of *adjusting*); *becoming an expert*, in which women learn about the nature health concerns and about potential interventions or services, has substantial overlap with *informing oneself* (a sub-process of *adjusting*); *harnessing resources*, in which women use their expertise to interact with the system to enhance care that can sometimes lack partnership from professionals or the system, overlaps with the process of *taking action to*

pursue intervention and the condition of *obstacles*; and lastly, *taking on more*, in which women choose to go outside the system and sometimes take risks as they do so, overlaps the concept of *questioning* (a form of *staying*, Appendix K)—although rather than taking risks, in autism, parents described minimizing risks to their child when disregarding professional recommendations. Considering the comparability and conceptual overlap with these two studies (Hayles et al., 2015; Wuest, 2000), it would be feasible to conduct an analytic synthesis, using methods such as *emergent fit* (Wuest, 2000) or *grounded formal theory* (Kearney, 1998), to extend the analysis of *making your own way* and produce a more broadly applicable theory.

Practice implications and relevance to patient-centered care in autism

This study illustrates, using parents of children with autism as a case, the depth to which the healthcare consumer's personal social and psychological world can be understood with a symbolic interactionist approach, and the importance of understanding consumers' experience, meaning-making, emotions and action in sufficient depth when defining what is appropriate care. Specifically, the findings illustrate that the majority of parents' social and psychological worlds related to autism—particularly how they define their expectations, priorities, problems and concerns, and many of the solutions—is situated outside any single clinical setting (i.e., it is distributed across multiple clinical settings and beyond). Moreover, parents mostly experience autism and reflect on how to respond to it in settings that are non-clinical whatsoever (for example in the home, or consulting with family or other parents about what action to take).

The findings further show how wide-ranging aspects of the caregiver's life situation might be clinically relevant for the professionals supporting them as they seek or navigate intervention for their child. Take the personal and often hidden aspects that can lead to *guilt* as an example. Consider information that a well-meaning clinician may give a parent about the advantages and

benefits of becoming more involved in implementing behavioral intervention—advice intended to serve the child's best interest. If the professional's communication succeeds in convincing the parent it is necessary to increase her involvement, however, it could have a harmful effect (likely unseen by the professional) if it exacerbates the parent's sense of guilt after allocating more time to her child with autism and neglecting her other children. Such guilt, we have seen, is highly distressing, often leads to negative self-talk, causing potentially clinically significant harms to parents' mental health. Thus, seeking sufficient understanding of how the parent operates to define concerns that merit taking action to navigate intervention is required to reduce the chances of harm occurring outside the clinical situation.

Other aspects of the theory point to the importance of seeking deeper understanding of parents' worlds in concrete and specific ways to optimize parent support. For example, professionals who support parents of children with autism prior to diagnosis may apply knowledge of the four steps of *coming to understand their child has autism* to sensitize themselves to the significance of a parent's early levels of certainty and urgency with respect to their child's autism. Both certainty and urgency provide indications not only of what step a parent may be at in the process of *coming to understand their child has autism*, but also of where they likely are in *adjusting to the need to navigate intervention*, including whether they have begun some of the sub-processes of *emotionally adapting* that are necessary to prepare or ready the parent for *taking action to pursue intervention*.

Professionals can apply knowledge and appreciation of where parents are in the process of *adjusting* to sensitively encourage them to progress more efficiently through this process to the point of being prepared for action. This has potential to empower parents to become involved and motivated to pursue appropriate intervention earlier, minimizing delays to *taking action* or

starting intervention, which parents defined as a major source of regret and contributor to stress.

Relevance to patient-centered care, shared decision making, patient engagement

The consequent general implication for practice—that professionals seek deeper understandings of patients' experience, meaning-making, emotions and action that occurs outside the clinical setting as an important strategy to improve the quality of support when discussing or deciding about intervention—is relevant to the areas of *patient-centered care*, *shared decision making*, and *patient engagement*.

Patient-centered care. Central to the idea of being *patient-centered* is the imperative for professionals to try "to enter the patient's world, to see the illness through the patient's eyes" (McWhinney, 1989, p. 111). The concept was developed to overcome the limitations of the traditional paternalist or "biomedical model" of practicing medicine in which the patient-clinician relationship is demoted and "the patient's illness is reduced to a set of signs and symptoms, which are investigated and interpreted within a positivist biomedical framework" (Mead & Bower, 2000, p. 1088). Patient-centered care also derives from a trend towards "deep respect for patients as unique living beings," where "patients are known as persons in context of their own social worlds,"; it follows that, "a good outcome must be defined in terms of what is meaningful and valuable to the individual patient" (Epstein & Street, 2011, p. 100). Patient-centered communication is central to achieving patient-centered care, which has been associated with improved health status and efficiency of care (Stewart et al., 2000). A 2012 Cochrane review concluded tentatively that interventions that promote a patient-centered approach have beneficial effects on health behavior and health status (Dwamena et al., 2012).

The general practice implication of this study, proposed above, is congruent with the ideas of patient-centered care. Specifically, the recommendation to seek deeper understandings of

parents' experience corresponds to two of Stewart and colleagues' (2003) six components of patient-centered care (*exploring both the disease and the illness experience*, and *understanding the whole person*) and the first of Mead and Bower's (2000) five dimensions of patient-centered care (*patient-as-person*). Some of the experiences documented in this study also reinforce another element of patient-centered care: the importance of the patient-physician relationship (for example, which Mead & Bower (2000) capture in the dimension of *therapeutic alliance*). Substantial data from this study reinforce evidence in the literature suggesting that clinicians' communication styles influence healthcare consumers' experience of distress and uncertainty regarding the condition they are coping with (Arora et al., 2009; Epstein & Street, 2011). In the case of parents of children with autism, repeated incidents show how primary clinicians' failure to listen to parents' concerns regarding the presence of developmental problems clearly increases parent distress and burden.

 Shared decision making. *Shared decision making* (SDM) has been described as fundamental to patient-centered care (Elwyn et al., 2014; Légaré et al., 2014; Légaré & Thompson-Leduc, 2014; Weston, 2001). SDM was similarly conceived as a solution to ethical and social problems with the traditional paternalist model of care, namely the lack of respect for patients' autonomy that is essential for them to have a voice and modicum of control over their own care (Blair & Légaré, 2015). While there are numerous definitions for SDM, which have been variously reviewed (Légaré et al., 2014; Makoul & Clayman, 2006; Moumjid et al., 2007), a recent source describes it concisely as "an interpersonal, interdependent process in which the healthcare provider and the patient relate to and influence each other as they collaborate in making decisions about the patient's health care," which "can modify the process and power dynamics of decision making by fostering collaboration" (Légaré & Witteman, 2013, p. 277). It

has also been portrayed as a clinician-driven method where the clinician explains the need to consider alternatives as a team, describes the alternatives in more detail, and helps the patient explore and form their personal preferences (Elwyn et al., 2014; Stiggelbout et al., 2012). Importantly, it is the clinician's act of eliciting the patient's preferences (beliefs and values, etc.; using value clarification methods) that stands to accomplish the original goals of SDM—respecting patients' autonomy and producing shared information that "informs what counts as a good decision, good care and good outcomes for those individuals" (Cribb & Entwistle, 2011, p. 211). The practice implication I outlined above corresponds to this key professional competency of eliciting and understanding the patient's preferences, which I argue can entail understanding parents' experience to a level of depth that has been described for patient-centered care.

While some authors have previously hypothesized that the decisional processes of patients that are relevant to SDM are likely "located in a cognitive, rational paradigm" (Wensing et al., 2002, p. 5), de Vries and colleagues (2013) have more recently drawn attention to the advantages of patients' *intuitive* decisional processes, and argued that decisional support efforts that force patients to use a deliberative-only model may lead to worse decisions. Multiple incidents in the data from this study suggest that parents' decision making about their child is highly influenced by intuitive thinking (for example, see Section 4.3, *Going into high gear, Fast intuitive vs. slow deliberative processing, An example of complementary thinking styles*). I propose that supporting parents' and other healthcare consumers' decision making in a way that harnesses the power of intuitive processes (in addition to incorporating strengths of the deliberative approach) requires a deeper understanding the patient's world to sufficiently accomplish the task of eliciting patient preferences within the SDM model. Thus, the innovative view of SDM that de Vries and colleagues suggest may involve understanding patients in a deeper more holistic manner that is at

least partly consistent with previously mentioned elements of patient-centered care—namely, the components *exploring both the disease and the illness experience* and *understanding the whole person* (Stewart et al., 2003); and the dimension *patient-as-person* (Mead & Bower, 2000). Consequently, there may be more conceptual overlap between SDM and patient-centered care than previous exploratory work has tentatively suggested (Wensing et al., 2002).

The nature of typical health decisions for different types of healthcare consumers can range in terms of how spontaneous and intuitive versus how slow and deliberative they are. For parents of children with autism, many decisions are part of a spontaneous and intuitive flow of action, rather than a single distinct deliberative process. Parents motivated by urgency thus experience decisions as the next necessary step on their path to take, or an obvious line of action spontaneously formulated based on all available information that has been tacitly converted to knowledge up to that point—not as a deliberate choice between options. Thus, it can be almost as if no conscious decision is being made at all. Still, these spontaneous decisions have similarities with deliberative ones. They can have implications for the future, including the potential for subsequent regret once impacts on the parent, family, or child are realized. Likewise, some steps that parents take (spontaneous decisions) may be agonizing—or in SDM terms, characterized by *decisional conflict*. This was apparent in one mother's decision to start her son on risperidone to restore family-functioning that had been seriously disrupted by his sleep problems, which involved acute anguish and guilt for the harmful side effects she knew she was exposing her son to; something that led her to break down in tears every time she gave him his pill. Therefore, even for some of the more spontaneous choices, which parents may not initially identify as discrete decisions, there is room for decisional support interventions such as those used in SDM to improve parents' planning process and potentially reduce their stress in clinically meaningful

ways. For such interventions to be effective, however, they would likely need to acknowledge and support intuitive processes as well as encourage deliberative ones.

Acknowledging and supporting intuitive processes in the context of SDM, as argued above, likely requires specifying new preference elicitation techniques that go deeper than what is currently suggested within the more traditional deliberative-only conception of SDM—something which would make the preference elicitation process more similar to analogous aspects of patient-centered care. Elicitation of "intuitively-formed preferences" may need to be viewed as something that is optimally accomplished by repeated interaction over the course of the clinical relationship with a parent (or similar type of healthcare consumer).

When supporting healthcare consumers whose decision making depends on intuitively-formed preferences, it is also important to consider the context and the relative centrality of the specific decisions being supported with respect to patient-defined concerns. As the experiences of parents in this study illustrate—and the qualitative findings from Li and colleagues' study (2014) of rheumatoid arthritis patients using methotrexate decision aid suggest—for some patients, the clinical encounter in which a professional shares information as part of a decision-support process may, from the patient's perspective, be only a single episode within a greater ongoing process of continued meaning-making and diverse action aimed at addressing the health concern they have defined. Such cases suggest that professionals can improve their position for providing support by seeking answers to some basic questions that reflect healthcare consumer-important considerations implied by the theory outlined here, such as the following:

- What, from the healthcare consumer's perspective, is the target of the greater action that the decision is a part of? What is she wanting to achieve?

- What, from the healthcare consumer's perspective, is the nature of the underlying concern(s) motivating the overarching action?

- Can the healthcare consumer articulate some of the underlying considerations that led her to define the original problem(s) as a concern? Why is the concern a problem? To whom?

- What level of urgency and motivation to act does she feel with respect to each concern?

- What else is the healthcare consumer doing, or considering doing, to address her concern?

Bearing the answers to such questions in mind not only puts the decision more explicitly in context, but also indicates where discussion about care should focus to be truly patient-focused (i.e., by seeking outcomes that matter to the healthcare consumer (Epstein & Street, 2011)). In this sense, generic aspects of the theory of *making your own way* provides a framework that I propose is relevant in the practice of SDM for understanding and defining patient preferences.

  Patient engagement. Gruman and colleagues (2010) defined *patient engagement* as "actions individuals must take to obtain the greatest benefit from the health care services available to them" (p. 351). The concept is highly consequential because, "Today, sick or well, people will not benefit from their health care unless they bring to bear considerable knowledge, skills and motivation to participate actively in the care that is available to them" (Gruman et al., 2010, p. 350). Using a strategy involving literature reviews, an environmental scan of advocacy web sites, and key informant interviews, Gruman and colleagues (2010) identified a comprehensive list of "behaviors" (i.e., tasks) that U.S. patients are expected to be able to perform to benefit fully from their available care, presented as the "Engagement Behavior Framework" (p. 352). This list illustrates that much of the action required to navigate health care takes place outside of clinical settings, a conclusion that the findings from this study of parents of children with autism reinforce.

Gruman and colleagues' work to expand the concept of patient engagement is very similar to the related field of health literacy, where authors have expanded the conventional view of this influential concept. Health literacy is now generally understood to be determined not just by the set of skills that healthcare consumers might apply in navigating the healthcare system and promoting personal health, but also by the demands that health contexts put on consumers (Canadian Council on Learning, 2008). Viewed this way, the list of skills required for health literacy becomes much broader than reading or numeracy. It includes, for example, the extent and level of a consumer's vocabulary, necessary for understanding of written and verbal information, which is in turn required for learning about disease, intervention, and prognosis (Baker, 2006). Likewise, pre-existing conceptual knowledge qualifies as a health literacy skill (Canadian Council on Learning, 2008; Nielsen-Bohlman et al., 2004). Similar to Gruman and colleagues, Murray and colleagues (2007) developed a list of the tasks involved in health literacy, which they ordered into categories; and it likewise includes health-related activities performed beyond the medical encounter, including in the home, workplace, or community.

The tasks that both the Gruman and Murray groups list are analogous to the tasks I describe for parents navigating intervention in this study (see Section 4.2, *Burdens*, *Work*). While Gruman and colleagues' Engagement Behavior Framework is intended to be generic, however, some tasks suggest it is optimally applicable to patients at risk for or affected by common specific conditions, such as diabetes and cardiovascular disease. Moreover, their list is not comprehensive enough to easily categorize some of the prominent tasks performed by parents of children with autism, such as training oneself to implement therapy. Not only are patient engagement behaviors and activities likely to vary substantially by therapeutic condition, but also by jurisdiction, with observable differences between country, province, and even region for

parents of children with autism (personal observations, including pilot interviews with non-Ontario participants). Thus, describing patient engagement behaviors in therapeutic-specific settings such as autism has the potential to develop more locally relevant lists.

A second important difference between the tasks listed in Gruman's model and the tasks identified for parents navigating intervention in this study, is the perspective from which each list was defined. The cited study's informants include non-patients such as labor unions, purchasers, health plans and universities, whereas this study defined tasks involved in navigating intervention directly from the experience of those performing them: researching, gaining access, planning, completing forms, coordinating and traveling to appointments, managing financial and human resources, negotiating obstacles, engaging in personal development to develop skills, implementing treatments or modifications, monitoring implementation, and evaluating effectiveness. Furthermore, I was able to describe the significance of these tasks from parents' perspectives. Specifically, each of these tasks can entail substantial *work* for the parent, which when combined represent burdens of sometimes overwhelming proportions in terms of the time and other expendable personal resources most parents dedicate to navigating intervention. Gruman and colleagues' framework of engagement-related tasks, by contrast, appear to vary highly in the amount of work and burden each would represent for the patient or caregiver, but the authors do no make any reference to the work involved in the behaviors they identify. Additionally, whereas I account in detail for many skills required for parents' various tasks required for navigating intervention, Gruman and colleagues make only general reference to the requirement of skills. Defining engagement activities qualitatively from the healthcare consumer's (i.e., parent's) perspective in this study allowed specific skills to be linked to specific activities and contexts (see Section 4.2, *Burdens*, *Work*).

A third contribution to the ideas of patient engagement is the important finding that parents'
(and likely other healthcare consumers') social and psychological readiness to meet demands of
engagement (i.e., demands of navigating intervention) is lowest at the point in time when they
are emotionally adapting to the central concern that requires their involvement or engagement.
Thus, according to the supplementary analysis presented in Appendix L (*Framework for
involving parents in intervention*), the need for support from the system with engagement varies
over time, being most intensive early on in parents' journey. In summary, if patient engagement
efforts are to be patient-centered, then qualitative consumer-centered research such as this study
has the best potential to identify highly relevant and concrete areas for change that consumers
most need help with to successfully meet the demands and expectations of engagement.

Relevance of urgency to understanding dual processing in decision making

A distinguishing aspect of the theory of *making your own way* is the explicit recognition it
makes of the influence that an individual's sense of *urgency* has on action. While urgency may
not be a generic characteristic that universally influences all healthcare consumers' action to the
same extent when they navigate systems of care, it is central to understanding the behavior of
parents of children with autism, particularly as they respond by *going into high gear*. I propose
that the mechanisms through which urgency appears to influence cognitive processing in parents
studied here, have implications for understanding healthcare decision making by consumers.

One of the interesting implications of urgency for motivated action and decision making by
parents of children with autism, stems from the influence urgency has on parents' thinking (i.e.,
the meaning-making underlying their decisions and action). I defined *urgency* in this study,
according to participant experience, as an emotional or psychophysiological response similar to
stress in which parents develop an unhesitating eagerness to embark on action to resolve the

perceived source of stress. It involves physiological changes that parents described experiencing, including physical sensations resembling panic. Fear-related triggers for urgency thus induce a stress response known to increase arousal and mobilize energy stores for rapid thinking (Wise, 2009). Parents associated this psychophysiological mode with rapid intuitive cognitive responses (as opposed to slow deliberative ones) that manifested in different ways. Examples of such intuitive responses include the suppressed self-awareness and disregard for personal limitations that would likely restrict willingness to invest personal resources in pursuing daunting lines of action in less urgent times; the *questioning* of advice from professionals (i.e., putting less stake in clinicians' ideas for action) when their advice seemed uninformed compared to the parent's expertise generally informed by substantial intimate knowledge of the child; and hurried, non-deliberative decisions about how to intervene that while seemingly rash, were informed by expertise whose implicit reasoning parents were sometimes able to later reflectively articulate.

While urgency, through the intuitive processing it stimulates, is an important influence on decision making and action in this study, it is given little or no emphasis by some of the behavior change theories that have been most influential in behavioral health research—something that is perhaps due to the lack of universality of urgency as a modifier of behavior across commonly studied situations, or because situations characterized by strong motivation to act (i.e., wherever individuals experience a sense of urgency) are rarely seen as problematic from a behavior change perspective. For example, in Bandura's (1986) Social Cognitive Theory, people's inclination to action is facilitated or limited by their perceived self-efficacy, or confidence that they can apply the required skills to meet situational demands. The influence of perceived self-efficacy on readiness for action represents a self-regulatory cognitive process that works when the individual takes time to reflect deliberatively on prospective lines of action.

In contrast to this, the findings here show how parents often rise above and disregard what they may perceive as limited skills or aversion to behavior that is beyond their comfort zone. Thus, perceived self-efficacy is perhaps the self-imposed limitation that I propose gets overruled under conditions of urgency when stress-related processes suppress self-inhibitory thinking and release the individual from this constraint. While Social Cognitive Theory acknowledges "emotional arousal" as an influence, it is positioned as weaker and less important than other factors (Bandura, 1997; Luszczynska, 2005). Likewise, other popular behavior change theories such as the Theory of Planned Behavior ignore intuitive psychological processes, such as urgency would trigger, because they are "deliberative processing models that imply that people's attitudes are formed after careful consideration of available information" (Conner & Sparks, 2005, p. 170). They therefore fail to explicitly address the role of rapid intuitive thinking.

It is only recently, as dual processing models have been accepted as relevant, that the idea of a fast intuitive mode of cognitive processing has become theoretically influential in the fields of judgment and decision making (Evans, 2008). While many terms have been used for the two alternative modes of cognitive processing (Evans, 2008), the labels System 1 and System 2 (Kahneman, 2003; Stanovich & West, 2000), which correspond to the rapid intuitive and slow deliberative (explicitly analytic) forms of cognitive processing, respectively, are perhaps most widely recognized. Dual processing models received some of their earliest attention in the field of knowledge translation in 2006, when Sladek and colleagues (2006) proposed such theory as a means to better understand and predict clinician behavior, with the goal of promoting behavior consistent with the research evidence. Those authors positioned deliberative thinking as the natural means for adopting research evidence, while intuitive thinking was relegated as an obstacle to be overcome because it naturally prioritizes personal experience over evidence and

underlies habits that need to be changed. Fortunately, such a normative a view, which conceives of intuitive thinking (and expertise that informs it) as uniformly inferior to decisions and action informed by the research evidence, is becoming less mainstream. More recently, Norman (2009) and de Vries and colleagues (2013) have addressed the value of intuitive thinking for healthcare decision making among professionals and patients, respectively.

The analytic findings of this study are consistent with the findings cited by these latter authors and others.[13] First, some qualitative observations are consistent with studies mostly from the field of psychology that have shown that intuitive processes are, under certain conditions, superior to deliberative ones (Bechara et al., 2000; Dijksterhuis et al., 2006; Klein, 2009; Pieterse & de Vries, 2011; Reimann & Bechara, 2010; Strick et al., 2011; Wilson, 2002; Wilson & Schooler, 1991). For example, numerous parents described how, compared to their own intuitive expertise-informed decisions and ideas about how to intervene with their child, professionals' advice that was drawn deliberatively from knowledge of their recent training, sometimes appeared clearly off-base and inappropriate. While this example does not appear comparable to research into single person decision making, decisions shared or negotiated between patients and care providers are a reality of health contexts and thus the example of this research is more relevant to the field of knowledge translation (note, the research cited above involves non-health decisions and settings). Parents in many cases described intuitively knowing what to do with their child, and often their actions succeeded in resolving problems. Recall the case of Hershel's mother (Section 4.3, *Urgency*, *Fast intuitive vs. slow deliberative thinking*) choosing to

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[13] Note, I did not consult the referenced literature on the strengths of intuitive thinking until after completing the qualitative analysis represented in Chapter 4; it therefore did not directly influence my construction of the findings. In other words, while the primary aim in grounded theory is to develop theory that is consistent with the data, I did not then also (as a secondary intention, or even subconsciously) make this aspect of the theory consistent with the literature.

mainstream her son despite professional advice to the contrary despite the effort of doing so—an intuitively-informed decision that would later be supported by research evidence and which apparently contributed to her son's university attendance and success in adulthood.

Second, qualitative findings from this research are also consistent with observational studies demonstrating how different kinds of experts rarely feel or outwardly appear to be making deliberative choices between options, but rather more often tend to spontaneously recognize the single best line of action to pursue (Klein, 1999, 2009; Norman, 2009). This is similar to the reports of parents in this study who most often talked about the next obvious step to take, as if no decision were being made at all.

As de Vries and colleagues (2013) note, an objection to applicability of some of the research cited above to health contexts is that, being derived from the areas of basic psychology and consumer research, it features decisions that do not resemble those of patients, which are more likely to be made under distressing conditions and often involve strong emotions. An advantage of this study, therefore, is that it provides preliminary qualitative evidence, in a relevant healthcare consumer group, that reinforces the relevance and value of intuitive processing for health-related decision making and action. Moreover, this study sheds detailed light from a social psychological perspective on one of the likely multiple mechanisms by which intuitive thinking manifests (i.e., by identifying and relating urgency-related causes, conditions, and consequences). The finding of the effects of urgency to stimulate intuitive decision making and action is potentially innovative, and warrants further dedicated study in other healthcare consumer populations.

de Vries and colleagues (2013) conclude from their conceptual review of the strengths and weaknesses of intuitive and deliberative decision making that patient decision support tools that

promote only deliberative cognitive processes may have limited effectiveness and harm the individual's natural preference construction processes because they ignore the importance of intuitive cognitive processes. Similarly, the theory of *making your own way* supports the idea of promoting intuitive processes, in addition to supporting deliberative processes, when intervening to support patient decision making. Since urgency is one of the factors that motivates parents to become highly proactive in pursuing intervention, it is possible that emotions that similarly stimulate an intuitive mode of decision making and action, generally also motivate healthcare consumers to be more involved and engaged in their health care. This would achieve another of the goals of shared decision making—promoting patient involvement in the decision and care process. If the plausible notion that patients' level of intuitive decision making corresponds to their levels of engagement can be confirmed by further research, this would be further reason to design decision support tools to preserve and promote intuitive processes.

This theory of *making your own way* therefore has a potential implication for decision aid developers. Those who support patients making specific decisions by using values clarification methods may benefit from seeking explicit understanding of how the discrete decision they are supporting fits in as part of a larger more centrally important process—a process that likely involves multiple other steps along a continuous flowing path of motivated action whose target is addressing a personally defined concern; and a process that, under natural conditions, would almost certainly involve intuitive cognitive processing through which the individual who is ready for action incorporates and acts on relevant new information and automatically ignores information that is irrelevant to the task of defining next steps to address the concern. In seeking understanding of how the decision fits in with this process, clinicians could consider the same questions suggested above for making shared decision making more patient-centered. This

theoretically indicated approach represents an additional strategy to preserve the intuitive cognitive processing that de Vries and colleagues (2013) concluded is a necessary ingredient of value clarification methods.

Implications for understanding and reducing delays to diagnosis

An important source of burden and stress for some parents navigating intervention is the lateness of diagnosis, which is required before parents can enroll their children to receive certain funded services. Addressing the problem of delayed diagnosis requires research that quantifies the magnitude of the problem, and that reveals the mechanisms by which it comes about so that appropriate interventions can be developed. I derive ideas from this research for potential approaches to feasibly study both aspects, and discuss how this study already contains most of the data that would be required for such analysis on a small pilot scale.

Quantifying magnitude of the problem. A common but crude indicator of delays to diagnosis is the child's age at diagnosis. The median age at diagnosis for 38 children of the 32 parents in this study was 36 months (with the mode just over 24 months), while ages range from as young as 20 months all the way to 10 years of age (see Figure 4.1.2). This can be compared to other recent published distributions, such as that of Valcenti-McDermott and colleagues (2012), who quantified the effects of different variables (e.g., ethnicity, maternal education, presence of specific signs of autism, family history of autism) on risk of being diagnosed after age 4 (although only up to age 6) among 399 children assessed at a U.S. tertiary care center serving a population that was diverse across many of the variables studied.

The distributions of age at diagnosis in this study and the study by Valcenti-McDermott and colleagues, while not strictly representative of the Ontario population, show that diagnosis happens later than the idealized age ranges for achieving diagnosis proposed in the literature. As

early as 1999, authors proposed that in ideal cases autism could be diagnosed with then-current tools as young as 18 months of age (Bristol-Power & Spinella, 1999). Bryson and colleagues (Bryson et al., 2004) assert that "many (but not all) cases of autism are detectable" between 18 and 24 months, and in this context, "emphasize that careful consideration should always be given to parent's concerns, which are typically legitimate" (p.220). In 2007, the American Academy of Pediatrics (Johnson et al., 2007) recommended that autism screening be conducted as early as 18 months to achieve earlier detection and diagnosis, a position that was recently reaffirmed (American Academy of Pediatrics, 2014).

This study, however, demonstrates that the practical ability to achieve a timely diagnosis is not determined so much by the sophistication of available assessment tools to detect and diagnose autism, but rather by a complex interaction of upstream influences—an idea that has been recognized by some authors (for example, Valicenti-McDermott et al., 2012). General influences identified here include the child's presentation of emerging signs and symptoms; parents' knowledge and emotional responsiveness, which in turn determines their perceptiveness and action in response to child signs and symptoms; professionals' knowledge and action; and structure of the system including standards of practice. As an example illustrating the complex interaction of these influences, some of the top ages at diagnosis in Figure 4.1.2 were partly explained by the child having high-functioning autism (i.e., low severity level, a group in whom signs of autism are typically noticed later, at least by professionals). But the mechanism by which severity level delayed diagnosis in these cases was largely due to professionals' failure to perceive autism or respond to parents' concerns, and only partly due to parents' delay in perceiving autism. Further illustrating complexity of upstream influences, the analysis of context

shows how many first-time parents' perceptiveness and pre-diagnosis knowledge of autism is influenced by socially constructed understandings that evolved historically and are still evolving.

Therefore, more accurately quantifying the magnitude of the problem of delayed diagnosis involves understanding approximately how much on average individual diagnoses are delayed by, according to a more accurate and relevant definition of *delay*. I propose that *delay* is a mix of three important factors. First, because of variation from child to child in severity and presentation of signs and symptoms, the definition for delay would need to be partly a function of the apparentness of early signs, which the parent is generally more likely to notice first. Second, since a purpose of achieving timely diagnosis (stated above) is to reduce parent stress related to late diagnosis, it would be appropriate to incorporate a measure reflecting parent perceptions of the delay to diagnosis. A single measure capturing both the apparentness of child signs and parent perceptions of delay is the interval between child age at first concern (reflecting both the apparentness of developmental delay from the parent's perspective, and motivation to start pursuing help) and child age at diagnosis. A third factor not captured by such a measure, and more difficult to operationalize, is the parent's perceptiveness or ability to detect signs of autism, which in turn may be considered a combined function of parent knowledge of milestones and red flags, and parent familiarity with her child (parents whose child spends days in daycare may be less directly familiar than parents who are fulltime caregivers). Lower parent perceptiveness would delay the age at first concern. Even without capturing parent perceptiveness, the interval from first concern to diagnosis is a better measure of delay to diagnosis than age at diagnosis.

Determining the interval from first concern to diagnosis entails first recording the age at the parent's first concern—defined here as the point in the process of *coming to understand their child has autism* at which the parent felt motivated to start taking action because of *knowing*

something was wrong. The reliability of estimates of child age at first concern was improved in this study by confirming the responses parents gave in pre-interview surveys with the accounts of the path to diagnosis they all provided in in-depth interviews. This study is the first I am aware of to record a distribution of the age at first concern (Figure 4.1.3). The median age at first concern was just under 2 years of age, ranging from as young as 7 months to as old as 6 years. Parents commonly noticed concerns around the 1-year mark, and just before the 2-year mark. This is consistent with the DSM-5 (American Psychiatric Association, 2013), which recognizes the variety of early ages when the onset of autism can first be perceived: "Symptoms are typically recognized during the second year of life (12-24 months of age) but may be seen earlier than 12 months if developmental delays are severe, or noted later than 24 months if symptoms are more subtle" (p. 55). In an editorial, Zwaigenbaum and Stone (2008) also refer to an early age at first concern, citing "12-18 months" as when parents "often recall having developmental concerns," going on to stress the aim of early identification research to narrow the gap between first concern and diagnosis (p. 427).

Quantitative data from this study regarding the interval from first concern provide a crude hypothesis-generating picture of the problem of late diagnosis. The median interval was 12 months, with 50% of children diagnosed after a wait of 1 year or less. Thus, if one were to assume that this very limited sample is representative of the Ontario population[14], and take 1 year as the cut-off for a reasonable time to obtain a diagnosis, approximately 50% of children with autism in this province are diagnosed with a delay in the process occurring after the parent's first

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[14] Although it is impossible to judge how representative the sample of 38 children of 32 parents recruited for this study is of the Ontario population of children with autism, and sample size notwithstanding, participants were selected widely from urban and rural areas, and the cases represent a variety of qualitative experiences of the process of obtaining a diagnosis.

concern. In the 4 most extreme cases (10%), this delay was at least 3 years. Quantifying delays to diagnosis in a larger representative sample, using a measure of delay that captures parent perceptiveness and accounts for normal variability in the apparentness of symptoms, would provide a more accurate idea of the size of the problem of delayed diagnosis.

Defining underlying mechanisms and outcomes of delay. Two important strengths of this study are that, first, the quantitative and qualitative data capture a high level of variation; and, second, the quantitative variables (age at diagnosis, age at first concern, interval between first concern and diagnosis) can be correlated at the individual level, both with each other and with detailed qualitative descriptions that participants shared regarding their path to diagnosis including how delays came about (this was the aspect of navigating intervention that I solicited most systematically in interviews). Thus, it is possible to conduct a more comprehensive mixed methods analysis to develop a dedicated specific theoretical explanation for the variability in the timeliness and delay of diagnosis. Such an analysis would correlate a quantitative measure of delay in each case to the upstream factors described in individual stories. It could even account for delay attributable to parent perceptiveness, since parents often described why they were slow in defining their first concern of developmental delay. The resulting theory would be useful to understand what parent-, professional-, and system-related factors to target to best improve the timeliness of diagnosis for the greatest number of parents. Developing interventions addressing the mechanisms associated with the most extreme cases of delay ($\geq$3 years) is most warranted.

A dedicated theory based on data from this study explaining delays to diagnosis would also account for the outcomes of false negatives that delay diagnosis, and contribute knowledge about the overall burden this causes (i.e., stress, lost resources pursuing alternative paths to diagnosis, etc.). An area where physicians are positioned to reduce such burden, is in how they handle

uncertain cases, since minimizing false negatives reduces delays to diagnosis to allow for earlier access to intervention. How to approach uncertain cases depends on the answers to two questions: To what extent does erring on the side of a positive diagnosis for uncertain cases result in more false positives versus fewer false negatives? Even if diagnosing uncertain cases results in a slight increase in false positives, might excessive caution in the name of accuracy result in more harm than good, when the consequences of these false positives are weighed against the burdens of delays to positive diagnoses? Along these lines, Bryson and colleagues (2004) have shared their expert intuition about the low risk of false-positive diagnoses, and imply the importance of timely access to intervention even in uncertain cases: "Our experience, as well as that of others, is that virtually all children initially suspected of having ASD have some form of developmental delay, whether autism/ASD or not, and that they should have the opportunity as soon as possible to benefit from whatever intervention services are available in their community" (p. 221). Further mixed methods research regarding the burdens related to detection and diagnosis is warranted to guide clinicians approach to uncertain cases more definitively.

Methodological strengths, limitations and opportunities for future research

General strengths and limitations. In addition to the inherent strengths of the grounded theory method outlined previously, I adhered closely to the model of grounded theory of Corbin and Strauss (2008), which I also argued (see Chapter 3, *Methods*) has the strengths of being flexible, fluid, and consistent with position of constructivism (Charmaz, 2014; Lincoln & Guba, 2013). In addition, explicit use of a symbolic interactionist framework helped me to construct a complete substantive theory that fits most of the quality criteria in Appendix M. Another noteworthy strength is the detailed rationale I provide regarding several important iterative

methodological decisions and approaches (Appendices C through G). The depth of thought directed at these issues helped shape and strengthen the research, and in one case so far led to a contribution to the methodological literature.

A general limitation is that I did the generative analytic work largely independently and not as part of a team. Thus, although committee members contributed analytically in some important ways at higher levels, only one interview was open coded by another committee member as part of a peer debriefing exercise. Grounded theory is appropriate to conduct in teams (Charmaz, 2014; Corbin & Strauss, 2008). Just as truly collaborative work generally produces better science in most fields and settings, combining multiple perspectives throughout a grounded theory research project expands the theoretical sensitivity, or backgrounds, from which analytic insights are drawn. Due to the standard academic expectation that grounded theory dissertations should be independent projects, however, using a team approach was not possible for this study.

Limitations and opportunities related to sampling. As stated in the Methods, from the outset of this study, I chose to interview primarily mothers (although not strictly mothers) for this study with the assumption this would provide the most useful data for understanding how parents of children with autism navigate intervention, and considering the finite resources I had available. This literature-supported assumption proved true, and so I did not alter this aspect of the sampling. I also sampled urban and rural parents, and less financially advantaged parents.

A necessary limitation of this study is the limited data I could collect to represent the experience of some prominent subgroups of Ontario parents of children with autism, which would have allowed development of further aspects of the central process in fuller detail and allowed for subgroup-specific insights. Studying these subgroups would have required focused recruitment efforts that would have substantially expanded the scope, data collection, and

resources required for this study. Since some of these subgroups represent important areas of experience, they also represent opportunities for future dedicated research, as will be described.

One major subgroup for which I had partial data was seasoned parents of older children. While I had high quality data from five seasoned parents, only one of these had a child transitioning to adulthood (age 18); and I did not interview any parents of adult children. Sampling more parents of young-adult and adult children would allow further development of the stage of *easing off* (particularly *Continuing to define and respond to autism-related concerns*), and potentially allow me to recognize and develop subsequent stages. Knowledge and services related to the transition to adulthood represent well-known gaps, and have become growing focus for policy and research in recent years (Gordon, 2015; Ontario Partnership for Adults with Aspergers and Autism (OPAAA), 2015; Taylor et al., 2012). Thus, a dedicated study of how parents of young adult and adult children with autism *make their own way* to intervention, would not only complement the theory developed here, but would contribute important knowledge about this underserved group that would be useful to advocates and policy-makers concerned.

Another obvious subgroup not represented in this study is fathers of children with autism. The data about fathers' perspectives came from the interviews with 3 father-mother dyads, the father-authored book *Carly's Voice*, and reference to fathers' experiences by the remaining interview participants (revealing, for example, noteworthy cases where the father was the most proactive parent). Since the analysis centered more on mothers' experience including their interactions with spouses, the findings largely ignore fathers' unique perspectives. It is reasonable to expect these perspectives to vary from mothers' perspectives for two reasons. First, most mothers in this study portrayed themselves as doing more of the work navigating intervention compared to their male spouses. Second there is evidence, both in the data collected

for this study and in the literature, that fathers respond to having a child with autism differently than mothers (e.g., Hastings et al., 2005; Rodrigue et al., 1992). Thus, the process of *adjusting* is likely to vary for fathers, and studying the source of this variation would likely reveal valuable knowledge about the differences in action and responses between fathers and mothers.

Two other significant Ontario subgroups that were sampled insufficiently to allow for in-depth understanding are new Canadians for whom the system (including language and ethnic culture) is less familiar than for native-born Canadians, and northern rural Ontarians. I interviewed 11 new-Canadian participants for whom language or ethnic culture had at least some influence on the experience and process of *making your own way*. This allowed for some interesting observations regarding the influence of non-Canadian ethnocultural identity on navigating (e.g., the existence of ethically-defined support groups that were effective at helping parents with otherwise limited skills to navigate the system; or the experience of subtle forms of discrimination as an obstacle). But I never aimed to systematically account for the problems and responses of this group in depth. Given the high proportion of new Canadians in Ontario, a dedicated study with this aim would be warranted. In addition to participant interviews conducted in English, observation of non-Canadian parent support group meetings, and interviews in participants' native language would yield useful data.

Future work: Developing further recommendations for policy and practice

Because *stress* was the dominant consequence of the burdens of *making your own way*, navigation-related sources of stress represent the logical targets for any intervention, recommendation, or change that could be derived from this study. A forthcoming analysis, *Participant-proposed solutions for helping parents*, is underway to suggest theory-supported targets for changes to policy and practice. Like the other supplemental analyses in the

Appendices, this product of the research is outside the scope of the dissertation, whose purpose was to develop a symbolic interactionist theory explaining how parents navigate intervention.

The dataset contains data that has been flagged for such analysis. Although it was not a central focus, it was natural to allow and sometimes encourage parents and professionals to share their ideas regarding potential solutions to problems they discussed. I flagged recommendations-relevant content by open coding it, resulting in 80 potential themes. Additionally, a supplemental analysis (Appendix L: *Framework for involving parents in intervention*) was developed to provide a framework for structuring and presenting the final analysis of *participant-proposed solutions for helping parents*. As part of this analysis, I will consider feasibility and plausibility of the many specific recommendations, and aim to produce a set of relevant, theoretically justified, and actionable recommendations for practice and policy. Given the ethical obligation for research to benefit the participant group that contributed data, this analysis is a priority.

As I have reflected elsewhere (Appendix C: *Reflexivity*), this ethical obligation extends to disseminating findings of this research that may help improve the worlds of parents. Indeed, numerous participants communicated their hopes that the research they were contributing to would improve the navigating process for future parents of children with autism. Three small efforts undertaken that lay the groundwork for future dissemination work include presenting the research proposal to Hamilton Best Start to stimulate enthusiasm and commit to sharing the final findings with them at a later date; sharing preliminary findings that Toronto Star reporters posted on the Autism Project blog (Gordon, 2012b); and participating in an Ontario Ministry of Children and Youth Services researcher engagement interview aimed at gathering knowledge for improving experience with the government's diagnosis and intervention services. In addition to

publishing the findings, I will continue dissemination activities that follow up with these organizations, with participants, and with other stakeholders who have expressed interest.

Conclusion

Here I have presented an empirical social psychological theory whose scope and focus is to explain how parents of children with autism continuously define and respond to autism-related concerns through a symbolic interactionist process, labeled *making your own way*. This central process comprises cycles of two overarching processes: the meaning-making process of *adjusting to the need to pursue intervention* and the related process of *taking action to pursue intervention*. Thus the actions involved in navigating systems of care are explained by *adjusting* and its four sub-processes: *defining concerns*, *informing the self*, *seeing what is involved*, and *emotionally adapting*. The central process changes over time as reflected by the three chronological but heuristic and overlapping stages: *beginning the autism journey,* where *adjusting* centers primarily on the general developmental concern of autism, but also involves defining other early specific concerns; *handling transitions*, where *adjusting* centers on specific autism-related concerns that arise as a result of new transitions; and *easing off*, where *adjusting* centers on concerns related to parents' long-term involvement in pursuing intervention to address concerns for this lifelong condition. As a result of the grounded theory methods used and the symbolic interactionist perspective, this core theory is defined from parents' perspectives and centered on their worlds ensuring its relevance and local applicability.

I have proposed that the central process and some of the other elements of this theory are generic, and therefore transferable to other healthcare consumer populations that must navigate systems of care to address their health-related concerns. In addition, some elements have implications for the fields of patient-centered care, shared decision making, and patient

engagement. The approach of seeking explicit understanding of how discrete decisions fit into the larger more centrally important and often intuitive process by which healthcare consumers define and seek to address their underlying concerns may usefully improve the values clarification methods that are used in patient decision aids by preserving intuitive cognitive processes and potentially encouraging greater involvement.

Finally, I have developed several supplementary (non-symbolic interactionist) analyses that extend the core symbolic interactionist theory. These analyses are intended to increase explanatory power and practical utility of the findings. They include, first, analyses of context, which examine how research-based information, perceptions of credibility of information, and understandings of autism itself are socially constructed. Second, the analysis of *staying* attempts to build a deeper understanding of parent behaviors that observers sometimes perceive as inaction, but which from parents' perspectives generally involve either subtle forms of underlying action or other explanations. Lastly, the framework for involving parents in intervention sets the stage for an important forthcoming analysis that will produce actionable recommendations, derived from participant data, aimed at addressing some of the burdens that Ontario parents of children with autism currently face as they navigate intervention.

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APPENDICES

Appendix A. Pre-interview survey

ID code:

Date:

To participants: Please don't write your name on this form!

Questions

1. How many children do you have with autism spectrum disorder (ASD)? _____

2. How many children do you have altogether? _____

A. If you have more than one child with autism spectrum disorder, please refer to the <u>oldest</u> here (Questions 3.A – 5.A).

3. A. When was your child diagnosed with autism spectrum disorder?
    Year (Month if known): _____

    When did you first suspect your child had a developmental problem?
    Year (Month if known): _____

4. A. What was the diagnosis? If you remember a specific diagnosis, please specify:
    _____

5. A. When was he/she born?
    Year / month (do not include the day): _____

B.   If you have another child with autism spectrum disorder, please refer to the next oldest here (Questions 3.B – 5.B).

3. B. When was your child diagnosed with autism spectrum disorder?
    Year (Month if known): _____

    When did you first suspect your child had a developmental problem?
    Year (Month if known): _____

4. B. What was the diagnosis? If you remember a specific diagnosis, please specify:
    _____

5. B. When was he/she born?
    Year / month (do not include the day): _____

6. Please circle all the types of professional therapy / care that your child (or children) with ASD currently receives.
    a. Intensive behavioral intervention (IBI)
    b. Other behavioral or educational therapy
        (e.g., applied behavioral analysis or ABA)
    c. Occupational therapy
    d. Physical therapy
    e. Speech and language pathologist services
    f. Private school (special needs)
    g. Daycare with a resource teacher
    h. Case management (family resource consultants)
    i. Other professionals (specify—e.g., chiropractor, naturopathic doctor):

        _____

7. To what extent do you feel the care that your child receives meets your expectations? (Circle a number from 1 to 7)

To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
1	2	3	4	5	6	7	0

8. To what extent do you feel you and your family are respected and supported by those responsible for services for your child? (Circle a number from 1 to 7)

To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
1	2	3	4	5	6	7	0

8. Please circle all that apply to your current situation:
    a. Daytime caregiver for your child/children
    b. Part-time employed
    c. Full-time employed
    d. Part-time student
    e. Full-time student
    f. Other (specify): _____

9. How many hours per week do you estimate you use the internet?
    _____

10. What is your current postal code (to define your rural status)? _____

11. If you have moved in the last 5 years, what was your previous postal code (to define your rural status)? _____

12. Have you moved in the past 5 years in order to be closer to services for your child (or children) with autism spectrum disorder?
    a. Yes
    b. No
    c. Other comment: _____

13. Please circle your level of education completed:
    a. Less than high school diploma
    b. High school diploma
    c. College diploma/certificate
    d. University undergraduate degree
    e. University graduate degree
    f. Other (specify): _____

14. What is your year/month of birth (do not include the day)? _____/_____

Appendix B. Initial stage primary interview protocol

Date and time of interview:

Interviewee ID and location:

Prior to interview

- Participant may take notes or provide journal listing 1) chronology of concerns (starting pre-diagnosis), or 2) types of interventions, may be useful to email before interview

- Phone reminder night before, giving my cell phone number.

Preliminaries

- The interview will take 60-90 minutes, and be recorded with your permission.

- Participation is voluntary, so you don't have to answer any questions you don't want to.

- And your identity will be kept confidential and any information you share in the interview will be protected, as was described in the consent form.

- The interview consists of open-ended questions, and the idea is for you to do the talking. I don't need to be asking you many questions because I want is to hear *your* story.

- It's important to remember the purpose/focus of the study during the interview: to understand the experiences when you've had when you receive, look for, or use information about interventions or services for your child(ren).

- Interventions can be anything from developmental services (government-funded or private), behavioral or educational therapy, services delivered in school settings, medications, biomedical treatments, diet options, etc.

- Progression: After asking you to talk about any concerns you may have had starting even
  before diagnosis, I'd like to hear about any interventions you may have considered (whether
  you used them or not), the decisions you ended up making about those interventions, the
  information that informed those decisions, and then sources of that information.

- Where did you hear about this study?

Questions

- To start, can you tell me a little about what your child is like now (without history)?

- Now, can you briefly tell me about when you first had concerns, starting with the time before
  your child was diagnosed—and think about how you met your information needs at this
  time? What did you do to try to address your earliest concerns?

- What other information did they give you when you received the diagnosis? Did receive any
  scores to understand where your child stands based on the diagnostic tests?

- This interview is about interventions, so take a minute to think about some of the funded
  services, behavioral or educational therapy, services in school settings, medications,
  biomedical treatments, diet or other options you may have considered at some point. Are
  there any you considered (even casually) that you would be comfortable talking about that
  you decided <u>not</u> to use? Remember, whatever you share with me will be kept confidential. (If
  there are lots, start with the most interesting ones.)

- For individual interventions used or not used (ask about categories not mentioned):

- What was the decision: to use it, just try it briefly, or to not bother with it?

- What knowledge or information did they have to go on when considering?

- Where did this knowledge or information come from (what source)?

- How was the source used (e.g., search terms used in Google, what was retrieved)?

- Can you talk about any times you considered <u>private options</u> and what that was like?

- To elaborate discussion on sources of information:

- Are there other sources of information about autism interventions that you use or have used, or that you might have a story or opinions about?

- What determines whether the information you get is something you will rely on or use?
  [Alternatively, if it is clear that credibility is important to them…]
  Who is a credible messenger for you? Where does information have to come from for you to consider it believable?
  [If they mention "evidence" (or any synonym), to probe their views further…]

- I am interested in what you said about ["evidence" or synonym]. Can you elaborate?

Recalling philosophical and emotional aspects of informational challenges:

- One of the things I'm interested in hearing about from parents is their philosophy or beliefs about autism, including how it's caused and the goal of treatment. What is your philosophy this way, and how does it affect the kinds of information you prefer (find credible)?

- Can you talk about what was the most emotionally challenging time(s) for you in terms of intervention-related information needs?

- How did you deal with it? How did things turn out?

Other:

- What role does your spouse play in seeking or discussing information?

- Do you have any document-format information about autism therapy you may have encountered (e.g., magazines, books, leaflets from a doctor's office, news clippings), which you could share copies of prior to next interview, or which you could recommend? Copying and postage will be reimbursed.

- So what would you say is the basic problem that parents of kids with autism (especially those in a similar situation to yours) face with respect to information about interventions?

Close of interview:

- Thank you very much for the interview

- Available for follow-up?

  [If faster recruitment is required...]

- Can you recommend any other parents who may be interested in participating?

Appendix C. Reflexivity: How the findings were constructed

The following description of my approach to reflexivity has been published in the journal *The Qualitative Report* (Gentles et al., 2014).

Reflexivity in qualitative research has been conceptualized and defined in multiple ways (Cutcliffe, 2003; Finlay, 2002; Mruck & Mey, 2007; Pillow, 2003). It often refers to the generalized practice in which researchers strive to make their influence on the research explicit—to themselves, and often to their audience. Methodological motives aside, a pragmatic reason for attending to reflexivity in any qualitative study is that it is a key requirement in quality appraisal or evaluation criteria, and research reporting guidelines for qualitative research (see Cohen & Crabtree, 2008; Tong et al., 2007). While there are several valid and convincing arguments against the appropriateness and utility of standardized criteria in qualitative research (for example, Dixon-Woods, 2004; Koch & Harrington, 1998), such criteria are nevertheless used by many granting agencies, peer reviewers, editors, and developers of qualitative literature syntheses at least in health to filter and select research proposals, manuscripts, and publications. Thus the practice and reporting of reflexivity has become almost an expectation (Koch & Harrington, 1998). Consequently, greater numbers of grounded theory researchers are incorporating the practice and making explicit reference to it in published study reports. A problem with the popular desire to legitimate qualitative research through reflexivity (whether to funders, thesis committees, journal editors, or readers of final publications) is the increasingly uncritical adoption of it, with most researchers failing to specify their understandings, positions, and approaches, ignoring how widely reflexivity has been conceptualized and the divergent ways it can be practiced (Pillow, 2003). Just as the authors who have written about reflexivity and

grounded theory represent multiple disciplines and countries, readers can interpret these statements and the following discussion to apply across many fields and jurisdictions.

Considering the relative recentness with which reflexivity has been described explicitly in the context of grounded theory (Mruck & Mey, 2007), the available guidance for how it might be approached critically within this research method is still in the early stages. Original published examples that illustrate thoughtful incorporation of reflexivity into specific research projects have potential value in this context, serving as non-prescriptive tentative models for other researchers and as sources for further methodological discussion. In this article, we illustrate a three-stage approach used in a doctoral candidate's grounded theory study in which the different understandings of reflexivity are first explored and mapped, a methodologically consistent position that includes the aspects of reflexivity one will address is then specified, and reflexivity-related observations are generated and ultimately reported. In describing how this approach can be implemented, we aim to contribute to the greater conversation regarding reflexivity in grounded theory by proposing that researchers attend more closely to specifying their own context-appropriate approach for each study.

In this grounded theory study I, the doctoral candidate (SJG), set out to define and explain how parents of children with autism pursue intervention for any of the multiple concerns related to their child's disorder. Dissertation committee members (KAM, SJ, DBN) provided extensive support and guidance through the process of defining a suitable approach to reflexivity. Because I was conducting this research to fulfill the requirements for a doctoral dissertation, however, most of the responsibility for methodological decisions rested with me. As such, the first person singular (I) is used hereafter to reflect primary agency of the investigator; the first person plural (we) is used when the other authors shared an important role in specific decisions or thinking.

Importantly, as the reciprocal influence between the primary researcher and committee members is challenging to delineate, the distinction between *I* and *we* may not be as separate and precise as it is presented here.

In the following sections, we first lay out some of the important characteristics of reflexivity both to establish its broad scope, and to lay out the considerations that might be relevant to a methodologically consistent approach. In doing so we draw on a dozen articles purposefully selected for their high level of influence (as judged by cross-referencing among authors) either generally (Chesney, 2001; Cutcliffe, 2003; Finlay, 2002; Koch & Harrington, 1998; Pillow, 2003; Walsh, 2003), or specifically for their relevance to grounded theory (Breuer, 2000; Hall & Callery, 2001; Mallory, 2001; McGhee et al., 2007; Mruck & Mey, 2007; Neill, 2006; Sword, 1999). Next, we specify a position on reflexivity that was adopted for the study, outlining the justifications and decisions for how to engage in and report on reflexivity throughout the research. Finally, we summarize the reflexive observations and considerations developed over the course of the research project; these reflexive findings were written in a manner intended to provide insight into how the substantive findings were constructed. We hope that elements from this account will resonate and be helpful to researchers struggling with the decisional process of defining a methodologically consistent approach to reflexivity within their unique grounded theory studies.

Mapping the Scope of Reflexivity

Although the origins of reflexivity in qualitative research are fragmented and contradictory (Finlay, 2002), one explanation slightly dominates based on its repetition by multiple authors: The idea of reflexivity within the qualitative research paradigm has evolved largely from influential (i.e., more likely noticed because they are frequently referenced) methodological

critiques regarding problems of representation in research, such as claims of objectivity and questions about researcher power (Lincoln & Denzin, 1994; Mruck & Mey, 2007; Pillow, 2003). The essential problem stems from the fact "that qualitative research reports are not so straightforward as their authors represent them to be" (Charmaz, 2003, pp. 268-269). Specifically, researchers' roles and influence in shaping the representations of participant experiences are never completely accounted for or addressed, and sometimes they are not even acknowledged. A common position is that the researcher and the researched should be seen as occupying the same world and mutually influencing (see Cutcliffe, 2003). Thus one can conceive of research as a social rather than one-sided process (see Mallory, 2001). The concept of reflexivity, however, has grown to encompass different meanings among the research traditions that helped advance it—including ethnography, hermeneutic phenomenology, and participatory and feminist research. Consequently, various authors have published a multiplicity of definitions(for example see Neill, 2006) and typologies (for example see Mruck & Mey, 2007). I considered breadth and scope of the concept, including the range of possible objectives and practices, after reviewing a selection of literature to decide how to approach reflexivity in my dissertation research (Breuer, 2000; Chesney, 2001; Cutcliffe, 2003; Finlay, 2002; Hall & Callery, 2001; Koch & Harrington, 1998; Mallory, 2001; McGhee et al., 2007; Mruck & Mey, 2007; Neill, 2006; Pillow, 2003; Sword, 1999; Walsh, 2003).

Most of the authors reviewed described how the general objective of reflexivity is to increase transparency and trustworthiness of the research report. At a more specific level, I conceived the meanings and possible aims for reflexivity as varying according to several characteristics. First, reflexivity may involve attention to *varying types of researcher interactions*: researcher influence on participants during data collection, participant influence on

the researcher, researcher influence via decisions affecting research processes, researcher influence on interpretation or analysis, and influence of the research on the researcher. Second, one can apply reflexivity to consider and address presence of researcher interactions *at different stages of the research process*: during topic selection or question formulation, throughout the ongoing process of research design, while interviewing or other forms of data collection, during analysis and interpretation, or during writing. Third, researchers may employ reflexivity to *handle researcher influence in different ways*: to neutralize researcher influence, to acknowledge researcher influence, to explain researcher influence, or to facilitate and capitalize on researcher influence. Finally, *one can view researcher effects differently*, either as problematic (e.g., referring to it undesirably as "bias") or as advantageous (i.e., constructivist views).

Authors in the literature have described several criticisms of reflexivity. On the one hand, numerous authors review concerns regarding the dangers of excessive reflexivity (Chesney, 2001; Cutcliffe, 2003; Finlay, 2002; Hall & Callery, 2001; Pillow, 2003). Particularly, by increasing focus on the researcher to the point of self-indulgence one risks shifting emphasis of the research and "blocking out the participant's voice" (Finlay, 2002, p. 541). Some authors have challenged usefulness of the practice, questioning whether it really produces better research (Kemmis, 1995; Patai, 1994; see Pillow, 2003). Others have suggested that it potentially inhibits free interpretive processes that enable more creative and valuable insights (Cutcliffe, 2003). In other words, reflexivity involves opportunity costs because it may distract the researcher from engaging in a more intuitive selfless analysis. I would go further and say that the trade-off, because a researcher's time is finite, is that it may reduce researchers' capacity for engaging with as much participant data as they otherwise would. Researchers can ask themselves stark questions along these lines: Would it be better to conduct and analyze one more interview, or

allocate the same time to reflexivity? In what pragmatic ways will reflexivity improve research quality? Which aspects of reflexivity have most benefit for my particular research process and research product?

In contrast to the warnings against excessive reflexivity, other criticisms argue that efforts to be reflexive are always inadequate because one can only ever provide a partial accounting of the effects of researcher interactions (Finlay, 2002). My own position is that there is value in sharing one's awareness about the situations in which researcher interactions may be consequential with one's audience, without necessarily proposing explanations to account for how these interactions might be consequential. This makes it possible for a balance to be reached in which reflexivity is employed conservatively and only as far as it serves the purposes that the researcher sets for it. The trade-off questions above helped me select which procedures or aspects of reflexivity to include and which to discard in defining my own balanced approach. Before further outlining the specific position and approach used in my study, I review how reflexivity has been discussed and practiced in the context of grounded theory, focusing particularly on ideas that inspired the adopted approach.

Reflexivity in grounded theory.

It is only in recent literature (since 2000) that reflexivity has received explicit attention in the context of grounded theory, and this has especially been within the constructivist framework (Mruck & Mey, 2007). Charmaz, the founder of constructivist grounded theory, refers explicitly to reflexivity in the second edition book (2014), whereas her treatment of reflexivity (aside from a glossary definition) was more implicit in the first edition (2006). Corbin, meanwhile, dedicates three paragraphs to reflexivity in the third edition *Basics of qualitative research* (Corbin & Strauss, (2008), pp. 31-32), although she mostly cites others' ideas that apply to qualitative

research generically (Cutcliffe, 2003; Finlay, 2002) rather than presenting an analysis of how the practice fits uniquely with grounded theory. Although Glaser's declared position on reflexivity appears ambiguous (as interpreted by some authors, see Mruck and Mey, 2007), contemporary Glaserian grounded theorists tend to view reflexivity as an appropriate part of the research process (e.g., Neill, 2006). It therefore appears that reflexivity is becoming progressively more accepted by the main traditions within contemporary grounded theory.

Hall and Callery (2001), provide one of the first proposals for explicitly incorporating reflexivity within grounded theory. They view reflexivity narrowly, however, only as "attending to the effects of researcher-participant interactions on the construction of data" (p. 257). They reason that their approach is consistent with the methodological position of symbolic interactionism on which grounded theory is based. From this position, interview data are logically understood as constructed from a process of interaction between the researcher and participant. The process of constructing data involves participants interpreting and ascribing meanings to questions and other researcher gestures, to which participants then respond. Likewise, researchers carefully monitor participant responses on many levels, subsequently responding according to their own interpretations of what is going on in the interview. Hall and Callery ultimately propose using reflexivity during the data collection step as a means of filling a quality gap in grounded theory. Importantly, they also suggest that reflexivity already exists in grounded theory since "theoretical sensitivity emphasizes the reflexive use of self in the processes of developing research questions and doing analysis" (Hall & Callery, 2001, p. 263). I agree and expand on this within my reflexive analysis below (see *Researcher influence on the analysis*).

Other authors also highlight the congruence of reflexivity with symbolic interactionism and grounded theory, and ways in which aspects of reflexivity are already inherent in grounded theory, especially according to constructivist approaches (Mallory, 2001; Mruck & Mey, 2007; Neill, 2006). Like Hall and Callery (2001), Mallory (2001) focuses on the researcher-participant relationship, but her version of reflexivity also applies to the effects of this interaction on analysis, rather than just data collection. She proposes specific procedures for an "analysis of difference" (p. 85) that are aimed at understanding the symbolic interaction processes (i.e., meaning-making, interpretation, and responding) from both the researcher's and participant's perspectives.

Mruck and Mey (2007) consider reflexivity in all stages of the research process. But their comments regarding reflexivity during writing are perhaps most interesting and useful. Specifically, they describe how researchers' concerns for their potential audience can influence the research product. In addition to catering to supervisors or journal requirements, concerns for participants' reactions can influence this final analytic phase of the research, "as some interpretations may be avoided or are shaded with the respective recipients in mind" (p. 527). It may be important to expose these forms of self-censorship since "they lead researchers to eliminate possible pointers to the communicative and contextual character of their research" (p. 527).

Specifying a Personal Position and Approach

My position on reflexivity is both that it is a broad multi-dimensional practice that has many uses and should take many forms within a grounded theory research project, and that the extent of its reporting should be limited to serve only those purposes the researcher justifies as worthwhile—usually consistent with the research objectives. Thus, I believe reflexivity should

be used (a) to account for the range of possible researcher interactions described in the reflexivity literature (see bulleted list below); (b) to consider broadly the various phases of the research process where researcher interactions can have influence; and (c) to respond primarily by acknowledging *where* researcher interactions have importantly influenced research processes, while any analysis one may decide to provide about *how* these interactions may have benefited or undermined the research does not need to be exhaustive and should never be excessive.

Reflexive Observations from the Study at Hand

We now describe how and where the specific reflexive observations and considerations from the grounded theory study of parents of children with autism were made and recorded. The original aim of this reflexive account was to provide insight into how the substantive findings were constructed. We organize this description according to the following types of researcher interactions in turn:

- Researcher influence on research design and decisions (e.g., revising the research question)
- Researcher-participant interactional influences during data collection
- Researcher influence on the analysis
- Researcher influence on the writing
- Influence of the research on the researcher

Researcher influence on research design and methodological decisions.

If one purpose of reflexivity is to account for the researcher's influence on the research process, a direct approach is to explicitly disclose one's "methodological decisions and accompanying rationales" (Lincoln & Guba, 1985, p. 327). I strived to report, at least to some extent, my personal influence and justifications for important procedural decisions as they were present at all phases of the research process, from initial topic selection to final analysis and

writing. I chose to record how reflexive aspects influenced my *a priori* decisions (i.e., those made at the proposal stage before data collection) in early chapters of my dissertation. Thus, in the first chapter I reported how personal interest and background led to selection of the research topic and initial research question. In the methods chapter, I reflexively considered the "role of the researcher," explaining my rationale for the specific grounded theory approach I selected, and justifying initial sampling and data collection decisions.

Numerous important or potentially controversial methodological decisions, however, were made as the research was ongoing—often in the later research phases. Thus, I dedicated later sections of my dissertation to providing rationales for the most contentious methods issues I felt warranted extensive justification. For this study, these methods issues included specific approaches to reflexivity, revising the research question, identifying the central category, and incorporating analysis of context.

Committee members had both explicit and implicit influence on the many methodological decisions throughout the research process. Numerous concrete influences were described in methodological memos, the most consequential of which were acknowledged in the dissertation.

Researcher-participant interactional influences during data collection.

Researcher-participant interactional influences comprise observations and reflections on my influence on interview participants including efforts to manage their perceptions, the influence of their responses on the data collected, and the influence of a co-constructive interactional process on the research process and product. These and other related topics are discussed in turn.

Researcher influence on participant perceptions. My interactions with research participants, from pre-recruitment to interview completion, all played some role in their

perceptions of me and the research, and ultimately the data they provided. Participants in the study included 32 mothers of children with autism (3 of these were mother-father dyads), and 8 professionals with expertise supporting such parents. Participants' perceptions were first formed through email, phone, and postal mail contact when I shared information about the study and provided consent materials. All participants learned I was a PhD candidate conducting the study for doctoral requirements.

Participating parents' subsequent contact with me consisted of a pre-interview phone survey. In most surveys, parents volunteered substantially more detail than was required by the structured questionnaire (in each case I was careful to balance the parent's enthusiasm with my wish to respect their time). As well as providing valuable extra background, this generally allowed time for meaningful interaction. Phone surveys were therefore an important opportunity to develop rapport prior to the recorded primary interview, and I felt it was worthwhile including this extra step as a novice researcher. Information collected also allowed me to develop outlines of participant stories and tailor individualized questions before the full interview. Toward the end of the study, however, I found I was able to combine the survey and interview in one interaction for the sake of efficiency. By this point I felt confident to develop rapport much more quickly due to increased knowledge and empathy towards parents' situations.

In preparation for interactions with parents during interviews, I reflected on personal biases, specifically ones that might interfere with my ability to respond with sensitivity and openness. Notably, I was aware of the hostile relationship between the anti-vaccine or biomedical therapy movements within autism on the one hand and the conventional scientific community on the other. The biomedical therapy movement has historically tended to reject traditional standards for scientific evidence because these represent a threat to the claims of effectiveness and safety

promoted for some of their more controversial therapies (Offit, 2008). Effectiveness claims tend to be justified based on indirect deductive biological rationales rather than direct epidemiological evidence. In an early journal reflection on my background and training in health research methodology, I concluded that my belief in traditional standards for research evidence threatened to cut me off from appreciating alternative views and approaches that different parents might use in appraising health information. To avoid imposing this bias on the analysis, I committed myself to openly learning how different parents justified their alternative understandings, particularly by those who saw value in biomedical therapy. I also felt the need to avoid any biasing aspect of my background from influencing data collection because I knew that parents embracing a biomedical approach could feel pre-judged if they perceived my training as underlying a critical stance during interviewing. Thus, in interview discussions with parents who had used biomedical options, I focused initial topic-related questions only on how such interventions were experienced as helpful, and later explored their views about biomedical information, which revealed complex and subtle positions regarding its credibility. In committing to appreciating alternative views, a potentially problematic aspect of my background became unimportant to our interactions and, I believe, to the analysis. Many parents who valued biomedical therapies had logically consistent justifications for using some while avoiding others, an insight that may have gone unnoticed if I remained closed to the possibility.

Gender. Gender is one of various sources of social difference—such as socioeconomic background, cultural ethnicity, and religion—with the potential to influence researcher-participant interactions. Indeed, I did experience (and reflexively analyzed in memos) differences in cultural ethnicity that led to delays in developing a highly trusting rapport with 2 of the 32 mothers who volunteered. I chose not to report on these further, however, because they resulted

in delayed disclosure for only two interviews and had little effect on the overall findings of the study (privacy was also a consideration). By contrast, since I had chosen to interview mothers, gender represented a social difference that applied to all interviews and had greater potential to influence the study as a whole. I therefore felt that consumers of this research deserved a considered answer to the question of whether gender was an issue in this research—although I ultimately did not perceive it as problematic.

In examining this issue, I turned to some of the literature on gender difference in interviewing. Reinharz and Chase (2002) have discussed some considerations with respect to the situation of men interviewing women. In one qualitative study they discuss, Padfield and Procter (1996), a man-woman research team with otherwise similar feminist backgrounds each interviewed separate halves of their all-woman sample. While no difference was observed in women's willingness to share attitudes even on sensitive topics including abortion, women appeared by several indicators more willing to share the fact that they had undergone abortion with the female interviewer. While abortion was not relevant to the focus of my study, it is not inconceivable there were other sensitive gendered experiences that mothers chose not to disclose because I was male. Reinharz and Chase, however, go on to highlight that the influence of gender is not fixed, being dependent on participating women's different perceived sense of skill dealing with men, while this source of difference can be minimized if the male interviewer downplays his gender. In the current study, aspects of interview encounters likely minimized gender influence, for example by offering a choice of three interview options in non-threatening environments. More importantly, according to the "researcher persona" I envisioned for myself (described below), I emphasized warm and supportive human interaction in which gender was demoted.

Initial 'researcher persona'. Chesney (2001) describes the concept of a "researcher persona" (p.129) by referring to Hammersley and Atkinson's (1995) discussion of impression management and their call for researchers to attend to their identity as part of the fieldwork. The persona one projects in turn influences what participants decide to share and the data that are constructed. In describing how she sought to construct an appropriate and successful ethnographic self-identity in her cross-cultural research setting, Chesney refers to struggling with the guidance of various ethnographic "gurus," which she felt required maintaining a falsely constructed self to maintain distance and prevent "going native." By contrast, my source for constructing a "researcher persona" was to draw on pre-existing aspects of my character that I felt would promote comfort in the research process and reduce distance. In my case, as a novice researcher with little prior interviewing experience beyond pilot interviews, using past experience served to increase confidence and focus in early interviews. The personal experience I drew on was 10 years of teaching nordic skiing to adult men and women. By visualizing myself in a similar guiding role, I aimed to use familiar interpersonal skills to create a safe, empathic, and sharing environment for participants to respond to during interviews. Perhaps as a result, nearly all participant interactions were warm and mutually trusting, with many parents and professionals volunteering that they enjoyed the interview experience. I interpret this as a sign that effects of gender difference on disclosure were likely minimized by fostering a persona that reduced distance.

Outsider position. An important source of difference prevented me from fully understanding the situations of parent participants throughout the research. This was the simple fact that although I was the researcher I did not have a child with autism myself. As noted, the majority of interview interactions were warm, and I drew on various strategies and experiences

to bring myself closer to participants. For example, when appropriate I would share my own experience simply as a parent as a gesture of reciprocity. But I always did so humbly, acknowledging that my experiences might only partially compare with theirs. Fortunately, parents appreciated my comparisons to typical parenting as a means to develop personal understanding, and some even encouraged me to use knowledge of the typical parent's experience of having to shift attention and energy away from oneself in adjusting to meeting the needs of a first child—more than one parent suggested I imagine how this could be at least an order of magnitude more challenging if I was adjusting to having a child with autism.

Parent participants provided numerous indicators, however, of how outsiders could never hope to have complete empathy for their situation. For example, multiple participants shared one mother's blunt assessment of professionals' capacity to truly empathize: "You have these therapists, and these workers, and these doctors saying this: 'And I know what you're going through.' Unless you lived it, no you don't." Parents' strong sense of an insider-outsider divide was reinforced by the many descriptions of the unique rapport and irreplaceable level of understanding that fellow parents of children with autism share with each other. As one woman put it, "I have my autism mommies and then I have my neurotypical mommies, which were my friends, right. And it's just not the same." Ultimately, however, this form of difference did not reduce rapport or willingness to disclose to a genuinely interested outsider—rather it seemed to increase parents' motivation to make their story known.

Sensitive topics. Indeed, resistance to sharing was rare in interviews. At the extreme end were participants who offered generously, "I have nothing to hide," or "I'm an open book, ask me anything you want." These comments usually arose in the context of my careful entry into sensitive topics such as personal mental health problems such as anxiety or depression. Aware of

the increased rates of mental health problems among mothers of children with autism (Gray & Holden, 1992; O'Brien, 2007), after the first seven interviews I began probing for evidence that the process of navigating intervention might contribute to participants' emotional burdens without asking about depression directly. After one parent spontaneously started discussing her own mental health, I learned that this was not a taboo subject and indeed one that was very relevant to the research because it was another autism-related problem for which parents struggled to find intervention. After thus discovering such topics were not always off-limits, I began listing mental health and marital problems as potential topics for discussion at the beginning of interviews, and otherwise reminding participants about the option of discussing these issues at relevant points during the interview. With this advance warning and extra time to consider what to disclose, at least half a dozen additional participants volunteered to share information regarding depression or anxiety, while some others I suspect chose to focus on one of the many other topics that were available for discussion. Overall, the participants who did agree to share their experience regarding sensitive topics were reflective enough that their contributions provided sufficient data to adequately develop these concepts and the relationships between them.

Evolving "researcher persona" and co-constructive interaction. As described above, the initial identity I envisioned for myself in interview interactions was drawn from pre-research experience. This was due to both a lack of research interview experience and of familiarity with parents' situations. But my *researcher persona* and relationship with participants was not static. It evolved with successive interviews. This evolving position has parallels with Breuer's (2000) analogy of *cabinet perception*, an astrophysics concept in which the scientific observer does not remain in an absolute or fixed position, but rather "is moved" as is the object of study (Section 3).

Breuer applied this as a metaphor to interview research, in which both the interviewer and participant can be conceived as part of a greater system. In grounded theory the *movement* referred to might be analogous to the shifting or evolution of a researcher's theoretical sensitivity (researcher position), and also of successive researcher-participant relationships and gestures (i.e., positions with respect to one another) over the course of a study. Indeed this happened in the current study, as mutual interactions with later research participants and the level of conceptual discussion in their interviews were often noticeably different compared to earlier ones. This change arose from my own shifting perspective and approach to interviewing, described next.

Early interviews featured participants providing simple factual information in response to questions I asked from my interview guide. This descriptive knowledge was more educational than theoretical, but it soon put me in a position to ask more psychological questions, which in turn brought more understanding and some ability to empathize with participants. Interviews slowly became more collaborative in terms of how understandings were mutually shared and interactively constructed. For example, I was able to raise an idea or concept based on knowledge from prior interviews and ask for parent participants to share their experience or perspectives in order to develop a better understanding of that idea—often this was a deliberate form of theoretical sampling. Overall, interviews shifted from being less descriptive to more conceptual, and even theoretical as linkages between concepts came to be discussed, although the exact mix depended on the participant. As the research progressed I would occasionally respond to participant contributions by speaking aloud my interpretations, partly so that this *in situ* form of analysis would be recorded and later transcribed, and partly to stimulate more reflective ideas from the participant. When this interpretation resonated, or a participant particularly enjoyed the conceptual exercise, there was sometimes a palpable sense of synergism

as we cooperatively developed concepts, with enthusiastic back-and-forth exchanges of anecdotes and experiential knowledge. In this sense my persona evolved from one of distance to being much closer to parents' situation in terms of my conceptual understanding and the valuable interactional relationships that were achieved in interviews. I suspect the experience of building synergy is an implicit natural occurrence for numerous researchers engaged in interview-based grounded theory studies. The transition from distant to close positions may have allowed for partial benefit of both the *etic* (outsider) to *emic* (insider) perspectives known in ethnography (Headland et al., 1990)—seeking greater elaboration on presupposed concepts while distant and achieving more intimate knowledge and insight while close (Mruck & Mey, 2007, p. 527).

Researcher Influence on the Analysis.

Theoretical sensitivity as a form of reflexivity. As Hall and Callery (2001) suggest, grounded theory methods already achieve reflexivity by means of theoretical sensitivity—the grounded theory practice of bringing one's background to bear on the study. Indeed, provided the researcher strives to be transparent about the major ways his or her background has influenced the analysis in the form of theoretical sensitivity, I believe one of the most relevant aspects of reflexivity (i.e., awareness of researcher influence on the analysis) can be achieved largely within the grounded theory method itself.

Corbin and Strauss (2008) describe how personal experience is brought into the analysis in a way that maintains primacy of the empirical data. The most instructive example of this is the analytic practice of *theoretical comparison*, where incidents from the researcher's experience are compared to incidents in the data to bring out properties and dimensions of the concept of which both incidents are examples. The incidents from personal experience are not used as data, but rather only to help the researcher see ways the conceptual phenomenon in question can vary. The

properties and dimensions revealed through such comparisons "give us ideas of what to look for in the data, making us sensitive to things we might have overlooked before" (Corbin & Strauss, 2008, p. 76).

Whenever theoretical comparisons to personally experienced incidents were used in the current study I made every effort to record them in memos. In most cases where they led to important developments in the analysis, the comparative incident from personal experience was described alongside the relevant finding in the dissertation. Thus, there were two concrete modes through which the influence of personal experience on the analysis was made explicit—one available by audit and the other apparent in the report. An example is the comparative use of my experience with a near car crash to bring out properties and dimensions of parents *responding to urgency*—a code used to characterize the emotion and action of parents of children with autism as they responded to the various conditions that rendered their situation highly urgent. The comparison allowed important development of this concept.

Researcher influence on the writing.

Mruck and Mey (2007) suggest that reflexive concerns for one's audience in writing up the research can lead to forms of self-censorship. Following their suggestion, I disclose explicitly my own concerns and how these affect the final report.

During the interview process numerous participants expressed a keen interest in reading the findings, and I think some will want to read beyond the brief summary I provide, and request to read the full dissertation. Thus, I am conscious of the potential reactions of individual participants because it is conceivable that any may read it. In addition, because the autism parent group is so involved and proactive compared to most patient or caregiver groups, it is also possible that some non-participating parents of children with autism may obtain and read parts of

the dissertation if they become aware of it. Some of these parents may personally know participating parents or professionals who have contributed to the study. In response to these possibilities and my commitment to confidentiality, I have strived to ensure data and representations of individual participants are in most cases sufficiently anonymous as to be unrecognizable even to those parents or professionals to which they correspond. I see this as especially important where sensitive topics are involved. This anonymization is a difficult task, however, as it is balanced with the need to provide sufficient information, which requires sometimes-arbitrary decisions about how much detail to provide. On the other hand, this form of self-censorship has may have blunted the richness of some of the accounts provided. Similarly, the ethical commitment to maintain confidentiality and anonymity of local support agencies, schools, and school boards led to the elimination of sometimes-valuable sources of contextual detail.

Influence of the research on the researcher.

In my opinion, there is a risk of appearing narcissistic or self-indulgent in describing influence of the research on oneself, so I will aim to be brief. I have described above how the interview process changed my researcher persona—the specific aspect of my identity involved in interactions with participants in this particular study. Over the course of the research I thus moved from early reliance on personal pre-research history to guide my interactions with parents, to using more specific experience and knowledge of parents as this progressively developed over the course of the research. I experienced this positively as a transition from being what I considered was a fairly good listener, to a much more empathic and effective interviewer—to a point where I was sometimes capable of anticipating aspects of participants' stories and spontaneously formulating theory-relevant questions that fit naturally with the flow of

conversation. Such successes contributed to my sense of expertise and identity as a grounded theory researcher.

In addition to this specific evolution of my researcher persona, I experienced changes to my broader identity in terms of the *personally relevant* understandings gained through the interviews. These new understandings, which relate to my roles as a parent (of neurotypical children), husband, citizen, and researcher, can be surmised by reading the dissertation findings. Those roles and the relationships they involve, because they were areas of personal growth, should therefore be interpreted as sub-interests of the research that may have subtly influenced aspects of the data collection and analysis.

Conclusion

The foregoing account represents one of the few published examples to illustrate the process of thoughtfully incorporating reflexivity into a grounded theory project. Considering the relative recentness with which the practice has received explicit attention within grounded theory, this paper contributes in several ways to the ongoing conversation regarding how to approach reflexivity in a methodologically consistent manner. First, we illustrate how much broader this concept is than many researchers have come to assume. This, in turn, implies the need for considered decision-making about what aspects of reflexivity to adopt within the context of one's research approach. Moreover, the dimensional approach used to map the scope of this concept is unique, differing from previous approaches of summarizing the multiple definitions (e.g., Neill, 2006) or multiple typologies (e.g., Mruck & Mey, 2007) in order to portray the varied reflexivities. As with those approaches, ours is based on an incomplete, albeit purposeful, consideration of the reflexivity literature. We therefore anticipate and encourage continued

efforts to define reflexivity within the context of grounded theory, perhaps expanding the scope we have laid out.

Second, we specify a consistent position and approach to reflexivity that we feel was appropriate for the study at hand. The different elements of this position—such as which of the different possible bi-directional researcher interactions (e.g., involving participants, research design, analysis) should be accounted for, which phases of the research to consider, and how extensively to describe specific researcher interactions—may stimulate further discussion regarding which aspects of reflexivity are consistent, or not, with grounded theory and symbolic interactionism.

Finally, the account of reflexive observations from the study at hand may resonate with other researchers' experiences, providing a model of one researcher's act of attending to researcher interactions. In this sense our paper adds to existing reflexive accounts in the literature that have usefully highlighted the individual value of reporting aspects of reflexivity (for example Sword, 1999). We hope this example will serve both as a tentative, yet useful, model for researchers seeking to define their own context-specific approach to reflexivity, and to advance methodological discussion of how to incorporate reflexivity into grounded theory research.

Table Appendix.C.1. Literature used to define the scope of reflexivity.

Reference	Definition	Objectives and utility	Notes
Koch & Harrington, 1998	Ongoing self-critique and self-appraisal during the study; provision of a reflexive account in the research report that signposts to readers what is going on while researchers.	To make a research account believable or plausible by accounting for researcher's contributions (personal experience data, knowledge and positioning of the literature, self positioning, and moral sociopolitical contexts).	Described from both a Gadamerian hermeneutic phenomenological standpoint, and a feminist standpoint. "We understand something by comparing it to something we already know."
Chesney, 2001	Implicit definition: Making the researcher's genuine self known, to oneself, one's participants, and readers of the research report; also, reporting influence of the research on the researcher.	To acknowledge researcher influence (on selection of the research focus, relationships with participants and data collected, the analysis, and writing)—both to participants and in research reports, all	Disadvantage: tension between revealing oneself as the researcher and avoiding criticisms of self-indulgence.

		for transparency and credibility. To foster disclosure from one's research participants. Can also be useful to guide and prepare future researchers to construct a research identity and position wrt participants.	
Finlay, 2002	Multiple varied theoretical understandings are reviewed. Overall, it is thoughtful, conscious self-awareness; and, acknowledging the existence of researcher bias and explicitly locating the researcher within the research process; it encompasses continual evaluation of subjective responses, inter-subjective	To account for how inter-subjective elements influence data collection and analysis, to promote trustworthiness. To identify impact of the researcher's position, enrich analysis, empower others, evaluate research processes, and promote transparency.	Disadvantage: too much self-indulgent application shifts emphasis away from the participant; it can only be incompletely carried out. Discusses theoretical origins of reflexivity.

	dynamics, and the research process itself. It is applied at the pre-research, data collection & analysis stages.		
Cutcliffe, 2003	Multiple varied definitions and understandings are reviewed. Overall, it is the understanding that the researcher is necessarily a part of the researched world due to mutual influence between the researcher and the researched; and the act of accounting for oneself— various techniques that one implements *during* the research process are reviewed.	To support the analysis, facilitate transparency, promote trustworthiness by acknowledging researcher influence. To promote empathy in the interactive process and therefore sensitivity to participants' experience. (To some, the objective is to suppress preconceptions and promote neutrality.)	Disadvantages: 1) completely accounting for the researcher is impossible, 2) over-emphasis on reflexivity inhibits free (non-self-conscious and uninterrupted) interpretive activity that can lead to more creative, intuitive, and valuable insights and academic accounts.
Pillow, 2003	Describes definitions and influences within anthropology, feminist research. Different types exist, and several published	Multiple uses are described.	Disadvantage: self-indulgent and unhelpful to the research or improving lives of the researched. Discussed

	typologies in addition to her own are reviewed.		from an ethnographic perspective. Problem of representation discussed.
Walsh, 2003	A typology of 4 types of reflexivity is presented: 1) personal, 2) interpersonal, 3) methodological, and 4) contextual.	1) Personal: to declare influence of the researcher's attitudes and expectations on the research. 2) Interpersonal: to determine how to most ethically interact with participants, and to analyze that interaction. 3) Methodological: analyze the effect of theoretical commitments surrounding the research. 4) Contextual: situating the study within its cultural and historical context of assumptions and	Discussed from a hermeneutic phenomenological perspective.

		practices in the field.	
Breuer, 2000	Implicit definition: Self-reflection to account for the influence of the researcher's evolving position and interactions with respect to participants (or object of study), and of participants' changing positions within a system of interaction with the researcher over the course of the research. Also, an accounting for influence of the research on different phases of the research (topic selection, method selection, relation to participants, interpretation, presentation, and other decisions).	To refine the analysis by accounting for dynamic interaction between the researcher and the researched; and to promote transparency by accounting for influence of the researcher.	Refers to a grounded theory perspective. A metaphor from astronomy-physics is used: "cabinet perception," where the observer is part of a system in which she changes position as she moves and is moved, and "the way the object of study appears is influenced by our own movement and the movement of the object" (p. 6).
Hall & Callery, 2001	The act of attending to the effects of researcher-participant interactions on the construction of data.	To promote transparency of how data are constructed, to increase rigor in	Discusses consistency with grounded theory and symbolic interactionism.

	("Relationality" refers to the act of attending to power and trust relationships between researchers and participants. Also, critically examining one's effect on the research process.)	grounded theory.	Reflexivity already exists in grounded theory in the form of Strauss and Corbin's (1998) version of theoretical sensitivity (consciously bringing one's background to bear on the analysis). **Offers a proposal** that researchers account for effects of interactions on data collection (and to incorporate relationality) as a new method added to grounded theory.
Mallory, 2001	Implicit definition (term reflexivity not used): Understanding and specifying the relationship between the participant and researcher, and analyzing the effects it has on data	To facilitate participant trust and disclosure, to improve understanding of the basic social problem (including greater appreciation of context that differs	**Offers a proposal** for a new optional method to be used in grounded theory: "analysis of difference". Discusses congruence of this method of incorporating

	collection and the analysis.	from the researcher's), to improve transparency of the researcher's position in the research process and findings.	reflexivity and symbolic interactionism and grounded theory with its constructivist and feminist influences. Discusses inadequacy of researcher demographic characteristics.
Neill, 2006	Multiple varied definitions are cited. Overall, it is defined vaguely as "reflective activity" on two levels: an 'effective component' (reflecting on process), and an 'affective component' (reflecting on self-awareness).	Account for effects of researcher-participant interaction; effects of researcher on the analysis. Specifically used to identify researcher-attributable factors affecting participation rates; to facilitate analysis (per GT via theoretical sensitivity).	Consistency with Glaserian grounded theory discussed.
McGhee et al, 2007	An awareness of how the researcher's identity and background may affect the	To limit researcher effects on the data, to prevent prior	Involvement of reflexivity in two stages of the research process

	research process.	knowledge from distorting the researcher's perceptions of the data.	are discussed: data collection, analysis. Discussed implications for the literature review in grounded theory.
Mruck & Mey, 2007	Multiple definitions exist. It can entail an analysis of how researchers, their interaction with participants and the contexts that both parties belong to may influence the research process over its different stages: topic or question selection, design, data collection, analysis, writing and publishing.	A chance for researchers to rethink, ground or justify their own research decisions, and to communicate the theory development process to co-researchers and participants.	Disadvantage: Impossible to achieve completely. Describes 'crisis of representation', reviews typologies, reviews literature on reflexivity in grounded theory, discusses consistency of reflexivity with symbolic interaction and grounded theory.

Appendix D. Revising the research question: Scope and focus

When using grounded theory, it is acceptable for the research question (and research problem) to be refined in response to the data one collects, as will be explained. The study of "how parents of children with autism negotiate intervention and fit information into that process" provides a unique and valuable case of how one proposal-specified research question was refined. This section describes methodological justification for revising a research question from the perspective of the grounded theory method, the story of how the research question came to be revised in the current study, and how the example this highlights the strength and value of grounded theory for defining better-targeted and more highly relevant research problems than is sometimes achieved by the more prevalent scientific approach used in health research that values reproducibility and a priori design.

Methodological principles from symbolic interactionism

Justification for much of the method of grounded theory traces back to the intellectual backgrounds of its two original developers, Anselm Strauss and Barney Glaser. The most defining principles of this research approach are founded in symbolic interactionism (from Strauss' background)—a social theoretical perspective developed largely by George Herbert Mead and then Herbert George Blumer, which was in turn derived from a form of pragmatism (particularly the ideas of John Dewey). Blumer (1969) provides the most complete summary of symbolic interactionism, notably its methodological implications for scientific social research.

First used in 1937, the term "symbolic interactionism" refers to a theory of human or group action intended to explain and guide scientific human social research. It is based on three premises (adapted from Blumer, 1969, pp. 1-21):

3) That human beings act toward things on the basis of the meanings that the things [i.e., physical objects, people or categories of people with whom one interacts, institutions, guiding ideals, others' activities, or situations] have for them,

4) That the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows [or oneself], and

5) That these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he or she encounters [i.e., the meanings that one uses to construct lines of action are not static].

Thus, "One has to get inside of the defining process of the actor [i.e., the process of forming and interpreting meanings, then constructing and choosing between different lines of action] in order to understand his action" (p. 16).

In describing the ideal methodological position that follows from symbolic interactionism, Blumer states that the goal of science should be to reflect the undeniable or "obdurate" nature of the empirical world. Furthermore, methodological principles (and methodology itself) should be defined to adequately consider and guide the *whole* scientific act, and not be fixated on scientific procedures only. Per Blumer, the scientific act includes the following:

- how to define the set of premises about the nature of the empirical world that orients the scientific act;

- how to define questions and propose or select problems that guide what should be studied;

- how to select, collect, and examine data;

- how to analyze or determine the relations between data;

- how to interpret findings;

- and how to select, define, and use the concepts that one will use through all these steps.

While Blumer addresses all these steps, what is most pertinent here are the ideas that apply to defining questions and selecting problems.

To select problems that respect the obdurate nature of the empirical world, Blumer (1969) insists that one must strive to "to develop a close and reasonably full familiarity with the area of life under study" (p. 37), in order to gain firsthand knowledge of it instead of relying on preconceptions or pre-existing theories to understand it. He emphasizes that the only way to define the kinds of research problems that should be studied in any "sphere of empirical social life" so that they reflect the problems actually experienced by actors in that empirical sphere, is to have direct contact with it. He acknowledges, however, that researchers are usually in the position of having to start their studies prior to having had such contact, bringing their imperfect preconceptions or stereotypes to bear on their initial definition of the research problem. These stereotypes or preconceived images must therefore ideally be "tested and revised" as the researcher gains familiarity with the empirical setting through direct contact. Blumer (1969) warns that "the scholar who lacks that firsthand familiarity is highly unlikely to recognize that he is missing anything" (p. 37). The most relevant implication of this methodological position with respect to revising the research question is that the researcher must have flexibility to respond to the data collected (p. 25): "Even though set by the problem, the data need to be constantly examined to see if they require a revision or rejection of the problem."

It is remarkable how well the methods of grounded theory seem to answer the symbolic interactionist principles laid out by Blumer. For example, in grounded theory, one starts with a preliminary idea of what one is interested in; and this often involves a premature guess about what the central problem and process are in the empirical (or substantive) area of study, which is

recorded in the research proposal in the form of a research question. As Schreiber states

(Schreiber, 2001b, p. 62),

> *"Grounded theorists begin with an assumption that participants share a problematic situation, which they (participants) may or may not articulate. Even though the researcher tries to approach the study "with as few predetermined ideas as possible" (Glaser, 1978, p. 3), she or he cannot unlearn what is already known. Thus, even the act of selecting something to study imposes a pre-existing conceptual structure onto the phenomenon. The researcher has already identified what she or he thinks the problem is and begins the study from that perspective. However, the first goal of the researcher is to understand the shared basic social problem from the participants' perspective. [...] Since the grounded theorist's ultimate goal is to learn how participants resolve or ameliorate the shared problem, it is vital to first learn what the problem really is."*

As one proceeds to gather primary data, grounded theory methods texts generally

encourage researchers to be aware of their *a priori* positions or ideas of what the situation is

about, subordinating these in favor of what the data actually have to say. Researchers are also

encouraged to be flexible to pursue what the primary data suggest is important or central in the

worlds of one's participants. For example (Oktay, 2012, pp. 48-49):

> *"In qualitative research studies, including grounded theory, the research question is initially stated as a broad area of interest, and it is only when the study progresses that a specific focus becomes clear. The research question is not something set in concrete, but rather something that reflects a starting point. It can be expected to change during the course of the research, as the researcher focuses the study. [...] What is important in grounded theory is to let the data structure the research question, and not vice versa."*

Thus, both its symbolic interactionist foundations and the methods of grounded theory

themselves support and encourage the researcher to be sensitive to the need to revise his or her

research question if the data suggest that this is called for. Encouragingly, there are cases of PhD

students who have successfully defended their grounded theory dissertations where the research

question was revised. For example, Vinitha Ravindran (University of Alberta), who submitted

her final dissertation in spring 2012, described how changing her research question from its

formulation in the research proposal to something that corresponded better with "what was

happening in the participants' lives as [she] saw the scenes and listened to their voices" was an

noteworthy part of the research process (presentation at Thinking Qualitatively, Edmonton, June 18 2012). I will try to illustrate with my own example how revising one's research question in grounded theory is a process that requires thoughtful consideration over time by the researcher.

How the research question was revised in the current study

The original research question[15] (and research problem) I defined in my proposal prior to any serious data collection focused on how parents navigate, use, and cope with problems related to "information about interventions." However, from the first interview onwards (and in every interview, I have consistently asked each parent to "consider the concerns you have had related to your child's autism, interventions to address those concerns, decisions made about those interventions, the information used to make decisions, the sources of that information, and any reflections on the information sources," as possible material for the interview), what parents consistently and emphatically discuss is their pursuit of intervention, especially services including diagnosis, funded intervention, accommodations at school, and other solutions that help address autism-related concerns. Parents would talk about how information fits into this process, but information was clearly not central to this process or the main problem they described. Sometimes parents' discussion of pursuing intervention would not even involve decisions, or the use of information to make those decisions.

I soon felt I could not defend my study as a grounded theory if I stuck to a preconceived information-centered problem and ignored the related, but clearly more relevant problem evident in the first few participants' data. To maintain my focus *only* on information I would need to either 1) abandon an open-ended approach with many of my interview questions, directing

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[15] Proposal research question: "What psychosocial process explains how Ontario parents of children with autism find and use information that informs their attitudes and decision making about intervention for their child?"

participants to answer very specific questions without expanding; or 2) discard large swaths of open-ended responses after making many arbitrary and impossible-to-justify decisions about what qualified as relevant to *my* pre-conception of the problem or not. Both options would leave me "forcing responses into narrow categories" (Charmaz, 2006, p. 18). It was obvious to me that I could not resort to encouraging parents to stay "on track" by avoiding talk about their struggle navigating and pursuing intervention, unless of course it was about the parts that featured some kind of interaction with information. I could feel my research focus and question was to starting to evolve naturally and a little out my control (despite the fact that I continued prompting participants to consider "information" and its uses before asking them the first interview question); it was drifting away from a preconceived idea not quite fitting the situation to a problem better matching the empirical reality of parents.

After a few more interviews (soon after number 7), I came to understand that if things changed too much and became too broad, I might not be studying what I had set out to research and my study would have changed. I needed to preserve my original interest: how parents use, feel about, and interact with *information* about intervention. But how could I do this while respecting the methodological principles of symbolic interactionism that I believe make grounded theory a valuable and appropriate method? The "new" broader problem, which parents were defining in their interviews, still contained my original interest, because "navigating intervention" was the main use that parents put "information" to. But "information" wasn't the focus because it wasn't talked about all the time.

I recalled a point in my proposal that I had included to allow for some flexibility: "per Corbin and Strauss (2008), 'if a participant brings up another topic that proves to be important to the investigation, the researcher will follow through on that topic' (p. 152)." The topic of 'how

parents navigate intervention' was clearly important, not only because navigating intervention is the principal use that parents put information to, but because any discussion of information cannot be separated from an understanding of parents' more central concern. That was key: Any discussion of information cannot be separated from an understanding of parents' more central concern—the problem related to their process of ultimately obtaining intervention.

Thus, my study was going to have to address and understand the central problem and process related to obtaining intervention. But my interest could still be maintained by asking, "how does information fit into that process?" Answering this revised question[16] will entail keeping the focus close to (and in fact answering!) my originally proposed question, but it acknowledges that there exists another larger process to be understood first.

The only other issue related to revising the research question is minor. Conventionally, at least according to the grounded theory literature, one revises the research question to become more focused—e.g., "Although the initial question starts out broadly, it becomes progressively narrowed and more focused during the research process as concepts and their relationships are discovered" (Strauss & Corbin, 2008, p. 41). In my case, however, it came to encompass a larger topic. The reason for this, however, can be explained by the possibility that my original question was mistakenly too focused, and it should have been framed more broadly and flexibly to be able to accommodate unanticipated realities in the research setting (see Appendix for a journal reflection about this and better initial questions I might have specified in hindsight).

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[16] The full version of the revised question is: "How do Ontario parents of children with autism navigate intervention, and how does information fit into this process?" Note, this question focuses on a broader process, navigating intervention, the exact nature of which is left undefined.

Lessons learned about the strength and value of grounded theory

This story of having to revise the research question illustrates a pragmatic application of some of the methodological principles of symbolic interactionism on which grounded theory was founded. It also provides a powerful lesson about how those principles give grounded theory considerable value as a method for studying relatively new areas such as use of health information by specific populations.

If I had chosen a different method—for example, usability testing methods to define how parents interact with and use web sites providing information on the many types of autism interventions—I would have carried forward with my interest in how parents of children with autism use information as well as my pre-conceptions about why this should be important. But I likely would have remained ignorant of the relevance of the resulting knowledge, and come away with only an incomplete understanding of how health information fits in with what is important to parents—for example, it does not seem to necessarily be to inform rational decision making as I originally had guessed. Instead, grounded theory permits and even encourages researchers to apply their emerging understanding of a sphere of social life as a means to check whether the problem they originally set out to study is relevant and corresponds to a problem defined by actors in the empirical area chosen for study.

Taking the lesson further, special care could be warranted in *any* area of health research concerned with social or behavioral phenomena whenever such research is guided by a "conventional scientific approach"—i.e., where the research problem is defined by non-inductive theory in preference to close firsthand knowledge of the empirical setting, and the research question is set in stone prior to data collection and cannot be revised. Even in developed research areas, if it is suspected that close firsthand knowledge of the setting could have been overlooked,

grounded theory may be a valuable option to consider because it achieves the important "…prior step of discovering what concepts and hypotheses are relevant for the area that one wishes to research" (Glaser and Strauss, 1967, p. 2).

Appendix E. Identifying the central category: Structure for the substantive findings

Here I describe my understanding and positions with respect to controversies in selecting a central category, and summarize how this process resulted in logically structuring the presentation of this grounded theory into the three substantive sections that follow.

The central (core) category and its identification or selection is highly important in grounded theory because it provides the initial structure for achieving theoretical integration or analytic development of the theory, since "It is the concept that all other concepts will be related to" (Corbin & Strauss, 2008, p. 104). Clarke (2009, pp. 205, 210) interestingly reinforces the idea that there is a "central analytic" or major "unit of analysis" in grounded theory—she notes that for most forms of grounded theory this is action (or process), whereas for situational analysis (her extension to grounded theory) the unit of analysis is the situation itself.

To identify and select a central category, Corbin and Strauss (2008) advise that the researcher consider the many categories developed over the course of the study and choose the one they judge "to have the greatest explanatory relevance and highest potential for linking all of the other categories together" (pp. 104-105). Strauss (1987, p. 36) lists 6 criteria that provide further guidance, among them are that the category is central with all the other major categories relating to or fitting under it, it appears frequently in the data with most cases having at least one instance of it, it fits or is logically consistent with the data, and it has clear implications for a more generic or 'formal' theory. Note, Glaser (1978, pp. 95-96) also provides a set of 11 criteria for selecting a core category.) Bearing these criteria in mind, one may select the central category from among the existing categories, or a more abstract category may need to be constructed to capture the story more completely (Corbin & Strauss, 2008).

Controversies

One of the controversial issues in grounded theory appears (superficially) to be whether or not the central or core category needs to be a *basic social process*, or *BSP*. The term *basic social process* is first prominently used in the main grounded theory methods texts in 1978, when Glaser dedicated a chapter to it and the related topic of selecting a core category. I will not review it in detail here except to point out that, although consistent with symbolic interactionism in its focus on human action, the definition of a *basic social process* is narrower and more restrictive than Corbin's version of *process* defined previously (Corbin & Strauss, 2008). For this reason I have personally chosen not to use the term, referring instead to process. Some authors refer to and critique the apparent perception in grounded theory that one's central category must be a 'basic social process'. For example, Charmaz (2006) states, "the early grounded theory texts prescribed discovering a single basic process" (p. 139). However, this perception and the resulting controversy seems instead to be the product of discourse among researchers that somehow evolved independently of the methods literature. Prior to such discourse being possible, Glaser (1978), for example had already described the relationship between core category and basic social process by stating "Grounded theory need not, of course, be restricted to the generation of BSP's…BSP's are just one type of core category" (p. 96). In a Student Questions and Answers chapter, Corbin (Corbin & Strauss, 2008) addresses this perception hinting at Charmaz' misattribution to the methods literature and clarifying her own position against it (p. 325): "Is using a 'basic social/psychological process' the only way to integrate a study? I notice that some researchers seem to assume this...No, the use of a basic social/psychological process isn't the *only* way to integrate the data to construct theory. This assumption (certainly not made in Glaser's (1978) discussion of basic social processes) represents a grave underestimation of the

complexity of the phenomena that are likely to be encountered in any given study." Adele Clarke (2009) provides perhaps the clearest example of how the central category can take an alternate form. Indeed this is always the case with situational analysis (Clarke's extension to the grounded theory method), where "the situation itself becomes the fundamental unit of analysis" (p. 210). In such studies, data collection and analysis focus more heavily and comprehensively on the structural conditions that make up the situation (what some researchers besides Clarke might consider context) rather than individual or group action (process). My position is that (clearly!) the central category in grounded theory need not be a process. Although the most important and central category in my study happened to be a process (described below), I did not intentionally seek one out to build theory around in response to a rigid perceived rule.

A second controversy is whether one should select only one central category or a small number of such categories when developing a grounded theory. Corbin's (Corbin & Strauss, 2008) suggestion is that when two or more possible central categories emerge, especially for beginning analysts, "to select one idea as the central category" by looking hard for a unifying idea, since "Having two central categories means having two different theories" (p. 105). Likewise, Glaser (1978, pp. 93-94) positions the core category as a unit of analysis, since one must "focus on one core at a time." When two core categories are discovered, his forceful advice is to focus the writing on only one and demote the other, noting "It [the demoted category] can still take a central focus in another writing." Charmaz (2006), on the other hand, warns that restricting oneself to seeking a single overriding process as one's central category when "numerous 'basic' social processes occur in a setting," can lead to analytic blockage (drawing on personal experience to illustrate her point). Considering this, she describes "choosing" to raise certain categories (in the plural, rather than singular) to the status of "theoretical concept" (p.

139). These ideas have led to thoughtful consideration of the relationship between two major categories within the current analysis— *adjusting to the need to navigate intervention* and *making your own way* (Section 4.3)—and how to structure the presentation of the theory, summarized below.

The central category and organization of the theory

Early in this study (see Appendix D, *Revising the research question*), I began to understand that *having to make your own way* fit well as the central over-riding problem experienced by parents. The corresponding central process that parents use to respond to it is *making your own way*. While Section 4.2 provides a loose theoretical rendering of most of the key elements comprising the situational problem of *having to make your own way*, it gives only an partial and unsystematic account of the situational context—as I emphasize later, this study is not a full situational analysis. Section 4.2 provides background and depth for denser theory development in Section 4.3, outlining the central process and main category, *making your own way*.

Although *making your own way* is the central process, *adjusting to the need to navigate intervention* (Section 4.3) is sufficiently important to warrant substantial analysis and attention. It is almost a mini-theory of how parents understand or construct their own meaning of the situation of *having to make your own way* partially described in Section 4.2. While *adjusting* is a subcategory under *making your own way*, it is a large one serving a key analytical purpose within the overall theory. From a symbolic interactionist perspective (the theory which states that people act toward things based on the meanings they ascribe to them) it provides the groundwork for understanding why parents respond the way they do when *making their own way*.

Appendix F. Analyzing context: Situating the study

At the outset of the study and even until I had collected extensive data, I lacked detailed awareness of how or even whether context would be incorporated into the final analysis. For Corbin and Strauss (2008), analyzing "context as structure" involves tracing the problems or circumstances faced by participants back to the relevant social, political, and historical conditions within which they arose (pp. 239-240). For these authors, the conditions that define context are usefully conceptualized as ranging from macro to micro. Meanwhile, Charmaz (2006) describes analysis of context as "learning how, when, and to what extent the studied experience is embedded in larger and often hidden positions, networks, situations, and relationships" (p. 130). Thus context can also be thought to consist of less obvious or tangible elements (structural conditions), which are more difficult to detect and trace. For Charmaz, this means that detecting and analyzing the influence of context requires having collected both rich and sufficient data. For this reason such analysis is less likely in smaller grounded theory studies, which in turn represents an important limitation because ignoring context generally results in "treating experience as separate, fragmented, and atomistic" (Charmaz, 2006, p. 131). The requirement for sufficient data to be able address context explains why in the current study I only gained an appreciation for specific structural conditions and the general relevance of context towards the end of the study when I was conducting my final set of interviews. Thus it was at this point, near the end of data collection, that I decided a more deliberate approach to analyzing and accounting for these aspects of context was warranted. Like the preceding accounts of reflexivity and revising the research question, this is a finding in itself. My approach to analyzing context was informed both by Strauss and Corbin's *conditional-consequential matrix* (Corbin & Strauss, 2008; Strauss & Corbin, 1990, 1998), and to a lesser extent by ideas from Clarke's

situational analysis (Clarke, 2005, 2009). I describe these influences below with the aim of providing readers a better appreciation of how context is presented in the next main section of the chapter—a mostly descriptive account of problematic aspects of parents' common situation.

The conditional-consequential matrix

Strauss and Corbin's conditional-consequential matrix (hereafter, the *matrix*) consists of a set of ideas for conceptualizing context with an accompanying diagrammatic representation, which together provide a heuristic device that researchers can invoke to account for context within their analyses. It views structural elements interactionally (as in symbolic interactionism), both as contextual conditions from which problems requiring a response arise, and as consequences or targets that can be changed by actors' responses. Moreover, these elements range from the micro to macro. The individual or person is always the most micro-level element, while more macro levels are specified flexibly according to the empirical setting (e.g., family, group, organizational, community, provincial, national, and international). Three slightly differing diagrammatic representations of the matrix have been published (Corbin & Strauss, 2008; Strauss & Corbin, 1990, 1998), but it essentially consists of concentric circles with the most macro level at the outside, while individual action is positioned as the central analytic. The authors note that this schematic is an overly rigid representation, however, and that grounded theory studies may just as easily focus on action or process at any other level of the matrix— many such studies focus on processes at the organizational level, for example. Thus, one of the uses of the matrix is to specify the level at which one is primarily directing one's data collection and analysis. In the current study this is the individual level—i.e., the action or responses of parents of children with autism. While this is seemingly obvious, it is useful to make one's focus explicit in order to avoid spending disproportionate amounts of time and energy analyzing

interactions with and the actions of contextual elements at other levels. Thus, the matrix both locates the study and reins in the analysis of context, as the following memo reflection illustrates:

> *In other words, while it is informative for me to consider the influence of context at the higher levels, I should not lose sight of the fact that most of the analysis for my study is and will be directed at understanding the individual level (particularly my data sources, which are mostly parents, but also the questions I directed at professionals, which were aimed at their knowledge of parent perspectives). Nevertheless, I have data—from parents, professionals, and documents—that provides insight into interesting influences of context. My purpose in bringing in context is therefore to develop the complexity of the theory, but not to shift its primary focus from the individual.*

I also used the matrix as a reminder of the range of social units (from micro to macro) to consider as possible sources of relevant structural conditions. For example, an important condition at the provincial level is the availability of funded, child-directed, autism diagnosis and intervention services provided the Ontario Ministry of Children and Youth Services. Finally, I used the matrix to prompt me to consider not just how contextual elements influenced individual action, but how these more macro elements could also be influenced by individual action in some cases. A concrete example of this reciprocal interaction, described in the next section, is the influence parents have on the research knowledge production process through their advocacy actions.

In analyzing context, I aimed to select a limited number of conditions to trace based on their pertinence to the theory according to what individual parent data indicated was important. In some instances I selected examples of such conditions for their power to illustrate broadly relevant conceptual properties, such as my use of the Diagnostic and Statistics Manual of Mental Disorders (in its multiple editions) as a case to illustrate properties of the contextual process of translation of autism research knowledge. Generally, integrating contextual conditions from macro levels of the matrix into the analysis pushed me to rely more on document data (defined as any text-based materials including web sites, technical or non-technical literature, records, and so

forth), in contrast to the more standard grounded theory analysis of action at the individual level which is most commonly captured by interview or observational data—although autobiographical or memoir-type documents are also useful (Corbin & Strauss, 2008).

Ideas from situational analysis

While the matrix was a valuable heuristic for the current study, I ultimately found it too limiting to rely on alone because the geopolitical macro-micro dimension it suggests does not draw attention to some less obvious forms of structural conditions (although Strauss and Corbin provide a quite diverse list of possibilities to consider for each level of the matrix (1998, pp. 194-195)). For this reason I also turned to Clarke's (2009) brief and partial description of situational analysis, primarily to broaden my perspective on the different forms that structural conditions can take. Note, instead of contextual conditions, Clarke refers to them as *conditional elements of the situation* because for her there is no such thing as outer context since her analysis focuses on the situation in its entirety. Importantly, Clarke's approach is consistent with symbolic interactionism, and was partly influenced by Strauss and Corbin's matrix. Clarke (2009, pp. 211-221) provides a rudimentary summary of Foucault's postmodernist ideas that serve as foundations for analyzing discourses within situational analysis, upon which I based my own understanding and appreciation for using *situational maps* which she goes on to describe. Although I jotted my own basic situational map at the outset of the research, I have used Clarke's outline mostly as a sensitizing reference to stimulate ideas about alternative "major elements in situations" to be alert for. Thus I identified conditional elements in my data including discourses (e.g., different versions of autism and intervention espoused by competing groups including traditional science and the biomedical movement, which may wash over parents influencing their constructions at different points in their journey), histories (e.g., evolving research-based

understandings of autism), sociocultural elements (e.g., the Canadian culturally situated practice of discrimination), and spatial elements (e.g., inconsistent services among regions leading to migration to gain access). Once identified, I sometimes theoretically sampled (usually by adding interview questions) to attempt to further develop and integrate these concepts. It is important to emphasize that the current study does not by any stretch qualify as a situational analysis because the predominant focus remained on action rather than on the situation, identifying it instead as a traditional grounded theory.

Ultimately, the approaches to analyzing context described above have allowed me to situate the current study in several ways. It is situated historically, for example, by considering how aspects of information that parents use cannot be assumed stable due to the fact that both the extent of autism research knowledge and the rates at which it was evolving and being translated were at a unique points when the interviews were conducted (see Appendix H, *Analysis of context: Evolution and translation of autism information*). It is also situated in time according to the evolving influence the biomedical movement has had up to this point on the credibility of autism- and intervention-related information (see Appendix I, *Analysis of context: Credibility of information*). Since the primary aim of data collection and analysis in this study was to explain individual action, attention to the more peripheral structural conditions was not as comprehensive or deep.

Appendix G. Member checking

Conceiving member checking as congruent with grounded theory

Member checking (or respondent validation) is traditionally conceived as a verification technique, "whereby data, analytic categories, interpretations, and conclusions are tested with members of those stake-holding groups from whom the data were originally collected" (Lincoln & Guba, 1985, p. 314). Since Lincoln and Guba described member checking as the most important procedure for establishing credibility in a qualitative study (Guba, 1981, p. 85; Lincoln & Guba, 1985, p. 314), this technique was subsequently positioned in commentaries (for example, Baxter & Eyles, 1997) and quality appraisal checklists (summarized in Tong et al., 2007) as necessary for ensuring rigor in qualitative research. In fact, Koch described how, of the techniques for achieving rigor in nursing research, member checking stood out as a "strong example of a 'rule'" (Koch & Harrington, 1998, p. 885). Researchers have even reportedly experienced difficulty publishing their work in specific journals without submitting to this as a requirement (Barbour, 2001).

Strauss and Corbin (1998) remind us, however, that "Every mode of discovery develops its own standards and procedures for achieving them" (p. 266). It follows that any method or procedure implied by a quality criterion should be used only if it is congruent with the objectives of one's chosen research approach. Indeed, there is no inherent standard, justification, or recommendation for the use of member checking to be found in the primary grounded theory methods texts (Charmaz, 2006; Glaser & Strauss, 1967; Glaser, 1978; Strauss & Corbin, 1990, 1998). This is because the procedure arose independently outside of grounded theory, having been developed in the literature outlining generic methods for qualitative research. Glaser (2004) argues that imposing techniques such as member checking used to promote trustworthiness

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within naturalistic inquiry (Lincoln & Guba, 1985)—a distinct methodology from grounded theory—is inappropriate because it "remodels" and corrupts grounded theory.

More recently, member checking has also been challenged within the evolving generic methods literature for the claim that it is a valid means either to verify the fidelity of findings (for example, Morse, 1994; Sandelowski, 1993) or to indicate the fundamental quality of a study (Cohen & Crabtree, 2008). This is not to say that the practice does not still have other potential value. But prior to employing it in grounded theory, one should establish its relevance by asking whether and how it can be used to support the original objectives of the method.

Beyond its traditional use for verifying the fidelity of interview transcripts and researcher interpretations in participants' eyes, member checks have since been reconceived as a means to refine interpretations and even generate new data to corroborate and further develop interpretations (Barbour, 2001; Sandelowski, 1993). As Charmaz (2006) notes, this revised purpose is consistent with the goals of grounded theory by providing the opportunity to gather new material to elaborate existing categories—in other words, theoretical sampling. She goes on to reference two researchers who described their technique of explaining one or more major categories to participants previously interviewed, gauging their reactions regarding the categories' fittingness, and if there was congruence with the participant's experience proceeding with discussion aimed at generating new properties of those categories (p. 111). As Corbin and Strauss (2008) note, however, this late-stage application of theoretical sampling for "filling in categories" is not restricted to consulting previous participants, but may be accomplished by consulting new individuals or even other types of data sources (p. 155). Thus, member checking can be envisioned as taking distinctly more flexible, fluid forms within grounded theory.

Finally, member checking in the service of late-stage theoretical sampling is also consistent with a methodological implication of symbolic interactionism—to maintain connections between interpretations and the empirical social world as the researcher reaches higher levels of abstraction (Blumer, 1969). Thus, the goal of member checking would be to reinforce the links between researcher interpretations and empirically observable experiences—something achievable in either follow-up or initial interviews.

Choosing the member checking approach

The research proposal specified that member checking would be carried out in the current study by returning a brief summary to participants for comment. This strategy, and several other common conceptions of member checking, discussed below, were discarded in favor of a strategy more consistent with grounded theory according to the ideas presented above.

The main problem with the idea of returning a brief summary of the research findings to participants relates to the fact that brief summaries of interpretive research such as grounded theory studies are necessarily abstract and highly conceptual. While participants are arguably qualified to comment on their own specific data contained in transcripts, a problem has been identified in the literature with exposing participants to broader researcher interpretations or abstractions. That is, there is potential for discrepancy between the individual's particular experience and the researcher's overview that was derived from multiple experiences (Barbour, 2001; Koch & Harrington, 1998; Mays & Pope, 2000). In the case of the current study, a two-page summary explaining the vastly complex and variable process of how parents make their own way to intervention would be so condensed and abstract that it's presentation to individual participants in the context of a 30-minute member checking interview was considered to have limited potential for stimulating meaningful feedback. Since it was not anticipated to be useful,

proceeding with this exercise as conceived in the research proposal would be an unethical use of participant or researcher resources. Therefore alternative forms of member checking were considered and discarded before adopting the strategy that was most congruent with grounded theory and needs of the study.

First, member checking in the form of returning transcripts to participants for verification was ruled out early on for several reasons. Not only is the practice not congruent with the goals of grounded theory as described above, but there are several ethical risks. Returning transcripts has been reported to sometimes elicit feelings of embarrassment among participants, threatening their sense of dignity, endangering the participant-researcher relationship, and reducing satisfaction with the research process sometimes to the point where a participant chooses to withdraw from the study (Carlson, 2010). Similar undesirable outcomes were reported when returning de-identified participant quotes in the context of an oral presentation to an audience that included a participant who reacted quite negatively to the experience (Goldblatt et al., 2011). Moreover, reviewing long transcripts—25-45 single-spaced pages in the current study— represents a substantial burden to impose on participants (Barbour, 2001), and utility of this exercise has been questioned (Koch & Harrington, 1998).

In the study's proposal and consent information I had specified 30 minutes for the final member checking interview to reduce burden on participants and encourage greater participation. In addition to congruence with grounded theory, several questions were considered: What material should be shared with participants, and how could this be presented in a time-saving way? What feedback should be requested that would be of maximum value to the study? How much time should be dedicated to arranging member checking interviews (considering primary interviews with some parents took months to negotiate)? Who should be selected for such

interviews considering some parents seemed more enthusiastic and reflective from their primary interviews? And finally, how, besides providing an honorarium, could the member checking exercise be designed to provide participants with an empowering sense of contributing to and shaping the research—considering numerous parents commented at the close of their primary interview that they had enjoyed having their voice heard and were happy that their contributions might have use to improve conditions for other parents like them? Ultimately, the idea of returning a summary for feedback was discarded in favor of the approach described next.

Checking categories in later-stage primary interviews

As discussed, member checking is congruent with grounded theory when done in the service of theoretical sampling by presenting important categories to participants for their feedback in hopes of developing further properties. After it became apparent through ongoing analysis what some of the important categories would be, opportunities for checking them naturally arose in the remaining primary interviews, both with parents and with professionals.

In interviews with parents that occurred later in the study I briefly described categories as a prelude to some questions, inviting them to provide comments that might stimulate further ideas about their properties. In some cases, parents went beyond their own experience to comment on what they had observed with other parents (similarly to professionals, as described below, although their perspectives and interactions were more limited). The most valuable insights, however, came from reports of direct experiences. Since not every category was relevant to every parent, I would not describe or probe into an abstract concept unless it was apparent from the parent's unfolding story that a particular category was relevant to her experience.

Interviews with professionals were started late in the study after the majority of parents were interviewed and the important categories had been identified. With all eight professionals,

many questions were at an abstract conceptual level, and much time consisted of getting more information on categories already established. These interviews were consistently enjoyable for interviewees, both because they involved conceptual discussions that each party had a strong interest in, and because the topics discussed resonated so deeply with professionals.

These interviews went far beyond checking concepts for their relevance, to analytically developing them. Professionals were ideally positioned to comment on researcher-constructed overviews derived from multiple cases precisely because their own knowledge consisted of experiences with many parents they had interacted with over their careers—overcoming the problem of relying on "individual experience" when member checking (Barbour, 2001; Koch & Harrington, 1998; Mays & Pope, 2000). Thus professionals could draw on many cases to illustrate the conceptual variability and relationships between concepts. Because these interviews were such a productive and efficient way to confirm and develop categories, they represented the most worthwhile and valuable form of member checking in the study.

Appendix H. Analysis of context: Evolution & translation of autism research knowledge

Case of the DSM

It has only been since 1943, with Leo Kanner's pioneering use of the term in his famous case series (Kanner, 1943), that *autism* has been understood to refer to the characteristic neurodevelopmental disorder that we know of today. It was only after a lag of 37 years, however, that this idea of autism was translated into an official diagnostic category by psychiatry's most authoritative resource for classifying mental disorders, the DSM, first appearing in its third edition, DSM-III (American Psychiatric Association, 1980). In previous editions (DSM-I, 1952; DSM-II, 1968), the less specific classification of *childhood-type of schizophrenia* was the principal category that would have captured children who later would qualify as having autism.

The fact that it took three editions for the term *autism* to be incorporated into the DSM reflects how the path research knowledge takes before it influences practice can sometimes be long and tortuous. (Detailed consideration of *how* the process of translating autism research knowledge occurs is outside the focus of this study, although some aspects will be described.) Kanner's usage of *autism* would have been translated via other modes that had lesser influence, prior to DSM-III. Considering how influential the DSM is on contextual aspects that influence parents' experience (including on the practices of diagnostic professionals, or the criteria for accessing services), it represents a particularly relevant mode of knowledge translation to consider.

Reflecting the rapid expansion of research in this relatively new field, the autism designation evolved rapidly within the DSM. Subsequent editions provided more specific and observable diagnostic criteria and definitions became progressively less restrictive (DSM-III-R [revised], 1987; DSM-IV, 1994; DSM-IV-TR [text revision], 2000). Participant interviews for

this study were conducted during the period of transition from DSM-IV-TR to the next edition, DSM 5 (2013), but prior to its publication. This period featured drafting of revisions to the autism diagnosis that had wide-ranging influence on participating parents' worlds. Just like adoption of Kanner's term autism, the research that these changes were based on started to have influence in numerous ways prior to its translation into DSM form. To illustrate how the structural processes of constant evolution and translation of autism research knowledge contribute to the complexity of parents' worlds, I briefly review what the changes since DSM-IV-TR were and what the DSM-5 revision process looked like. I then refer to participant data to show how the evolving research knowledge at this point in autism history influenced professional practice and parents' language, conceptions, and ability to understand autism within the study.

Of the numerous important changes to the concept of autism that have been translated (at least partially) with the transition from DSM-IV-TR to DSM-5, I will review only one: the replacement of categories or subtypes of the disorder with the concept of an autism continuum consisting of a single category. Historically, the DSM had specified multiple types of autism: DSM-III featured three categories, DSM-III-R featured two categories, while DSM-IV and DSM-IV-TR featured five categories under the umbrella of pervasive developmental disorders. Only three of the latter five categories were considered true forms of autism, however, and are of significance in the current study: autistic disorder (or classic autism), pervasive developmental disorder not otherwise specified (or PDD-NOS), and Asperger's syndrome. In DSM-5, these three categories were merged into a single designation, *autism spectrum disorder* (ASD), reflecting scientific consensus that the previous categories were arbitrarily applied and that the empirical evidence better fits with a conception of autism existing on a continuum. Within this

new unified diagnosis, individuals are further specified according to severity as "requiring very substantial support", "requiring substantial support" or "requiring support."

Tracing DSM-5 influences in the data

Only two parent participants explicitly mentioned the DSM in their interviews. It is nonetheless possible to trace some less concrete ways in which the DSM-IV-TR and the research knowledge generated in the subsequent transition period likely influenced parents' understandings and their physicians' practices. At the time of planning the study, "autism spectrum disorder" (language later to be incorporated in DSM-5, but absent from DSM-IV-TR) was widely understood to encompass all three categories of autism, and so I even chose to use this familiar language in recruitment materials for this study. In interviews, most parents demonstrated they understood autism according to both the three-category scheme and the continuum scheme. Thus, more current research knowledge—not yet incorporated into the DSM edition of the time, but rather translated via other modes—had influenced both professional practice and downstream parent knowledge. For example, several parents whose child had Asperger's understood this diagnosis to be the same thing as high-functioning autism. In some cases, the categorical scheme led to confusion for parents. One parent was told her son had PDD-NOS, but she did not understand this to be a form of autism until months afterwards through her own research. Another parent had difficulty understanding the reasons for distinctions between categories after professionals changed her son's diagnosis from autistic disorder to PDD-NOS.

For some parents, the existence of a newer but incompletely translated scheme for diagnosis alongside the older scheme was a source of confusion. The variability with which different parents understood autism according to either of these two schemes reflected the variability with which the newer scheme was being translated to the professionals who generally

served as parents' most foundational information sources. New knowledge about autism diagnosis was also disseminated to some parents with variable consistency through agency newsletters, blogs, email groups, and direct interactions with other parents. Some diagnosing professionals seemed to be working from different iterations of the DSM naming conventions when recording or communicating their diagnoses. Underlying this variability are multiple modes of translation besides the DSM (for example, personal development activities and other forms of training, or publications) functioning independently and with differing reach and influence on professionals in their unique contexts. The variability in language for referring to autism sometimes left parents with unclear understandings when unfamiliar vocabulary was encountered.

Interactive nature of producing and translating research knowledge

The production and translation of autism research knowledge is a two-way interactive process, one where parents (individually and collectively) affect the work of researchers and developers of knowledge products, in this case the DSM. The revision process of DSM-5 (American Psychiatric Association, 2013) was described in its Introduction as a "massive undertaking that involved hundreds of people" (p. 5) and spanned 12 years. Planning involved 13 international conferences of scientific experts to plan the research phase and review the world literature from diverse areas such as cognitive neuroscience, brain imaging, epidemiology, and genetics. The corresponding 13 work groups (consisting of over 130 members and over 400 advisors) then developed proposals for revising diagnostic criteria. These criteria were then field-tested in different settings to demonstrate reliability and usefulness. In the three years leading up to publication in 2013, draft criteria were subjected to public review from both professionals and consumers via the DSM web site—the first time for a DSM revision process to include a public

review phase. In total, feedback was solicited over three rounds of drafts, generating over 13,000 web responses and numerous organized petitions. It is via this review phase that the DSM task force allowed consumer advocates such as parents of children with autism to have their concerns considered and possibly incorporated, and thereby have a direct and concrete influence on the DSM-5 product.

At the 2012 International Meeting on Autism Research, I witnessed parents engage in the process of interacting with and influencing the translation process—if only to a small extent. In a highly attended session, titled "An update on the DSM-5 recommendations for autism spectrum disorder and other neurodevelopmental disorders," Dr. Susan Swedo, chair of the Neurodevelopmental Workgroup responsible for revisions to the autism diagnosis, gave a passionate defense and clarification of what was by that point the final version to be published. As an indication of how controversial and consequential this entry in DSM-5 was, she reported that the committee had by that point received over 6,000 comments solely about the decision to merge the prior categories into a single diagnosis. One of the conceivable implications of this revision was that fewer people would qualify for the diagnosis, leaving some children ineligible for funded autism therapy. One of the main thrusts of Dr. Swedo's presentation was to reassure people that based on field testing data this reduction in diagnoses would not be the case. During the question period, it became apparent that the audience for this talk was filled with a high proportion of advocates—mostly parents—because Dr. Swedo was pressed with some of their questions. Just as these questions helped her clarify a few points in defense of the DSM-5 in the session, she reported how the feedback received during late stages of the revision process described above (including from parents) had helped the committee add important clarifications that would logically reduce the likelihood of people being unfairly excluded by the new criteria.

A notable characteristic of the interactive nature of the process of translating knowledge into the DSM revision is the extent to which parents are in a position of power by having influence over the defining process. In the case of the DSM, their involvement was apparently controlled by the small group of researchers who designed the revision process. But questions can be asked how this group came to allow for this bidirectional interaction by adding a public review phase. To what extent did it involve researchers' awareness of the controversial nature of diagnoses such as autism, and the need to preemptively demonstrate a proactive responsiveness to consumers' concerns? Were researchers motivated by a sense of moral obligation considering the contemporary standards to include stakeholders' voices through practices such as integrated knowledge translation or participatory action research? Both these thoughts suggest potential ways that consumers may have had background power (traceable to deeper or less obvious structural conditions, such as popular discourses about ethical conduct of research); this power gave them indirect influence that led to the inclusion of a process allowing two-way interaction, while the foreground power (resulting from more explicit structural conditions) resided with the researchers. The idea of where power lies is relevant when we consider other relevant examples where parents feel a stake in influencing research knowledge production and translation. For example, the influence that parents have had on the research agenda as a result of the controversial notion that vaccines cause autism is a case where parent advocates (and others fomenting the debate) had more foreground power because they were the drivers of the process of having their concerns heard (Offit, 2008). The influence of parent calls for obtaining diagnosis at earlier ages is another example. And later, we will see how some parents struggle to have their voices heard in striving to influence other structures besides research that define their situational context, such as laws and policies.

Research knowledge production can thus be seen as a macro condition in parents' common situation that affects their understandings and subsequent action via an intervening process of knowledge translation. This process directly impacts both the professionals that parents then interact with, and the information sources that parents ravenously consume. On the other hand, research production can be viewed as a partial product of parent action whenever parents 1) participate in research (which many parents consider a form of advocacy), or 2) advocate in ways that influence the research agenda. This bidirectional relationship between parents of children with autism and research production is almost a cultural one—consuming research knowledge and advocating are more integral to parents' identity than for most other health conditions. For example, some parents I interviewed reported having participated in numerous studies, describing it almost as a personal policy and duty they felt. A majority described participating in my study as a form of advocacy where they were motivated to contribute to something that might possibly reduce some of the struggles that they had to endure for other newer parents in the same situation. In addition, parents referred to explicit knowledge and benefits (often privileged access to intervention or services) that they took away personally as a result of participating in research.

Summary

The case of the DSM illustrates several features of the complexity of autism knowledge (in addition to aspects such as the volume of information, discussed above). First, its complexity is partly due to the relative newness of autism as a field, and to constant and rapid evolution of new research knowledge. The effects of this evolution process are mediated by the process of translating new knowledge into changes in practice and understanding, something that occurs via multiple modes (information products) each with variable uptake—both in terms of lag times and reach. Second, there is also variability in when and where outdated knowledge is retained. As a

consequence, parents develop inconsistent, unclear, or incomplete understandings of autism, especially in the early stages of learning about the disorder after discovering it in their child. Parents usually meet these challenges, as will be described, by putting extensive work into building clearer and more comprehensive understandings of autism. Third, some parent advocates also feed back on the processes of evolution and translation of research knowledge to partly shape the new information disseminated. Finally, because the processes of evolution and translation of research knowledge are influenced by structural conditions that are sometimes hidden, their effects on parents can be difficult to trace.

Of course, there are many other modes or information products, besides the DSM, that translate autism knowledge and ultimately influence parents' understandings. In most cases, the characteristics of complexity described here apply to those modes as well. It is possible to question how any information source contributes to complexity by considering the quality and currency of the research knowledge on which its content is based, the timeliness of its production compared to alternative sources of comparable but not necessarily current information, the extent of its reach and influence on professional practice and parent understanding, and conflicts with other information or understandings a parent may have. This discussion of complexity also applies to information about autism intervention (i.e., not just about the disorder), although additional issues arise there because information about intervention is used more instrumentally to inform parents' action (see Section 4.2, *Intervention*).

Appendix I. Analysis of context: Credibility of information about intervention

The most important reason for complexity of intervention-related information is the fact that much of it is not based on traditional research evidence, which has resulted in varying perceptions of its credibility. Traditional research evidence is defined here as evidence derived from studies of an intervention's direct effects on final outcomes, irrespective of the mechanism of action. Other forms of evidence are referred to below as nontraditional evidence.

The existence of intervention-related information that is both supported and unsupported by traditional research evidence has several implications for parents' interactions with such information. Before elaborating on these implications, it is useful to differentiate three basic forms of intervention-related information that are unsupported by traditional research evidence, at least in parents' experience. The third of these forms leads to a discussion of an influential element in the situational context of autism—the biomedical movement—that especially contributes to the complexity of parents' interactions with information.

The first form of intervention-related information unsupported by research evidence comprises any information for which research evidence is unnecessary or irrelevant. This includes any information, besides claims about an intervention's effectiveness or harm, which would help the parent navigate or pursue an intervention—for example, names and phone numbers of providers of the intervention being sought, the waitlist duration to expect, or what strategies to use in negotiating effectively with a child's school.

The second form consists of any information stating simply that the effectiveness or harm of an intervention is not known, sometimes with the explanation that adequate research evidence is not available. Parents may consult their professional about music therapy, or look up several forms of biomedical therapy on an evidence-based web site and get this inconclusive answer.

There are many autism interventions whose effects are described as unknown or uncertain, reflecting that fact conclusive and reliable research evidence about effectiveness is more difficult to generate in the case of autism compared to most other health conditions. This is partly due to the high variability among individuals with autism both in their deficits and in their responsiveness to intervention. Studying intervention effects is also made difficult by the complexity of many treatments such as multi-component behavioral interventions, and by the number and difficulty of measuring different relevant outcomes. This makes it difficult for the producers of research evidence, mainstream scientists, to answer the most useful questions, such as what interventions work best in what types of people with autism. Thus, while some under-researched interventions may well be effective and safe, there is no reliable evidence to say so. Much of the information available from what many parents consider mainstream sources (e.g., government-funded and reputable web sites, traditional medicine practitioners) therefore describe the effects of many interventions as uncertain, to the frustration of parents who need a conclusive answer. Interestingly, several parents interviewed for the study indicated they had some appreciation for the difficulty in generating traditional research evidence about the autism interventions they seek.

The third form of information unsupported by traditional research evidence includes any information about effectiveness that is either not supported by any research evidence, contradicts traditional research evidence, or is supported by nontraditional evidence. Nontraditional evidence, in turn, can take at least two forms. One form consists of research findings about the individual components of a mechanism of action, or indirect effects, which are linked together using logic to provide a theory or argument for the effects of an intervention. A second form of nontraditional evidence includes claims about effects that are based on repeated or expert

experience. Briefly (without extensively justifying why), my position is that both these forms of nontraditional evidence have merit, especially in cases like autism where traditional research evidence is lacking and difficult to generate; but, similar to traditional research evidence, these alternative forms of evidence are susceptible to flaws that make them less valid (for example, when the logic used to link together multiple components of a mechanism of action is identifiably weak). As will be described, an important producer of nontraditional evidence, particularly mechanism-of-action arguments, is the biomedical movement. The credibility of information associated with this movement, however, came to be perceived unfavorably.

Case of the biomedical movement

Parents' perceptions and interactions with information about autism intervention are invariably influenced by discourses about credibility. To provide contextual understanding of ideas about credibility, the paragraphs below make some of these discourses explicit by discussing their origins. Subsequent paragraphs then describe how these discourses play out in the Ontario context in terms of how parents in this study defined their own positions about what is credible information regarding intervention.

Many of the actors that parents encounter in the world of autism—including many researchers, professionals, and indeed approximately one quarter of the Ontario parents I interviewed—tend to favor traditional research evidence and often also hold critical opinions of information that promotes nontraditional evidence about interventions, perceiving it to be fundamentally biased. Their views derive, at least partly, from two dependent conditions or realities of the autism world in which parents are situated. The first is what some participants described as their own, and many parents', *vulnerability* to misinformation during the most desperate stage of their journey pursuing intervention—a stage when they were eager to try

anything. The second condition, dependent on the first, is a discourse about the biomedical movement that portrays the actions of some of its most influential actors (clinicians, independently-funded researchers, politicians, celebrities) as unethical because they appeared to take advantage of parents' desperation and vulnerability. At the source of this discourse are reports about the relevant events that have appeared in numerous news reports, television documentaries, and other popular media; many of which have also been summarized in the 2008 book by Paul Offit, *Autism's False Prophets*. This discourse is also promoted by the dominant or mainstream scientific community, whose traditional standards for evidence differ from those of the biomedical movement.

Offit's book describes a battle between biomedical movement and other actors within autism situation (researchers, journalists, politicians) who promote a traditional evidence-based view of science. In the following paragraphs I summarize the relevant aspects of the opposing sides: first by introducing aspects of the evidence-based medicine (EBM) movement whose evidence standards represent the basis for defining what is valid traditional research evidence, and second by describing the biomedical movement itself. Next, I outline how this conflict has contributed to a discourse underlying unfavorable perceptions of nontraditional evidence.

Standards of the evidence-based medicine (EBM) movement. The EBM movement aims to popularize (e.g., through systematic education of clinicians) an approach to healthcare decision making that explicitly incorporates what EBM practitioners determine to be the "best available" research evidence. The movement is characterized primarily by its position on the standards for valid research evidence, and to a lesser extent by its position on appropriate targets

for intervention. For purposes of the theory, *traditional research evidence* is that which adheres to widely accepted standards, such as those established by the EBM movement.[17]

Originators of the EBM movement (self-described research *methodologists*) described their initial position in 1992, which "de-emphasizes intuition, unsystematic clinical experience, and pathophysiologic rationale as sufficient grounds for clinical decision making" (Guyatt, 1992). This position has been qualified and revised several times since to recognize the need to balance the role of evidence in decision making with other considerations, including the professional's clinical expertise in assessing the problem (which produces the types of information that have always been used in clinical decision making) and information about patient preferences (Haynes et al., 2002). Nevertheless, EBM is still best know for the clear rules it has developed for judging research evidence as more or less reliable and valid. These rules, for example, prioritize evidence from systematic reviews and randomized controlled trials as more valid than evidence from other research designs. Other forms of evidence from lesser (but still rigorous) research designs are designated as "low" or "very low" quality (Schunemann, 2006). By extension, some forms of evidence are dismissed altogether as unworthy of informing medical decisions. The information that is produced or used by adherents to these high standards therefore goes uninformed by vast expanses of research evidence. As a result, for many questions about intervention effects, EBM-faithful producers of information will claim, simply, that the answer is not known (just as many systematic reviews published by the Cochrane Collaboration on which they are based conclude there to be insufficient evidence). Many of those who opposed the biomedical movement

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[17] Even though many researchers in the field of autism are probably more familiar with the distinct set of evidence standards of the American Association, I chose to illustrate EBM evidence standards (as the basis for defining what qualifies as valid *traditional research evidence*) because they have influenced intervention research more broadly across fields and have codified the rules for evidence most comprehensively and rigorously.

described in Offit's book would have held such standards for the validity of evidence, and used them to devalue the credibility of biomedical claims.

Biomedical movement. The biomedical movement is a loose association of individuals and organizations that promote a unique view of autism and how to respond to it. Its philosophical positions can be characterized in several ways, but here I describe only its position regarding what is the appropriate target of intervention and its position on nontraditional evidence because these have implications for the credibility of information. The biomedical position on the nature and acceptability of autism is addressed in Section 4.3 (see *Coming to understand autism*).

The term *biomedical* has a unique connotation in the arena of autism, but one which is elusive because it has not been explicitly defined by an authoritative source (as far as I am aware after consulting various sources of biomedical information including books and the Internet). Moreover, its meaning is evolving as the biomedical movement continues to refine itself (described further below). Because it is useful for understanding the position of the biomedical movement on intervention-related information, I next develop an explicit definition for the term *biomedical* in the sense that the biomedical movement has traditionally used it to describe intervention and research evidence.

The term *biomedical* refers not just to the biomedical movement or its philosophy. A quote from Robert Sears' influential and popular biomedical guidebook for parents, *The Autism Book* (2010), implies that *biomedical interventions* are treatments that target hypothesized causes of autism (p. xiii):

> *"A number of medical, nutritional, and vitamin-based treatments have been shown to not only improve symptoms but also address some of the possible underlying medical and biological causes of autism. Together, these treatments are called the biomedical approach…there are a number of medical, nutritional, allergic, and infectious conditions that can also [in addition to 'genetic susceptibility and environmental toxic exposure'] contribute to autism."*

Sears later describes the biomedical approach to developing research evidence about biomedical treatments (p. 60):

> *"It focuses more on active trial and error. It theorizes about the causes and jumps right into treatment. It starts with small test groups, then expands when something shows promise. Because it almost always involves natural treatments, the error part of this trial-and-error approach is simply that the treatment doesn't work, not that it causes any harm. The proof that something works is achieved more by consensus and not by traditional scientific method, although the majority of the biomedical theories have now been validated in the traditional medical literature [consisting, in the references provided, of animal studies and clinical studies with designs much weaker than clinical trials]. The benefit is that it offers children hope now. The drawback is that time and money may be spent on something that ultimately doesn't help some kids."*

Indeed, the book goes on to describe research evidence focused predominantly on autism's proposed pathophysiology and the theoretical mechanism-of-action of interventions, which is used to make deductive arguments about their effects; and while direct effects are sometimes studied empirically, it is generally with weak research designs. Sears' portrayal of biomedical interventions and research evidence is generally consistent with that of other authorities within the biomedical movement.

Sears' and others' use of the term *biomedical* also has similarities to its use outside the arena of autism (at least to describe intervention and research). For example, *biomedical* is one of four major themes of research funded by the Canadian Institutes for Health Research, which defines it as follows (2014):

> *"Research with the goal of understanding normal and abnormal human functioning, at the molecular, cellular, organ system and whole body levels, including development of tools and techniques to be applied for this purpose; developing new therapies or devices that improve health or the quality of life of individuals, up to the point where they are tested on human subjects. Studies on human subjects that do not have a diagnostic or therapeutic orientation."*

Importantly, this definition distinguishes biomedical research involving interventions (which stop short of testing effects in humans) from clinical research of intervention effects (which by definition is conducted in humans). Consistent with this, many sources promoting biomedical

treatments within the autism arena frequently reference *in vivo*, or animal, studies as evidence to support their arguments about an intervention's mechanism of action and by extension its effects.

Yet another form of evidence that Sears (2010) and many biomedical proponents sometimes use to support claims of intervention effects is expert experience: "I've seen biomedical treatments work over and over again [in my ten years of treating autism as a pediatrician and biomedical practitioner]" (p. xv).

In the absence of an explicit definition of *biomedical intervention* within the autism arena, for purposes of further discussion I will define it, consistently with the meanings implied by the movement, as follows: a category of autism treatments that target hypothesized causes of autism, whose mechanisms of action and effects are supported predominantly by preclinical research evidence; while research evidence of effects in people with autism is also sometimes available, this generally does not come from the rigorous study designs used in mainstream clinical research; reported expert experience is also used as evidence to support claims of effect.

The biomedical-EBM conflict and perceptions of credibility. The biomedical movement portrays itself as in conflict with the "mainstream medical approach" (Sears, 2010, p. 59), often describing it in conspiratorial terms. For example, Sears (2010) portrays mainstream medicine as aware of various theories and data supporting a biomedical approach, but these "are kept restricted and not made available to the public" (p. 60). Indeed, making conspiratorial claims is the main strategy for attacking the credibility of mainstream science used by many pro-biomedical actors (individuals, media sources, and organizations)—such as the discredited researcher Andrew Wakefield, the magazine *The Autism File*, or Jenny McCarthy's organization *Generation Rescue*. Many of these actors are located in the United States. Their attacks on the credibility of mainstream science did not appear to have influenced the perceptions of the

Ontario parents interviewed for this study, even those who were pro-biomedical (see Appendix C, *Reflexivity*, for my approach to promoting openness and trust when discussing biomedical content).

The history of the conflict between the biomedical movement and mainstream science is portrayed extensively in the book *Autism's False Prophets* (Offit, 2008), although this is from the perspective of mainstream science—consider that the author, Paul Offit, is a successful researcher who developed the rotavirus vaccine. This history illustrates why those who favor mainstream science hold such strong perceptions about the lack of credibility of the biomedical movement. The main reason is the apparent conflict of interest of biomedical proponents (clinicians, independently-funded researchers, politicians, celebrities) who have produced and promoted the information on which biomedical claims are based. Their actions are portrayed as taking advantage of the desperation of parents of children with autism, generally for personal gain.

There are numerous well-known battles involving actors from the biomedical movement. The most famous is the story of Andrew Wakefield, who in 1998 published a case series (a very weak study design) of 12 children suggesting that the measles component of the MMR vaccine caused autism—although his argument was indirect with several logical flaws. The study was revealed to be fraudulent and seriously ethically flawed (Deer, 2011). The publishing journal since retracted the article (Editors of Lancet, 2010), and Wakefield was stripped of his medical license (Godlee et al., 2011). Still, Wakefield was successful enough in originally promoting the study's findings that it had enormous influence, reducing measles-mumps-and-rubella (MMR) vaccination rates worldwide and diverting substantial resources towards research that ultimately disproved the relationship between vaccination and autism. Mainstream science proponents have

portrayed Wakefield as exploiting parents' vulnerability to such an argument (because the timing

of MMR vaccination coincides with the onset of autism) for personal financial gain (he was

involved in an egregious conflict of interest) and his desire for prestige and fame. The

biomedical movement including Wakefield himself, meanwhile, has portrayed him as a scientific

maverick whom mainstream medicine wants to silence, and an iconic hero fighting for the truth

and for parents (for example, Long, 2009).

The Wakefield story and numerous others[18] illustrate two realities, as constructed by the

pro-mainstream–science discourse, which undermine (whether deservingly or not) the credibility

of the biomedical movement. The first is the moral corruption of actors in the biomedical

movement who have taken advantage of parents' vulnerability to misinformation. The second is

the flawed nature of the evidence that these actors have used to support their claims, evidence

whose flaws stem more from defective logic, rather than the fact that it makes use of

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[18] Numerous other examples are described in *Autism's False Prophets*. I summarize two of them for illustration: 1) A description of how pharmaceutical companies and unscrupulous physicians profited financially by selling or administering secretin, whose effectiveness for improving autism symptoms was supported only by anecdote, to fill the high demand from parents who had heard it heralded in various media as a new breakthrough treatment. 2) A description of the researchers Mark and David Geier, whom Offit (2008) considered "the very centerpiece of the movement" (p. 134). This father-son team published several studies suggesting that thimerosal (a mercury-containing preservative in some vaccines) caused autism, and that affected children could have their mercury removed by means of chelation therapy and treatment with Lupron to suppress their testosterone production. They conducted this research despite deriving income from serving as expert witnesses on behalf of plaintiffs suing vaccine manufacturers, testifying in more than 90 trials (i.e., they appeared to manipulate the scientific record to support their litigation interests, putting themselves in a position of conflict of interest). Moreover, their Lupron study was seriously ethically flawed—for example, the institutional review board required to approve it was formed after study had started, and consisted of anti-vaccine activists and family members; moreover, they had filed a patent application with TAP Pharmaceuticals for an autism indication for Lupron. The methodology (and credibility) of publications were discredited by a review in the journal *Pediatrics* that compared the quality of their research to four much higher-quality studies refuting the thimerosal theory, and concluded that the Geiers' work was "of poor quality and cannot be interpreted" (Parker et al., 2004, p. 793).

nontraditional evidence (based on mechanism-of-action arguments or expert experience). Whether deservingly or not, therefore, this discourse has discredited biomedical interventions and pro-biomedical information in the eyes of many within the autism arena.

Mixed messages about credibility of biomedical information and intervention. An important distinction should be made: while the damaged credibility of the biomedical movement is due to a perception of moral dishonesty and defective logic that some of its proponents use to make claims about interventions, it is not due to a reliance on nontraditional evidence per se (i.e., evidence based on mechanism-of-action arguments or expert experience). There are numerous conceivable situations where nontraditional evidence is accepted as credible. For example, some forms of qualitative research aim to develop theory explaining how (i.e., using mechanism-of-action–like arguments) a complex intervention (involving behavioral processes or multi-level changes) works. Such evidence is treated as more reliable if it is developed rigorously and based on strong logic. Also, clinicians and patients often rely on professional opinions based on expert experience as a personal and less transparent form of evidence (not yet formalized through research) to guide what course of action to follow in addressing health concerns. Such opinions are more trustworthy if the expert has no conflicts of interest besides the patient's wellbeing. In other words, even nontraditional forms of evidence have at least some standards for credibility. Importantly, some from the EBM side view traditional research evidence (i.e., based on quantitative EBM standards) and nontraditional evidence (provided it meets certain standards) to be compatible and complementary (for example, Green & Britten, 1998; Sackett & Wennberg, 1997).

This distinction is relevant because it helps explain a recent trend in which some autism researchers identifiable as being on the side of mainstream science have come to see value in

evaluating some biomedical interventions further according to EBM standards. For these researchers, the biomedical movement has thus become a kind of a pipeline or source of preclinical ideas worthy to be developed through formal clinical research (for example, Anagnostou & Hansen, 2011; Bent et al., 2014). These ideas include biological treatments with minimal potential for harm such as melatonin and omega-3 fatty acids. This trend manifested itself in this study by the numerous Southern Ontario participants who reported participating in clinical trials run by the Autism Treatment Network (ATN).

The ATN is a branch of Autism Speaks, a large well-funded science and advocacy organization based in the United States (although the ATN has two sites in Canada) that was founded in 2005 by individuals who had a pro-biomedical mandate. The organization's position on biomedical interventions has become more subtle and nuanced over the years. The Toronto ATN site includes physicians and researchers at Holland Bloorview Kids Rehabilitation Hospital and Sick Kids Hospital. The researchers at these respected institutions favor EBM standards, and the trials that participants described participating in (mostly involving omega-3 fatty acids) appeared to be blinded randomized controlled trials (i.e., of high quality by EBM standards).

Both the trend within science of evaluating biomedical interventions according to EBM standards, and the interactions of parents in the autism community with respected mainstream researchers have resulted in shifting perceptions of what the biomedical movement is. ATN researchers who refer to the supplements and dietary treatments using the word *biomedical* while at the same time generating traditional research evidence regarding their effects, ultimately shift and blur the meaning of the term. (Recall how the original definition for *biomedical* proposed above excluded evidence "from the rigorous study designs used in mainstream clinical research.") These researchers are contributing to a new discourse that for the first time defines

biomedical interventions and research evidence as credible according to the same ethical and evidentiary standards that were used to discredit it. This new discourse is problematic, however, because it is inconsistent with the earlier history of the biomedical movement as portrayed in Offit's book (2008). It ultimately sends mixed messages that provide no direction to the parent regarding how to handle the legacy of potentially harmful treatments such as chelation therapy (which some participating parents still described being offered by Defeat Autism Now, or DAN, doctors) or the flawed and misleading information still highly available in books and on the Internet (about which numerous parents described their resentment). *Biomedical*, therefore, has evolved to have multiple inconsistent meanings.

Summary

The various conflicting contextual influences described above make the informational landscape that parents must navigate highly complex. This context influences Ontario parents' understandings and positions with respect to intervention-related information in sometimes nuanced ways (see Section 4.2, *Information, Ontario parents positions regarding intervention-related information*).

Understanding information use among parents of children with autism was one of the original motives for this study. This Appendix highlights some of the context underlying the complexity of intervention-related information and how this plays out in terms of Ontario parents' relationships with such information. While some of the detail regarding parents' positions on biomedical information may seem obvious to those in the autism arena, it is important to make them explicit to reveal their variability and subtlety.

Appendix J. Prominent forms of publicly-funded and private intervention in Ontario

Publicly-funded intervention

Ontario IBI and ABA. Ontario's public child-directed autism programs and services are funded by the Ministry of Children and Youth Services (MCYS). The two programs that parents are most aware of are the Autism Intervention Program (AIP), which provides Intensive Behavioral Intervention (IBI Program), and Applied Behavior Analysis (ABA)-based Services and Supports (ABA Services). The Ontario IBI Program provides the child with IBI therapy (a form of ABA that is intensive because it involves 20-40 hours per week of highly structured therapy targeting specific behaviors and promoting development) to appropriately diagnosed children who qualify. Qualifying generally involves waiting for and undergoing an assessment where the child must be found to be "towards the severe end" (Ontario Ministry of Children and Youth Services, 2006). Children who qualify after an assessment are then added to a IBI therapy waitlist, which can be both quite substantial and highly variable in length, ranging from slightly less than two years to four years depending on the regional service provider—this time range corresponds both to accounts provided by parents in this study, and to an investigative report of wait times for Ontario's nine regional service providers published online in 2012 by the Toronto Star (Gordon, 2012a). According to the latter report, as of June 2012 there were 1700 children on the waitlist compared to 1400 children receiving treatment. Once families reach the bottom of the waitlist, they can choose to receive therapy either directly from their regional service provider (the "direct service option") or from an approved therapy provider they identify and contract themselves (the "direct funding option," or DFO). With either model, the child is theoretically eligible to receive 20-40 hours of therapy per week, although parents in the study generally reported receiving 20-30 hours. Children are discharged from the IBI Program when,

according to ongoing semi-annual progress evaluations, they are no longer considered to be benefitting sufficiently—something that many parents see as an arbitrary decision. Discharge may happen after as little as one year of therapy.

The Ontario ABA Services program comprises a broader, but less intensive, range of services delivered to support the child and family. This program was rolled out in the summer of 2011 just before enrollment for this study began, and so some parents interviewed were among the first to experience the program. Qualifying is not a problem since the program is intended for anyone on the spectrum with a confirmed diagnosis. ABA Services throughout Ontario is intended to provide more focused support in four areas of focus: communication, social skills, daily living, and behavior management and emotional regulation. Based on parents' reports, the organization and form of available services varied depending on the region administering them. In some regions, parents received two-month-long blocks of weekly therapy sessions of two hours, with module-specific names such as "Social Skills 2" generally taking place at the host agency. Parents reported having to select and register for these ABA programs, experiencing waitlists of up to several months, and having to re-register to start each new block of therapy. Other regions apparently coordinated intake to the ABA program directly from the point of diagnostic assessment. Parents from these regions described receiving calls with suggestions to participate in programs consisting of one or a few sessions with a highly specific focus (e.g., toileting) before being invited to participate in sessions on a new topic relevant to their situation a few weeks later; sessions could take place at the host agency or at the family's home, and some parents reported follow-up telephone support.

Other funded programs and services that the MCYS participates in offering are accessed through other organizations that share in administration and funding: the School Support

Program (accessed through individual school boards within the Ministry of Education), and

Summer Camp funding (accessed through Autism Ontario), and several less critical programs

that parents interviewed for the study discussed less frequently (March Break camp funding,

respite funding, transition supports for adolescents with ASD; accessed through a variable

assortment of regional child developmental or other agencies).

Funded preschool services. Regions provide publicly-funded preschool speech and

language services to children up to age five. Unlike the autism programs described above, or the

school supports described below, a diagnosis of autism is not needed. Parents instead can self-

refer, although they often first connect through another point in the community such as an

Ontario Early Years Centre. Parents also commonly access occupational therapy and some

physiotherapy services, which are also publicly-funded at the preschool stage. After age five,

children become ineligible for preschool services, and subsequent funded speech and language or

occupational therapy services can only be accessed in school. There is much variability across

schools and school boards, however, in how therapy is provided. While some parents were

fortunate to have a speech and language pathologist (SLP) working face-to-face with their child

in the school, in most cases the SLP only visited the school rarely and only to consult with the

child's teacher and not to work with the child directly.

School supports and services. A number or supports and services exist within the school

system. The School Support Program, jointly run by the MCYS and Ministry of Education, is the

primary mechanism for providing children with autism with accommodations and resources,

within the constraints and limitations of school boards and schools. This Program provides

school boards with ASD consultants who travel between schools to provide educational and

consultation services to educators, participate in *team meetings* that bring together educators and

individual parents of a specific child (including identification, placement and review committee, or IPRC, meetings). In these meetings, ASD consultants provide recommendations regarding accommodations or resources that can be used to help a child with a diagnosis of autism. Parents described their experience of this program in the context of interactions with their child's school staff, especially through team meetings. Some parents described being aware that ASD consultants exist in their school board, but believed that their child's school never engaged their services to address the specific case of their child.

One of the more common supports that parents reported pursuing for their child was the help of an educational assistant (EA). Parents often perceived, however, that school-specific constraints or variation between school boards ultimately determined their availability. Although many parents are eager for their services, EAs are less educated than teachers and may not have expertise in autism. A small number of parents in some school boards reported their child being placed in a Section 23 class (named after the relevant section in the Ontario Education regulatory document *Grants for Student Needs*), a class intended for children with the most intensive needs that cannot be met in a regular classroom. While such a placement was often seen as a rare and hard-to-qualify-for privilege because it provided more access to effective ABA-based therapy, parents occasionally also saw disadvantages to their child being segregated with other low-functioning autistic children because of the lack of typically developing peers to learn from (if they felt their child was ready for that).

Funding. Parents described applying for funding from many sources including the Disability Tax Credit and other tax credits, Assistance for Children with Severe Disabilities (ASCD) and other assistance programs, Special Services at Home (SSAH) and other sources of respite funding, funding for summer and March Break day camp from various government

sources and charities (e.g., President's Choice Children's Charity), and so forth. Applications are often long and involved, and some families find out they are ineligible based on their income. In addition, even with funding, it is often up to parents to research and coordinate the support services available in their region for which the funding is intended, such as respite workers or seasonal camps (sometimes involving hiring a support worker).

Adult supports and services. Once the parent's child with autism turns 18 (s)he becomes ineligible for programs and services provided by the MCYS. Services received through school are discontinued in the year the child turns 21. A more restricted set of services for adult children 18 years and older are provided by the Ministry of Community and Social Services (MCSS). These include the Passport Program (which provides funding for various supports and services) and Residential Supports. Many of the individual services funded by the MCSS are provided by numerous community agencies, access to which is simplified by accessing a single portal, Developmental Services Ontario. Only one parent interviewed for this study who had an adult child with autism had experienced navigating adult services. She described her prospects for finding residence for her daughter in a group home as dismal due to decades-long waitlists in which spaces usually become available only after someone dies. Numerous parents still in the early stages of navigating autism described already thinking about the adult supports they would have to navigate in the future.

Private intervention

Private interventions can be divided into two main types: conventional behavioral and other therapies that involve the services of a therapist, and alternative or biomedical therapies. Of the two, conventional therapies are generally likely to cost more overall than biomedical

treatments. Both types can be considerably expensive, and are therefore inaccessible to some parents with less access to financial capital.

Private speech and occupational therapy. Private speech and language therapy was one of the more common forms of private intervention described by parents interviewed for the study, reflecting the prevalence and urgency of parents' concerns for the speech and communication of their child. Such therapy is expensive, often costing close to $200 per hour of individual therapy. One participant, a somewhat financially well-equipped mother, opted to begin private services rather than wait nine months for funded therapy for her newly diagnosed child. Another mother started weekly speech and language therapy for her son after he turned five and became ineligible for funded preschool services; she said she would continue paying for private therapy even after in-school speech and language services finally started because she felt the private option would address needs not covered in school. Still another parent opted to supplement the funded preschool speech and language therapy her son received with private therapy because she had an insurance plan that covered it.

Several things limited access to private speech services. The most obvious limitation is cost. As one low-income parent remarked, "it wasn't happening," after she researched and found out the hourly cost. Another parent lamented, "I wish I could afford one hour every day. But I can only afford one hour a week at this time because they're so expensive." Another limitation one parent reported was the prevalence of waitlists to see a private therapist in her area, sometimes six months long. Another parent reported difficulty in finding appropriate expertise to deal with the problem of apraxia, which affects the muscles used in speech for a certain proportion of individuals with autism.

Other private language-related options include technology to help with communication, such as the popular software Proloquo2Go, a Picture Exchange Communication System (PECS)-like voice app for iPads, which costs $220 and replaces much bulkier PECS binders that nonverbal children with autism might otherwise have to carry around.

Parents also turned to private occupational therapy for similar reasons parents turned to private speech and language therapy. A small number of parents reported their child receiving integrated or simultaneous speech and occupational therapy, which they found to be remarkably successful.

Private behavior therapy. Some participants describing seeking or implementing private behavior therapy, which could take three forms: hiring a professional ABA agency to deliver the therapy (either at the agency or in the home), receiving ABA in a private school setting, or setting up one's own in-home behavioral intervention program. This last option is by far the most labor-intensive for parents.

Seeking a professional ABA agency involved searching a list such as the Abacus web site maintained by Autism Ontario—just as parents who qualify for Ontario's IBI Program and choose the Direct Funding Option must do. Parents reported difficulty, however, selecting someone appropriate because Ontario has no mandated credentialing system for ABA therapists. The Ontario Association for Behaviour Analysis (ONTABA) promotes internationally-recognized certification with the Behavior Analyst Certification Board (BACB) in the United States, but many perfectly good professionals in Ontario work without such certification. Also, it was not uncommon for parents to disagree with their current provider's approach and ultimately have to seek out a new agency. The upheaval of changing providers could be difficult because of close relationships that were lost and the uncertainty of locating another reliable provider.

Setting up an in-home behavior intervention program involved extensive researching, often developing a personal consulting relationship with a preferred expert, recruiting and training one or more junior staff to work directly with the child, and setting up a room in the house for daily therapy. Programs were created either to fill the gap while their child was on the long waitlist for funded IBI, or to extend therapy after a child had been discharged. Parents reported being stretched to pay for their in-home programs, which often required stressful negotiations to obtain a substantial bank loan. In the end, sometimes parents were only able to afford a couple of hours of therapy each weekday. One parent reported that her program cost $60,000 for one year.

Diets. Diets and other gastrointestinal (GI) interventions (e.g., laxatives) could be prescribed or recommended by a mainstream physician, a biomedical practitioner (e.g., naturopath), or initiated by the parent. Close to one fifth of parents described their child suffering from distinct GI problems (such as diarrhea, constipation, vomiting, or bloating), most of whom reported resolving these concerns by modifying the child's diet. The following description resembles several parents' accounts:

> *"And his stomach, it looked constantly like it was swollen and really just bloated, but badly, like hard to touch and everything. And he used to literally, like, dig his hands into his stomach. And within probably three to four weeks of removing gluten and removing dairy, his stomach flattened. Like, it literally flattened."*

Parents started diets in response to confirmed, perceived, or possible GI intolerances to wheat, dairy, or sometimes soy—the gluten-free, casein-free (GFCF), and sometimes also soy-free (GFCFSF) diets. But parents did not adopt these diets uncritically. Among the 32 parents interviewed, only one described starting a GFCF diet for her child in the absence of GI problems. Moreover, numerous parents considered the potential nutritional loss or harm due to restricting their child's available foods and several described pulling back from the diet accordingly, especially in the case of picky eaters such as the following mother: "He was so unwilling to

expand his diet that we had to leave some of the wheat in just so that he was eating." Further

contributing to parents' critical adoption or maintenance of diets, the cost in terms of both time

and money was a dissuading factor. Shopping and cooking appropriate foods added substantially

to parents' already high workload. In addition, instituting the diet sometimes had to be

accompanied by strenuous efforts to push the child to like new foods to balance his or her

nutritional intake. While many foods that parents prepared as part of the diet were quite healthy,

tests by a pediatrician showed at least one parent that her child was deficient in vitamin D and

iron. Another parent, meanwhile, observed that resolving GI problems improved the child's

ability to absorb other things that were previously ineffective, namely melatonin. In summary,

coping with the disadvantages and adhering to diets was most often motivated by the parent's

concern (sometimes fear) for the child's GI problems, as one mother summarized: "I'm really

loving the no-vomit, and my stress level's gone down."

> ***Biomedical therapies.*** Biomedical interventions comprise a wide range of therapies aimed

at modifying the child's biology or physiology. The characteristic philosophy associated with

biomedical therapy is introduced under Information, below. Therapies can in include an

assortment of medicines and supplements, the GFCF diet (used within a biomedical approach to

target autistic symptoms rather than primarily treat GI problems), chelation therapy, secretin,

antifungal or antibiotic treatments, and hyperbaric oxygen therapy. The evidence to support most

biomedical interventions is poor quality by the standards of traditional research evidence, and

parents process information about biomedical options in different ways (see Information, below).

Parents who used biomedical treatments generally appraised some form of evidence about

specific options first, and avoided those they felt could ever harm their child. For example, no

parent described using chelation therapy and many were aware of reports that it had caused

fatalities in the past. In another case, a parent curious about whether to start her daughter on secretin (a digestive hormone, and one of the first interventions promoted by the biomedical movement in the late 1990's, which has been discredited by clear research evidence showing it is ineffective) first consulted a homeopath, who informed her that it does not work.

Biomedical therapy can come with significant costs. While individual supplements are not necessarily expensive (e.g., $10 for several months supply of melatonin), some parents reported spending $6000 per year on all the supplements they used—including digestive enzymes, probiotics, vitamin B12 injections, assorted other vitamins and minerals, amino acids, omega-3 fatty acids, and so forth. These would be sourced from health food stores or online. Hyperbaric oxygen therapy costs $125-$250 per session, with some sources suggesting a dose of forty sessions is necessary to see effects (costing $5000-$10,000). The costs of consulting biomedical practitioners—usually naturopaths, but sometimes medical physicians—are not covered by OHIP (the Ontario Health Insurance Plan) and can represent another considerable expense. Laboratory testing of biological samples (which may include the child's blood, urine, stools, or hair) that such practitioners often recommend is also expensive.

For many parents, pursuing and implementing biomedical therapies can also consume a lot of time. Parents interviewed described spending time researching, travelling to extra appointments, shopping and preparing food for diets, administering supplements (often by mixing or disguised them with other foods), and experimenting and monitoring (sometimes conducting n-of-one trials, manipulating one intervention at a time, and recording and plotting results).

Unexpected forms of intervention. In addition to alternative, but recognized forms of intervention, parents occasionally stumbled on forms of intervention from unique and

unexpected sources that were distinctly therapeutic. One parent described the therapeutic effects of a new dog: "[Son with autism] thought that this puppy was the best thing that ever happened. And the first day that we brought him home, he went from having a two-word vocabulary to learning the dog's name. So he learned [dog's name], he learned "run," he learned "ball," he learned "play," he learned "come," he learned "sit," in two days." Similarly, parents generally characterized their interactions with other parents of children with autism as one of the best forms of personal mental health therapy they could find, and this was mostly because only such parents could ever claim to understand their situation as well.

Appendix K. Supplemental analysis: Staying

Staying: Forms of non-action from both observer and parent perspectives

Pursuing intervention contrasts with *staying*, a category of parent responses defined from the perspective of people who observe the parent—professionals and sometimes other parents. *Staying* refers to any situation where the parent neglects to initiate a course of action that the observer feels would likely be effective, beneficial, or lead to progress in addressing what they believe is or should be a parent-held concern related to autism. This includes not capitalizing on opportunities to be proactive or advocate, not seeking or accepting relevant recommendations or other information from professionals, or otherwise neglecting to seek, obtain, or implement intervention.

Importantly, *staying* is *not* a symbolic interactionist process because it is neither defined to be present nor always explained here from the parent's perspective. It therefore stands as a supplementary analysis that is located slightly outside the core theory of *making your own way*. Despite being informed by a different perspective, *staying* is an undeniably apparent phenomenon that was commonly observed and independently described among both professionals and parents interviewed. As an example, one professional with decades of experience helping parents spontaneously volunteered her perception without prompting: "Some parents, you know, get overwhelmed…and they get kind of paralyzed, and they don't know what else to do." Addressing this phenomenon here provides important insights from a different perspective on the process of *making your own way*.

The insights in this section have potential value for any professionals engaged with helping parents: firstly, because they promote understanding of why parents sometimes appear not to pursue, obtain, or implement an interventions or recommendations that professionals provide;

and secondly, because they highlight the need to continue supporting parents through their process of *making their own way* whatever their outward choices may be. An important proviso is that insights based on professional perspectives alone cannot possibly be fully informed by understanding of the parent's experience, and may include elements of the professional's personal judgmental analysis.

The name s*taying* does not represent language used by participants. Numerous other *in vivo* terms were considered, but none captured the full range of instances where an observer perceived the parent as not taking action to pursue intervention when they felt she had an opportunity to do so. For example, *freezing* usually did not capture inaction due to *not knowing*, and *being passive* did not apply to critically *questioning* professional recommendations. *Staying* was ultimately adopted after discussions with my committee because in one word it implies any non-kinetic (non-*moving*) response, and this seems to capture the full range of heterogeneous behaviors participants reported on.

This section begins by drawing attention to the value-laden and potentially dangerous nature of *staying*. I then discuss why this concept is so important and useful to understand. Next, I describe the various different forms of *staying* and connect them with potential explanations from the parent's perspective that come from the symbolic interactionist theory of *making your own way*. Because *staying* represents a diverse array of parent responses, numbered examples are provided throughout the section to illustrate the characteristics discussed.

The value-laden nature of staying

It is important to recognize that this concept is not defined from the parent's perspective, but rather from that of the outside observer who lacks intimate familiarity with the parent's personal understandings and explanations for her actions. An implication of this is that value

judgment is unavoidable in how *Staying* has been outlined here according to the information

contributed by autism professionals in this study, sensitive and empathetic as these professionals

generally were to parents' situations. Example 1 illustrates a specific aspect of this implication.

> *Example 1. Some time after their son's diagnosis, his parents are convinced that certain biomedical issues—solving their son's constipation, and implementing a new diet—are so paramount to addressing his autism that they pursue these at the expense of accessing mainstream intervention. These parents appear to put all their faith and energies into these alternative interventions, while passing up what the professional knows are important interventions that have a good chance of helping their child.*

In this case, the professional who defines the parent as *staying* also defines what is

important and worthwhile intervention according to her values. One can alternatively imagine,

for example, how a biomedical practitioner might perceive the same parent to be *staying* if she

did not institute the diet he believed was indicated. While the professional above had the parent

and child's interests in mind, we will assume that the she did not probe the parents deeply about

the knowledge and reasoning that led them to their decision. If we assume this is the case, the

professional's values (informed by different knowledge and understandings) are at odds with the

parent's values with respect to intervention. Furthermore, professionals' understanding of the

most important concerns may not match parents' understanding. Here, we can imagine one

hypothetical explanatory scenario: that the parents, after witnessing the effects of their son's

gastrointestinal comfort, reasoned that he would never be able to engage with any therapist for

long enough to benefit from therapy until his constipation was first resolved, which was why

they felt his diet was a higher priority scenario. Other explanations could be hypothesized based

on the theory of parents *making their own way*, and many scenarios are possible. The point here

is that a professional or other observer's perception of a parent behavior, when not informed by

explicitly probing that parent about her understandings and motivations, is necessarily one-sided.

Even sensitive speculation will not generate a reliable explanation about the true parent understandings, reasoning, and events underlying the path she has followed.

Stigmatization is a potentially dangerous consequence of identifying or describing a single parent, or class of parents, as *staying*. This is because of the high risk of underappreciating the complex circumstances or reasoning that explains their behavior. As a result, there is a chance for an observer's projected explanation to discredit the parent—for example, implying traits of gullibility, ignorance irrationality, or other cognitive fallibility where none played a role. When applied to groups, professionals should consider the risk of alienating cultures or communities. Still worse, suggesting that the parent's behavior is a barrier to the child receiving effective intervention may imply that the parent is negligent or not acting in the child's best interests. The value-laden nature of *staying* is therefore problematic, and the concept should be used carefully.

One approach for reducing the risk of stigmatizing parents, suggested by one of the professionals interviewed, is to be attentive or sensitive to cultural differences. This entails accepting the fact that what may be defined or expected as a healthy or functional response from one perspective may not necessarily be from the point of view of another culture. Seeking to understand cultural differences of the parent may therefore reveal different possible explanations from the *parent's* perspective, which explain why he or she appears not to pursue the professional's suggestions or opportunities regarding intervention. A very similar approach to reducing the risk of stigma when conceiving of parents as *staying* is to consider additional possible parent explanations suggested by the theory of *making your own way*, as will be discussed below. Professionals should be mindful that they can never be fully confident they understand the psychological explanations and justifications that lie behind parent behaviors.

Utility of understanding staying: The example of stigma

Despite its value-laden nature, the concept of *staying* is important because of its potential to yield clinically useful insights. Expert professionals, such as those who shared their thoughts on why parents neglect to pursue intervention here, have a perspective with significant advantages. First, they are generally better informed than parents about system-related context and can comment on its conditional influence on parents' responses. Second, expert professionals have broad knowledge of parents as a population and can make comparative statements—for example, comparing differences in conditions between parents who *move to pursue intervention* in a given situation versus those of parents who *stay*. These aspects of experts' perspectives allow for unique and powerful insights and innovative hypotheses about why parents may not move forward to pursue an intervention that seems to be an option.

Provided the effort is made to seek out possible explanations from the parent's perspective, the concept of *staying* can potentially help professionals to deepen their understanding of why some parents appear to ignore or pass up recommendations, opportunities, or forms of intervention that have value from the professional's perspective. With this more sensitive understanding, professionals may feel better equipped to continue to support such parents to articulate and ultimately address their own concerns.

Examples 2 and 3 illustrate how insight into the phenomenon of *stigma* (which observers tended to associate with parents *staying*) was derived from expert professionals' ability to comment on system-related context and on parents as a population.

> *Example 2. One diagnostic professional observed that new Canadian parents in whose cultures it was common for stigma to be associated with having a child with autism differed from each other in their willingness to accept an autism diagnosis according to the parent's level of awareness of the system. Parents with greater knowledge and trust that the system was ready to provide valuable support if autism was openly acknowledged were more likely to see the benefits of a diagnosis. This was because for*

them, diagnosis clearly provided access to intervention. Such parents also had some appreciation for the greater level of acceptance of autism within Canadian society, leading them to view the stigma they experienced within their cultural communities as easier to overcome personally compared to less assimilated new Canadian parents who lacked this understanding.

Example 3. Another professional described her observation that numerous aboriginal families in the communities she served had great mistrust and sometimes even fear of the government-funded system "because of past hurts." As a result, they were often unwilling to engage with agencies or professionals providing services. Notably, they were more likely to perceive disadvantages, including feeling judged by the system, if their child was labeled as having autism. Within many rural aboriginal communities, meanwhile, the child with autism is naturally accepted and supported regardless of diagnosis according to the "ancestral aboriginal attitudes" of the local community.

Together, these two professionals' accounts shed light on the relationship between the likelihood of parents seeing the autism label as stigmatic and therefore disadvantageous to their particular situation and their understanding of the system's potential to respond supportively. This notion is reinforced by the following comment from the parent's perspective:

"My whole thing was like, it's worth it for me to do that [label my son as having autism] because I know that he's going to get support and help, and then that's going to help him be a better individual in the long run, right? But if you don't know that, as a parent, and if you don't have that support…like, let's say in Serbia, I don't think that they would have that support. Like, they wouldn't have that understanding."

Another professional proposed that parents' ability to *accept* a diagnosis of autism is not only related to culturally-defined *stigma* (leading parents to resist the autism label), but also to parent-perceived *cachet* (leading parents to embrace the autism label). As this professional observed, within greater Canadian society there is now a *cachet* associated with of autism in which some parents see the label as desirable, a phenomenon that has slowly developed over the past twenty years or so. The timeline of this growing *cachet* corresponds to increasing public advocacy and levels of government-funded support for autism, which confers more benefit on having the label. Also, autism is increasingly being understood as a far-from-rare disorder that affects families of all socioeconomic backgrounds and nationalities, which further reduces

stigma. Finally, as the stories of parents' experiences with autism become increasingly publicized, the autism label may even confer a recognizable status on parents as an elite group who have learned to cope with extreme situations of parenting and navigating intervention that few will ever truly experience.

Stigma and *cachet* can be thought of as opposite poles of the same dimension, which together are a condition of the parent's sociocultural context. Both stigma and cachet are defined by discourses about autism formed by the cultures or groups whose opinions matter to the parent—including the parent's local sociocultural (non-dominant ethnic) network, and the more distant group of government-funded agencies and professionals the parent interacts with. These discourses seem to vary between national-level (ethnic) cultural groups according to each group's experiences of their government-funded system interactions, but they also vary over time within the same national culture.

Observer-perspective forms of staying and parent-perspective explanations

As discussed, *staying* is an observer-defined concept that can lead to useful clinical insights, but which is problematic because it is defined based on incomplete information from the parent's perspective and unavoidable value judgment and speculation from the observer's perspective. One of the solutions to this problem, proposed above, was for professionals to be attentive to cultural differences of parents they support as this could reveal alternative possible explanations for staying from the *parent's* perspective.

A second proposed solution for improving understanding of the explanations for *staying* is to consider additional possible parent explanations suggested by the theory of *making your own way*, which is the overall objective of this section. This section is organized around a presentation of various forms of *staying*, defining each form first from the observer's perspective,

and then connecting this with potential explanations from the parent's perspective. Thus, one objective is to illustrate most of the range of possible behaviors that were considered *staying* from the observer's perspective. The connected parent-perspective explanations are derived from parent data that in most cases correspond to specific stages within the theory of *making your own way*. The objective of making links to parent experiences is not necessarily to propose specific explanations for the observer-defined perspectives on *staying* (since the matching of explanations to behaviors is speculative in some cases), but primarily to illustrate the simple fact that it is possible to identify plausible explanations from the parent's perspective. Ultimately, this section is intended give the reader a deeper appreciation and sensitivity for how aspects and stages within the parent process of *making your own way* may explain the parent behaviors that professionals sometimes observe.

The various forms of staying to be discussed are organized within three main categories: *not knowing, being overwhelmed*, and *questioning*. These categories and the subcategories used to further classify the forms of *staying* are somewhat arbitrary, since multiple valid categorizations are possible—the organization below itself was the product of extensive and frequent rearrangements. As a result, a small number of the examples and concepts themselves overlap with other categories. The main purpose of these three categories is to illustrate the breadth of behaviors that observers in this study considered to be *staying*, and provide a structure for making several specific analytic points.

Not knowing

Not knowing refers to situations of parent non-action to pursue intervention that can be attributable to their lack of knowledge or awareness of anything relevant about their situation, including knowledge about how to respond (skills). Four forms of not knowing will be

discussed: Not knowing about the opportunity to act earlier, Lacking advocacy skills, Not

recognizing red flags, and Not being socially connected to people who know.

Not knowing about the opportunity to act earlier. This form of not knowing refers to

situations in which the parent(s) were delayed in initiating an action related to pursuing

intervention due to a lack of awareness that it was an option for them to act. Example 4

illustrates this phenomenon, not from a professional's perspective but rather from the participant

parents observing their own situation in hindsight and recounting it during an interview. The

observer in this case was simultaneously me, the researcher listening to these parents' story, and

the parents who observed and recounted this behavior in hindsight.

> *Example 4. A highly educated couple responded to strong suspicions that their daughter had autism by focusing all their energies on pursuing an assessment and diagnosis for their child. In doing so, they decided it was better not to pursue any kind of intervention until after obtaining the diagnosis, which in hindsight was unnecessary. These parents' failure to pursue intervention was due to their flawed understanding that the earlier they could obtain a diagnosis, the sooner they could start therapy because, they felt, only the diagnosis could tell them adequately what they were dealing with and how to respond. They realized in retrospect, however, that it would have been possible to start therapy based only on the concerns they had at the time. The mother recalled, "We thought that was the right order. Now we kind of know differently. But how would you know that? You wouldn't."*

Although these were not the only parents to describe waiting for the diagnosis before

acting to pursue intervention, this behavior was not commonly described among the parents I

interviewed. Nevertheless, their example ultimately illustrates the effect of a lack of advocacy

skills—knowing when to question professionals or the system, knowing about the need to push

for a more immediate response to one's concerns (discussed next)—which parents generally

develop at some point in the process of *adjusting to the need to navigate* intervention. These

particular parents, however, were at too early a stage to have learned about the realities of their

situation. They had not yet learned that the system is unequipped to adequately take care of

things where autism is concerned, nor that taking things into their own hands was an option.

These forms of awareness (of the context and of ones options) perspective are prerequisites for action from a symbolic interactionist.

The most noteworthy consequence of not knowing about the option to take earlier action, for these and other parents, was a sense of regret at having lost the opportunity to intervene earlier, because parents felt this would have optimized their child's developmental trajectory. Their frustration could be significant considering parents' almost universal awareness of the evidence of the benefits of intervening early. Sometimes parents described how they felt professionals or agencies played a role in such delays, although usually without resentment or blame. Additionally, in many cases the parent attributed the lost opportunity to her own naïveté and failure to advocate more forcefully at the time. This idea of *lacking advocacy skills* is described in more detail, next.

Lacking advocacy skills. Advocacy skills are specific and non-specific skills that parents use to pursue intervention or overcome obstacles. At a non-specific level, they refer to the predisposition to be proactive, which most parents learn is necessary at some point in *making their own way*—a predisposition that was observed to be lacking in Example 5 (below). At a specific level meanwhile, advocacy skills include, for example, parents who "may not recognize that they're capable of doing conflict resolution." As one professional remarked, parents who feel less of a sense of empowerment behave more passively.

The relationship between lacking advocacy skills and apparent passivity is more complex, however, due to parents' sense of urgency. Parents usually develop a sense urgency soon after *coming to understand the child has autism*, and often respond by *going into high gear*. As described previously (Section 4.3, *Going into high gear, Transcending personal limitations*), parents motivated by urgency can disregard more reflective awareness of personal limitations to

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their skills (self-efficacy), as their responses became more immediate, intuitive, and physiological according to the varied stresses they react to. There were many *example*s of parents in such situations recruiting whatever skills they had to make up for specific skills they lacked. Urgency, meanwhile, also increases parents' predisposition to be proactive (*non-specific* advocacy skill), empowering them further. Thus, observers likely only ever observe parents to be passive due to a lack of advocacy skills in situations the parent does not consider urgent.

> *Example 5. A professional who coordinates a free therapeutic program that can be adapted to parents' needs commented on parents' willingness to suggest modifications: "A lot of the times I find the parents are not active enough in asking for what they would like to see—what their children or what their family require. So we just put it [i.e., the program] out there [without modifications]. And they'll jump on it. A lot of them take advantage of the program, and they're not shy about it. They like it and appreciate it. But they just don't seem to be aware of their own power and the fact they have a right to request specific things they want."*

Similar to many skills, specific advocacy skills are progressively developed as the parent gains more experience applying them to the corresponding tasks; and, to a lesser extent, by cognitively learning about relevant skills from information sources. Parents also become more motivated to learn and develop the varied skills used for navigating intervention as they gradually learn how useful and needed they are to meet the demands of systems they interact with. Advocacy skills are therefore developed further as parents progress through the processes of *adjusting* and *making their own way* to intervention. Early on in these processes, parents are more likely to lack awareness of the need for such skills or lack proficiency.

Importantly, if the parent never becomes aware of a skill she lacks, it is an external judgment to say that she lacks that skill. Observers should be particularly sensitive to the natural timeline for developing these skills by considering where the parent is in the process *making her own way*. Earlier on, the parent may not have interacted with the system long enough to understand the nature of its demands or to have practiced the skills to respond. When the

professional in Example 5 was asked whether there were any parents with a better understanding that they had a right to request things, her response was, "The more experienced ones—definitely!" For this reason, newer parents will often need extra support and guidance until they develop their own advocating skills.

Not recognizing red flags. Another form of not knowing leading to delays in pursuing intervention, described by a number of parents in the study, is being unaware of the red flags or signs suggestive of autism in the child. Several parents reported that while they did not know, it later became evident that the professionals around them did know. Such parents often remarked that they did not understand why professionals withheld such information, and some even expressed resentment because they felt they could have started taking action sooner had they known. Such parents could perhaps be made less resentful had they been informed about two realities from professionals' perspectives: First, therapists such as SLPs or occupational therapists, whose services the parent may engage before ever seeking a diagnosis, are not authorized to make a diagnosis. Second, when such therapists suspect autism in a child whose parent seems unaware of the red flags, they are generally highly cautious about how directly to suggest to that parent pursue further assessment because some parents who are not ready for such information can be highly reactive, and their responses can be antagonistic and problematic for professionals. Still, the potential consequence of this type of *not knowing* for the parent is similar: regret at losing opportunity to intervene earlier.

Not being socially connected to people who know. People who know can include other parents of children with autism with knowledge to share, or relatives or friends that come from related professions (e.g., educators, therapists) or otherwise have expertise that position them to share valuable knowledge. Parents in the study made many firsthand references to sharing with

other parents, or otherwise having experts they could turn to. Parents born in Ontario (or Canada) also had a subtle cultural advantage because their history of social connections and interactions had allowed them the opportunity to construct deeper understandings of the system and how to go about seeking help in Canadian society. Parents who were observed to lack knowledge because they were not socially connected therefore tended to be new Canadians, especially those who could not find groups of their own ethnicity or nationality to connect with. They contrast with stories of members from some ethnic communities—for example, Somali, Filipino, or Mexican—that formed networks in certain areas with surprisingly effective knowledge-sharing capabilities that could overcome language barriers.

Both participant professionals and parents commented extensively on observing other new Canadian parents they suspected were not socially connected and missing out on intervention. While many such observations could only be speculative, Example 6, provides some direct insight from one parent's perspective who experienced the effects of cultural and social isolation on her knowledge.

> *Example 6. This new Canadian mother described having no time for social connections due to the need to care for her son 24 hours a day, and did not seem to be socially connected to other members of her ethnic community who could help her. Responding to a question about how her isolation affected her level of knowledge, she acknowledged that "maybe there are things in Canada I don't know about it." When asked if she had interacted with other parents who shared information with her, she recalled only one. She contrasted her own knowledge with that of the other, better-connected parent: "I felt at that time that this Canadian lady, she knows about many things I don't know about it. And she has a lot of information better than me. And I was surprised." She described wanting to follow up with this woman about where or how she got all her knowledge, but sadly she lost her contact information.*

Another new Canadian parent, who similarly lacked connections with other groups of parents of children with autism, described experiencing challenges connecting with other parents of children with autism who shared the same Section 23 classroom as her daughter. This prevented her from networking to obtain what she felt was readily available information about

intervention opportunities other parents seemed be taking advantage of. Both this parent and another parent in the study expressed their certain sense, based on vivid personal experience, that some barriers were related to subtle forces of discrimination that ultimately restrict the free flow of information to new Canadians.

Being overwhelmed

Being overwhelmed implies two things. First, experientially, it refers to the emotional sense of not being able to cope with the stress of a situation. Second, more abstractly, it can imply any situation where the demands imposed by one side (the system) are greater than the capacity of another side (the parent) to meet them. Two important characteristics of *being overwhelmed*, therefore, are stress and the mismatch between parent capacity and system demands.

This subsection begins by discussing how the observer and parent experiential perspectives have been integrated in this analysis of *being overwhelmed*, before going on to consider three overlapping potential explanations defined from the parent perspective:

- *not being ready*,

- the parent's *psychological coping capacity*, and

- *having competing priorities*.

Integration of observer and parent perspectives. While both parent and observer perspectives are represented in the examples and discussion of *being overwhelmed* below, most of the relevant data was from parents' perspectives. Much of the discussion and examples are therefore from the parent perspective.

The term, *overwhelmed,* itself best represents the parent's perspective since parents used it proportionally more often to describe the first-person experience compared to those observing their non-action in such situations. Rather, the term that was often used by observers (both other

observing parents and professionals) in describing the overwhelmed parent's outward appearance, was *frozen*. An observer-perspective synonym for *being overwhelmed*, therefore, is *freezing*. Observers also used analogies such as *not moving*, and *being stunned*.

In some cases, *being overwhelmed*, as defined from the parent perspective, may appear outwardly to the observer to have another explanation. For example, it is quite easy to attribute passive responses to *lacking advocacy skills*, described above as characteristic of many early-stage parents. Example 7 presents the perspective of one professional on parents *being overwhelmed*, which may ultimately be attributable to varied possible explanations from the parent perspective.

> *Example 7. Sharon, a social worker, described her approach in encouraging and supporting parents to complete the lengthy application forms for funding or services that they are eligible for. She has a noteworthy level of sensitivity, which clearly informs her perspective and the strategies she describes. For one, she appreciates parents' varying desire to be organized, which she probes them about so she can tailor her approach their different personal styles for organizing information. She also understands how many of the parents she sees have too much on their plate, which leaves them "overwhelmed." From what she sees, "They're so often just trying to deal with what's in front of them...all they're trying to do is get through the day and maybe, you know, shower." To illustrate the challenges that result in terms of convincing parents to complete these applications, she described from her perspective the example of a parent who had neglected to complete her application for Social Services at Home (SSAH) two years after Sharon had first helped her with it. At the time, SSAH was known among many parents for having its funding temporarily but indefinitely suspended, meaning it could be years before funds would begin to be released to applicants on the waitlist. Sharon therefore often had to do a "selling job" to convince parents the funding would return and the benefit of getting on the waitlist sooner. This particular mother admitted to "shelving" the application, which Sharon understood to be due to the mother's "process" of grieving and accepting the diagnosis—she recalled the mother commenting in the session two years prior, "I can't do this right now. Like there's just too much." Sharon noted how this mother also would have been highly preoccupied with the daily challenges of caring for her child. At the most recent appointment two years later, however, she seemed more receptive to Sharon's arguments and saw the need for completing the application.*

The apparent explanation for the parent's behavior in Example 7 corresponds to the idea *not being ready*, which is expanded on next.

Not being ready. A parent's state of *being overwhelmed* can sometimes be explained by her sense of *not being ready* to take a step forward. This idea can be further divided into two more specific parent-perspective explanations, which will be considered in turn: 1) the parent *needing time to adapt to difficult aspects of adjusting*, and 2) the parent *needing to get organized*. Example 7, above, illustrated the case of a mother *needing time to adapt to difficult aspects of adjusting*—specifically, adapting to the knowledge that one's child has autism (in this case the parent's perspective was recalled by a professional highly sensitive to her situation).

The moment when some parents most apparently *need time to adapt* is during the diagnostic assessment. Numerous parents described in powerful terms how they were not able to *hear* anything from the professionals around them. Likewise, several professionals described their awareness of this, as one who aptly summarized: "I really believe that parents hear about the first, I'd say max, two to five minutes of what you say. And then they're so overwhelmed that…you know, you're explaining all these services, and you're explaining what the next steps are—zap, gone—out of their heads." The parent's *needing time to adapt* to the knowledge her child has autism can extend past the assessment, however, into a longer mourning period where, as one parent put it, "they end up not moving."

One professional shared her perspective on parents who have not yet accepted or adapted to the knowledge that their child had autism, and that it is a permanent condition: "For some reason they don't want to be involved so much. I don't know what it is. Maybe they just *can't*. They just can't cope with it, or they can't manage it. But they want you to fix it. And it's not a fixable thing… But, you know, all you can do is offer it [i.e., therapy requiring the parent's involvement]. And when they're ready, they can take it." Meanwhile, in a separate interview, a

mother spontaneously acknowledged that after she eventually came to accept that the autism was not going to go away, it became a lot "easier to help."

As discussed previously (Section 4.3, *Emotionally adapting*), the emotionally difficult aspects of adjusting are not restricted to adapting to the knowledge that one's child has autism, but can also include grieving, accepting an uncertain and potentially fearful future for the child, surviving other emotional strains associated with *making your own way*, and redefining one's roles and self according to new occupational requirements. The challenges of *emotionally adapting* vary according to the particular circumstances of every parent. The parent's need for more time adapting to any of these aspects may explain her apparent behavior of *freezing* or lacking a proactive interest in intervention.

Needing to get organized is the other possible explanation for *not being ready*, which some parents use as a strategy to handle the complexity of autism information before further pursuing intervention—as Example 8 illustrates.

> *Example 8. This parent admitted to being very organized and liking to feel in control. She recalled a point where, after five years of accumulating information relevant to autism and pursuing intervention in big boxes, everything was completely mixed up and she felt like she was drowning in paper. In response, she asked her husband to "watch everything" so she could drop everything for nearly a week in order to organize this mass of information into large tabbed binders—she displayed six during the interview. In addition, she had assembled four folders dedicated to tracking expenses for insurance and tax claim purposes. Maintaining this level of organization over time also required significant work because "as time goes on, the binders evolve and have to be kept current." But having everything easily accessible made it easier for her to respond to requests for information, complete intake and other application forms, and review stored information whenever it came time to consider what new interventions might be appropriate for her son's most recent problems, which evolved constantly.*

Needing to get organized provides an alternative explanation why some parents, such as some parents observed by the professional in Example 7, defer completing long application forms. Parents who tend to see the benefits of order may be likely to put more work into getting organized. As the parent in Example 8 noted, since completing such applications can entail

searching for information stored in multiple places, it may actually be more time-efficient to first organize this information as preparation for completing numerous forms at the same time.

Ultimately, *getting organized* is an effective means for some parents to recompose themselves and regain control by establishing a calmer physical and mental space for making decisions about the next steps to take in pursuing intervention—illustrated in Example 9.

> *Example 9. This parent described needing to take a pause from researching to get organized: "My bedroom had papers all over the floor. And I sort of knew where everything was. But it was starting to get overwhelming. And I compare it to rebooting a computer. I had to take a step back from it, and organize the information that I did have. And that gave me sort of a sense of control again, and a sense of peace, and a sense of, 'Oh yeah, OK. I remember that. I've dealt with that. That can be filed over here. Now I can put this away. I'm done with that piece.' Or, 'Oh yeah. I wanted to look into that.' Now I was actually able to utilize the information better, because I was stopping the research end of it. [...] Sometimes you have to regroup, make the next plan of attack, and then move forward."*

Whether it is explained by *needing time to adapt to difficult aspects of adjusting* or *needing to get organized*, it may be useful for professionals to try to understand how the parent's *not being ready* can be a temporary or self-limited state, and one which usually serves a worthwhile purpose from the parent's perspective.

Psychological coping capacity. *Having a reduced capacity to cope psychologically* refers to the effects of mental health burdens related to depression, anxiety, or even acute states shock after receiving unexpected news, which apparently consume the parent's psychological resources and leave her less equipped to handle the stresses and emotional demands of *making her own way*. For example, mental health burdens like depression can make the parent hypersensitive to some of the challenges of her situation, leading to avoidance of stressful thoughts or activities that are emotionally difficult to face, as Example 10 illustrates.

> *Example 10. One mother described how severe depression led her to avoid planning for the future: "This is a whole other level that I have to make sure that I don't get myself…you know, I can't think about whether [my son] will have babies or not, or whether he'll go to university, or whether he'll get married. And I can't think of what*

> *will happen when [my husband] and I are gone because that is just…like it's consuming, and it'll just eat you alive, right? So I have to keep it in check. So I just focus on the daily stresses. And we get through that. And I don't worry about the other stuff, and I'll get to it when we get there, right."*

Occasionally, the parents' first experience with depression or anxiety pre-dated their experience with autism. Regardless, for many parents, their psychological burdens were either triggered or resurfaced, often more powerfully, after a crisis or traumatic event related to the child's autism. For example, Martha, who had pre-existing depression, described a "tsunami of depression" after the diagnosis. Highly stressful events that reduce psychological coping capacity also involved aspects of the child such as difficult-to-manage behavior, and stresses directly attributable to navigating intervention (for further examples, see Section 4.2, *Stress*). Whatever the source of psychological burden, the consequence of *being overwhelmed* is never absolute—the parent always retains some functional ability to respond. Importantly, the lowest points in parents' functioning are invariably temporary states. Indeed, all parents interviewed who acknowledged mental health burdens still shared remarkable stories of successful coping and highly motivated action subsequent to their low points.

From some professionals' perspectives—which, as mentioned, may involve judgment that is not necessarily informed by complete knowledge of parents' perspectives—mental health burdens appeared to impede some parents' participation and involvement in intervention (e.g., generalizing behavior therapy to the home, engagement with educators at child's school). In addition, burdens appeared to these professionals even to limit some parents' capacity to engage with their child—something professionals saw as an important an ingredient in the success of some forms of intervention. Additionally, both depression and anxiety appeared to lead to what observers perceived as avoidance behaviors (e.g., avoiding involvement in therapy or other intervention, avoiding assertive forms of engagement with their child). One professional

suggested that a universally promising intervention for helping parents engage more with intervention and with their child would be to connect them with mental health support early on.

When present, *having a reduced capacity to cope psychologically* often overlapped with other explanations for being overwhelmed (e.g., *not being ready*, and *having competing priorities*). For example, in the case of *not being ready*, the effects of reduced psychological coping capacity are most apparent during the early stage of *beginning the autism journey* when stresses of *emotionally adapting* are typically the highest. In this situation, *staying* frequently manifests as *not being ready* due to *needing time to adapt to difficult aspects of adjusting*.

Having competing priorities. A form of *being overwhelmed* that limits the parent's capacity for involvement in intervention is *having competing priorities*. The examples presented here predominantly illustrate priorities besides the demands of dealing directly with autism itself. Although many *competing priorities* may themselves be emotionally stressful and affect parents' capacity to cope psychologically, their more defining effect is to absorb parents' time and cognitive attention, as Example 11 illustrates.

> *Example 11. Miriam described being past the point of suspecting something might be wrong to knowing there was a developmental problem with her nearly two-year-old daughter. She took her to their family doctor, who advised her to engage her child with age-appropriate play and social interaction. Miriam says she would have pushed more forcefully for further assessment, but this was just after she had given birth to her second daughter. "It was overwhelming with the two of them so close together." She put off being proactive about pursuing the diagnosis, which she feels now would have led to an earlier diagnosis, to meet the more immediate demands of caring for her newborn.*

Example 12 illustrates how some competing priorities are very stressful emotionally, affecting the parent's capacity in multiple ways. It also shows how the overwhelmed parent's inability to attend to everything requiring her attention can lead to struggles with guilt.

> *Example 12. Dilin described needing to take a big pause from advocating so energetically at the time her marriage started to break down. On the one hand, she knew she could not continue at that pace because she had not been sleeping or eating properly. So at the point when she and her husband separated, she "crashed, I guess*

you would call it, emotionally." She then "stopped the research end of things for a while" and allowed herself to take a break, "Like, I gave myself permission basically to take some time off." At the same time, her anxiety disorder got worse, because her life had to change direction yet again (her future had already been profoundly redefined once by her son's autism). She had been a fulltime caregiver with no income, and now she had to adapt to the fact that her estranged husband had completely discontinued financially supporting the family. This was another dire situation, "Because now it wasn't about just raising the kids and helping [son with autism] ...So I had to take some of the concentration away from the autism and the intervention, and put it on just providing basic necessities for my family." She was pursuing legal action to force her husband to provide support, but this required large blocks of her scarce time, and she had still not been successful at the time of the interview. She reported living in poverty and relying on food banks for the first year, and had since withdrawn her retirement savings and borrowed from family. This was in addition to having remortgaged the house years earlier with her husband before he left in order to pay for therapy, so that now she reported being at the point of personal bankruptcy. She had therefore started working part time, which stretched her precious time even more. "So again, I feel like I'm pulled in all directions. And I can't quite give each the attention it needs. So I'm giving as much as I can to each sort of branch. And that's where the guilt comes back in again, because you can't give everything that [son with autism] needs right now." She described struggling to be at peace with her inability to do enough. By now she had also developed hypertension and, only two months prior, cardiac problems, which she and her doctor suspected were due to the pressure she was under and her failure to take enough care of herself. Caring for herself has since become more of a priority because Dilin understands that she is the only person her children have to look out for them.

Example 13 is of a chronic competing priority observed from a professional's perspective.

Example 13. One professional described a mother she once supported whose husband was unemployed, abused substances, did not participate in parenting, and was verbally abusive to the family. The professional equated this mother's situation with that of a single mother with no support, because it was apparent that her husband was a constant drain on her time and energy.

What these and many other examples of competing priorities have in common is their

immediacy—they cannot be deferred. The child with autism is usually not in a life-or-death

situation and most potentially disastrous autism-related outcomes are farther away at some

unclear point in the future. So the urgency of many forms of action to pursue intervention

becomes less immediate. There are many types of activities or responsibilities related to *making*

her own way that parents may defer as a result, such as spending less time engaging with the

child to encourage social interaction or reinforce behaviors, missing or being late for

appointments or therapy sessions, researching less or not following up on information, or not following up with professionals or agencies.

When professionals remarked on parents' inability to meet the demands of various forms of intervention by themselves, their inability was most often attributed to having other priorities that competed for the parent's time and attention. Professionals described two important implications of this: either that demands on the parent needed to be scaled back (e.g., by asking the parent to discontinue a 12-week training program and re-register later when she has more time); or more preferably, that more strategic support of the parent should be built into the intervention (e.g., one professional observed personalized coaching from nurses to be more effective than a handout at motivating parents to follow through with implementing visual schedules at home).

Finally, to simplify discussion, the focus above has been on competing priorities besides those related to dealing directly with autism itself. The examples of autism-related priorities competing with one another are both common and apparent, both in terms of parent experience and from professionals' perspectives. Such priorities include both the demands of parenting the child with autism (including acute crises), and the demands of navigating intervention (including participating in its implementation). These consume parents' available time and energy, or divert their focus, in much the same way as the non-autism–related priorities described above. Likewise, the excess of priorities leaves many parents struggling with a sense of guilt for not doing more.

Questioning

Questioning refers to situations where parents do not accept or act on the information or recommendations of a health professional or the greater system they have interacted with. The two perspectives on parent behavior, that of the experiencing parent and that of the observing

professional, probably have greater potential to be mismatched for *questioning* than for other forms of staying. This is because parents are often unlikely to discuss their reasons for not following advice, disbelieving information professionals provide, or disengaging from the services of a professional they are *questioning*. Therefore, many of the corresponding behaviors apparent from the professional's perspective, such as mistrusting, deciding not to take up a recommended option, or discontinuing a relationship with the professional, are never completely explained or revealed to them from the parent's perspective.

As upcoming examples from the parent's perspective will illustrate, *questioning* is also a natural act through which parents involve themselves more deeply in pursuing intervention, by critically weighing, filtering, and deciding among the complex informational and intervention-related options in front of them. Therefore, paradoxically, while *questioning* qualifies as a form of *staying* (in which the parent neglects to initiate a course of action that the observer feels would likely be effective, beneficial, or lead to progress in addressing what they believe is or should be a parent-held concern related to autism), it is often also a form of action that can be quite proactive.

Although parents sometimes *question* professionals' information or recommendations at a point during the process of *adjusting*, this act is ultimately done to support the process of *pursuing intervention* (recall the processes of *adjusting* and *pursuing intervention* sometimes overlap). Example 14 illustrates how *questioning*, in the form of mistrust of information, can explain a behavior such as denial occurring early in the *adjusting* stage. Interestingly, this case of denial is reported from the parent's perspective.

> *Example 14. In the course of seeking the reason for their son's delayed speech, a family took their son to an Ontario Early Years Centre, which referred them to their regional Preschool Speech and Language Centre. The Speech and Language Centre in turn referred them to a developmental pediatrician who saw them four months later and*

diagnosed their four-year-old son quickly in the first appointment. When asked about his feelings at the early stages after the diagnosis, the father replied, "Just kind of confused, I guess. I was in denial mostly. I just assumed, 'Oh, he just doesn't want to talk.'" He reported quietly questioning the validity of the diagnosis based on the reasoning that "It was [only] an hour visit and they'd already made the assumption 'This is what he has.'" This example of the father's questioning took place within a process of pursuing intervention for speech delay, a much more limited concern than their son's autism, which completely took the family by surprise when it was diagnosed so suddenly.

The option of *questioning* professional wisdom that parents of children with autism have reflects their power and responsibility for ultimately determining the route for addressing concerns and what interventions are implemented. But, as described previously, it is easy for parents to feel like they are *making her own way* in the dark (see Section 4.2, *External obstacles*), and this sometimes makes the outcomes of their *questioning* seem quite uncertain. Any feelings of uncertainty, combined with the parent's awareness of her own responsibility, can turn the act of going against professional recommendations into another unwanted source of anxiety.

Parents interviewed for this study provided numerous examples in which a professionals' ideas or recommendations were at odds with their own thinking on how to deal with the child or how to adjust an intervention to accommodate for the child's idiosyncrasies. In many cases, especially those involving newly trained or very young professionals who lack experience but still give advice that is incongruent with the parent's knowledge, the parent seemed to have greater experience and wisdom than the professional she was dealing with. In such cases, critically *questioning* (sometimes refusing professional recommendations) seems to be an almost essential strategy for parents *making their own way*. *Questioning* (or *actively agreeing*) is usually preferable to *passively trusting* professionals for parents who have *adjusted* to the realities of having to make their own way (see *not knowing* above). Example 15 illustrates how *questioning* can sometimes lead to better decisions that benefit the child.

> *Example 15. The book A Mind Apart uses examples of real individuals with autism to illustrate the disorder's many aspects. The example of Hershel (Chapter 7) illustrates the case of a determined mother who disregarded the advice a specialist whom she had recruited to diagnose her son. This was sometime in the 1950's, and the specialist had recommended she educate her son separately from typically developing children and eventually institutionalize him. Instead, based on her own intimate knowledge of her son, she decided it was better to integrate him as much as possible. This included enrolling him several community activities, and in regular kindergarten despite "having to fight" with the school, the school board, and administrators to do so. It later turned out that her intuitive actions were probably the best thing this mother could have done. But she made these decisions on her own, remarkably, prior the existence of any research evidence "that mainstreaming children with autism was more beneficial in most circumstances than setting up special schools and segregating them from their peers" (p. 110). The author of the book, an expert with over 30 years supporting families with autism, attributed Hershel's positive outcome—he was in university at the time—to his mother's forceful actions.*

This is a powerful example because it illustrates how a parent's *questioning*—based on intuition informed by extensive familiarity and knowledge of the child—can potentially lead to decisions that are superior not only to a professional's recommendations, but also to the prevailing wisdom and science of the time.

Finally, *questioning* can be a process not just of making decisions between known options for addressing autism-related concerns, but of deciding whether it is beneficial to continue devoting energy to advocating for special needs or more worthwhile to focus on other aspects in the parent's life. These are decisions, implicit and explicit, that flow from parents *seeing the need for balance* once they have entered a process of *easing off*. The result is that the more seasoned parent may appear to some observers to pursue fewer of the available interventions that may hold promise for helping their child. Of course, the other way to interpret such behavior is to understand that the parent and family have become more comfortable with her child as he is, and the mother's restoring attention to herself is a natural equilibrating process that strengthens the family system surrounding the child with autism.

Conclusion to staying

In conclusion, the conceptual terrain regarding why parents appear to *stay* is complex and broader than presented here. There are certainly examples even within the data for this study that the categories above do not account for. Particularly, I have avoided discussing some forms of *staying* for which I have information from observers' perspective but not the parent's. Rather than providing a comprehensive account, therefore, the intent of this subsection is to draw attention to the fact that *staying* can take numerous forms, and to increase readers' sensitivity to the many different possible explanations why parents sometimes appear not to pursue what an observer believes is the best course of action.

Appendix L. Supplemental analysis: Framework for involving parents in intervention

An important aspect of the findings was the substantial body of proposed recommendations that both parents and professional participants offered for improving the problematic aspects of *having to make your own way*. The *framework for involving parents in intervention* outlined here was developed primarily as a tool for structuring the presentation of these recommendations for improving support to parents. This framework combines two analytic ingredients: a theoretical perspective regarding modifiability of health contexts suggested by the health literacy literature, and a notion of *stages of parent capacity for involvement* that is derived directly from the previously described theory of *making your own way*. These two ingredients and their implications in the form of a framework for involving parents in intervention are described next.

Health literacy perspective

Health literacy has been defined in several ways. The Institute of Medicine has defined it as, "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (Nielsen-Bohlman et al., 2004, p. 2). Some authors and organizations propose conceiving health literacy as a dynamic state comprising a combined function of individual healthcare consumers' skills on one side, and the demands placed on them by their particular health context on the other (Baker, 2006; Murray et al., 2007). Thus, health literacy "may vary depending upon the medical problem being treated, the healthcare provider, and the system providing the care" (Baker, 2006).

These ideas can be considered in terms of a simple theory: Health literacy involves consumers applying personal *skills* to complete *tasks* related to finding and processing health information and obtaining health services. These tasks, in turn, are determined by *demands* of the health context, which is defined by the problem consumers seek to resolve and the systems of

care (including professionals) that are available to help them resolve it. At a basic level, the concepts that are most relevant here are parent *skills* and system *demands*.

Importantly, this health literacy notion of skills and demands was not imposed in an *a priori* fashion in constructing the theory of *making your own way*. Rather this notion was brought in at the final stages of analysis—after the full dataset had been analyzed from a symbolic interactionist perspective. At this point it was clear to see how these two concepts were consistent and had relevance with the central concept of *making your own way*. The notion was ultimately used as an analytic device in formulating an explicit understanding of how parents' skills (or capacity) at different stages of *making your own way* can be matched or mismatched with demands of the system.

The main utility of this health literacy perspective is that is helps identify and distinguish analytically between the two aspects of parent experience and system-related context, as well as articulate how they both fit together. Bearing this perspective in mind also helped me distinguish explicitly between interview informants in terms of who likely provided the most valuable information on each aspect: parents provided the most insightful information on parent experience, while professionals generally had the deepest and least speculative knowledge about system-related context.

Parent skills can be defined differently from varying perspectives including the researcher's (mine), the participant observer's (both professionals and parents observing other parents), or that of the subjective parent. As I described earlier (Section 4.2, *Burdens*, *Work*, *Skills*), the full skillset that is often required of parents of children with autism is daunting and thus parents themselves frequently feel they lack certain skills. Participant observers sometimes perceived parents to lack individual skills in specific situations. The skills they perceived other

parents to lack most often included either language and literacy skills, or social and negotiation skills. Meanwhile, the skill that parents most often perceived themselves as lacking was knowledge. Even parent participants whose first language was not English, and whom others might consider to lack fluency, almost never considered their English language skills as lacking.

Aspects of the experience of navigating intervention that parents described in interviews as being problematic generally indicated a mismatch between parent skills and system demands from a health literacy perspective. As well as parents describing such problems at a personal or more general level, both parents and professionals provided ample information in the form of *proposed solutions*. The health literacy perspective therefore made a useful component of a framework for organizing where potential solutions should be targeted along the stages of parents *making their own way*, as will be described.

Parent capacity for involvement vs. system demands. There are many aspects of the systems that parents turn to for intervention that require their involvement to a greater degree than for almost any disorder. Although they will vary by region, some relevant contextual aspects that shift responsibility onto parents include fragmentation (lack of integration) and highly diverse services, inadequate case management and informational support, limited resources within publicly funded systems including the lack of time available to professionals, high financial costs for private therapy options, the high volume and frequency of appointments or therapy sessions to attend, limitations to the availability or geographic location of autism experts, and the requirement of many programs to generalize child behaviors to the home and other settings. Involving oneself in intervention—coordinating and travelling to appointments, raising funds to cover costs, interacting with and facilitating communication between multiple professionals, implementing therapy at home, negotiating with educators for special

accommodations, shopping and cooking for special diets, administering medications and supplements, approaching other parents for play dates, or tending to personal mental health and wellbeing—is a central manifestation of parents' proactive drive as they pursue intervention. Parents are not always well positioned, however, to respond positively to these needs to be involved. Their capacity (or predisposition) for involvement is defined by the resources at the parent's disposal at that specific point in time—including her skills, and finite expendable resources including time, financial resources, and physiological reserves (energy) for coping physically, emotionally, and cognitively. Limitations to these resources have been discussed previously as *internal obstacles*. They may be one explanation for why some parents are perceived by observers to be non-proactive, or *staying*. On the other hand, when system requirements or demands are well matched to a parent's capacity, asking for parent involvement in intervention works well. Parent involvement in intervention generally encourages greater engagement with the child, which improves the child's social connectedness. As some professionals point out, this may in turn contribute to improving child outcomes.

When the requirements or demands of the system are poorly matched or exceed a parent's capacity, calling for parent involvement can have negative consequences. First, it often leaves the parent feeling overwhelmed, sometimes to the point of a frozen paralysis where she is unable to take action. One parent, Susan, described her feelings towards the end of an arena assessment (a form of diagnostic assessment that brings multiple professionals together simultaneously) in which she received many successive recommendations for actions she could take to help her son in the context of hearing an inconclusive diagnosis. At that moment Susan was too preoccupied with the impending need to advocate for a more definitive reassessment to pay any attention. "I was completely overwhelmed. It wasn't like one person giving me…it wasn't an OT giving me

recommendations or the PT. It was everybody at once. And it was just too much." Feeling overwhelmed in turn contributes more stress to the parent's already emotionally stressful situation around the time of diagnosis.

The parent can potentially respond with feelings of frustration and resentment towards the system. In Susan's case, she felt forsaken after the arena assessment. Compared to the professionals surrounding her she felt profoundly underequipped to help her child. For example, Susan recalled one professional introducing the idea of using picture schedules with her son. But she was in no position to hear much of the advice given at that particular time, and yet she would receive no support from this professional to help her further understand or implement this intervention once she left the room. Recounting her feelings soon after the experience, she recalls how she simply could not understand why all this responsibility was being "dumped back" on her, especially considering that there had been experts much better equipped to help right in the same room during that assessment. She recalled thinking exasperatedly, "You're giving us a diagnosis and you're pushing us out the door. That's awesome."

In some circumstances where a parent is overwhelmed, requesting her involvement when she is not ready can trigger an acutely angry and resentful response that results in the parent *disengaging* from the professional or system that is trying to help. A highly experienced therapist described such an incident with a mother who was highly anxious and at a particularly stressful stage of adjusting to problems related to her child's sleeplessness:

> *"Her son has been up, like, five to six times a night. And I was careful in the way I said it. But I said to her, 'I think it would be good if you just had an EEG, just to see if there's any seizure activity [as disrupted sleep patterns can be a sign of seizure disorder].' And she turned around and called me a liar. And I said, 'You know, I have no ability to diagnose or anything, but I think it's something worth looking at.' But I haven't seen her. Like, she sends her husband now. So sometimes you can even...you can have the best of intentions, and you have information, but people are so anxious they can't even hear it. Or they get angry at you for giving them that information."*

Disengaging can in turn mean further delaying or missing opportunities for effectively involving the parent in intervention. From the professional's perspective, the parent is observed to be *staying*, which can explained by various legitimating processes from the perspective of the parent. While these processes are unknown in this case, the mother's feeling overwhelmed was almost certainly one of them. Importantly, the processes leading a parent to disengage and the resulting missed opportunity for involving her in intervention can often be traced to the mismatch between the parent's capacity for involvement at an early stage of *adjusting* to a serious problem or transition, and the demands placed on her by the system—even when demands are placed carefully and sensitively, as in the example above.

Stages of making your own way and implications for involving parents

The parent process of *making your own way* has three stages or sub-stages that are relevant for involving parents: first, is the early part of the stage of *beginning the autism journey*, in which the parent readies herself for *taking action*; second, are the later parts of *beginning the autism journey* and the stage of *handling transitions*, which generally includes a periods of high motivation for participating in action, including the phenomenon of *going into high gear*; and third, there is the stage of *easing off,* in which parents moderate the intensity of their energy for *taking action to pursue intervention*. In each stage, the parent's capacity for involvement varies. As we have just seen, parents have the least capacity for involvement at the early part of the stage of *beginning the autism journey*, prior to *emotionally adapting* to their new situation and *informing their self* about autism and options for action. It is at this stage—when parents' personal stress is usually most acute, when marital strain is most likely, when parents are least knowledgeable, least organized or cognitively prepared for action, lack relevant skills, are most emotionally most vulnerable, or closest to the breaking point—that systems need to provide

maximum support to the *parent* within the intervention they provide. The aim should be to support the family's early mental health-related needs, allowing the parent to gather the personal resources she will need when she is ready to take action. This will maximize parents' capacity for effective involvement in future stages, both in intervention and with the child. Targeting intervention at the family system at this stage strengthens the child's home environment, which, as several professionals pointed out, may ultimately be the best strategy for helping the child.

In becoming ready for *taking action* (including *going into high gear*), after *emotionally adapting* and progressing sufficiently through other sub-processes within *adjusting*, parents are highly motivated to participate in finding and implementing intervention. It is at this point therefore that parents are usually much more receptive to being somehow involved in intervention. This is when the capacity of parents comes closest to matching system demands, as parents' motivation leads them to develop skills for navigating intervention. At this stage systems should provide maximum opportunity for parents to be involved in intervention and interacting with the child.

In the third stage, *easing off*, parents have expended substantial resources participating in finding and implementing intervention and are now pursuing greater balance in their lives by reclaiming personal identity outside of special needs. It is at this stage when it makes sense for systems to reduce demands on the parent by assuming more responsibility for supporting the child as he or she progressively transitions to adulthood. If the parent has been well supported at the earliest stages, and then allowed maximum opportunity for involvement as she became ready for it, child outcomes by this stage will likely be more positive. This includes greater independence and possible vocational success, reducing potential dependence on the system to support the adult child.

In other words, the stages of *making your own way* have implications for how systems can cater to parents' readiness and capacity for involvement across the lifespan of the child. Next, numerous proposed solutions that were offered by participating parents and professionals are discussed in terms of where within this stage framework should changes to the system be positioned to best support parents' timely involvement in intervention targeting autism-related concerns.

Figure Appendix.L.1. Diagrammatic representation of the *framework for involving parents in intervention*, which matches system demands to parent capacity for involvement.
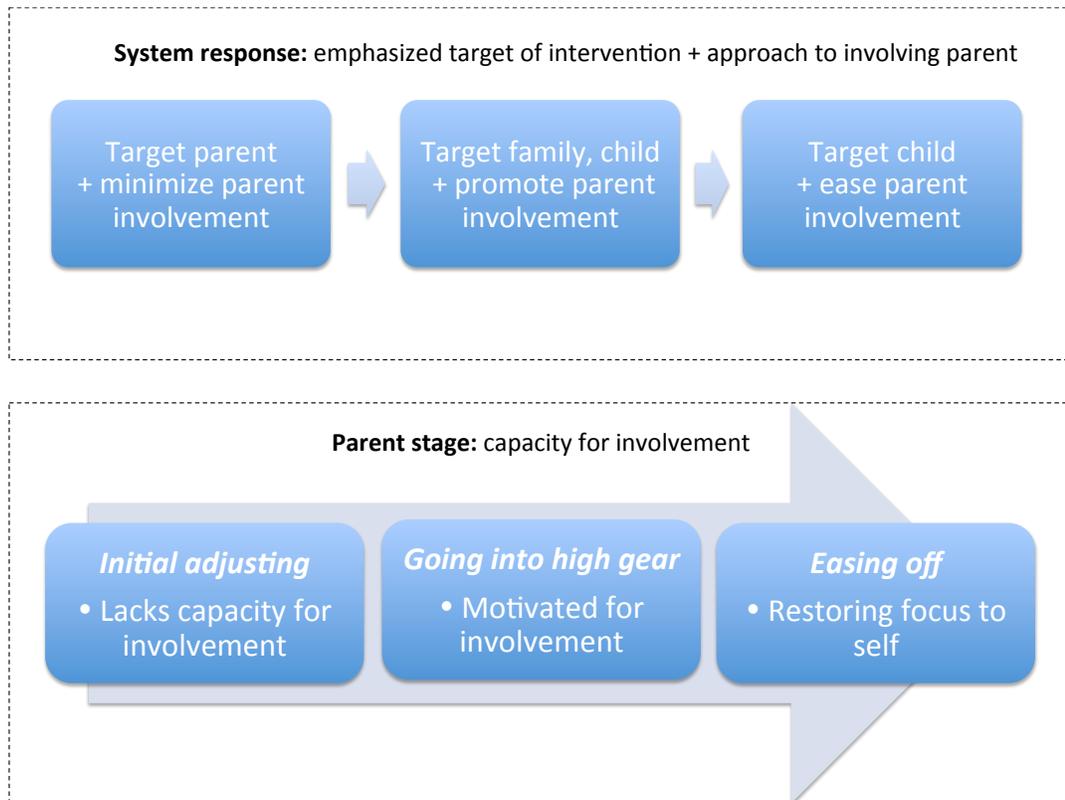
While this framework was originally developed as a device for organizing solutions in the following discussion, it may prove to be useful for other purposes.

Appendix M. Appropriate criteria for evaluating grounded theory

For evaluation and critique of any qualitative study to be relevant and valid, those evaluating such studies should take care not to apply inappropriate standards that project an inconsistent methodology onto the research (Cohen & Crabtree, 2008; Dixon-Woods, 2004). Ideally, evaluators should have sufficient understanding of the methodology on which the researcher's method is based. As I have indicated, the primary methodology used here is symbolic interactionism (Blumer, 1969), with the addition of more recent constructivist ideas from the relevant grounded theory developers (Charmaz, 2006, 2014; Corbin & Strauss, 2008).

In the absence of in-depth methodological knowledge, and even in support of it, evaluation criteria specific to grounded theory are a useful resource; and all the major grounded theory developers have provided their own versions (Charmaz, 2006, 2014; Corbin & Strauss, 2008; Glaser & Strauss, 1967; Glaser, 1978; Strauss & Corbin, 1990, 1998). Below, I suggest the criteria of Charmaz (2006, 2014) as a highly usable and appropriate tool for evaluating this study—note, while I have used Corbin and Strauss (2008) as my primary methods guide, I find Charmaz' criteria more usable because they are more concise, and are still appropriate because they are mostly consistent with Corbin and Strauss' criteria. I reproduce Charmaz' (2014) list without commentary simply for reference, so that anyone wishing to evaluate this study can have an appropriate set of criteria at hand to guide their critique:

Credibility

- Has your research achieved intimate familiarity with the setting or topic?
- Are the data sufficient to merit your claims? Consider the range, number, and depth of observations contained in the data.

- Have you made systematic comparisons between observations and between categories?

- Do the categories cover a wide range of empirical observations?

- Are there strong logical links between the gathered data and your argument and analysis?

- Has your research provided enough evidence for your claims to allow the reader to form an independent assessment—and *agree* with your claims?

Originality

- Are your categories fresh? Do they offer new insights?

- Does your analysis provide a new conceptual rendering of the data?

- What is the social and theoretical significance of this work?

- How does your grounded theory challenge, extend, or refine current ideas, concepts, and practices?

Resonance

- Do the categories portray the fullness of the studied experience?

- Have you revealed both liminal and unstable taken-for-granted meanings?

- Have you drawn links between larger collectivities or institutions and individual lives, when the data so indicate?

- Does your grounded theory make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights about their lives and worlds?

Usefulness

- Does your analysis offer interpretations that people can use in their everyday worlds?

- Do your analytic categories suggest any generic processes?

- If so, have you examined these generic processes for tacit implications?

- Can the analysis spark further research in other substantive areas?