Surviving the labor market: understanding the experiences of women and men with autism

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ABSTRACT

People with Autism Spectrum Disorder (ASD) constitute the fastest-growing developmental disability population in North America, yet their employment outcomes are significantly poorer. Little attention has been given to the role of gender in shaping their employment experiences and the interface between their work and family demands. This qualitative research is intended to enable the 'voice' of people with autism to be heard through the content analysis of naturally occurring discourse in an on-line autism forum. The research is composed of three substantive studies. The first study investigated the role of gender in career exploration and job-seeking experiences. Guided by the Stages of Considering Work, the study examined how women and men with autism experienced three consecutive sets of vocational barriers related to contemplating employment, defining career goals, and finding jobs. The second study explored gender differences related to challenges in the workplace to maintain employment, including workplace mental health, social interaction, executive function, communication, disclosure, accommodation, sensory environment, and corporate cultures. The third study investigated the domestic experiences of women with autism as mothers, housekeepers, and caregivers, and how they negotiated the interface of work and family demands. Guided by the work/family border theory, the study showed how gender and disability identities significantly influenced their work-family experiences. Overall, this research informs gender-sensitive policies and practices to improve the employment and work-family balance experiences of individuals with autism.

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PREFACE

This thesis comprises three substantive chapters that are either accepted (Chapter 2), submitted and under review (Chapters 3), or ready for submission to academic journals (Chapter 4). The lead author conducted each individual study design, data collection and analysis, and manuscript preparation. The main chapters in this thesis are:

Chapter 2:

Nagib, W*.*, & Wilton, R. (2019). Gender matters in career exploration and job-seeking among adults with autism spectrum disorder: evidence from an online community. *Disability and rehabilitation*, 1-12.

Chapter 3:

Nagib, W*.*, & Wilton, R. Examining gender differences in workplace experiences among adults with autism: evidence from an online community. *Journal of Vocational Rehabilitation* (Under review).

Chapter 4:

Nagib, W., & Wilton, R. In her own voice: juggling work, family, and caregiving roles by women with autism. (Ready for submission).

Chapter One

Introduction

Research in the geographies of disability explores disabled peoples' experiences of space and place and the ways that the design and production of space works to disadvantage (or enable) persons living with physical, developmental, emotional or intellectual differences (see Chouinard, 1997; Crooks et al., 2008; Hall & Wilton 2017). In addition to physical barriers, disability geographers have explored the institutional, social and political processes that produce disabling spaces. Recently, the labor market and workplaces have become an emerging area of their focus. Geographers' work has critically demonstrated how the material spaces of work, coupled with the organization of labour processes, workplace social environments, policies, and practices can both undermine and/or enable individuals who do not conform to non-disabled or 'ableist' norms (see Gleeson, 1998; England, 2003; Wilton, 2004; Chouinard & Crooks, 2005; Hall & Wilton, 2011; Hall & McGarroll, 2012; Evans & Wilton, 2019). This thesis extends the literature within the field of disability geographies by focusing attention on the experiences of women and men with autism as they negotiate the labor market and the interface between work and family domains.

1.1 Autism and employment

Autism Spectrum Disorder (ASD), also known as autism, is a lifelong condition that is characterized by persistent deficits in social communication and social interaction *and* restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric

Association, 2013). In North America, the population of individuals diagnosed with autism is reported to be increasing rapidly, surpassing that of any other disability group. In fact, according to reports, roughly 1 in 59 children in the United States and 1 in 66 children in Canada have ASD (Baio et al., 2018; Ofner et al., 2018). Further, an estimated 500,000 individuals with autism are expected to join the workforce in USA within the next five years (Johnson & Joshi, 2016).

In contrast to common misconceptions, many individuals with ASD are willing and capable of working, yet their employment outcomes are significantly poorer than both the larger disabled and non-disabled populations (Townsley et al., 2014). A recent study found that only 32% of adults with autism were employed either full-time or part-time compared to 47% of adults with disabilities in general and 80% of adults without disabilities (The National Autism Society, 2016). A study of youth and adults with ASD in Ontario showed similar results: only 30.2% of the respondents had either full- or part-time employment (Stoddart et al., 2013). In addition to unemployment, researchers estimated that 45% of adults with ASD were considered underemployed (Baldwin, Costely, & Warren, 2014). On the other hand, individuals with ASD who manage to secure employment are often highly valued by their employers for their trustworthiness, reliability, low absenteeism and meticulous attention to detail (Hagner & Cooney, 2005; Bissonnette, 2015). Thus, unemployment and underemployment have resulted in the poor use of a valuable workforce available in the form of adults with ASD (Hayward et al., 2016).

The inability to find stable and suitable employment is a grave concern among those on the spectrum (Griffiths et al., 2016).   In a recent survey (Griffiths et al., 2016), adults with ASD identified finding jobs that allow for financial independence as their primary objective and the most challenging issue they face. In addition to financial hardship, failing to engage in the world of work as a key marker of 'full citizenship' and 'adulthood' in modern societies heightens their sense of alienation from the rest of the working community (Rosqvist et al., 2014). Vocational exclusion also arouses feelings of depression, low self-esteem, and frustration among adults with ASD (Ohl et al., 2017).

Tackling the problem of un- and underemployment for adults with ASD is partly about addressing the challenges individuals face *in* workplaces as well as understanding and addressing problems faced while thinking about and looking for work. The process of seeking employment presents many challenges for those with ASD, which include scoping relevant job opportunities, completing the job application and interview, and overcoming the unfavorable attitudes of prospective employers towards recruiting employees with autism. In most cases, such attitudes are underpinned by misperceptions and lack of knowledge regarding autism (Scott et al., 2018). Problems associated with retaining a job are linked to challenges in the workplace context, such as acclimatizing to the physical office environment, communicating with colleagues, managing assigned job tasks and duties, and coping with job-related stress and pressure. The fear of discrimination or exploitation often prevents those with ASD from talking about their condition with workplace peers or seeking support (Dudley et al., 2015; Richard, 2015; Chen et al., 2014; Johson & Joshi, 2014; Townsley et al., 2014; Muller et al., 2003).

1.2 Research gaps in employment, gender, and autism

To date, little attention has been given to the role of gender in employment challenges for individuals with autism. Women's experiences in managing the interface between work and family demands are also relatively absent from the current literature. Many researchers have called for deeper and richer investigations, particularly qualitative, to unpack the complex relationship between employment, gender, and disability including autism (Lindsay et al., 2017; Lindsay et al., 2017a; Hayward et al., 2016; Sung et al., 2015). Thus, there is a critical need for such investigations to identify gender-specific needs and inform gender-focused support (Sung et al., 2015). A focus on gender continues to gain ground in current research, as many journals now require more rigor and transparency in reporting gender to ensure the generalizability of results (Lindsay et al., 2017a). This doctoral research aims to address two related gaps in the current literature: 1) to understand the role of gender in shaping the employment experiences of individuals with autism, and 2) to explore women's experiences in negotiating the interface between work and family demands.

1.2.1 The Role of Gender in Securing and Maintaining Employment

Although a growing number of studies have investigated the impediments to gaining and maintaining employment among individuals with autism, little attention has been paid to the role of gender in shaping labor market experiences of this population (Lindsay, 2017; Hayward et al., 2016). Exploring gender-related barriers is essential. First, existing literature reports that women with ASD continue to lag behind men regarding employment outcomes. Holwerda et al. (2013) noted while that while 65.5% males with ASD were unemployed, the

unemployment rate for females was much higher at 76.5%. An Australian study reported that

nearly 67% of those with ASD who were inadequately employed were women (Hayward et al.,

2016). Beyond those with ASD, evidence on the employment experiences of persons with

disabilities also highlights gender-related differences. For instance, males with disabilities are

reportedly more likely to be engaged in full-time employment, earn better pay, and derive

greater happiness from their jobs than their female peers (Coutinho et al., 2006; Doren et al.,

2011). Second, there is an emerging evidence-base to support the existence of gendered

manifestations of autism (Bargiela et al., 2016). Women with ASD are usually more social,

emotionally expressive, and approachable, with reduced hyperactivity/impulsivity and fewer

behavioral issues than men. Compared with men, women with autism are, on average, more

likely to demonstrate better communication skills, initiating and maintaining a conversation,

eye contact, using appropriate body language, and concealing autistic behaviors to 'fit in' with

the neurotypical world (Kreiser & White, 2014; Dworzynski et al., 2012). However, women with

ASD are also reported to have more mental health problems than men (Kreiser & White, 2014;

Dworzynski et al., 2012). Researchers have also identified several gender-specific social barriers

that can impact the employment choices of women with disabilities such as gender-role

expectations and stereotypes, family responsibilities, and paternal overprotection (Lindsay et

al., 2017). Finally, recent research has highlighted gender differences in vocational

rehabilitation predictors of successful competitive employment among individuals with ASD

(Sung et al., 2015). Men were found to benefit from vocational counseling, guidance and job

search assistance more than women. The study called for gender-specific vocational services for

people with ASD. Despite the significance of gender in the rehabilitation process (Ahlgren &

Hammarstorm, 2000), a recent study found that most vocational specialists did not tailor their practice accordingly (Lindsay et al., 2017). Given the prominence of gender in various aspects of the autism experience, it is not surprising that researchers have voiced a need to explore how gender influences the employment of adults with ASD (Hayward et al., 2016; Sung et al., 2015). It should be noted that while gender can be defined as the socially constructed behavioral norms for each sex (Warf, 2006), in this study attention to gender in securing and maintaining employment will be limited to individuals self-identified within the constraints of a gender binary as females and males.

1.2.2 Work-family Experiences of Women with Autism

A dominant notion in contemporary society is that women ought to succeed in their careers at the workplace and simultaneously fulfill their duties as nurturers and caregivers at home (Jacobs & Gerson, 2001). These conflicting demands, reflecting multiple identities as career women, mothers, and partners, are often a source of stress for women (Graham et al., 2004), as the traditional emphasis placed on care-related responsibilities necessitates professional sacrifices and constant juggling of time between family and work commitments.

Work-family research conducted to date has focused on women belonging to specific racial (Kachahaf et al., 2015), cultural (Valk & Srinivasan, 2001), or professional groups (Penney et al., 2015). Very few studies have examined the work-family intersection of women with disabilities (Cook & Shinew, 2014; Ozbilgin et al., 2011). Among the few available studies, Skinner and MacGill (2015) studied the lived experiences of ten working mothers with dyslexia, while Cook and Shinew (2014) explored the work-life balance of eight employed individuals

with physical disabilities, including five women. The latter authors concluded that "there is a need for more research about the work-life negotiations of individuals with all types of disabilities, as the work-life concerns of individuals with cognitive disabilities may be quite different from people with physical disabilities or with psychiatric impairments" (Cook & Shinew, 2014, P. 435). To this end, the present study is among the first to specifically address the work-life interface of women living with Autism Spectrum Disorder.

By doing so, the study also contributes to the scarce literature on the motherhood experiences of women with autism and their perceptions of parenting and caregiving (Tint et al., 2018). Recent research (Sandin et al., 2017) has estimated the heritability of autism to be 83%, suggesting that many women with autism are likely to give birth to children who also live with autism. Matthews et al. (2011) indicated that given the elevated level of stress associated with raising a child with autism, these parents are at a higher risk of experiencing a host of adverse outcomes compared to parents of children with other disabilities. Montes and Halerman (2008) found that families raising a child with autism were four times as likely to quit, change jobs, or not take a job at all as were commensurate parents with neurotypical children. Given these findings, it is reasonable to suggest that working women on the autism spectrum may be doubly disadvantaged. Not only do they have to cope with the demands of their own disability at work and home, they also have to shoulder the additional intense and prolonged responsibility of caring for their disabled children (Crettenden et al., 2014).

1.3 Research objectives

This thesis addresses these abovementioned knowledge gaps through the following objectives:

- The first objective is to explore the role of gender in shaping the experiences of adults with autism in **finding and securing employment**. This thesis investigates the gender differences in career exploration and job-seeking of adults with autism (Chapter 2).

- The second objective is to examine the differences and similarities among employed women and men with autism with respect to the challenges they face in **maintaining employment** (Chapter 3).

- The third objective is to investigate the work-family experiences of women with autism. This thesis investigates their experiences with domestic roles as mothers, housekeepers, and caregivers, and how they **negotiate the interface of work and family demands** (Chapter 4).

By doing so, the study bridges gaps in the literature and contributes to informing policies and services that can be used to support this population.

1.4 Method

One of the critical challenges facing Disability Studies is how to make central the voices of individuals with disabilities in research (Ashby, 2011). Adults with autism are described as 'some of the most excluded and least heard people in society' (Kanfiszer et al., 2017, p. 663). As caregivers for children with disabilities, mothers with autism maybe even more invisible in research (Canadian Center On Disability Studies, 2008). This research intends to enable the

'voice' of people with autism to be heard through researching naturally occurring discourse in an on-line autism forum. Individuals with autism have increasingly turned to social media such as online forums to share personal experiences, disclose their challenges, and seek support and advice from their peers (Biyani et al., 2012; Davidson, 2008). The relative anonymity of the internet, the absence of anxiety associated with face-to-face interaction, and the environment of trust commonly established among members of online support groups (Pfeil & Zaphiris, 2010), encourage individuals with autism to express deeply personal opinions and to discuss sensitive issues more freely than in traditional qualitative research settings (Holtz et al., 2012). The literature increasingly stresses the importance of relying on the first-hand accounts of individuals with autism when investigating their life experiences (Johnson & Joshi, 2016). As such, discussion forums represent a unique source of data, allowing researchers to learn from individuals with autism themselves without the risk of influencing participant responses. Through content analysis of this rich online data, this research investigates the experiences of individuals with autism relevant to the research objectives. Therefore, the research contributes to an emerging field of qualitative research that uses data from internet forums as analysis material. As a secondary objective, this study aims to unpack the strength and challenges that accompany this relatively novel approach, examining its validity for future research on similar topics.

1.5 Organization of the thesis

Following the introductory chapter, chapters two to four include manuscripts in a sandwich thesis format that together meet the objectives of the research as follows:

Chapter Two investigates the role of gender in career exploration and job-seeking experience among adults with autism. The study drew on a qualitative content analysis of 714 randomly sampled posts (357 by women and 357 by men) from an online autism forum. This chapter uses the 'Stages of considering work' framework to inform the analysis (Goldblum & Kohlenberg, 2001; Conyers & Boomer, 2017; Conyers & Chiu, 2014). Guided by this framework, the chapter explores how women and men with autism experience three consecutive sets of vocational barriers, including barriers to contemplating employment as a life goal, barriers to defining career goals, and barriers to finding jobs. This chapter highlights gender-sensitive policies and practices that could assist adults with autism through the stages of the career decision-making process.

Chapter Three explores the similarities and differences among employed women and men with autism with respect to the challenges they face in maintaining their employment. The study draws on a qualitative content analysis of 714 randomly sampled posts (357 by women and 357 by men) from an online autism forum. The chapter investigates how women and men with autism experience challenges related to the workplace mental health, workplace social interaction, executive function, workplace communication, disclosure, and accommodation, workplace physical and sensory environment, and corporate cultures. This chapter provides recommendations for vocational services and business management that would help to accommodate the unique needs of employees with ASD.

Chapter Four investigates the domestic experiences of women with autism as mothers, housekeepers, and caregivers, and how they negotiate the interface of work and family

demands. This chapter draws on a qualitative content analysis of 4,452 posts from an online autism forum. As a conceptual framework, the chapter incorporates Clark's (2000) work/family border theory and its extension by Cook and Shinew (2014) and Emslie and Hunt (2009) to investigate how gender and disability identities influence work-family experiences of women with autism. The chapter contributes recommendations to service providers and future research toward improving the work-family experiences of women with autism.

Chapter Five highlights the methodological, theoretical, and substantive contributions of the research. The chapter is concluded with the limitations of this research and directions for future studies.

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Chapter Two

Gender matters in career exploration and job-seeking among adults with autism: evidence from an online community*

2.1 Abstract

The purpose of this study was to explore the role of gender in career exploration and job-seeking experiences among adults with autism. The study drew on a qualitative content analysis of 714 randomly sampled posts (357 by women and 357 by men) from an online autism forum. The stages of considering work: contemplation, preparation, and action, informed the analysis. The finding showed several similarities and some differences. In the initial stage of deciding whether or not to seek employment, low self-esteem, rejecting paid employment as a life goal, fear of losing disability benefits and parental overprotection influenced both genders. Gender roles and family responsibilities further constrained women. In the stage of defining career goals, common issues included the need for autism-tailored career-matching tools and sector-specific guidance, and lack of self-employment support. Women were further limited by assumptions about stereotypical jobs to which they should aspire. In the job search stage, overly specific job descriptions, a lack of social networks, and transportation barriers influenced both genders. While women talked more frequently about unfavorable experiences in employment support services, men recounted more difficulties with job applications and interviews. Implications for research and practice were discussed.

2.2 Introduction

People with Autism Spectrum Disorder (ASD) constitute the fastest-growing developmental disability population in the United States, with approximately 1 in 59 children diagnosed with ASD (Baio et al., 2018). Accordingly, it is estimated that over 500,000 individuals with autism will be entering the labor market in the next five years (Johnson and Joshi, 2016). Despite common misconceptions, many individuals with ASD are willing and capable of working, yet their employment outcomes are significantly poorer than both the larger disabled and non-disabled populations (Townsley et al., 2014). A recent British study found that only 32% of adults with autism were employed either full-time or part-time compared to 47% of adults with disabilities in general and 80% of adults without disabilities (The National Autism Society, 2016). Similarly, in an Ontario study of 480 youth and adults with autism, only 30.2% of the participants reported full or part-time employment (Stoddart et al., 2013). In addition to unemployment, researchers estimated that 45% of adults with ASD were considered underemployed (Baldwin et al., 2014). On the other hand, individuals with ASD who manage to secure employment are often highly valued by their employers for their trustworthiness, reliability, low absenteeism and meticulous attention to detail (Hagner & Cooney, 2005; Bissonnette 2016). In this sense, adults with ASD constitute a potentially underutilized workforce (Hayward et al., 2016).

The consequences of these poor labor market outcomes are cause for significant concerns. In a recent survey (Griffiths et al., 2016), adults with ASD identified finding jobs that allow for financial independence as their number one concern and the most challenging issue

they face. In addition to financial hardship, failing to engage in the world of work as a key marker of 'full citizenship' and 'adulthood' in modern societies increases the risk of social exclusion and isolation (Rosqvist et al., 2014). Adults with ASD have also reported feelings of depression, low self-esteem, and frustration as a result of continuous vocational exclusion (Ohl et al., 2017).

Tackling the problem of un- and underemployment for adults with ASD is partly about addressing the challenges individuals face *in* workplaces, but it also about understanding and addressing problems faced while thinking about and looking for work. The process of career decision-making is complex (Amir & Gati, 2006). It involves the ability of an individual to define the problem, clarify values, identify and evaluate career alternatives, establish a plan, and act to achieve career goals (Peterson et al., 2002). For individuals with ASD, the process is often characterized by internal and external barriers. Internal barriers include low self-efficacy in relation to employment (Lorenz et al., 2016), a lack of self-confidence in making decisions (Walker, 2015), difficulties confronting new experiences and changing routines (Adreon & Durocher, 2007), challenges with communicating needs, interests and strengths, and disclosure of disabilities (Mynatt et al., 2013), as well as social anxiety, and organizational and interactional difficulties (Ohl et al., 2017). External barriers include employers' discriminatory attitudes, negative family influences, financial concerns, and lack of support (Ohl et al., 2017). While existing research has highlighted the difficulties associated with defining career goals and the job-seeking process, we know less about how these experiences differ for women and men.

Investigating the role of gender in career exploration and job seeking is therefore essential. First, an increasing body of literature reported that women with ASD continue to lag behind men regarding employment outcomes. Holwerda et al. (2013) reported an unemployment rate of 76.5% for females and 65.5% for males and found that males are 1.62 times more likely to find jobs. An Australian study reported that two-thirds of individuals with autism who were considered to be underemployed were females (Hayward et al., 2016). Further, males with disabilities are more represented in full-time employment, receive higher wages, and are more likely to report job satisfaction (Coutinho et al., 2006; Doren et al., 2011). Second, there is an emerging evidence-base to support the existence of female-specific manifestations of autism (Bargiela et al., 2016). Women with ASD tend to show a higher tendency toward sociability, emotionality, and friendship and less hyperactivity/impulsivity and behavioral problems than do men. Compared with men, women with autism are, on average, more likely to demonstrate better communication skills, initiating and maintaining a conversation, eye contact, using appropriate body language, and concealing autistic behaviors to 'fit in' with the neurotypical world (Kreiser & White, 2014; Dworzynski et al., 2012). At the same time, women with ASD exhibit more mental health problems than men (Kreiser & White, 2014; Dworzynski et al., 2012). Although this gender difference is also evident in the population as a whole (Gove et al., 1973), a recent study found the rate of mental health conditions among women with ASD (35.7%) to be almost six times higher than women without ASD (6.2%) (Rydzewska et al., 2018). A Canadian study has also identified several gender-specific social barriers that can impact the employment choices of women with disabilities such as gender-role expectations and stereotypes, family responsibilities, and paternal overprotection (Lindsay

et al., 2017). Finally, recent research has highlighted gender differences in vocation rehabilitation predictors of successful competitive employment among individuals of ASD (Sung et al., 2015). Men were found to benefit from vocational counseling, guidance and job search assistance more than women. The study suggested that there is a need for gender-specific vocational services for people with ASD. Despite the significance of gender in the rehabilitation process (Algern & Hammarston, 2000), a recent study found that most vocational specialists did not tailor their practice accordingly (Lindsay et al., 2017). Given these issues, researchers have called for further attention to the role of gender in employment for adults with ASD (Hayward et al., 2016; Sung et al., 2015).

In a recent review of literature, Hayward et al. (2016) concluded that the limited available research was not able to accurately ascertain gender differences in employment for adults with autism. Among 11 analyzed articles, only one distinguished challenge in workplace experience by gender. The study (Muller et al., 2003), which reported no significant difference, was based on a sample size of 18 participants with only five females. At the same time, there is a growing body of qualitative research on the lived experience of women with ASD, which discusses employment with little to no gender comparison (Webster & Garvis, 2017; Haney & Cullen 2017; Baldwin & Costley, 2015). Most of these studies focused on employment outcomes and experiences on the job, with little attention to defining career paths and finding work. It can be concluded that there is a paucity of research directly exploring the role of gender in employment for people with ASD, especially concerning career exploration and job-seeking

Increasing research has underscored the need of further studies, particularly qualitative, to unpack the complex relationship between employment, gender, and disability including ASD (Lindsay et al., 2017; Lindsay et al., 2017a; Hayward et al., 2016; Sung et al., 2015). It is argued that there is a critical need for such an investigation to identify gender-specific needs and inform gender-focused vocational support (Sung et al., 2015). A focus on gender continues to gain ground in current research, as many journals now require more rigor and transparency in reporting gender to ensure the generalizability of results (Lindsay et al. 2017a).

Based on the available literature, it can be hypothesized that women and men with ASD may exhibit different challenges in their journey toward achieving employment. To test this hypothesis, this study investigates the role of gender in career exploration and job-seeking experiences of adults with ASD. The results of this exploratory study can help provide vocational practitioners and employers with insight into barriers and support needed to assist both males and females with ASD throughout the career decision-making process.

2.3 Theoretical framework

As a conceptual framework, this study incorporated the stages of considering work suggested in the literature: a) contemplation, b) preparation, and c) action (Goldblum & Kohlenberg, 2001; Conyers & Boomer, 2017; and Conyers & Chiu, 2014). The stages reflect an adaptation to the theory of change (Norcross et al., 2011) in the context of employment for people with disabilities and chronicle illness (Conyers & Chiu, 2014). Each stage captures part of a sequence of career decision-making and activities that a person would follow while seeking employment. **Contemplation** is when a person is considering making an employment-related

change but has not yet made a decision. Within this stage, the critical question to address is: *Is any change feasible?* This requires an evaluation of the benefits and risks associated with seeking employment. **Preparation** is a stage when a person is intending to take action but has not yet engaged in effective action. The key question at this stage is: *What kind of change is the best?* This stage involves exploring vocational options, setting goals, and developing plans to achieve these goals. As one moves into the action stage, the main question to address is: *How to achieve the stated goals?* The associated tasks are the implementation and refinement of vocational goals with a focus on removing vocational barriers. This may involve vocational skill training, job search, the application process, job interview, and seeking vocational support and counseling (Conyers & Chiu, 2016).   Each of these stages reflects incremental degrees of commitment to engaging in the process of career exploration and job-seeking (Conyers & Boomer, 2014). However, the process of considering work is nonlinear. While individuals follow the sequence to move forward, negative employment experiences may lead them to reconsider their decisions, cycling back to an earlier stage. It should be noted that the fourth stage of considering work, ***resolution***, is outside the scope of this study as it involves activities related to assessing and maintaining the achieved employment and adapting to new work situations (Goldblum & Kohlenberg, 2001).

2.4 Method

It is increasingly argued that researching the life experience of individuals with autism should rely on their first-hand accounts (Johnson & Joshi, 2016). Discussion forums represent a unique source of data, which allows researchers to learn from individuals with autism

themselves, without the risk of influencing participant responses. Individuals with autism have increasingly turned to social media such as online forums to share personal experiences, disclose their challenges, and seek support and advice from their peers (Biyaniet al., 2012; Davidson, 2008). Individuals broadcast questions to a virtually connected network and obtain answers from like-minded members of the network (Hong et al., 2015). They interact online from a familiar setting such as their own home, which may facilitate more accurate and detailed assessments of their needs. Such anonymity is not only associated with a high degree of self-disclosure but also contributes to reducing anxiety often experienced by people with ASD during face-to-face communication (Jordan & Caldwell-Harris, 2012).

Using ASD online forums as a research resource allows access to a large, ecologically valid data source, which is increasingly used in a wide range of ASD studies (Jordan & Caldwell-Harris, 2012). Online textual data has been used to explore women's experiences with diagnosis, employment, and relationships (Haney & Cullen, 2017), the experiences of students with ASD in academic libraries (Anderson, 2017), religious belief systems of persons with ASD (Caldwell-Harris et al., 2011), the attitudes of ASD community members toward changing diagnostic criteria (Parsloe & Babrow, 2014), the difference between neurotypical and ASD special interests (Jordan & Caldwell-Harris, 2012), and types and topics of support sought by ASD community (Hong et al., 2015).

Several studies addressed the validity and trustworthiness of online data. Sussman and Sproull (1999) found that people are more straight-forward and honest when delivering bad news via online communities compared to face-to-face interviews. Pfeil and Zaphiris (2010)

reported that people in online communities often build an environment of honesty and trust, and that cases of dishonesty are rare. Further, Back et al. (2010) studied online forum users' profiles and reported that most users accurately describe themselves online. Methodologically, Caldwell et al. (2011) found consistency between the results of content analysis of ASD forum postings (covering 192 unique posters) and a survey completed by 61 participants with ASD about religious belief.

2.4.1 Selection of online forum

The online forum for this research was identified through a Google Internet search with the phrases "Autism online forum" and "Autism discussion forum". The first three forums that appeared on both results were selected for further analysis. WrongPlanet.net was identified as the largest and most active online forum for individuals with autism. Created in 2004, WrongPlanet now has over 80,000 members, mostly from North America, who have contributed over 7 million posts, making it one of the largest and most active online communities for individuals on the autism spectrum and the most frequently identified in related research (Anderson 2016; Parsloe & Babrow 2016; Jordan & Harris 2012; Jordan 2010).

2.4.2 Data Collection

The study focused on threads posted on employment specific sub-board titled "Work and Finding a job." At the time of data collection, this sub-board hosted 6,104 threads containing over 56,000 posts, offering a rich environment for studying ongoing employment experiences of individuals with autism. For most posts, the poster's profile, including age, gender, diagnosis, and sometimes location, is provided. Typically, the thread is created by an

individual who initiates the first post to seek support and advice about one or more employment concerns. To capture the spectrum of posted employment experiences, the study analyses the initial posts of each thread. For this study, 714 threads were randomly sampled (12% of the entire population of posted threads). This offers a representative sample size similar to other research of this type (Hong et al. 2015). Collection criteria required that autism diagnosis and gender of the poster be disclosed either explicitly in his/her public profile or implicitly within the posted text. The initial post should also address employment-related difficulties and should contain a question identifying the issue of concern. The threads were stratified by gender to ensure equal representation by women and men; data collection produced a data set of employment-related threads initiated by women (n=255) and men (n=252). The majority of posters (81% of women and 78% of men) contributed only one post each. Others posted more than once, as shown in Table 2.1. While almost 60% of men posters were under the age of 30, only 41% of women posters were under 30, as shown in Table 2.2. This could be attributed to the fact that women tend to be diagnosed at a later stage of their lives (Bargiela et al., 2016). Overall, the 714 sampled threads were authored by 507 different forum participants.

2.4.3 Ethical considerations

This study was deemed not to involve human subjects as no interaction occurred between the researchers and the forum posters and was thus exempted from further review by the McMaster University Research Ethics Board. To avoid violating individuals' privacy, the study followed recommendations by Hanna and Gough (2017) and Jordan and Harris (2012) to

only analyze a public and open access forum that receives a high volume of traffic and does not refer to usernames or other identifying information. In addition, the authors contacted the moderator of the forum and achieved his consent to utilize the textual data.

# of posts per poster	Women Posters		Men Posters	
	Number	%	Number	%
9	1	0.4%	0	0.0%
8	0	0.0%	0	0.0%
7	3	1.2%	1	0.4%
6	0	0.0%	4	1.6%
5	5	2.0%	1	0.4%
4	5	2.0%	6	2.4%
3	9	3.6%	8	3.1%
2	25	9.9%	36	14.1%
1	204	81.0%	199	78.0%
	252	100%	255	100%

Table 2.1 Number of posters and frequency of posting

Age group	Women		Men	
	Number	%	Number	%
15-20	8	3%	10	4%
21-25	31	12%	44	17%
26-30	65	26%	100	39%
31-35	69	27%	48	19%
36-40	23	9%	19	8%
41-45	12	5%	10	4%
46-50	26	10%	13	5%
51-55	12	5%	7	3%
56-60	4	1%	6	2%
> 60	2	1%	0	0%
Total	252	100%	255	100%

Table 2.2 Age group of posters

2.4.4 Data analysis

The analysis was guided by the research question, with the overall aim to compare experiences of career exploration and job-seeking among women and men with ASD. To focus on gender differences, posts by males and females were analyzed separately before comparing and contrasting the results. The data were analyzed following a multiple levels process. The first level of analysis involved reading through each post and assigning concrete labels to individual passages of text reflecting the stages of considering work: contemplation, preparation, and action. The second level involved content analysis that began with open coding to identify detailed themes and subthemes describing the experiences of posters at each stage. According to Vaismoradi et al. (2013), content analysis is used in exploratory studies with a significant amount of mediated text to identify universal codes and to find significant meaning through counting to interpret their frequency. The frequency and percentages of occurrence of each code were recorded as a proxy for the prevalence of particular experiences among the online community members. Finally, the themes developed by males' and females' posts were compared and contrasted using a constant comparative method (Boeije, 2002).

Credibility was obtained through (a) verification using an initial literature review to establish validity, and (b) triangulation by multiple researchers. Around 10% of the threads were randomly selected for double coding and agreement between the two authors. Transferability was achieved by providing a thick description of the experiences of the online community members, supported by representative quotes, and discussing how the findings relate to other adults with ASD.

2.4.5 Software

The study used Nvivo 11 for Windows as a platform for capturing, organizing, and analyzing data. The sample threads were collected using the NCapture facility. The initial posts have been organized as 'cases' where the posters' profiles (age, gender, occupation) were stored. After entering the codes as nodes, the data query functions were used to facilitate the analysis.

2.5 Findings

This section examines similarities and differences among men and women's experiences of career exploration and job-seeking based on sampled posts from members of the online autism community. The findings were derived from the qualitative analysis of posts to the "Work and finding a job." Among the pool of the sampled employment-related posts, 60% of males' posts addressed issues related to career exploration, and job-seeking compared to only 50% of females' posts. The remaining posts addressed in-the-job challenges. This may imply that challenges in identifying career paths and achieving employment are more prevalent among men with ASD. Meanwhile, the average number of codes in a female's post is higher than that in a male's post.

Table 2.3 presents the main codes, organized according to the stages of considering work, together with their frequency and percentages of occurrence. The analysis revealed several similarities and some differences between women and men with ASD as they navigate

their career options and seek jobs. The findings were organized using the stages of considering work: contemplation, preparation, and action.

		Men		Women		Total
		#	%	#	%	
Contemplation (Is any change feasible?)	Gave up - Losing benefits - parent and family influence - utopian ideas	33	**14%**	32	**15%**	15%
Preparation (What change is best?)	Paid employment	79	**34%**	68	**33%**	33%
	Self-Employment	16	**7%**	13	**6%**	7%
Action (How to achieve stated goals?)	Job search & accessibility	40	**17%**	43	**21%**	19%
	Vocational rehabilitation	15	**6%**	17	**8%**	7%
	Application process	25	**11%**	15	**7%**	9%
	Job interview	26	**11%**	21	**10%**	11%
	Total	**234**	100%	**209**	100%	100%
	The average number of codes per post	1		1.3		

Table 2.3 Emergent themes by gender

2.5.1 Contemplation

About 15% of the analyzed threads were initiated by members who were in the stage of considering whether employment was a feasible option.   An almost equal percentage of females (15%) and males (14%) described a number of psychological, social, and financial factors that affected their decisions to join the labor market. Six subthemes emerged: I am unemployable, against paid work, losing benefits, negative perceptions of the job market, gender role expectations, and parental overprotection.

Many posters, both males, and females described themselves as "unemployable" after multiple experiences of failure either to obtain or maintain employment. Their negative experiences left them with extremely low self-esteem, a sense of depression, and a loss of direction. As one male member said:

> *"I have finally accepted the truth; I'm too damaged to work. It's the truth, and it would take way too long to explain why, just trust me here. So, there goes a major goal in my life".*

The traumatic experiences of others left some younger posters in transition-age (15-25 years) with a sense of fear of attempting to join the workforce. A female member expressed *"I literally have to fight through that just to apply in the first place".* Another inquired whether he *"should see a therapist over the negative psychological imagery the word "job" now creates in [his] mind?".*

Some posters, both males, and females took an oppositional stance, questioning the status of employment as the main path toward a good life and self-satisfaction. A male poster described, *"I hate and totally disagree with the ethics of working just to get money like most people do, I don't want to sell out my happiness for money".* Another male poster said, *"...working for more money is going to be a death sentence for me."* Despite being academically qualified, a female poster said she did not care about jobs and that she only applied *"out of a sense of obligation"* and inquired " *Why do people view those 'who don't want to work' negatively?"* Members discussed utopian ideas for *"getting around the system"* such as *" to try and live somewhere out of the city, off the grid, grow vegetables indoors and outdoors,... and*

enjoy living away from our corrupt and imperfect society". *Others called for establishing "an*

autistic company...run by autistics and employing autistics based on autodidaction special

interest …to be as a small town specifically for autistics".

Posters, mostly women, decided not to pursue paid work because they were concerned

with losing disability benefits. For example, one woman described, *"this position probably*

would only pay a little more than I am receiving in benefits. Also, if I take this job and am

unsuccessful, I will no longer be eligible for unemployment". While others acknowledged the

difficulties of staying on income benefits, they indicated that this was preferable to finding

themselves in a short-lived or poorly designed job. As one man explained, *"Being on welfare is*

not ideal, but having a job that is not accommodating to my needs is not ideal either".

However, most posters expressed their willingness to return to the workforce. A woman

described, *"I'm on disability now, although I still try to contribute to society with my research. I*

hope to work again someday".

Perceptions that the current job market offered few opportunities also eroded the

motivation of some individuals, both males, and females, to seek employment. A male poster

expressed, *"Finding a job is a real challenge for anyone these days. If you are autistic or have a*

disability, it is 10 times harder to gain employment. I know people who are not autistic who

cannot find jobs. Why is it like this?

Female posters also repeatedly talked about the impact of gender role expectations on

their vocational decision-making. For example, women reported not looking for work because

of pressure to meet unpaid family responsibilities, *"I had to stick at this job, of bringing up my*

son, because the taboo on dropping it was too huge to break". Other complained of being

overly controlled by their partners who were *"heavily investing in traditional gender roles, that*

as the man it's his job to provide, and that if you take part in that [paid work] you are

diminishing him". They felt that close persons often took advantage of their disabilities to

influence their decisions, "*They all use my AS [Aspergers] as a reason for the controlling, but it*

happened all my life".

Finally, many younger posters, both males and females, described parental over-

protection as influencing their vocational decisions, mainly when it involved travel or residential

relocation. A male poster said, "*I don't think my parents would trust me enough to let me move*

out of town even if I did move in with some of their relatives ". Youth posters considered this as

a barrier toward their desires to "*experience new things, and to become more independent"*. In

contrast, the pressure to move out was a major driver toward seeking employment. A male

poster expressed, *"My parents nag me to move out, a lot, but I can't afford to. I am the typical*

30 y.o nerd still living in his parent's basement. I did not expect my life to end up this way".

2.5.2 Preparation

Almost 40% of the analyzed posts were made by people who had decided to enter the

labor market but were still unsure about their career paths. They sought support and advice on

identifying career options or validation in pursuing their vocational choices.

Career & job choice

A key concern addressed by the posters (33%) was identifying appropriate career fields

or choosing the right jobs, with almost equal rates of posting among males (34%) posters and

females (33%). Four significant subthemes emerged: career guidance, field-specific information, career biases, and late-career bloomers.

Many posters, both males and females, expressed a desperate need for guidance in setting career goals. For example, a male poster described, *"I am hopeless when it comes to finding out what I want to do in life and how I want to live it... Any advice?"* They often sought help in identifying careers and jobs that fit their ASD-related social, sensory, and executive functions limitations. For example, a man described, *"Things I do not want to do: interacting with the public, anything that involves driving, anything with multi-tasking and strict time limit or quota, where I will be doing something different every day, or where I will be in a noisy place".* Others stressed their values; a man articulated, *"I want a job with a well-defined goal or endpoint. A job where I sell my work, not my personality. Somewhere where the boss will recognize my social limitations and be OK with them"*. Meanwhile, other posters were looking for jobs that valued their ASD-related strengths. For example, a man inquired, *"Can Aspies make a career from their attention to detail?"* Posters also sought advice on ways to turn their hobbies into a career. A male poster said, *"I tried to find anything suitable for my list of special interests, skills, talents, and desires for many times but failed"*. Others debated whether this may *"take all the fun out of it [the hobby]"*. While many posters were looking for fulfilling careers, others resigned themselves to finding a job in which they could just survive. A female poster described, *"not a get-rich career, but it gives you enough money to live better than minimum wage"*. Posters voiced the need for an ASD-focused career matching resources or online tests. For example, a female poster wrote*, "I need to DIY resources and tests, in order to re-assess myself and think 'outside the box'"*.

The majority of posters, both males, and females, were in need of information on the suitability of a specific career or a job of choice. They frequently reported a lack of ASD-specific information on various career fields. A woman described, *"I cannot seem to find any information at all on being an Asperger's sufferer and being a teacher"*. Posters urged other members of the online community to share their experiences in various professions. They posted detailed inquiries such as: *"Is it suitable for aspies [ASD]?", "What rolls …would I be suited for?", "what [do] the job prospects look like"*, *"Any pros and cons", "How much are you paid*?". They also sought advice on career preparation and planning, such as: "*How one may go about getting started*?" and "what skills *would I need to develop?"* They also inquired about the social, physical, and sensory environments associated with their fields of choice.

Occupations	Male	Female	Total
STEM occupations	**46%**	15%	33%
Social services and helping occupations	9%	**32%**	19%
Art, design and entertainment occupations	10%	11%	11%
Unskilled Labor work	10%	6%	8%
Sales and food services occupations	7%	9%	8%
Healthcare occupations	6%	11%	8%
Administrative and office work occupations	6%	6%	6%
Military and security occupations	4%	4%	4%
Educational and library occupations	3%	6%	4%

Table 2.4 Contemplated occupations

Posters were interested in a wide range of fields including teaching, science, media, medicine, tourism, community service, special needs support, psychology, law, nursing, gardening, IT, art, policy, and urban planning. Others sought more "adrenaline-fueled" fields such as Police, firefighting, EMT, and the military. Although some posters tried to classify fields

as ASD-(un)friendly, others argued that there were vocational niches in every field where a person with ASD could thrive. A female poster said, *"I find that it is the day-to-day activities of a job that can make it tolerable, (or intolerable), rather than what the general field or job title implies"*.

Significantly, gender differences were noted in the career and job choices (Table 4). Almost half of the male posters (47%) showed interest in STEM jobs followed by art (10%), social services and helping professions (9%), and sales (7%). By contrast, one-third of females (32%) talked about service work and helping occupations, followed by STEM jobs (15%) and art (11%). The link between gender and career choice was open to debate, however. While one woman inquired, *"what are good jobs and careers and education to peruse for a girl who is shy, introvert and quiet?"*, others argued, *"Why would any job be better or worse based on your gender (unless you're talking about social attitudes toward a particular line of work)?"*.

Many posters believed that the society tended to associate ASD with STEM types of jobs, ignoring the vast range of careers they can thrive in, a man describes, *"Society's biases are such that they think Aspies are incapable of performing any other job"*. Another articulated, *"The problem is unless their degree was in STEM, they are pretty much in the same boat as someone who never finished high school"*.

Posters frequently viewed themselves as disadvantaged and thus unable to achieve financial stability or embark on a career as early as many neurotypical people. For example, a man explained, *"As an Aspie, I have not had your typical career where you stay in one area most of your working career, I had to take what was available at the time just to survive. I think I am*

paying the price for it now".   For many women,late diagnosis had contributed to what they understood as a career mismatch. For example, one woman said, *"I wish I had known this when I was younger! It is much better to have your personality suited to your field. However,I did not know I was aspie until recently".*

Aspirations for Self-employment

About 7% of the analyzed threads revealed aspiration for self-employment among Wrong Planet members with roughly equal rates among men (7%) and women (6%). For some, self-employment was seen as *"the natural answer to the realization that you [people with ASD] cannot cope with corporate life"* and as *"a great idea for ASD people*." Three related subthemes emerged: reasons for considering self-employment, type of business, challenges, and support.

Self-employment was the preferred career path for some young posters, both males, and females, entering the labor market. They saw self-employment as an opportunity for *"managing one's work routine, probably not interacting with people very much and determining the kind of work you will do, hopefully around an interest"* and *"being judged by the work you get done rather than by your social skills or lack thereof."* Other posters sought temporary self-employment to *"make a little bit of money freelancing and to get that experience"* required to support future employment applications. Conversely, self-employment was seen as a last resort by some people. After repeated failures to land a job, one man said, *"I am tempted to go toward self-employment now as I fear I have about crossed the unemployable threshold anyway".* After disclosing her diagnosis, a female member indicated, *"I do expect to be made redundant and if that happens to plan to go self-employed anyway so might be a catalyst for*

positive things". Due to family caring commitments, another female member believed that the only *"practical option ... was to turn [my] hobby ... Into a small microenterprise and go self-employed".*

Most posters showed interest or experience in online business that could be operated from home, car, or elsewhere with less interaction with others and minimal investment such as bookkeeping, data analytic consultancy, graphic design, and writing and editing. Others discussed online entrepreneurship in eBay retailing, the stock market, and real-estate. Hobby-based businesses such as handicrafts and painting were also noted. Experienced self-employed members of the online forum were able to spot non-home-based business opportunities that *"do not require a lot of human interaction,"* such as steam cleaning and painting construction equipment, dairy farming, and crane driving.

To consider self-employment posters sought advice on choosing the right type of business, the process to set up a business, the personal *"qualities that are needed to be successful in self-employment"*, and securing funds to support business needs and sustain basic living necessities. Posters also pointed to difficulties in marketing, networking, communication with clients to *"negotiate fees and draw up contracts"*, and *"organizing and planning tasks".*

Members expressed negative experiences when seeking support from vocational agencies. A male poster describes: *"I don't have any support or funding from social services. I get literally no help from any organization that I know of, they all tell me to go to each other in a huge loop"*. They expressed the need for vocational programs to support self-employment,

"Support, day to day, someone to go to on the spot if I get demotivated/stuck/upset/ doesn't understand what to do".

2.5.3 Action

Almost half of the posts were initiated by people who had already decided on a career path and were attempting to find employment in their careers or jobs of choice. These posts highlighted various challenges related to job-seeking actions.

Job search and accessibility

Almost 20 percent of the analyzed threads expressed concerns related to job accessibility with a slightly higher rate among female posters (21%) than males (17%). Three subthemes described the barriers that made jobs either geographically or socially inaccessible for individuals with ASD namely: the nature of job requirements, networking, and transportation.

Posters, both males, and females criticized job postings that listed generic skills such as *"good verbal communication skills"* even though these skills were not essential to the position. They noted that the inclusion of these skills requirements could easily dissuade them from applying for roles that they might otherwise be good at. They considered this *"hiring attitude"* as discriminating against *"people with challenges in these areas (but marketable skills in other areas)."* Due to ongoing difficulties in achieving and maintaining employment, many posters reported being unable to satisfy the common requirement of *"experience in a similar position"* and felt *"stuck in the cycle of having no experience, have no job."*

While highlighting the importance of networking for landing a job, many posters found networking difficult. One woman said that *"networking is extremely tough, and getting to know someone just for the sake of landing a job is a crapshoot."* Others questioned, *"HOW do I gain these elusive powers?"*

Both male and female posters described how lacking the ability to drive limited their job opportunities. For instance, a male poster explained, *"everything in my area seems to be either retail, sales, customer service, call centers (all of which I cannot do well because of Aspergers) or else driving (which doesn't work as I do not have a license)."* Similarly, members also reported difficulties using public transport. A female poster explained *"Many aspies [ASD] have problems with public transport. I live with eight people who have varying degrees of ASD, and only one of them enjoys taking the bus/train. I would like to take the train but only if it had NO people on it. For me, it is a sensory issue, plus I get frightened because I am not able to control where the bus goes"*.

Job interviews

About 11% of sampled threads discussed concerns with job interviews, with very similar rates between male (11%) and female (10%) posters. Two subthemes emerged: the problems with conventional interviews and the ways that ASD might interfere with interviews.

Members viewed job interviews as a significant barrier that undermined their efforts to achieve employment. A male poster explained, *"regardless of how capable a person you are, you might as well not bother with college or university because if you are no good at interviews, you will not be getting a job. That is the way it is, and I hate myself thoroughly"*. Many posters,

mostly males, reported negative interview experiences. For example, a male poster described the interview process as *"something that discriminates against aspies [ASD]."* Another criticized the recruitment process for being *"so rigid and inflexible that a person with a disability such as mine might never get through".* Although members doubted the utility of the interview process, arguing that *"a good interview does not necessarily mean a good job performance"*, they recognized that *"it is not likely to change anytime soon. It is why you have got to either play the game or find a way around it".* Under-employment was noted as a likely consequence of failing interviews. A male poster with a Master's degree in Psychology explained, *"I did have one job, but there was no interview for this. Merely a case of checking you were a human being. It was factory work, involving pressing a mold onto icing on Christmas cakes."*

Posters also thought that ASD traits tended to override qualifications in the interview situation. As one woman shared, *"I am completely confident in my abilities to carry out this job. However, I am NOT confident that my dear Asperger's will stop for a day and I will survive the interview".* Others talked about failing to make appropriate eye contact, reading social cues and body language, firmly shaking hands, and babbling on after answering the question. They also reported lacking a sense of the amount of detail required during interviews. One woman commented, *"I do not know when to shut-up. LOL, I'm thinking it is an Aspie thing, maybe----we want, so badly, to be understood, that we just keep talking, and talking, and talking".* Citing their black-and-white thinking, posters talked about being brutally honest in the interview and lacking a sense that *"there are just some things people do not need to know."* Handling nervousness in interviews was also a frequently cited challenge. A woman explained, *"I am just*

really worried that I will have a meltdown during the interview or generally will feel hugely

uncomfortable and not just fail to get the job but also knock my confidence even further."

Posters also reported that interviewers sometimes misunderstood their ASD traits. A man said,

"I had to explain to him that the reason I was not looking him in the eye WASN'T that I was

racist and didn't like him." This reinforced the struggle of deciding whether or not to disclose

ASD during an interview.   Members also reported how the strategies they developed to

compensate for their ASD challenges in daily life did not work and *"backfired during an*

interview situation."

Application processes and requirements

About 9% of the sampled threads highlighted members' difficulties in preparing job

applications, with a slightly higher rate among males (11%) than females (7%). Two subthemes

emerged: difficulties with application documents and recruitment tests.

Threads revealed that the preparation of application forms, resumes, and cover letters

can be a struggle. One man reported that the associated anxiety can get to *"the point now*

where I have panic attacks just thinking about opening Word to start it". Tailoring resumés to fit

specific employer's needs or to explain a "spotty work history" or a "long unemployment gap"

was repeatedly reported as a *"difficult task".* Both male and female posters debated the risks

and benefits of disclosing their disability in the application documents.

Both male and female posters also frequently reported failure to pass personality and

career tests that are often part of the application process. A woman described, *"This can often*

be difficult to do, given many Aspies have a strong honesty streak and find answering differently

than they feel not an option". They described these tests as *"designed for NTs", "designed to bring in extroverted individuals free of mental affliction,"* and therefore could be considered as *"a form of neurodiverse-discrimination"* and *"should be outlawed".* Interestingly, one of the sampled threads reported the results of a poll among Wrong Planet members where 95% of the voters (n=79) thought these tests were discriminatory.

Vocational Rehabilitation Services

About 7% of the sampled threads talked about experiences with vocational rehabilitation and employment training services with a slightly higher rate among females (8%) than males (6%). Two central themes emerged: challenges with VR staff and challenges with VR systems and processes.

The analysis revealed very mixed experiences with VR and employment training. Both male and female posters believed that counselors played a key role in shaping their experiences with VR services. A man described, *"It all depends on the person you are assigned. Hopefully, you will get a nice counselor that cares"*. Counselors were often described as "*pretty unfamiliar with ASD and assumed that you can get a job without any additional state services and they decline your application for help"*. Many members of the online forum complained that counselors tended to push them toward minimum wage jobs. For example, a woman explained, *"They don't care what your "wants" / needs are, they don't care if you have a degree / don't have a degree, they don't care that you're not interested in whatever type of job, all they care about is that they can say they've placed another person"*. Counselors were also described as being discouraging, blaming, intolerant, and sometimes insulting as illustrated by the following

quotes: *"Even when I asked in concern, If I got a low paying job and what it I got stuck there the head guys basically just said "Better than going hungry"; "If I ask what was going on after waiting months, I'd be accused of being rude for being 'impatient'."; "they were condescending jerks with helpful statements like "you are lucky even to have a job at all!", "you obviously are lazy as jobs are plentiful for University graduates".* However, some posters reported positive experiences. For instance, a woman described, *"My caseworker understands working with people with ASD though, and that has been a good thing. I've not had as many of the issues that others on here are talking about".*

Posters also reported that the process had not been well explained to them. A woman illustrated, *"I have no idea what they offer and what I am eligible for and it was my feeling that she should have told me A B and C and then ask what I wanted".* The process was constantly criticized as being bureaucratic and very slow, as described by a male poster, *"Be very patient. Be very VERY patient. It can take months for each stage of the process".* A woman described how hard it was to be qualified for the service, *"I am thinking of applying multiple times to see if I can eventually be qualified".* VR programs have repeatedly been reported as being useful in building employment skills rather than in finding jobs, as illustrated by a male poster, *"It was very useful, not so much for finding a job, but as a way to think in general".* VR services were seen to be *"generally having a poor reputation for putting persons on the autism spectrum into higher-skill jobs" while "great at serving persons with Intellectual Disabilities".* Meanwhile, many posters acknowledged the geographical unevenness of access to ASD-focused vocational services; one woman based in the US commented, *"It does depend on the state. I know Massachusetts is trying to get an autism only division for Mass Rehab, and from what I've heard*

they are worth going to".

2.6 Discussion

This exploratory study examined the career exploration and job-seeking experiences of women and men with ASD through the context of an online forum. The study analyzed 714 posts initiated by an almost equal number of women (n=252) and men (n=255) self-identified as being on the autism spectrum. Analyzing posts made by members could guide vocational support toward the most pressing employment challenges as voiced by the individuals with ASD themselves and also inform gender-specific interventions and workplace accommodation (Sung et al., 2015). It was noted that among the pool of the sampled employment-related posts only 60% of males' posts addressed issues related to career exploration and job-seeking compared to 50% of females' posts. This may imply that challenges in identifying career paths and achieving employment prevail more among men with ASD. Meanwhile, the number of issues (presented in the analyses as codes) discussed in individual posts by women was higher than that of men's posts. This may suggest that a woman with ASD may exhibit more complex issues in navigating the career development process, in line with findings of previous disability research (Lindsay et al., 2017a; Conyer & Chiu, 2014).

The study drew upon the stages of considering work to unpack factors affecting career decision making-process of adults with ASD (Goldblum & Kohlenberg, 2001). Results revealed several similarities and some differences between women and men with ASD as they navigate through the contemplation, preparation, and action stages of considering employment.

Although some studies on the employment outcome of people with ASD (The National Autism Society, 2016; Greffiths et. at., 2016) found that between 24% and 40% of their participants were not interested in seeking employment, little detail was provided about the reasons. The current analysis highlights important issues that hindered adults with ASD from considering employment as an option. Low self-efficacy and an aversion to job-seeking based on negative past experiences impacted the motivations of both women and men. A lack of awareness of employment openings and a sense of few opportunities in the local labor market were also cited as barriers. Other members, while academically qualified, found it difficult to see employment as a path for self-satisfaction. Similar to Conyer and Chiu (2014) results also point to concerns about the potential loss of disability benefits. In line with previous literature (Lindsay et al., 2017a, 2017b), women, especially wives and mothers, repeatedly cited gender role expectations as influencing their vocational decisions. Finally, both males and females found parental overprotection as a vocational barrier especially when traveling was involved. The significant rate of adults with ASD who either decided not to join the labor market or found it difficult to decide, suggests that further research is needed to unpack the reasons and address their concerns. Vocational psychologists and clinicians can be trained to assist young adults with ASD in overcoming mental health issues, which lead them to "give up" finding employment.

The majority of forum members, both males, and females, who decided to join the workforce revealed the need for assistance in setting career goals, defining their career paths, and identifying jobs that suited their interests, talents, values, and limitations. Moreover, many expressed interest in online ASD-tailored career-matching tests and tools to assist them in

making career choices. These tools help to identify discrepancies between vocational demands and an individual's knowledge, resource, and skills (Cobb & Alwell, 2009). This finding reinforces the results of a recent systematic review of career planning tools for people with ASD (Murray et al., 2016). The only two available tools lack strong reliability or validity in areas required for predictive tools, leading the authors to argue for more ASD-specific tools. Another critical concern voiced by forum members was the need for resources addressing workplace experiences of employees with ASD across various employment sectors. This will not only assist job-seekers with ASD to make informed career decisions but may also help employers and vocational professionals to identify and address sector-specific barriers (Schartz et al., 2002). The sparse literature has mostly focused on STEM sectors (Cullum and Ennis-Cole, 2014; Jennifer et al., 2013). Further research should investigate other sectors where jobs might be found - such as retail and hospitality – but that is often labeled by ASD online community as 'unfriendly.'

Consistent with a survey by The National Autism Society (2016) the results confirmed that there is no "shortlist" of right jobs for people with ASD. Members expressed interests and reported success in a variety of jobs including those suggested by the literature as 'unsuitable' for people with ASD, such as military careers and firefighting jobs (Bolte & Hallmayer, 2011). Gender differences were noted in the career and job choice of online community members. Consistent with research on other disabilities (Lindsay et al. 2017a) as well as the general population (Beede et al., 2011), many men were interested in STEM jobs, while women were more likely to gravitate toward feminized employment in service jobs and helping professions. To reduce gender inequality in employment outcome, vocational specialists and educators

should make more effort to encourage females with ASD into non-traditional and highly employable disciplines, such as STEM. The results also suggest that efforts to support early diagnosis of women will probably reduce the risk of taking unfavorable career decisions. Sector-specific studies, highlighted earlier, could also provide examples of successful female role models in male-dominated fields.

Posters, both males, and females, also expressed interest in self-employment as a way to gain greater control over their work, more compatibility with gender role expectations, and as a last resort after repeated failure to land jobs. The findings highlighted the type of required support realizes self-employment as a viable option as voiced by adults with ASD. Consistent with (Ashley & Graf, 2017), the need for ASD-focused self-employment vocational support programs was suggested.

The results revealed four main challenges that hinder individuals with ASD from achieving their career choices with few gender differences. The most frequently reported barrier, by both males and females, was related to job accessibility, followed by difficulties with application documents and tests, then challenges with conventional job interviews, and finally challenges with vocational rehabilitation services. Access to jobs was affected by both social and geographic barriers. Consistent with Markel and Elia (2016), the attitudes of employers, reliance on overly specific job descriptions and demands for a similar experience, which may not be essential for the job, affects job accessibility for job seekers with ASD. Unlike their neurotypical peers, they often interpret the language in the job posting literally and may refrain from applying if they do not meet a single criterion. Also, the fact that half of all jobs are

usually filled through social contacts (Markel & Elia, 2016) renders a significant portion of available jobs as inaccessible for individuals with social differences such as those with ASD. Geographically, lacking the ability to drive or using public transit further restricts their opportunities to the locally available, often minimum wage jobs. In line with recent research (Lindsay, 2017b) this finding highlights the urgent need to expand vocational rehabilitation services to cover transportation-related training and support for both women and men with ASD. The findings also suggested that the preparation of application documents, resumes, and cover letters may be challenging for job seekers with ASD, especially men.

Moreover, an essential finding of this study is the consensus among forum members, both males, and females, about considering personality tests as discriminating against them and constitute a severe barrier toward achieving employment. As widely discussed in the literature (Markel & Elia, 2016) the conventional, rigid, and inflexible interview process was perceived as discriminatory. The results confirmed findings of earlier research that women with ASD, who may be better able to camouflage their ASD, may perform better than male peers in conventional interviews (Lai et al., 2017)

Members' experiences with VR services supported findings of previous research (Yamamoto & Olson, 2016) related to the discrepancy between the goals of VR counselors and clients. Many posters saw VR counselors as principally concerned with achieving case closure with less concerned with clients' career aspirations. Furthermore, while acknowledging VR services for being successful in building vocational skills and serving persons of intellectual difficulties, members perceived the services to be slow, bureaucratic, and less helpful in finding

jobs for high-skilled persons with ASD. These findings necessitate improving vocational services by promoting policies to empower clients, especially females, through negotiation and self-advocacy. Supported employment programs should be ASD-focused, addressing gender-specific needs across the contemplation, preparation, and action stages. They also need to be more responsive to the strengths and interests of individual clients. Further, service providers should work on reducing the paperwork and time involved in the vocational rehabilitation process.

"Nothing for us without us" is an essential slogan of the neurodiversity movement which advocates for the rights of individuals with ASD. The voices of the ASD community can inform business efforts to move toward more inclusive recruitment practices. For example, Instead of generic job descriptions, and in line with the 'Dandelion Principle' suggested by Austin and Sonne (2014), jobs should be designed to maximize potentials for particular individuals to create values. On the other hand, the typical 'un-structured first date' style interview, is not only discriminating for the ASD community members but also inefficient as a recruitment tool in general (Brafman & Brafman, 2008).   Instead, Ori and Brafman (2008) suggested 'structured Joe Friday interview,' which depends on 'aptitude tests' and measures skills and talents rather than the experience of communication abilities. Finally, promoting the design of physical work environments that reduce sensory stimulation and allow some degree of privacy and control over one's space will help to create more autism-friendly jobs (Scheiner & Bogden, 2017; Nagib & Williams, 2017). Interestingly, these inclusive practices are in line with recommendations of recent literature in innovation management. Soraya (2011) suggested that the solutions to many of the challenges faced by those with ASD in the workplace boil down to good management practice.

2.7 Limitations of Study

There are some limitations to this study. First, one limitation of collecting data from online forums is that there is no way to verify the diagnosis or posters' profiles reported on the forum. However, research on Internet forum user-profiles concluded that most users accurately describe themselves online (Back et al. 2010). Another limitation of the forum, members most likely were on the high-functioning end of the spectrum. The findings are thus primarily generalizable only to this group rather than the entire ASD community. Also, as noted by Finfgeld (2000), some populations may have little to low access to forums due to a lack of equipment and skills. Finally, the majority of the posters, especially the males, were relatively young, as shown in table 2. Thus the findings could therefore reflect more the workplace experiences and needs of younger age groups. This study is limited to posters self-identified within the constraints of a gender binary. However, increasing studies reported high rates of gender variance among people with ASD compared to those without ASD, with higher variance in women as compared to men (Bejerot et al., 2014; Van Schalkwyk et al., 2015). The interface between gender variance and career experience of people with ASD requires further investigation.

2.8 Conclusion

By examining content from an online autism community, this study investigated gender differences in career exploration and job-seeking experiences of adults with ASD. The results suggested that similarities in career decision-making barriers outnumber the differences. In the initial stage of deciding whether or not to seek employment and the following stage of choosing

a career, gender differences were predominantly traceable to traditional gender role

expectations with respect to family responsibilities, partners and parental control, and women

being steered towards feminized jobs. While these pressures also shape the experiences of

neurotypical women, the disabling barriers that women with ASD confront intersect with these

gender norms to create a 'double disadvantage' in these women's search for employment. In

the stage of realizing their career of choice, women expressed more unfavorable experiences

with employment support services, while men expressed more difficulties with the job

application process and interviews. The study suggested further research and services to

enhance the career decision-making process for both males and females with ASD.

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Chapter Three

Examining gender difference in workplace experiences among adults with autism: evidence from an online community

3.1 Abstract

Despite the poor employment outcomes of adults with autism evident in literature, little attention has been paid to the role of gender in shaping their labor market experiences. Recent research emphasizes the critical need for such an investigation to inform gender-specific vocational support and workplace accommodations. This exploratory study investigated the gender-based difference among employed adults with autism about both types and severity of the challenges they face in the workplace. The study drew on qualitative content analysis of 714 randomly sampled posts (357 by women and 357 by men) from an online autism forum to explore on-the-job challenges as voiced by individuals with autism. The overarching observation was that women were more likely to experience greater workplace challenges. Women expressed greater concerns related to workplace stress, social interaction, and interpersonal communication. Additionally, women were disadvantaged by gender-related office expectations, especially about appearance. Men revealed a higher struggle with deficiencies in executive functions and disclosing their disability. Over-stimulating physical environments influenced the workplace wellbeing of both women and men. The result suggested that gender-sensitive vocational approaches in addition to flexible, communicative, structured, and supportive management behavior, are needed to improve the workplace experiences of adults with autism.

3.2 Introduction

With one in 42 males and one in 189 females in the United States being diagnosed with autism, it is estimated that over 500,000 individuals with autism will be entering the labor market in the next five years (Johnson & Joshi, 2016). Notwithstanding educational attainment, levels of skills, and the desire to work, it is evident that the employment outcomes of this growing portion of the population are poor (Townsley et al., 2014). The National Autism Society (2016) estimated that only 32% of adults with autism were employed either full-time or part-time compared to 47% of adults with disabilities in general and 80% of adults without disabilities. Similarly, in an Ontario study of 480 youth and adults with autism, only 30.2% of the participants reported full or part-time employment (Stoddart et al., 2013). In addition to unemployment, adults with autism appear to experience issues with underemployment. An Australian study found that 45% of 130 employed with autism were considered underemployed (Baldwin et al., 2014). Given reported employment outcomes, it is evident that adults with autism constitute a potentially underutilized workforce (Hayward et al., 2016).

A significant body of research has investigated the challenges faced by individuals with autism in navigating the labor market and the factors that contribute to successful employment (Dudley et al., 2015; Richard 2015; Chen et al., 2014; Johson & Joshi, 2014; Townsley et al., 2014; Muller et al., 2003). When seeking employment, it is repeatedly reported that individuals with autism experience difficulties with job search, application, and the recruitment process, in addition to discriminatory employers' attitudes. Difficulties in maintaining employment were ascribed to issues in coping with workplace social and communication demands, changing job

routines, executive function demands, overwhelming workplace sensory environment, and workplace stress and anxiety. Individuals with autism frequently experience workplace discrimination, difficulties in disclosing their 'stigmatizing' identity or attaining appropriate accommodation, or vocational support.

Notwithstanding the growing literature exploring employment barriers faced by adults with autism and their experience in securing and maintaining employment, little attention has been paid to the role of gender in shaping labor market experiences (Lindsay, 2017; Hayward et al., 2016). Exploring gender-related barriers is essential. Several researchers suggested that there is a critical need for gender-specific vocational support for adults with disabilities. (Lindsay, 2017; Sunset al. 2015; Coutinho et al., 2006). First, an increasing body of literature reported that women with disabilities, in general, continue to lag behind men regarding employment outcomes. Lindsay et al., (2017) reported employment rates ranging from 50 to 76.6% for males with disabilities compared to 1 to 27% for females with disabilities. Disabled males are more represented in full-time employment, receive higher wages, and are more likely to report job satisfaction (Coutinho et al., 2006; Doren et al., 2011). A similar pattern was found among adults with autism. Holwerda et al., (2013) reported an unemployment rate of 76.5% for females and 65.5% for males and found that males are 1.62 times more likely to find jobs. An Australian study reported that two-thirds of individuals with autism who were considered to be underemployed were females (Hayward et al., 2018). Second, there is an emerging evidence-base to support the existence of female-specific experience of autism (Bargiela et al., 2016). Women with autism tend to show a higher tendency toward sociability, emotionality, and friendship and less hyperactivity/impulsivity and behavioral problems than do men. Compared

to equivalent men, women with autism are also more likely to demonstrate better communication skills, initiating and maintaining a conversation, eye contact, and using appropriate body language. A growing number of studies hypothesize that women are better at 'camouflaging' or 'masking' autism and concealing their differences to fit in with the neurotypical world. However, this tendency to hide autistic behaviors can be mentally and emotionally exhausting and lead to a high incidence of mental health problems for women with autism (Kreiser & White, 2014; Dworzynski et al., 2012). Research also found that hormonal changes due to menstrual cycles may exacerbate behavior problems, such as self-injury, in females with autism (Thompson et al., 2003). Given these issues, researchers have called for more attention to the gender-based difference among adults with autism about both types and severity of employment challenges as being worth further investigation (Hayward McVilly & Stokes, 2016; Sung et al., 2015).

In a recent review of literature Hayward, McVilly and Stokes, (2016) concluded that the limited available research was not able to accurately ascertain gender differences in workplace experiences for adults with autism. Among 11 analyzed articles, only one distinguished challenges in workplace experience by gender. The study (Muller et al. 2003), which reported no significant difference, was based on a sample size of 18 participants with only five females. At the same time, there is a growing body of qualitative research on the lived experience of women with autism which discusses employment with little to no gender comparison (Kanfiszer et al., 2017; Webster & Garvis, 2017; Haney & Cullen 2017; Baldwin & Costley, 2015).

Through content analysis of an online autism forum, this exploratory study aims to address the following research question: What are the differences and similarities among employed women and men with autism with respect to the challenges they experience in the workplace?. It is argued that there is a critical need for such an investigation to inform gender-specific vocational support and workplace accommodation. A focus on gender continues to gain ground in current research as many journals now require more rigor and transparency in reporting gender to ensure the generalizability of results (Lindsay et al. 2017)

3.3 Method

Adults with autism are described as 'some of the most excluded and least heard people in society' (Kanfiszer et al., 2017, p. 663). This research intends to enable the 'voice' of people with autism to be heard through researching naturally occurring discourse in an on-line autism forum. Individuals with autism have increasingly turned to social media such as online forums to share personal experiences, disclose their challenges, and seek support and advice from their peers (Biyaniet al., 2012; Davidson, 2008). The relative anonymity of the internet, the absence of anxiety associated with face-to-face interaction, encourage individuals with autism to express personal opinions, recount difficult experiences, and discuss sensitive issues more freely than in traditional qualitative research settings (Holtz et al., 2012). Therefore, discussion forums represent a unique source of data that allows researchers to learn from individuals with autism themselves, without the risk of influencing participant responses.

Employing online forums as a source of information is increasingly used in a wide range of ASD studies (Jordan & Caldwell-Harris, 2012). Textual data from online sources has been used, for example, to explore women's experiences with diagnosis, employment, and relationships (Haney & Cullen, 2017), the experiences of students with ASD in academic libraries (Anderson, 2017), religious belief systems of persons with ASD (Caldwell-Harris et al., 2011), the attitudes of ASD community members toward changing diagnostic criteria (Parsloe & Babrow, 2014), the difference between neurotypical and ASD special interests (Jordan & Caldwell-Harris, 2012), and types and topics of support sought by members of the ASD community (Hong, Abowd, & Arriaga, 2015).

The validity and trustworthiness of online date have been assessed in a number of studies. Sussman and Sproull (1999) found that people are more straight-forward and honest when delivering bad news via online communities compared to face-to-face interviews. In a recent review, Pfeil and Zaphiris (2010) examined honesty in online support communities and concluded that forum members typically build an environment of honesty and trust and that cases of dishonesty are rare. In another study of online forum user-profiles, Back et al. (2010) reported that most users accurately describe themselves online. Significantly, Caldwell et al., (2011) compared the results of content analysis of ASD forum postings (covering 192 unique posters) and a survey completed by 61 forum participants and found consistency between the two data sets. Jamison et al. (2017) provided evidence that data from online forums may provide additional insights compared to traditional data sources.

3.3.1 Data Collection

Data was collected from WrongPlanet.net, a popular online forum used by individuals with ASD. Created in 2004, WrongPlanet currently has more than 80,000 members, who have contributed over 7 million posts, making it one of the largest and most active ASD online communities and the most frequently identified in related research (Anderson 2016; Parsloe & Babrow 2016; Jordan & Harris 2012; and Jordan 2010). WrongPlanet is also a public forum that does not require passwords to be accessed.

The study relied on threads posted on employment specific sub-board titled "Work and Finding a job". When the data were collected, this sub-board hosted 6,104 threads containing over 56,000 posts, offering a rich domain for examining the employment experiences of individuals with autism. For most posts, the poster's profile, including gender, age, diagnosis, and sometimes the location, is provided. Typically, a new thread is created by the individual who initiates the first post to seek social support and advice about one or more employment-related concerns. To capture the spectrum of posted employment experiences, the study focused on the initial posts of each thread. A sample of 714 threads was randomly selected, equal to 12% of all posted threads. This offers a representative sample size similar to other research of this type (Hong et al. 2015). Collection criteria required that autism diagnosis and gender of the poster be disclosed either explicitly in his/her public profile or implicitly within the posted text. The initial post should also address employment-related difficulties and should contain a question identifying the issue of concern. The threads have been checked to ensure both genders contributed equal numbers of threads. The process of data collection produced a

data set of employment-related threads initiated by an almost equal number of women (n=255)

and men (n=252) addressing various employment-related concerns for individuals who are self-

identified as being on the autism spectrum. The majority of posters (81% of women and 78% of

men) contributed only one post each. The others posted more than once. While almost 60% of

male posters were under the age of 30, only 41% of women posters were under 30. This could

be attributed to the fact that women tend to be diagnosed at a later stage of their lives

(Bargiela et al., 2016).

3.3.2 Ethical consideration

As the study did not involve any direct interaction between the researchers and online

users, it was exempt from a review by the McMaster University Research Ethics Board. To avoid

violating individuals' privacy, the study followed recommendations by Hanna and Gough (2017)

and Jordan and Harris (2012) to only analyze public and open access forum that receives a high

volume of traffic and do not refer to usernames or other identifying information.

3.3.3 Data analysis

Qualitative content analysis was applied to capture employment challenges addressed

by posters and to analyze gender differences in workplace experience. As Vaismoradi et al.

(2013) noted, content analysis can be used in exploratory studies with a large amount of

mediated text to identify universal codes and to find significant meaning through counting and

to interpret their frequency. The data were analyzed following a multiple levels process. First, a

deductive approach to data analysis was applied with an initial coding framework derived from

a highly cited systematic review of the literature addressing employment challenges for

individuals with autism (Muller et al., 2003). The framework identified five common barriers to employment success. The initial framework was continuously revised to accommodate new codes that emerged through the coding process. The recording of codes was independent of the length of the forum posting. For example, a long post could qualify for only one code while a short one might qualify for multiple codes. Second, the frequency and percentages of occurrence of each code were recorded as a proxy for the prevalence of particular experiences among the online community members. The aim was not to achieve a statistically significant result but to gain insight into the broad differences of experiences identified by each gender. This approach is frequently applied in exploratory studies with the goal of depicting the 'big picture' of a given subject (White & Marsh, 2006).   Finally, the themes developed by males' and females' posts were compared and contrasted using a constant comparative method (Boeije, 2002). Credibility was achieved through (a) verification using an initial literature review to establish validity and (b) triangulation by multiple researchers. Around 10% of the threads were randomly selected for double coding and agreement between the two authors. Transferability was achieved by providing a thick description of the experiences of the online community members, supported by representative quotes, and discussing how the findings relate to other adults with ASD.

Verbatim quotations were included not only to illustrate themes but, more importantly, to enable the voice of women and men with autism to give their own views about vocational challenges, policies, and practices that affect them directly. According to Corden and Sainsbury (2006), using participants' own spoken words made more impact than the researcher's narrative in conveying life experiences to readers. It is also a way of demonstrating the value of

what they said. As the study was undertaken mainly to explore differences between women and men, gender type was used to attribute quotations within the following narrative. This approach of attributing by category is acknowledged by Corden and Sainabury (2006) and applied in similar forum analysis studies (Anderson, 2018).

3.3.4 Software

The study used Nvivo 11 for Windows to facilitate capturing, organizing, and analyzing data. The sample threads were collected using the NCapture facility. The initial posts have been organized as 'cases' where the posters' profiles (age, gender, occupation) were stored. After entering the codes as nodes, data query functions were used to facilitate the analysis.

3.4 Results

This section highlights the experiences of Wrong Planet members in navigating the labor market as derived from the qualitative content analysis of (n=714) posts of the "Work and finding a job" sub-board. The majority of the posts (69.7%) addressed the employment experiences of Wrong Planet members and barriers to maintaining employment. This study focused on analyzing workplace experiences and the challenges of maintaining employment. Table 3.1 highlights the themes that emerged and the number and percentage of related codes by gender. There was a total of 417 instances of codes from which women contributed about 60% (n = 249), and men contributed about 40% (n=168). Figure 1 displays the structure of the emerging codes.

| Themes	Men		Women		
	Number of codes	%	Number of codes	%	% of the total number of codes
Workplace mental health	35	20.8%	69	27.7%	24.9%
Workplace social interaction	28	16.7%	68	27.3%	23.0%
Executive function deficiency	44	26.2%	21	8.4%	15.6%
Workplace communication	14	8.3%	25	10.0%	9.4%
Workplace accommodation	13	7.7%	22	8.8%	8.4%
Disclosure	16	9.5%	13	5.2%	7.0%
Physical and sensory env.	11	6.5%	17	6.8%	6.7%
Corporate culture	7	4.2%	14	5.6%	5.0%
Total	**168**	**100%**	**249**	**100%**	**100%**

Table 3.1 Coded themes by gender
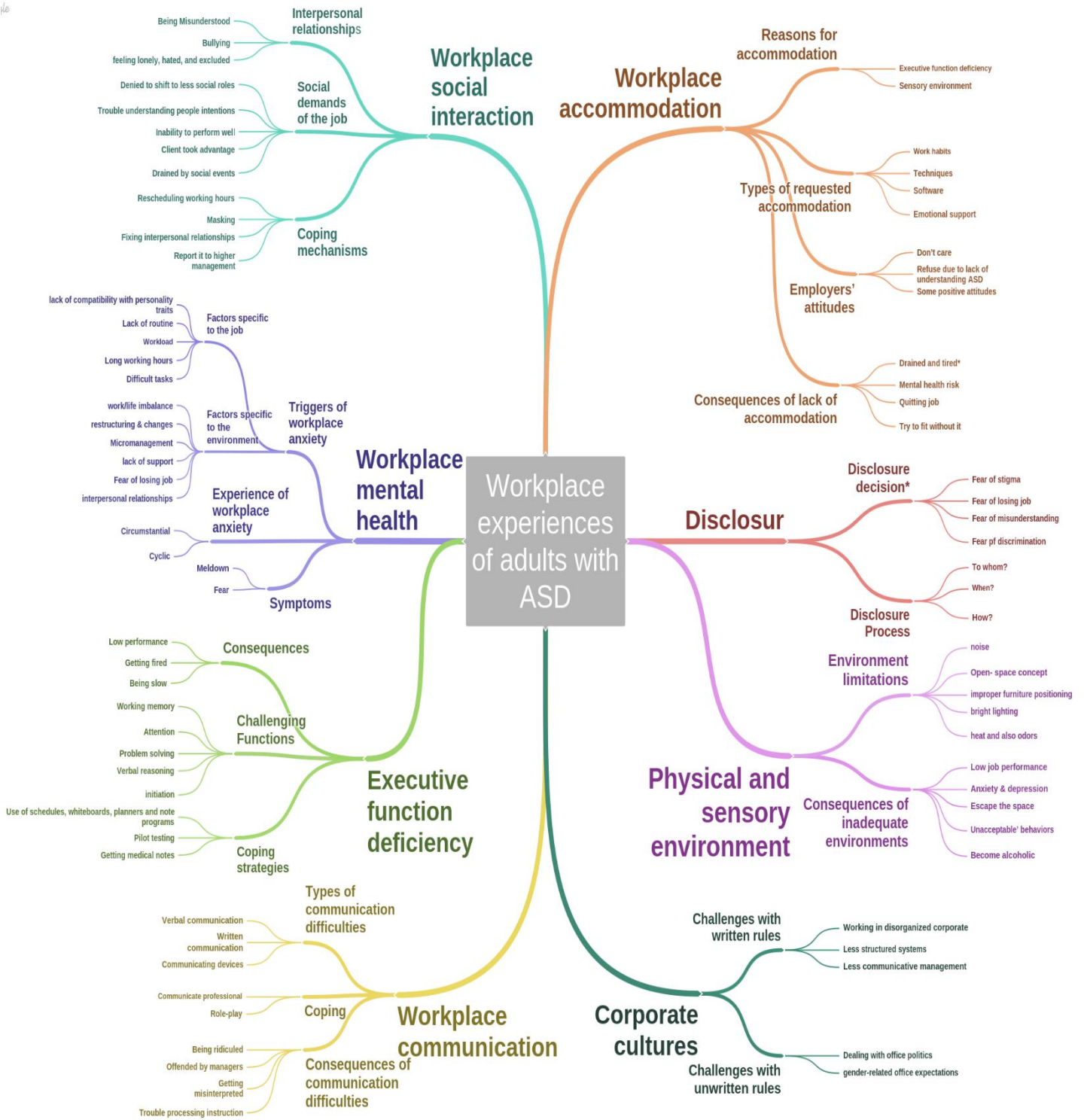
Figure 3.1 The structure of emerging codes

3.4.1 Workplace mental health

Almost a quarter of the identified codes discussed the experiences of workplace anxiety and stress and its enormous physical and mental cost with a higher rate among women (27.7%) than men (20.8%). Two subthemes emerged: the triggers of anxiety and the experience of workplace anxiety.

The workplace factors that are associated with stress and health risk can be categorized as those specific to the job and those linked to the social and organizational context of work. Both genders reported being stressed due to factors intrinsic to the job such as work overload or under load, long working hours, lack of routine, and sensory-stimulating physical environment. A male member described the stressful working context in a nursing home: "*You do not get a break all day. There are people everywhere. The distractions can easily cause you to make a med error. Your workload is heavy. ..I don't feel this occupation is conducive to my mental health*". Difficult or complex tasks and time pressure were also cited. A female member posted: *"I am so stressed…I find that because I am quite rubbish at this, I have to come home and work in the evening to catch up so that I can hit my deadlines"*. Management style also contributed to workplace stress. Both genders reported incidences of over-supervision as sources of stress. A female member described: *"I have always had a very hard time at work because of my anxiety; I feel as if I am being stared at and analyzed constantly its as if I'm on stage"*. A male member criticized, *"They micromanage everything I do. Pretty bad choice for someone with Aspergers, eh?"* Organizational cultures with little attention to employees' wellbeing exacerbated the risk as expressed by a female member *"I'd like some support from*

anyone but all people say is "aahh jobs are stressful sometimes, you just gotta get through it, it'll pass. I feel I'm on the very edge of breaking down". Organizational restructuring without adequate consultation was also cited as a source of stress, *"With this new change, all the things that help me to cope in everyday life would not be accessible".* Fear was identified as a major source of stress. Posts from both genders cited *"fear and panic about the day ahead….what if today's going to be a bad day?, what if I get yelled at?, what if we're short-staffed, and I have to do twice as much work?, what if I get overwhelmed and have a panic attack?".* Expectations of job loss either for not been up to the required skills or for no apparent reason, were noted. A male member posted, *"My therapist told me that's a fear many of her Aspie clients share, whether or not it has any basis in reality."*

Female members more commonly reported stress linked to interpersonal relationships with co-workers, supervisors, and clients: *"I got in a fight with a supervisor over a rather petty issue…I was called into the office to talk to her with another manager, and I lost all my words. I couldn't talk".* Female members identified a lack of compatibility between job and personality traits as a major source of stress: *"I'm really scared that I will have to become a full-on woman for work… I can't help who I am and feel screwed up because of my inner mentality. I'm going to be working with little kids and will have to become all womanly and girly".* Stress associated with work-interests balance was also more noted among female members, *"And these are huge books. I will stay up late reading them and then be tired of work, which doesn't help my burnout".*

Members revealed rich accounts of their personal experiences of workplace stress and its impact on their lives. Some members described the experience of stress as circumstantial and unavoidable: "*I was asked to give a presentation to 30 people - something which stressed me greatly*". Other members from both genders reported incidents of *"waking up with fear and panic"* even before going to work. A female member reported experiencing cycles of a panic attack and inquired, *"how do I manage to stop this cycle from repeating?"*. Workplace stress manifested itself in changes in behavior such as being withdrawn, aggressive, and unmotivated. Members also reported physical symptoms, "*I start to suffer from physical pain. My stomach starts hurting badly, I get these horrible headaches that take a day to go away*", and cognitive symptoms *"I've hit the point where my body is switching off, and I can't concentrate"*. Members also reported a range of psychological impacts of workplace stress including experiencing a panic attack, meltdown, and crying.

3.4.2 Workplace social interaction

About 23% of the communicated codes revealed members' concerns with issues related to the social environment and interpersonal relationships in the workplace, with a much higher rate among women posters (27.3%) than men (16.7%). Three themes emerged: interpersonal relationships, social demands of the job, and coping mechanism.

The analysis revealed a recurring theme of *"experiencing a great deal of difficulty interacting with colleagues"*. ASD-related social and communication deficiencies were misunderstood by co-workers, as one female member noted, *"I'm known by my co-workers as being in my own little world. Some even accuse me of ignoring them and being only focused on*

my patients. I don't purposely try to do this". Members repeatedly experienced incidences of bullying and harassment by co-workers and supervisors: *"Some co-workers boss me around, talk to me like I'm a child, or even yell at me. Some laugh at my awkwardness"*; *"I am been bullied at work by my line manager and the people manager. Who do I tell I am been bullied?"* Consequently, members poignantly described immense feelings of being lonely, hated, excluded, and being in a hostile work environment that frequently led them to lose their jobs. In the words of a female member, *"just the fact that my coworkers disliked me, and this is what's happened at most of the jobs I've had. After a couple of months, my coworkers decide I'm the scum of the earth and either sabotage my work or badmouth me or both, and I get fired"*. Some members reported experiencing significantly more difficulties in socializing with friendly co-workers whose communication style was hard to be followed (e.g. too many facial expressions, gestures, variations in tones). Many members expressed disappointment and frustration from what they saw as the unfair weight placed on social relationships in work environments: *"Recently, I've realized how my lack of involvement in office politics has hindered me in some ways. Sadly, it's not always how good you are at your job but how well-liked you are"*; *"I am quite certain I would get a negative review. This is so frustrating and upsetting. Why can't I be normal and have normal work relationships?"*

Members revealed concerns that their disability would get in the way of their being able to perform well in jobs with high social demands. A female member working in the service sector noted: *"I do not want to deal with all the things like answering phones, meeting clients, acting formal, long hours, etc. that are so hard to deal with because of my Asperger's"*. Clients often took advantage of them, *"I have trouble understanding people's intentions and emotions*

and my client has found my weakness". Other members reported being drained by workplace parties, conferences, and public events, *"But at work, it is going to be at least 15 people if not 30! That's way too many people and too much noise for me. I HATE HATE parties".* While some members complained of being denied the opportunity to shift to less social roles, others insisted on overcoming their social difficulties, *"To me, it seems like my boss is unreasonable, but I do understand that customer service is important... I want to succeed at this job".* Females felt trapped by the society in stereotypical female jobs, which are often socially demanding, in the words of one, *"I ALWAYS seem to get stuck on customer service, because I am female. I am convinced this is the case. I've tried to specify that I DON'T want to work with the public, but they never listen".* They frequently provide reviews of such jobs to alert other members, *"I wouldn't recommend nursing to someone with Aspergers. This job relies too much on interacting with others".*

Members shared their experiences in coping with workplace social challenges. Female members frequently sought conformity with neurotypical co-workers, utilizing their cognitive skills to conceal or compensate for their social deficiencies. In the words of a member, *"I'm so accustomed to hiding my Asperger's by passing it off as me just being painfully shy & introverted—which works splendidly in most social situations"* . However, they expressed potential risks associated with having to *"put on a mask daily".* As one member noted, *"it would be too stressful. You lose your sense of self and .finally crack under the pressure and cry and have your normal depression stress anxiety".* Others sought to cut or reschedule working hours to reduce the social demands. On deciding between *"solitary and social environments,"* some members chose to counter their social challenges. A female member expressed, "I feel that if I

"lock myself up" in an office all day with nobody to talk to, I'll just be encouraging my introverted behavior, and maybe surrounding myself with others is a better idea". While some members worked hard to fix their relationships with coworkers, "I have discovered a way to get co-workers to think the best of you, and to forget their perceived slights from you: bring food for everyone and put it in the break room. I have done this with great success". Others decided to follow corporate rules and "to elevate the situation to the next level of management".

3.4.3 Executive function deficiency

About 15.6% of the identified codes highlighted members' concerns with issues related to the deficiency in the cognitive processes that help regulate, control, and manage thoughts and actions; with more than a three-fold higher rate of occurrence among male posters (26.2%) compared to women (8.4%). Three subthemes emerged: challenges with various processes of executive function, consequences of deficiencies in executive function, and coping strategies.

Members talked about their struggles with deficiencies in executive functions encompassing: attention, problem-solving, verbal reasoning, cognitive flexibility, initiation of actions, and working memory. They complained about their inability to concentrate, do things on time or block out distractions *"I find it hard to focus on one thing for a lengthy period or for a productive period of time and the slightest distraction will send me off doing something else. I keep getting distracted, by one thing or another, and completely lose sight of what I started"*. Members also encountered issues with following verbal instructions, paraphrasing, and analyzing texts or speech; one male member said: "*I had trouble constructing thoughts and sentences after hearing it"*. Many members also reported difficulties arising from having

cognitive inflexibility. They discussed hardship associated with coping with changes, adapting to new rules, or stopping an activity to begin another *"…there is just the problem of task switching from when I was doing something during the idle time"*. A female member found that

> *"Keeping up with the pace of meetings, especially constant mind-changing or course-changing, is one of the challenging aspects of work that I can think of, with my having Aspergers".*

Members also struggled with the "*getting started*" phase of an activity *"Sometimes, I can't seem to begin the next thing. I know the steps, but there seems to be an impenetrable barrier between me and just starting. I can lose half a day to this ghastly state".* They also complained about their inability to multitask, follow multi-step verbal instructions and perform some tasks without help "*I struggled with multitasking because I was expected to do desserts, and although they were easy, I used to get overwhelmed with multiple orders".*

Some members were devastated to share the consequences of lacking some of the cognitive processes. They believed that such challenges were barriers to not only doing "well" but to successfully maintaining their jobs. A male member said: "*Poor executive functioning make working more difficult because it requires more mental effort to be responsible and keep track of multiple things at once*". A female member stated: *"I was fired because they said I was going too slow and couldn't keep up with the pace".*

Some members refused to give up and decided to deploy strategies to try overcoming this ASD associated barrier. For example, to cope with the inability to focus, some members advised on the use of schedules, whiteboards, planners and note programs "I've got Microsoft

Outlook to remind me of meetings and deadlines, and note programs for a list of things to do".

For dealing with issues related to verbal reasoning, a male member suggested:

> *"One tip/trick I found that has worked well, and this has diminished the issue somewhat*
>
> *(but it still persists now and then) is to provide the boss/manager with a sample of what*
>
> *you've done, or a "shell" of the document with a brief explanation of what you intend to*
>
> *put in each main section, and describe how you intend to relate the sections based on*
>
> *the objective of the project or business case (that way, it conveys that you're a big-*
>
> *picture thinker who "gets it")".*

Others questioned: *"Should I get some kind of doctor's note explaining my needs due to my autism?"* However, these strategies didn't always work "*despite my use of notes and a whiteboard to compensate for lack of executive function, I can't very well tell my audience to "slow down" if the rest of them are otherwise keeping pace amongst themselves"*.

3.4.4 Workplace Communication

About 9.4% of the identified codes revealed members' struggles with communication in the workplace, with a higher rate of occurrence among women posters (10%) than men (8.3%). Two subthemes arose: types of communication difficulties and consequences of communication difficulties.

Both genders discussed challenges with various types of communication. However, difficulties with verbal communication were more noted among females: *"I always manage to say something wrong, or something I'm not supposed to say."* Another female member sought

advice on references to help translate the meaning of catchphrases: *"I'm having trouble understanding my coworkers because they use a language I am unfamiliar with"*. A male member complained about having to work 12+ shifts because *"I kind of have a{n} issue saying no to someone (aspie issues)"*. Written communication was cited as a "preferred" method for some members; a male member said: *"besides communicating through email at work, I also tend to prefer to communicate with friends through email as well"*. However, some members recounted receiving many comments on their written communication skills; a female member said: *"I was told by my last manager that I was "too direct"*. Some members, particularly those with auditory processing problems, reported on difficulties communicating through some devices; a female member said: *"When talking over phones and that type of speaker mediums, I can't always hear clearly what people are saying, I just hear noise"*

Members believed that lacking communication skills has inhibited their careers tremendously and also their social lives. A male member complained about how people think of him as stupid *"They haven't seen what I can do…but I have to take the time to arrange their words and understand what they are saying"*. Another male member was ridiculed for having troubles in processing instructions: *"I often have to ask people to repeat themselves or elaborate… some people will literally write you off as dumb/slow because of this"*. A female member discussed how she felt seriously offended by her manager: *"she thinks I'm mentally challenged. She thinks I can't read a clipboard, excuse me I do calculus"*. Members also expressed concerns about getting misinterpreted all the time *"I am so sick of people misinterpreting me"*. A female who has difficulty modulating her tone of voice said: *"I*

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accidentally 'snapped' at two of my coworkers. I really, honestly didn't mean to be rude or mean. I was trying to communicate something quickly, and when I do that, (I have been told) I sound harsh". On the other hand, some members believed that it is not only their fault: "*the person training me keeps giving me vague instructions and not thoroughly explaining how things work*" and "*my boss..... She takes everything personally. Doesn't communicate directly".* Members also revealed some of their strategies to try to overcome communication difficulties. A female member noted that "*I role-played with my partner about how to talk to someone in a nice tone of voice when I am trying to say something urgently".* Another decided that "*the best way I have been able to manage this is to just keep everything 100% professional all the time. I never talk about anything with anybody that isn't business-related"*

3.4.5 Workplace accommodation

Workplace accommodation accounted for 8.4% of the identified codes with a slightly higher rate among women posters (8.8%) than men (7.7%). Four subthemes arose: reasons for accommodation, types of the accommodations requested, employers' attitudes toward accommodation, and the consequences of lack of accommodation.

In a bid to highlight the significance of being formally or informally accommodated in the workplace, members discussed the various struggles they have experienced on "a near-constant basis", particularly due to executive function deficiency: "*I have been criticized at work for everything from lack of eye contact to stiff posture to atypical speech to verbal volume modulation to overly formal and verbose writing style".*

Also, members reported problems with time management, multitasking, attention, adjusting to changes, and understanding instructions. Other members believed that their struggles stemmed from the surrounding environment, *"Residents are constantly screaming, yelling and wheeling their chairs…call-bells and lights are constantly buzzing"*. Another member expressed how *"furniture is positioned so I have to sit with my back to the door…I can't concentrate because I'm always looking over my shoulder"*.

Members looked for advice on the types of accommodation that might benefit them or have benefited others, including "*work habits, techniques, and software*" to help improve "*productivity or work relationships*". A male member requested two adjustments *"one to my location in the office, and the second for written instructions"*. In trying to cope with changes, another member discussed the need for a *"prep period before shifts…I would have time to prepare little things to some degree, get comfortable with changes… give myself a little space from being with employees as well"*. Another questioned if there would be any value in *"…bringing in a volunteer to help me due to a job where my workload can on occasion be overloaded"*. Others focused on the significance of being accommodated at a more basic level: *"I need understanding, patience, and forgiveness"*. Achieving conditional success was cited by a female member: "*If it's a friendly/patient colleague, sometimes I'm able to say 'can you just give me a second' and I try making a quick note of what I'm doing*".

Despite a long list of needs and requests, many members were still negotiating whether to seek accommodation or not. There are multiple reasons for this including, *"people assume you're retarded"* and *"[people] thinking my condition is nothing but an excuse"*. Others reported employers' criticisms and attitudes either because they don't care or don't know much about

ASD: "I was told that my psychological problems are my own and that I am already heavily accommodated". A female member complained: *"I feel that they dismiss me as not having a problem. Maybe this is because I appear 'normal'".* Another complained that "*my manager claims that until she has the accommodation paperwork, there's nothing she can do to help".* On the other hand, some fortunate members reflected on experiencing positive employers' attitudes *"I struggled with multi-tasking, but the team grew to like me and started playing to my strengths. This was accompanied by much appreciation "and "I've never had anyone really offer me accommodations… I was so overwhelmed with the consideration he put into it, I nearly cried".*

Some members who were denied accommodation expressed that *"when I leave at the end of the day, I'm so drained and tired; I just want to go home and sleep. I don't feel this occupation is conducive to my mental health".* Other dissatisfied members had *"some serious concerns about their support".* While some members decided to quit, *"I asked for changes in my pay and transportation, but both have been ignored…another reason why I'm leaving",* few others decided to take a step further and "*comment on this in the tribunal (it added to the stress)".* While employers and service providers were tagged with blame, some members felt that *"it's my job to make myself fit their world"* and "*I would like to inform my manager on the positive traits as well as disadvantages that we commonly face. What websites/information can I show him that would help him understand more about the spectrum?"*

3.4.6 Disclosure

Challenges related to disclosing ASD diagnosis in the workplace were found in 7% of the analyzed posts with an almost double rate of occurrence among men (9.5%) compared to women (5.2%). Two subthemes emerged: disclosure decision and disclosure process.

Members discussed the difficulties associated with disclosure, and many were contemplating whether to disclose or not. Some felt uneasy about identifying as "*someone who would need accommodations for their disability, "*especially that *"a lot of AS individuals report flat-out discrimination when they come clean about the condition"*. Many worried about "*getting fired or being treated like less than normal"*. One man complained: *"[I am] living life as an imposter, forever and every minute worried about being caught as if I different neurology was a crime to hide"*. Some members were firmly against the idea; why bother if *"normal people will never understand"*. A female member stated: *"people assume you are retarded and don't understand ASD".* On the other hand, others believed that disclosure was inevitable in their case; they mentioned reasons such as needing the help and accommodation and being *"bad at hiding it"*. One woman was obliged to disclose because *"one of the ladies has noted there's something wrong"* with her. As a consequence, members shared various experiences; "*this situation ended positively- I wasn't fired after all"*. Others highlighted responses that were *"not the most validating"*: "*if it begins to affect your work, we can talk more about it"*. A member uncovered his struggle "*to hide it*" after he was advised by his employer to "*not talk about those sorts of things"*. Another successful member reported that he was advised by his employer to "*keep it to s*elf" in fear of "*losing the businesses if people found out you aren't able*

to do the job".

Members questioned to whom to disclose: "*Did you disclose only to HR and your supervisor, or to everybody?*" While some members were unsure about what to disclose and the best way to do so; a member said: *"I just don't know what to physically say and how to bring it up. I don't know how much to say and what to cover"*, others believed that it's all about deciding on when to disclose. A member said: "*I have taken the decision that I do not tell employers about my diagnosis as I have no trouble at the stages leading up to a job. But Iam having second thoughts as to whether it would be beneficial to tell them when I get the job or during the role*".

3.4.7 Workplace physical and sensory environment

Physical and sensory environments are connected to employees' motivation, performance, satisfaction, and engagement in the workplace. This is particularly challenging for those with ASD, due to sensory-processing disorders. About 6.7% of the identified codes reflected concerns about physical and sensory environments, with an almost equal rate among women posters (6.8%) and men (6.5%). Two subthemes were derived: environment limitations and consequences of inadequate environments.

Members discussed how various aspects of the physical and sensory environments have a powerful influence not only on how they perform but also how they perceive and remember experiences at the workplace. Most of them targeted explicitly space designs, particularly the open- space concept, improper furniture positioning, bright lighting, particularly fluorescent;

different noise sources, such as from co-workers and telephones, in addition to heat and odors. A female member revealed: *"they decided to pull out a couple more walls, so I have even more background noise and insane conversations to try and block out"*. Another member mentioned: *"The lights bother me, the odors bother me and the sounds bother me--and it's hard to work"*.

As a result, members encountered various challenges, which they describe as *"unbearable", "distressing", "annoying"* and *"unnecessary"*. The open-space design *"left me feeling very vulnerable and exposed"*. In a bid to escape noise overload, a member questioned how *"to come up with a good excuse to leave early or not come in at all…That's way too many people and too much noise for me"*. Members also reported on how over-stimulation from the environment made them react in a way that was not really understood by others in the workplace, *"I just sat there and stimmed [performed repetitive actions, such as flapping the hands, wiggling the knees, spinning in a chair, etc] and couldn't look at anyone because I was so overloaded by everything …I've been drug into supervisor's office and told that my behavior is unacceptable"*. A member reported on how he couldn't cope and *"became a functional alcoholic to numb sensory overload from the noise and the heat…I left because I wanted out of the industry"*. On the other hand, few members appraised their current workplace environments and acknowledged the potential positive outcomes *"I feared the open-plan office layout and interactions with other people, but those aspects don't seem overly bad. In fact, I kind of figure that had I been provided with my own isolated office, or a desk next to a window, I'd probably spend more time absorbed in myself/staring out the window"*.

3.4.8 Corporate cultures

Corporate rules, policies, actions, and expectations reflect the values of the business and define its strategies, including clarifying job expectations, providing training and monitoring, making sure instructions are concise and specific, ensuring a well-structured work environment, instituting a code of conduct policies to be followed and supporting employees to prepare for changes. About 5% of the identified codes revealed members' battles with various corporate rules and behaviors with a slightly higher rate among women posters (5.6%) than men (4.2%). Two subthemes emerged: Challenges with written rules and challenges with unwritten rules.

Members often expressed how working in disorganized corporations could be challenging, *"I always seem to be hired by mickey mouse organizations who seem to muddle through hand to mouth, and it is frustrating. No one ever seems to know what they are doing"*. Members also voiced that less structured systems such as *"matrix organizations caused unnecessary stress for workers on the autism spectrum because there are too much social time and not enough structure."* Members often reported negative experiences with less communicative management systems where physical, technological or, organizational changes were applied without enough preparations or consultation with them, *"Before the change, I was always a top-rated employee. After the change,I have oscillated between top ratings, very low ratings, and even the lowest possible rating"*. They also complained from an exhausting work environment where the value of training and skill development did not empathize, *"I put in [extra hours] to try and get up to speed in a job where I was given minimal training".*

Members often expressed their inability to pick up corporate unwritten rules. For them, rules are "*something your boss must give you in print if you request it. Otherwise, it just does not exist*". Their common belief was that "*unless you are a vapid, status-obsessed social parasite, you cannot win the game of office politics. This is one major reason why so many aspies trouble staying employed*". They attempted to cope by being "*diplomat, rational, and conciliatory*". However, others believed that *"doing the job well and keeping yourself professional by not getting involved with office politics isn't always enough."* Some women members reported a problem dealing with offices' expectations of female appearance and dress code. A woman complained of being thought "*androgynous*". She questioned, *"What does dressing like a woman mean to you? To me, well, I'm a woman, so however I dress, I am dressed like a woman."* Another woman argued that "*if you have a good job in which the employer values your real skills, you could ignore other people's social games and wear jeans and a t-shirt*".

3.5 Discussion

This exploratory study examined the gender-based difference among employed adults with autism about both types and severity of challenges they face in the workplace as expressed by members of an online forum. The study analyzed 714 posts initiated by almost an equal number of women (n=252) and men (n=255) self-identified as being on the autism spectrum. Analyzing posts made by members could guide vocational support toward the most pressing employment challenges as voiced by individuals with autism. Revealing gender-specific

vocational barriers also informs gender-specific interventions and workplace accommodation (Sung et al., 2015). The results of this study demonstrated that maintaining employment was the primary concern of the forum members, followed by issues related to job search and defining a career path. An important and overarching observation to make from this study is that women with ASD were more likely to experience greater workplace challenges than their male peers. The study contributed evidence to examine this argument as called for by previous research (Hayward et al., 2016).

The results revealed eight related barriers with noticeable gender differences. Mental health is apparently a significant area of concern for employees with ASD. Complaints of workplace stress and associated mental health consequences among women posters were much higher than their male peers. Thus, the results confirmed the findings of earlier studies (Baldwin & Costley, 2015) that women with ASD are more susceptible to mental health risks. Members experienced a variety of workplace factors causing stress including factors unique to the job and those related to the social and organizational context of work. The findings point out that stress associated with interpersonal relationships, stereotypical gender role expectations and self-identity, and life-work balance were more pertinent to women. Women also are more likely to experience a higher incidence of adverse psychological impacts of workplace stress such as panic attacks, meltdown, and crying. These findings point to the need for specialized counseling, psychology and social support services that are attuned to the close relationship between work conditions and stress in women with ASD. An inclusive and less stressful work environment should avoid micromanagement, be more open and communicative

especially about restructuring, and provide employees with more control over their work conditions.

The second most cited barrier among WrongPlanet.net posters related to difficulties in social interaction with co-workers, supervisors, and clients and the associated experiences of being misunderstood, bullied, and the feeling of being lonely, hated and excluded. Although social difficulties in the workplace were frequently cited in the literature (Muller et al., 2003), the findings of this study suggest that women with ASD may experience or express greater social challenges in the workplace than men. Both genders expressed difficulties in coping with socially demanding jobs. However, women were more disadvantaged due to society's bias toward socially demanding stereotypical female jobs. Such jobs, as argued by Johnson and Joshi (2016), were frequently associated with experiencing higher levels of perceived discrimination and low self-esteem, and therefore significantly impacting workplace well-being among women with ASD.

The third most reported barrier found in posts related to challenges with various processes of executive functions. Males conveyed hardship in different aspects of executive functions at a frequency almost three-fold higher than women, consistent with Lehnhardt et al., (2015) who reported higher processing speed and better executive functions in females with ASD. However, the posts did not reflect gender differences in the type of deficiency. Posters from both genders reported experiencing a deficiency in various aspects of executive functions suggested by Kahn and Dietzel (2008), including working memory, planning and organization, initiation, shift, and self-monitoring.

Challenges with verbal, nonverbal, and written communications constituted the fourth most important barrier toward maintaining employment. Women reported communication-related barriers in the workplace at a frequency slightly higher than that of their men peers. This result is consistent with Write et al. (2017) who suggested that while females with ASD exhibit better social and communication skills than males, they tend to have more challenges with utilizing these skills in day to day activities.

Struggling with the hard decision of whether to disclose their disability was more common among men. Knowing that women tend to be diagnosed later in life than men, this finding contradicts Johnson and Joshi (2016) who argued that disclosure was more opt to trigger stigma among individuals who were diagnosed later in life. Members also debated and shared their experiences about when to whom, and the best process to disclose. On the other hand, the fear of requesting necessary accommodation or being denied a requested accommodation was cited among women posters at a higher frequency than the men posters. However, the needs of "understanding, patience, and forgiveness" as an essential emotional form of accommodation were strongly featured among women. This finding appears to strengthen the argument of Lindsay et al. (2017) that adequate social support is a major facilitator to maintaining employment among women with disabilities.

Disorganized, poorly structured, and less communicative corporate environments or settings where training and skills development are less valued were experienced as challenging for both genders. Additionally, women were disadvantaged by gender-related office expectations, especially concerning appearance. Women with ASD often struggle to fit the

traditional feminine, fashion and appearance-conscious stereotype (Kanfiszer et al., 2017). According to Simone (2010), many women with ASD believe that spending money and time on their appearance is 'illogical and stupid'. However, evidence suggests that appearance impacts women's employability and success in the workplace (Mahajan, 2007). Literature also reported appearance-based discrimination as a result of coworker reactions to or stereotypes about gender-related appearance (Malos, 2007). This highlights the need to expand vocational rehabilitation services to cover appearance-related guidance for women with ASD.

Much of the research on ASD in the workplace focuses on helping individuals adapt to the working environment (e.g., Hendricks, 2010). However, the newer theoretical perspective of the social model of disability view disability as a social construct and place the onus on society to eliminate the barriers that create "ability" gaps. The voice of the ASD community, as presented in this research, sheds light on general characters and behaviors of organizations and business management that help to accommodate the unique needs of employees with ASD. These include: 1) being understanding of the particular characteristics of ASD, anti-stigma, and counter stereotyping; 2) being flexible and adjusting to their varying needs; 3) providing direct communication and clear instructions; 4) providing structure and a predictable environment; and finally 5) being willing to provide continuous support. According to Seitz and Smith (2016), there is a dearth of organizational research on these topics. In practice, Richard (2015) demonstrated how contemporary forms of work organization, task allocation, and employers' control could severely discriminate against employees with ASD. He argued that management experts should cooperate with ASD specialists in the design and implementation of employment diversity management practices

The results of this study reinforce arguments of previous research (Haney & Cullen, 2017; Jordan & Harris, 2012; Jordan, 2010) about the value of discussion boards as part of the online community of individuals with autism. Members collectively shared their experiences and feelings and receive support in the form of experientially-derived personal strategies for managing workplace challenges. The uniqueness and practicality of such support, the sense of community, and the emotional value of the online interaction with like-minded individuals were often endorsed by the members, as the following quotes illustrate: "*Such posts are what make this site going on amidst quite much nonsense [other websites]"; "Here, though, I feel like I have community. Moreover, I enjoy reading through your answers and your questions because I think, These people here are like me!. You all have been important to help me pass"; "it was therapeutic for me to write it, and I know that some people read it, and took it to heart, so thank you."* These findings suggest the need for future research to address the benefits of online forums related to improving the employment outcome of individuals with autism. Hong et al. (2015) noted that research could contribute design recommendations to enhance the online Q&A experience for individuals with autism. The findings also support the value of analyzing the rich and first-hand textual information from online communities to gain a better understanding of labor market experiences in the context of autism (Hang and Cullen, 2017). The study looked only at the initial post of sampled threads and focused on exploring challenges in maintaining employment. Future research may include a more in-depth analysis of threads to explore gender-differences related to coping mechanisms, field-specific (e.g., IT, retail, science, etc) experiences and career development challenges. On a methodological note, other approaches to the analysis of online threads have been cited in research such as

discourse analysis, narrative analysis, comparative keyword analysis and phenomenological thematic analysis (Seale et al., 2006; Mo et al. 2009).

3.6 Limitations of study

There are some limitations to this study. First, there is no way to verify the diagnosis or posters' profiles reported on the forum. However, recent research on internet forum user-profiles concluded that most users accurately describe themselves online (Back et al. 2010). Second, forum members were most likely on the high-functioning end of the spectrum. The findings are thus primarily generalizable only to this group rather than the entire ASD community. Also, as noted by Finfgeld (2000), some populations may have little or no access to forums due to a lack of equipment and skills. Third, the majority of the posters, especially males, were relatively young. Thus the findings may emphasize the workplace experiences and needs of younger age groups. Finally, the study is also limited to posters' self-identified within the constraints of a gender binary. However, increasing studies reported high rates of gender variance among people with ASD compared to those without ASD, with higher variance in autistic females than males (Bejerot & Eriksson, 2014 and van Schalkwyk et al., 2015). The interface between gender variance and workplace experience of people with ASD requires further investigation.

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Chapter Four

In her own voice: juggling work, family, and caregiving roles by women with autism

4.1 Abstract

Using content analysis of an online autism forum, this study explored the domestic experiences of women with autism as homemakers, mothers and caregivers, and their negotiation of the interface between work and family demands. Clark's (2000) work/family border theory served as the primary theoretical framework to investigate how gender and disability identities influence work-family experiences of women with autism. The study revealed how autism-related social communication and executive function challenges impacted women's capacity to perform their domestic roles and described how the fear of being misjudged might discourage them from seeking support. While motherhood amplified their physical, sensory, and mental health challenges, it provided them with a positive sense of acceptance, a purpose in life. Also, being on the spectrum allowed them to better relate to their children with autism and understand their needs. Due to domestic responsibilities, mothers experienced career disruption, adjustment, and reduction in work performance. The study showed that their work-family balance was influenced by the way they positioned themselves on the femininity-masculinity spectrum and the way their self-care needs, specifically personal time, space and special interests, were incorporated into the work and family domains. Implications for research and practice were discussed.

4.2 Introduction

Autism Spectrum Disorder (ASD), referred to as "autism" (in this paper) is by far one of the most rapidly advancing developmental disorders in North America and is reported to affect around 1% of the population (Stoner & Stoner; 2016). Autism is a lifelong condition that is characterized by persistent challenges in social communication and social interaction *and* restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013). Although autism has historically been described as a predominantly male disorder, with a widely cited ratio of 4:1, there is growing evidence that women with autism are often under-identified (Tint et al., 2018). Studies that have screened population-based samples have found that the actual male to female ratio for autism prevalence might be as low as 2.5:1 (Kim et al., 2011) or 1.8:1 (Mattila et al., 2011).

While adults with autism generally have been characterized as 'some of the most excluded and least heard people in society' (Kanfiszer et al., 2017, p. 663), the needs and experiences of mothers who are on the spectrum maybe even more invisible (Tint et al. 2018; Rogers et al., 2017; Canadian Center on Disability Studies, 2008). Using content analysis of an online autism forum, this study aims to highlight the voices of women with autism, with particular attention to their domestic experiences as homemakers, mothers and caregivers, and their negotiation of the interface between work and family demands. In so doing, the study sheds light on the experiences of women with autism, while also informing policies and services that can be used to support this population. At the same time, the study helps to broaden the existing work-family research, which has given relatively little attention to the experiences of

women with disabilities. Conceptually, the study draws from, but also extends, Clark's (2000) work/family border theory to consider the ways in which the struggle for work-family balance is shaped by the lived experience of autism.

Women and Work-Family Balance

In the contemporary economy, there is a growing expectation that women should have competitive and successful careers and should simultaneously be nurturing wives, mothers, and homemakers (Jacobs & Gerson, 2001). These conflicting expectations also have the potential to create role strain for women who must juggle multiple role-related identities assumed within the context of employment, parenting, partnership, and motherhood (Graham et al., 2004). In order to fulfill typical responsibilities, women often face additional pressure to prioritize their care roles, make career sacrifices, and struggle with dividing their time between family and work commitments. Research suggests that those engaged in multiple family and work roles might also experience reduced marital satisfaction (Voydanoff, 2005), psychological strain (Kelloway et al., 1999), physical illness (Peeters et al., 2004), depression (Vinokur et al., 1999), and mistreatment (Grzywacz et al., 2003).

To date, most work-family research has been conducted with women from a relatively narrow population representing specific racial (Kachahaf et al., 2015), cultural (Valk & Srinivasan, 2001), or professional identities (Penney et al., 2015). However, very limited research to date has investigated the work-family interface for women with disabilities (Cook & Shinew, 2014; Ozbilgin et al., 2011). Among the few available studies, Skinner and MacGill (2015) studied the lived experiences of ten working mothers with dyslexia. Cook and Shinew

(2014) explored the work-life balance of eight employed individuals with physical disabilities, including five women. Their study concluded that "there is a need for more research about the work-life negotiations of individuals with all types of disabilities, as the work-life concerns of individuals with cognitive disabilities may be quite different from people with physical disabilities or with psychiatric impairments" (Cook & Shinew, 2014, p. 435). To this end, the present study is among the first to specifically address the work-family interface of women living with autism.

While there is a growing literature on the employment and workplace experiences of women with autism, little is known about their experiences in the home domain. In recent work, Tint et al. (2018) identified a gap in research related to autistic women's experiences of motherhood and their perceptions of parenting and caregiving. Available studies focused on women's experience with medical service during pregnancy and birthing with little attention to motherhood and housekeeping roles (e.g., Suplee et al., 2014; Gardner et al., 2016; Roger et al., 2017).

Within the work-family literature, the few studies that have addressed autism focused on the experiences of working parents of children with autism. Matthews et al. (2011) suggested that given the elevated level of stress associated with raising a child with autism, these parents are at a higher risk of experiencing a host of adverse outcomes compared to parents of children with other disabilities. Montes and Halerman (2008) found that families with a child with autism were four times as likely to quit, change their jobs, or not take a job at all as were comparable parents with neurotypical children. Research indicated that the severity

of autism, the behavioral problems, and self-care difficulties observed in the children with autism contributed to decreasing family cohesion, somatic complaints, parental burnout, and feeling of social isolation (Carter et al., 2009). At the same time, recent research (Sandin et al., 2017) has estimated the heritability of autism to be 83%, suggesting that many women with autism are likely to give birth to children who also live with autism. As a result, working women with autism may be doubly disadvantaged. While they have to manage the demands of their own disability in both work and home domains, they may face additional demands in the home domain as caregivers for disabled children with exceptional, intense, and prolonged responsibilities (Crettenden et al., 2014).

4.3 Theoretical framework

To conceptualize work-family interface for women with autism, this study incorporates Clark's (2000) work/family border theory, also known as border theory, and its extension by Cook and Shinew (2014), and Emslie and Hunt (2009). Clark (2000) defined work-family balance as "satisfaction and good functioning at work and at home, with a minimum of role conflict" (p. 751). The theory conceptualizes work and home as two distinct domains that influence each other and aims to explain how people manage and negotiate the border between them in order to attain balance. These borders can be physical, temporal, and/or physiological. Clark (2000) described people as border-crossers who move between domains. Such borders vary in 'permeability': the extent to which elements from one domain may enter another. Borders also vary in 'flexibility': the extent to which borders may expand or contract, which may apply to the

flexibility of location or hours of work. 'Blending' occurs when a border has a high degree of permeability and flexibility, and the two domains overlap. By contrast, borders that are very impermeable and do not allow blending are understood as 'strong'. The strength of the borders and the spillover from one domain to another influence work-family concerns. For example, a work domain that allows for flexible working hours has weak borders and may promote balance.

Three key concepts make border theory particularly useful in conceptualizing work-family interface for women with ASD: "central participation", "other domain awareness", and "border crossing". Individuals are viewed as "central participants" of a domain because of their perceived competence, their affiliation with the central members, and their internalization of domain culture and values. Clark theorized that individuals who are central participants within their workplace communities receive more support in managing work-life balance than do employees who are perceived to be more peripherally engaged. This concept is significant given that women with autism typically struggle to achieve and maintain employment due to difficulties in executive functions, managing workplace social demands, and navigating office politics (Baldwin & Costley, 2016) resulting in less opportunity to establish themselves as central participants. Clark's concept of "other domain awareness" or people's ability to understand aspects of their colleagues' lives that differ from their own is also important for the current study given that co-workers and supervisors are typically unaware of the unique work and life challenges of women with autism. The social and communication challenges and the stigma associated with autism typically hinder women with ASD from negotiating their needs related to work-life balance (Haney & Cullen, 2017). Finally, in the concept of "border crossing"

Clark posited that the ease or difficulty with which individuals move between work and home domains is influenced, in part, by the degree of permeability and flexibility of each domain in terms of one's roles and responsibilities. This concept is significant for the current study as women with autism take their disabilities and the responsibilities related to disability management with them across domains (Cook & Shinew, 2014).

While Clark's border theory considers identity in terms of the various roles a person plays in work and family domains, it does not address the integration of other identities such as gender and disability, a limitation that Ozbilginet et al. (2011) observed in the work-life literature more generally. Emslie and Hunt (2009) argued that gender is both central to any discussion about work-family intersection and embedded in the ways that workers negotiate home and work life. Their study suggested that the work-family balance of women is influenced by the way they position themselves in relation to femininity and masculinity. For example, women who identified with the traditional gender roles as 'female carers' tended to have relatively weak boundaries between family and work life. How might gender norms shape the lives of women with autism? Baron-Cohen's (2002) 'extreme male brain' theory proposed that the cognitive profile of individuals with autism is characteristically 'male' and that those individuals, on average, show a shift towards "masculinized" scores on measures of empathy and systemizing. A recent study reported a significantly higher rate of gender variance, identified as having a gender identity different to one's biological sex, among natal females with autism (34%) compared to neurotypical natal females (3%) (Cooper et al., 2018). The same study showed that women with autism experience lower social identification with their biological sex group. Qualitative research also suggests that girls and women with autism do

not identify as readily with the construct of femininity or traditional gender roles and find more difficulty in socializing with other women (Kanfiszer et al., 2017). How gender is embedded in the way women with autism negotiate home and work life is something that will be explored in detail in the analysis that follows.

Cook and Shinew (2014) extended Clark's theory in the context of disability. They argued that the degree of permeability of both work and family domains to accommodate disability self-care issues – that is the range of daily activities and behaviors undertaken by individuals to promote and restore their health (Pelicand et al., 2015) – is critical to work-life negotiation. Recent research reported that the rate of mental health conditions among women with autism (35.7%) is almost six times higher than neurotypical women (Rydzewska et al., 2018). Due to challenges in social communication and sensory integration, women with autism may often experience anxiety, stress, frustration, and depression in everyday situations. The research reported that sensory overload, the demands of social interaction, unexpected changes in routine, and disappointments as key sources of anxiety and stress among individuals with autism (Trembath et al., 2012). Also, research evidence suggests that women with autism often attempt to camouflage or mask their autism, which can be mentally and emotionally exhausting and lead to a high incidence of mental health problems (Kreiser & White, 2014; Dworzynski et al., 2012). As anxiety and stress build up, women with autism may experience a 'meltdown' or 'shutdown' in work or family domains. Meltdowns are periods of psychological distress, which can include crying, self-harm, and volatile behavior. Shutdowns are when a person retreats and withdraws, becoming non-responsive and uncommunicative (Milner et al., 2019). The research suggested that during pregnancy, birthing, and early mothering when women with autism are

already anxious, their tolerance for sensory overload is lowered, which means a meltdown or shutdown can be triggered more easily (Rogers et al. 2017). Removal of sensory stimuli, having time alone, and engaging in a special interest are frequently cited as coping strategies to avoid or recover from this intense period (Trembath, 2012). It can, therefore, be hypothesized that the ability to accommodate self-care strategies at home and workplace may influence the work-family interface.

Employing Clark's border theory (2000) and its extension by Emslie and Hunt (2009) and Cook and Shinew (2014) as a framework (Figure 1), the study aims to respond to the following research questions:

1. How do women with autism experience domestic roles, particularly motherhood and housekeeping?

2. How do domestic roles affect their work-life?

3. How does gender variance influence the women's experiences of work-family interface?

4. How do disability self-care strategies influence the women's experiences of work-family interface?

WORK DOMAIN

Managing borders

Role-related identity

Q2: How do domestic roles affect the their work life?

Gender identity

Q3: How does gender variance influence the experiences of work-family interface?

Disability identity

Q4: How does disability self-care influence the experiences of work-family interface?

FAMILY DOMAIN

Q1: How do women with autism experience domestic roles?
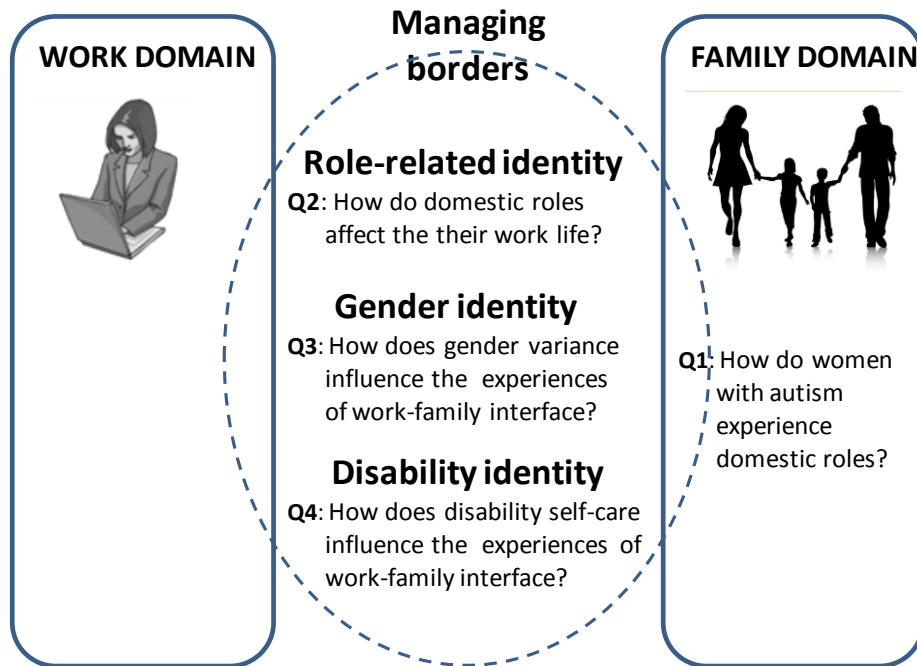
Figure 4.1 Theoretical framework and research questions

4.4 Method

Online Discussion forums offer a unique source of first-hand data that allows researchers to learn from individuals with autism themselves, without the risk of influencing participant responses. With the relative anonymity of the internet and the absence of anxiety associated with face-to-face interaction, individuals with autism may be willing to express personal opinions, recount difficult experiences, and discuss sensitive issues more freely than in traditional qualitative research settings (Holtz et al., 2012). Individuals broadcast questions to a virtually connected network and obtain answers from like-minded members of the network (Hong et al., 2015). Hence material from online forums might be considered as a proxy for 'everyday discourses' within the online autism community.

Engaging with ASD online forums as a data source provides access to a large, ecologically valid data source. This type of forum research is now used in a growing number of ASD studies (Jordan & Caldwell-Harris, 2012). Online textual data, for example, has been used by authors to explore a range of topics including experiences with diagnosis, students access to library services, religious beflieds within the ASD community, and the range of supports sought by those living with ASD (see Haney & Cullen, 2017; Anderson, 2017; Caldwell-Harris et al., 2011; Hong et al., 2015).

A number of studies have explored the validity and trustworthiness of online data. For example, Sussman and Sproull (1999) noted that people are more straight-forward and honest when delivering bad news via online communities compared to face-to-face interviews. Pfeil and Zaphiris (2010) reviewed literature related to honesty in online support communities and found that forum members often build an environment of honesty and trust and that cases of dishonesty are rare. Further, Back et al. (2010) studied online forum users profiles and reported that most users accurately describe themselves online. Methodologically, Caldwell et al. (2011) compared a content analysis of ASD forum postings on religious beliefs and a survey of forum participants on the same subject and found broad consistency in the views expressed.

4.4.1 Selection of online forum

The online forum for this research was identified through a Google Internet search with the phrases "Autism online forum" and "Autism discussion forum". The first three forums that appeared on both results were selected for further analysis. WrongPlanet.net was identified as the largest and most active online forum for individuals with autism. Created in 2004,

WrongPlanet now has over 80,000 members, mostly from North America, who have contributed over 7 million posts, making it one of the largest and most active online communities for individuals on the autism spectrum and the most frequently identified in related research (Anderson, 2017; Parsloe & Babrow, 2016; Jordan & Harris, 2012; Jordan, 2010).

4.4.2 Data Collection

This research focused on threads posted on women-specific sub-board titled "Women's Discussion." When the data were collected (November 2018), this sub-board had 2,528 threads containing over 58,000 posts, offering a rich environment for studying experiences of women with autism. For most posts, the poster's profile, including age, gender, diagnosis, and sometimes location, is provided. Typically, the thread is created by a woman who initiates the first post to seek support or advice or share her experience with others. The discussion board threads were sampled using the advanced Google search. Boolean searches used combinations of the following keywords: "mother; motherhood; kid; child; children; housekeeping; family; chores; home; house; gender; feminine, masculine; balance AND work; workplace; job; career". 758 threads contained information that met the sampling criteria. These threads were read in entirety to determine relevance to the study, and 371 were finally selected. The sampled threads included a total of 4,452 posts with an average of 12 posts per thread. A small number of posts were found to be written by male members and were excluded from the analysis.

4.4.3 Ethical considerations

This study was deemed not to involve human subjects as no interaction occurred between the researchers and the forum posters; it was thus exempted from further review by the McMaster University Research Ethics Board. To avoid violating individuals' privacy, the study followed recommendations by Hanna and Gough (2017) and Jordan and Harris (2012) to only analyze public and open access forums that receive a high volume of traffic and do not refer to usernames or other identifying information. In addition, the authors contacted the moderator of the forum and received his consent to use the textual data.

4.4.4 Data analysis

The analysis was guided by the research framework, with the overall aim to explore women's experiences related to each of the research questions. The data were analyzed following a multiple levels process recommended by Miles and Huberman (1994). The first level of analysis involved reading through each post and assigning concrete labels to individual passages of text reflecting the relevance to each of the research questions. The second level involved content analysis that began with open coding to identify detailed themes and subthemes describing the experiences of posters. According to Vaismoradi et al. (2013), content analysis is used in exploratory studies with a significant amount of mediated text to identify universal codes and to find significant meanings. Credibility was obtained through (a) verification using an initial literature review to establish validity, and (b) triangulation by multiple researchers. Around 10% of the threads were randomly selected for double coding and agreement between the two authors. Transferability was achieved by providing a thick description that documents the

complexity and multiplicity of the experiences of the online community members (Whitley &

Crrawford (2005), supported by representative quotes, and discussing how the findings relate

to other adults with autism.

4.4.5 Software

The study used Nvivo 11 for Windows (QSR international, 2015) as a platform for capturing,

organizing, and analyzing data. The sample threads were collected using the NCapture facility.

The initial posts have been organized as 'cases' where the posters' profiles (age, gender,

occupation) were stored. After entering the codes as nodes, the data query functions were

used to facilitate the analysis.

4.5 Results

4.5.1 The experiences of women with autism as mothers and housekeepers

The data offered an in-depth overview of the experiences of women with autism as

mothers and housekeepers, including their challenges and strengths in addition to the impacts

of domestic roles on women's health and wellbeing.

Motherhood experiences

Challenges related to social interaction were highly reported. Many women discussed

struggling with building social networks and handling the range of social communication that is

often part of the day - to - day parenting. Tasks such as setting up play dates, meeting other

parents and their kids in playgroups, communicating with teachers, attending school events, and taking kids to medical appointments can sometimes be overwhelming. A mother noted: *"I find it too difficult to attend parents meet in his school none of his classmate's parents is my friend no one helps me with notes and other assignments i feel quite depressed due to this"*.

These challenges may interfere with an important aspect of motherhood, which is the ability to be advocates for their children, particularly at school, with other family members, and in social situations. Many mothers found these situations intimidating or hard to handle, especially those who have a child on the spectrum who needs a strong parent advocate: *"I can't be as involved in their school lives as I'd like, and can't network with other moms for play dates, birthday parties, and the like."*

Mothers also encountered difficulties in understanding their child's feelings as a result of being on the spectrum: *"My main issue is trying to "organise" my daughter's feelings properly. Not only was this not done for me as a child, my emotions are more raw than usual (I think because of my HFA [High-functioning autism]) so they get in the way of recognising her feelings"*. As a result, they were concerned that they might be unable to teach their children basic social skills and were not well placed to act as social role models for their own children: *"I am social failure and don't know how to teach my son anything...nothing his grades are poor his social skills are poor and he is just lacking behind like me"*. Another mother said:

"I have no friends or family though and wish I could give them some kind of decent extended family or other adults to model after...I'm always concerned with whether my kids are happy,

getting what they need, feeling loved. But I'm a terrible social role model and when I'm overwhelmed, not as emotionally available as I'd like".

On the other hand, women talked about the fact that being on the spectrum could also mean that they had unique strengths, especially if they were parenting a child with autism. Several participants expressed how being on the spectrum has positively contributed to their motherhood roles: *"I find that I am much more accepting of their special traits - they are the way they are, and I never even thought about questioning them/their traits. I am so much better at helping them because I know how it is".*

Others tried to be in tune with their children by learning from their own childhood sufferings: *"I'm very empathetic to my kids, always on their side and learned from my mother how NOT to parent… However, since I remember everything that happened to me, I can use those things as references to respond to my kids the way I would have liked."* Many mothers of children on the spectrum believe that they have a particular unique advantage that stems from their ability to better explain the neurotypical (NT) world to them in a way that makes sense and also explain their children's behaviors to the NT world in a way they understand: *"I'm an Aspie mom raising an Aspie kid, and we understand each other perfectly. I honestly think I'm a better mother to him than any NT mom could be, because I have almost 30 years of experience in "translating" NT norms - I know how he feels in any given situation".*

Housekeeping experiences

Women realized how being on the spectrum affected their roles as homemakers and their responsibilities to create structure within the home environment. A woman commented: *"You*

might be an Aspie if all your Internet bookmarks are meticulously organized, but your

apartment looks like a disaster area!!" They frequently attributed problems with daily chores

and house management tasks to executive function challenges associated with autism. As one

woman described:

"I finally figured out what "executive dysfunction" is and realized that, no matter how much I

care, I'm not going to be able to keep the house and meals using the same methods as an NT".

Aspects of executive function that were repeatedly cited include difficulty in memorizing

basic daily tasks:"*I don't do well with remembering all the kinda stuff like doing their lunch in*

the mornings and stuff. So with my son (13years), I had to actually put "make son's lunch" in my

PDA to remind me every morning for school". They also reported difficulty in formulating plans

and organizing household tasks. For instance, a woman explained: "*It's not that I'm lazy, it is not*

that I can't clean. I can. It's that I get totally lost and overwhelmed when I try to figure out how

*to organize the whole 'cleaning the house' thing....But I *can* follow a schedule that gives me*

specific instructions of what to do when". They struggled with task initiation and procrastination

as a woman expressed: *"I am a terrible housekeeper. Things pile up, and the whole place is*

pretty cluttered. I don't know why I just can't seem to get on top of it. I see it and don't know

where to begin, so I don't". Lack of attention and losing focus while involved in household

activities were also repeatedly cited: *"The problem with trying to clean is that there always*

something interesting that end up distracting me, I have to fight the temptation to go overboard

and burn out".

In addition to executive function, some women attributed their struggles with housekeeping to another autism-related disorder. One forum participant defined it as *"Asperger Aversion Avoidance Syndrome, where you have an overwhelming tendency to avoid things you don't like or have no interest in".* Women frequently reported being stressed by even simple everyday expectations and attempting to avoid these to a remarkable extent, for instance: "*I hate housekeeping and don't do it until it reaches critical mass.*"; *" I tend to let it pile up until I keep tripping, and then I go into a mad organization frenzy".*

On the other hand, autistic affinity for systems enabled some women to establish a structure within the household: "*couldn't manage household chores if I didn't create routines. I can be very efficient in these areas, but only if I stick to a specific schedule and do things the same way".*

Many women voiced the need for 'practical' housekeeping support services similar to what is offered to seniors and other disability groups. A women commented: *"Every time I hear an ad on the radio for home health care for seniors ("We can help with meals, light housekeeping, personal hygiene, and bill paying so that your loved one can remain living independently at home longer"), it occurs to me that similar support would be helpful to many people with AS [Aspergers Syndrome]*". Having such a service would allow them to focus on other parenting responsibilities. Mothers also asked for structured parental coaching services: *"where they help you plan what you need to do and check back to help you follow through".*

Impacts of domestic roles on women's health and wellbeing

Women discussed how domestic roles, particularly motherhood, were associated with both negative and positive consequences on health and wellbeing.

Negative outcomes

Several women found that their autism traits were heightened during pregnancy and shortly after giving birth, particularly around mental health issues. As one woman described:

"All of my AS traits have without a doubt become exponentially more pronounced. I feel like I have aged 20 years. My anxiety is through the roof. My associated OCD [Obsessive-Compulsive Disorder] tendencies have all been exaggerated. My ability to handle things (my body, my mind, everything) has become far more limited. My brain's capacity just seems to be reduced. The point at which I become overwhelmed has become much shorter...I guess the only thing I can attribute it to is the physical, biological, chemical, etc. changes that pregnancy and childbirth effects."

For mothers on the spectrum, with particular sensory needs, living with the noise, mess, smell and the chaos of children can be overwhelming and lead to sensory overload. They often described their daily life as *"a sensory torture"* from which they felt "*totally DRAINED at the end of the day"*. Having children on the spectrum while lacking support may add to their challenges. For example, a woman described: "*I am homeschooling all 3 of them as they are on the spectrum and I live in an area with terrible services....Homeschooling isn't easy, it's a sensory nightmare for me and I just scrape by".*

Autism-related challenges coupled with lack of services left many mothers with a feeling of depression, guilt, low self-confidence, and inadequacy for not being able to perform well in their domestic roles. For instance, a woman posted: *"I'm always on the brink of melting down from sensory overload and guilt from being a bad mother and wife and feeling useless and worthless and frustrated"*. Another woman felt extremely dispirited coping with the needs of her neurotypical son: "*I was convinced my son would be better off without me as his mother. I put him in foster care for 8 months while I sought counseling. We reunited right before he started first grade".*

These feelings were exacerbated by the stigma surrounding autism, causing some women to refrain from seeking any help to avoid their parental capacity being questioned, and led them to feel further alienated and different. As one woman posted: *"I am currently having to prove again that I am a good mum, I do need support for executive functioning, accessing services, etc, but this is not a reflection on my parenting skills".*

Experiences with public support systems also brought mothers into contact with others who had the power, due to their professional status, to judge their parenting rights and capacity. For example, one woman recounted: "*They [social workers] actually started proceedings to take my kids away from me, not because there was any evidence of abuse or neglect, but simply because I disclosed my diagnosis"*. The fear of their children being removed because of their diagnosis, communication differences, or misunderstanding their parenting style was frequently expressed and reinforced by stories on the news. The sense of being marginalized and powerless was also extended to medical services. Some women experienced

being treated as a medical object rather than a human individual. A woman complained: "*I'm sick of being treated like a passive consumer of care. I have more agency at Walmart than I do at the psychiatrist's office"*.

Positive Experiences

Despite difficulties, many women, especially older women, found motherhood to be a positive experience. They commented on the uniqueness of their relationship with their children, which brought joy and deepened their self-understanding: "*My three children are all grown up. I think raising children was the best experience of my life and led me to the deepest insight into myself. Your own children will say things to you that almost no one else will"*. Their children provided them with a sense of acceptance, appreciation and of being understood which may lack in other relationships: "*No matter your deficits, children know when you are trying hard and loving them."*

Motherhood also motivated women to push back against their autism-related challenges. For example, a woman commented: "*I've been able to dramatically reduce my own meltdowns and have been forced to find ways to keep severe anxiety at bay since having a child, because you simply can't be a responsible parent if you aren't able to control yourself"*. Another woman described how motherhood promoted her communication and social skills: *"My daughter was my best therapy, because I had to figure her out, and communicate with her, and also deal with all the people who are drawn to interact with women who have babies"*.

4.5.2 The impacts of domestic responsibilities on women's work lives

The analysis revealed that domestic roles, particularly caring for children with autism impacted the women's work-life in a number of ways. Three main themes emerged: impact on work arrangement, impact on work performance, and positive impact on women's career advances.

With regard to the impact on work arrangement, there were two groups, women who made a decision to leave paid work and those who chose to balance demands of work and home. An overarching observation was the experience of women electing to take on a full-time caring role. However, women reported different reasons beyond removing themselves from the work domain. Many women, particularly those having children with autism, believed that only the mother could help the child even if specialized services are available.   Therefore, they prioritized the child's needs over their own career, as one forum participant described:

"Kids [with autism] have a stronger need to learn at home, or from someone they are very close to than perhaps children with other conditions, simply because they do tend to thrive only in a more limited social circle. The concept of me earning more money for my family has always been so far behind what I saw my son needing"

The data revealed many stories of women who sacrificed a high profile career: *"The president of the local Autism Society, the vice president of the local Autism Society, and I are all former female attorneys with children with classic autism who decided to quit their jobs at some point to help their kids."*.

The amplification of autism-related traits and mental health challenges as a result of the pressure of juggling both motherhood and employment was also cited as a reason for relinquishing employment. A mother posted: *"I have not worked since she was born... I never handled stress well and it makes my AS [Asperger] worse and my anxiety and it affects me physically. Not good for when you have kids so parenting and full-time work be too stressful".*

The affordability of reliable services also made financial sense for some mothers to quit their jobs to support their children. A mother noted: *"Private services are expensive; the private help necessary for a child with severe issues can quickly exceed whatever income the mom brings in".*

Another overarching theme was the impact of their domestic roles on work performance. Women felt that managing caring demands of a special need child depleted their mental resources. A woman posted: *"My ability to focus on my job (which is important since I am a single mom) IS impaired by my need to constantly manage appropriate care for my daughter-not just a school that APPROPRIATELY educates her but also therapies, camps, social skills classes, etc. Hunting for services is a full-time job on its own".*

Being on the spectrum could also exacerbated the adverse impact of domestic demands on their careers. Some women were no longer able to put in more time and effort at work to compensate for being slow due to autism-related challenges. One woman described how losing this coping mechanism negatively impacted her work performance: *"I worked at my own pace which is naturally slightly slower than some but not all of my peers. Now I can't work in the evenings (much) or at weekends, and I am struggling to get through the work. Concentrating and original thought are also harder at the moment".*

Another common theme was the experience of adjusting work life to be compatible with caring demands. Mothers frequently reported having to shift to part-time hours, home-based employment, or accepting roles they would not otherwise have chosen. For example, a woman described having to sacrifice a higher income for the sake of more job flexibility: *"Now I work full time in a job that barely pays over minimum wage, but it allows me flexibility to still go to doctor/school appts when I need to, which seems to be several times a month".*

On the other hand, some women saw becoming a mother as positive in relation to career development. For example, a woman described how being on the spectrum and a mother to a child with autism helped her to succeed in her job at a school for special-need children: *"I have children of my own on the spectrum, I understand where the kids are coming from, and they seem to know that I'm one of them too".* Others found that motherhood boosted their self-confidence and determination to provide their children with positive role models, either through returning to education or pursuing a career.

Factors that women found conducive to successful work-family balance

The threads revealed how women with autism strive to achieve balance in various aspects of life. For them *"finding balance seems to be the key to a happy life: balance between work and life, balance between intervening/steering vs. backing off, balancing between friendly and advocative".*

In many threads, women shared their perspectives and experiences on the factors that influence successful work-family balance. An overarching theme was the role of supportive others in both work and family domains. Women frequently acknowledged the crucial role of supportive supervisors and family-friendly workplace management that understand and accommodate their needs: "*I have a very flexible boss who allows me to adjust my schedule as I need to. Sometimes, if the kids are out of school and my ILs [Independent Living Service workers] are not available but I have to be in the office for client meetings, I just bring the kids with me. So [having a] flexible job that can be done from home when needed is key to my survival*". In the home domain, a supportive partner who provides emotional or instrumental support was thought to be important for achieving balance. A woman explained: "*I have two kids and a full-time job, so I can relate to being stressed out. My husband is really good about giving me "me" time when he's home, during which I read books or play video games. I'm pretty lucky in that way*".

Another theme focused on the role of reliable, affordable and accessible day services: "*I think that both parents working seems to be successful if you are dealing with an Aspi (rather than classic autism), you can afford top-notch childcare, and you have a great school providing you with support*".

4.5.3 The influence of gender variance on women's experiences of work-family interface

The analysis revealed that women's identification with gender roles and expectations was an important factor in shaping work-family experiences. Rather than assuming gender

homogeneity among women, the analysis showed that different gendered practices, that is different way of negotiating work family interface, were linked to different gender identities among mothers.

Many women expressed their discomfort with the stereotypical roles, behaviors, and activities associated with their sex. One forum participant commented on the ideological constructs of femininity: "*For me, it is something bad. It is like a contract which was signed before my birth between my parents and society about my responsibilities and rights... and I never got to read it or have a say about it in the least. I wish I could step out of it*".

Some women explicitly referenced the 'extreme male brain' theory of autism (Baron-Cohen, 2002) and identified themselves as having masculine characteristics. They recalled personal histories of not adhering to gender expectations with respect to female interests and identifying more with the men in their lives. A woman described: *"I also tend to have the "male mind" of Simon-Cohen. I tend to hang out with guys discussing things like weightlifting and soccer and computers instead of with women discussing well, whatever they discuss. I really think a lot of NT females are catty, shallow, and self-centric. They also like to gossip all the time and keep drama going. I don't have time for all that mess"*.

Significantly, women who saw themselves as masculine often sought work/family balance through role-reversal with "caring" partners. They reported many accounts of being the bread-winners for a stay-at-home husband. One woman commented: "*My husband and I have the reversed roles. He stays at home and raises the kids while I work... I think a lot of time we might have found the right balance. We have the same values, raising our kids*". Another forum

participant elaborated: "*U just described me. Female with AS [autism] living in a male world (R &D, engineering, sailboat racing, skiing, dog training). I am lucky that I earn enough to support a partner who does the traditional stuff for me. I am also lucky that I found him in the first place*".

This type of gendered role-reversal was also mentioned by stay-at-home 'masculine mothers' with husbands taking responsibilities for, or sharing, traditionally feminine tasks. One woman commented: "*Definitely. I am a stay at home mom but not a typical one (lol). I prefer to study science with my son and discuss history with my daughter than bake cookies...I used to think that my husband make a better mom to the kids than I do whereas I would have make a better dad*". They frequently reported missing the "caring instinct" that makes them enjoy caring for their loved ones. A woman commented: "*I personally have taken care of kids, men, and my mom when she was dying, but I never got any pleasure from it. It was just a duty on my plate that I did out of love, but it's always been anything but pleasurable. It's just something that takes time away from my interests. I think perhaps I'm just a masculine woman*".

However, other women firmly rejected Cohen's theory and identified themselves as feminine and enjoyed being "*super caring and emotional*". These forum participants positioned themselves as 'female carers' whose identities were closely bound up with their families. In negotiating the tensions between work and family domains, they were more likely to take time out of the labor market or arranged their paid work around their family life. For example, one woman described: "*When you sit there with your infant in your lap trying to decide who is going to work full time, and you know that infant prefers being with mommy, mommy is going to be*

the one to cut back on work: you do what you believe your CHILD wants: He wants mommy. No daycare, no grandmother, no dad: mommy".

Data also highlighted the intersection of gender and class. Some working-class women, although they embraced a traditional feminine identity, noted the practical need for employment in order to sustain their family. Their plans were influenced by financial resources and the availability of support. For example, a mother who worked full-time in a low paying job while caring for children with autism noted: "*I hate the amount of time I spend outside the house, but really, there aren't a lot of other options. I work or we starve... we live in a very economically depressed area and got basically zero autism support".*

4.5.4 The influence of disability self-care on women's experiences of the work-family interface

The analysis revealed that women with autism adopted two main self-care strategies to overcome stress and anxiety associated with their roles in the home and work domains: having calming time pace and engagement in special interests.

Calming time and space

Most women talked about an ongoing need for alone time to avoid the adverse impacts of daily stress at home and work: *"I still have "meltdowns" occasionally, but I've learned to tell my child to give me a minute, and then I go into another room until I'm calm if we're at home, or we go take a "quiet time" break in the car or a bathroom if we're in public".* A woman described

how she spends the time alone: "*To recharge, I shut my systems down (i.e. eyes close, body limps). My mind is blank and black (as my eyes are closed and I am not using my brain). I lay there till I feel better or until I fall asleep*".

They highlighted the importance of prioritizing time for self-care, as one mother argued: "*In general, I think as an autistic parent you really must watch out for overload and take care of yourself, giving yourself the quiet time you need and get over the idea that this is selfish somehow*".

The data also revealed that women varied in the way they experienced "me-time". While some forum participants said they needed a few hours to "recharge" after socialization or sensory overload, others reported the need for a much longer time. A woman described how she felt about this: "*I have a need for alone time that is really hard to satisfy. I feel guilty about how much I need and how it seems like it is never enough*". While some reported that need to be completely away from people, others said that they just need to avoid interaction; a woman described: "*I am at the level where i can recharge amongst other people, almost as if i was NT, although that recharge is very slow and only works with certain people*".

Some forum participants also described how an intense need for me-time might impact their work-life in ways that others would not understand. For example, a woman noted: "*Yes, which is why I can only work part-time. But nobody understands me when I say this. People just say ''nobody likes working full-time but some of us haven't got the choice''. I know that is true* but needing alone time isn't always the same as wanting". Others found work that provides the

required personal time *"I do like to be alone sometimes and am going to incorporate it into my workday. I am alone all day because I clean houses for a living"*.

The need for a private space stemmed from women's need to relax from camouflaging or masking their autism, which is mentally and emotionally exhausting and to express the real self. A woman posted: "*I need privacy to be my freakish self, I hate having to watch what I'm doing all the time so my autistic traits or my trans-ness is kept hidden. I don't want other people watching, judging, commenting*". Private space was also sought to provide control over the level of interaction with others, as well as the level of sensory stimulation.

Women described how the required personal spaces could be dynamic as a response to the mental state: *"When I'm angry/upset, my personal space grows to the size of my bedroom or backyard. And I have a big backyard. Then there are times when I don't mind if people come closer to me"*.

Women expressed how this self-care strategy may impact their choices in both home and work domains. One woman said: *"I sometimes dream of being married again, but that would mean no space to myself again! Unless we could build a house with separate sections"*. Another commented: *"I think if I'd had to share a bedroom I wouldn't have gone to university in the first place. I can't think of anything worse"*. The need for personal space was also cited in the workplace environment: "*Open plan offices have really sabotaged my work life....What destroys me is having to have my social skills on 'standby' all the time. And yeah, I hate people walking behind me too"*.

Special interests

Special interests (SI) form part of the core feature of autism. This theme discusses the meanings and importance of special interests for women with autism, types of SI, how they evolve, and their interface with both home and work domains. Women shared some areas of their obsession such as: programming, video games, T.V shows, mythology, music, creative activities, animals and autism. While many of these interests could seem quite normal and similar to those of NT people, members were quite aware of the differences: *"I think what makes hobbies different for NTs is that they don't obsess over their favorite subject 24/7 like we do".*

Women emphasized the significance of SI as part of their identity "*My special interests ARE me"*. They believed that being obsessed with a favorite topic is part of restrictive and repetitive behaviors that characterizes autism. A woman stated: *"If I were to fight my special interests, I wouldn't be celebrating my autism, and I'd also be very miserable".* This intense attachment with their SI was compared by one member to "the bonding of a mother with her baby". Another commented: *"I liken it to that crazy limerence in the honeymoon phase of dating".* One woman explained how this inevitable bond has shaped her perceptions: *"The entire world becomes viewed through your special interests"*. Another stated: *"Most of the things I should be doing (obtaining food aside) are related to my special interest…Everything else, I build into my routine".*

Forum members expressed the importance of SI to their mental health and wellbeing. One women said *"When I'm depressed or stressed out, I throw myself even deeper into my*

obsessions because they help me cope better". Others looked as SI as *"form of escape"*, *"buffer against a bad mode"*, and "important to sanity sometimes" Also, most women believed that SI played a crucial role in their social lives. They frequently reported that it mediated social interaction and friendship: *"All my closest friendships have been based around shared special interests"*. It was a base for some serious relationships: *"I got to know my husband because of my special interest as we share it"*.

Women discussed how special interests are part of their every-day life. They frequently reported an intense engagement with their SI to an extent that could be physically and mentally draining, a woman posted: *"I've talked about mine for six hours straight today, and have been thinking about it for eight hours more, and I am so exhausted and my chest and back hurt and I want to cry"*. It was evident that the high intensity of engagement can impact negatively on women's wellbeing in the family domain. Women posted: *"It can actually ruin one's everyday life and one's life in the long term"*, *"they interface with the ability to lead an independent existence. Billing goes unpaid, health is neglected, hygiene is neglected, etc."*. For some, it provoked a feeling of guilt for the time spent. SI also interfaced with the work domain. Some women described how SI affected their performance at work: *"I got in trouble at my job for doing my special interest at work"* while hindering others finding one: *"I spend far more time playing guitar and drums than I do look for a job"*.

Forum participants looked at converting their SI into a career as an opportunity to overcome their employment challenges. They recalled shared personal stories of SI as a unique advantage. For example, a woman described: *"I turned my hobby and obsession into my job… I*

have much easier time advancing my career than others, I easily beat competitors, not necessarily because I am more skilled, but primarily because I am more dedicated to it and invest huge amount of time".

However, the data also revealed that fitting SI into work-life could be challenging and may not necessarily lead to a successful career. Some women recorded losing motivation toward their special interests for many reasons such as undergoing a period of depression, the interest reached a high level of complexity, the emergence of another interest, or the feeling that there was no more information to acquire. For example, one woman described why she abandoned a promising career as a writer: *"once I realized no more progress/insight could be reached or I felt confused because of the uncertainty I gave away all my books and threw my articles away".* Others felt that the enjoyment of spending time in their SI overrode the motivation to progress in a career. A woman described: *"I made my last SI my job and it's ballet. It's for 18 years now but I never had a "career" because I simply love the routine of doing training more than the competition of getting a job…I cannot connect with the other dancers because they see it merely as a job".* Also, some women were afraid that their SI might lose the calming effect if adapted into a full-time job. A woman argued: *"it turns something fun into work and at the end of the day, your hobby might not relax you anymore; you might not enjoy the work and feel bad because you think you should".*

With the high level of engagement with SI, converting SI into a job may impact negatively on the family life. For example, a woman who developed her obsession in programming into a home-based business described: *"this is where AS rears its ugly head - I*

can't do it unless I can focus on it obsessively, to the exclusion of almost all else. In fact, it is so hard for me to switch gears, pulling myself away is just too painful once I get absorbed. I know I'd just "disappear" as he puts it and it would lead to more fights".

4.6 Discussion

The findings of this research contribute to our understanding of the life experiences of mothers with autism. In particular, this study is among the first to specifically consider the work-family balance of this group, thus offering insights about a population of workers that are largely absent from the literature. The findings also have important implications for improving the domestic experiences of women with autism as mothers and home keepers.

The study revealed how being on the spectrum impacted women's capacity to perform their domestic roles. Many forum participants reported struggling with the day-to-day parenting tasks that require social communication with schools, medical services, as well as other mothers. This challenge is intimidating as it interferes with mothers' ability to advocate for their children, particularly those with autism, at services, and in social situations. Social deficits also make it difficult for mothers with autism to teach their children basic social skills or to act as social role models. Some mothers recognized the benefit of attending weekly family social support groups for increasing social interaction for them and their children. Others called for services that facilitate interaction with other autistic mothers for social support and validation. This resonates with the findings of a recent systematic review (Atkinson-Jones and

Hewitt, 2018) which provided consistent evidence for the effectiveness of social skills groups in reducing social impairments and increasing social interaction for adults with ASD.

The findings also showed how autism impacted their roles as homemakers responsible for creating structure within the home environment. Problems with executive functions such as working memory, planning and organization, task initiation, and attention resulted in struggles with daily chores and house management tasks that appear to come easily for neurotypical women. While these domestic challenges in the context of autism have rarely been addressed in the literature, similar experiences have been described among women with other developmental disabilities (Smyth et al., 2015). The findings also suggest that some women may also experience Pathological Demand Avoidance, a subgroup within the Autism Spectrum Disorder that has been rarely cited in qualitative research, which makes them stressed by even simple everyday chores and attempt to avoid these to a remarkable extent (Gillberg et al., 2015). The findings suggested that service providers should consider offering practical housekeeping support similar to what is offered to seniors. Women with autism may also benefit from structured parental coaching services.

Motherhood and domestic roles also bring additional challenges to women's health and wellbeing. Consistent with Gradner et al. (2016) and Roger et al. (2018), the study confirmed the amplification of autism-related sensory challenges due to hormonal change during pregnancy and shortly after giving birth. Living with the noise, mess, smell, and chaos of children extends mothers' sensory challenges in the home domain and leads to sensory overload. Recent literature provided evidence that physical elements of the home environment

can be designed or modified to alleviate sensory challenges associated with autism (Nagib & Williams 2017, 2018; Owen & McCann, 2018). While these efforts focused only on the needs of children with autism, future studies should address creating an autism-friendly home environment that also accommodates the needs of mothers.

Experiences of sensory overload and the need for a long period of "me time" to "cool down" often conflict with children's needs. On the other hand, suppressing their own needs could also lead women to burn out. This, and other autism-related limitations, often leaves mothers with feelings of depression, guilt, low self-confidence and inadequacy that in turn, contribute to increasing mental health difficulties. Reinforcing the findings of recent research on the wellness of women with autism (Tint et al., 2018; Baldwil & Costley, 2015), the current study emphasizes the need for specialized counseling and social support services that are attuned to the needs of mothers with autism.

At the same time, life histories of feeling different, isolated, and being stigmatized, often cause women with autism to refrain from seeking any help even from family members to avoid their parental capacity being questioned. Consistent research evidence (Surmen et al., 2015; Taylor & Marrable, 2011) suggested that increasing awareness and understanding of autism in a way that emphasizes difference rather than deficit can reduce prejudice and encourage individuals with autism to express their needs.

The worry of being misunderstood by powerful professionals also discourages mothers from disclosing their challenges in parenting and, therefore, benefit from available services. Consistent with frequently cited experiences of mothers with other disabilities (National

Council on Disability, 2012), some mothers reported fearing that being misunderstood may lead to losing custody over their children. Evidence (Pohl et al., 2016) showed that 1 in 6 mothers with autism in the UK who were assessed by social services had their children placed for adoption on compulsory basis. An environment of trust may be readily established if professionals are knowledgeable and well-trained to serve mothers with autism, and if mothers are empowered to advocate for their needs and rights (Kai & Crosland, 2001).

In this study, many women expressed positive views of motherhood and unique relationships with their children as giving them a sense of acceptance and appreciation, a purpose in life, and also spurred them to confront autism-related deficits. In contrast to neurotypical mothers who often experience an initial feeling of desperation, and self-blame (Da Paz et al., 2018), mothers with autism were more accepting of having a child with autism. In addition, they empathized particularly with parental strengths including the ability to relate to and benefit from their own childhood experiences and being more capable of understanding the child's needs and behaviors and facilitating the communication between the child and the neurotypical world. This is in contrast with previous research which doubted the mothers' understanding of children's cues (Gardner et al., 2016). These findings reinforce the recent movement toward a strength-based approach for service providing that focuses more on internal strength, resourcefulness, and areas of competence, and less on shortcomings and weakness. Recent literature found this approach to be a promising avenue for enhancing parent-child interaction, facilitating parental well-being, and assisting parents in coping with the variety of chronic stress associated with raising a child with autism (Steiner, 2011). While the

focus was on neurotypical parents, further research in the case of mothers with autism is needed.

There were several ways in which domestic responsibilities affected the work lives of women with autism. The overarching observation was the experience of career disruption because of their role as primary caregivers of their children with autism. Forum participants frequently reported being unable to remain in employment. This is consistent with the experience of almost 60% of neurotypical mothers of children with autism (Baker & Drapela, 2010). The commonly cited reasons by both groups were the labor-intensive nature of parenting a child with autism and the lack of affordable quality schools and services (Stoner et al., 2016). Both groups also experienced career adjustment toward more time-flexible jobs to meet parenting demands. Adjustments included shifting to part-time, home-based employment, or accepting underemployment. However, the findings also revealed unique ways in which being on the spectrum was thought to render the experience of 'juggling' motherhood and work lives. First, mothers with autism may decide to relinquish employment due to the amplification of autism-related traits and mental health problems associated with parenting stress. Second, due to parenting demands, they may experience a reduction in work performance as a result of losing old coping strategies at work: the extra time they once had in the evening and weekends to make up for being slow due to autism-related deficiencies. This suggests that vocational rehabilitation specialists should tailor their practices to support mothers with autism overcoming their specific challenges.

A strength of this study is its contribution to understanding how the experiences of women with autism in negotiating the interface between work and family domains are influenced by the way they position themselves in relation to femininity and masculinity. As such, the study responds to recent calls in the literature for prioritizing the voices of women who are members of both the autism and gender diverse communities and exploring their experiences through qualitative evidence (Cooper et al., 2018; Kanfiszer et al., 2017). Consistent with the literature (Baron-Cohen, 2002; Cooper et al., 2018), many women identified themselves as having masculine characteristics and recalled personal histories of not adhering to traditional gender expectations. The study also revealed the following key findings: First, women who identified themselves as being 'masculine' presented a range of non-traditional responses to work and domestic roles starting from performing the masculine bread-winner and striving to find a stay-at-home partner who takes care of complete 'feminine' domestic responsibilities, to being the "stay-at-home" wife with an untraditional division of domestic labor. This suggests that achieving a balance between work and domestic roles requires finding a compatible partner on the masculinity/femininity spectrum (Kachel et al., 2016). Second, in contrast to Baron-Cohen (2002), many women with autism identified themselves as 'feminine' and firmly rejected Cohen's "extreme male-brain theory". They enjoyed the traditional gender roles and arranged their paid work around their family life. Finally, the study pointed to the importance of socio-economic position when considering the interface between work and family domains. Consistent with Emslie and Hunt (2009), the study identified a group of 'pragmatic' working-class women with a traditional feminine identity who

realized the practical need for employment in order to sustain their family. For this group, securing sufficient income is a more pressing concern than balancing work and family life.

A key finding of this study is that it provided evidence that the intense engagement in special interests may hinder the quality of life and well-being of women with autism in both the home and work domains. This is contrary to the notion proposed by Grove et al., (2018) that special interests had positive impacts rather than obstacles to functioning. The study also extended the current literature on using the special interest to increase the employability of individuals with autism (Koenig & Williams, 2017; Kirchner & Dziobek, 2014). While literature frequently reported the advantages of converting their special interests into jobs, little was mentioned about associated challenges (Goldfarb et al., 2019). The results of the current study reported cases of negative outcomes due to losing motivation in the special interest and the emergence of new interests. This is in contrast to Turner-Brown et al. (2011) who argued that special interest is in some way circumscribed or inflexible. The results also suggested that motivation toward special interest could be driven predominantly by the enjoyment and pleasure of engaging in the activity while missing the goal-oriented and competition-driven aspects required for vocational success. This is somehow in line with the finding of recent research that intrinsic factors play a more important role than extrinsic factors in the motivation to engage in special interests (Grove et al., 2018). Overall, the results of the current study suggest that there is a need for further research and clinical efforts to address the motivational problems associated with engaging special interest in the work domain with the goal of improving vocational success, long-term stability, and well-being.

In conclusion, the work-family balance of women with autism is the result of the interplay between various factors related to role-related identity, gender identity, and disability identity. It is, therefore, should be perceived as a personal issue to be dealt with using individual strategies that suit one's needs, characteristics, and opportunities and not merely as a structural problem caused by lack of job flexibility or lack of affordable child care. Further research should concentrate on the work-family balance of women from different economic classes, marital status, levels of workplace responsibilities, occupations, ages, and geographical locations.

4.7 Limitations of Study

There are some limitations to this study. First, one limitation of collecting data from online forums is that there is no way to verify the diagnosis or posters' profiles reported on the forum. However, research on internet forum user-profiles concluded that most users accurately describe themselves online (Back et al. 2010). Another limitation is that, as argued by Jordan and Caldwell-Harris (2012), WrongPlanet.net members most likely are on the high-functioning end of the spectrum. The findings are thus primarily generalizable only to this group rather than the entire autism community. Also, as noted by Finfgeld (2000), some populations may have little to low access to forums due to a lack of equipment and skills. Members also tend to contribute only to the threads of their interests. Therefore, unlike other qualitative data sources (such as interviews). It is difficult to acquire the perspective of each individual participant with respect to every area under investigation. Finally, this study focuses on

mothers with autism, and therefore, the work-family experiences of single women are not addressed.

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Chapter Five

Conclusion

People with Autism Spectrum Disorder (ASD) constitute the fastest-growing developmental disability population in North America, yet their employment outcomes are significantly poorer than both the larger disabled and non-disabled populations (Townsley et al., 2014). However, the complex relationship between employment and gender in the context of autism remains under-researched. The breadth of the chapters in this doctoral research contributes to our understanding of the role of gender in shaping the experiences of adults with autism in securing and maintaining employment and how they negotiate the interface of work and family demands.

In so doing, the research bridges gaps in the literature and contributes to informing policy and service provision that can be used to support this population better. This final chapter highlights the methodological, theoretical, and substantive contributions of the research. It then discusses the limitations of this research and directions for future studies.

5.1 Methodological Contribution

This thesis contributes to an emerging field of qualitative research that relies on data from internet forums as analysis material. Therefore, a secondary objective of the study was to

examine the strengths and challenges that accompany this relatively novel approach and examine its validity for future research on similar topics.

Consistent with strengths identified in previous literature, the online forum used in this research offered access to a large number of prospective participants from a hard-to-reach group who are often described in research as excluded (Jamison et al., 2018). This allowed for exploration of the employment experiences of 507 participants (Chapter two and three), which exceeded the sample size of any study included in related systematic reviews and thus increased the generalizability of the findings (Lindsay et al., 2019; Hayward et al., 2016). The forum made it possible to reach a large number of women and to balance the number of both male and female participants, overcoming frequently cited barriers to examine the role of gender in life experience (Lindsay et al., 2019; Halladay et al., 2015). In this way, the research also responded to Haney and Cullen's (2017) call to "expand qualitative analysis of online discussion forums to examine female-specific themes" (p. 69).

Like most internet forums, Wrongplanet.net is hierarchically structured. Hence, it was comparatively easy to find, select, and sample discussion boards relevant to the research questions. In a sense, discussion boards constitute a kind of unmoderated 'virtual focus group' (Holtz et al., 2012), in which members discuss matters of their concern without the researcher interfering or influencing the expression of thoughts. Hence material from the forum can be considered as 'natural voices', representing a proxy for 'everyday discourses' within the online autism community. Relying on such material enables this research to respond to the increasing

calls to incorporate the voices of people with autism into research (Kanfiszer et al., 2017; Webster & Garvis, 2016; Bölte, 2014).

Much like focus groups, the cross-communication between members on a thread's topic provokes new and even more detailed responses and adds depth to the themes in qualitative research. With the relative anonymity of the internet and the absence of anxiety associated with face-to-face interaction, individuals with autism may be willing to express personal opinions, recount difficult experiences, and discuss sensitive issues more freely than in traditional qualitative research settings (Holtz et al., 2012). Consistent with research on online stroke forums (Jamison et al., 2017), this research provided evidence that data from online autism forums may provide additional insights. For example, a recent survey by Grove et al. (2018) did not provide evidence that special interest may hinder the quality of life for adults with autism. The authors suggested that other research methods may be needed. Through forum analysis, this research (chapter four) was able to demonstrate empirically the negative impact of intense engagement in special interests on the life functioning of women with autism.

Another advantage of online data is that the material already exists in digital format. This eliminated the need for the labor-intensive procedures like the transcription of audio material and the associated potential for ambiguity or distortion of participant views. Also, the public accessibility of the analysis material makes it possible for other researchers to retrace the analysis process, from sampling to the final analysis and reappraise the researchers' findings. This adds more transparency to analysis than is usually achieved in qualitative research (Holtz et al., 2012).

This research found qualitative analysis software to be invaluable for the purpose of analyzing online forums and managing the issues associated with data overload. Nvivo 11 for Windows (QSR international, 2015) provided a useful platform for capturing, organizing, and analyzing a large data set of over six thousand posts. The sample threads were collected using the NCapture facility. With this tool, it was possible to store threads in their original format (as PDF files), so that the idiosyncrasies of interaction in the online context would not be lost. The posts have been organized as 'cases' where the posters' profiles (age, gender, occupation) were stored. After entering the codes as nodes, the data query functions were used to facilitate the analysis.

On the other hand, the use of online forums as a data source may raise potential concerns around anonymity, privacy, confidentiality, and informed consent compared with the more traditional qualitative approaches. Whereas the relative anonymity of the internet is an advantage as it reduces the social constraints associated with autism, it remains difficult to verify participant identity and diagnosis. However, previous research has provided evidence that personal information and diagnosis reported via online registers are reliable (Lee et al., 2010; Back et al., 2010).

From an ethical perspective, using data from an online forum may raise a concern of whether communication in the forum is private and therefore, informed consent of the users is required. However, there is consensus in the literature that open access forums such as WorngPlanet.net, which can be read by everyone without the need for registration or a password, can be considered as public domain and therefore data can be used without asking

for informed consent from forum participants (Hanna & Gough, 2017; Jordan & Harris, 2012; Seale et al., 2010). As the forum administration reserves copyright on all posted material, the researcher did contact the moderator and received his consent to use the textual data. At the university level, the study was deemed not to involve human subjects as no interaction occurred between the researchers and the forum posters; it was thus exempted from further review by McMaster University Research Ethics Board.

Overall, this research demonstrated that an online autism forum can be considered a trustworthy source of data for qualitative research on employment and gender issues and may represent an important adjunct to traditional qualitative data collection methodologies. However, this method also came with a few limitations that will be discussed in the limitation section of this chapter.

5.2 Theoretical Contribution

There are two major theoretical contributions to this research. First, the research extended Clark's ***work/family border theory*** by integrating both gender and disability identities into the theory in the context of autism. While Clark's border theory considers identity in terms of the various roles a person plays in work and family domains, it does not address the integration of other identities such as gender, disability, racial identities or sexual orientations, a limitation that Ozbilgin et al. (2011) observed in the work-life literature more generally. Emslie and Hunt (2009) described the theory as "gender-blind" and argued that that gender is both central to any discussion about work-family intersection and embedded in the ways that

workers negotiate home and work life. Their research integrated gender into Clark's work/family border theory to explore the ways men and women in mid-life negotiate work/family interface. Cook and Shinew (2014) extended Clark's theory in the context of physical disability. To this end, this research is the first to bring disability and gender identities together. By doing so, the research responded to Cook and Shinew's (2014) call for work to address the "intersection of disability with other identities and the impact of intersecting identities on work-life management" (p. 435). Further, by addressing the work/family interface in the context of autism, this research also responded to Cook and Shinew's (2014) call for "more research about work-life negotiations of individuals with all types of disabilities" (p. 435).

The findings of this research provide support to Clark's border theory but also suggest some ways to extend it. Three key concepts of border theory were particularly useful in conceptualizing the roles of both gender variance' and 'disability self-care' in the work-family interface for women with autism: "central participation", "border keepers", and "border blending". Women with autism as 'central participants' in either work or home domains were influenced by the way they position themselves on the feminine/masculine spectrum. Masculine women strongly identified with the work domain and hence were 'central participants' of this domain. As suggested by Clark's border theory, being 'central participants' in the work domain meant that masculine women were more likely to have a stable career.

The research also supports Clark's notation regarding the role of 'border keepers', such as husbands and supervisors, in defining the domain rules and therefore influencing women's work/family experience. However, the research findings also suggested that masculine women

may exercise significant agency in shaping their family domain by choosing a feminine 'border keeper' (husband) who accepts a gendered role reversal. This extent of commitment to the work domain and control over the family domain has not been observed by Clark (2000) or Emslie and Hunt (2009).

The findings also support Cook and Shinew's (2014) extension of the border theory which suggested that 'disability self-care' represents a third life domain, which considerably influences both work and family domains. The degree of permeability of both work and family domains to accommodate disability self-care issues was critical to the work-family negotiation of women with autism. This research extended the knowledge of disability interaction with border theory in two ways: First, the findings added to our understanding of the main elements that characterize the self-care domain in the context of autism: calming time, me-space, and special interests. Second, the findings suggested that the border of the self-care domain may expand and 'blend' with the other domains in a way that impacts the quality of life and well-being of women with autism. For example, intense engagement in special interests for long hours may 'blend' the temporal borders between self-care and family domains and hence negatively influence the well-being of women with autism. On the other hand, converting special interests into jobs, which 'blends' the temporal and physical borders with the work domain, may benefit women with autism.

The second theoretical contribution involves incorporating the ***stages of considering the work conceptual model*** into an exploration of the role of gender in employment experiences among individuals with autism (Goldblum & Kohlenberg, 2001). This theoretical framework

helped us better understand the relationship between interest in work among individuals with autism and the actual practice of finding and maintaining employment. The results underscore the importance of assessing each of the work stages individually, to help better understand the factors that may pose the greatest challenge for individuals with autism to engage in employment. The ability to break the complex employment process into discrete stages of assessment can help guide vocational specialists to evaluate the barriers and facilitators of employment in each of the stages. This will better inform the selection of targeted resources, policies, and interventions for each specific stage.

5.3 Substantive contribution

Chapters two and three respond to calls in recent literature for further studies, particularly qualitative, to examine gender differences in employment experiences among individuals with disabilities and to identify gender-specific needs and supports. (Lindsay et al., 2019; Lindsay et al., 2018; Hayward et al., 2016; Sung et al., 2015).

The first substantive chapter (chapter two) contributed to the literature by extending our knowledge of the career exploration and job-seeking experiences of women and men with ASD through the content analysis of an online forum. The study drew upon the stages of considering work to unpack factors affecting career decision making-process of adults with ASD (Goldblum & Kohlenberg, 2001). Results revealed several similarities and some differences between women and men with ASD as they navigate the contemplation, preparation, and action stages of considering employment. Factors such as low self-esteem, negative past

experiences, sense of scarce opportunities in the local labor market, fear of losing disability

benefits and parental overprotection may hinder both genders from contemplating

employment as a life goal. The study also found that other people, while academically qualified,

decided not to join the labor market as they found it difficult to see employment as a path for

self-satisfaction. Barriers to defining career goals included an absence of ASD-specific career-

matching tools, employers' perceptions of ASD stereotypical jobs, and lack of self-employment

support. Women were further limited by stereotypical yet socially challenging female jobs.

Overly specific job descriptions, lack of social networks, transportation barriers, and

discriminatory personality tests, were cited by both genders as barriers to job accessibility.

While women reported more unfavorable experiences with employment support services, men

identified more difficulties with job applications and interviews. This chapter offered the

following recommendations for vocational specialists and clinicians supporting employment

goals?: 1) to acquire necessary training to assist young adults with ASD in overcoming the

mental health issues, which lead them to "give up" finding employment; 2) to provide resources

that address workplace experiences and success stories of employees with ASD across various

employment sectors; 3) to provide online ASD-tailored career-matching tests and tools to assist

people in making career choices; 4) to reduce gender inequality in employment outcomes by

supporting the engagement of women with ASD into non-traditional and highly employable

disciplines, such as STEM, and provide them with examples of successful female role models; 5)

to support early diagnosis of women in order to reduce the risk of making unfavorable career

decisions; and 6) to promote self-employment programs for individuals with ASD. Service

providers should empower clients through negotiation and self-advocacy, promoting ASD-

focused programs, and reduce the paperwork and time involved in the vocational rehabilitation service process.

The second substantive chapter (chapter three) extends our understanding of the gender-based differences among employed adults with autism regarding the challenges they face in the workplace. The results revealed eight related barriers with some noticeable gender differences. Workplace stress, the top reported barrier, was more often reported by women, who also reported higher incidences of psychological impacts such as panic attacks, meltdowns, and emotional distress. Women also expressed greater social challenges, particularly those who engaged in socially demanding jobs. Additionally, women were disadvantaged by gendered workplace expectations, especially about appearance. Women posters reported communication-related barriers and the fear of requesting accommodations at a higher frequency than men posters. Men posters conveyed more hardship in different aspects of executive functions and in making disclosure decisions. The views and experiences of this sample of posters within the ASD community, as presented in this chapter, shed light on general characters and behaviors of organizations and business management that help to accommodate the unique needs of employees with ASD. These include: 1) being understanding of the particular characteristics of ASD, anti-stigma, and counter stereotyping; 2) being flexible and adjusting to their varying needs; 3) providing direct communication and clear instructions; 4) providing structure and predictable environment; 5) being willing to provide continuous support; and finally, 6) less stressful work environments should avoid micromanagement, be more open and communicative especially about restructuring, and give the employees more control over their work conditions.

Chapter four extended our understanding of the domestic experiences of women with ASD as mothers, housekeepers, and caregivers, and provided one of the first research efforts to explore how women with ASD negotiate the interface of work and family demands. By doing so, this chapter responded to many calls in recent literature. First, it responded to a call by a recent Canadian study (Tint et al., 2018) to bridge the gap in current autism research related to understanding women's experiences of motherhood and their perceptions of parenting and caregiving. Second, it responded to Cook and Shinew's (2014) call for "more research about work-life negotiations of individuals with all types of disabilities" (p. 435). Third, a significant contribution was addressing the work-family experiences of women with different positions on the masculinity/ femininity spectrum. This responded to recent calls in the literature for prioritizing the voices of women who are members of both the autism and gender diverse communities and exploring their experiences through qualitative evidence (Cooper et al., 2018; Kanfiszer et al., 2017).

The findings revealed the impacts of the autism-related social communication and executive function challenges on women's roles as mothers and housekeepers. A significant finding that has been rarely cited in qualitative research was the potential impact of Pathological Demand Avoidance, a sub-category within Autism Spectrum Disorder (Newson et al., 2003)., which makes them stressed by even simple everyday chores. Domestic roles may bring additional challenges to women's physical and mental health including the amplification of autism-related sensory challenges, in addition to feelings of depression, guilt, low self-confidence, and inadequacy. The fear of their parental capacity being questioned which may lead to losing custody over their children, may discourage women from disclosing their

challenges and seeking support. On the positive side, as carers to children with ASD, women were more able to relate to and benefit from their own childhood experiences and being more capable of understanding the child's needs. Due to domestic responsibilities, mothers with ASD experienced career disruption or adjustment for many reasons such as the labor-intensive nature of parenting a child with autism, lack of affordable quality schools and services, and the amplification of autism-related traits and mental health problems associated with parenting stress. Due to parenting demands, they may experience reduction in work performance as a result of losing extra time they once had in the evening and weekends to make up for being slow due to autism-related challenges. From a gender perspective, women who identified themselves as being 'masculine' presented a range of non-traditional responses to work and domestic roles starting with performing the masculine bread-winner for a stay-at-home 'feminine' partner to construct an untraditional division of domestic labor. By contrast, women who identified themselves as 'feminine' firmly rejected Baron-Cohen's (2002) "extreme male-brain theory" and arranged their paid work around the demands of family life.   However, for working-class feminine women securing sufficient income was a more pressing concern than balancing work and family life.

Disability self-care also impacted work-family experiences for women with autism. A significant contribution of this chapter was the presentation of empirical evidence that the intense engagement in special interests may negatively impact the quality of life and well-being of women with autism in both the home and work domains. The chapter also provided evidence on the motivational challenges associated with converting their autism special interests into jobs.

The chapter contributed the following recommendations for service providers to enhance the work-family experiences of women with autism: 1) to consider offering practical housekeeping support similar to what is offered to seniors and other disability groups; 2) to offer structured parental coaching service and social support groups that are attuned to the needs of mothers with autism; 3) to adopt strength-based approach for service provision that focuses more on internal strength, resourcefulness, and areas of competence, and less on shortcomings and weakness; 4) to establish an environment of trust that emphasizes difference rather than deficit, reduce prejudice, and empower mothers with autism to advocate for their needs and rights, and 5) to promote individualized work-family counseling strategies that suit one's needs, characteristics, and opportunities, rather than a unified a strategy that only focuses on providing job flexibility or affordable childcare.

5.4 Limitations

There are a number of limitations to this research. Analyzing the collected online data revealed the following limitations of the forum as a data source. First, the majority of forum members were mainly from North America and most likely are on the high-functioning end of the spectrum. The findings are thus representing the views of this sample rather than the entire autism community. Also, as noted by Finfgeld (2000), some populations may have little to low access to forums due to a lack of equipment and skills.

Further, the majority of the posters, especially the males, were relatively young (60% of the male posters were below the age of 30). Thus, the findings may connect more closely with the workplace experiences and needs of younger age groups

Counting the frequency and percentages of occurrence of codes as a proxy for the prevalence of particular employment experiences among the online community does not lead to a statistically significant result. However, as argued by Vaismoradi et al. (2013), this method is acceptable, given the exploratory nature of this research. The study of the work-family interface (chapter four) was limited to address the experiences of women with autism, which could be significantly different than their male peers. The study was also limited to exploring the intersection of gender and disability identities, while others, such as racial, cultural, and religious identities, may influence the work-family experience of individuals with ASD.

5.5 Future Research Direction

Through conducting and analyzing the current research, several ideas for future research have emerged. Many of these build from the needs and challenges voiced by members of a specific autism community, while others are related to the highlighted limitations and the theoretical frameworks. The autism community could also benefit from exploratory qualitative research that addresses workplace experiences of employees with ASD across different employment sectors. Further, research should focus on improving employment experiences in labor-intensive industries, such as retail and hospitality, where jobs can easily be found yet labeled by ASD online community as 'unfriendly' sectors. Future research should also

investigate ways to promote the engagement of women with ASD into male-dominated yet highly employable industries, such as STEM.

The current research also suggests avenues of future research to enhance the wellbeing of mothers with ASD. Recent literature found the strength-based approach for service providing to be promising for improving parent-child interaction, facilitating parental well-being, and assisting parents in coping with the variety of chronic stress associated with raising a child with autism (Steiner, 2011). While the focus was on neurotypical parents, further research in the case of mothers with autism is needed.

Recent literature provided evidence that physical elements of the home environment can be designed or modified to alleviate sensory challenges associated with autism (Nagib & Williams 2017, 2018; Owen & McCann, 2018). While these efforts focused only on the needs of children with autism, future studies should address creating an autism-friendly home environment that also accommodates the needs of mothers with ASD.

The findings of the current research also highlighted the need for further research to address the motivational problems associated with an engaging in special interest in the work domain to improve vocational success, long-term employment stability, and well-being.

There are many avenues to extend the methodological and theoretical sides of the current research. For example, to confirm the online forum as a reliable data source, it will also be interesting to compare the findings of the current research with those of future research addressing the same research questions and using traditional qualitative methods such as interviews or focus groups. Further, quantitative studies may provide additional verifications

for the prevalence of employment challenges among women and men with ASD as presented in chapters two and three. Such research should be based on surveying a large sample size with an equal number of participants from both genders. The findings of the current research may inform the survey design.

The current research addressed the work-family interface for women with autism. How men with autism negotiate the interface between work and family demand remains a gap in the literature. Further research should investigate the work-family balance of individuals with ASD from different economic classes, marital status, levels of workplace responsibilities, occupations, ages, and geographical locations. In addition to gender and disability identities, the theoretical framework for the current research can be extended to integrate other identities such as racial, cultural, and sexual orientations.

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APPENDIX A: McMaster Research Ethics Board Clearance

Fri, Feb 10, 2017, 10:19 AM

Szala Meneok, Karen <szalak@mcmaster.ca>
to me

Good morning Wasan, My apologies, I'm not sure what happened to my earlier response to you.   Please let me respond about your interest in accessing and analysing posts from the www.wrongplanet.net website. I understand from our conversation that you have a project that has two phases.

·   In Phase II, which is still in the design phase, you mentioned that you are considering research that would involve online surveys of persons who have been diagnosed with Autism Spectrum Disorder. We discussed your plan to submit an ethics application for those research activities. I'm happy to assist with that.

·   In Phase I, you want to start by analysing comments made on the public area of www.wrongplanet.net .

·   I understand that www.wrongplanet.net is a web community designed for individuals (and parents / professionals of those) with Autism, Asperger's Syndrome, ADHD, PDDs, and other neurological differences that provides a discussion forum, where members communicate with each other, an article section, with exclusive articles and how-to guides, a blogging feature etc.

·   You mentioned that www.wrongplanet.net has both open-discussion areas as well as some password and registration restricted discussion-lists. For restricted fora, there is a presumption of privacy on the part of people who post on them.   Therefore we discussed the fact that a researcher is obliged to obtain ethics clearance to access and use those comments for research purposes.

·   I understand that for Phase I of your research project, you want to <u>only analyse comments posted on the public fora</u> of www.wrongplanet.net   As these public comments are made using aliases and are posted in an area where anyone with internet access can see and read then making them publicly available.

·   If however, you wanted to link these public comments with other data sets there is a possibility that that linking could re-identify people who have made a post, and therefore you would need to contact the research ethics board to determine your next steps should you want to link data sets.

·   <mark>Thus if you only intend to analyse comments posted on the <u>public for a</u> of www.wrongplanet.net as outlined above then you do not require ethics clearance at this time.</mark>

·   If I have any of this information in error or it these details change, contact the McMaster Research Ethics Board for advice on how to proceed.
Best wishes for your interesting research project.

Cheers, Karen

APPENDIX B: Consent from the Moderator of WrongPlanet.net

Inbo›x

WASAN NAGIB <nagibwf@mcmaster.ca>

to alex

Hi Alex,

My name is Wasan Nagib, I am a PhD student at McMaster University, Ontario, Canada and a mother of a YOUNG boy with autism. I am writing to ask for your permission to use Wrong Planet forum's data in my PhD research.

My research focuses on paid employment for adults with autism. The forum's posts on employment would provide valuable insight on the employment-related issues and experiences that are a concern of people with autism.

While I plan to look at the content of posts, I will not use their usernames or any identifying information in my research and only public posts will be studied. The analyses would help to inform the design of an online survey in the second phase of my research, which looks at workplace experience, including challenges, coping mechanisms, required accommodation.

I have read the terms of service and intend to credit Wrong Planet as the source of data for my research.

Thank you and I look forward hearing from you. Please let me know you should require any additional information or if you have any questions.

Wasan Nagib

Alexander Plank <alex@alexplank.com>

Jan 31, 2017, 5:36 PM

to me

yeah that's fine

Alex

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