

MSc. Thesis – Kajaani Shanmugarajah; McMaster University – Rehabilitation
Science

FUNCTIONING AND NEURODEVELOPMENTAL DISORDERS

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**EXAMINING EVERYDAY FUNCTIONING IN FAMILY-CENTRED SERVICES
FOR CHILDREN WITH NEURODEVELOPMENTAL DISORDERS**

By KAJAANI SHANMUGARAJAH, B. Arts Sc.

A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the
Requirements for the Degree Master of Science

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TITLE: Examining everyday functioning in family-centred services for children with neurodevelopmental disorders

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LAY ABSTRACT

To support the shift in health care that focuses on the abilities of children with neurodevelopmental disorders (NDD) rather than their ‘problems’ or ‘deficits,’ we need to further understand how family-centred services (FCS) can better fit this change in thinking. This thesis explores paediatric health care focused on addressing ‘everyday abilities’ for children with NDD in research and clinical practice over two studies. Study #1 reviews some of the current ways that everyday functioning is measured in paediatric health care, examining 14 clinical tools developed for children with NDD. Study #2 reports key patterns that describe the experiences of parents of children with autism, in regards to how they think about their child’s abilities, and the care their child receives. Overall, this thesis studied new ways that we can explore the abilities of children with NDD in FCS, specifically concerning how parents and clinicians describe and measure functioning.

ABSTRACT

Neurodevelopmental disorders (NDD) refer to conditions that can be present during a child's early developmental period, and are typically characterized by challenges in a child's personal, social, academic, or occupational functioning. Autism spectrum disorder (ASD) is an example of NDD, impacting 1 in 66 children in Canada. While interventions vary across this heterogeneous group of impairments, everyday functioning is an important outcome to families. However, this concept of functioning needs further examination with respect to whether and how it is incorporated within the instruments and concepts used in family-centred services (FCS), and how this is understood by parents. This thesis is composed of two studies: a narrative review identifying function-focused measures published in the literature for children with NDD; and a qualitative study examining how parents of children with ASD perceive their child's abilities in relation to family-centred services. Fourteen clinical measures were described in the review based on how they utilized the International Classification of Functioning, Disability, and Health (ICF) to describe child functioning. In the qualitative study, five themes (Parenting Approaches, Accepting My Child, Managing Child's Challenges, Doing the Right Thing for My Child, and "The Disability Tag") were identified as influential factors that can affect how parents perceive their child's abilities and functioning. As the cultural shift within interventions for children with NDD continue to move beyond the historically prominent deficit-focused lens, and towards the integration of neurodiverse abilities, this study enables us to understand better how concepts of function-focused care are operationalized in family-centred services and intervention systems.

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LIST OF ABBREVIATIONS

ABA	Applied Behaviour Analysis
ACSF-SC	Autism Classification System of Functioning: Social Communication
ASD	Autism Spectrum Disorder
BFMF	Bimanual Fine Motor Function
CAPE & PAC	Children's Assessment of Participation and Enjoyment & Preferences for Activities of Children
CAP-HAND	Children's Assessment of Participation with Hands
CFCS	Communication Function Classification System
FOCUS®	Focus on the Outcomes of Communication Under Six
GOAL	Gait Outcomes Assessment List
GMFCS-ER	Gross Motor Function Classification System Expanded & Revised
IBI	Intensive Behavioural Intervention
ICF	International Classification of Functioning, Disability & Health
ICF-CS	ICF Core Sets
ICF-CY	International Classification of Functioning, Disability & Health – Child & Youth
ID	Interpretive Description
MACS	Manual Ability Classification System
NDD	Neurodevelopmental Disorders
PEM-CY	Participation and Environment Measure for Children and Youth
SAAAC	SAAAC Autism Centre
WHO	World Health Organization

DECLARATION OF ACADEMIC ACHIEVEMENT

In examining this topic, the student investigator (Kajaani Shanmugarajah) was the main contributor to: the development of the research questions and objectives; study design and methodology; conducting a systematic search strategy (Chapter Two); data collection and the development of recruitment strategies; interviews with parent participants; transcription of interviews; data analysis and interpretation and writing of Chapter Three. This study was approved by the Hamilton Integrated Research Ethics Board (Project #12772).

The co-investigators in this thesis included: Dr. Briano Di Rezze, OT, Ph.D. Associate Professor, School of Rehabilitation Science, McMaster University; Dr. Peter Rosenbaum, MD, FRCP(C), Professor, Department of Pediatrics, McMaster University; and Dr. Mohammad Zubairi, MD, MEd, Associate Professor, Department of Pediatrics, McMaster University.

The co-investigators provided ongoing feedback and support throughout the research process. They assisted in refining the research questions, proposed methods, interview guide, and interpretations of the findings.

CHAPTER ONE: INTRODUCTION

Introduction

The study of everyday abilities or *function* are concepts that are often examined in the context of care by clinicians, researchers, and families of children with neurodevelopmental disorders (NDD), including autism spectrum disorder (ASD). Function can be explored in a multitude of ways, ranging from longitudinal studies that examine development pathways and daily living skills for young children and adolescents with NDD, to models like the ‘F-Words in Child Development’ that provide a set of ideas to promote abilities-based thinking for children with disabilities in home, clinic, and research-based settings (Di Rezze et al., 2019; Palisano et al., 2020; Rosenbaum & Gorter, 2012). At the same time, it is important to consider how function has been understood by individuals involved in family-centred services and in the research that is used to inform clinical goal-setting and care.

Over the last 50 years, there has been a growing momentum to reconsider the ways in which we understand function within the realm of childhood disability. There are various ways that it can be described by professionals that work with children with NDDs (and their families), and in research settings (Üstün & Kennedy, 2009). For example, the concept of “functioning” (as distinct from ‘function’) is described by WHO’s International Classification of Functioning, Disability, and Health (ICF) as the positive and neutral elements of an individual’s body functions, activities, and participation in life situations (World Health Organization, 2001). Expanding beyond a reductionist, diagnosis-based view of disability, the ICF framework has provided a paradigm shift in

the ways in which clinicians and researchers conceptualize and use “functioning” within interventions for children with NDDs (Rosenbaum & Novak-Pavlic, 2021). Evidence in the literature also suggest that everyday functioning is meaningful to families for their children, so promoting a strengths-based approach alongside functioning would be imperative in family-centred services (FCS) that prioritize family quality of life, resilience, and inclusivity (Almasri et al., 2018; Ferrer et al., 2017; McConachie et al., 2018).

Using concepts derived from the ICF, functioning can also be described by the clinical tools and measures that are developed for children with NDD. These measures can *describe* specific aspects of function (e.g., Autism Classification System of Functioning: Social Communication [ACSF] describes levels of social communication functioning among young children diagnosed with ASD); *predict* concurrent/future status of an individual’s functioning capabilities (e.g., Gross Motor Function Classification System [GMFCS] examines gross motor function for children and youth with cerebral palsy (CP), and has been explored longitudinally to validate its predictive capacity); or *evaluate individual change* over time (e.g., Gait Outcomes List [GOAL] evaluates gait priorities and functional mobility for ambulant children with CP) (Di Rezze et al., 2016; Rosenbaum et al., 2008; Rosenbaum, 2015; Thomason et al., 2018). Since these measures are used by clinicians and families, it would be beneficial to understand how these measures describe functioning, and the importance of examining this concept.

This work will explore the role of functioning or function-focused care in research and clinical practice, with a specific focus on examining current function-focused tools

used for children with NDD (as reported in Chapter 2), and parent perspectives about ASD and everyday functioning (as presented in Chapter 3). This study will also examine the roles of strengths/abilities-based approaches for children with NDD, as these concepts can be intertwined with functioning. The movement towards the acceptance of abilities/strengths-based approaches to disability has emerged from a historically deficit-focused worldview, including the clinical utility of ICF-based tools that focus on the contextual factors of functioning beyond an individual's health conditions; and the neurodiversity movement that views (and celebrates) disability as child difference rather than disorder (Gan et al., 2013; Kapp et al., 2013; McMahan et al., 2021). Therefore, this work can be important for clinicians, researchers, families and the community where children live and grow. Studies have also reported that prioritizing strengths-based practice within interventions can promote both better health outcomes for children and overall family quality of life (Emily & Grace, 2015; Niemiec et al., 2017; Williams et al., 2021).

Background Information

As described in the *Diagnostic and Statistical Manual of Mental Disorders - 5th edition*, neurodevelopmental disorders (NDD) refer to a group of conditions that present during a child's early developmental period and are characterized by developmental deficits in a child's personal, social, academic, or occupational functioning (American Psychiatric Association, 2013). The prevalence rates for NDD in developed countries range from 7-14% of all children, and include diagnoses such as: cerebral palsy,

attention-deficit/hyperactivity disorder, learning disabilities, and intellectual disability (American Psychiatric Association, 2013; Boyle et al., 2011). Autism spectrum disorder (ASD) is a common NDD, affecting as many as 1 in 66 children in Canada (Public Health Agency of Canada, 2018). Children with NDD, including ASD, can present a heterogeneous range of symptoms and cognitive functioning (Viljoen et al., 2021). However, ASD is often characterized by restrictive, repetitive, and stereotyped behaviours as well as challenges in communication and social interactions (American Psychiatric Association, 2013). Historically, individuals with NDD have had unaddressed needs and limited opportunities to participate in different environments among their neurotypical peers (i.e., school and social participation), often due to the negative portrayal within these groups as “being disabled” (Menezes et al., 2021; Winchell et al., 2018). There is a growing number of children who have NDD, and clinicians need to understand more fully how to highlight the context in which a child’s “deficits” may have an impact on daily functioning (Boyle et al., 2011; Viljoen et al., 2021).

History of ASD & Focus on Deficit

Looking specifically at the history of ASD, the term *autism* was introduced in 1911, but characterized in 1943 by American psychiatrist Leo Kanner (Harris, 2018; Kanner, 1965). In his research with 11 children with ASD, he explored common patterns of “autistic” behaviours using a set of symptoms that could be later used to diagnose *infantile autism* (Kanner, 1965). However, he often made many comparisons between ASD and schizophrenia, which had led to continuous debates about whether ASD was

considered to be part of the schizophrenia complex or should be taken as its own entity (Harris, 2018; Kanner, 1965). This lack of clarity also led to ASD being classified as infantile psychosis in the DSM-II (Harris, 2018). It was not until 1980 (37 years later) that the term *infantile autism* became its own unit and entered the American Psychiatric Association's Diagnostic and Statistical Manual, DSM-III. Initial symptoms of infantile autism included pervasive lack of responsiveness to others, deviant language development, and unusual responses to the environment (American Psychiatric Association, 1980). With the new knowledge learned about this condition over the years, in 2013, autism was classified as ASD in the DSM-5 (American Psychiatric Association, 2013).

Since ASD was first introduced in 1911, there has been a strong emphasis on remediation for children diagnosed with ASD to gain/regain skills (Akhtar & Jaswal, 2013). Behavioural treatments for ASD have also had a problematic history, with therapies such as Intensive Behavioural Intervention (IBI) and Applied Behaviour Analysis (ABA); before the 1990s, early forms of these interventions used aversive stimuli such as sensory punishment or negative reinforcement to ensure children diagnosed with ASD learned desirable behaviours (Smith & Eikeseth, 2011). These children were artificially trained to fit “normal” social standards, which emphasized the deficits of these children (Kapp et al., 2013; Kirkham, 2017). There have been significant modifications to the ways in which behaviour treatments and therapies are conducted for children with ASD today (Kirkham, 2017). However, some practices continue to focus on efforts to achieve normal behaviour, “eliminating” autism-related stereotypical

behaviours (i.e., jumping, yelling, hand-flapping), and “fixing” other limitations of the child (Kirkham, 2017).

“Deficit-based approaches” or “deficit-view” are common terms that characterize how certain individuals and groups have been labeled, studied, and/or understood (Dinishak, 2016). Many academic studies have either limited or token discussions regarding the gifts and talents of individuals with ASD, and often create gaps in research designed to promote positive child participation and functioning (Dinishak, 2016; Robertson, 2009). These approaches are critiqued for prioritizing interventions that focus mainly on the perceived deficits and limitations of individuals, rather than exploring the diversity in the strengths of individuals with ASD (Baron-Cohen, 2017; Dinishak, 2016).

ASD and Neurodiversity

Disability can be studied using two theoretical frameworks: the medical model and the social model of disability. The medical model views disability as a disease, disorder and/or illness that requires specific diagnosis, treatment and rehabilitation for the individual to be a productive member of society (McMahon et al., 2021; Miller & Rosenbaum, 2016). This traditional thinking about disability focuses on the treatment of the disorder, rather than the individual’s functional capabilities and the contextual environment of the individual (Miller & Rosenbaum, 2016). In contrast to the medical model, the social model views disability as a social construct created by the individual’s environment; therefore, the key to “alleviating” disability is by addressing the contextual factors that cause inequity and segregation (McMahon et al., 2021).

The refined characterization of ASD emerged from a lack of neurological evidence that linked ASD with dysfunction, and an increased understanding of the heterogeneity of abilities among individuals diagnosed with ASD (Baron-Cohen, 2017). The neurodiversity movement, championed by disability and autistic advocates in the 1990s, fought for the rights of individuals with ASD to be recognized and accepted as individuals with a *difference* rather than a *disorder* (Baron-Cohen, 2017; Kapp et al., 2013; Kenny et al., 2016). This contemporary movement celebrates the range of strengths within this population, promoting equity and social inclusion of individuals diagnosed with ASD (Jaarsma & Welin, 2012). Encapsulating the social model of disability, autistic self-advocates often argue that autism represents one's identity, and cannot be separated from the individual (Owren & Stenhammer, 2013). This movement aimed for social change in the ways in which we think about ASD and disability, and to rethink how clinicians conduct behavioural intervention programmes for children with ASD, such as ABA therapy (Jaarsma & Welin, 2012; Kapp et al., 2013). For example, both the social model of disability and neurodiversity movement helped promote abilities/strengths-based practice within interventions for children with ASD (McMahon et al., 2021). By exploring the positive functioning of children with ASD, this group is then better recognized as being capable individuals (Green et al., 2014).

The Introduction of ‘Functioning’ using the ICF

To better understand, conceptualize, and standardize how ‘functioning’ would be defined in clinical practice, in 2001 the World Health Organization developed the International Classification of Functioning, Disability, and Health (ICF) framework (World Health Organization, 2001). Blending the medical and social models of disability, the ICF is a contemporary conceptual framework that challenges deficit-focused thinking and proposes an integrated biopsychosocial model of human functioning and disability (World Health Organization, 2001). Using this model, needs that exist beyond the biomedical scope of practice, such as within social, functional, and educational settings, can be better addressed.

The framework utilizes four key domains: body function & structures (functioning at the level of the body); activities (functioning at the level of the individual); participation (functioning as a member of society); and contextual factors (personal and environmental factors that can exist as facilitators or barriers) (World Health Organization, 2001). These four domains are interconnected and interact with one another in ways that make it possible to examine the different aspects (positive, neutral, and negative) that can occur between an individual’s health condition, such as ASD, and their context (World Health Organization, 2001). With the ICF framework, functioning is defined by both the positive and neutral interactions of the four domains that exist between a person and their contextual environmental.

The ICF provides a universal application for *all* individuals to describe their experiences of functioning, while managing a health condition (rather than focusing only

on individuals that are traditionally labeled as “disabled”) (Schneidert et al., 2003). This framework acknowledges how environmental and social contexts can play key roles in influencing how functioning can operate beyond individual limitations, as well as the complex and multi-dimensional nature of disability as a social construct (Castro et al., 2013; Schneidert et al., 2003).

Functioning & Function-Focused Care within Clinical Measures

By prioritizing functioning in the services and interventions that are designed for children with NDDs (“function-focused care”), we are able to promote more optimistic thinking among parents and clinicians towards disability, as well as create a common language that can be used by practitioners and families (Williams et al., 2021; World Health Organization, 2001). Clinicians are utilizing abilities/strengths-based approaches within their interventions, such as the use of different therapies to explore child strengths beyond academic and/or social skills (i.e., music, art therapy) (D’Amico & Lalonde, 2017; Hosseini et al., 2015; Schweizer et al., 2017). However, this approach can vary among practitioners and services, depending on the extent to which family needs within FCS are prioritized by practitioners for children with NDD.

Although functioning is defined in the ICF as encompassing all positive and neutral interactions of the four domains (body functions & structures, activities, participation, and contextual factors), there are multiple ways that research has defined ‘functioning’ to capture how a child is involved in life situations, especially in the clinical measures that are developed for children with NDD (Üstün & Kennedy, 2009). Beyond

clinical measures that utilize the ICF definition of functioning, other measures were developed prior to the publication of the ICF that also focus on child functioning and abilities. These measures include: Vineland Adaptive Behavior Scales (Sparrow et al., 1984, 2016); Adaptive Behavior Assessment System (Harrison & Oakland, 2000, 2015); and Behavior Assessment System for Children (Reynolds & Kamphaus, 1994, 2015). However, functional tools that have been developed post-publication of the ICF use different ways of measuring and describing functioning (e.g., Assistance to Participate Scale) (Bourke-Taylor et al., 2009). The variability in the use of the term *functioning* indicates the likelihood that there are gaps in how we may understand and operationalize this term for children with NDDs (including ASD) and their families.

Functioning in Family-Centred Service

Using the definition provided by Rosenbaum et al. (1998), family-centred service (FCS) refers to a set of approaches and ideas that can be utilized within the services delivered for children with special needs and their families (Rosenbaum et al., 1998). In FCS, clinicians recognize that families are unique, are the experts on the abilities and needs of their child, and are typically the constant in their child's lives (Rosenbaum et al., 1998). This approach to planning, delivery, and evaluation of health care services is built by a mutually beneficial partnership between families and clinicians, and can lead to better health outcomes, improved experiences in health care, and better allocation of resources (Carrington et al., 2021; Kokorelias et al., 2019). For these reasons, FCS is

desired in practice, as it allows clinicians to better understand and address specific needs that a family may have for their child.

Parents often experience a strenuous journey during their navigation of an ASD diagnosis for their child (Gentles et al., 2019a). From initial concerns to service navigation, parents typically seek the best interventions that fit their child's and family's needs, and that promote overall better health outcomes (Azad et al., 2019; Gentles et al., 2019a, 2019b). Evidence has shown that parents value outcomes across all domains of their child's functioning, including but not limited to: child abilities, difficulties, activities, and participation (McConachie et al., 2018). In these instances, parents emphasize the importance of lifelong functioning with an ASD diagnosis, especially in skill development for future functioning and promoting "autism-friendly" environments that can promote participation (Castro et al., 2013; McConachie et al., 2018). Parents play important roles in identifying and managing both the functional impairments and skills of their child, as these functional markers are often what drive health seeking-behaviours (Azad et al., 2019; Viljoen et al., 2021).

Although functioning is not implicit in FCS, decisions made together by clinicians and families can lead to goal planning within therapy, and clinical measures and assessments can guide these partnerships in different directions (directions that may not necessarily be function-focused). By examining both clinical measures and the perceptions of parents, we are better able to understand the roles of these components, specifically in the ways in which they guide parent-clinician partnerships within FCS. Overall, the study of functioning by examination of function-focused clinical measures,

and using parent perceptions of the functional impact of a child’s diagnosis, can help inform clinicians regarding what is meaningful to families in intervention planning for NDD, including ASD (Elder et al., 2017; J. Smith et al., 2015; Viljoen et al., 2021).

Study Objectives

The overall purpose of this thesis is to acquire a better understanding of how function-focused care is operationalized in research and clinical practice for children with NDD, with a specific focus on the ASD population.

This study will address the following research questions:

1. How do measures used in clinical and research contexts for children with NDDs reflect ICF-based conceptualizations of ‘functioning’?
2. What are parents’ perceptions of the everyday abilities of their child with ASD:
(a) regarding the child’s overall functional abilities; (b) navigating the ASD diagnosis; and (c) navigating interventions and/or supports.

Thesis Outline

This thesis consists of four chapters: Introduction, Manuscript #1, Manuscript #2 and a concluding chapter that discusses findings from both research studies in the context of function-focused care and disability (and considerations for future practice). Chapter 1 (Introduction) provides an overview of the literature, including: background information,

definitions of key terms, guiding theoretical frameworks (specifically the ICF), overall study objective, and research questions for each manuscript.

Chapter 2 utilizes a narrative review for the central methodology. Narrative reviews are a common form of literature, often used by the medical community; they can provide a comprehensive, critical, and objective analysis using current understandings of a topic, and can help identify patterns in the literature in order to seek potential gaps in knowledge (Baker, 2016; Green et al., 2006). This methodology was selected as an effective way to review clinical tools used in paediatric health and rehabilitation because of its high potential for individual insight and speculation compared to most quantitative synthesis approaches (Allen, 2017).

Chapter 3 reports a qualitative interpretive description study that will explore the perspectives of parents of children with ASD, with an aim to examine their experiences with both their child and the health systems as these experiences relate to function-focused care. This study utilizes Interpretive Description (ID) for the central methodology. ID is a type of qualitative methodology that utilizes a constructivist and naturalistic orientation towards knowledge generation and inquiry (Thorne, 2016; Thorne et al., 2004). ID requires the recognition of investigators' knowledge and contribution to the study as well as the declaration of the specific lens that would be utilized to analyze the data (Thorne, 2016). For this work, the critical lens includes: (a) findings from an investigator-led knowledge synthesis that examines existing literature on parent and clinician perceptions of an ASD diagnosis and interventions; (b) the definition of 'functioning' derived from the ICF by WHO; and (c) investigators' knowledge and

expertise regarding function-focused care for children with neurodevelopmental disorders.

Using semi-structured interviews, ID critically explores meaning and potential explanations within the experiences of participants to produce clinically relevant knowledge based on the findings from the data (Thorne, 2016). This research enables a deeper meaning and understanding of the phenomena of interest, as it seeks answers to questions that cannot be calculated or quantified (Cleland, 2017). Qualitative methods are important in this field of research, as they allow for participants to be given a platform to share their experiences. Key information such as specific approaches that families have found helpful may provide information about what families may expect from ASD interventions that can be beneficial to the field, and potentially uncover recommendations for clinicians on the ways in which potential challenges within function-focused care may best be addressed. Although Chapter 3 is focused primarily on an ASD population, virtually all of these ideas can be related back to the larger discussion of functioning and NDD. Chapter 3 focuses on the ASD population to maintain feasibility and to develop practical recommendations that may be most suited for this population.

In Chapter 4, we present a concluding discussion of the findings from the two manuscripts, and discuss recommendations for future research as well as potential areas of improvement in clinical settings.

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**A narrative review of function-focused measures for children with
neurodevelopmental disorders**

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**CHAPTER TWO: A narrative review of function-focused measures for children
with neurodevelopmental disorders**

Abstract: Clinical measures in health and rehabilitation settings are often used to examine child functioning to better support the diverse needs of children with neurodevelopmental disorders (NDD) and their families. The WHO's International Classification of Functioning, Disability, and Health (ICF) framework reflects a focus of health beyond biomedical deficits, using the concept of functioning to create opportunities for measurement development involving this construct. In the measures developed in the field of childhood NDD, it is unclear whether and how these tools measure and incorporate the ICF framework and its domains within health care contexts. Understanding how these measures utilize the ICF will enable researchers and clinicians to operationalize function-focused concepts in studies and clinical practice more effectively.

This narrative review aims to identify and describe function-focused measures that are based on the ICF for children with NDD, as described in the peer-reviewed literature. This review used a systematic search strategy with multiple health-focused databases (Medline, PsycInfo, EMBASE, EMCARE), and identified 14 clinical measures that provide direct support for children (aged 0-21) with NDD in paediatric health (and other) settings. Results described the measures that were primarily developed for three main diagnostic populations [cerebral palsy, autism spectrum disorder, and communication disorders]; had varying contextual use (clinical-only or multiple settings); and for which authors had conducted psychometric tests in the measure's initial development studies,

with the most common being content validity, interrater reliability, test-retest reliability. Participation (79%, n=11) & Activities (71%, n=10) were the most common ICF domains captured by the set of measurement tools. Overall (71%, n=10) of the identified measures utilized multiple ICF domains, indicating that the ‘dynamic nature’ of the interactions of the ICF domains was generally evident, and that this result differentiated from ‘linking rules,’ commonly used in research and clinical practice. The implications of these findings suggest that clinical measures can be an effective application of the ICF’s defined concepts of functioning for children with NDD.

1. Introduction:

Neurodevelopmental disorders (NDD), as defined by the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), refer to a group of conditions that present during a child’s early developmental period and are characterized by developmental deficits that may create challenges in the child’s personal, social, academic, or occupational functioning (1). Common examples of NDD include autism spectrum disorder (ASD), communication and/or language disorders, attention deficit/hyperactivity disorder, motor disorders (including cerebral palsy [CP]), learning disorders, and developmental coordination disorder (1). The prevalence rate for NDD in developed countries range from 7-14% of all children (2). Children with NDD may experience challenges in different environments, potentially impacting their functioning within academic settings (school), daily living skills (home), and the broader community (3-7). The DSM-5 describes these challenges as a symptom of excess, deficit, or delay in

key aspects of child functioning, especially when considering the achievement of expected developmental milestones (1).

Historically, biomedical models and thinking have greatly influenced clinical practice, including the field of childhood disability (8,9). This traditional way of thinking focused on the attributes of a child's deficits and limitations, for diagnostic purposes and to treat aspects of the child's 'disability' (10,11). In 2001, the International Classification of Functioning, Disability, and Health (ICF)—a contemporary conceptual framework—challenged these practices and highlighted the paradigm shift to think beyond the biomedical model to an integrated biopsychosocial model of human functioning and disability (8). This biopsychosocial model emphasizes that individuals with disabilities have needs that extend beyond the medical scope of practice, and are often broad-based in nature within social, educational, and functional settings (12).

As shown in Figure 2.1, the four key domains of the ICF are: body function & structures (functioning at the level of the body); activities (functioning at the level of the individual); participation (functioning of a person as a member of society); and contextual factors (personal and environmental factors that can exist as facilitators or barriers) (8). The ICF framework defines functioning as an umbrella term to describe the interactions of these four domains, examining the positive or neutral aspects occurring between the individual's health condition(s) and their context (8). 'Disability' is an alternate umbrella term used to describe the interactions of an individual's impairments, activity limitations and participation restrictions, examining the negative aspects of the interaction between the individual's health condition(s) and their context (8).

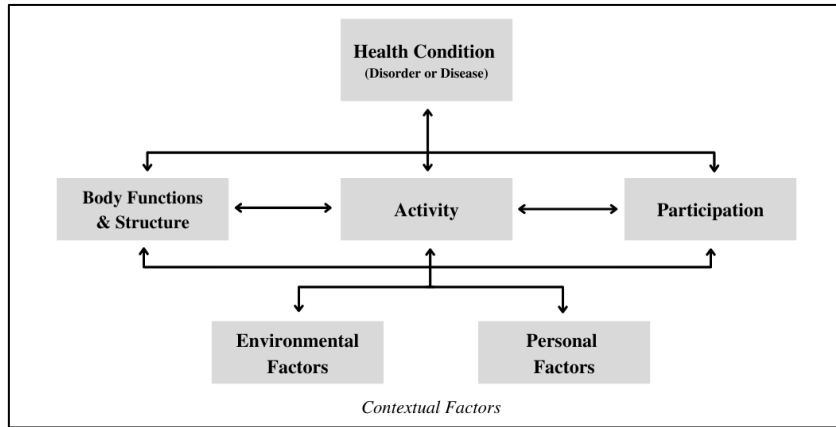


FIGURE 2.1: International Classification of Functioning, Disability, and Health Framework (8)

This ICF framework depicts the interactive and non-linear nature of the core domains, establishing that these conceptual domains are not independent when examining functioning and/or disability. The framework is representative of the biopsychosocial perspective, as it recognizes how the influences of physical, psychological, and social factors within ‘functioning and disability’ can be understood from the viewpoint of the individual with respect to their health condition (13,14). Without focusing on single descriptors to label a child’s functional abilities, this framework utilizes a holistic approach that still highlight the nuances in the interactions of the different elements that build a child’s functional profile (14,15). This framework indicates a paradigm shift in the ways that researchers and service providers understand disability, as it provides a multidimensional perspective that both classifies functioning independently from the individual’s diagnosis and views disability as product of person-environment interactions (12,15,16).

Children with NDD exhibit a wide range of levels of functioning within and between their diagnostic groups (17). In addition to the ICF framework, the field of NDD has seen growth in the concept of functioning that takes into consideration the heterogeneous level of abilities within diagnostic populations that extends across NDD (10). For example, within ASD literature, the concept of neurodiversity views neurological differences as inherent human variation, rather than as a disorder, and celebrates the individuality of a person—regardless of their capabilities (18,19). This change in thinking in the field of ASD has had a great influence in promoting various abilities and child differences within ASD interventions, including the language that is being used to describe the diagnosis (19,20).

Similar concepts of functioning started in the field of CP, in relation to interventions in paediatric rehabilitation. Rather than using the traditional approaches of CP that attempt to normalize movement patterns and minimize the development of secondary impairments, there is an increased emphasis on enabling the child to master various tasks and participate in different activities (21,22). Over the last 20 years, in the field of CP, clinical care and research have examined child functioning as it relates to interacting contextual factors (22,23). Although the needs and abilities of children with NDD (and their families) are heterogeneous, everyday functioning is continually regarded as an important outcome to families (24).

Examining clinical contexts in particular, there is a notable emphasis of functioning in the ICF, as this term is often used to describe abilities-focused processes—otherwise commonly referred to as function-focused care (12,24,25). Within this type of

paediatric care planning, there are typically certain measures used with families to promote child functioning or child abilities. Although these measures may have the appropriate psychometric testing completed to illustrate their effectiveness in clinical utility, it is also important that there is some consistency with the language that is being used with these measures (20,26,27). For example, the terms ‘function,’ ‘functional,’ and ‘everyday functioning,’ are used synonymously in the literature, whereas the ICF’s conceptualization of functioning emphasizes it as the complex interactions between the four domains (10). There are various measures that aim to assess concepts related to function, such as adaptive behaviour (e.g., Vineland Adaptive Behavior Scales (28), Adaptive Behavior Assessment System (29), Behavior Assessment System for Children (30)). However, these measures are not based on the ICF, and therefore describe everyday function differently compared to ICF-based measures.

Operationalizing the ICF framework (i.e., its domains and the interactions between them) within measurement tools can create opportunities for the ICF to be widely utilized in clinical environments for children with NDD (14). It is unclear how many measures in the field of NDD are developed using the definitions and concepts of the ICF framework. It has been demonstrated in the literature that clinical measures can be mapped on or ‘linked’ to the ICF framework by following a set of established and standardized rules, as described by Fayed, Cieza & Bickenbach (2011) (31). With NDD interventions shifting to focus more specifically on strengths and support needs, there is a need for further description of how measures that purport to be function-focused are utilized in clinical systems. The focus of this study is directed towards examining how

researchers who have developed ICF-based measures conceptualized their measure, specifically with whether and how the ICF domains were utilized in paediatric clinical contexts and research.

2. Methods:

We undertook a narrative review and synthesis of the peer-reviewed literature to understand existing function-focused, ICF-based measures that are used with children diagnosed with NDD. A narrative review summarizes and describes previously published information with an interpretation of the contents of different studies using a comprehensive, critical and objective analysis (32,33). This study was guided by SANRA, the Scale for the Assessment of Narrative Review Articles, specifically by reviewing the six items deemed necessary for a quality review: (1) justification of the review's importance for the reader; (2) review focus/aim(s); (3) description of literature search; (4) referencing; (5) scientific reasoning; and (6) relevant and appropriate endpoint/presentation data (33).

We used a two-stage approach to review the literature. The first stage was to identify original research texts that (a) focused on children (18 and younger) diagnosed with NDD defined by DSM-5, and (b) referenced the ICF framework. Both criteria needed to be stated within the abstract of the study. Initial keywords were generated for each conceptual category of the research aim with the guidance of a trained librarian in a health sciences library to form the search strategy. Keywords were identified within three categories (NDD diagnosis, child [age range 0-18], and ICF), and were used to search the

following databases: Medline, PsycInfo, EMBASE, and EMCARE. Search terms were developed and customized for each database. Abstracts were then screened to identify whether any measures were used in an intervention study and/or discussed in the literature; we also required the clinical measure to be the focus of the abstract. Searches were restricted to both English language journals and publication date (2002-April 2021), as selected papers were required to be published post-publication of the ICF in 2001. Studies were excluded if the aim was to translate the measure to explore psychometric properties within an alternate language/country/context. Measures that were used within indirect care (i.e., measures that focused on data collection and/or inter-professional collaboration) were also excluded. Lastly, secondary studies (i.e., systematic reviews, scoping reviews) as well as editorials and commentaries were excluded. The titles and abstracts of the resulting articles from the database search were exported to Covidence (34), a reference managing software. Duplicate records were then deleted using the software.

The second stage required full-text screening to identify whether select measures were ICF-based, and to identify whether the study reported the development of the measure. If a study described an ICF-based measure but was not the original paper of the measure's development, hand-searching was conducted to retrieve the original article describing its development. Hand-searching for original articles was accomplished by looking at the reference lists of the indexed articles that had described the use of these measures within their abstracts. This task was also completed using Covidence (34).

This study used a matrix to extract key details including age ranges, context(s), diagnosis sample, as well as descriptions and psychometric properties of the measures described. Details and descriptions of these measures were determined by using its original development article. After the characteristics of the included measures were extracted, the original studies of the measures were analyzed again to extract ICF-related details, specifically regarding the ICF domain(s) that were prioritized by the measure and how this framework influenced the measure's initial conception. Measures were categorized by using the definitions of the four domains of the ICF framework (body structures and function, activities, participation, and contextual factors).

3. Results:

The initial search identified 2811 published abstracts. After duplicates were removed, 1947 papers remained. These papers were reviewed by title and abstract with the first set of inclusion criteria, resulting in 141 potentially relevant studies. For the second stage, full-text versions of these studies were obtained and reviewed to assess whether they fit the second set of inclusion criteria, at which time 97 studies were excluded. Studies were excluded mainly for having a non-relevant focus—not focused on an ICF-based measure providing direct support for children with NDD; focusing on a non-paediatric sample; or being based on secondary data. The 44 papers that remained included 9 studies that described the initial development of an ICF-based measure, and 35 articles that described the use of ICF-based measures but were not the measure's original development paper, for which hand-searching was then necessary.

From the 35 articles, five additional ICF-based measures for children with NDD were identified and included; these comprised of four additional studies (35-38), and one manual (39). In total, 14 initial development studies describing 14 individual measures were included. This information is summarized using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart in Figure 2.2 (40).

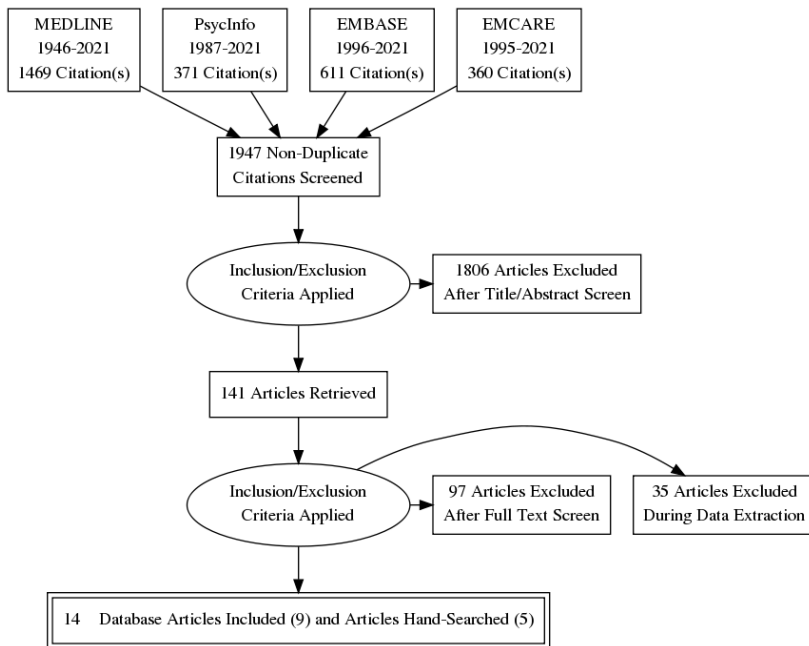


FIGURE 2.2: PRISMA (40) Flowchart of Search Strategy

The 14 measures originated in seven countries including Canada, US, UK, Australia, Sweden, Switzerland, and Taiwan. These measures were predominately described as either assessment and/or outcome measures (64%, n=9) or classification systems (36%, n=5), and could be utilized in various contexts including home, community, educational, and clinical environments. The most common diagnosis was CP (50%, n=7), followed by non-diagnostic/multiple diagnoses (29%, n=4), ASD (14%, n=2), and communication disorders (7%, n=1). Age applicability of these measures ranged from 0-21 years. The diagnosis sample, age groups, and brief descriptions are reported in Table 2.1. The common characteristics of these measures are also described.

<i>Measure Acronym</i>	<i>Measure Full Name & Citation</i>	<i>Type of Measure</i>	<i>Country of Origin</i>	<i>Primary Context(s)</i>	<i>Diagnosis Sample</i>	<i>Age Range</i>	<i>Construct of Interest</i>	<i>Brief Description</i>
ICF-CS	ICF Core Set ⁽⁴¹⁾	Standardization for Assessment and Description	Switzerland	Multiple (i.e., clinical, home, educational, community)	Multiple versions with different diagnoses (ASD, ADHD, CP)	Multiple versions with different age ranges	Functional Abilities	This measure uses select categories from the ICF classification to describe relevant information in regards to an individual's level of functioning; this helps facilitate a systematic and comprehensive system for either a specific health condition or health context (41). There are two versions of this measure: ICF Comprehensive Core Sets and ICF Brief Core Sets (41).
GMFCS – E&R	Gross Motor Function Classification System Expanded & Revised ⁽³⁵⁾	Classification System	Canada	Clinical	Cerebral Palsy	0-18 years	Gross Motor Function	A 5-level classification system that describes gross motor function for children and youth with CP, specifically focused on self-initiated movement when a child sits, walks, and/or uses a wheeled mobility device (35).
MACS	Manual Ability Classification System ⁽⁴²⁾	Classification System	Sweden	Clinical	Cerebral Palsy	4-18 years	Manual Ability	Developed from the GMFCS, this 5-level classification system examines typical manual performance of children with CP, specifically in regards to a child's ability to handle objects (i.e., assistance needs, potential adaptations required, quantity/quality of performance) (42).
BFMF	Bimanual Fine Motor Function ⁽⁴³⁾	Classification System	Sweden	Clinical	Cerebral Palsy	Not specified	Fine Motor Function	A 5-level classification system that examines fine motor function in children with CP, specifically in regards to a child's ability to grasp, manipulate, and hold objects for each hand (43).
CFCS	Communication Function Classification System ⁽⁴⁴⁾	Classification System	USA	Multiple (i.e., clinical, home, educational, community)	Cerebral Palsy	2-18 years	Communication	A 5-level classification system used by clinicians for children with CP, to classify and understand the patterns of a child's performance in everyday communication effectiveness with a partner (44).
ACSF:SC	Autism Classification System of Functioning: Social Communication ⁽³⁶⁾	Classification System	Canada	Multiple (i.e., clinical, home, educational, community)	ASD	3-5 years	Social Communication	A 5-level classification system that provides a simplified method to describe social communication functioning for preschool children with ASD (36). This measure provides parents and service providers with an understanding of the potential differences in social communication abilities based on a child's capacity and typical performance within different contexts (36).
GOAL	Gait Outcomes Assessment List ⁽⁴⁵⁾	Assessment Measure	Canada	Clinical	Cerebral Palsy	Not specified	Gait Priorities	An assessment measure that evaluates gait priorities and functional mobility for ambulant children with CP, addressing the spectrum of needs and/or goals of these children and their caregivers (45).
FOCUS®	Focus on the Outcomes of Communication Under Six ⁽⁴⁶⁾	Outcome Measure	Canada	Clinical	Communication Disorders	0-6 years	Communication	An outcome measure that evaluates change in communicative-participation, examining 'real world' changes in preschool children's communication abilities (46).
QYPP	Questionnaire of Young People's Participation ⁽⁴⁷⁾	Assessment Measure	United Kingdom	Clinical	Cerebral Palsy	13-21 years	Participation	A 45-item questionnaire assessing participation frequency across multiple domains for children and adolescents with cerebral palsy (47).
MEVU	Measure of Early Vision Use ⁽⁴⁸⁾	Assessment Measure	Australia	Clinical	Cerebral Palsy	Not specified	Vision	A measure that examines typical performance with 'how vision is used' during a child's everyday activities, interactions and environments (48).
CAP-HAND	Children's Assessment of Participation with Hands ⁽³⁷⁾	Assessment Measure	Australia	Multiple (i.e., clinical, home, educational, community)	No specific diagnosis	2-12 years	Participation	A parent report questionnaire, examining upper limb abilities across disorders, as well as the extent to which children participate in life situations (with a focus on hand use) (37).
CAPE & PAC	Children's Assessment of Participation and Enjoyment & Preferences for Activities of Children ⁽³⁹⁾	Assessment & Outcome Measure	Canada	Multiple (i.e., clinical, home, educational, community)	No specific diagnosis	6-21 years	Participation and Activity Preferences	Together, CAPE & PAC are self-report measures that examine children's participation and activity preferences within six dimensions of activity (39). CAPE documents the extent to which children with or without disabilities participate in everyday activities outside of their mandated school activities. PAC examines children's specific activity preferences (39).
-	ICF-CY Based Questionnaire ⁽⁴⁹⁾	Assessment Measure	Taiwan	Clinical	ASD	3-6 years	Functional Profile	This measure comprises of 118 items using the ICF-CY structure to evaluate the functional profiles of preschool children with ASD (49).
PEM-CY	Participation and Environment Measure for Children and Youth ⁽³⁸⁾	Outcome Measure	USA	Multiple (i.e., clinical, home, educational, community)	No specific diagnosis	5-17 years	Participation and Environment	This parent-reporting survey allows parents, researchers, and service providers to better understand a child's participation patterns in home, school, and community settings, by studying both participation and environmental factors at the same time (38).

TABLE 2.1: General Description and Characteristics of ICF-Based Clinical Measures

3.1. Assessment (and Outcome) Measures

The following nine ICF-based measures have a primary focus on the assessment of a specific construct of interest: ICF Core Sets (ICF-CS) (41), Gait Outcomes Assessment List (GOAL) (45), Focus on the Outcomes of Communication Under Six (FOCUS®) (46), Questionnaire of Young People's Participation (QYPP) (47), Measure of Early Vision Use (MEVU) (48), Children's Assessment of Participation with Hands (CAP-HAND) (37), Children's Assessment of Participation and Enjoyment & Preferences for Activities of Children (CAPE & PAC) (39), the ICF-CY Based Questionnaire (49), and the Participation and Environment Measure for Children and Youth (PEM-CY) (38). These types of measures describe details of functioning, can observe and evaluate a child's abilities and limitations within the construct of interest (otherwise referred to as outcome measures—a subset of assessment measures), and in some cases, it may be used to predict within-person change over time (26). These assessments can be completed by various individuals that are familiar with and/or are knowledgeable about the child's competencies within their daily routines, including caregivers, clinicians, and teachers (39). With the conceptual grounding of the ICF, these measures can provide a comprehensive and clinically useful understanding of a specific phenomenon, which can then be used for various applications within research and practice (39).

3.2. Classification Systems

The remaining five ICF-based measures are classification systems that can be used for children with NDD: Gross Motor Function Classification System Expanded & Revised (GMFCS-ER) (35), Manual Ability Classification System (MACS) (42), Bimanual Fine Motor Function (BFMF) (43), Communication Function Classification System (CFCS) (44), and Autism Classification System of Functioning: Social Communication (ACSF:SC) (36). The GMFCS-ER (35), MACS (42), BFMF (43), and CFCS (44) each individually describe functioning in children with CP based on specific constructs (i.e., gross motor function, manual ability, fine motor function, and communication), and the ACSF:SC (36) describes social communication functioning in children diagnosed with ASD. In these classification systems, level I typically describes child functioning with the highest level of ability in that aspect of functioning, whereas levels IV-V typically describe child functioning with more significant limitations (43). The five levels in these systems are ordinal, describing different levels of a child's abilities for a specific construct (36). It is important to note that the differences between these levels are not equal, as these systems provide a simplified guide for families and clinicians to communicate level of functioning within the clinical process (43).

3.3. Psychometric Properties of Development Studies:

The studies in which these measures were first established were published between 2002 and 2021. Almost all measures were initially published in journal articles (93%, n=13), with one measure (CAPE & PAC (39)) described in a manual format. Most studies of these measures (64%, n=9) provided some psychometric testing information during the measure's development. The most common forms of testing include content validity, interrater reliability, and test-retest reliability (29%, n=4). Other types of psychometric testing include various types of construct validity testing, such as discriminant validity, expert validity, and concurrent validity (each 7%, n=1) or were generally described as construct validity (14%, n=2). The CAPE & PAC (39) Manual did not specify the type of reliability and validity results (see Table 2.2).

<i>Measure Acronym</i>	<i>Development Study</i>	<i>Diagnosis Sample</i>	<i>Description of Psychometric Properties in Development Article</i>
ICF-CS	A guide on how to develop an International Classification of Functioning, Disability and Health Core Set ⁽⁴¹⁾	Multiple versions with different diagnoses (ASD, ADHD, CP)	Not included in the development article.
GMFCS – E&R	Development of the Gross Motor Function Classification System for cerebral palsy ⁽³⁵⁾	Cerebral Palsy	Not included in the development article.
MACS	The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability ⁽⁴²⁾	Cerebral Palsy	External construct validation process was initiated, involving rehab professionals within paediatric rehabilitation and parents of children with CP (42). Interrater reliability was conducted using testing between parents and therapists (42).
BFMF	Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy ⁽⁴³⁾	Cerebral Palsy	Not included in the development article.
CFCS	Developing and validating the Communication Function Classification System for individuals with cerebral palsy ⁽⁴⁴⁾	Cerebral Palsy	The second and third phases of the measure’s development focused on revision and validation using nominal group studies and Delphi surveys (content validity) (44). The fourth phase measured interrater reliability among clinicians and parents as well as test-retest reliability (44).
ACSF:SC	Developing a classification system of social communication functioning of preschool children with autism spectrum disorder ⁽³⁶⁾	ASD	Interrater reliability reported good for parents and very good for professionals (36). Content validity of level descriptions and ratings were trialed by participants in each stage of measure development using surveys (36).
GOAL	The Gait Outcomes Assessment List: validation of a new assessment of gait function for children with cerebral palsy ⁽⁴⁵⁾	Cerebral Palsy	Concurrent validity was assessed comparing the GOAL with two related valid and reliable assessments of motor function (45). Further studies will be required with larger cohorts to assess validity and reliability of the GOAL in different populations (45).
FOCUS®	Development of the FOCUS (Focus on the Outcomes of Communication Under Six), a communication outcome measure for preschool children ⁽⁴⁶⁾	Communication Disorders	Parents completed the Pediatric Quality of Life Inventory (PedsQL) at the start and completion of treatment to evaluate FOCUS’ content validity (46). Parents and clinicians completed the FOCUS measure twice within a 1 week period for test-retest reliability (46).
QYPP	The Questionnaire of Young People's Participation (QYPP): a new measure of participation frequency for disabled young people ⁽⁴⁷⁾	Cerebral Palsy	Test-retest reliability was examined by intra-class correlations using a two-way mixed model; results were comparable with other participation measures (i.e., GMFCS, MACS) (47). Using a rigorous expert review of the measure's item pool, content validity was maximized; known-groups (discriminant) validity was also supported (47).
MEVU	Measure of Early Vision Use: development of a new assessment tool for children with cerebral palsy ⁽⁴⁸⁾	Cerebral Palsy	Not included in the development article.
CAP-HAND	Development and Psychometric Evaluation of a New Measure for Children's Participation in Hand-Use Life Situations ⁽³⁷⁾	No specific diagnosis	Evidence for construct validity was established using Rasch analysis. Differences in summary scores of each domain between children with and without disabilities were also significant (37). Test-retest reliability using ICCs of the measure was moderate-high, except for a single dimension scale. Internal consistency varied across the dimensions, providing preliminary evidence for construct validity and reliability (37).
CAPE & PAC	Children's Assessment of Participation and Enjoyment & Preferences for Activities of Children Manual ⁽³⁹⁾	No specific diagnosis	Information from the measure’s longitudinal study was used to examine the technical characteristics of the CAPE and PAC (39). The data provided evidence of reliability and validity of the CAPE and PAC (39).
ICF-CY Based Questionnaire	ICF-CY based assessment tool for children with autism ⁽⁴⁹⁾	ASD	This measure has evidence of good interrater reliability, expert (construct) validity, and reflects the functional profile of preschool children with autism (49). Further testing is required to confirm other psychometric characteristics (49).
PEM-CY	Development of the participation and environment measure for children and youth: conceptual basis ⁽³⁸⁾	No specific diagnosis	Not included in the development article.

TABLE 2.2: Psychometric Properties Described in the Measures’ Initial Development

3.4. ICF Domains of Measures:

To understand the role of the ICF framework in the conception of these clinical measures, it was important to analyze what ICF domain(s) were prioritized, and the specific foundational concepts from the ICF framework during the initial development process (see Table 2.3). All listed measures included at least one domain of interest, and the ICF-CS (41), GOAL (45), and ICF-CY Based Questionnaire (49) using all four ICF domains. The most common domain across measures was Participation (79%, n=11), followed by Activities (71%, n=10), Contextual Factors (43%, n=6), and Body Structures and Function (29%, n=4). 71% of the measures (n=10) used more than one domain of the ICF.

	<i>Body Structures & Function</i>	ICF Domains		<i>Contextual Factors</i>	<i>Total Domains</i>	How is the ICF described overall?
		<i>Activities</i>	<i>Participation</i>			
ICF-CS	✓	✓	✓	✓	4	This instrument selects essential categories that cover each component of the ICF.
GMFCS – E&R		✓		✓	2	“Our group’s perspectives have evolved and been shaped considerably by the World Health Organization’s (WHO) International Classification of Functioning, Disability and Health (ICF) [...] The basic ideas concerning capacity and performance were included in the original GMFCS concepts but have been sharpened considerably with the publication of the ICF” (35, p251).
MACS		✓			1	"The focus is on manual ability, as defined in the International Classification of Functioning, Disability and Health [...] the classification looks at activities and gives a single ‘level’ for the collaborative use of both hands when handling objects in daily life" (42, pp549-52).
BFMF	✓	✓	✓		3	"Motor function and learning disability were important predictors for participation restrictions in children with CP. The ICF has the capacity to be a model to help plan interventions for specific functional goals and to ascertain the child’s participation in society" (43, p309).
CFCS		✓	✓		2	"The purpose of this study was to create and validate the Communication Function Classification System (CFCS) for children with CP, for use by a wide variety of individuals interested in CP. This required a shift from the traditional focus on body structure and function (i.e. assessing components of speech, language, and hearing problems), to a focus on activity/ participation, specifically the way in which to classify a person’s communication capacity within real-life situations" (44, p705).
ACSF:SC		✓	✓		2	"Using the ICF activities and participation framework, resulting autism classifications will focus on how children’s differing social communication affects their activities and participation in daily lives" (36, p943).
GOAL	✓	✓	✓	✓	4	“Used with gait analysis, the GOAL provides comprehensive assessment across all International Classification of Functioning, Disability and Health domains” (45, p.619).
FOCUS®			✓	✓	2	"The constructs used in the FOCUS are derived from the ICF framework to measure changes in communication and their impact on participation. The response set in part II of the FOCUS (i.e. ‘cannot do at all’ to ‘can always do without help’) was designed to evaluate the shift from capacity to performance by evaluating the level of assistance required to complete items successfully" (46, p51).
QYPP		✓	✓		2	"In developing the new instrument, we differentiated activities from participation at the level of ICF sub-domains, regarding activities as simpler elements of functioning at body level while participation usually includes those sub-domains made up of a number of activity functions and where the result is of intrinsic social and personal importance" (47, p501).
MEVU		✓			1	"This new measure is conceptually grounded within the Activity level domain of the International Classification of Functioning, Disability and Health as a measure of a single visual ability construct" (48, p1).
CAP-HAND			✓		1	"The conceptual frameworks underlying the development of the Children’s Assessment of Participation with Hands are the ICF and the ICF-CY, in combination with additional participation definitions/attributes proposed by Coster and Khetani (37, p1046). ICF provided only an initial framework for the measure’s development.
CAPE & PAC			✓		1	"The CAPE and PAC both focus on a subset of the ICF domains of participation and are based on two taxonomies, or classifications, of leisure and recreational participation" (39, p7).
ICF-CY Based Questionnaire	✓	✓	✓	✓	4	“The ICF-CY based questionnaire for children with autism comprised 4 domains: body functions, activities, participation and environment” (49, p679).
PEM-CY			✓	✓	2	“As defined by the International Classification of Functioning, Disability, and Health (ICF), participation and environment are multidimensional constructs that have been challenging to measure” (38, p238). The ICF provided an initial framework for the measure’s development.

TABLE 2.3: ICF Domains Prioritized in the Development of the Measure

4. Discussion:

This study is the first of which we are aware to identify ICF-based clinical measures for children with NDD. We have reported the psychometric properties and characteristics of 14 measures that are grounded in the ICF framework, using the information gathered from the initial development studies. We also identified the prominent ICF conceptual domain(s) that these measures represent, and the extent to which the framework was captured, including its interactive nature. There may be more ICF-based measures for this population that exist outside the clinical context (i.e., educational-based measures) and some of these tools may be applicable to other settings; however, the intent of this study was to examine how ICF-based clinical measures were operationalized in practice. Therefore, only health-focused databases were consulted.

The initial development studies for the selected measures included varying levels and types of psychometric properties conducted and described. Some studies (ICF-CS (41), GMFCS-ER (35), BFMF (43), MEVU (48), and PEM-CY (38)) placed emphasis on the process that the research team experienced when developing the measure, rather than describing specific psychometric characteristics of their measure. These studies had concurrent publications that described the conceptual processes and psychometric testing separately. The remaining studies combined psychometric testing with the measure's development process. The most common psychometric tests that were completed were interrater and test-retest reliability as well as content validity. It is important for clinical instruments to demonstrate good psychometric properties (27), and 64% of the measures were introduced with some form of psychometric testing conducted. These results provide

a descriptive overview of the function-focused tools developed in the field of childhood NDD, but since potential subsequent psychometric studies were not included in this study, it is difficult to provide comment on the overall rigour of the state of function-focused tools in this field. Future research should examine levels of rigor found in the psychometric properties of the listed tools.

The 14 measures varied in their constructs of interest, age ranges, and diagnoses. These constructs ranged from very specific functional skills (i.e., BFMF: bimanual fine motor function (43)) to broader areas of interest (i.e., ICF-CY-Based Questionnaire: building a functional profile for children diagnosed with ASD (49)). For age applicability, two measures (CAP-HAND (37) and CAPE & PAC (39)) had expanded upper-age ranges to 21 years old. Many measures focused on specific diagnoses: CP, ASD, and communication disorders. With the broad spectrum of diagnoses involved in DSM-5's definition of NDD, this highlights the need for great representation in other NDD populations. To fill these gaps, measures like the ICF-CS have been continually adapted with subsequent publications to explore the clinical utility of this measure in multiple communities within disability research and practice, including within NDD (50). These diagnosis-based populations include ASD, CP, and ADHD, but the outreach in these diagnosis populations continue to grow today (50,51).

Furthermore, these results indicated that measures such as the CAP-HAND (37), CAPE & PAC (39), and PEM-CY (38) could be potentially used with any child or youth, regardless of whether they are diagnosed with any condition of NDD, as these measures are not diagnosis-specific. In addition, although a key population of the users of

FOCUS® (46) is young children with communication disorders, this tool is designed to address communication needs across all young children with or without disabilities.

These findings are important, as they illustrate function-focused measures that examine abilities across diagnoses/conditions—an emerging trend (15). With the various diagnoses categorized within NDD, these measures have a wider scope in reaching different communities, thus creating more opportunities to utilize the concepts of the ICF in clinical and research settings. It is important to note that the ICF is still considered a contemporary framework, and that measures are continuing to be developed, such as the MEVU (48) that was published one month prior to conducting the database search for this narrative review.

With the heterogeneity of functional abilities within NDD, and the emerging measures that are being developed without a focus on any specific diagnosis, non-diagnostic ICF-based measures create opportunities for further examination of the continuum of abilities across diagnoses. By doing so, the goal of these measures shifts towards capturing profiles of individual abilities as well as unique differences among children (12). Furthermore, there is some evidence in today's literature that indicates that neurological similarities (i.e., brain structure/activity) that may affect an individual's social communication abilities may exist across diagnoses such as autism and attention deficit hyperactivity disorder; this shows that a child's overall abilities may also overlap across diagnoses (52). This example can be used to challenge the ways in which we can define, diagnose, and 'treat' NDD, specifically with how we approach functional perspectives for these populations (53). Measurement tools may still involve

neurophysiological processes in their design, but by focusing on a more individualistic foundation, this shift in thinking may better suit the cultural direction of how function-focused care is understood with today's ideas (12). By utilizing these measures across the populations of NDD, we better understand the diversity in the needs of children within their communities. These needs may exist beyond the core domains (i.e., addressing participation needs), and can potentially extend to how we can utilize these measures to improve the overall quality of life of children with NDD (13,27,28). As the ICF promotes this understanding that these four domains can build a unique functional profile of a child, the ICF can be seen as a supporting resource within the use of FCS to support a child's individualized needs. When this type of care continues to play prominent roles in the design and development of intervention plans for these individuals with disabilities, this may need to be more apparent in the tools that we develop as well. This approach utilizes the biopsychosocial model and will be a more relevant application of the ICF.

Furthermore, with children receiving school supports that are often integrated with health services, exploring function-focused measures that are applicable in educational settings, such as the Functional Abilities Classification Tool (54), is also important to examine in future work.

The development studies demonstrated variability in how ICF concepts were foundational within their measures. Some studies explicitly stated that their measure was conceptually based in the ICF whereas others used the ICF to develop their measure's items or constructs. Both the Participation and Activities domains were predominately represented throughout all measures whereas Contextual Factors and Body Structures and

Function were not as prominent. The ICF-CS (41) and ICF-CY-Based Questionnaire (49) utilized a holistic approach of the framework rather than focusing on specific domains, and this is evident simply looking at the naming of these tools. Other measures utilize the ICF combined with other frameworks, such as the CAP-HAND (37), that uses the definitions provided by both the framework and what is described by the authors of the PEM-CY (38) to configure a definition for participation that is suitable for the needs of CAP-HAND (37). These results align with the literature, specifically regarding the shift in thinking the ICF proposes: this framework has motivated health service providers to focus beyond “body structures and functions” to include the other roles (i.e., activities, participation) that can impact a child’s level of functioning and health (55,56).

There are different ways that tools and measures interact with the components of the ICF, and some measures can still utilize this framework without using it for its conceptual basis. It is here that the use of the ICF linking rules may become more relevant, as the rules provides an effective method to link meaningful “concepts” of non-ICF-based measures to the most precise category(s) in the ICF framework (57). These concepts could describe health condition, functional activities or any of the contextual factors (31,57). This ‘linking process’ differentiates from what is being studied in this narrative review, in that we are examining the extent to which ICF-based measures involve the domains of the framework, and the dynamic interactions they capture. This review focused on identifying measures that used the ICF for the initial conception, rather than the measures that have only considered the ICF post-publication or in an ‘after-the-fact’ exploration. With the linking process, the developers of non-ICF based measures

undergo the steps required in understanding the ICF to link certain items of their measure to the most relevant domains of the framework (58). However, the use of linking individual concepts of a measure to the ICF framework may not be as effective in demonstrating the interaction between the concepts, especially between activities/participation and contextual factors (59). Of the identified measures, 71% utilized more than one domain of the ICF, often highlighting the various ways in which the nuanced interactions influenced the development of the tool. For example, the PEM-CY (38) evaluates both participation and environmental factors in different settings, and can provide problem-solving strategies to adjust contextual factors within these settings to support further participation (38). As described earlier, the dynamic nature of the interaction of these non-linear domains is one of the most easily identifiable components of the framework. Although there is variability with how these interactions are explicitly described, when a measure is ICF-based and correctly utilizes the framework as a core component, the interactions of the domains are more likely to be inherently captured within the use of the measure.

5. Limitations:

There are a couple of limitations to report about this study. To begin, there were varying levels of psychometric data that emerged across the initial development studies of the selected measures. While psychometric testing of measures is an ongoing process, we recognize that the original development manuscripts would only have captured psychometric testing at its initial development, and that subsequent studies could have

tested additional properties, potentially with other populations of children. We also recognize that the contributors of the development studies may have differed from the original developers of the measure. The aim of this review was to provide an overview of the current ICF-based measures developed for children with NDD, in which we focused on using the development studies as the main sources for this work.

A second limitation relates to study screening process. We selected measures that explicitly used the ICF in the screening of study abstracts in the identified health databases, either in the development study, or in a subsequent published study of the measure that was used to locate the original manuscript. Although there is the potential for other measures to incorporate the ICF framework in some capacity in the development and/or design of their measure, the focus of this work was to identify the measures that explicitly used the ICF and its domains as a foundational element in its work.

6. Conclusion:

This narrative review can serve as a potential resource for clinicians/researchers looking to use measures grounded in the ICF framework for children with NDD. These 14 measures can play important roles in creating effective applications of the ICF for exploring child functioning in both research and practice (15,54,60). As measures are continuing to be developed using the ICF framework at their foundation, this emerging knowledge can help inform function-focused care. By understanding how function-focused care is operationalized within the measures that we create, we are also able to better understand functioning in clinical care for children with NDD, and whether there

are gaps in what is measured. These gaps are also evident in NDD populations where these ICF-based tools are not applied. Future research can explore the expansion of existing ICF-based measures across NDD populations and ages (i.e., adults), in addition to examining measures that impact functioning in other childhood contexts (e.g., home and educational settings).

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7.1. Conflict of Interest Statement:

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

7.2. Author Contributions Statement:

KS completed the search and wrote the manuscript with support from BDR, PR, and MZ. BDR supervised the project, with help from PR and MZ as part of the supervising committee. PR, MZ, and BDR conceived the original idea. All authors reviewed the results and contributed ideas to the final manuscript.

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**Parent perceptions of the everyday abilities of their child with autism: an
interpretive description**

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CHAPTER THREE: Parent perceptions of the everyday abilities of their child with autism: an interpretive description

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Abstract

Historically, interventions for children with autism spectrum disorder (ASD) have focused on a child's impairments rather than child abilities or what they can do. While interventions vary across this heterogeneous group of impairments, addressing abilities could help improve success in everyday activities. To better understand how to improve participation-based outcomes, it is important to examine parent perceptions of their child's functional abilities and the factors that may shape these perceptions. This study utilized interpretive description and semi-structured interviews to explore critically the qualitative experiences of parents related to the expectations of their child's development; the factors that influence these perceptions; and their perceptions of the services they receive. Five themes emerged that represent the various potential influences on parent thinking about the abilities of their child with ASD: Parenting Approaches, Accepting My Child, Managing Child's Challenges, Doing the Right Thing for My Child, and "The Disability Tag". Based on these findings, we recommend different communication strategies between clinicians and parents to help address and minimize potential challenges within function-focused care.

Introduction

As defined by the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), autism spectrum disorder (ASD) refers to a set of developmental disabilities that are often categorized by challenges in social communication (verbal and non-verbal), social interaction, and restrictive/repetitive behaviours (American Psychiatric Association, 2013). ASD impacts 1 in 66 children in Canada (Public Health Agency of Canada, 2018). Children with ASD have diverse needs and may require certain interventions and/or supports to accommodate both the child's strengths and challenges.

Parents of a child with ASD may experience a number of barriers navigating their child's diagnosis and interventions. For example, parents may have concerns about their child, including their child's potential behavioural deviations from expected developmental milestones (Gentles et al., 2019a, 2019b; Lappé et al., 2018). Other challenges for parents may include navigating appropriate supports that meet the various needs of the child (and family), while balancing their own emotions (i.e., stress, anxiety, feeling overwhelmed) throughout the process (Gona et al., 2015; Lopez et al., 2018; Yorke et al., 2018). These concerns and attitudes about their child having an ASD diagnosis can be linked to how a parent may perceive their child's level of abilities; these perceptions may also vary cross-culturally, given the cultural, ethnic, and socio-economic diversity that exists in Western societies (Raghavan & Waseem, 2007; Ravindran & Myers, 2012; Yorke et al., 2018; Zeleke et al., 2019). Overall, while navigating ASD-related care, parents typically feel a strong sense of responsibility to promote their child's well-being (Lappé et al., 2018).

Historically, it was common for health care practitioners to view ASD with a deficit focus, as there was a strong emphasis on “treating” an individual to fit to “normal” social standards (Baron-Cohen, 2017). With the recent rise of the neurodiversity movement that aims to prevent the drive toward normalization of individuals with ASD, there has been more of a social acceptance of the ASD diagnosis (Jaarsma & Welin, 2012). These abilities-focused initiatives are also more common as a child gets older, such as within adult programs that address the contextual factors that may influence how individuals on the spectrum learn to be independent, and that promote overall quality of life (Palisano et al., 2020; Russell et al., 2019). This new idea of understanding ASD as *difference* rather than *disorder* helped encourage this notion of utilizing function-focused models to promote overall health outcomes for children with ASD, and to continue providing supports that are meaningful to families (Baron-Cohen, 2017; Gardiner et al., 2018).

This shift is also evident in the International Classification of Functioning, Disability, and Health (ICF) from the World Health Organization (World Health Organization, 2001). The ICF is a framework for health that emphasizes the needs of individuals with disability beyond the medical model (i.e., the ICF is a biopsychosocial model) (Miller & Rosenbaum, 2016; World Health Organization, 2001). The ICF defines ‘functioning’ as a way to describe the interactions between an individual's health condition(s) and their context, utilizing a holistic approach to better understand the nuances that build a child's functional profile (Castro et al., 2013; World Health Organization, 2001). Strengths-based practices often focus intervention goals towards removing or accommodating the barriers that potentially hinder a child's functional participation (i.e., contextual and/or environmental challenges) (Donaldson et al., 2017). By doing so, skills can continue to be taught to the child and goals in educational/therapy practices can still be achieved (Donaldson et al., 2017; Finke et al., 2019). For example, clinicians can target their interventions to prioritize “meeting a person where they are,” utilizing an individual's existing skills and abilities to promote functional participation (Finke et al., 2019, p.2064).

According to Rosenbaum and colleagues (1998), family-centred service (FCS) refers to a set of approaches, values, and attitudes in services delivered for children with special needs, and their families (Rosenbaum et al., 1998). In the FCS model, clinicians recognize that each family is unique; that the family is a constant in the child's life; and that parents are the experts on the abilities and needs of their child (Rosenbaum et al., 1998). Clinicians work with families to help them make informed decisions about the services and supports they receive that best addresses their child's strengths and needs. (Christon & Myers, 2015; Rosenbaum et al., 1998) Studies have shown that effective communication between parents and clinicians is optimal in the delivery of quality health services (Almasri et al., 2018; Christon & Myers, 2015). It is imperative that clinicians better understand how to support the diverse ways in which parents perceive their child's strengths and abilities. By understanding the perceptions of parents, this approach may provide beneficial information for clinicians, such as targeted awareness campaigns that focus on the acceptance of individuals with ASD, improved knowledge about ASD, and increased supports for parents who may exhibit feelings of distress and guilt when navigating their child's diagnosis (Derguy et al., 2018).

With the shift in ASD interventions towards the integration of neurodiverse abilities in clinical outcomes, there is a need to understand how parents perceive their child's abilities in daily life. The purpose of this study was to examine parents' perceptions of the everyday abilities of their child with ASD. Specifically, we sought to understand parents' understanding of the following: (a) their child's overall functional abilities; (b) navigating the ASD diagnosis process; and (c) navigating interventions and/or supports. These findings can be used to suggest strategies to inform clinicians on how function-focused care can be better implemented in clinical settings.

Methods

Design

This study examined perceptions of parents of children with ASD using the qualitative approach, interpretive description (ID), as described by Thorne (2016) (Thorne, 2016). ID aims to generate knowledge about a clinical phenomenon with theoretical, clinical, and scientific lenses informing the research (Thorne, 2016; Thorne et al., 2004). ID acknowledges the rich and complex nature of human experience, focusing not only on the commonalities that may exist across a group, but also better understanding the diversity within shared experiences (Thompson Burdine et al., 2021; Thorne, 2016; Thorne et al., 2004).

Perspective of the Research Team

Similar to other qualitative designs, ID also acknowledges the ways in which the investigators' knowledge may influence the pursuit of the indicated research question via reflexive practices; therefore, it is imperative to include the different roles and "lenses" that will be used in the study's analysis (Thorne, 2016). The primary investigator (KS) is a Master's student in Rehabilitation Science, a research trainee who has previously worked with children diagnosed with ASD (and their families) and has a research interest

focused on the perceptions of an ASD diagnosis and the use of abilities-focused interventions within ASD supports. The senior author, BDR, is an occupational therapist and scientist who has dedicated several years to study the impact(s) of rehabilitation interventions and the development of measures that can be used to improve the participation and functioning of children and youth with neurodevelopmental disabilities. PR is a developmental pediatrician and researcher with strong interests in the quality of health services offered to families of children with disabilities; parent and family well-being; and the paradigm shift in clinical work towards a positive outlook on ‘disability’. MZ is also a developmental pediatrician and researcher with both a research and clinical focus on the care and support systems for children and youth diagnosed with autism and related neurodevelopmental disorders. MF and SG are qualitative researchers and experts in the field who were invited to be consultant members of the analytical team in this study. MF’s expertise is focused on the selected qualitative methodology, and SG’s expertise focuses on his in-depth knowledge of caregivers’ process of navigating autism-related intervention and their information use, which relate to his own program of research and contributions to function-focused tool development.

The following sources of knowledge formed the critical lens for this research design: (a) findings from the knowledge synthesis led by KS regarding existing literature exploring parent and clinician perceptions of an ASD diagnosis and interventions; (b) definitions of ‘functioning’ and ‘ability’ derived from the WHO’s ICF; and (c) our collective experiences regarding function-focused care for children with neurodevelopmental disorders (World Health Organization, 2001). This lens was used to scaffold (or build) new understandings of the potential impact(s) of function-focused care among families of children with ASD. As ID is designed with an end goal of developing a practical component, the interpretation of this work was directed towards using parent experiences to inform clinicians with recommendations on the ways in which challenges in function-focused care among families of children with ASD may be better addressed.

Participants & Sampling

Prior to beginning recruitment we obtained institutional ethics approval from the Hamilton Integrated Review Ethics Board (Project Number: 12772). Recruitment for interviews was conducted in conjunction with SAAAC Autism Centre, a community-based site, using convenience sampling. This site was selected for its convenient location (Greater Toronto Area), their partnership and interest in the work, and to increase the likelihood of an ethnically and socioeconomically diverse sample. The PI (KS) sent a participant information and consent form as well as the research team’s contact information to the organization, who passed this information on to their networks of families via email. After initial contact was established with families, KS collected consent forms online using REDCap (survey platform) and scheduled interview slots (Harris et al., 2009, 2019). Verbal consent was obtained again at the start of the participant’s interview.

Participants were selected based upon the following criteria: (a) ability to communicate with interviewers in English; (b) being a parent of a child or youth diagnosed with ASD; and (c) child must have received some form of ASD health service in Ontario (i.e., diagnostic service, treatment program, therapy, specialized service).

Interview Process

A semi-structured interview guide was developed by the research team to be used as a tool to encourage parents to reflect on their journey with their child's diagnosis, and to understand their perceptions of their child's abilities and experiences with function-focused care in paediatric health and rehabilitation systems. Interview questions and probes were initially grouped into three central categories to reflect the three-part research question (parent perceptions regarding their child's overall functional abilities, navigation of their child's ASD diagnosis, and navigation of their child's interventions).

Semi-structured interviews were conducted by KS from June-November 2021. Due to COVID-19, this study utilized video interviews with Zoom that were audio recorded and later extracted for verbatim transcription (Zoom Video Communications, 2016). All identifying personal information was anonymized to maintain confidentiality. Note-taking was conducted throughout all interviews to record changes in body language and/or behaviour as well as verbal tone. To maintain study rigor, the PI conducted reflexive practices with the use of journaling and maintaining audit trails throughout study procedures as well as check-in meetings with members of the research team for coding and analysis.

Data Analysis

In accordance with Thorne's (2016) guidelines, the processes of data collection and analysis occurred concurrently (Thorne, 2016). Immersion with the interview data was first conducted by both reading through each transcript and listening to audio files multiple times. Each interview was then analyzed for emerging categories and to refine codes. Data immersion continued throughout the early period of analysis to deepen the PI's relationship with the data, and to better understand participant experiences.

A subgroup of the research team (KS, BDR, MF) was then established to oversee data analysis. The analytical team met bi-weekly to identify key ideas, patterns, as well as any issues that might have arisen during initial interviews. KS was responsible for initial open coding, and met with the other members of the analytical team to review patterns, and potential categories/themes across the transcripts (Thorne, 2016). PR, MZ, and SG also provided early guidance with identifying potential overarching themes as well as points for further exploration: as developmental paediatricians, PR and MZ shared their clinical expertise on working with children with ASD (and their families), whereas SG shared similar findings from previous research on caregivers' processes of navigating intervention (Gentles et al., 2019a, 2019b; Koziarz et al., 2021). Following Thorne's guidance, the analytical team used open coding and constant comparative approaches to identify key similarities and differences among the individual participant experiences,

which would later be used to highlight common patterns (and outliers) within the data (Thorne, 2016). Themes were labeled as “forces” or factors that have been found to have potentially influenced how parents may perceive their child’s abilities during multiple points of the parent’s journey navigating their child’s diagnosis. Identification of these forces was in line with methodology of ID, as this design seeks to understand the various forces that can influence a phenomenon (i.e., social, environment), and utilizes this acquired knowledge to inform clinical practice (Thompson Burdine et al., 2021). The ID methodology endorses interpretation throughout the analytical processes; therefore, interpretations regarding parent experiences continued throughout the results and discussion section of this paper (Thorne, 2016).

Overall, three categories were used to organize the inductive themes in this work. The first two were deductively formulated by using the *a priori* interview categories and the research question: (i) parents’ overall perceptions; and (ii) parents’ perceptions when navigating ASD services. The third category was developed inductively from the data, and focused on the process of learning that can occur when a parent navigates these different experiences in paediatric ASD care.

Results

Participant Demographics

A total of 5 parent participants were interviewed. Interviews were conducted in partnership with the SAAAC Autism Centre with parents of children diagnosed with ASD. All participants lived in the same region in southern Ontario, Canada, and were parents of one child with ASD. Three parent participants identified as female, and two identified as male. Almost all children of the participants were male (n=4), ranging from 3-9 years of age (\bar{x} =5). Most children (n=4) lived with two parents in their home, and birth order and number of children varied among the sample.

Overarching Structure of the Findings

Five themes emerged from the data, alongside three cross-cutting categories that provided further insights/detail about each theme. The five themes are: (i) Parenting Approaches, (ii) Accepting My Child, (iii) Managing My Child’s Challenges, (iv) Doing the Right Thing for My Child, and (v) “The Disability Tag”. Moreover, three categories were developed based on a priori questions from the interview guide and inductive coding from the transcripts. The three categories are: (1) Overall Perceptions, (2) Navigating ASD Services, and (3) Process of Understanding. Category One and Two were established based on the proposed interview guide whereas Category Three was inductively identified via the transcripts. The relationship between themes and categories is described in Table 3.1. These themes and their relationships to the three categories are described below using exemplar verbatim quotes drawn from the interview data.

	Themes				
	Parenting Approaches	Accepting My Child	Managing Child’s Challenges	Doing the Right Thing for my Child	“The Disability Tag”
Category One:	Overall Perceptions: How parents currently think about their child (most recent perceptions)				
Category Two:	Navigating ASD Services: Parents’ perceptions of their child (including abilities) when navigating the ASD diagnosis process and post-diagnosis services for their child				
Category Three:	Process of Understanding: Parents’ learning that may take place throughout these different clinical and life experiences (i.e., process in better understanding their child, knowledge acquisition about ASD)				

Table 3.1: Parent Journey Categories and Corresponding (Emerging) Themes

Theme 1: Parenting Approaches

Parenting approaches refer to the general guidance, strategies, and teaching patterns reported by the parent. These can vary among parents for different reasons, such as the parents’ upbringing, personal values, sociocultural norms, and advice given to parents during a vulnerable time. Exploring this theme at multiple points of a parent’s journey can indicate the possible ways that parenting approaches influence how a parent thinks about their child (and their child’s abilities).

Relationship with Overall Perceptions (Category One):

The relationship between parenting approaches and parenting philosophies (or approaches to parenting) may influence the way parents describe their child's abilities. Within this relationship, a common finding among parents was how some compared their child with ASD to neurotypical children, including the child’s siblings:

"He doesn't talk as how a four-year kid talks, right? That's why. He won't make friendships as how a four-year-old kid makes friendship [...] but it is not same as a level of four years old kid." (Participant 2).

"He should be having everything, like doing everything like other children [...] Because he is going with them. Like even in the daycare, he is sitting with them, but he's not doing the activities. Even if he is sitting with the circle time, he will just lay on the floor" (Participant 4).

However, these comparisons were not always negative. Some parents shared that they understood that their child’s abilities and development timelines were different:

"But in terms of accomplishments, I don't know. I mean, even with my own three kids, they all move and grow at different rates. So I don't know that I'd be able to say that, you know, I wish he did this, or he should have done this now" (Participant 3).

Parents expressed mixed attitudes in how they described their child, especially when some compared their child with other neurotypical children. Some parents worried about their child's lack of participation and social interactions with other children, and felt their child would fall behind. However, as suggested in the quote above, some parents recognized that all children (including siblings) grow and adapt at different rates. This parenting trait of comparing a child to others may vary in the extent to which it is used about (or in reference to) a child, but it does occur.

Relationship with Navigating ASD Services (Category Two):

Parents may use different approaches when they are first learning about their child, and there may be various differences in recognizing what their child can do. This finding was present in the experiences shared by parents at the beginning of their journey in navigating their child's "difference". For example, one mother shared that there were differences between her and her child's physician in acknowledging the child's ability to maintain eye contact:

"I wouldn't say it's important for me. Rather, when I have been to the doctor, then he asked me whether he had given eye contact. I never knew eye contact is so important in life, actually" (Participant 2).

A developmental skill important to the physician when diagnosing the child with ASD was not as significant to the parent, demonstrating how some skills and abilities may be more or less desirable to parents (due to the recommendations of others). Acquisition of such skills may vary due to what the parent determines as important for their child.

Similarly, therapists' goals may influence how a parent utilizes certain services for their child. For example, some parents may be unaware or not feel confident in guiding their child to acquire certain skills. These skills may be therapist-driven, but some parents may feel a sense of dependency towards the therapist in finding a style of teaching that best fits the child's needs.

"So [the therapists] obviously are doing things that, you know, we would not really think of doing so we obviously have some sort of agenda or methodology there in regards to how they're conducting their services" (Participant 3).

"When I communicate to [therapists], it's more about goals. Because every six months you decide on the goals of this, and then we evaluate that, where is he from the goals which we decided" (Participant 1).

In the first example, there is some indication of feelings of dependency that a parent may have towards clinicians for their child. When parents are unsure of specific approaches to use, they may be more willing to abide by guidance suggested by clinicians they have found supportive. In other instances, such as the second example, parents may work with therapists to identify certain goals for their child. Goal-setting can play an important role in how a parent behaves with their child; however, this practice is being established by guidance and communication with the therapist. These goals may not be derived by the parents themselves, but may emerge from efforts of collaboration to seek child progress.

Relationship with Process of Understanding (Category Three):

Parenting approaches can shift over time since they can continually learn about their changing and developing child and adapt their strategies as necessary. In this process, parents may experience shifting attitudes in the ways that they may want to guide their child, and potentially in the ways they have perceived their own parenting approaches for their child over time. For example, in one parent's self-reflection of their approaches with their child, they shared their past feelings:

"Maybe I am not doing some good parenting with them. I used to think that way. I used to feel guilt, even with my first child, whether I'm doing good, whether I'm feeding good, or whether I'm parenting good or not. Every time I used to feel, "Oh maybe there's some problem with me, not with my kids, because kids are kids, right? They don't know anything. It's always depends on parents. How do you take care of them?" (Participant 2).

This parent experienced feelings of uncertainty and guilt regarding their own parenting strategies at the beginning of their journey with their child. The parent may notice changes in their own confidence levels of their personal parenting strategies throughout their journey. This process of learning and understanding may exist in a blend of what they observe with their child and environment (i.e., other parents), as well as elements of learning that are self-taught. For example, another parent shared their experiences with what they had learned about their child over time:

"Well, I've learned that in terms of the challenges, they differ, so it's not a cookie cutter look. So every child is going to be different in terms of what their challenges are, in terms of strength, it's the same thing, they'll all be different. They have something they're good at. And for most of the parents I've spoken to, it's just about, you know, finding what that thing is, and using that to sort of help them to get to wherever, whatever goal that we're trying to get them to [...] I think it was something that I observed and, you know, self-taught to some extent. Again, it was only when I started to do things for my son did I know that 1) there were so many children that were diagnosed on the spectrum and 2) you know it wasn't as bad as I had thought" (Participant 3).

This parent acknowledges that this way of understanding of their child's abilities and challenges partially derives from attitudes that are both observed and self-taught. This process of "finding what that thing is" indicates the shifting nature of how parents may change certain aspects in the approaches and guiding principles they may use for their child over time. This idea also suggests a more abilities-focused guiding approach that caters towards what a child *can do* to develop further skills.

Theme 2: Accepting My Child

This theme specifically focuses on the idea of eventually accepting their child for who they are as individuals. This idea was present in the experiences of parents, as some parents felt that to be able to accept their child, they needed to rethink and/or adjust the ways in which they thought about their child's skills and abilities. In contrast to the previous theme that was more about their "action" or "approach", the nuance here is that it is a difference in "thought" and framing.

Relationship with Overall Perceptions (Category One):

A parent may manage their expectations at different points of their journey in learning more about their child, and this information may be beneficial in understanding how a parent acknowledges their own overall perceptions towards their child's abilities. For example, when thinking about key characteristics that are used by parents to describe their child, there is some acknowledgement that their child may have certain skills as well as challenges in different areas of life.

"Sometimes, I wouldn't say...he does have a couple of like, I don't know, quirks I guess like that, but they don't...they don't interfere with his necessary day-to-day function" (Participant 5).

"He's come a long way since he started [...] so I would say he's, you know, satisfactory. Is he great? No. Is he terrible? I don't think so either. So he's somewhere in the middle" (Participant 3).

Although these quotes do not explicitly mention how they have managed specific expectations with their child, we see some patterns of acceptance towards a child for who they are. The first quote that uses the word "quirks" may be a way for a parent to describe their child's difference, and the parent also acknowledges that these "quirks" do not interfere with the child's everyday functioning. This acknowledgement is important because it suggests that the parent utilizes an abilities-focused approach with their child based on everyday functioning, rather than this idea of focusing on how a child's difference is a child's deficit. Similarly, using the second quote, a parent may acknowledge the level of their child's capacity and performance; this suggests that the parent does not have high expectations for their child, but rather is more accepting of their child's current abilities. However, not all parents think this way. One parent held a high expectation for their child to achieve key social skills, and so they found their child's inability to interact with others to be a significant deficit:

"How would you survive if we were not able to interact with the other person? How would you survive? There is a difference between robot and human being right? A robot doesn't do social interaction, doesn't have emotions, doesn't feel, cannot describe needs, and so on and so forth" (Participant 1).

This parent needed their child to learn certain skills, as they felt it was an important indicator of being “a human being”. This finding suggests an opposite approach to the other examples listed above. There is a lack of acceptance towards their child’s level of social abilities, but rather a strong emphasis for their child eventually to learn these skills for them to “survive”. This type of understanding reflects a different point of view, indicating that some parents could continue to have their expectations for their child with ASD, and be unaccepting of their child’s differences in key skills and abilities.

Relationship with Navigating ASD Services (Category Two):

Throughout a parent’s journey with their child, they may experience different feelings and negative attitudes towards their child receiving an ASD diagnosis. One significant and common aspect of this journey occurs when a parent accepts their child has ASD. This moment in time can vary both in the length of time it takes among families, and the specific factors that can lead up to acceptance. One parent discussed their rationale for why they were finally able to accept their child’s diagnosis:

"Finally, with that strong heart, I was confident like if I'm able to get him diagnosed now, I may be able to like help him out, how to lead a right life. Instead of just staying in the dilemma that he doesn't have or if not accepting what autism is. It's no point. It's not good for my child. It's not good for me. It's not good for anybody in my family then" (Participant 2).

The experiences shared by this parent indicates that they wanted to accept their child’s diagnosis both for the child’s quality of life and for the family unit as well. This overcoming of emotions and towards acceptance of their child’s diagnosis can take place within ASD interventions as well. For example, when parents are unaware of certain therapeutic and communication strategies that are used for children with ASD, such as PECS (Picture Exchange Communication System), they may be initially scared to engage in such interventions. Continuing with the journey of Participant 2, they shared their initial attitudes when recommended to use PECS for their child:

"Initially I got very much scared with PECS. I was like when he is talking and he's saying...why you people are using PECS for him? Because in the beginning, he stopped using the words when I started using the pictures. But eventually, after a month, a couple of months, he was increasing his words. He started attaching those pictures to his communication. And then I felt happy. Okay, that was a good decision for him. So I don't mind whether it's verbally, non-verbally or PECS system" (Participant 2).

The parent initially did not want to use PECS for their child; they had certain expectations for their child to communicate verbally, as well as expectations for the interventions that clinicians chose to use for the child. This parent was worried that by using this strategy, their child would not be able to communicate verbally and/or lose the language that they had already developed. However, it was within this journey of using this intervention strategy that allowed the parent to reconsider the overall method of communication, and be accepting of the intervention strategy. A parent that may have strongly endorsed verbal communication was now satisfied with any form of communication from their child. This example of managing personal expectations as well as acceptance of new strategies has shown to be an influence in how parents now think about their child's communication abilities.

Relationship with Process of Understanding (Category Three):

One of the key patterns observed in the data is the idea of shifting parental attitudes towards child capabilities. Three parents describe what they have observed in their child over time, specifically in regards to what they have learned:

"Not changed, but I'm more educated, let me put it this way [...] what I have learned is what I see every day in my child. And there are certain behaviours, which are manifested. Each one is different. So it's nothing like...but it's more about acceptance" (Participant 1).

"Yeah, you know what, maybe these children are lacking in certain areas. But that's not to say that, you know, they're not intellectual, that they can't do things by themselves, that they can't live somewhat of a normal life that, you know, any other child would. So I think it's a shifting attitude" (Participant 3).

"The main thing is that he understands what you're saying, but he struggles a little bit with communication. So to just...the helpful tips that we've learned about giving him time to process the questions that you're asking him in like form a response" (Participant 5).

Participant 1 shares that their perceptions about their child have come from being more educated over time; these perceptions were developed with what they have seen in their child, with a level of acceptance towards their child's different behaviours. Participant 3 provides a different perspective, sharing that they have developed a shifting attitude that does not focus on the deficits of a child, but rather what the child can do. Participant 5's experiences indicate that the parent has undergone a process of actively learning more about their child, and the ways in which they can be more supportive in helping with challenges that the child may have. All three examples provide a more positive approach of a parent thinking about their child. These experiences all exemplify the small initiatives that parents are taking in better understanding, managing personal expectations, and accepting their child for who they are.

Theme 3: Managing Child's Challenges

This theme refers to how a child's potentially maladaptive behaviours and/or challenges may impact how parents perceive their child's everyday abilities. Maladaptive behaviours can include stereotypical ASD behaviours (i.e., flapping, spinning, rocking), self-inflicting behaviours, repetitive movements, and behaviours deemed by parents to be generally undesirable. These challenges can be a cause for concern for safety, and often increase parental stress. However, another conceptualization of these behaviours is referred to as 'interfering repetitive behaviours,' with the idea that certain behaviours (i.e., spinning or rocking) may be pleasurable to the individual on the spectrum, and therefore, treatment may be undesirable (Jacques et al., 2018). The spectrum of behaviours that may exist for children with ASD may cause parents to experience conflicting emotions about their child.

Relationship with Overall Perceptions (Category One):

When parents have concerns about their child's challenges, these can play a role in the overall perceptions that a parent may have when describing their child. For example, one parent was describing their home situation with their child, and the challenges they face managing their child's maladaptive behaviours while being a single parent at home:

"Yeah, this is repetition, like every time jumping, climbing...without knowing [whether] he can jump over this space or not. Even on the dining chair, he starts jumping, and it's so danger[ous]. He starts climbing on the windows. And we know the step...he can put only his feet size where he can stand. But still, he doesn't care. He just wants to stand over there. He starts sliding over the railing of the stairs. So I cannot even go washroom when he's at home" (Participant 4).

The experience that this parent shared indicates a high level of concern regarding their child's behaviours. The parent not only worries that the child puts themselves in this position, but that the child does it carelessly without knowing. The parent uses words like "dangerous" to describe the situation that she faces in managing her child's challenging behaviours. When parents experience difficult situations, such as what is described above, it is more likely that these safety concerns heavily influence how they think about their child overall.

Relationship with Navigating ASD Services (Category Two):

The impact of concerns on parents can take place prior to the child being diagnosed. A parent may have initial concerns about their child's development, or notice atypical behaviour. Although the child's challenges may not be dangerous or evoke a need for increased safety, these challenges can be what drives parents initially to connect with clinicians regarding their child's development. One parent describes their rationale for why they believed that seeking help was important for their child:

"So when he was younger, when he was just like developing one to two to three, we didn't have any particular concerns really, except his use of language was atypical. And at first we were like...okay, you know, he's only one, let's just give him more time; he's only two, let's just give him more time; he's only three, let's just give him more time. But then he got to, you know, like three and a half. And we thought, okay something's different here. Maybe we should have a look at this" (Participant 5).

This parent shared that language was of concern. Although the parent waited to see whether the child would develop certain skills, it was this atypical language for which the parent chose to seek help from a clinician. This idea of seeking help for behavioural concerns also exists post-diagnosis, when a parent accesses certain services to help with their child's challenges. Parents typically used strong language to indicate the extent to which ASD interventions played important roles in addressing behavioural concerns:

"Well, with the ABA, I think it's aimed to help to change problematic behaviours or reinforce good behaviours. From the time that he's been in it, we've seen good changes and good progress. So I think that's what that's for" (Participant 3).

"The first goal is I want him to talk. I want him to talk and to be like, following the commands, and to be peaceful calm, more...not so much hyper or to understand the hazards especially [...] Obviously, I have to study because I want to improve my son. These days, I'm just knowing about autism, whatever everybody tells. I'm going to learn it" (Participant 4).

Whether the goal was to “change problematic behaviour” or to “improve my son,” there was a strong emphasis within these experiences that indicated that ASD interventions were utilized to promote a certain type of “good” behaviour, whereas other behaviours were deemed undesirable. ABA was a common example shared by parents, who typically noted that the overcoming of behaviours was one of the primary reasons why they even attended such services for their child. In such instances, there is some indication that there is a level of deficit-focused thinking that may occur either within implementing specific interventions, such as certain ABA practices, or within the communication that may occur between parents and clinicians.

However, skill development may also utilize a strengths-based approach. Participant 4 shared that despite having certain behavioural goals and expectations for their child, they did notice that their clinicians utilized their child's strengths to further develop skills.

"I think both are going hand in hand [...] Because they have to see, which is the interest of the child. And then they can make it better [...] I think she [therapist] works on the strength, like my child, he likes to play the songs. If somebody is swinging him and then singing also. So it's, I take it like a strength, whatever he likes, but also they work on the area of improvement because they want them to

be a better? [...] They work on both because they want to do what he likes. And the same way they want to do something new, which he could learn." (Participant 4).

In these experiences, parents may learn and understand more about strengths-based approaches, which contrast with the earlier examples of focusing on the deficits and challenges of the child. Therapists are seen as individuals that can guide children (and families) to focus on the strengths of the child by using what the child is interested in, such as songs, to improve certain skills. In this example, the therapist can have a strong influence in helping parents reconsider their child's abilities, especially when parents are focused on "fixing" behavioural concerns.

Relationship with Process of Understanding (Category Three):

When dealing with challenging behaviours, parents can gain new understandings about their child, especially as their child gets older. In these instances, parents may experience dealing with new behavioural challenges with their child, as indicated by this parent's experience below:

"It's a problem for me because I cannot control him. As the days are going...he is growing [...] he is getting the height too" (Participant 4).

When new challenges arise, they may become the parent's primary focus both in the ways they think about their child, and what specific services they acquire to manage these challenges. This process of understanding about their child can change over time, such as a parent experiencing different attitudes towards their child. An example could be changing levels of parent hope for their child's future. A lack of hope may also feed into deficit-focused thinking about their child's abilities. However, parents may also learn more about their child's abilities when seeing their child learn and adapt positively in new environments. For example, one parent reflected on what they had observed with their child's skill development in daycare:

"Well I mean, he's come a long way since he started. Before he used to be very reserved by himself in his own little world. Now, at least you know, he's doing things with the other kids, he's in the vicinity of other kids. The daycare says that, you know, he's adapted pretty well, in terms of you know, lining up and walking to the playground and what have you" (Participant 3).

The nuances in language, "he's come a long way since he started," provide a different perspective: a reflection of child growth over time. Although challenges can arise as a child grows, there are opportunities for child development as well. For this parent, seeing their child participate in daycare had allowed them to develop more hope and positive thinking about their child's abilities and behaviours.

Theme 4: Doing the Right Thing for My Child

Within parent experiences, there was a strong emphasis on the idea of analyzing how parent advocacy within ASD systems about “doing the right thing” can influence how parents may perceive child abilities. This advocacy is also balanced with parent emotions throughout their journey.

Relationship with Overall Perceptions (Category One):

Overall, parents may feel "personally responsible" for advocating for the necessary supports for their child while balancing the emotional needs of being a parent of a child with ASD. For example, some parents felt that they were not doing enough for their child overall. These feelings can include guilt, stress, and anxiety about providing enough, as indicated by Participant 5:

"I have some guilt like some feelings about the pressure to do enough and provide enough. So I sometimes worry that like you know [...] I guess it's just societal stuff. And like I kind of, I don't know, I kind of personally struggle with a little bit of like just anxiety" (Participant 5).

This example is a clear indication of the tug-of-war that may exist for a parent of a child with ASD. When a parent must balance advocating for the needs of their child with their own personal challenges of being a parent (i.e., “the pressure to do enough”), this group may experience unaddressed personal needs and supports that can have an influence in their overall perceptions towards their child. This pressure can be linked to parental stress, and may have negative impacts on the relationship between the parent and the child, and/or between the parent and the child’s clinician. Similar to how parents may focus solely on a child’s challenges (Theme Three) when thinking about their child, this conflicting battle between action and emotion can be the primary focus of a parent who just wants to do the best for their child.

Relationship with Navigating ASD Services (Category Two):

These feelings of balancing action and emotion during parent advocacy can start at the beginning of the parent’s journey in navigating an ASD diagnosis for their child. Some parents expressed that they were not immediately able to receive a diagnosis, or that they had mixed responses among practitioners (or between a parent and clinician) regarding their child’s expected developmental milestones.

"Actually, the nurse practitioner didn't have any concerns. He actually didn't miss any of the developmental milestones, but that's because sometimes there's too much focus on the checklists [...] they're asking the typical questions like, ‘Oh does he speak in 1-4 word sentences,’ or you know, whatever the question is. And it's like, I think more detail is warranted...like yes he is, but his use of language is atypical [...] it wasn't like a normal-flowing, logical conversation that you would expect to have with a typical three-and-a-half-year-old. So I'm actually the one that requested he be seen by a developmental paediatrician. And then that took a

couple of months. And then he was...so we were able to have his first assessment done in this January of 2021. And he was diagnosed." (Participant 5).

This reflection indicates that the parent had to advocate for their child to receive the final diagnosis, and felt challenges in communicating with clinicians about concerns over their son; it also indicates the differences in guidance and opinions among clinicians. Such challenges in communication and support can also continue after the child is diagnosed. Post-diagnosis, some parents shared that they experienced several challenges in accessing initial supports and services for their child. In these times, parents typically felt these challenges were time-sensitive, as certain supports had child age requirements and long waiting periods. Two parents shared their anger and frustration towards accessing initial services for their child:

"They are all money-making. So nobody is interested in child, they are interested in how many sessions you would want to have [...] When it comes to government-granted institutions, there are 2-3 years of waiting. So there's not even a point, you can't stop the age of a child, right?" (Participant 1).

"And I feel very angry and very frustrated because early intervention is stressed so highly. I feel like society is saying that it's over, like my child's already failed because he's not going to be able to receive these services in time" (Participant 5).

These experiences reflect the challenges among parents regarding collaboration with professionals in a given system. Participant 1 shares the discrepancies between private and publicly available services, sharing that the quality of services can vary, and both have different challenges (i.e., waiting lists, lack of therapist engagement). Participant 5 shared that despite early intervention being recommended so highly by professionals in the field and greater society, there were no supports available for their child that fit the parent's needs and/or timelines. In these desperate situations, parents want to do the best for their child, and provide the necessary supports; however, when such supports are not accessible to families, they can create often stressful situations. Parents may feel that their child has "already failed" because they are not accessing these services in time. Although these feelings do not link directly to child abilities per se, they link to how parents may feel towards ASD services (and related organizational systems) and the extent to which they believe that their child will succeed with an ASD diagnosis.

These mixed feelings can also exist when parents access certain interventions for their child. Some parents felt unsatisfied with how some of the services operated. Main concerns included long waiting periods for publicly-funded programs, service costs, and lack of therapist engagement:

"If I had to depend on [Organization], I don't think my child would make any progress at all. It's all about, you know, finding and reaching out to different, smaller agencies to begin with, or agencies that are looking at you as a person as opposed to just a number" (Participant 3).

"Professionals are just sort of like trapped within the system that is created, like they're not able to provide services, even if they would otherwise because of the limitations that are made on the way things are set up. I would like it if there were more publicly funded services that were available for a longer period of time. I don't think that kids should get cut off at four with the idea that they get started receiving services in school because the services do not start in school-wide for, it takes years to get that going. And the services in school are not adequate" (Participant 5).

Although these experiences did not make parents think about their child's abilities differently, they did influence how parents thought about ASD services overall. Parents have a level of dependency with these agencies in managing child progress. When parents feel unsatisfied with certain services, this may translate to parents thinking that their child may not "make any progress at all". Parents also typically felt they had a responsibility in advocating for their child by choosing specific services they believed would be best for their child (i.e., smaller agencies over larger agencies). This finding suggests that parents perceive individual child progress is linked (and perhaps dependent) on quality services; it also suggests that parents typically perceive that they have a significant responsibility in choosing the right services for their child to progress in skill development.

Relationship with Process of Understanding (Category Three):

Our findings indicated a vast array of challenges that parents have endured during their journey in navigating ASD services, and advocating for the best for their child. This journey can allow parents to reflect on the emotional aspects of being a parent of a child with ASD. For example, one parent shared their experiences of balancing costs of services with their personal guilt of not providing enough for their child:

"I left feeling like 'wow, here's all these things that are wrong with my kid,' and here's all these feelings that he has, and I was feeling very guilty, like this is all my fault. Maybe I didn't do enough of this. And if he had gotten diagnosed sooner, he could have gotten more services maybe. But it's also like, there's so many services and they're also so expensive. I mean, even the funding that you get, even if you get the one-time \$20,000, which I have not received yet, and they're changing again. But even if you receive that, that's \$20,000 to split between like all these different services that they're telling you [that] you need for all these different things that they're telling you are wrong with your child. And that's just not...it's not financially reasonable. I don't make \$100,000 a year, I'll just say that, but even if it was \$20,000, it covers maybe five months of like one particular kind of service. So to get coverage for one kind of service, maybe for

most 10 months would cost like \$40,000. That's like...that would be like 2/5ths of \$100,000 salary" (Participant 5).

This reflection indicates the larger challenges that parents may endure while navigating ASD systems. Our findings show that parents typically want to do the best for their child, but these feelings can change over time. When parents are forced to make difficult decisions that impact their financial stability and emotional well-being, these feelings may transcend into how they think about the need for different ASD services. Upon parents' reflections, financial constraints were found to be large determinants in the services that parents choose and forego for their child, despite pressures from external individuals to attend certain services. Although parents may not learn something specific about their child in these self-reflections, as parents navigate through their journey, they are more aware of some of the challenges in the decision-making process for their child.

Theme 5: "The Disability Tag"

The final theme reflects the social impressions towards the label of disability. All parents discussed some of the societal stigmas associated with the labels of disability and ASD, with one parent who used the label "the disability tag". These social stigmas may be derived from different individuals that interact with the family's life, or what is consumed via media platforms. Often times these labels are portrayed negatively, focusing on child deficits and what children with ASD cannot do.

Relationship with Overall Perceptions (Category One) & Process of Understanding (Category Three):

These categories were combined because our findings indicated that parents' current and overall perceptions towards the label of "disability" had been built based on what they learned and understood about disability and ASD throughout their journey. Many parents also suggested that the term "disability" should not be associated with any member of society. When parents reflected about how this label had influenced their thinking, all parents shared the negative connotations often associated with "disability". One example is listed below:

"It's seen always negative [...] I think disability should not be applied to anyone [...] Everybody has disability, right? You would have certain weaknesses; I would have certain. So rather use it for all of us, or don't use it because someone termed as disabled, they have a lot of other abilities, right? Someone who is termed as able may have a lot of disabilities, which you don't see it on the face" (Participant 1).

This parent suggests that all children have strengths and challenges, offering an abilities-based perspective. These findings were common among parents who believed that the label “disability” that was used in society did not capture the wide range of abilities that children with ASD can have. Almost all parents had different perspectives towards the diagnosis, often highlighting that their child is more capable than what society suggests. They had positive perceptions towards their child’s abilities to contribute to society, as suggested below:

"I don't want to like box him into any particular path or anything. But I think it's important that you don't...that kids with neurological differences aren't discounted that they're not...you know, "oh they're incapable, and so just send them away, put them in a home whatever," to remember that they can contribute to society and they do have places in relationships and in the community and in the workplace" (Participant 5).

Parents were positively able to highlight their child’s abilities when asked to reflect on the negative societal perceptions towards disability. However, this journey in coming to this understanding about their child varied among parents. Some parents discussed that negative remarks made by others in public settings had negative impacts (i.e., guilt, distress) towards how parents thought about ASD. These impacts can create obstacles in the parents’ journey in learning about their child and ASD overall. Others discussed that social unawareness of ASD created environments in which parents worried that their child may be socially isolated, causing some fear among parents of the environmental challenges that their child may be exposed to throughout life.

Relationship with Navigating ASD Services (Category Two):

Parents varied in their knowledge about ASD prior to their child’s diagnosis. Some were fully unaware about ASD, and others had heard about the diagnosis, but were unsure of how their child would adapt:

"I didn't know what autism is. I didn't know what [the] autistic mind is thinking. I didn't know how the brain functions, or how they might be thinking. And fortunately, I'm so happy that there is a solution for this. There is a treatment for this, and there are people to help me out to tackle these problems with my son" (Participant 2).

"I didn't know too much about autism at all. And so for someone like me, who only knew like the stereotypical factors that were in children, I would think that people would think that, you know, they're severely disabled, that they can't live on their own, they can't do anything" (Participant 3)

Initial perceptions that parents held about ASD typically focused on the challenges of ASD, such as the quote provided by Participant 3. Parents typically built their knowledge source about ASD using the internet and the help of clinicians. Most parents shared that

they did not receive much initial support from developmental paediatricians about ASD beyond general descriptions regarding the diagnosis, answering questions, and general guidance about next steps. Participant 2 felt that the solution to their son's diagnosis was by using treatment and interventions. This notion of dependency on interventions is similar to what was described in *Parenting Approaches*, and in our findings was found to be important to parents upon discovering their child was diagnosed with ASD.

Discussion

The experiences shared by parents in this study provided new insights on factors influencing their perspectives about their child's abilities, and the autism health services their child receives. Overall, five themes emerged from the data: Parenting Approaches, Accepting My Child, Managing My Child's Challenges, Doing the Right Thing for My Child, and "The Disability Tag,". Each theme described content related to each of these a priori categories: Overall Perceptions, Navigating ASD Services, and Process of Understanding. The interactive relationship between the categories and themes represents what parents may experience when learning about their child's functioning over time.

In ID methodology, it is imperative that emerging themes are interpreted using the critical lens that was devised in the initial research question. Our interpretive lens in this study consisted of definitions provided by the ICF, existing literature on parent perceptions and ASD, and our team's clinical experience in autism health services. Study results demonstrate how environmental influences (i.e., service costs, waitlists) can pose significant barriers for families, which is similar in concept to the ICF's contextual factors and existing literature that describes the impact of ecological factors and ASD on family quality of life (Derguy et al., 2018; Malik-Soni et al., 2021; Smith et al., 2020; World Health Organization, 2001). In our sample, parents typically felt that they were "falling behind" if they did not access services for their child promptly post-diagnosis; however, parents felt stuck because services were not always readily accessible for families due to environmental barriers. These contextual factors can contribute to how parents perceive their child's abilities, and often these influences are linked to clinicians working in ASD systems. In the following paragraphs, we discuss the important findings that emerged from our results, and relevant literature to support these ideas.

Some literature has reported that parents can prioritize certain child skills and achievements, or have certain expectations for their child (Finke et al., 2019; McConachie et al., 2018). The prioritization of such skills is similar to the first theme in this study, *Accepting My Child*. Certain skills may be desired due to parental assumptions, including the idea that academic and independent living skills that are attained in childhood years will lead to a positive life trajectory for that individual through to adulthood (Gibson et al., 2015; Rosenbaum & Novak-Pavlic, 2021; Shannon et al., 2021). This finding aligns with our results. For example, one parent strongly believed that social skills were one of the most important ways that their child could prosper later in life. Another parent feared their child might put themselves in dangerous situations without appropriate interventions, and so they prioritized safety over all other concerns. This parent may not

easily apply a strengths-based lens (or realize their child is progressing well) because the child may exhibit behavioural challenges that overlook the child's other capabilities. In these examples, clinicians were also found to be important supports for both the child and family, especially when parents had specific needs for their child.

Furthermore, we described the process in which parents experienced moments of learning and better understanding of their child, and this was apparent specifically within the *Process of Understanding* category, and its relationship across the five themes. This category indicates what parents learn about their child throughout the child's clinical and life experiences. In the literature, it is reported that parents typically believe they are not well enough equipped to parent their child with ASD, especially at the beginning of their journey (Crowell et al., 2019; Karst & Van Hecke, 2012). Parents can come to an understanding about their child by making meaning of their child's diagnosis; Gentles et al. (2019) list these meaning-making processes as: defining concerns, informing the self, seeing what is involved, and adapting emotionally (Gentles et al., 2019b). These processes can occur over a period of time, but can also depend on the extent to which parents are able to accept their child's diagnosis and come to terms with the related implications (Depape & Lindsay, 2015; Dieleman et al., 2018; Gentles et al., 2019b). Acceptance can lead to better parent engagement and advocacy in their child's care, and create opportunities for more positive, strengths-based (or function-focused) perspectives towards their child's skill development (Finke et al., 2019; Gentles et al., 2019a). By developing positive envisioning for a child, parents can also feel more confident to self-identify as a parent of a child with ASD, and take the steps to better understand their child's unique traits (Dieleman et al., 2018; Finke et al., 2019).

A third finding from this study indicated that positive perceptions towards functioning can help improve the support process of a child with ASD, as was present in *Doing the Right Thing for My Child*. Studies, including that of Ferrer et al. (2017), found that parents that typically held more positive perceptions towards their child's diagnosis developed warmer relationships with their child, and thereby built a stronger foundation as a family unit when accessing and utilizing ASD supports (Ferrer et al., 2017). However, parents that experienced some form of psychological distress outside their child's diagnosis were also more likely to view their child as more problematic, which in turn can lead to poorer clinical outcomes for both the child and family (Yorke et al., 2018). Parents and caregivers may experience a number of additional barriers that may influence their perceptions towards their child and affect how they participate in their child's care, including but not limited to: parent knowledge about ASD and services, expectations of the parent, and the overall relationship between parents and clinicians (Chlebowski et al., 2018; Finke et al., 2019). Overall, the findings of this study support that parents want to do the best for their child; however, external factors can compromise parental perceptions of their child's abilities, and therefore, may impact the level of parent involvement in their child's care. The impact of external factors should be considered by clinicians to better support the family's needs.

The last important finding from this study, emerging from themes including *Managing Expectations* and *Doing the Right Thing for My Child*, were the benefits of the inclusion of parent perceptions in clinical practice and FCS. In our sample, we found that when parents are able to forego their initial hesitations and fears about the diagnosis, and prioritize their child's needs, they can become strong advocates for their child's care. This level of involvement is beyond what was previously described in the last section. Within the intersection of FCS and ASD supports, more clinicians are involving parents and caregivers in the planning and delivery of ASD interventions (Almasri et al., 2018; Gentles et al., 2019a). Some studies have found that when parents believed they had some control with the coordination and delivery of their child's ASD services, this engagement could improve overall family well-being (Ferrer et al., 2017; Haney et al., 2018). Parent advocacy for their child can be important to many parents of a child with ASD; however, this group may also experience varying degrees of willingness to engage in their child's care (Gentles et al., 2019a; Lappé et al., 2018). Hesitation may arise from the parent's personal situation or broader worldview that can be associated with their preconceptions of an ASD diagnosis (Gentles et al., 2019a). Since these perceptions play a significant role in the intervention and support process of the child, it is important for clinicians to cultivate an environment that best addresses individual child and/or family needs (Chlebowski et al., 2018; Elder et al., 2017). Parents in our sample wanted to support their child in every way they could, often sharing that advocacy was important in ensuring their child could lead a positive life trajectory.

Limitations

Our first limitation is that the sample size in this study consisted of five participants, which may not capture the wide range of parent perceptions outside of one community. For reasons of feasibility, our method of data collection, and the limitations of COVID-19, and despite planning for a wider recruitment, we were able to recruit at only one community site in Southern Ontario. In addition, parents that were not associated with ASD organizations were not included. We recognize the potential selection bias within our sample, as only families that agreed to participate in this research study were included. Although this study involves a small sample, this work captured parent perspectives on an important topic that could be expanded to different sites as we hope to exit the restrictions tied to this pandemic.

Furthermore, we did not collect personal factors (i.e., parent gender, ethnicity, race) that could shape the dynamics of the interactions between a parent and child. We recognize that our sample cannot be generalized to all parents of children with ASD. In future work, we plan to provide improved avenues to recruit a more diverse sample that includes families that are often not granted opportunities to participate in research.

Finally, parent perspectives were not necessarily reflective of typical autism services because in the context of when data was collected, autism services were not all delivered as they are traditionally provided. COVID-19 impacted our findings in that many parents expressed that they were either not able to access services, or attended modified services

(i.e., online sessions, virtual care) that parents believed impacted their child’s progress and development. As the child demographic in our sample consists of children that were recently diagnosed, many of these families have only experienced navigating ASD services during a pandemic. Therefore, their experiences may be skewed when compared to parents who have been in the ‘usual’ system for much longer. Although we accounted for these challenges during our interview questioning, we acknowledge that this issue was quite prevalent among the stories shared by families.

Despite these limitations, we believe that this study makes a positive contribution to the study of functioning for children with ASD and their families. We partnered with SAAAC Autism Centre, an organization based in the Greater Toronto Area to gather a diverse range of perspectives of parents with varying cultural and socioeconomic backgrounds. We believe the stories of these families can help address knowledge gaps in function-focused care within FCS implementation, and can help promote the study of abilities among children with ASD.

Implications for Clinical Practice

In the ID methodology, Thorne suggests that the product of the qualitative interpretations should include the identification of practical recommendations using the findings from the data (Thorne, 2016). We propose the following health care applications based on the five themes.

Increase Support(s) for Families of Newly-Diagnosed Children

Although parents in this study experienced a process of learning about their child, they still experienced a variety of fears and negative attitudes towards the diagnosis. Most parents felt they did not receive adequate initial support from their developmental pediatricians and/or other clinicians at the time. Early intervention was also highly stressed to some parents, who then believed their child would not succeed without parents investing in ASD-based services for their child. Based on the results of this study and support from the literature, we see the value of increasing the opportunities made available by clinicians for further engagement in emotional support for families of recently-diagnosed children with ASD (Jacobs et al., 2020). More hope and a positive outlook towards the child’s life at the beginning of the diagnosis may relieve parents of some of the hesitations they have towards their child acquiring certain skills for success (Carbone et al., 2013; Jacobs et al., 2019; Jacobs et al., 2020). The inclusion of clinical tools may also be used to guide partnerships, such as the Measures of Processes of Care (MPOC) or the Autism Classification System of Functioning: Social Communication (ACSF) to continue dialogue regarding function-focused thinking (Di Rezze et al., 2016; King et al., 2004). By building a more effective system of supports and mentorship between clinicians and families at the beginning of a parent’s journey, parents may be more confident in how they think about their child, which could then lead to more effective clinical outcomes.

Increase Communication between Caregivers & Clinicians

In the study's findings, environmental factors (i.e., clinicians, ASD services) impacted parental perceptions of their child's abilities, regardless of the child's (and parent's) life situation. This result is similar to what has been observed in previous literature, such as Almasri et al. (2018), who recommended that clinicians engage in ongoing conversations with families, especially when sharing information beyond the child's condition, including broad-based questions that pertain to multiple aspects of the child's and family's life (Almasri et al., 2018). When parents do not receive adequate support from their clinician(s), they may experience feelings of hopelessness and frustration that can lead to a lack of parent confidence towards their child's diagnosis and future care (Almasri et al., 2018; Locke et al., 2020; Mire et al., 2017). These feelings could be mitigated by addressing parent needs when interacting with the family, and providing more opportunities within organizations for peer/parent mentorship supports (Carrington et al., 2021; Kokorelias et al., 2019). Since clinicians play a large role in shaping parents' perceptions throughout the parents' journey, these increased supports and counselling can reduce parental stress, and empower families with a more positive outlook towards their child's functioning and abilities (Almasri et al., 2018; Elder et al., 2017; Rosenbaum & Novak-Pavlic, 2021; Schwartzman et al., 2021).

Clinical Awareness of Power Imbalance

Parents typically valued certain skills and traits more than others, and this was often based on recommendations given by clinicians; this finding may be linked to potential power and knowledge differences between a parent and clinician. For example, a parent may forego or alter their initial understandings of how to parent their child because of clinician recommendations, potentially resulting in a lack of parent confidence towards the guidance of their child (Avendano & Cho, 2020). However, some parents may experience the opposite effect, such as clinicians that use similar guidance strategies to the parent, which can encourage parents who feel lost to be able to regain a sense of hope for their child (Casagrande & Ingersoll, 2021; McDowell, 2021). In both instances, clinicians hold a certain level of power that can influence what approaches parents may use to interact with their child. Although the impact of clinicians may be dependent on a variety of factors (i.e., how often the parent interacts with the clinician, service access, parent willingness to engage), clinicians should recognize their positionality when working with families, and continue to serve as critical allies that value parent/family perspectives at the forefront of care (Almasri et al., 2018; Reitzel et al., 2021; Rosenbaum et al., 1998).

Conclusion

This study utilized the methodological approaches of ID to better understand the experiences of parents of children diagnosed with ASD, and how they perceive their child's everyday abilities. Based on what we have learned from families, we propose that future research explore in more detail the extent to which clinicians have impacted parents' perceptions of their child's abilities, especially if their child is newly-diagnosed. Specifically, we hope that future research can provide better tools and strategies that can

be used in addition to current procedures, but that focus on addressing the needs that are meaningful to families. By doing so, this approach better supports individualized family-centred practice, helps build a stronger parent-clinician partnership, and increases the likelihood that strengths-based discussions and approaches are utilized in care.

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CHAPTER FOUR: CONCLUSION

Introduction

This thesis sought to examine the concept of everyday functioning in the context of FCS for children with NDD. Two main studies (reported in Chapters 2 and 3) were conducted to enhance our understanding of childhood disability. In Chapter 2, we examined the literature to describe clinically-based measures based on the ICF (World Health Organization, 2001). In Chapter 3, parents shared their perceptions of the everyday abilities of their children diagnosed with ASD, including factors that influenced how they think about their child. Overall, this thesis contributes new knowledge regarding: (1) function-focused clinical measures in developmental disability and how the concept of functioning is described for children with NDD, and (2) how parents perceive the functioning, or everyday abilities, of their child with ASD within the context of ASD services.

Chapter 2 utilized a narrative review methodology to examine clinical measures (assessment/outcome measures and classification systems) that are grounded in the ICF framework and used for children with NDD. Fourteen measures were identified from the review based on how they utilized one or more of the four ICF domains used to describe child functioning: body structures and function (29%, n=4), activities (71%, n=10), participation (79%, n=11), and contextual factors (43%, n=6). Although participation and activities were the most commonly used domains, this study also highlighted the dynamic and interactive nature of the ICF framework, as 71% (n=10) of the identified measures assessed multiple ICF domains. Overall, these findings provide an effective description of

the application of the ICF's framework to describe functioning for children diagnosed with NDD.

Chapter 3 consisted of a qualitative study that utilized an interpretive description methodology to capture how parents think about the everyday abilities of their child with ASD, and the services that their child receives as these relate to function-focused care. Five parents were interviewed to better understand their experiences navigating their child's care using interpretive description (ID). We identified five themes (Parenting Approaches, Accepting My Child, Managing My Child's Challenges, Doing the Right Thing for My Child, and "The Disability Tag") that demonstrate the varied influences that parents may experience throughout their journey that can impact how they perceive their child's abilities and functioning. These themes can provide clinicians with useful suggestions on how to improve their communication with families, such as promoting function-focused thinking throughout a parent's navigation of services and providing more initial supports and recommendations for families unsure of next steps for their child. These practices can promote more optimistic thinking about child abilities and utilize the values of FCS to better address family needs.

Contributions to Knowledge

Extending the Literature

The examination of child functioning is an important area of exploration for children with NDD. New ways of thinking (i.e., social model of disability, ICF framework, neurodisability movement) help increase the social recognition of disability

as ‘human difference’ rather than a ‘disorder’ (Baron-Cohen, 2017; Castro et al., 2013; Miller & Rosenbaum, 2016). I sought to understand how the concept of functioning can be understood via the measures developed and utilized in clinical settings, as well as from the perceptions among parents of children diagnosed with ASD. Overall, this work supports the growing momentum of strengths-based approaches used within FCS and function-focused care.

Historically, measures and assessments developed for children with NDD focused on the deficits and limitations of a child. However, there are a number of scholars, including Mottron (2017) writing in the ASD literature, who suggest that this way of measurement may not be effective across groups of individuals with wide ranges of abilities and challenges (Kapp et al., 2013; Mottron, 2017; Patriquin et al., 2016). In addition, as examined by Leadbitter and colleagues, there is a wide range of interventions that focus on the reduction of autism symptoms, rather than the goodness of fit between an individual and their contextual environment (Leadbitter et al., 2021). Within the vast array of strengths-based measures developed for children with NDD, these measures may utilize different theoretical underpinnings, which may not capture the concept of functioning in the same way. Therefore, it was important to begin to understand this new wave of function-focused measurement, especially using the widely-recognized framework for health of the ICF.

Chapter 2 provides a resource for clinicians, researchers, and families of the ICF-based measures that are currently available for children with NDD. That chapter highlights information about these measures, includes details about their psychometric

properties and clinical context(s), and focuses on what ICF domains are prominent among these measures. Although this research supports other literature that has emphasized the popularity in use among activities and participation domains, the findings specifically highlight the importance of the domain interactions (i.e., multiple domains examined in the measure), which were present in only 10 measures (Jette et al., 2007). Since functioning is defined by the positive and neutral interactions between the four domains (body structure and function, activities, participation, and contextual factors), it is important for researchers to take these interactions into account when developing measures in the future. In the literature, new measures are being developed based upon the principles of the ICF for children with NDD. In addition, a number of studies have mapped their existing measures to the ICF using the ICF linking rules established by Cieza et al. (2005) (Ballert et al., 2019; Cieza et al., 2005; Granberg et al., 2014). However, prior to the publication of Chapter 2, there were no literature reviews that examined function-focused clinical measures based on the ICF that could be used for children with NDD. Purpose-designed ICF-based measures are different than existing measures that are mapped onto the ICF domains using ‘linking rules’; the former allows for the ICF’s definition of functioning to be at the forefront in the measure’s development, rather than the ICF being considered as an afterthought (Cieza et al., 2005). When measures are based on the ICF, they may also be more likely to consider the interactions between domains, rather than focus on the four domains itself.

Existing literature has examined parent and clinician perceptions of an NDD diagnosis, especially among parents of children diagnosed with ASD (Finke et al., 2019;

Jacobs et al., 2019). Many scholars have studied the diverse needs that may be required to better support children diagnosed with ASD and their families (Derguy et al., 2018; Glazzard & Overall, 2012; Marsack-Topolewski & Graves, 2020). In addition, early support by clinicians during a child's diagnosis was found to be a high predictor in improving familial attitudes towards disability, child health outcomes, and overall quality of life for both the child and family (Almasri et al., 2018; Ferrer et al., 2017; McConachie et al., 2018). However, there is little to no information available that examines specifically how parents perceive their child's 'functioning' and everyday abilities. In Chapter 3, we examined the strengths and challenges that parents identified with their child, but more particularly, the factors and journey that had led parents to how they currently think about their child. All parents that I interviewed had identified several of their child's skills and abilities, with a few parents sharing their journey in rethinking the functional capabilities of children diagnosed with ASD. This research is an addition to the growing literature examining the abilities of children with disabilities, and provides an indicator of how parents think about their child with ASD.

In Chapter 3, I reported potential barriers and supports that may influence how parents perceive their child's abilities. To begin, parents shared that they valued certain skills for their child, such as increased safety recognition or development of social skills. For these parents, such skills were important in order for their child to fit in with their social surroundings. For example, the mother who had concerns about her child's safety when crossing the road would not have to worry excessively about their child if they had developed that skill. For this parent, safety was of the utmost concern; therefore, many of

the interventions that this parent chose revolved around teaching her child about safe practices to develop independent skills. However, parents may also alter how they think about their child's abilities as they navigate their child's diagnosis and learn more about their child over time. This finding was especially prevalent among some parents who expressed their appreciation that their child could be a functional member in society after seeing their child thrive in different environments as they got older (i.e., daycare vs. home settings). These parents, who may initially have held negative impressions regarding an ASD diagnosis, were able to be more accepting of their child's abilities, and develop a more positive outlook for their child over time.

Similar to the findings present in the work of Ferrer et al. (2017), this research supports the argument that positive parent perceptions about their child's health condition can lead to improved support processes for the child (Ferrer et al., 2017). Parents that shared positive perceptions about their child were typically also strong advocates for their child's care (Ferrer et al., 2017; Gentles et al., 2019a). However, when external factors (i.e., financial constraints, lack of support at home) contribute to parent perceptions, these may increase psychological stress for the parent and/or cause parents to view their child as more problematic (Derguy et al., 2018; Ferrer et al., 2017). Parents may also experience hesitation to engage themselves in their child's care (i.e., their worldview towards disability) (Gentles et al., 2019a, 2019b). Following the recommendations of FCS to promote family quality of life, clinicians should also consider how parent perceptions and engagement may influence a child's care, and use this knowledge to address more effectively the diverse needs of families (Almasri et al., 2018).

It is important to note that the influence of clinician behaviour on the perceptions of parents is not a novel finding: there are different examples in the literature that support this argument (Carbone et al., 2013; Jacobs et al., 2019d; Ridge & Guerin, 2011). The primary aim of Chapter 3 was to identify strategies that clinicians could use to better address family needs for children diagnosed with ASD within FCS. Rosenbaum et al. (1998) share that a core value and approach in FCS is clear communication between family stakeholders and clinicians so that clinicians can address family needs, and families can feel better supported by their child's health care providers. In Chapter 3, communication between parents and clinicians—especially during initial diagnosis of a child—was seen among parents as a significant barrier, indicating that there may continue to be gaps in FCS implementation in clinical settings. Communication gaps between parents and clinicians were also identified in the literature (Almasri et al., 2018; G. King & Chiarello, 2014).

This parent-clinician relationship can be additionally problematic if the clinician does not recognize their power and positionality, and its influence on parent perceptions. For example, the Centers for Disease Control and Prevention (2020) states, “The earlier intervention can begin, the better for long-term outcomes. However, each child's response to intervention may vary. It is never too late to begin teaching a child with autism new skills.” This type of thinking is highly prevalent among clinicians and researchers involved in ASD care (CDC, 2020, n.p.; Jacobs et al., 2019). However, parents of children diagnosed with ASD, especially those who face barriers in service access for their child (i.e., financial constraints, waitlists for services) may feel overwhelmed by this

type of messaging (Kanne & Bishop, 2021). As shared by some of the interviewed parents, they also feel a lack of confidence regarding their child's outlook if they do not access appropriate interventions for their child. One parent shared: "I feel very angry and very frustrated because early intervention is stressed so highly. I feel like society is saying that it's over, like my child's already failed because he's not going to be able to receive these services in time". If clinicians continue to endorse early interventions without proper systems being put in place for parents, this disconnect may negatively impact how parents think about their child's life trajectory, and promote deficit-focused thinking.

The impact of power and positionality on families is not truly captured in Rosenbaum et al. (1998), but it exists in similar conceptual models with this type of parent-clinician collaborative thinking (i.e., cultural humility) (Moon & Sandage, 2019; Rosenbaum et al., 1998). Some organizations, notably the SAAAC Autism Centre, have implemented cultural competence toolkits to describe the importance of clinician and parent relationships at the level of diagnosis (Shanmugathan & Sivapalan, 2022). Further efforts within FCS should acknowledge power and positionality to help bridge communication gaps between parents and clinicians. Overall, this research contributes to existing literature regarding the importance of recognizing the roles of clinicians (and social systems), and how their perceptions can influence how parents think about their child's everyday abilities.

Exposing the Nuances in ‘Disability Language’

It is important to consider how language can be linked to deficit-focused thinking. Language can impact how parents may think about their child, such as in the measures that clinicians use that focus on the diagnosis and treatment of the “negative” aspects of disability, or how disability may be described by clinicians. In Chapter 2, I did not examine prominent ASD tools used in clinical care, or other tools that exist beyond those that are ICF-based. Tools including Childhood Autism Rating Scale, Second Edition (CARS-2) and Autism Diagnostic Interview, Revised (ADI-R) are commonly used by clinicians, and could promote a certain way of thinking (Schopler et al., 2010; Lord et al., 1994). For example, the Autism Diagnostic Observation Schedule (ADOS) Calibrated Severity Score is a commonly used diagnostic measure for children with ASD, and utilizes a 10-point metric to diagnose the “severity” of autism (Wiggins et al., 2019). Clinicians who use these measures seek to identify autism-related symptomatology and traits among children whom they believe to be diagnosed with ASD (Provenzani et al., 2020). Although these measures seek to diagnose ASD, the language surrounding “severity” may be considered to some as part of the normalization agenda (Leadbitter et al., 2021). Families may also experience the study of severity as a negative impression towards ASD and disability (Kissel & Nelson, 2016). Therefore, it is important to understand more clearly the role of language when developing measures for children with NDD, so clinicians can measure functioning using inclusive language with families within FCS and can focus on what *is* rather than what *is not*.

Furthermore, Bottema-Beutel (2020) states, “What people say or write produces specific versions of the world, one’s self, and others, and language conveys, shapes, and perpetuates ideologies” (Bottema-Beutel et al., 2020, p.3). Appropriate language within ASD research and interventions is imperative to help promote identity formation among children with ASD (Botha et al., 2021; Jones et al., 2015). However, some parents typically fear that identity-first language may impact their child being defined by their disability. This fear may also be linked to deficit-focused thinking, due to the societal stigmas surrounding disability (Anderson-Chavarria, 2021; Kapp, 2018; Russell et al., 2019). Parents may also want to separate their child from their disability, which could prevent parents from accepting their child for who they are. Clinicians that focus on child abilities when communicating with parents can help promote positive thinking towards disability, and should provide opportunities for open communication about language use within disability to help promote identity formation within function-focused care.

Implications for Stakeholders

FCS is made effective by combined efforts of parent stakeholders, clinicians/service providers, as well as policy makers who design the systems in which children diagnosed with NDD receive care. The following sections examine the implications that emerged from this research that contribute to the literature regarding FCS, alongside recommendations on how we can better address the gaps in knowledge within function-focused care and research.

Implications for Clinicians/Service Providers

Within FCS, clinicians should continue to help parents articulate their goals for their child (i.e., child functional outcomes, quality of life). By articulating clinical goals based on functioning, families can focus on their child's abilities, which can promote a more meaningful and positive outlook for their child's life. (Finke et al., 2019). Parents may have certain goals and priorities for their child, which can change over time; the findings of this research help support that clinicians should (1) address potential knowledge gaps among parents regarding their child's care, and (2) keep note of what parents prioritize for their child over time (Finke et al., 2019; Gentles et al., 2019b). By reassessing and addressing parents' evolving hopes and concerns related to a child's diagnosis, these consultations may lead to a better parent-clinician alignment and higher satisfaction on both sides (Jacobs et al., 2019). Moreover, if parents prioritize specific skills for their child, it may be beneficial for the clinician to understand why parents have certain beliefs, and the processes in which these perceptions arise (Haney, 2018). For example, if parents have concerns regarding their child's emotional or behavioural challenges, and these influence how they make decisions about their child's interventions, clinicians can use that information to better understand the meaning and context behind the parents' preferences, and tailor their recommendations to better fit the family's needs (Haney et al., 2018; Lappé et al., 2018).

Clinicians may also find opportunities for patient education when parents express these concerns, especially at the beginning of a parent's journey—a time when parents feel they need the most support from their clinicians. Within these initial consultations,

clinicians can highlight concepts of neurodiversity, or more specifically that ASD results in a wide range of abilities among children. By informing parents that individuals with ASD can both be productive members of society and live fulfilling lives, this encouragement can help prevent misinformation and dispel some of the negative stereotypes that are often associated with ASD (Jacobs et al., 2019; Locke et al., 2020). Overall, increased communication between parents and clinicians throughout a parent's journey, and ensuring both parties are speaking the *same* language, can alleviate some of the burdens often felt by parents when navigating an ASD diagnosis and supports (Palisano et al., 2020). Overall, these efforts can help parents feel more confident in advocating for their child's strengths and abilities (Lappé et al., 2018).

Implications for Parents/Caregivers

An important implication for parents that also emerged in the findings of this research is the increased focus on the strengths and challenges that are specific to child and family needs (Gardiner et al., 2018). Parents and family stakeholders may hold onto specific preconceptions about an NDD diagnosis that may prevent them from fully accepting their child's diagnosis. Parents should focus on having their voices heard by clinicians, so that clinicians can truly address child and family needs (Almasri et al., 2018). Parents should also find ways to engage continually with their child's care, to better understand their child's skills and challenges (Gentles et al., 2019a). By undergoing the *Process of Understanding*, as described in Chapter 3, parents may feel more

empowered to think positively about their child’s trajectory, which can help improve overall family quality of life and well-being.

Implications for Future Policies

Areas of consideration for future government policies could include the prioritization of *functional* outcomes among children with NDD, rather than promoting the *treatment and alleviation of disability* (Ferrer et al., 2017). Government policies could promote ICF-based tools and ways of thinking positively about disability in FCS. For example, F-Words of Child Development is a conceptual model that consists of six factors (Functioning, Family, Fitness, Fun, Friends, and Future) that transcend from each ICF domain, and are listed as important components for child development (Rosenbaum & Gorter, 2012). Some organizations have also taken steps to change their language in their messaging, such as Autism Speaks who removed the word “cure” from their mandate in autism research (Autism Speaks, 2022). Positive messages within policies can promote resilience among families of children with disabilities, an philosophy that aligns with the growing number of strength-based approaches used within current clinical care models (Zuna et al., 2016).

Furthermore, as reported in Chapter 3, many parents identified challenges with the system, specifically with the lack of easily accessible information about ASD services and funding. Therefore, appropriate measures for knowledge dissemination should be put in place, so that families are more successful in navigating ASD services. Collaboration across agencies and increased organization of funding information may be two avenues

for which families may be able to locate information and access services that are relevant to their needs (Zuna et al., 2016). Lastly, current supports for children with NDD are typically concentrated on early interventions for preschool children; however, this may not address the challenges that may be experienced by those with NDD across the lifespan; policy planning at organizational levels should consider expanding supports to fit the diverse range of needs as children grow and adapt with their diagnosis as well as the needs of their families (Yi et al., 2020).

Recommendations for Future Research

Based on the emerging concepts gathered from the two studies, I propose two directions for further research within the topic of functioning for children with NDD. The first recommendation includes the longitudinal examination of perceptions among parents of children diagnosed with ASD in multiple diverse communities. In future longitudinal studies, we could include parent perceptions at multiple timestamps navigating their child's diagnosis (and as their child grows), to better understand parents' journey and the potential challenges they may undergo over time. For example, parents could be interviewed at the time of initial diagnosis to understand their perceptions about their child and what factors may have influenced those; these factors would be evaluated at baseline using the ICF domains, and measured again over several points to explore change. Factors such as societal stigmas about ASD may not be as important to families later on in their child's journey as much as they may have impacted parents during initial

diagnosis. Since the ICF presents a cross-sectional picture, involving a longitudinal dimension into this type of research could produce more enriching findings.

The second avenue for this type of research could potentially involve the inclusion of the perspectives of individuals diagnosed with NDD regarding function-focused care and strengths-based approaches used by clinicians in FCS. The perspectives of parents are widely studied, especially regarding an ASD diagnosis; however, there continue to be fewer opportunities for self-advocates to share their experiences navigating these systems, and the potential challenges they may experience that prevent them from expressing their capabilities. Moreover a widely recognized criticism in ASD research by self-advocates in these communities is lack of knowledge regarding the perceptions of individuals with ASD (Chown et al., 2017; Dinishak, 2016). The involvement of individuals with NDD would be an appropriate next step in examining functioning within FCS, and could increase opportunities for individuals on the spectrum to participate (and be research partners) in addressing the knowledge gaps in this research space.

Strengths & Limitations

This research has made important contributions to the study of functioning. I identified several ICF-based clinical measures for children with NDD to examine how child functioning could be measured using the ICF domains. I also examined the perceptions of parents of children with ASD to better understand how they think about their child's abilities and health systems as these relate to function-focused care within FCS. A key strength in Chapter 2 is that the results of the study provide a practical

resource for the use of function-focused measures in clinical settings. Parents, clinicians, and organizations who utilize this review will be informed of the measures' demographic details, associated psychometric work, and the different ICF domains that are captured by the measure. This study is also published and open-access in the Frontiers' research topic: *Families and Functioning in Childhood and Adolescence*. The benefit of the review being open-access is that it allows families to access the findings of the study, builds on existing evidence that is widely accessible, and increases exposure to function-focused research.

In Chapter 3, a strength of this study was the inclusion of the SAAAC Autism Centre in Scarborough, ON, Canada as the research partner for recruitment. SAAAC is home to a diverse set of families, varying in cultural and socioeconomic backgrounds, who are not often granted opportunities to participate in this type of research. By involving diverse parent experiences, we can continue to building evidence related to the topic of study. Furthermore, the involvement of ID as the central methodology for Chapter 3 allows for a more clinically-relevant discussion about child functioning, and the ways in which parents' ideas about their child's abilities can be incorporated in practice. We interpret the experiences of parents to provide clinically-oriented implications, which are not typically captured by simply using qualitative description methodology.

There are several limitations that were captured in Chapter 2 that need to be addressed. The first limitation of Chapter 2 involves the varying types of psychometric data that was present among the selected measures within their development studies. The development studies were the main sources used in this work; therefore, there are some

considerations to be recognized. By utilizing studies of the development of the measure, and not subsequent papers that may have reported other properties or populations, not all relevant information regarding the tool may be captured. We selected measures that explicitly included the ICF in the abstract of their development paper (or a subsequent paper that was linked to its original published development study) within recognized health databases. Although there is a potential for other measures to use components of the ICF within their conceptualizations, the aim of this study was to find measures that explicitly utilized the ICF domains as a foundational aspect in the measure's development. Further research should compare ICF-based measures with measures that utilize the ICF linking rules, to further conceptualize the impact of the ICF in measurement development to describe functioning. This type of research would lead to a more comprehensive study of functioning for children with NDD.

Lastly, an important limitation to address in Chapter 3 is the small sample size ($n=5$) for parent participants in the qualitative study. We recognize that this sample size may not capture the diversity among parents of children with ASD. We also sampled at one site, which could pose a biased sample with similar experiences from one community. These limitations are largely due to the project's scope and feasibility during COVID-19. Although this study may not be highly generalizable to all parents, we believe that the emergent themes of this work capture the breadth and uniqueness of parent perspectives regarding the everyday abilities of children diagnosed with ASD – and these themes could be further explored in subsequent studies. All five interviews contributed rich data and stories that highlighted significant factors that either inhibit or a

promote strengths-based approaches in examining child functioning. Furthermore, no personal factors (i.e., race, ethnicity, socioeconomic status) were included in the demographic collection of participant data, which may have influenced the findings of this study. Although interviews provided opportunities for individuals to share their perspectives that they believed may influence how they think about their child's abilities, these personal factors were not seen as significant contributors with this specific sample. We hope that future research expands this topic of study to include a larger sample size, and collects key demographic data, to understand more fully the diversity of experiences among families, and to identify the contributing factors in applying function-focused practices in FCS.

Conclusion

As we continue to prioritize child functioning in family-centred services for children with NDD, this research examines how functioning is operationalized in research and practice, and how it is understood by the families involved in this type of care. Overall, this research highlights the nuanced aspects of conceptualizing functioning for children with NDD, as there is a growing paradigm shift in how we utilize both the social and medical models of disability within rehabilitation systems and FCS. By including functioning as a core concept in FCS, service providers can continue to promote abilities-focused thinking, helping to improve the health and well-being of children with NDD and their families.

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Appendix A: Letter of Information/Consent



Participation Information & Consent Letter

Project Title	Parent perceptions of the everyday abilities of their child with autism
HiREB #	12772
Student Investigator Telephone	Kajaani Shanmugarajah: McMaster University 905-525-9140, ext. 27850
Email	shanmugk@mcmaster.ca
Supervisors	Dr. Briano DiRezze: <i>CanChild</i> , McMaster University Dr. Peter Rosenbaum: <i>CanChild</i> , McMaster University Dr. Mohammad Zubairi: McMaster University

This Participation Information Letter outlines key areas of a research project in which you may be interested. We believe that your participation will help us, as service providers, to understand important issues about the work we do, and learn how to do our work better with parents of children with autism. We would like to invite you to take part in this study, as explained in the next few pages. We thank you in advance for your consideration.

Please remember—it is okay to say “**No**” to this invitation, if you are not interested in being involved with this project. Your decision will have **no impact** on the services you receive at your organization.

What is an Information Statement?

The following pages tell you about this research project, and the steps that can be expected. This information can help you decide whether you would like to participate in this project. Please read this letter carefully, and do not hesitate to contact us if you have any questions or concerns about this project.

What is this research study about?

As we shift to a health culture that looks at and promotes what children *can do*, in addition to the challenges a child has, we seek to better understand how we can improve autism services and parent-clinician relationships to better fit the unique needs of children and their families.

We are interested in understanding what is important to families of children with autism and how they function together in autism research and clinical practice. We want to learn more about your experiences as parents of young child with autism on how you think about your child's everyday abilities, current autism services, as well as your experiences working with health professionals for your child's care.

Who is undertaking this project?

This project is being led by Kajaani Shanmugarajah, a Master of Science student at McMaster University in the Rehabilitation Science program. This project will be part of Kajaani's work for her degree. Kajaani has a genuine interest in pursuing the study of child development and of the experience of families of children with autism. She has experience working with children and families in hospital and community-based organizations.

Dr. Briano Di Rezze is both an Associate Professor at the School of Rehabilitation Sciences and a *CanChild* Scientist at McMaster University with almost 20 years of experience working with children and youth with disabilities, and their families. He is also a member of McMaster Autism Research Team (MacART). His research focuses on the impact of rehabilitation interventions and the development of measures that can be used to improve the participation and functioning of children and youth with neurodevelopmental disabilities.

Dr. Peter Rosenbaum is a Professor of Pediatrics and the Co-founder of *CanChild* at McMaster University. With more than 45 years of experience as a developmental pediatrician and researcher, he continues to have strong interests in the quality of health services offered to families of children with disabilities; parent and family well-being; and the overall shift in clinical work towards a positive outlook on 'disability'.

Dr. Mohammad Zubairi is a Developmental Pediatrician at Ron Joyce Children's Health Centre & Assistant Professor in the Department of Pediatrics at McMaster University. Dr. Zubairi is also involved with multiple research-focused initiatives including McMaster Autism Research Team (MacART), McMaster Education Research, Innovation and Theory (MERIT) Program, and was a former board member at the SAAAC Autism Centre. His research and clinical work focuses on the care and support for children and youth diagnosed with autism and related neurodevelopmental disorders.

Who can participate in this project?

This project is designed to explore family experiences. We would like to conduct interviews to learn more about your experiences with your child, ways in which 'function' has both played a role in how you think about your child's everyday ability, and your expectations of your child's autism care in paediatric health systems.

We are looking for parents to participate in the study who...

- a. ...are able to communicate in English with interviewers.
- b. ...have a child diagnosed with autism.
- c. ...has received some form of autism health service in Ontario for their child.

What will you be asked to do?

In late-spring, you will receive an invitation to participate in a 1-hour interview conducted virtually used Zoom by the student investigator of this project. If you agree, you will be recorded for the hour-long duration of the interview, with the student investigator taking notes on a personal computer. All personal information will be stored securely on *CanChild's* online server, and will only be accessible by the members of this research team. Interview information, including Zoom interview link, will be sent through email.

Are there any risks to you in doing this study?

The risks involved in participating in this study are minimal. Although the questions are designed to be engaging, you may feel uncomfortable with the questions asked throughout the interview process. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. It is also okay to stop to take a break, and you can withdraw (stop taking part) at any time of the interview and we will then only use what you tell us with your permission. If you would like access to mental health support after the interview, we will direct you to resources within your organization and in the community. We describe below the steps we are taking to protect your privacy.

We recognize that no external virtual platform provides full security against privacy breaches; however, we will take appropriate steps to best mitigate this concern. This study will use Zoom (McMaster licensed account) to collect participant data, an externally hosted cloud-based service. If you are concerned about the use of this software for the interview, we will provide alternate arrangements for your participation (i.e., telephone interview).

What are the benefits of this project?

We know that family perceptions play a large role in the support and care process of the child, and so it is important to understand how service providers can create an

environment that best supports the individual needs of families. By better understanding how we examine everyday abilities within autism care, we hope to find strategies to improve autism services, further build parent-clinician relationships, and potentially uncover gaps in our knowledge to further advance what we know about how ‘function’ should be measured within autism research and practice. We will also provide some resources at the end of the interview that may be helpful for you and your child.

Confidentiality

Every effort will be made to protect your confidentiality and privacy. We will not use your name or any information that would allow you to be identified; however, we may use direct quotes gathered from interviews, so you may be identifiable through the story you tell. All information collected throughout this interview process will be de-identified and only known by the student investigator and her supervisors. No individual at your organization will have access to any interview data (audio files or student investigator notes). This interview data will be encrypted and stored securely on the research team’s online server.

Although we will protect your privacy as outlined above, if the law requires it, we will have to reveal certain personal information (e.g., concerns about child abuse).

What if you wish to withdraw from this project?

Your participation in this project is voluntary. If you decide to participate in this project, and change your mind, you are able to withdraw your consent at any point or time of this study. Your decision to withdraw from this project will not be known to any individual outside the three researchers. If you choose to withdraw, there will be no consequences to you—this decision will in no way impact your child’s or family’s services.

How do I find out what was learned in this study?

We expect to have this study completed by approximately **April 2022**. A plain-language summary of the findings from this study will be sent to every family that participates.

Who should I contact for more information?

For more information, please do not hesitate to contact:

Kajaani Shanmugarajah
shanmugk@mcmaster.ca
905-525-9140, ext. 27850

Dr. Briano Di Rezze, PhD, OT Reg. (Ont)
direzzbm@mcmaster.ca
905-525-9140, ext. 20009

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

**IF YOU ARE INTERESTED IN PARTICIPATING IN THIS STUDY, PLEASE SUBMIT
THIS FORM ONLINE BY [DATE]**

Appendix B: Recruitment Poster



PARTICIPATE IN A STUDY:
Sharing your thoughts on what your
child with autism CAN DO
in everyday life

Parents & Caregivers

Do you have a child that is diagnosed with ASD and receiving health services like medicine or therapy?

Share your experiences

Our research team invites you to share your thoughts on how you think about your child's everyday abilities, current autism services, and experiences working with service providers.

Participate in an Online Interview



For more information
about the study, contact
Kajaani Shanmugarajah, MSc(Candidate)
at shanmugk@mcmaster.ca

*This project has been reviewed by the Hamilton
Research Ethics Board under Project #12772*

Appendix C: Interview Guide

Hi [Insert name],

My name is Kajaani, and I am a Master's student in the Rehabilitation Science program at McMaster University. I would first like to thank you for participating in this interview. Today, I would like to ask you a few questions about your child, your child's everyday abilities, your family, and your overall thoughts about the autism-related services that you have received for your child. This interview should take less than one hour.

I would like to remind you at this time that I will be recording our conversation and be taking a few notes on my computer; the primary reason for this is just so I don't miss anything. Is this okay with you? (Pause for response). Please remember that throughout this interview process, it is okay to take a break whenever you would like, or if you feel at all uncomfortable. You are also free to withdraw from the study completely at any point during our conversation, or afterwards, so just please let me know. I really appreciate the time that you are taking to help us researchers and service providers learn more how parents think about the everyday abilities of their child with autism. In the future, this could help the therapists, doctors, and other health care providers that work with your child to better assist with how to help your child as they grow up.

Do you have any questions before we begin?

Section 1: Intro Questions

- i) Can you confirm your name and the name of the organization your child is currently receiving services from? **[not recorded]**
- ii) How many children do you have and how many children do you have with autism?
- iii) How old is your child with autism now?
- iv) Briefly tell me about your immediate family. Specifically, I would like to get to know who lives with you in your home.
- v) Whereabouts do you and your family live?

ASD & Abilities:

- i) Overall, tell me about your child with autism...
 - o How do you describe this diagnosis to the people around you?
 - o Does this description change depending on who you talk to?
 - o (If applicable) Do you believe there are any differences with how you interact with your child with autism compared to your other children?
- ii) How would you describe your child's abilities or what they can do?
 - o What is your child good at?
 - o Are there any skills that your child has that you wish for them to continue?

- Do you have any concerns about your that you see in regular life activities for their age?
 - Why do you have these concerns?
- iii) How would you describe your child's ability to participate in activities during (a) school (b) social get-togethers (with friends/family) (c) home?
- iv) Does your child show any repetitive-stereotypical behaviours?
 - How do you feel about these behaviours?
- v) How do you believe society thinks about children with autism?
 - Do you agree with this belief?
 - Is there anything that you wish others would know about autism?
- vi) What are your thoughts about the word, "disability"?
 - Do you think that this word "disability" should be applied to children with autism?
- vii) Is there anything that you think they should accomplish for their age?
 - Is this something that you think about often?
 - Are there any situations or individuals that made you think this way?
 - Have you always had these beliefs (or has this belief changed over time)?
- viii) What do you expect your child to achieve/or be better at over the year?
 - Over the next 5-10 years?

ASD Diagnosis:

- i) Can you please tell me a bit about your journey with your child's diagnosis of autism?
 - How old was your child when he/she received a diagnosis?
 - Do they have any other diagnoses?
 - What were things that you noticed about your child around this time? (Things that he/she was good at or had difficulty with?)
- ii) What did you know about autism at the time of initial diagnosis?
 - Who did you meet with outside of your family and how did they speak about your child? (could probe further if needed - his/her abilities or challenges)
 - How was the initial diagnosis described to you?
 - How long has it been since your child was diagnosed? Has your knowledge about autism changed since that time?
 - If so, what have you learned (ask about outlook about strengths and challenges)?
- iii) After receiving the diagnosis, what were your next steps?
 - Why were these steps important to you?
 - Was there anything and/or anyone that helped you in making decisions about your child during this time?

ASD Services

- i) Are there any autism-related services that your child is currently receiving?
 - Why is it important for you to attend these services?
 - How do they aim to help your child in everyday life?
 - Do you believe these professionals focus on the strengths of your child or areas of improvement?
- ii) What were some of the services you have used in the past?
 - How do they aim to help your child?
 - How do you think they treat your child when they see them? (explore if deficit/behaviour focus or if explore goals or strengths/interests that will allow better participation)
 - Do you believe these professionals focus on the strengths of your child or areas of improvement?
- iii) Was there anyone with a specific approach towards your child's care that you found helpful?
 - Why did you find them helpful?
 - What were your expectations of your child's ability at this time?
- iv) How would you describe the professionals that you have worked with in the past for your child's care?
 - Was there ever an instance where you felt that your needs for your child and/or your family were not met?
 - What were your expectations of your child's ability at this time?
- v) Do you have any other experiences in health care that describes things that professionals said or discussed about your child influenced how you think about them?
- vi) Do you have any recommendations on how health service providers can improve either what they do/how they speak to children and families in ways that make them feel optimistic about the future?