Exploring the Employment Experiences of Adults with Autism

by

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Abstract

There is room for increased exploration into the needs of adults with Autism Spectrum Disorder (ASD), specifically in the area of employment. This study explored the employment experiences of adults with ASD as perceived by both parents of adult children with ASD and adults with ASD. The qualitative data gained in this study highlighted a number of themes derived from interviews with parents of adult children with ASD and adults with ASD, themes including ‘Communication’, ‘Economic Considerations’, ‘Education’, ‘Consistency’, and ‘Barriers.’ These themes highlighted common issues experienced by parents of adult children with ASD and adults with ASD in Newfoundland and Labrador. Adults with ASD made many positive comments about their current employment situations and personal support systems. On the other hand most participants expressed dissatisfaction with autism related training programs, the education level and skill set of support workers and employers specifically tasked with providing employment support to adults with ASD, and the amount of funding available for quality programs. Further research should explore employers and support workers perspectives on this topic as well as transition programs to better inform ways to support individuals with autism in the workforce.

DEDICATION

In loving memory of my mother, Judy Cochrane (1951-2013), who taught me compassion for individuals of all abilities at a very young age. Her strength and tremendous work ethic as a psychiatric nurse and counsellor inspired me to embark on a career in the helping profession. I treasure every moment we shared and miss you every day.

To my daughter, Jesse, who has a vibrant and creative spirit and amazes me with her warmth and compassion every day. I love you.

To my husband, Mark who stands by me through all of my endeavours—you are a true support and my best friend.

To my father, Bill who always has 100% faith in anything I tackle.

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Chapter 1: Introduction

Research on adults with autism spectrum disorders (ASD) and life outcomes suggested employment is an area in need of detailed exploration (Gerhardt & Lanier, 2011; Nicholas, Attridge, Zwaigenbaum, & Clarke, 2015; Parsons, 2015). While there have been studies investigating life and employment outcomes through quantitative research approaches (Billstedt, Gillberg, & Gillberg, 2010), qualitative measures are rarely employed to highlight the employment experiences of adults with ASD. When it comes to adulthood and corresponding life outcomes, employment is a huge factor. The purpose of my research was to explore the employment experiences of adults with ASD using the perspectives of adults with ASD and their parents. What are the stories and experiences of these adults with ASD and parents of adult children with ASD? By giving adults with ASD and parents of adult children with ASD a voice, we can discern the strengths and needs within our provinces system that currently support (or could better support) adults with ASD and their parents.

To best represent this story a qualitative research design was used to explore participants experiences. This approach allowed participants to articulate their experiences with employment and tell their story in their own words (Creswell, 2007).

Some questions this research addressed were:

1) What employment services did individuals with ASD avail of?
2) What services are available to adults with ASD?
3) What are the main barriers to gaining and maintaining employment for adults with ASD?
4) What would help support employment for adults with ASD?
5) What are the career goals of adults with ASD?
6) What would be most helpful in preparing adults with ASD for the workforce?

Parsons (2015) conducted an online survey exploring the life satisfaction of 55 adults participants with ASD. Parsons (2015) noted "…respondents tend to be least satisfied with their current employment situation compared to other aspects of their lives" (p. 415). From this finding, Parsons (2015) urged for more research into employment accommodations and programing for adults with ASD.

Nicholas, Attridge, Zwaigenbaum, and Clarke (2015) completed a comprehensive review of research on job support programs for adults with ASD. The findings suggested studies should be replicated to ensure the viability of tested programs (Nicholas, Attridge, Zwaigenbaum, & Clarke, 2015). Reviewing employment challenges for adults with autism, Hendricks (2010) argued employment was a basic human right, further stating adults with ASD deserved equal opportunity for employment in their respective communities. Hendricks (2010) also spoke to the individuality of adults with ASD and argued that this individuality can be a barrier to employment as each individual needed a unique set of accommodations in the work environment. Hendricks (2010) further reported a trend of underemployed or unemployed individuals with ASD in their communities.

Hillier et al. (2007) evaluated a job support program for adults with autism using surveys and rating scales. This study also evaluated job satisfaction for adults with ASD 3 months, 6 months, and 1 year after commencing employment, noting that satisfaction would often decline with the passage of time. In their study Taylor and Mailick (2014) made a startling realization— as adults with ASD transition out of high school they are continually met with unsuccessful attempts to become gainfully employed. Over a 10 year span, Taylor and Mailick (2014) found that employment opportunities narrowed as participants aged.

In my experience with employment in Newfoundland and Labrador, I have worked with many individuals with ASD throughout the lifespan as a home therapist, teacher, Child Management Specialist (CMS), and Behaviour Management Specialist (BMS). As a new researcher in the Counselling Psychology Program I met with adults with ASD and/or their parents to hear their stories regarding employment. It is unsettling to know that in spite of all of the early intervention for children with ASD in our province, we fail to have solid systems in place for adults with ASD in the workplace. In my role as a BMS I was often left helping families in their search to find meaningful daily activities/employment for their adult children with ASD, with varying degrees of success. Once children with ASD reached the age of 9, early intervention programming was no longer available, and once high school graduation takes place adults with ASD no longer have a supportive educational community. What do adults with ASD do after high school? What have they experienced on the road to employment? I hoped to answer these questions through this research project.

Theoretical Framework: Social Model of Disability

I hoped to understand what the experience of employment is like for individuals with ASD from their own perspective and/or from the perspective of their parents. The social model of disability highlights the experience of persons with disabilities (Hughes, 2010; Oliver, 1983). Oliver (1983) stated we should look at "...the way the physical and social environments impose limitations on certain groups or categories of people" (p.23) rather than at the limitations of the particular disability. The Social Model aims to provide a new way for individuals with disabilities to be seen by society and the world of work. Individual and medical models of disability tend to focus on what the person *cannot* do, unlike the social model where the focus is on what the person *can* do (Oliver, 1983; Oliver, 2013). The social model of disability was written by individuals labelled as having a disability, giving this model a unique perspective. Oliver (1983) began his journey in developing this model in the early 80's while Levitt further expanded on its application and usefulness 30 years later (Oliver, 1983; Levitt, 2017).

Oliver (1983) formulated the social model of disability based on The Fundamental Principles of Disability (Union of Physically Impaired Against Segregation, 1976). Oliver (2013) suggested professionals in special education and other service areas use the social model to view individuals with disabilities in a more person centered way. The intention of the social model was to base relationships between those diagnosed and those not diagnosed with disabilities on strengths versus impairments. When individuals with disabilities experience barriers (such as a lack of access to programs and services), a sense of powerlessness and social isolation can be experienced by these individuals and their caregivers (Hughes, 2010). Biglan (2015) suggested that society help develop a nurturing environment that shapes positive contingencies for those labeled with disabilities, and work to remove barriers so that all persons have adequate access to services and employment.

In the social model of disability, the disability is not the defining feature; the person is (Durell, 2014; Hughes, 2010; Oliver, 2013). The social model highlights "…the structures and barriers that people experience" (Hughes, 2010, p. 509), and sheds light on the systemic denial of basic human rights such as choice and control to those labelled with a disability, since society has pre-set structures and services for these individuals (Oliver, 1983; Durell, 2014; Hughes, 2010). Durell (2014) further highlighted how society's view of disability shapes its reaction and treatment of those labelled as "disabled."

Levitt (2017) posited other barriers can be highlighted by this model, such as economic and environmental disadvantages. Levitt (2017) called for a contextual analysis of disability by country, maintaining that accurate application of the social model of disability would be remiss to exclude other cultures, and citing that only the UK has applied the social model of disability to people with disabilities thus far. Finally, Woods (2017) expanded on Levitt's (2017) advice by applying his thoughts regarding the social model of disability to individuals with ASD. Woods (2017) claimed that application to neurodivergent (those who think and act in varied and creative ways "…but fall within normal behavioural variations exhibited by humans" [Masataka, p.85, 2017]) people had not yet occurred. Applying the social model of disability to ASD allowed a new way of thinking, and allowed individuals a reprieve from the medical model of disability (many services for individuals with ASD tended to hinge on medical labels and pre-planned treatments/interventions (Woods, 2017). Neurodivergent people are faced with the reality of trying to fit into a predominantly (so called) neurotypical (those considered to be "typically" developing and fitting "societal norms") world (Woods, 2017). Woods (2017) wrote

> The primary goal of the social model has always been to take the focus from the individual impairment, and to shift the gaze towards societal structures. This now needs to happen by Predominantly Neurotype institutions taking responsibility for making adjustments. The social model should be shifting the burden of making adjustments away from autistic people onto Predominant Neurotype institutions (p.5).

Conclusion

"Seeing the person first" has been at the center of debate regarding the language surrounding disability. Individuals with ASD have a unique set of characteristics that present differently for each individual. Often, approaches to working and communicating with individuals with ASD must be individualized to be successful (Schall, 2010). Working with an individual with ASD’s strengths is one way to build this individualized intervention. It was my hope that this study help inform current practices regarding supports for individuals with ASD throughout their entire lifespan but especially in the transition to adulthood. Early intervention is vastly important to positive life outcomes for individuals with ASD, but so too is continued support throughout the individual's lifespan. ASD is a lifelong journey.

Chapter 2:Literature Review

Overview

To explore the experience of employment as perceived by adults with ASD and parents of adult children with ASD a literature review was conducted using Memorial University's research libraries databases. This literature review attempted to provide an overview of the empirical research on employment as experienced by adults with ASD. Initially, the search terms used were 'autism' and 'employment.' This search revealed over 13 000 potential sources many of which were not relevant to this study. To narrow the results, 'adults with' was added to the initial search terminology and 'peer reviewed items dating from 2000-2017' was added to the search criteria. Newspaper articles, conference proceedings and reviews were excluded from the search results which revealed 3380 potential search items, with many articles irrelevant to the study. Adding quotation marks to the employment search term narrowed the search to 188 peer reviewed results. Any articles not specifically referencing adults with ASD and employment were excluded from the final literature review. The following literature review provides an overview of employment for adults with ASD as told by this researcher, guided by the results/themes derived from participants in this research. This review does not claim to be all inclusive. The final search path used was : adults with autism and "employment" which resulted in 188 peer reviewed articles.

The Centre for Disease Control [CDC] (2016) reported that 1 in 68 children were diagnosed with ASD. Many programs have been developed in Canada to help young children with ASD learn important academic, social, emotional, and self-help skills (Burrows, 2004), and the school system offers continued support until the age of 21 (Parsons, 2015). What is next for an individual with ASD? Autism Spectrum Disorder (ASD) is a lifelong journey (Centre for Disease Control, 2016). Children with ASD grow into adults with ASD and must acquire new skills as the context changes from dependence to independence (McClannahan, MacDuff & Krantz, 2002; Parsons, 2015). A key force in the development and support of individuals with ASD is their parents/guardians (Muller & Cannon, 2016, van Heijst & Geurts, 2015). For the purposes of this literature review, I considered prior research on employment services for adults with ASD, barriers to gaining and maintaining employment, and perspectives of parents/guardians in the lives of individuals with ASD. The overall intention of this research was to investigate (through previous research and then through my own research) how employment was experienced by adults with ASD world-wide to see how it compared to the employment experiences of adults with ASD in Newfoundland and Labrador. The voices of parents and adults with ASD portrayed this experience.

Edwards, Watkins, Lotfizadeh, and Poling (2011) examined the percentage of studies which included adults with ASD in their sample. Of the 146 studies reviewed only 1.7 percent of them examined issues related to adults with ASD (Edwards et al., 2011), with 62.1 percent aimed at children with ASD aged 2 to 8 years. While a large body of research supporting the development of children with ASD is valuable, it is more important to ensure their success is continued throughout the lifespan (Billstedt, Gillberg, & Gillberg, 2010). Opportunities to participate in meaningful employment is key to the success of adults with ASD (Parsons, 2015).

The findings from this literature review reveal numerous factors impacting attainment and maintenance of employment for individuals with ASD. These factors are organized into themes related to significant findings from this study. The themes identified are as follows: ‘Communication’, ‘Economic Considerations’, ‘Education’, ‘Consistency’, and ‘Barriers’.

Using the voices of adults with ASD and parents of adult children with ASD helps readers see the impact of employment experiences on the participants in this study. It was my intention in completing this research to expand on the knowledge base of employment experiences of adults with ASD. I will start with an overview of the characteristics of ASD and then proceed to discuss what the research reveals about employment experiences of adults with ASD.

Autism

According to the Diagnostic and Statistical Manual of Mental Disorders-V (DSM-V), ASD is a neurodevelopmental disorder characterized by deficits in social skills, deficits in communication, and repetitive and restrictive behaviours (American Psychiatric Association [APA], 2013). APA (2013) defines a deficit in communication as one of three things: difficulty understanding body language, inability to interpret or express appropriate responses to social engagement (i.e. picking up on humor, knowing when someone is happy or sad, etc.), and difficulty establishing and nurturing lifelong relationships. The DSM-V further notes that ASD can fall under one of three levels which indicates the amount of support an individual with a diagnosis with ASD would need (APA, 2013). Level one ("requiring support") describes an individual who may need encouragement and prompts to engage socially and who may find transition and unexpected events difficult. (APA, 2013). Level two ("requiring substantial support") describes individuals with limited language and social skills, finite interests, and an inability to accept and manage changes in the environment (APA, 2013). Level three ("requiring very substantial support") describes individuals with minimal to no communication skills, limited interest in socialization, and an inability to tolerate change (APA, 2013). In the world of work, "Adults [with ASD] who have developed compensation strategies for some social challenges still struggle in novel or unsupported situations and suffer from the effort and anxiety of consciously calculating what is socially intuitive for most individuals" (APA, 2013, p. 53). Individuals with ASD self-reported that social communication was a factor hindering success in the workplace (Chen, Leader, Sung, & Leahy, 2015; Hedley et al., 2017).

Schall (2010) reported that repetitive and restrictive behaviours impacted the individual's ability to gain and maintain employment, and that no two people with ASD are the same. While the criteria to diagnose an individual with ASD is specific, the actual presentation of symptoms amongst individuals with ASD is diverse. As such programming and supports must be individualized. The APA (2013) noted the diagnostic criteria for Autism Spectrum Disorder includes social communication deficits, inflexibility with routines, fixation on ideas, erratic vocalization and movements, enhanced sensitivity to environmental variables (noise, light, etc.), and an inability to properly conceptualize tasks in general. As such, supporting an individual with a diagnosis of ASD requires flexibility and creativity to promote success on the job.

Communication

Barriers to employment are experienced by many groups of people. For individuals with ASD the barriers can be magnified, as individuals with ASD have unique additional challenges including deficits in social skills / communication, and repetitive / restrictive behaviours. Chiang, Cheung, Li, and Tsai (2012) reported (on a study which used secondary data from the National Longitudinal Transition Study 2 [NLTS2]) that low communication and social skills negatively impacted employment for individuals with ASD, and that "high social skill[s] is a significant factor associated with participation in employment" (p.1840). Chiang et al., (2012) urged for quality social skills training for individuals with ASD to better prepare them for work.

Lorenz, Frischling, Cuadros, and Heinitz (2016) studied employment of individuals with ASD using a survey with both quantitative and qualitative measures, reporting that when individuals with ASD were "...in non-autism-specific employment the most frequent problem fell into the category of social problems of communication (15 percent)" (p. 6). Moreover, day to day interactions with colleagues and customers proved difficult when individuals with ASD were placed in employment settings not specifically designed for them (Lorenz et al., 2016). This research highlighted the importance of social skills training for individuals with ASD as well as the need for co-workers and support workers to have specific expertise and knowledge of how to support adults with ASD in the workplace. Supports pairing social skills training with trained support workers in the area of ASD would enhance the employment experience of adults with ASD, and encourage sustained employment. Support workers could help facilitate social exchanges between adults with ASD and their coworkers on the job and as opportunities arise. Much like in any job setting where you learn skills in situations that are relevant and in context (Balwin, Costly & Warren, 2014; Booth, 1991).

Krieger, Kinebanian, Prodinger, and Heigl (2012) analyzed how environmental contingencies shaped the experience of individuals with ASD in employment situations using the "Ecology of Human Performance Framework" (p. 142). The Ecology of Performance Framework noted that while ASD presents differently amongst individuals, social communication issues and general inflexibility is common to most cases. Krieger et al. (2012) examined how effective communication and flexibility were key components in most work environments. Moreover, "adapting to a particular work culture requires constant negotiation of these social and cultural values and norms" (Krieger et al., 2012, p. 142). The interviews in this study further explored the role of social supports and their impact on the success of adults with ASD in the world of work (Krieger, et al., 2012).

In 2014, the Canadian Autism Spectrum Disorders Alliance (CASDA) completed a National Needs Assessment Survey across Canada to identify the strengths and needs of services across Canada for individuals with ASD. The survey included responses from caregivers of individuals with ASD, professionals working with individuals with ASD, and adults with ASD. Forty percent of self-advocates (adults with ASD) from the National Needs Assessment Survey identified the need for social supports/skills training if employment was to be maintained (Canadian Autism Spectrum Disorders Alliance, 2014). Bolman (2008) used case study research to report that Shane (an individual with ASD) experienced difficulty understanding job instructions, failed to seek clarification of job demands, and found it difficult to accept comments about job performance. Had supports been in place these issues could have easily been worked through, but unfortunately Shane's employment was terminated. Baldwin, Costly and Warren (2014) echoed similar issues, citing that a number of adults with ASD recalled "working relationships" as "negative experiences". Participants stated that communication was confused and unclear and they sometimes felt socially excluded (Baldwin, Costly & Warren, 2014).

Further research which incorporated the perspectives of adults with ASD reported issues with social communication as a key concern in the workplace (Griffith, Totsika, Nash, & Hastings, 2011; Hedley et al., 2017). Hedley et al. (2017) also included the perspectives of family members, support staff, and coworkers, who had worked alongside adults with ASD in a three year long supported work environment (Hedley et al., 2017). Support workers discussed modifying their own communication style (minimizing sarcasm, etc) to more effectively communicate with adults with ASD on the job, while adults with ASD and family members noted improvements with social communication after being involved in the three year program, demonstrating that experience in this particular work program enhanced their communication skills.

Griffith and colleagues (2011) reported on the perspectives of eleven adults with ASD (some of whom were employed). Communication proved difficult in employment settings and work relationships (Griffith et al., 2011). One participant reported asking for clarification regarding work tasks, her employer would mock her and make her feel like she should simply know what to do (Griffith et al., 2011). Another participant discussed how interacting with coworkers could be awkward and isolating because of the way the participant communicated (Griffith et al., 2011). From the research above mentioned, the strongest theme related to communication was social communication, specifically difficulties interacting with colleagues and employers.

Economic Considerations

Economic considerations are another factor impacting employment of individuals with ASD. In spite of The Universal Declaration of Human Rights having stated that all populations have the right to equal and equitable employment (UN General Assembly, 1948), household income, funding, waitlists, and provincial economic outlook continue to impact access to equitable and/or supported employment. Chiang, Cheung, Li and Tsai (2013) (using data from the National Longitudinal Transition Study 2 [NLTS2]) reported low socioeconomic status (SES) had a negative impact on the individual's ability to attain employment, and urged for more efficient support systems; systems to reach low income families so they might better navigate the structures that support individuals with ASD. The researchers from this study determined that individuals with ASD who graduated high school and were from high socioeconomic status (SES) were 17 times more likely to gain employment than those from lower SES.

In Canada, the National Needs Assessment Survey conducted by the Canadian Autism Spectrum Disorders Alliance (CASDA) reported a similar theme. Upon reviewing comments from survey participants, CASDA (2014) quoted a caregiver who echoed the above theme:

> We recognize we are part of a fortunate few who could pay for private services for our son. Most people we meet are not in this position and they wait too long for help. Our family struggled mentally with all the issues we faced in the early days. I can't imagine adding financial strain on top of that. We need to do more to help families in dire financial situations (p.33).

In the same survey, 92 percent of professionals, 75 percent of caregivers, and 45 percent of self-advocates from the sample interviewed reported having experienced both a lack of services and extensive waitlists, implying insufficient funding in certain service areas.

CASDA (2014) reported over half of caregiver participants reported receiving financial support from the government, but just over 20 percent reported it was enough to meet the needs of their child or adult with ASD. It was clear from the CASDA survey that many Canadian caregivers, though receiving support, felt it could be expanded to better support individuals with ASD. In The Economy 2017 report by the Government of Newfoundland and Labrador the rate of those unemployed rose to 13.4 percent (in 2016) from 12.8 percent (in 2015). Overall, the economic projections in Newfoundland and Labrador are expected to worsen, implying that opportunities for employment will decrease (Government of Newfoundland and Labrador, 2017). The report stated "Government deficit reduction measures are expected to lower spending in the public sector. As such, there will continue to be a decline in economic activity in the province, as previously forecasted" (Government of Newfoundland and Labrador, 2017, p.15). The need for more services and funding is clear, as evidenced by the National Needs Assessment Survey by CASDA and the literature discussed above, but with the economy currently in Newfoundland and Labrador one can only foresee further barriers associated with accessing services for adults with ASD.

Education

Education and transition planning play a key role in helping individuals with ASD obtain employment (Chiang et al., 2013). Chiang et al. (2013) reported those individuals who participated in career counselling were 5.7 percent more likely to gain employment post high school. Chiang et al. (2013) further reported that employment opportunities can be impacted if an individual fails to graduate from high school and/or has an intellectual disability. Moreover, schools and outside agencies must work together to build a transition program so individuals with ASD feel supported and experience successes during the move from school to work (Wilczynski, Trammell & Clarke, 2013).

Billstedt, Gillberg, and Gillberg (2010) reported that caregivers "…expressed their concern about not being able to offer a meaningful occupation and daily activity to the individuals with ASD" (p.11). Many caregivers wished they still had access to a facility providing the structure and routine they experienced in the school system (Billstedt, Gillberg, & Gillberg, 2010). Hendricks (2010) outlined a number of barriers interfering with the employment of adults with ASD, one being the diverse needs of adults with ASD and their subsequent requirement for intensive supports in the workplace (Hendricks, 2010; Taylor & Mailick, 2014).

A second barrier was the necessity for employers and coworkers to be accommodating and sensitive when working with adults with ASD (Billstedt, Gillberg, & Gillberg, 2010; Hagner & Cooney, 2005; Hendricks 2010). Adults with ASD shared similar perceptions. In Griffith and colleagues (2011) one participant stated "Employers on the whole don't know much about autism and autism is a very complicated impairment" (p. 540).

Wehman and colleagues (2017) completed a randomized clinical trial placing individuals with ASD in one of two treatment groups: one went through the regular special education curriculum and the other used Project SEARCH curriculum which included added elements of Applied Behavior Analysis (ABA). Participants (all between the ages of 18 to 21) were followed for up to 12 months post-graduation (Wehman et al., 2017). Better success with employment was found in the latter group (which included ABA as part of its treatment [Wehman et al., 2017]). ABA allowed for more individualized supports for individuals with ASD, as the supports were designed using data collected through functional behavioural assessments. Specific evidence based strategies, such as visual supports and task analysis, were used to support individuals with ASD transitioning to employment post high school (Wehman et al., 2017). In an earlier study Wehman and colleagues (2013) thoroughly described the use of these behavioral technologies (visual supports, task analysis, etc) and how the interventions were designed under the direct supervision of a trained Behaviour Analyst. For example, Wehman and colleagues (2013) described using "…social skill cue sheets, and behavioral checklists to assist students in following their schedule and understanding how to cope with difficult social expectations at work (p. 148)." ASD presents differently amongst individuals, and the added ABA allowed for better individualization and success (Wehman et al., 2017). A program combining career related curriculum and supportive services framed by the practices of ABA could support a solid transition from school to work for adults with ASD.

Morgan, Leatzow, Clark, and Siller (2014) tested the effectiveness of implementing an ‘interview skills curriculum (ISC)’ with young adults with ASD. Participants were randomly assigned to two groups: Group one was the ISC and group two was a waitlist/control (Morgan et al., 2014). Overall, the study showed emerging support for interventions teaching interview skills. Interview skills have also been studied and implemented via web, virtual reality, and video based formats (Rausa, Moore & Anderson, 2016; Smith et al., 2015; Strickland, Coles, & Southern, 2013). Lorenc et al. (2017) also confirmed that teaching interview skills to adults with ASD could improve employment success and benefit life outcomes overall.

The 2014 Needs Assessment Survey highlighted a concern that there was an insufficient number of trained professionals to provide adequate services to individuals with ASD in Newfoundland and Labrador (CASDA, 2014). Demographics for trained professionals cited an average of 11.3 years working with individuals with ASD (CASDA, 2014, p.16). In spite of this,, both professionals (73 percent), and caregivers (46 percent), reported a lack of training specific to the needs of individuals with ASD. This report reveals a need for changes in the approach to professional development in working with and supporting individuals with ASD in the province of Newfoundland and Labrador. The Behavior Analyst Certification Board [BACB] (2017) has recommended professionals working with individuals with ASD have a level of academic knowledge and experience appropriate to their role and hands on experience paired with a rigorous certification process (similar to that of psychologists). Throughout my years of working in the field I have observed that Newfoundland and Labrador has no such regulations. If appropriate education, experience, and certification is required in professional roles such as nurses, doctors, and psychologists, why is it not required for professionals who work with individuals with ASD?

Consistency

Throughout this literature review, consistent and organized programs (including individualized supports, employer support, and the input of individuals with ASD) were cited as key to promoting successful work placements. Hagner and Cooney (2005) interviewed supervisors of employees from one specific program employing adults with ASD, finding that when supervisors were open, gave clear directions, modified tasks appropriately, and provided a supportive environment for employees with a diagnosis of ASD (Hagner & Cooney, 2005), their employees (with varying degrees of support and job descriptions) maintained employment for six months or more. (Hagner & Cooney, 2005). It can be suggested "…that supervisory and management style has a great deal to do with the success or failure of an employment experience for an individual with autism" (Hagner & Cooney, p. 97).

Cimera, Wehman, West, and Burgess (2012) compared the use of sheltered workshops (employment for individuals with disabilities at designated sites separate from the general workforce) to supported employment (supporting people with disabilities in typical job settings in the community) for adults with autism. Cimera et al. (2012) found individuals participating in sheltered workshops earned lower wages, and maintaining sheltered workshops actually costed more than providing supported employment. Overall, "...individuals with ASD who transitioned to supported employment from sheltered workshops were employed at rates comparable to their peers and worked nearly identical hours as individuals remaining at sheltered workshops" (Cimera, et al., 2012, p. 92). Further, the Canadian Association for Community Living (2011) noted that sheltered work environments underestimated the skill sets of individuals with disabilities. The Canadian Association of Community Living (2011) argued for policy makers to establish “A commitment to the development of ‘Employment First’ policy initiatives that include clear definitions of employment and principles, cross-departmental and inter-jurisdictional policy and ongoing processes of capacity development at the local level” (p.29). Overall, employment programs should highlight the strengths of the individual.

The United Nations [UN] (2006) noted that access to fair employment is a basic right of an individual with a disability, and that employment helps promote inclusion in society. Oldman, Thomson, Calsaferri, Luke, and Bond (2005) examined the effectiveness of moving individuals from a sheltered workshop model to a supported employment model in British Columbia. By the end of their conversion to a supported employment program Oldman et al. (2005) reported that 50 percent of their sample “… were competitively employed (p.1439).”

Wehman et al. (2012) tested a supported employment model consisting of four steps. The four steps included: “…(a) the development of a job seeker profile and assessment (b) guiding the job development and career search, (c) conducting job site training and (d) designing long term supports to promote job retention” (p.160). Using these steps and supports allowed employees with a diagnosis of ASD to have their unique needs met and their employment status maintained (Wehman et al., 2012).

Nicholas, Attridge, Zwaigenbaum, and Clarke (2015) stated “Supported employment generally focuses on the vocational tasks required of a job, including micro- and mezzo- level skill requirements for employment stability” (p. 238). Their study found if an individual is given adequate support to perform a job role then they are able to participate in meaningful employment within society (Nicholas, Attridge, Zwaigenbaum, & Clarke, 2015). Hillier et al. (2007) developed a 2 year vocational support program that assisted 9 individuals with ASD gain employment. The program helped train participants, find suitable jobs, and scaffold the skills the individuals' required during employment (Hillier et al., 2007). With individualized supports and appropriate employment placements many adults with ASD experienced success with employment.

Schall and colleagues (2015) compared a supported employment program against Project SEARCH Training. The Supported Employment model involved four phases (establishing a 'job seeker profile', moving to 'job development', engaging in 'job site training', and ensuring 'long term supports') while the Project SEARCH model had the added benefit of "…extensive career development and exploration activities" (Schall et al., 2015, p. 3998). Overall, both groups showed success with employment (Schall, et al., 2015). Schall and colleagues (2015) found that "…adults with ASD can secure and maintain competitive employment in their communities when given intensive, individualized support" (p. 3998).

Schall (2010) discussed how employing Positive Behavior Supports (PBS) can be a systematic and meaningful method of supporting individuals with ASD in the work environment. PBS is an evidence based method using principles of behaviour analysis to support groups and individuals (Schall, 2010). Using case study research, Schall (2010) individualized job supports for a man named DJ. This case study demonstrated how functional behavioural assessment (FBA) could be used to individualize behaviour supports (Schall, 2010). DJ was reported to dislike being corrected when completing work tasks, and in response he would "...become most noisy and pushed others away" (Schall, 2010, p.111). To curb maladaptive behaviour Schall (2010) employed antecedent strategies (i.e. ensured job and skill match, adapted work tasks, accommodated sensory needs, etc.), taught replacement skills (i.e. how to request breaks and tolerate correction), and reinforced desired behaviour (i.e. requesting a break) while using extinction to decrease maladaptive behaviour (i.e. loud vocalizations). Once individualized supports were in place the data from baseline to intervention showed a significant decrease in DJ's disruptive behaviour (Schall, 2010). Schall (2010) further wrote how this type of support needs to be blended into the environment to preserve the individual's dignity.

Gilson and Carter (2016) tested the use of a modified job coaching package designed to promote independence on the job for individuals with ASD. Using a single case, multiple probe design the researchers measured three participant's success with the use of a “bug-in-ear” (p.3594) device designed to receive prompts for work tasks and social opportunities at their place of employment (Gilson & Carter, 2016). It was found that this type of device did have benefits for participants, increasing independence in completing work tasks and engaging in social opportunities for all participants (to some degree) (Gilson & Carter, 2016). If adults with ASD are supported throughout their employment experience many skills can be learned and success achieved.

Barriers

From the literature many themes emerged in the barriers category, including navigating supports, stress, medical needs, behavioural concerns, comorbid diagnoses, variation of symptoms, and program criteria (Eaves & Ho, 2007; Griffith et al. 2016; Hedley et al. 2017; McClannahan, MacDuff & Krantz, 2002; McDonough & Revell, 2010; Muller & Cannon, 2016).

Eaves and Ho (2007) completed follow up interviews with caregivers and individuals with ASD from a sample of individuals with ASD born between 1974 and 1984 in British

Columbia. The study found that many individuals with ASD experienced difficulty navigating eligible services, and reported having no support finding employment (Eaves & Ho, 2007). Of the small sample that did find employment, most were employed for fewer than ten hours a week. (Eaves & Ho, 2007). In their study, McDonough and Revell (2010) highlighted how supports would vary from state to state and communities and schools should work together to help families transition young adults with ASD into employment. McDonough and Revell (2010) stated "It is clear for youth with ASDs and their families that moving from the secondary level education system to the adult services is truly a mix of opportunities and challenges" (p.99). From The National Needs Assessment Survey caregivers reported System Navigation/coordination of services (CASDA, 2014, p.32) as a barrier to successful employment. One caregiver stated "Services should not be geared to making their autism appear to 'go away', but rather helping them be supported and successful in the world as they are….They deserve to be given the tools they need to be meaningful contributors to our society" (p. 33).

In Hedley et al. (2017), one participant reported on having ADHD, as well as ASD, which made it hard to focus on the job at times. In Muller and Cannon (2016), participants reported "...challenges related to the young adults' mental health, behavioral issues and/or medical needs" (p.99) as barriers to maintaining employment. In an earlier study, Muller, Cannon and Yates (2008) interviewed adults with ASD to gather perspectives related to social interactions. Many participants highlighted stress related to social interactions and expectations. Griffith et al. (2011) found similar concerns as adults with ASD reported stress at work and difficulties dealing with other mental health concerns such as depression. The experience of stress is reported often by both parents of adult children with ASD and adults with ASD (Hedley et al., 2017; Muller & Cannon, 2016).

McClannahan, MacDuff and Krantz (2002) discussed how behavior could impact job performance and maintenance. Some individuals in this study were reported unemployable due to "...severe aggression, intermittent but severe self-injury, or serious health problems (McClannahan, MacDuff & Krantz, 2002, p.19)" In reporting on Shane's experience, Bolman (2008) also commented that behavior could be a barrier to employment.

McClannahan, MacDuff and Krantz (2002) also highlighted the downside of program cutoffs by stating "policies that specify an age for program exit may cause loss of important data about the long-term effects of services" (p.24). A full picture of how interventions work across the lifespan would better serve individuals with ASD. CASDA (2014) reported similar issues with participants from Newfoundland and Labrador who cited "Being too old to receive service" (p.91) as a barrier. Program criteria and cutoffs in Newfoundland and Labrador are fairly specific. To avail of the provinces Applied Behaviour Analysis programing individuals must have a diagnosis of ASD and be between "18 months to pre-grade four entry level" (Eastern Health, 2013). Another program offered by the province provides behavioural supports to families and caregivers caring for individuals with a formal diagnosis of Intellectual Disability. Individuals with ASD availing of this program must also have a diagnosis of Intellectual Disability and significant behavioural concerns as identified by the program's eligibility assessment (Eastern Health, 2013).

Conclusion

The literature review has shown a variety of factors that can impact successful employment opportunities for adults with ASD (CASDA, 2014; Hillier et al., 2007;

McClannahan, MacDuff & Krantz, 2002; Nicholas, Attridge, Zwaigenbaum, & Clarke, 2015; Schall, 2010). With the rise of supported employment in North America and the UK it seems only natural to include the voice of adults with ASD when it comes to policies surrounding their employment. The preamble of the UN Convention of Rights for Persons with Disabilities states: "...persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programs, including those directly concerning them." My goal was to understand the experiences of adults with ASD and parents of adult children with ASD with employment in Newfoundland and Labrador, and to hopefully better inform policy makers and funding agents in the province.

Chapter 3:Methodology

Overview

This research study explored the employment experiences of adults with ASD living in Newfoundland and Labrador through interviews, fieldnotes, reflexivity, and member checking. Interviews were conducted during the 2015 and 2017 academic year, and sought the perspectives of adults with ASD and parents of adult children with ASD. This project endeavored to answer the following research questions:

1. What experiences did adults with ASD have when employed in Newfoundland and Labrador?
2. What types of employment services were available to adults with ASD in Newfoundland and Labrador?
3. What did adults with ASD and/or parents of adult children with ASD perceive as barriers to gaining employment in Newfoundland and Labrador?
4. What did adults with ASD and/or parents of adult children with ASD perceive as barriers to maintaining employment in Newfoundland and Labrador?
5. What did adults with ASD and/or parents of adult children with ASD believe would help support their employment?

This study sought to understand the employment experiences of adults with ASD and the parents of adult children with ASD, give adults with ASD and their parents a voice, and help discern the strengths and needs in Newfoundland and Labrador's system of supports as identified by the participants.

Design

Qualitative research methods were used to study the employment experiences of adults with ASD through the perspectives of adults with ASD and parents of adult children with ASD. For an in depth look into these experiences this study incorporated aspects of phenomenology, which aims to interpret and give meaning to the everyday experiences of individuals through their perception. (Denzin & Lincoln, 2005; Merriam & Tisdale, 2015). Moustakas (1994) stated "In phenomenology, perception is regarded as the primary source of knowledge, the source that cannot be doubted" (p.52). For this study the experience/phenomena under study was employment, and the 'perceptions' used to garner 'knowledge' were the shared experiences and observations of adults with ASD and parents of adult children with ASD in employment situations and in seeking employment.

As part of the process of qualitative research, collected data are reviewed to make meaning/interpret findings (Creswell, 2012). In this study, data was collected using semi-structured interviews and fieldnotes. Semi structured interviews were chosen to allow the researcher the structure of a preset list of questions and prompts while allowing participants the freedom to answer and expand on their descriptions as needed or desired (Wilson, 2013). While closed-ended questions would have resulted in valuable information regarding participants' experiences, open-ended questions gave participants the opportunity to explore these experiences in their own words, and as such provide a more thorough and accurate picture of these experiences (Creswell, 2012; Denzin & Lincoln, 2005). Fieldnotes allowed the researcher to process and reflect on the data on an ongoing basis (Given, 2008), while regularly evaluating the researcher's own personal influence on interpretive findings (Denzin & Lincoln, 2005; Given, 2008).

As part of the process of designing this study, the Interdisciplinary Committee on Ethics in Human Research (ICEHR) at Memorial University of Newfoundland and Labrador reviewed all documents pertaining to this research. Pertinent documents to the research proposal included the recruitment letter (Appendix A), questions for interview (Appendix B), and consent forms (Appendix C) highlighting the risks and benefits of participation, the purpose of the research, the participants' right to withdraw, and the methods used to ensure confidentiality. Following feedback from ICEHR changes were made and approval was granted. Pseudonyms were given to participants and organizations mentioned throughout this thesis to protect the anonymity of those involved.

Participants

This research aimed to describe employment as experienced by adults with ASD in St. John's, Newfoundland and Labrador. Newfoundland and Labrador is a rather large geographic region consisting of a little over 520 000 people (Newfoundland and Labrador Statistics Agency, 2017). The participants involved in this study resided in the urban center, St. John's. In order to best highlight these experiences both parents of adult children with ASD and adults with ASD were recruited. Morse (1991) noted participants included in a study should have experienced the phenomenon or been close to someone who has experienced the phenomenon. Research has shown that adults with ASD often live with parents well into adulthood (Billstedt, Gillberg, & Gillberg, 2010), giving parents of adult children with ASD a unique and intimate perspective to share with researchers. Accessing both adults with ASD and parents of adult children with ASD allowed for two perspectives on the same topic and a diverse view of employment experiences.

Eligible participants in this research were adults with a diagnosis of ASD and parents of adult children with ASD, wherein the individual with ASD was currently employed or had attained employment post high school. A total of five individuals participated in this study; three were parents of adult children with ASD (all mothers, one a single parent) and two were adults with a diagnosis of ASD (one male and one female). Four interviews captured the experiences of the five individuals, as one mother and son were interviewed together. The adults with ASD ranged in ability, with one participant having pursued post-secondary education and all having successfully completed high school in some form (i.e. high school leaving certificate, academic diploma, etc.). All varied in their communication style, with two adults having verbal conversation skills and the other two having limited vocalizations but the ability to communicate with gestures and pictures. While the sample size was small, Creswell (2012) noted this is common and acceptable in qualitative research, as data collected from a few participants can reveal an intricate representation and rich description of participants' experience, and adding numbers for the sake of adding numbers can "…result in superficial perspectives" (p. 209). Data garnered from this sample yielded many valuable insights into the lived experience of adults with ASD and parents of adult children with ASD seeking employment.

A nonprobability convenience sampling procedure was used to recruit participants for this study, meaning the sample was "…willing and available to be studied" (Creswell, 2012, p. 145). Participants were recruited through word of mouth and through a recruitment letter sent to the Autism society (who shared the letter with their email membership, website visitors, and twitter followers). Recruitment letters and consent forms were given to potential participants for review prior to their participation in this study. Any questions or concerns about the research were answered before beginning the interviews, and participants were informed of their right to withdraw at any point throughout the study up until data analysis was complete.

Setting

Two interviews took place at Memorial University's campus in a private counselling room or office, and two occurred at a location of the participants choosing. The mother and son dyad were interviewed in the same location at the same time. The researcher accommodated setting changes at the request of the individual participants to increase their comfort level during the interview process. Accommodating requests and ensuring a comfortable and quiet place can help participants feel more at ease during the interview process (Morse, 1991; Whiting, 2008).

The Role of the Researcher

In qualitative research, the researcher is the instrument through which meaning is made and data is interpreted (Tufford & Newman, 2010). It is imperative the researcher be mindful of personal values, knowledge, and experiences that may shape or bias research findings (Tufford & Newman, 2010). Throughout the research process written notes were made regarding the researcher’s attitudes and beliefs towards employment services for adults with ASD. During interviews, more notes were taken and later reflected on to explore the researcher's developing impressions and garner insight into personal beliefs and attitudes which could have influenced interpretation of data (Ahern, 1999). Once a researcher identifies potential biases he or she is meant to keep those ideas at the forefront to ensure they do not influence data to fit into preconceived categories or themes.

I began my research with the knowledge that my work experiences have left me with a specific world view of how services are mapped out for adults with ASD. My presupposition was that support workers in this province need more training in the area of ASD and other disabilities (specifically in the area of Applied Behaviour Analysis) to better support individuals accessing or attempting to access current supportive services. As a researcher I have indirect experience with the phenomena at hand, because through my work I have directly helped families find information on employment for their sons or daughters with ASD and/or other disabilities, and have at times became emotionally invested in their experiences, as it can cause great dissatisfaction and sadness in families when services cannot be found or availed of for various reasons. With this in mind, I kept a journal throughout the interviewing and research process which helped avoid personal biases influencing the themes and the interpretation of participants interview transcripts. In addition to this, frequent discussions with my thesis supervisor helped curb my personal bias when developing themes and interpreting data.

Data Collection

Semi structured interviews were chosen as one method of data collection. Galetta (2013) noted how "...semi structured interviews allow for the exploration of lived experience as narrated in the interview" (p.9). This was an effective way to explore the employment experiences of adults with ASD and parents of adult children with ASD. Questions were open ended which allowed participants to speak freely, with their own thoughts and impressions guiding the interview and limiting influence from the researcher's perspectives (Creswell, 2012). Every interview began with the following question, "What have been your/your son's or daughter's experiences with employment?" As participants engaged with the research questions, the researcher took notes and made comments in an exercise book to capture initial impressions and thoughts regarding the interviews. Creswell (2012) noted that interviews helped capture experience in detail. All participants were interviewed by the researcher. Interviews were between 30 and 50 minutes in duration, and used the same questions. Prior to the interview, consent forms were reviewed and questions entertained to ensure participants were informed of their involvement in the research, and aware that they could withdraw at any point. All interviews were voice recorded, transcribed verbatim, and reviewed against the original voice file for accuracy.

A second source of data was fieldnotes (also referred to as memos [Groenewald, 2004]). Fieldnotes included jot notes (with some formed sentences and paragraphs) taken during the interviews, and the researcher’s own reflective comments written after the interviews. Birks, Chapman, and Francis (2008) purport that “...the writing of memos is central to the process of investigating phenomena within the qualitative domain” (p.69). Fieldnotes taken during each interview were reviewed, summarized, and appended with impressions made. Overall, these notes showed a progression of the researcher's understanding of the qualitative research process and the views affecting the researcher's interpretation of the participants’ experiences in employment/seeking employment.

While member checking increased the credibility of the research, it also served as a data source (Hoffart, 1991). Creswell (2012) described member checking as “…a process in which the researcher asks one or more participants in the study to check the accuracy of the account” (p. 259). In this study the researcher employed member checking in the form of email correspondence. Both Amy and Tracy were asked via email for input regarding both the tables of derived formulated meanings/significant statements (Appendix D) and the researcher's written notes regarding potential overarching themes. While Tracy emailed the researcher to confirm that the data interpretation was applicable and in line with her experiences, Amy offered further input. Originally, the researcher had not considered including self-disclosure under the education theme. But Amy saw self-disclosure as an education opportunity for her employer and as such suggested it be housed under Education. She explained she disclosed her diagnosis in the following way: "I have autism and this is how it affects me in this job---these are the things that are easy for me and these are the things that are challenging." Data collected during this post interview dialogue helped to shape the overarching themes, and made for a richer understanding of this particular theme overall (Creswell, 2012; Denzin & Lincoln, 2005; Galetta, 2013).

All data collected was stored on a password protected computer and any notes, reflective writing, or printed transcripts were kept in a locked filing cabinet.

Interview Structure

The researcher began each interview with the general question "What have been your/your son's / your daughter's experiences with employment?" In response, the participant was allowed as much detail as they were willing to provide. If the flow of the interview halted, the researcher would follow up with "Can you tell me more about that?" to encourage further expansion on the topic. If required, variations of the following questions were asked to ensure a thorough exploration of the topic.

- Have you/your son or daughter availed of any supports while seeking employment? If so, which ones? Tell me your experience with these supports?
- Have you/your son or daughter experienced any barriers to employment? If so, please explain using examples.
- What type of supports would you like to see in place to aid you/your son or daughter with employment? Would your experience change with these supports in place?
- Is your experience different from others seeking employment?
- Is there anything you would like to add?

Analysis process

All interviews were recorded to an audio file on a computer, transcribed by the researcher, and checked for accuracy. Each transcript was emailed to the thesis supervisor for review and comments. The researcher also made comments and notes on initial findings directly to the digital copy of each transcript using the commenting feature in Microsoft Word. The researcher and supervisor met on multiple occasions to review the original transcripts and discuss findings and directions for themes. The researcher then extracted significant statements from all the transcripts and formulated meanings from these statements. Significant statements and formulated meanings were organized into a table format, with significant statements on the left and their formulated meanings on the right (Appendix D). Statements and formulated meanings were then reviewed with the thesis supervisor, and further possibilities for themes were discussed. Prior to formal discussions with the thesis supervisor regarding themes, the researcher had identified the following themes: Funding, Training of Staff, Availability of Employment, and Communication. After discussions with the thesis supervisor, broader categories were determined which could house more specific items (i.e. funding could be housed under Economic Considerations, training of staff could be housed under Education, etc). The researcher decided on the following final themes: ‘Communication,’ ‘Economic Considerations,’ ‘Education,’ ‘Consistency,’ and ‘Barriers.’ Each table was then printed and color coded according to theme. The researcher reviewed each transcript again, highlighting significant statements with the color of the theme to which the statement belonged.

Once each significant statement was highlighted on the printed copy, the researcher returned to the digital table to copy and paste highlighted text from each transcript to the appropriate theme (See Appendix E for an example using the Communication theme). This allowed the researcher to see all participants comments related to the theme in one place, and get an overall sense of what to include in the final theme description.

The researcher used two methods of data analysis, first applying elements of Colaizzi’s (1978) method to make meaning of interview transcripts, and second using the process of comparative thematic analysis as articulated by Guest, MacQueen, & Namey (2012). Colaizzi’s (1978) method encourages researchers to:

1. Thoroughly review transcripts to develop a deep understanding of participants’ experiences (One approach would be to first transcribe the interview then read and reread the transcripts to get a sense of the narrative).
2. Revisit each transcript to find all quotes pertaining to the experience under investigation. This process of extracting significant sentences and phrases helps the researcher organize significant findings and begin to develop each participant's story.

3. Infer/translate meaning to quotes pulled from transcripts. By placing formulated meanings on significant sentences and phrases, the researcher begins to summarize and group these findings.
4. Review all significant meanings and sort them into category/theme clusters. In categorizing each significant meaning from each participant, the researcher begins to see where participants may have similar or dissimilar experiences.
5. Provide a detailed description of the theme/categories using the voice of the participants. The researcher incorporates specific quotes used to formulate and describe the experiences at hand, and supports their usage through description.
6. Have participants review descriptions to ensure the researcher's interpretation is in line with their experiences. If any new information arises from this review, add it to the final analysis description. Researcher and participant should come together to revisit the experience/phenomenon being studied to ensure overall accuracy of interpretation. Should there be discrepancies the researcher would make modifications to the original analysis.

Guest, MacQueen & Namey (2012) encourage researchers to do a comparative thematic analysis of their data, describing the process as follows: "...an analyst simply examines the differential expression of themes across groups and notes which themes/concepts are similar across groups and which are different" (p.162). By applying this method, the researcher found that parents of adult children with ASD and adults with ASD did often highlight different points under each theme. Table 2 shows this comparison of descriptors cited by parents to those cited by adults with ASD under each theme.

Table 2: Comparison of Parents and adults with ASD descriptors of themes

Parent Descriptors	Theme	Adult with ASD Descriptors
-"he's not verbal enough" -"by the time we found out what it was, ...it was way way too late." -"...But guy A didn't know what guy B had done." -"Yeah there was no communication." -"No-one asked him why he was spending his time in the bathroom." -"...we're still waiting to hear." -"He can follow some simple directions. A complicated three or four or five step direction would not be suitable." -"I know about that program but it requires a communication skill level that's higher than he's able to reach at this time."	**Communication**	-"You know, they say it like it is and, I don't know, I just find it easier to interact with children compared to adults." -"...if I can't read a person or work out what they're thinking, I get stressed out." -"...sometimes need more time to like process and respond to stuff. Like in the moment can be hard for me." -"Well it was more of a misunderstanding." -"...sometimes I give off the wrong body language signals."
-"unless there's new funding" -"...they will fund people who currently are working first." -"...we put his name on the waiting list.." -"… the opportunities weren't very plentiful…" -"...he required full time job coach." -"the last number of years the Considerations for employment has been pretty bleak here in this province."	**Economic Considerations**	-"I've never availed of anything like that." -"...I did feel I was, in a sense underemployed?" - "I think if there was more funding for stuff like that… job training or job coaches or whatever, I could see that being beneficial to a lot of people…" -"...they only take like ten people a year."
-"They started with a board and		- "...through my undergrad I was

[wrote] down which I was totally against...He was already using an IPOD.” - “he doesn't need to be totally shadowed. He needs to be shown how to do something... and then do it.” - “I was really surprised by them to be honest with you because I figured that they would understand what autism was about? And understand some of the sensitivities around autism?” -“...they really matched his employment to his difficulties.” -“The skills training. He was taught to do a number of different skills that could be marketable in different situations… office cleanup comes to mind immediately.” -“there was a program in his high school of job placement experience, and he was in a number of different placements throughout his, actually junior high as well.” - “I think that at the high school level there needs to be a very close connection between the high school program and the supportive employment agencies…” - “But I think that there's an element of the population that's kind of left out, and as I've said the Strides is filling that gap somewhat, but the need is greater than they can meet.”	**Education**	never able to take a full course load, it was just too much for me.” - “...multiple times I kind of… changed my focus…” - “I found my final year incredibly difficult [high school].” - “I once took a career course. ...it taught me about interviews.”
- “ She’d have to rehire him, and then have the party, it was like by the time we found out what it was, and she found out that they didn’t have it, it was way way too late.” - “Even if they had something that was a day... like work a day... you know, that would be at least		- “In terms of supports, I think I’ve been lucky in having a lot of support from my family…” - “I also have a really good psychologist who’s been a huge support…”

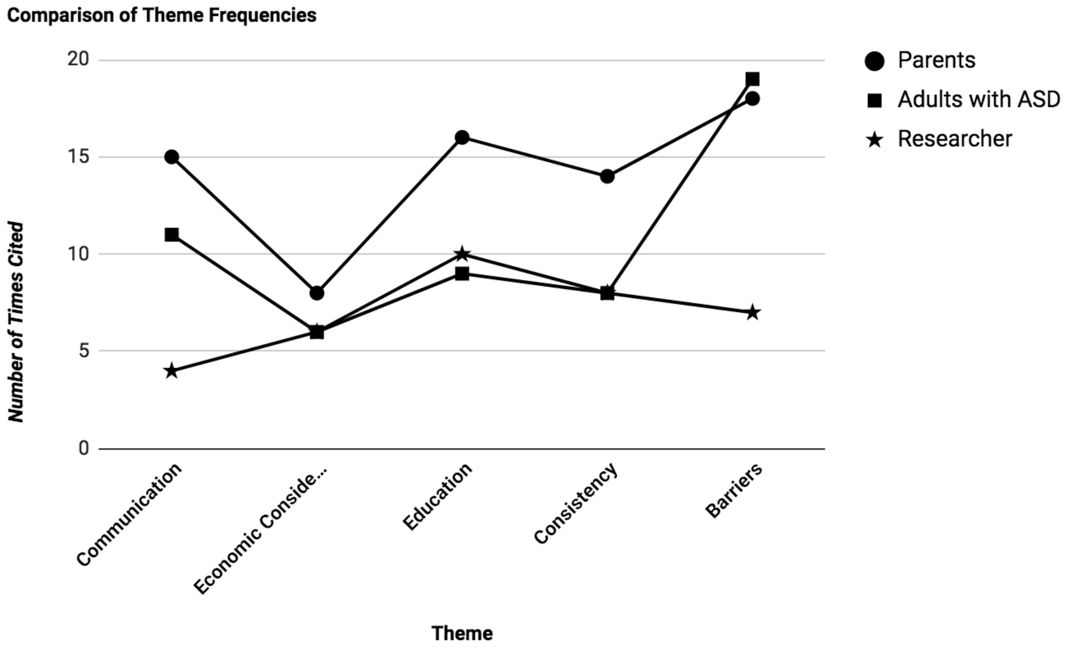
something?” - “So then so you gotta wait around and see when you gets into the next one. So you lost that little bit of consistency.” - “so every time he's at work she comes by, unless she's ill...but everyday that he works she stops in to make sure everything's going ok.” - “it's a perfect placement for him. I don't think that I could have asked for a better placement for him so it's really good. So I don't mind waiting.” -“I think the last year that he was there I think the schools relationship with the employment agencies was cut, and the follow through just didn’t happen.” - “It was out of his routine. He was tired in the evenings and wanted to relax, like most people do after a days work.” - “I think he would need a full time consistent job coach.”	**Consistency**	-“now she's my job counselor.” -“they called in a substitute for someone to fill in on the last day, and ironically that very individual is my current job coach.” -“...she found me a job…”
- “A lot that [My son] could do on his own but then he started to have seizures and unfortunately he had seizures on top of the stairs.” -“I can't work. I gave up working because, well, [My son] doesn't sleep. He doesn't sleep because he [has] the daytime [to relax]... he doesn't [have] a job to get up and go to and work...” -“I think one of the issues was that he required a full time job coach, and that was something that may have been a difficulty at the time, or some sort of barrier.” -“[The] biggest issue for the whole		- “...going into a situation where I don’t really know what to expect can be stressful…” - “The main issue for me was whether or not I would be able to successfully do the work…” -“I just felt so overwhelmed with the workload.” -“ ...I would get physically ill…” -”I think initially it’s hard to know whether to disclose because you don’t want people to assume up front that you can’t do the job…” -“the whole picture wasn’t complete

employment thing was navigating how to get there, how to get him into [The Program], how to get those things done.”	**Barriers**	basically. So then when I got the autism diagnosis things kind of came together and for the first time…” - “It was a bit noisy at first.” -“I tend to get overwhelmed without some… without any guidance.” -“Yeah I was rather nervous at the time.” -“I always freaked out a bit.... due to not knowing what to... where to go from there.” -“it was my own kind of fear of not knowing what the future would hold.”

Using a table to represent thematic comparisons helped the researcher garner a deeper understanding of both participants perspectives under each theme (Guest, MacQueen, & Namey, 2012).

Guest, MacQueen & Namey (2012)’s method was also used to analyze fieldnotes made by the researcher during the interview process. The researcher first highlighted significant statements on the original notes using colored leads, and then made a table in a word document to sort notes into their overarching themes (See Appendix F). The researcher then identified the frequency of theme occurrence between all data sources (Adults with ASD, Parents of adult children with ASD, and the researcher) to determine the strength of themes derived from analysis (Guest, MacQueen & Namey, 2012). See Figure 1.1.

Figure 1: Line Graph Comparing Theme Frequencies



The line graph shows both adults with ASD and parents of adult children with ASD placed similar importance on each theme as evidenced by similar line patterns for both groups. The researcher's frequency count was significantly lower in the themes of Communication and Barriers, which indicated that the respondents placed less value on these themes initially. Line patterns for Economic Considerations, Education, and Consistency were fairly consistent amongst all three data sources as lines sloped in the same direction for these themes.

Trustworthiness of Data

To ensure credibility of qualitative research triangulation needs to be considered. Patton (1999) stated "It is possible to achieve triangulation within a qualitative inquiry strategy by combining different kinds of qualitative methods, mixing purposeful samples, and including multiple perspectives (p. 1193)." Triangulation was achieved in this study by using two data sources (fieldnotes and interviews), two types of participants (adults with ASD and parents of adult children with ASD), and analyst triangulation (researcher and thesis supervisor analyzing the data independently of each other [Creswell 2012; Patton, 1999]). While fieldnotes and interview transcripts yielded many similar findings, discrepancies were noticed regarding the importance of some themes as identified by figure 1.

Analyst triangulation was achieved by having the researcher and thesis supervisor review transcripts separately and later meet to compare potential themes and significant findings. Using analyst triangulation broadened the researcher's perception of certain significant statements (Patton, 1999). Two themes initially developed by the researcher were ‘Funding’ and ‘Availability of Employment.’ The thesis supervisor helped the researcher place these themes under one category called Economic Considerations, which allowed for a more succinct theme with clear descriptors. Themes were finalized with the thesis supervisor in a meeting on July 31, 2017.

Member checking was employed to further ensure the interpretive credibility of this research. Throughout the interview process, the researcher would occasionally paraphrase and summarize participants’ answers to ensure interpretation was accurate in the moment (Given, 2008). One example from the interview with Jane is as follows: “OK. So the funding was, am I right in saying, it was a little unstable? You were unsure of if it was going to come through? Or?” This type of member checking helped ensure credible accounts in the moment (Given, 2008). The researcher also had two participants review their interview transcripts and associated tables of significant statements and formulated meanings to further ensure interpretation was accurate and give the respondents a chance to add comments (Given, 2008).

Chapter 4: Results

Overview

In this chapter, results and data analysis of the five participants were reported. Data was collected and organized through qualitative methods using thematic analysis (Creswell, 2012; Guest, MacQueen, & Namey, 2012; Merriam & Tisdale, 2015), and from this data five themes emerged. Throughout the course of this chapter each theme explored will begin with a general overview and then be described as they apply to each participant. Perspectives of parents of adult children with ASD will be evaluated separately from adults with ASD to give the reader a sense of how their experiences differ. Emerging themes were Communication, Economic Considerations, Education, Consistency, and Barriers, and will be examined in that order.

For confidentiality and readability, each participant and organization were given pseudonyms (see Table 3).

Table 3: Participant & Organization Pseudonyms

Participant	**Pseudonym**
Parent 1	**Jane**
Parent 2	**Alice**

Parent 3	**Tracy**
Adult with ASD 1	**Amy**
Adult with ASD 2	**Jason**
Organization 1	**Supportive Works**
Organization 2	**Employment Time**
Organization 3	**Strides**
Organization 4	**The Education Program**
Organization 5	**The Day Program**

Communication

All of the participants in this research study raised the issue of communication. Individuals with ASD were more likely to report difficulty understanding, trouble communicating their needs, and the inability to read body language as significant communication issues while parents of adult children with ASD were more likely to cite their dependents verbal skill level and general communication ability as issues. Additional concerns raised by parents included poor communication between employers and their employees with ASD, a lack of communication between and within organizations, and misunderstandings due to the *style* of communication of adults with ASD. Parents further expressed confusion regarding the availability of services and what the programs would entail, a direct result of poor or limited communication from support services. Overall the theme of communication represented more significant points than any other theme in this study, and is clearly a huge issue for adults with ASD and parents of adult children with ASD when navigating the world of work.

Communication Style of the Individual with ASD

Jane articulated frustration with the organization her son used to support his attaining and maintaining employment, believing that one of the problems was this organization's failure to recognize her son’s talents and abilities when seeking work placements. While her son’s verbal communication was limited (he used just one or two word phrases to express himself vocally), he could adequately express his ideas through painting (artwork), effectively navigate the internet (conduct basic research, etc.), and easily read and follow written directions in lists. In spite of his strengths in these areas, Jane’s son was placed in a restaurant environment where none of these skills were an asset, and his communication style negatively impacted the duties he could perform. “He didn’t serve people [in the restaurant setting in which he was employed] where the other guy did, because [my son] isn’t verbal enough.” As such, Jane’s son was limited to busing tables and delivering orders, when this job called for much more.

Jane further explained how her son was ineligible for certain programs because of his communication style. “Well, he’s not verbal enough. He couldn’t go to [The Education

Program]. He’s smart enough, but because he’s not verbal enough he can’t do [The Education Program].” Communication styles; especially those of individuals with ASD with limited verbal skills, limited opportunities to access programs and supports.

Tracy had similar challenges to Jane accessing programs due to her son's communication style. Tracy states “Yes, we actually did consider [The Education Program] at one point, and I know about that program, but it requires a communication skill level that's higher than he's able to reach at this time.” This is unfortunate because while Tracy’s son had minimal vocalizations and signs for highly preferred activities, he could easily be taken through a hands on task and complete the necessary steps successfully (ex: drying dishes and putting them away). Like Jane, Tracy found her son could learn tasks through demonstration or modeling. This suggests that communication is not simply verbal, and having an expansive vocabulary isn’t always necessary. Tracy remarked “He can follow some simple directions. A complicated three or four or five step direction would not be suitable. And he learns things by watching somebody else do them or somebody else taking him through the skill.” Communication can be achieved through actions, tone, behavior, and body language. How an individual with ASD presents to others is not always indicative of their skill level, and as such employers and support services may be unintentionally underestimating their employees/clients capabilities, making it difficult to use resources effectively when supporting their clients’ individual needs.

Even when individuals with ASD do have adequate verbal skills, communication remains an issue. While Alice’s son could ask and answer questions sufficiently, his employer chose to address concerns with his parents instead of directly with him. Alice remarked “... and the people at [Strides] started to complain that he was spending a lot of time in the bathroom [but] no-one asked him *why* he was spending his time in the bathroom.” If supportive agencies and/or employers choose to communicate with parents instead of directly with the individual, this is a problem. With open communication, situations might be readily resolved and individuals with ASD might experience enhanced success in employment settings.

Transition Services Communication with Parents

Parents expressed frustration with the lack of clear answers regarding available services and wait times to access those services. Alice discussed how she and her husband worked hard to find available supports for their son after high school, routinely making inquiries to supportive employment agencies, the local health authority, and school professionals regarding post-graduation steps for their son. Alice was often met with prolonged waitlists and sometimes missed deadlines when information regarding programs was miscommunicated to her by the professionals working with her son. Alice stated “I think it was in April or May... his case manager came to us and said you know you could apply for this particular program, [The Education Program]… And we applied but the deadline for the application was the 28th of February, and it's like... ok what was the point of even applying for it, right?” And while Alice would religiously attend school meetings and continuously advocate for supports throughout her son's schooling (keeping the lines of communication between family and school open), the transition from high school to the world of work was still inadequately supported.

Alice experienced further confusion with government funded agencies. While inquiring about her son's eligibility for one particular program she was initially informed he was eligible, but upon further investigation the funding agency (through interview with a prior job coach) deemed he was ineligible “Because he required too much support for that particular service.” Individuals with autism often need help becoming independent, and some individuals may need lifelong support. Government agencies may need to rethink how they structure services as the current criteria excludes a valuable portion of our population making it difficult for these individuals to access services.

Parents further expressed concern with agencies failing to communicate the waitlist status of certain programs. In some cases parents were told they would be contacted when their son was eligible for particular services, but contact was never made. According to Alice "…we put his name on the waiting list for those things, for [Supportive Works] and we're still waiting to hear." Alice had been on this waitlist an estimated 5-8 years with no updates. Jane expressed a similar concern, citing "Apparently he went on the [wait] list after this new crowd started." explaining that while her son had been on this list for a number of years there were still 52 people ahead of him. Waitlists were identified as being unreasonably long for supported employment agencies currently in place in Newfoundland and Labrador. Tracy described how Supportive Works (an employment agency) had established a rapport with both her sons school and some of the other parents of children with disabilities. She discussed how they would regularly hold meetings to outline their services and complete visits with students. During her son's final year at school, however, Supportive Works discontinued involvement with the school without notice, leaving her and her son with little direction for future programming and employment.

When parents of adults with ASD were finally able to access services, they were often wrought with confusion. Regarding an employment opportunity which ended abruptly, Jane made the following comments: "Then they hired a different guy. To the point that I had all the forms filled out and everything. But guy A [Employer] didn't know what guy B [Strides] had done…" Jane further stated in reference to the same program: "Yeah, there was no communication [from the employer]. And I think they must have fell short at [Strides] too, because [Strides] were the ones that were dealing with it.” When implementing programs, organizations require thorough planning and a well-researched, organized, and deliberate execution. Most importantly, all organizations connected to the program need clear and open lines of communication.

Progressing through the Strides program, Jane’s son secured janitor work. While describing this experience, Jane discussed how her son was abruptly laid off, and how (typically) when employment ended amicably in this program, participants would receive a celebration or party. If an individual was fired, a party would not be given. However, due to miscommunication within the Strides program, Jane’s sons’ end of employment was overlooked, and no celebration occurred. Subsequently he used the lack of celebration as an indicator his own behavior was at fault. As a consequence, the son would overcompensate with his duties at home, sometimes needlessly repeating tasks multiple times such as putting dishes away and taking the garbage out, causing further stress for the parent. Jane said “So in [my son’s] mind he got fired. If you get fired it’s because, now because [my son] can’t talk, but like he knows what’s goin[g] on, he [knew] everyone that got fired they did something really bad because the staff would be talkin[g] amongst themselves.” In the preceding case, an agency responsible for empowering individuals with a diagnosis of ASD only further isolated the individual, instilling feelings of inadequacy and anxiety while at the same time distressing the parent. Overall, the experience for this parent was one of upset and confusion with how agencies communicated the services they provided. When there is a lack of proper communication, families feel added stress.

Communication: Perspectives of Adults with Autism

Communication issues for Jason and Amy included difficulties sending and receiving nonverbal social cues and difficulties processing and responding to questions. Jason remarked “I'm always giving off the wrong body language signals. Well it's just sometimes I give off the wrong body language signals.” For an employment situation this could cause difficulties as co-workers and employers could misinterpret those signals. In Amy’s current place of work, she finds it hard to read the social cues of some individuals. She stated

> There are definitely things that I find hard, in terms of like the interactions with… mostly like… right now, parents… like I have no trouble with the kids, because kids are in a sense very easy to understand? You know, they say it like it is and, I don’t know, I just find it easier to interact with children compared to adults. And that’s something I find hard, like reading other people I guess and, when you don’t get… when things are hidden, that’s a challenge for me. Like if I can’t read a person or work out what they’re thinking, I get stressed out. I just find it hard.

This difficulty with interpreting social cues causes added stress to an employment situation. Individuals with ASD have a number of barriers to face on a day to day basis, and with the numerous interactions that occur between family members and the general public daily, the pressure of questioning “am I reading this person right or am I sending off the wrong signals” is an additional challenge. It must take incredible strength for an individual with ASD to persevere in spite of this.

Amy further discussed how she can “...sometimes need more time to like process and respond to stuff. Like in the moment can be hard for me.” Employers must consider an individual's processing time if they are to set up adults with autism for success. Jason shared how he is sometimes unable to interpret certain social nuances: “Well I learned ways to get around. Like one time in [The Education Program] my disability had gotten the better of me and some joke went on. Well it was more of a misunderstanding.” Individuals with ASD by nature of their diagnosis have core deficits in the areas of social communication (American Psychiatric Association, 2013). They can often misread statements and body language (American Psychiatric Association, 2013). It is clear that both Amy and Jason have experienced some difficulties in this area of social communication. For employment services to facilitate in this area they might consider setting up peer mentors or an employee education program on effective communication with individuals with ASD.

Parents of adults with ASD presented a number of communication issues related to both supportive services and the communication style of individuals with ASD. Parents also expressed a desire their adult child with ASD’s skills be recognized, and their unique communication styles accommodated. Adults with ASD expressed frustration surrounding difficulties with social communication and the unique challenges these difficulties create in the work environment. Communication issues was a recurring theme in the interview process that must be addressed to support success in the workplace for adults with ASD.

Economic Considerations

Parents described how limited funding and waitlists can negatively impact opportunities finding and sustaining meaningful employment. One parent discussed how the current economic situation in Newfoundland and Labrador impacted employment opportunities for her son, as finding suitable placements for employment proved difficult. Parents reported that much needed funds failed to reach all the individuals who needed support, with many people left out and opportunities limited. Also, where some funding programs might be sufficient in the beginning, these programs could not support the individual long term, (as the supported individual would age opportunities would disappear). This may speak to the value society places on individuals with ASD. If society values these individuals they should support them through the entire lifespan.

All the parents who participated in this study identified funding for supported programs as an area of concern. Jane felt accessing funding was a lost cause. She remarked "Yah but that is basically unless there's new funding because the reason they [The Day Program] haven't taken anybody in for like 17 years or so, most of the people that were in there were in their 50s, ah, it's because nobody leaves." Alice echoed similar concerns with limited funding and spaces as Jane by restating what one agency said to her

> ...the funding comes from us, and so then she actually said to me she said the way this program works, is that they will fund people who currently are working first, so they give the agency so much money. And she said so we will fund the people who are currently working first, and then if there's any money left over, or someone drops out of employment, then we'll take on a new client.

In a similar vein as both Jane and Alice, Tracy was given the impression that getting funding for a full time job coach would likely not be possible. Tracy stated "I think one of the issues was that he required a full time job coach. And that was something that may have been a difficulty at the time, or some sort of barrier." This indicates that there are not always adequate funds to access specific supports based on individual needs. In reference to the Employment Time program Tracy stated "I think the last year that he was there I think the school's relationship with the employment agencies was cut, and the follow through just didn't happen." Jane, Alice and Tracy all experienced various types of funding related issues. However, Alice experienced an interesting variation in that her son had to be employed *before* he could be considered for a specific program. Parents of individuals with autism are already facing a number of challenges with providing meaningful daily programs for adult children with ASD. Some agencies seem to be building the illusion of helping but in actual fact make their programs unreachable to parents and individuals with ASD.

Tied to the idea of inadequate funding was the reality of waitlists. Jane described waitlists as being unreasonably long, noting that her son tried to access The Day Program when he left high school 7 years ago, and was still "…[number] 52 on the [wait]list." Parents have experienced long wait times while trying to provide meaningful activities/employment for their adult children with autism.

Tracy also discussed how Newfoundland and Labradors economic considerations could be impacting opportunities. She said "First of all there has to be a job available. And you know for the last number of years the considerations for employment has been pretty bleak here in this province." Recent economic reports have identified an increase in unemployment in Newfoundland and Labrador (Government of Newfoundland & Labrador, 2017). Statistics Canada (2017) reported high unemployment rates in 2009 (15.5 percent) and 2010 (14.7 percent) for Newfoundland and Labrador, with a gradual decrease from 2011(12.6 percent) to 2014 (11.9) and then another increase in 2015 (12.8 percent) and 2016 (13.4 percent) (Newfoundland & Labrador Statistics Agency, 2017). Compared to other provinces Newfoundland and Labrador still leads with higher unemployment rates (Newfoundland & Labrador Statistics Agency, 2017).

Economic Considerations was a common thread amongst all parents. Waitlist, access to funding and overall employment rates were key elements for this group.

Economic Considerations: Perspectives of Adults with Autism

Amy and Jason shared a different perspective when it came to this theme. Amy identified some success with employment and expressed concern for others who may need more support finding employment. Jason alluded to the idea of funding.

Amy had demonstrated that she was somewhat successfully navigating the world of work. She said "I've been kind of lucky in that I've been able to get to where I am without [supports]." Amy's comments highlighted how a certain level of independence/skill can help an individual become more financially secure. However, Amy's case likely demonstrated an exception to the rule. Amy also expressed a concern for others with ASD who may need supports. She commented "I think if there was more funding for stuff like that… job training or job coaches or whatever, I could see that being beneficial to a lot of people who might otherwise not be able to succeed or do as well in the workforce." While Amy has been able to establish a level of independence she notes concern for others and highlights that funding opportunities tend to be limited for individuals with ASD.

In reference to The Education Program Jason mentioned that "… they only take like ten people a year." This number is startling. In the 2012-2013 supportive services enrollment statistics document it was reported that 439 individuals with ASD were enrolled in the Newfoundland and Labrador School system in the eastern region. A transition/post high school program offering just 10 slots for all students with disabilities (not just those with ASD) leaves a significant number underserved. In order for support services to succeed, the allocation of funds to these programs must scale appropriately to the populations' need.

Education

This theme speaks to the education level of support staff, employers, agencies, and the individuals with ASD. It was suggested by participants that some agencies and support staff were unaware of the core deficits of autism and how to accommodate individuals in their work environments to best promote success. However, some experiences were positive and in line with the individual's strengths and differences. Parents further highlighted the need for transition type programs for individuals when they are preparing to leave high school.

Access to Education Opportunities

Jane gave a pretty bleak overview of the supports she received while Alice had both positive and negative experiences. Jane remarked "...uh high school? Was a joke. They didn't do anything with him there. So, um, then he came out he was doing art therapy at [Strides] anyway so then we'd just schedule these things so instead of weekends he was doing them midday." Jane attempted to fill her son's day with meaningful programs once he left high school. Eventually, she availed of an employment program through Strides. The employment program through Strides underestimated her son's skill set and once the employment program ended, there was no further support maintaining employment. Alice's son and Tracy's son both availed of the Strides program and reported similar experiences. Once their sons were initially trained there was typically no follow up from the Strides personnel.

About a year after their experience with Strides, Alice's son was able to avail of 'The Education Program.' The Education Program offered training related to employment as well as other daily living skills such as budgeting. She said "So it's really, they really matched his employment to his difficulties... [The Education Program] did." Her son is still employed and followed by this program whereas Jane and Tracy's sons were not able to the reach that particular program because of their son's communication style. This speaks to the varied experiences amongst individuals with ASD when it comes to access to education opportunities that support employment. Those individuals who are considered level two or three as per the DSM V(APA, 2013) require more supports and are even less able to access employment. This is not to minimize the experience of those who are able to function more independently, it is just to highlight that access can be considered an individual experience. Individuals with ASD, while they fall under a specific set of diagnostic criteria, are all different and require specific support. Such supports would take into consideration the individuals specific strengths, break down tasks and incorporate visual supports.

With regards to Strides, Tracy was pleased overall with the training her son received. Tracy said "The skills training. He was taught to do a number of different skills that could be marketable in different situations… office cleanup comes to mind immediately. And it was quite an involved training program, which I thought was quite good." But in spite of this training her son's actual employment experience was a negative one. Tracy's son found work through the Strides program as a janitor, but his hours at this job were not suitable. Tracy explained

> It was out of his routine. He was tired in the evenings and wanted to relax, like most people do after a day's work. And to get up after just kind of getting through the day,

> doing leisure type activities... then to go to work at five or six o'clock in the evening... he found it difficult.

Tracy also reported an issue with a consistent job coach. “Where his communication is so limited, he would need a job coach at all times. And if that job coach is not a consistent worker, and somebody who can take the time to be with him all the time, then it's gonna be difficult to maintain.” This particular job ended in failure.

Transition Programs from High School to the Working World

Transition programs were not evident when interviewing parents. All parents discussed how they had to search for employment type services once their adult child with autism left high school. Tracy said:

> I think that at the high school level there needs to be a very close connection between the high school program and the supportive employment agencies, and that relationship should continue beyond high school, and even if there's no employment obtained immediately, I think... I don't know on whom the onus would be to maintain that connection and maintain that relationship so that something could be developed... And I also think that the employment agencies should have some input into letting teachers know what types of skills are somewhat in demand in the employment world? So that a program can include the development of some of those skills? Or else maybe even a transitional program after the school year so that the students will continue on, but develop employable skills.

Tracy shared some important ideas on how to remedy this gap. Along the same lines as Tracy, Jane remarked “Yeah, sort of like put where they had the girls, like you know they’d bring the 14 and 15 year olds and they’d show [th]em welding and they’d show [th]em carpentry[Skills Canada]…” A program whereby individuals could test their interest level on the job would be a useful way to transition out of high school as long as there was a follow up person or employment counselor to contact when and if needed.

Alice discussed how her son faced further challenges accessing supports out of high school. There was no real guidance from his former case manager besides the suggestion they apply for a program whose deadline was actually past due. She said “…7 out of 7 days [my son is] not really doing a whole lot of things, and just for lots of reasons he doesn't qualify for respite and he doesn't qualify to have someone come and pick him up and bring him out to stuff…” This implies her son has a certain skill level that is just above a criteria level to avail of certain supports/programs and just below the level to engage in post-secondary training. Alice in this case had to try and find creative ways to make her sons days more meaningful as she could not access those supports (respite, etc.), whereas Tracy was able to avail of a respite worker to take her son to various activities.

Knowledge of Autism by Agencies and Support Workers

Jane and Alice shared similar thoughts with regards to their sons’ involvement with Strides. Jane shared how Strides underestimated her son’s skill set and didn’t use his current communication style. Jane said “Ya. They started with a board and [would] write down [a list] which I was totally against because it was backwards. He was already using an iPod [for lists].” She further recalled “A few mornings he showed up early. Went in, started, got the crowd in a panic because they couldn't find him. Mainly because whatever his list was, he already had it done." This speaks to the overall lack of organization of this particular program and the underestimation of this individual's skill set. If he could complete all work tasks and go missing it is clear he could have been provided with more work and his skills set was likely not adequately assessed from the beginning. This would further infer that staff were not adequately trained to meet this individual's needs. Jane further remarked "…he doesn't need to be totally shadowed. He needs to be shown how to do something... and then do it." Jane also said "...they don't give him enough, they don't expect him to do enough in my mind."

Alice stated:

> I was really surprised by them to be honest with you because I figured that they would understand what autism was about? And understand some of the sensitivities around autism? Noise is one of the things that's really really difficult for [My son], and that's why he was spending his time in the bathroom.

This further illustrates the lack of training and/or preparation of the organizers. If an assessment of skill level had been completed and an understanding of ASD had been transferred to support workers, Alice's son could have had more success in this environment. It could be suggested that the environment was not suited to Alice's son's skills set and sensitivities. When searching for a career people typically choose something they like or have a knack for. Choice was not present for this individual and this outcome highlights the consequences of his sensitivities not being considered (by placing him in a loud warehouse environment). Individuals with ASD often need to be supported in certain situations, but should be afforded the opportunity to choose which career they would like to embark on. Tracy further spoke of Strides and noted how certain job coaches were better suited to work with her son than others while he was employed with them.

Also, for the few months he was employed he had between 3 to 4 different job coaches. This turn over in support staff is not advisable when working with individuals with ASD. Again, it is crucial that individuals supporting and working with adults with ASD have appropriate training.

Education: Perspectives of Adults with ASD

One adult expressed that having employers and coworkers educated in the core deficits of autism can help to better support adults with autism in the workplace. Both adults expressed difficulty with coursework in high school and/or university and one expressed both the positive and negative aspects to certain education opportunities.

Amy has had a positive experience in her current employment situation. She reflects:

> Yeah, I do. They've been really… especially [The Manager] has been super supportive. … from what she's expressed to me I think she likes the idea of having someone on the spectrum in the department.

Further to that relationships with colleagues have been reported as positive. She states "...I haven't had any issues or anything with any of my colleagues, everyone's really great. Like I'm lucky in that way. It's a good team." Amy works in an environment where her colleagues have a certain knowledge base when it comes to autism and other developmental disabilities.

Amy further reports how formal schooling has presented challenges for her. She said,

> I think the biggest barrier for me has been the education side of things. Growing up I always wanted and thought I would be a physician but eventually I realized that med school would be way more stressful than… I don't know, I just realized that it wouldn't

> be worth it for me, to put myself through that stress, because school has, especially in late high school, and throughout university, it's been very stressful.

Amy further states "...through my undergrad I was never able to take a full course load, it was just too much for me. So it took me a lot longer than my peers to kind of get through my degree." Jason related similar difficulties with school. He remarked "I found my final year [high school] Jason related similar difficulties with school. He remarked "I found my final year [of high school] incredibly difficult." In light of these challenges both adults expressed that having supports inside and outside the education environment helped them succeed in these settings.

Upon reflection on The Education Program, Jason further stated "...after my contract with the warehouse was done I spent about a year or so [without employment]." Jason recalls a gap in time between his first employment experience up until space became available at The Education Program. The Education Program offered skill development and readiness for employment. They also helped Jason find his current job and continued to follow up with him. Jason further reported that "well there were some, but there were some times where there were some bad things and good things... In [The Education Program]."

Consistency

All parents expressed inconsistency within programs, a lack of follow up in some cases, and an inability to provide a consistent routine for the individual. There were also some good points with regards to consistency; some participants reported experiencing good follow up and consistent employment/job coaches. All above descriptors are illustrated in the following summaries and quotations.

Alice is currently happy with her son's placement. After years of searching for employment that considers her son's strengths, she expressed how The Education Program has successfully done this for him. Alice stated:

> He's in an environment that suits him, it's quiet, it's not, you know, they do have some public but it doesn't have a lot of traffic, a lot of their clientele order online and like it's businesses and stuff like that…it's a perfect placement for him. I don't think that I could have asked for a better placement for him so it's really good. So I don't mind waiting.

For Alice, the waiting, confusion, and hassles experienced finding her son employment paid off, whereas Jane and Tracy and are still left searching, trying to build meaningful employment activities throughout their sons' days rather than leisure activities. Jane lamented the fact that her son cannot avail of anything consistent. She said "Even if they had something that was a day... like work a day... you know, that would be at least something?" Jane further explained "So then so you got [to] wait around and see when you get into the next one. So you lost that little bit of consistency." Jane wanted a typical employment scenario for her son even if it was only a day or two a week.

In reference to the Strides employment program Tracy discussed how work hours were unfavorable for her son. He was scheduled to work in the evenings during a time when he would typically be unwinding for the day. Consistency for Tracy's son meant routine that suited his regular patterns of activity. Typical routines must be taken into account when considering a work placement for adults with ASD. Tracy further reported her son needed consistent workers. She said "I think he would need a full time consistent job coach." Throughout the interview Tracy mentioned how her son works better when he and the respite worker are comfortable with each other. Individuals with autism often prefer consistency and sameness. While not every scenario can offer consistency, it is important for employers to at least be aware of this and accommodate when possible.

Consistency: Perspectives of Adults with ASD

Where parents primarily identified inconsistencies within employment supports, adults with ASD mainly identified the consistent supports that helped get them where they are today. Supports such as professionals, family, and friends were identified as key elements for establishing consistency and success maintaining an employment placement. Adults with ASD interviewed were able to answer and ask questions throughout the interview process (with one having completed post-secondary education) whereas adults with ASD discussed by parent participants were noted as having minimal verbal communication skills except for the mother and son pair that were interviewed together.

Amy discussed family, friends and professionals at great length, and how their continued involvement has helped her further her education and career. Amy recollects :

> In terms of supports, I think I've been lucky in having a lot of support from my family, like even now I live at home, I moved back home after I came back from [City], because I knew I'd be going back to school and stuff, I knew that would be stressful and just not having to worry about cooking or getting the groceries or whatever. But I think if I didn't have those supports, I don't think I would be where I am right now without that support…

She further discussed how her psychologist has been a great support with navigating potential employment settings and how her first employment experience away from home was embarked on with a close friend. Emerging into independence when one becomes an adult can be filled with peaks and valleys for any individual. Having supportive family, friends and professionals at one's side can only strengthen experiences in the world, and these supports can be key to establishing long term success.

Jason related to Amy's idea of support. He recalled how The Education Program instructor has continued to follow him and helped him secure his current job. He said "...I met this woman…She was a… she popped in every now and then due to the place being nonprofit. She always gave presentations about how to work out in the world and, well, now she's my job counsellor." Jason further establishes how professional supports can be key to success in the workplace for individuals with ASD.

Barriers

A variety of barriers were revealed by adults with ASD and parents of adult children with ASD. Parents highlighted stress relating to medical concerns, inconsistent scheduling, navigating supports, meeting their dependent's individual needs, and the unknown. Adults with autism discussed the stress of self-disclosure, late diagnosis/misdiagnosis, and the unknown.

Barriers: Perspectives of Parents

Jane discussed how a medical issue impacted her son's need for supports: "A lot that [my son] could do on his own but then he started to have seizures and unfortunately he had seizures on top of the stairs." Seizures impacted her son's independence. It is important to take into consideration the whole person when supporting individuals in the work environment, while remaining aware that the individuals needs could change.

Jane and Tracy agreed that regular work hours and consistent schedules are important to establishing success in the workplace for their sons. Jane would like to see meaningful hours like any individual would experience on the job—a full day as opposed to an hour here or there. Tracy would like to see typical hours of work that anyone would chose when seeking employment. As discussed before, evening hours were not suitable for her son.

Alice discussed concerns related to the stress on her son while Jane discussed stress due to her own employment situation. Alice discussed how her son would feel stress in anticipation of going to work, but further added "…when he's there, he's ok…" Jane highlighted how her own employment situation has been impacted by her inability to find a full time job or build a consistent daily schedule for her son. Jane is a single mom trying to provide a quality of life for her son but it is very difficult given her situation, "I can't work. I gave up working because, well, [My son] doesn't sleep. He doesn't sleep because he got the daytime [to relax]... he doesn't [have] a job to get up and go to and work..." Functional patterns and schedules are disrupted by the lack of structured and meaningful activities during daytime hours, negatively impacting a parent's ability to maintain employment of their own and causing more stress.

Individual needs were not always targeted or supported effectively. Tracy remarked,

> [I had] some frequent contact with [Supportive Works], but nothing came up in terms of a possibility for him. I think one of the issues was that he required a full time job coach, and that was something that may have been a difficulty at the time, or some sort of barrier.

In many cases the increased need for support actually yielded less opportunities. Alice discussed how finding programs that fit her son's needs was difficult. "[The] biggest issue for the whole employment thing was navigating how to get there, how to get him into [The Program], how to get those things done." Alice's comment illustrates how actually finding a program, job placement, or simply navigating the system could be a huge barrier for individuals with ASD. Alice stated

> ...I just think that they could do a better job in helping families navigate? …I mean we went through all kinds of services… I think that they should write... like they should give parents a guide… This service will provide services for THIS type of individual. It would just make it so much easier to navigate it.

Often services and supports are not identified in areas where families and individuals can easily make contact with them and/or determine what the best fit would be for their adult child with ASD.

Barriers: Perspectives of Adults with ASD

Stress is a barrier common to all of the adults with ASD interviewed in this study. Amy articulated "...going into a situation where I don't really know what to expect can be stressful..." Jason remarked "I always had a freak... I always freaked out a bit. Due to a certain... due to not knowing what to... where to go from there." As a potential solution, Jason offers:

> ...I made a suggestion and this is the same suggestion I should probably pass along to you to pass along to other clients... if they're too stressed out or for some reason can't seem to go, they should probably have someone or something that they're comfortable with go with them, like someone or something that they... that would ease their stress.

Having someone help navigate a new situation or task on the job could help minimize the stress related to the unknown for individuals with ASD.

Amy discussed stress related to the disclosure of her diagnosis. Having been diagnosed late in life, the decision to disclose her diagnosis to employers and peers was her own. She recalled

> I think initially it's hard to know whether to disclose because you don't want people to assume up front that you can't do the job or whatever, so it is tricky to know, and in some cases you probably shouldn't, like as a [support worker] you probably shouldn't tell, you don't want people to think you can't …do the job.

Amy added "If there was more support even for that, like not necessarily like job coaches and stuff, but just being able to say to someone up front,…I do have a disability and I may need accommodations,…that would be helpful." Fear of discrimination when interviewing or searching for a job was very real for Amy. She expressed numerous times how the stress of her current workload coupled with concerns regarding self-disclosure caused her to become physically ill. This speaks to overall conceptions in our society; as a society we often underestimate the abilities of individuals with any diagnosis, be it a mental health issue, a physical disability, or a developmental disability. For Amy, self-disclosure actually worked in her favor, as her manager was supportive, and continues to check in with her regarding her workplace needs.

Amy also experienced confusion throughout the diagnosis process.

> ...initially in late high school I was diagnosed with a mood disorder and anxiety in my last year, and then was treated somewhat unsuccessfully with medication… and they never really could pinpoint what it was,...the whole picture wasn't complete basically. So then when I got the autism diagnosis things…came together and for the first time ….I felt like I understood who I was, but also being able to move forward was possible in a way that hadn't really seemed possible before...

Better detection for diagnosis of adults with ASD would help alleviate stress and confusion in individual lives, allowing individuals to focus more on navigating work, keenly aware of their strengths and needs.

Conclusion

Parent participants as well as adults with ASD identified a desire for more individualized supports throughout various stages of employment. Participants urged that the individual as a whole (including but not limited to their strengths, communication style, and emotional needs) be considered when finding and securing employment placements. Many negative aspects were revealed regarding supports, including a lack of communication and the overarching concern that funding be available to help service adults with autism, the need to keep up with the growing need for supports. Much of what was reported in this theme is echoed (Edwards, Watkins, Lotfizadeh, and Poling (2011); Billstedt, Gillberg, and Gillberg (2010)) that more funding and research must consider ASD across an individual's lifespan (as opposed to just their early years) if society is to support a meaningful quality of life for this group.

Chapter 5: Discussion and Conclusions

Summary of Significant Findings

This research explored employment experiences of adults with ASD through the perceptions of adults with ASD and parents of adult children with ASD. ‘Communication’, ‘Economic Considerations’, ‘Education’, ‘Consistency’, and ‘Barriers’ emerged as consistent themes, with both adults with ASD and parents of adult children with ASD having shared many perceptions related to these themes. Examining these perceptions; exploring both unique and common ways participants’ perceptions related to these themes allowed for a richer understanding of how employment is experienced for this group within an urban setting in the province of Newfoundland and Labrador, and could inform recommendations for stakeholders in this area going forward.

Participants reported frustration and confusion navigating the system as it exists, and ultimately finding and availing of appropriate supports, largely due to communication issues. Communication problems were revealed between organizations and families as well as between organizations and adults with ASD. Adults with ASD reported their challenges with social communication and its impact on their employment experience. Oftentimes miscommunication or underestimation of skills occurred. Baldwin, Costly & Warren (2014) and Lorenz, Frischling, Cuadros, and Heinitz (2016), also found social communication to be a barrier and a concern for individuals with ASD engaged in employment which, supports the results of this study. Supportive agencies need to better design programs to meet the individual needs of adults with ASD in the workforce, and better support these programs when they are in place. Parents in this study reported that the communication style of their sons caused employers and support workers to underestimate their sons’ ability to speak for themselves, leading to problems in the workplace which could have been easily resolved. Chiang et al.(2012) suggested that social skills training be a part of the employment experience. When examining data from interviews with parents of adults with ASD, Muller and Cannon (2016) noted the "...need for improved social learning and communication skills" (p.99). Communication style of the individual with ASD is an important consideration in an employment setting, and the extent to which it is accommodated often determines success or failure for the individual.

Under the theme of Economic Considerations, parents of adult children with ASD and adults with ASD mainly reported on insufficient funding and long waitlists, creating a situation in which programs were hard to find, difficult to access, and poorly ran. Many programs changed year to year, and when individuals availed of them they were short term, leaving individuals with ASD and their parents searching for new ways to fill their days. Muller and Cannon (2016) agreed:

> The second most common theme was lack of adequate funding and support services for adults with ASD. Some parents described financial hardship relating to the loss of the Maryland ASD Waiver when young adults' education entitlements came to an end. Some complained of the challenge of finding day programs(p. 99).

Overall funding and cutbacks contributed to financial concerns for the participants in this study (Muller & Cannon, 2016). The recent budget report in Newfoundland and Labrador noted similar issues referencing cutbacks and decreased spending in certain program areas (Government of Newfoundland and Labrador, 2017). The CASDA (2014) further supports this finding; parents, self-advocates and professionals all noted how funding was an issue when accessing much needed services.

The literature review revealed that household income impacted the likelihood of an adult with ASD attaining employment. Chiang et al. (2012) found adults with ASD who came from high earning households were more likely to be employed or to have participated in employment than those who did not. The current study did not take this into account and therefore cannot speak to the impact household income may have had on the participants in this group.

Often organizations tasked with supporting individuals with ASD fell short on providing supports addressing the core deficits of ASD, possibly due to a lack of appropriate education and training of staff. Knowledge of ASD by agencies and support workers was identified as a subtheme under the broader theme of education. Muller and Cannon (2016) found similar complaints in their study, stating "Some [parents] complained of the challenge of finding...professional support staff well-versed in strategies for working with adults with ASD" (p. 99). Further to this, the CASDA (2014) purported similar findings citing that 46 percent of caregivers reported professionals and paraprofessionals needed further training in how to support individuals with ASD. Lack of training and education is continuously highlighted by the participants in this study.

The education theme did shed light on the scarcity of education based transition programs or employment supports available to individuals with ASD post high school. Parents of adult children with ASD and adults with ASD both reported concerns with the lack of employment and education related programming and how some programs take very few (ten) applicants per year. From the CASDA (2014), survey results the top five needs identified for adults with ASD were "Employment or Day programs (61 percent); Life skills training (52 percent); Social skills training (48 percent); Post-secondary educational programs (47 percent); and housing/residential programs (43 percent) (p.43)." On a national level employment programs are a growing concern.

Under the theme of consistency, it was identified that supportive agencies sometimes failed to provide adequate support to individuals with ASD, as evidenced by a lack of follow up and follow through. All parents reported follow up was weak and nonexistent in some cases, and gave details of how this inconsistency impacted their sons. All participants specifically highlighted a lack of follow through when availing of the Strides program. Muller and Cannon (2016) also reported this. Parents in their study highlighted "...the importance for individuals with ASD of jobs with steady, predictable routines" (Muller & Cannon, p. 97). Further to this Wehman and colleagues (2017) developed a training program that ensured consistent and predictable routines for the trainee with ASD. Their program utilized the skills of a variety of professionals (behavior analysts, education specialists, employers, etc.) who continually collaborated to ensure the individual with ASD was being adequately supported. The end result being that when an individual with ASD is supported and there is follow up employment can be successful (Wehman et al., 2017).

Adults with ASD reported consistency as vital to supporting their success in the workplace. One participant gave examples of how having a consistent job coach was extremely important, while the other offered consistent support of families and understanding coworkers as examples of supports that worked for her. The theoretical framework of the social model of disability suggests an appropriately supported environment is one that considers the person first, what they *can* do (how they communicate, and how they see information, etc.) as opposed to what they *cannot* do. If society begins to see the strengths in people with ASD and prioritize finding creative ways to utilize those strengths, we will be closer to reaching this model.

Regarding barriers, one of the key findings was that stress tended to have a negative impact on work experiences for adults with ASD. Both parents of adult children with ASD and adults with ASD reported stress related to job performance, interacting with colleagues, reading and sending social cues, and going to and from work. Griffith et al. (2011) and Muller et al. (2008) reported similar findings related to stress, noting that coping strategies should be taught to adults with ASD so they can better manage these symptoms on the job, and coworkers should be taught to how to approach individuals when they are stressed. In The National Needs Assessment Survey (CASDA, 2014), one self-advocate remarked:

> Treat us with respect. I know myself and I know what I can and can't do. I am capable of making informed decisions about myself. Never assume you know me better than I know myself. And when I'm obviously in distress, show some sympathy instead of treating me like a manipulative child! (CASDA, 2014, p.34)

Medical concerns were also cited as a barrier. One parent discussed how seizures impacted the types of tasks her son could perform. In Eaves and Ho (2008), and Muller and Cannon (2016), parents reported the same concerns, citing seizure and digestive issues, mental health concerns (such as depression and anxiety), and behavioural concerns (such as self-injury) impacting employment opportunities for their adult children with ASD.

Late diagnosis was also a barrier. One adult participant discussed how her late diagnosis hindered her abilities to understand her strengths and needs. The Needs Assessment Survey echoed similar concerns (CASDA, 2014), stating that self-advocates reported improved self - knowledge once a diagnosis was formalized.

One parent cited the lack of daytime support for her unemployed adult with ASD as a barrier to her being able to successfully engage in her own employment, and as such provide financial support for herself and her son. She also lamented the subsequent lack of structure in his days, and the effect this had on his sleep schedule (Her son was up most of the night and asleep by day). McCabe (2009) looked at this phenomenon with mothers in China, citing mothers experienced "...an overwhelming sense of responsibility toward their children that often mean[t] sacrifices in their own lives, including in seeking careers and identities apart from being a mother" (p. 130).

Limitations and Future Research

While this research highlighted valuable points related to employment in Newfoundland and Labrador for individuals with ASD there are limitations to note. The sample size was small and one of convenience, meaning it was not a true representation of the whole population of adults with ASD in Newfoundland and Labrador who have been employed. Also this study did not take into account household income. Prior research has done this and found positive links between high household income and employment (Chiang et al., 2012). Also, this research did not take into account the perspectives of employers, support workers, or educators. Including these perspectives could further enhance the context of employment for adults with ASD in Newfoundland and Labrador. Furthermore, this research only focused on the experiences of those who have been employed and not those currently seeking employment. A larger sample size including the perspectives of those currently seeking employment could have given this research a real time lens with which to view employment, providing further ways to contrast the experiences of participants.

Future research might include the viewpoint of employers with an aim to determine what they have been doing to support individuals with ASD in the workplace, what they have found to be successful or unsuccessful in this regard, and what resources they feel they might need to improve the employment experience of their adult employees with ASD. Also, an examination into the structure of current programs alongside a review of government policies and funding for adults with ASD would be useful to see where gaps exist. Another important research area would be current established transition programs like Project SEARCH (which includes elements of ABA and promotes individualized programming in the workplace) (Wehman et al., 2017). Testing such programs in this province might help education programs enhance what they offer in the form of career development for individuals with ASD. Lastly, adopting professional standards of practice (i.e. certification) across provinces, and establishing minimal education expectations for professionals working closely with adults with ASD, might ensure a skill set in these professionals which allows them to more successfully support adults with ASD in the workplace.

Conclusion

There is an increasing body of research examining the lifelong outcomes of adults with ASD (Billstedt, Gillberg, & Gillberg, 2010; Gerhardt & Lainer, 2011; Hedley et al., 2017; Hendricks 2010; van Heijist & Guerts, 2015) but while the literature expands the focus is varied. Much of the research is centered on supported employment programs (Nicholas et al., 2015; Wehman et al., 2017). While looking at the effects of supported employment programs is valuable, getting perspectives from adults with ASD and parents of adult children with ASD provides further insight into the unique strengths of this group (Griffith et al., 2011; Muller & Cannon, 2016).

This research suggested that there are some key items to consider when supporting adults with ASD in the workplace. Communication should be open and adapted to the individual with ASD's strengths. Organizations and employers must work together to make employment successful and the experience a positive one. Funds should be allocated to either properly support existing programs (allowing them to scale to the demand), or create new programs where needed. Professionals and paraprofessionals supporting individuals with ASD should have an appropriate level of education, and programs should be designed with careful consideration (i.e. addressing barriers like stress and other factors which may impact successful employment) and implemented with fidelity. Finally the whole person must be considered when they are being supported by services.

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Appendix A:

Recruitment Letter

Dear Participant,

Are you interested in exploring your experience with employment as an adult with autism? Do you have a son or daughter with autism and would you like to share his or her experience with employment? I am currently pursuing graduate studies in the Faculty of Education at Memorial University. My research is focused on exploring the employment experiences of adults with autism in Newfoundland.

I am looking to interview 5 adults with autism (who are currently employed or have been employed) and/or their caregivers. The research will require you and/or your caregiver to engage in a 30 to 60 minute interview that will take place on campus at Memorial University in a private counseling room located in the Faculty of Education. Adults with autism and/or their caregivers will be interviewed at separate times. However, caregivers will be asked to remain on site during the interview should they be needed. If you are interested in participating please review the attached consent form.

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research you can contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.

If you have any questions or need additional information, please contact me via email r75kec@mun.ca or phone 709-728-2636.

My supervisor for this project is Dr. Sharon Penney who can be contacted at scpenney@mun.ca or 709 864-7556.

Thank you for your consideration.

Sincerely,

Kerrie Cochrane

Appendix B:

Interview Questions

1) What have been your / your son's / your daughter's experiences with employment?

Interview Prompt: Can you tell me more about that?

Alternate questions used if needed:

1) Have you/your son or daughter availed of any supports while seeking employment? If so, which ones? Tell me your experience with these supports?
2) Have you/your son or daughter experienced any barriers to employment? If so, please explain using examples.
3) What type of supports would you like to see in place to aid you/your son or daughter with employment? Would your experience change with these supports in place?
4) Is your experience different from others seeking employment?
5) Is there anything you would like to add?

Appendix C:

Informed Consent Form

Title:	Exploring the Employment Experiences of Adults with Autism	
	Researcher:	Kerrie Cochrane, M.Ed (Candidate) Faculty of Education Memorial University of Newfoundland Phone: (709)728-2636 Email: r75kec@mun.ca
	Supervisor:	Dr. Sharon Penney, Associate Professor Faculty of Education Memorial University of Newfoundland Phone: (709) 864-7556 Email: scpenney@mun.ca

You are invited to take part in a research project entitled *"Exploring the Employment Experiences of Adults with Autism."*

This form is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. It also describes your right to withdraw from the study. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is the informed consent process. Take time to read this carefully and to understand the information given to you. Please contact the researcher, Kerrie Cochrane, if you have any questions about the study or would like more information before you consent.

It is entirely up to you to decide whether to take part in this research. If you choose not to take part in this research or if you decide to withdraw from the research once it has started, there will be no negative consequences for you, now or in the future.

Introduction:

My name is Kerrie Cochrane and I am a graduate student with the Faculty of Education at Memorial University. As part of my graduate program I am completing a Master's thesis titled *Exploring the Employment Experiences of Adults with Autism*. I am conducting this research under the supervision of Dr. Sharon Penney.

Purpose of study:

The purpose of this study will be to provide readers with a snapshot of what the lived experience and journey toward employment is like for adults with autism in

Newfoundland. I plan to explore these experiences by using a phenomenological framework/research design.

In particular this study will examine:

1) What are adults with autism experiences with employment in Newfoundland?

2) What employment services have been availed of/ are available to adults with autism?

3) What are the main barriers to gaining and maintaining employment?

4) What would help support employment for adults with autism?

5) What are the career goals of adults with Autism?

6) What would be most helpful in preparing this population for the workforce?

What you will do in this study:

For the purposes of my research I will ask you to participate in a 30 to 60 minute interview in a private counseling room at Memorial University. Appointment times will be made at your convenience. The interviews will be audio recorded to ensure accuracy. If you prefer not to be audio recorded but would still like to participate, this researcher will notate the interview and review it with you. Once the interviews are transcribed you will be given the opportunity to review them to ensure they are an accurate reflection of what you wanted to say. The transcripts and all interview notes will be used for research purposes only and my supervisor and I will be the only two individuals to have access to the data. Data collected may be reported on in articles, conference and workshop presentations, reports, and/or book chapters.

Length of time:

There will be one session per participant and the interview should take no longer than 30 to 60 minutes.

Withdrawal from the study:

_Participation is completely voluntary and you may withdraw at any time, up to the point where data analysis is completed, by informing my supervisor, Dr. Sharon Penney or me verbally or via email at any time. All data collected from you at that point will be returned to you and/or destroyed as per your request. Also, if you decide during the interview that you would like to discontinue and not have your information used you are free to let the researcher know and the interview will be stopped immediately and all data collected will be returned to you or destroyed.

Possible benefits:

This study allows you an outlet for your story and a place to feel empowered. Also, this research will give the scientific community a window into the lived experiences of adults with autism seeking or currently employed.

Possible risks:

If at any point throughout the interview you become upset we can stop the interview and discuss your concerns. Caregivers will be on site during the interview process and available to intervene should they be needed. If necessary, I will refer you to emergency or another mental health service. At the time we can discuss which service would be the best fit for you.

Confidentiality:

The ethical duty of confidentiality includes safeguarding participants' identities, personal information, and data from unauthorized access, use, or disclosure.

I will take all necessary steps to achieve confidentiality. Pseudonyms will be used during the transcription process and within all related written materials. Should you have any further questions or concerns both my supervisor and I will be available to talk with you.

Anonymity:

Anonymity refers to protecting participants' identifying characteristics, such as name or description of physical appearance.

After the interviews have been recorded (on a password protected device) they will be transcribed with pseudonyms. If employers' names are mentioned they will also be given a pseudonym. Any unnecessary information that may lead to identification will be omitted as well. The information collected throughout this project will only be viewed by my supervisor, Dr. Sharon Penney and me. All papers, notes, recordings, and devices used in this project will be stored in a locked cabinet for five years then destroyed.

Every reasonable effort will be made to ensure your anonymity and you will not be identified in publications without your explicit permission.

Recording of Data:

During the interview I will use an audio digital recording device that will be password protected. Also, notes taken during the interview will be kept in a locked cabinet.

Storage of Data:

Interviews and data will be stored on a password protected USB device and computer. All hard copies of data will be stored in a locked filing cabinet. Consent forms will be stored in an alternate locked filing cabinet. Only my supervisor, Dr. Sharon Penney and I will have access to the data and other related research materials. Data will be kept for a minimum of five years, as required by Memorial University's policy on Integrity in Scholarly Research. At the end of 5 years all data/information collected during this research project will be destroyed. The data collected may be reported on in articles, conference and workshop presentations, reports, and/or book chapters.

Reporting of Results:

The thesis will be publically available at the QEII library.

All information in the thesis will be reported using direct quotations and/or summaries where appropriate and only with the express permission of participants.

No names (only pseudonyms) or identifiable information will be attached to direct quotes or summaries.

Sharing of Results with Participants:

I will offer to review the results with each participant as well as offer to provide them with a summary of the final results.

You are welcome to ask questions at any time before, during, or after your participation in this research. If you would like more information about this study, please contact: Kerrie Cochrane at 728-2636 or via email: r75kec@mun.ca or Dr. Sharon Penney at 864-755 or via email: scpenney@mun.ca.

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, such as the way you have been treated or your rights as a participant, you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.

Consent:

Your signature on this form means that:

- You have read the information about the research.
- You have been able to ask questions about this study.
- You are satisfied with the answers to all your questions.
- You understand what the study is about and what you will be doing.
- You understand that you are free to withdraw participation in the study without having to give a reason, and that doing so will not affect you now or in the future.
- You understand that if you choose to end participation **during** data collection, any data collected from you up to that point will be destroyed.
- You understand that if you choose to withdraw **after** data collection has ended, your data can be removed from the study up to the point that data analysis is complete.

I agree to be audio-recorded Yes No

I agree to the use of direct quotations Yes No

By signing this form, you do not give up your legal rights and do not release the researchers from their professional responsibilities.

Your signature confirms:

I have read what this study is about and understood the risks and benefits. I have had adequate time to think about this and had the opportunity to ask questions and my questions have been answered.

I agree to participate in the research project understanding the risks and contributions of my participation, that my participation is voluntary, and that I may end my participation.

A copy of this Informed Consent Form has been given to me for my records.

____________________________ ____________________________

Signature of participant Date

Researcher's Signature:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

____________________________ ____________________________

Signature of Principal Investigator Date

Appendix D:

Example of Significant Statements with Formulated Meanings

Significant Statements	**Formulated Meanings**
"We have been involved in some employment training, and after that did secure part time employment. It did not go particularly well, and there hasn't been any experience with employment since then."	Partnerships between employers and supportive employment structures should be established to promote success. Disorganization can have ill effects on individuals with autism and their families.
"...number of years after high school was finished. It was through [Strides]. They did have a work training program and a system of supports in place for people they were able to secure work for, and a lot of good things about it"	Maintaining momentum and quality of employment programs is important to individual success.
"But in the long run it was not quite suitable."	Maintaining momentum and quality of employment programs is important to individual and family success.
"The skills training. He was taught to do a number of different skills that could be marketable in different situations… office cleanup comes to mind immediately. And it was quite an involved training program, which I thought was quite good."	Skills training in a variety of areas can provide positive experiences for individuals.
"Yes, there was an extensive interview with the family to find out what his interests were and what his skills were at that particular time leading up to the program."	Assessment can help guide and determine appropriate job placements for individuals with ASD
"Yes, there was a part time job. It was after hours office cleaning, so he would start at either five or six in the evening." "Ah yes [Strides] did work pretty hard to secure a placement for him, and that was the one that they were able to get."	Partnerships between employers and supportive employment structures should be established to promote success.

“Well I think it was… the opportunities weren’t very plentiful, so it was more just see what we could get that would be in keeping with what he knew how to do.”	Timing of work hours should be in line with the individual's typical schedule to be considered successful.
“That was quite difficult. He had a support worker who did a number of community activities with him, but it was something that had to be planned out each day, and to see what might be available, like take him for a swim or maybe do some volunteer work with a local farmer.”	Individuals with Autism need transition programs to help them succeed in the world of work.
“The [Supportive Works] personnel were brought into the school and there were some transitional possibilities discussed. It didn’t transfer into employment. I think the last year that he was there I think the schools relationship with the employment agencies was cut, and the follow through just didn’t happen.”	Communication between families and supportive programs needs to be clear. Partnerships between employers and supportive employment structures should be established to promote success. Disorganization can have ill effects on individuals with autism and their families.
“Yes, that was the aim, but I can’t quite remember how that went after he finished school. But there was no… and he had been in contact also with [Employment Time]. That was another agency. I don’t even know if any of those are still operating.”	Disorganization can have ill effects on individuals with autism and their families.
“ …some frequent contact with [Supportive Works] but nothing came up in terms of a possibility for him. I think one of the issues was that he required full time job coach. And that was something that may have been a difficulty at the time, or some sort of barrier.”	Funding opportunities need to be reviewed so adults with Autism can better access services.
‘I can’t quite remember, so it was quite a long time ago, and I think we all may have just given up.”	Struggle with securing employment can make families feel defeated.

“I think they’re doing some training in there but we haven’t pursued it and it hasn’t been offered to us, so it may be that they consider that he’s been trained, I don’t know, like they may want to give other people opportunities, and heaven knows there’s enough clientele to need the service.”	Prior experiences with agency programs can have a negative impact on families and their willingness to reach out/try new programs.
“First of all there has to be a job available. And you know for the last number of years the climate for employment has been pretty bleak here in this province.”	Programs should be connected with job placements prior to commencement so there is a connection between the program and
“Probably. A lot of it would depend on the place of employment, and the current staff at that place of employment. You know, you may be able to withdraw a full time job coach for part of his day if he were set up with specific things to do and that somebody who is already on staff could kind of oversee it, but that would require commitment on the employers part, and I don’t know that... you know if they can get a worker that they don't have to do that with, you know, I don't know that they have the incentive to... I don't know if employers would have the incentive to depend[?] on somebody with those needs.”	Collaboration amongst service providers and employers could improve consistency for individuals on the job.
“I would like to see him work in the daytime. Evening hours were not suitable for him, as we learned.” “It was out of his routine. He was tired in the evenings and wanted to relax, like most people do after a days work. And to get up after just kind of getting through the day, doing leisure type activities... then to go to work at five or six o'clock in the evening... he found it difficult.”	Hours and time of day re: work hours can affect individuals ability to perform to potential on the job.
“I think he would need a full time consistent job coach.” “I hadn't thought about that! But the full time, suitable job coach is to me the most important ingredient”	Consistency within job personnel would help promote success for individuals

“Plus the fact that he would have a job that he would find interesting off the start. And he would need to have his needs taken into account... such as having a break every hour”	Meaningful employment should be accessible to all groups.
“But he needs to see the end of that task, and something that he likes in terms of a break in between, before going back to that task. And, you know, I think that he has skills to offer, but he would need a setup that would accommodate his own needs.”	Individuals with autism can benefit from tasks being broken into parts/task analysed.
“He can follow some simple directions. A complicated three or four or five step direction would not be suitable. And he learns things by watching somebody else do them or somebody else taking him through the skill.”	Knowing skill level of individual is key to maintaining independence and supplying enough meaningful work for individual.
“Yes, we actually did consider that at one point, and I know about that program but it requires a communication skill level that's higher than he's able to reach at this time.”	Transition programs should fit many individuals across the spectrum not just those who are considered vocal verbal, Communication barrier
“He does. He does actually, but you know he's not happy if he's not kept busy.” “Because he's reasonably contented now. Um I think he could be more... I don't want to say productive, but I think he could have a more... I don't know how to put this... I think he could enjoy his life more if he had more interesting things to do... things that he enjoys, and thing that help out others.”	Individuals with autism deserve and need meaningful activities/quality of life.

Appendix E:

Example of Sorted Quotes Under Relevant Theme

Communication

Jane- “He didn’t serve people where the other guy did because [MY SON] isn’t verbal enough.”

Jane- “Well, he’s not verbal enough. He couldn’t go to [The Education Program]. He’s smart enough but because he’s not verbal enough he can’t do [The Education Program]”

Jane- “So he can’t come and do an interview because he’s not verbal”

Jane- “And then it was like too late to do it then. She’d have to rehire him, and then have the party, it was like by the time we found out what it was, and she found out that they didn’t have it, it was way way too late.”

Jane- “Then they hired a different guy. To the point that I had all the forms filled out and everything. But guy A didn't know what guy B had done…”

Jane- “Yeah there was no communication. And I think they must have fell short at [Strides] too, because they were the ones that were dealing with it.”

Alice- “... and the people at the autism society started to complain that he was spending a lot of time in the bathroom”

Alice- “No-one asked him why he was spending his time in the bathroom.”

Alice- “I think it was in April or may... his case manager came to us and said you know you could apply for this particular program, [The Education Program] …And we applied but the deadline for the application was the 28th of February, and it's like... ok what was the point of even applying for it, right?”

Alice- “they determined that he met they're eligibility criteria, then they asked us permission to interview with his job coach at the autism society, and after they interviewed with her, they said no. They wouldn't take him. Because he required too much support for that particular service, right?”

Alice- “But we put his name on the waiting list for those things, for [Supportive Works] and we're still waiting to hear.”

Tracy- “I think the last year that he was there I think the school's relationship with the employment agencies was cut, and the follow through just didn’t happen.”

Tracy- “I think they’re doing some training in there but we haven’t pursued it and it hasn’t been offered to us, so it may be that they consider that he’s been trained, I don’t know, like they may want to give other people opportunities, and heaven knows there’s enough clientele to need the service.”

Tracy- “He can follow some simple directions. A complicated three or four or five step direction would not be suitable. And he learns things by watching somebody else do them or somebody else taking him through the skill.”

Tracy- “Yes, we actually did consider that at one point, and I know about that program but it requires a communication skill level that's higher than he's able to reach at this time.”

Appendix F:

Coded Researcher Notes

Communication	Economic Considerations	Education	Consistency	Barriers
'lack of communication on the job'	'52 on [wait]list for [Day Program]' 'Frustrations with wait lists'	'[not] expected to do enough [in] school.' 'Underestimating skill set.'	'[work] full day not half."	"Issues around disclosure [others] perceptions."
'Communicating in interviews'		'Fear of not being able to do the schoolwork.' 'Need[ed] help navigating [through] higher education.' '[need] more job training [and] coaching.'	'Supports--family [and] a good psychologist.' 'Good experiences with employment to date.'	'[found] interview[s] stressful' 'Issues around disclosure--[people's] perceptions'
'No awareness of [the Education Program at first].'	'[Put on waitlist for Supportive Works] after high school but have not heard back.	'Concerns with knowledge of autism at [Strides].' '[taught] interview skills, hygiene, budgeting.'	'[The Education Program] found him [adult child with ASD] employment afterwards.' 'Able to find him a job [and] job coach.'	'No support transitioning out of high school.' 'Rejected from program because needs were

‘Verbal level--simple instructions [and] learns through modeling	‘Issue [is that her son] needed [a] full time job coach.’ ‘[There are a] number of people who need the service.’ ‘Interesting points related to economic Considerations’	‘[number] of career opp[ortunities] [explored] at high school.’ ‘School class did recycling [and] food prep[aration].’ ‘[There was] assessment--pre program [Strides] [and an] interview with [the] family.’	‘Days needed to be planned out of high school [son] had a full time support worker.’ [Supportive Works] brought into school but didnt transfer to employment [there was] no follow through.’ ‘One staff worked hard to make it happen [placement with Strides program].’	‘Issues with hours of work’ ‘Hard to find a placement

Appendix G:

Researcher's Resume

Kerrie Cochrane
6 O'Neil Avenue, St. John's, NL, A1C 5G4
709-728-2636
kerriecochrane@yahoo.ca

Professional Highlights

- Completing final steps to become provisionally registered as a psychologist in Newfoundland and Labrador.
- Pursuing BCBA (Board Certified Behavior Analyst) designation. I have acquired 1300 of the 1500 supervision hours required to sit for the board exam.

Work Experience

Educational Psychologist	Newfoundland & Labrador English School District (NLESD)	Anticipated Start Dec. 2017
Behaviour Management Specialist	Eastern Health, St. John's Long Term Care & Community	January 2016-August 2017
Child Management Specialist	Eastern Health, St. John's	August 2011-Dec 2015
Counselling Internship with Educational Psychologist (High school setting)	Newfoundland and Labrador English School District, St. John's	January 2015-April 2015
Substitute Teacher	Newfoundland and Labrador English School District, St. John's	April 2009-June 2011
ABA Therapist	Private Home, St. John's	January 2008-May 2008
Substitute Teacher	Nova Central School District	November 2006-April 2007

Education

Masters of Education in Counselling Psychology	Memorial University of Newfoundland	Anticipated May 2018
Graduate Certificate in Applied Behavior Analysis (Mixed Delivery)	Pennsylvania State University, State College, Pennsylvania	August 2015
Masters of Arts in Art Education (Online Cohort)	Edinboro University of Pennsylvania, Edinboro, Pennsylvania	August 2011
Bachelor of Education (Primary/Elementary)	Memorial University of Newfoundland	August 2009
Bachelor of Education (Secondary)	Memorial University of Newfoundland	August 2005
Bachelor of Science (Psychology Major/Statistics and History minor)	Mount Saint Vincent University, Halifax, Nova Scotia	May 2003

Research Experience

Thesis: “Exploring the Employment Experiences of Adults with Autism”	Submitted for Review October 2017 Memorial University
Action Research Project: “Environmental Art Action: An examination into how art that is environmentally centered can improve grade 6 students’ awareness of environmental issues and promote action—a curriculum of doing.”	Completed March 2011 Edinboro University

Certificates and Professional Development

Association for Behavior Analysis International (ABAI) 43rd Annual Convention (Denver, Colorado)	May 2017
Teaching Verbal Behaviour to Children with Autism-Carbone Clinic	April 2017
Gentle Persuasive Approach in Dementia Care (1 day-Eastern Health)	January 2017
Essential for Living Assessment and Curriculum Guide (2 day--New Jersey)	October 2016
Non-Violent Crisis Intervention (CPI) (Eastern Health)	June 2017
WISC-V: A Comprehensive Overview (1-day--Eastern Health)	March 2015
Picture Exchange Communication System (PECS) (2 day--Pyramid Consultants)	February 2012

Awards

Outstanding Graduate Student (2011)	Edinboro University

Professional Memberships

Association for Behavior Analysis International (ABAI)

Atlantic Provinces Association for Behaviour Analysis (APABA)

Canadian Psychological Association (CPA)

Volunteer Experience

From 2001-2011: Friendly visitor at the Waterford hospital; Research assistant with a forensic psychologist, Survey developer for the Woman’s Film Festival; Coordinator of children’s art clubs and school fundraisers.

References

Available upon request