

**Exploring the Social Experiences of Adults on the Autism Spectrum: Views on
Friendships, Dating and Partnerships**

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Abstract

This thesis utilizes original quantitative and qualitative research and takes a structural/critical perspective of disability. Methodology involves participatory action techniques as questions were formulated from discussions with volunteers with autism/Asperger syndrome. The paper draws on the limited qualitative research in this area; including Sperry & Mesibov's 2005 study ("Perceptions of Social Challenges of Adults with Autism Spectrum Disorders") as well as Hurlbutt & Chalmere's (2002) long term qualitative study of 3 individuals with autism.

Persons with autism were surveyed regarding their experiences and opinions of relationships, their day to day lived experiences and their aspirations. The survey provided an opportunity for respondents to share both negative and positive experiences, as well as possible insights into how their communities could be more inclusive and provide better social opportunities.

While there is a considerable amount of research from the perspective of families, service providers and educators about persons with autism spectrum disorders, there is a startling lack of research involving the personal accounts of individuals with autism regarding their own social experiences. This study attempts to address this disparity by giving adults with autism a voice.

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Statement of Original Authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

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I. CHAPTER 1: Introduction

Research Question

This study examines the experiences of adults with autism as they attempt to develop and maintain friendships and romantic relationships.

Introduction

I became interested in this topic unexpectedly and rather slowly – through my work at Causeway Work Centre, in Ottawa, Ontario. Causeway provides vocational supports to any person with a self-identified barrier to employment. This organization deals with clients with all types of disabilities - including persons diagnosed with autism spectrum disorders.

As a member of our Employment Supports Program team, I see clients on a regular basis for up to 5 years – and over time, I came to know several clients diagnosed with autism spectrum disorders. Many of these individuals are highly motivated, intelligent and articulate; but I started to notice one particular issue brought up over and over again. Although many of these individuals were able to get and keep jobs with relatively minimal assistance, they often had an entirely different concern. They spoke frequently and intensely about experiences of social isolation. This goes against the popular misconception that persons with autism neither want nor need close social relationships with others. A response to this myth is well-articulated by a participant in Sperry & Mesibov's 2005 study examining the social experiences of adults with autism:

I've been in dating relationships, so don't tell me autistic people cannot handle marriage relationships or dating relationships. It's a matter of choice. If

you really want to make it work, you will go for it. I mean it makes me so angry when people say ‘well, normal people can get married and autistic people can’t.’ That’s garbage! (p.372)

Qualitative evidence as well as common sense indicates that people with autism have varying attitudes, interest and involvement in the realm of the interpersonal – and of course, the same can be said of the general population. However, both personal experience and the current literature indicate that despite often comparable levels of social and romantic interest, persons with autism spectrum disorders can experience significant barriers to connection. For instance, the interpersonal concerns that my clients brought up included, but were not limited to: uncertainties about how to begin romantic relationships, confusion over social rules and mores at work and even alienation from family members. Although individual experiences varied, there was an overarching message of loneliness. It seemed that feelings of isolation were sometimes reduced by being connected to a supportive work environment. But for some, this only seemed to emphasize a distinct feeling of “otherness”. They saw their workmates developing close friendships and did not understand why they were excluded.

The literature I consulted did not fully answer my questions. Most of it was centred on social skills training for children and youth and generally contained recommendations from an outsider’s perspective (usually from the viewpoint of a family member, school or agency). There were few descriptions of experiences of the *adult* with an autism diagnosis – and scarcely any in their own words.

Due to my aforementioned background, I must be explicit in my own bias. I both work and volunteer with persons with disabilities in Ottawa and as such, have a non-objective interest in the population and issue at hand. I also have my own pre-conceived notions – as described above – about what might be found in the research results.

Theoretical Context

This research is first and foremost informed by a social model of disability, defined by authors Oliver & Barnes as: "...disadvantage or restriction caused by a contemporary social organization which takes little or no account of people who have...impairments and thus excludes them from the mainstream of social activities" (Oliver & Barnes, 1998, p.18). This pertains to the following research project in several ways. Firstly, the project was purposefully constructed to include participants in the research process by allowing them to guide the researcher in the creation of a survey instrument. Through this process the researcher is acknowledging that the traditional practice of excluding persons with autism from research processes and academia further contributes to their exclusion from wider society and can be viewed as an oppressive act. This movement towards participatory action is by no means perfect or complete, but constitutes a starting point as well as an acknowledgement of the importance of including the voices of persons with autism in the research as much as possible. Secondly, the project adheres to a social model of disability as it asks respondents to consider external variables such as work, school and available social opportunities in their communities and recognizes that wider structural issues have just as much of an impact on the quality of life of persons with autism as any

symptomatology or factor related to a diagnosis. In fact, it is likely that for some individuals, external factors have an even greater impact on social experiences than any individual factor alone.

Related to the discussion of the social model of disability is the concept of “neurodiversity”. Neurodiversity is a relatively new concept in the discourse pertaining to persons with autism; first described by adults with autism looking for a positive label to describe their differences – different ways of thinking, processing and expressing information (Krahn & Fenton, 2007). Proponents of the neurodiversity perspective argue that neurological uniqueness is rather common in the natural world and should not necessarily be equated with disadvantage. They consider many current mental illnesses, emotional and behavioural impairments to also fall under the umbrella of “neurodiversity”, including not only autism/Asperger syndrome, but also Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder, bipolar disorder, schizophrenia, and various cognitive impairments, among others.

Furthermore, neurodiversity advocates promote positive understandings of autism and the countering of public rhetoric that describes autism as pathological and undesirable. Many oppose the idea of “curing” autism – rejecting a medicalized view of neurological difference and embracing the idea of wider social change and inclusion instead (Bumiller, 2008). This is interesting in the face of overwhelming public interest in investigating causes and cures. Currently, the most popular treatment is Applied Behavioural Analysis and Intensive Behavioural Intervention models of intervention for children with autism. Neurodiversity advocates criticize ABA/IBI for attempting to entirely rid children of autistic traits – as well as it’s

restrictive, repetitive and time-consuming nature. These therapies also do not directly address social skills per se but instead focus on the acquiring of language skills and other cognitive abilities. Children learn these skills within a repetitive teaching routine involving various tasks interspersed with rewards in quick succession.

That being said, to simply present neurodiversity as the whole truth is not entirely accurate. To do so would also partially negate the purpose of this proposed research project: to explore the lived social realities of persons with autism from an individual perspective. If the interpersonal problems faced by persons with autism are largely caused by a society that does not understand nor accommodate them (an extreme characterization of the neurodiversity movement) – why seek to understand the individual experiences of persons with autism at all? The answer instead would be to focus *all* energies on understanding and changing the structures that oppress individuals with social differences; and in doing so, we would be rejecting the idea that persons with autism might also desire or benefit from supports and programs that help them to connect socially. The idea that all social issues or barriers experienced by individuals with autism are the result of oppressive external forces can also be somewhat belittling as it implies that they are merely powerless victims within an unjust system. In fact, some individuals with autism have communicated that they are very content to interact within a unique autism “culture” and that they do not necessarily feel compelled to engage in social interactions with most neurotypical persons (Hurlbutt & Chalmere, 2002). Yet others still enthusiastically support the ABA model of therapy and credit it for drastically improving their life quality.

In response to the idea of the person with autism as a victim (and the dominant “deficits model” contained in most past and current research) this study will also take a strengths-based model as much as possible. This is difficult because social “impairments” are a defining trait of DSM autism diagnoses; yet to ignore the positive adaptations and experiences of the study participants would produce an incomplete picture of their lived realities. Persons on the spectrum often rise above societal barriers and expectations as well as their own individual challenges to make connections with others. As there is very little research available exploring how adults with autism connect socially – and even less concerning “successful” social connection - it will be very interesting to explore this topic in greater depth.

Statement of the Problem

1. This study is designed to investigate the social experiences of adults on the autism spectrum; to explore the lived social realities of participants, which might include: potential barriers to inclusion, suggestions for change and social experiences both negative and positive.

Significance of the Problem

Autism spectrum diagnoses are increasingly prevalent and are associated with serious implications for learning, social integration and overall quality of life (Fombonne, 2003; Matson & Kozlowski, 2011; Hughes, 2009; Newschaffer, Croen, Daniels, Giarelli, Grether, Levy, Mandell...Wyndham, 2007). There is also considerable research already indicating a link between diagnoses of autism spectrum

disorders and increased rates of social isolation as well as reported feelings of depression and anxiety (Barnhill, 2001; Hutton, Goode, Murphy, Le Couteur & Rutter, 2008; Kim, Szatmari, Bryson, Steriner & Wilson, 2000; White & Roberston-Nay, 2009). However, it is my belief that this experience of social isolation and related emotional sequelae are not solely “individual” problems to be studied from psychological, physiological or neurobiological perspectives alone.

Admittedly, examining autism through a social models lens is complex; particularly because “social impairments” have always been a large part of Autism Spectrum Disorder diagnoses. The following traits were noted by Kanner (1943) and they are still a major part of the current DSM diagnosis: lack of acknowledgement of others and difficulty understanding the non-verbal communications of others (gestures, facial expressions and body language). Ozonoff, Pennington & Rogers (1991) suggest that these characteristics represent an undeveloped “theory of mind”; that persons with autism have difficulty understanding, predicting and empathizing with the perspectives of other people. Ostensibly as a result of these social differences, many persons with autism often report employment difficulties (Spicer, 1998). “Higher functioning” adults also report their own particular difficulties attempting to meet social needs related to increased self-awareness and their unique position between neurotypical persons and persons with more severe disabilities (Howlin, 2000).

However, simply noting that persons on the autism spectrum experience social challenges does not provide any clear cause and effect relationship; and research on possible neurobiological differences (e.g. Neuhaus, Beauchaine & Bernier 2010)

while interesting, does not necessarily help us integrate autistic persons into our communities. In my opinion, the continuous focus on the functioning of the individual alone without consideration for social context only serves to further exclude autistic persons from mainstream society. Autistic persons are deemed both socially unworthy and socially undesirable as a result. When we label autistic persons as “socially impaired”, persons with autism are stigmatized and unnecessary hierarchies are created. Instead of working together towards creating inclusive communities, our efforts are instead spent on finding cures and causes. This is certainly the dominant ideology today and clearly evident in most of the available research.

Platonic relationships such as friendships and work relationships can be challenging, but romantic relationships add yet another layer of complexity. Gougeon (2010) views autism and sexuality as a particularly controversial topic due to the persistent stereotyping of the disabled person’s sexuality. It is possible that this contributes to rather sparse amount of research and discussion in this area. Griffiths (2003) notes that society tends to label the sexuality of individuals with developmental disabilities as child-like, deviant or hypersexual. Persons with disabilities must often constantly deal with state, agency and family interference when it comes to dating and sexuality choices as a result. Even though that interference might be well-intentioned – as in the case of parents fearing for their child’s vulnerability to sexual predation – it is still a reality that many persons with disabilities are subject to a high degree of intrusion and sexual/romantic “policing” by others.

Yet, despite all of this, there is little research on the social experiences of persons with autism – in their own words. A cursory glance at the existing literature reveals this issue is generally explored from the perspective of the family or agency involved with the individual diagnosed with autism. While these outside views are certainly valuable and add richness to our understanding of the issue, it does not give us much insight into the internal experiences and day-to-day realities of the individual. The importance of internal thoughts is especially important when we consider that many persons with autism have different ways of communicating that are not always heard.

Defining Terms

In this study, “persons with autism” or “persons with autism spectrum disorders” will encompass any person with diagnosed autism, Asperger syndrome or pervasive developmental disorder not otherwise specified. It is used here as a non-specific term to describe a range of possible diagnoses and identities. “ASD” will also be used from time to time when brevity is required.

“Social experiences” will refer to any interpersonal relationship, but focusing primarily on friendship and dating relationships in this paper. It could also include other important relationships, such as collegial, workplace, volunteer or mentor associations.

Lastly, there will be some discussion of the neurodiversity debate.

“Neurodiversity” refers to the movement of individuals who have cognitive, social or emotional differences (in this case, autism) and who view their neurological differences as valid and not inherently flawed or in need of curing. By contrast, the

word “neurotypical” is also used to refer to persons without autism – and generally people who do not have any significant cognitive, emotional/social challenges or other diagnoses.

Limitations of the Study

The population sample will be restricted to the Ottawa, Ontario, Canada urban area. Thus, any research results will be most applicable to that area. As well, a major limitation of the study involves the sampling method: as the participants will be recruited from non-profit service centres and other organizations, adults on the autism spectrum who do not access services in the community will be necessarily excluded from the survey and interviews. This could mean that the voices of more isolated/under-served individuals *or* those who do not feel the need to access services are both excluded from this research. This represents a potential self-selection bias that will be difficult to counter (i.e. how would one reach adults who do not access services?). [Also see section relating to recommendations for future research].

Thesis Outline: Description of Chapters

The initial chapter preceding this outline introduced the topic by explicating the research question, as well as a brief explanation of its importance both within the literature and as a matter of individual and wider social significance. The second chapter will consist entirely of a literature review, with the following subheadings: Social Functioning Deficits and the Autism Diagnosis, The Neurological Evidence for Differences in Social Functioning, Are Individuals with Autism More Socially Isolated?, Defining and Measuring Friendship and Loneliness, Further Evidence for Social Interest and Social Disconnectedness, Sexuality: Interest and Access, The

Effects of Social Disconnectedness on the Individual, Current Interventions, and How are Adults with Autism Faring? Research in Their Own Words.

The third chapter will outline the research design for the project, including a description of methodology, the population and sample, instrumentation, data collection, data storage and data analysis techniques.

The fourth chapter details the research findings and the analysis. The first part will concern all quantitative findings, including: frequencies, and various cross tabulations and graphs. The second part will examine the qualitative findings by grouping participant responses into themes, including: Structure and Familiarity, Crowds versus Small Groups, Positive, Negative and Mixed Social Experiences at Work and School, Making Friends, Suggestions for Improving Connectedness from Participants, Social Disinterest of Lack of Access? and Online Interaction.

The fifth chapter contains the discussion, which analyzes the findings in greater detail and compares and contrasts these findings to current literature as well as current disability theory and discourses. The conclusion follows as a relatively brief overview of each preceding section with recommendations for future research.

II. CHAPTER 2: Literature Review

Introduction

It was not that long ago that many individuals with autism spectrum disorders, developmental delays or other cognitive impairments were forced to live out their lives in relative isolation, separated from the rest of society; in both “sanatoriums” as well as the hospitals and long-term care facilities of the more recent past (Lemay, 2009). Thus, at least comparatively speaking, it appears that some progress has been made towards the social inclusion and overall improved quality of life for persons with autism since the deinstitutionalization movement of the 1970’s and 80’s (Lemay, 2009). The noble vision for more inclusive communities is described by Knoll & Peterson (1992):

In inclusive communities, we move from focusing on services provided exclusively by agencies to support for involvement in typical community activities, based on the needs and choices of the individual. Disability service agencies work in partnership with community services, support networks (friends, families, peers) and the person with the disability. The primary role is to help connect and support the individual in school, home, community and work (p.1).

This is certainly a good vision, and the emphasis on community comes close to validating the need for social connection. However, it does not quite address the more intimate social needs of persons with disabilities, and indeed, most human beings: the need for friendships and romantic partners. It can be a relatively simple matter to refer a person to adequate vocational or educational supports - but an entirely different and more complex undertaking is to ensure that someone is not

lonely. This outcome is also much more difficult to measure. Yet there is ample evidence to indicate close relationships are desired by persons on the autism spectrum (Gougeon, 2010; Sperry & Mesibov, 2005; Hurlbutt & Chalmers, 2002; Hobson, 1992), although they might have different ways of processing social and emotional information. Temple Grandin, (an autism activist, professor, author and animal science doctorate recipient – and person with autism) has a fascinating way of describing her unique perspective on human relationships (1990):

All my thinking is visual; I have almost no verbal thought. When I think about abstract concepts, such as relationships with people, I use visual images, such as a sliding glass door. Relationships must be approached gently because barging forward too quickly may shatter the door. Thinking about the door was not enough; I had to actually walk through it (p.5).

It is the hope of this author that this study will shed some light on the social experiences, preferences and insights of persons on the autism spectrum – from their perspectives and in their own words. There is considerable evidence to indicate persons with autism have difficulties starting and maintaining intimate relationships, engaging in socially appropriate behaviours, maintaining employment and in gaining inclusion into their communities (Sullivan & Caterino, 2008; Travers & Tincani, 2010). Marriage, Wolverton & Marriage (2009) also found that multiple life outcomes – including the attainment of stable employment and long-term relationships – seemed particularly out of reach for autistic individuals with co-existing intellectual disabilities. [“Autism” of course is quite complex and many persons on the spectrum (especially those with Asperger’s Syndrome) are considered

“high-functioning” and have normal or above average IQ scores. However, intellectual disability does remain an issue for many persons with autism spectrum disorders]. At the same time, there is evidence that “high-functioning” individuals, such as those with Asperger syndrome, have their own particular struggles related to gaps in services and higher rates of loneliness due to increased social awareness (Whitehouse, Durkin, Jaquet, & Ziatas, 2009).

This literature review will focus on a few specific areas relevant to the research question, including: exploring the social/communication deficits inherent to the autism diagnosis, neurological evidence for social/communication differences, research exploring levels of social interest and social isolation of persons with autism, the effects of social isolation as well as an examination of current “treatment” models for improving social connectedness in persons with autism (most notably the social skills training model). There will also be a brief summary of qualitative research from the perspective of persons with autism.

Social Functioning Deficits and the Autism Diagnosis

Why do social skills (and thus the quality of future social interactions) develop along a different trajectory for persons with autism than their neurotypical counterparts? Social skills and communication deficits have always been central to the diagnosis of autism (Kanner, 1943) and these topics continue to dominate the literature today – with the greatest interest in *children* with autism in particular.

The DSM (APA, 1994) describes the following social deficits in persons with autism: poor eye contact, a failure to develop peer relationships appropriate to their

developmental level, abnormal emotional intonations in voice and speech, marked impairment in the use of multiple non-verbal behaviours such as eye-to-eye gaze, facial expression, body postures and gestures to regulate social interaction and the failure to spontaneously seek to share enjoyment, interests or achievements with other people (p. 126). The DSM further summarizes the deficits as affecting all domains essential to social connection including communication, restricted interests/sensory activities and repetitive behaviours, among others.

More recent research has only seemed to affirm the original diagnoses outlined by Kanner. Children diagnosed with autism continue to be associated with a multitude of social/behavioural markers, including: less “eye gaze” and joint attention with interactive partners (Baker, Koegel & Koegel, 1998), problems imitating simple motor movements (e.g. “patty cake”) (Stone, Ousely, Littleford 1997), difficulty orienting to social stimuli in general (Dawson, Mentzoff, Osterling, Rinaldo & Brown, 1997), difficulty understanding facial expressions and their meaning (Celani, Battachi & Arcidiacono, 1999), lack of outward response and difficulty understanding other people’s distress (Hauck, Fein, Waterhouse & Feinstein, 1995), decreased instances of social interaction initiation (Fein, 1995) as well as impairments in spontaneous play and the initiation of pretend/imaginary play (Libby, Powell, Messer, & Jordan, 1998).

It becomes evident that the vast majority of literature in this area has indeed been focused on young children (e.g. Gena, Krantz, McClannahan, 1996; Timler, Vogler-Elias, & McGill, 2007). Particular attention has been paid to the categorizing of behaviours (and hypothesizing on their causes) along with the effectiveness of

certain interventions – especially in school-based settings and as they pertain to learning in class. Popular behavioural interventions, such as the dominant Applied Behavioural Analysis model, nearly always feature the adult as the mediator/agent of change. There is very little research demonstrating interventions based *within* childhood or adolescent social structures. Furthermore, there is even less research demonstrating the efficacy of these early interventions in improving social skills and connectedness into adulthood and over the lifespan. Weiss & Harris (2001) noted that literature on “social skills” for “older students and adults [with autism] is “quite limited” (p. 796) and this still seems to hold true 10 years later.

The Neurological Evidence for Differences in Social Functioning

Schultz, Grelotti, Klin, Kleinman, Van der Gaag, Maroi & Skudlarsk (2005) speculate that aberrations in face perception are actually at the root of all social deficits intrinsic to the autism diagnosis. They point to the marked neurological differences observed during social perception exercises – notably, the perception of facial expressions and identity – between persons with autism versus neurotypical individuals (Schultz, Grelotti, Klin, Kleinman, Van der Gaag, Maroi & Skudlarsk, 2003; Grelotti, Gauthier & Schultz, 2002; Joseph & Tanaka, 2003)

Schultz et al explain: “...aberrations in face perception, perhaps stemming from developmental failures of the amygdala signaling system, not only affect social perception, but are compounded to create deficits in social knowledge as well. This would have a profound influence on the social skill areas that are deficient in autism” (p.126). For neurotypical individuals, it might be difficult to imagine a world where

faces and their expressions are confounding, as most people perceive and process their meaning unconsciously and automatically, but: “Given that all faces are perceptually similar in terms of their features...and configuration...this seemingly simple act of everyday face recognition turns out to be an unprecedented feat of visual perception” (Schultz et al, 2005, p.127).

This view is supported by a neuroimaging study by Dawson, Webb, Wijsman, Schellenberg, Estes, Munson & Faja (2005) where the face recognition skills of *parents* of children with autism were studied as well. It was found that their brain patterns mirrored the atypical response seen in individuals with autism; that is: “a failure to show a negative component latency advantage to face compared to nonface stimuli and a bilateral, rather than right lateralized, pattern of N170 distribution” (p. 679, 2005). This very technical description basically describes the fact that persons with autism demonstrate a unique brain response to seeing faces. Whereas neurotypical persons generally react to seeing faces with increased activity in the right hemisphere exclusively, both hemispheres of the brain show significant activity in persons with autism.

Are Individuals with ASD More Socially Isolated?

There is evidence to suggest that children with disabilities are more vulnerable to loneliness and social isolation (Luftig, 1988; Pavri & Luftig, 2000; Williams & Asher, 1992). A study of 20 adolescents authored by Locke, Ishijima, Kasri, London (2010) found that classmates with autism experienced significantly higher levels of loneliness, had lower “friendship quality” (less companionship and helpfulness within

their friendships) as well as lower “social network status” among peers. A full 71.4% of adolescent respondents with autism were rated as “isolated” or “peripheral” within the classroom’s social structure.

Another study of 235 adults and adolescents with autism living at home investigated participation in social/recreational activities and levels of peer relationships (Orsmond, Krauss, Seltzer, 2004). Their respondents reported low levels of social connectedness overall, though certain individual and environmental differences seemed to mediate levels of social participation. They found that engagement in social/recreational activities increased along with greater levels of independence and better social skills (individual traits) *as well as* higher levels of inclusion in school settings and number of services received (environmental/structural factors) (p. 245).

Defining and Measuring Friendship & Loneliness

Loneliness is a complex concept that is difficult to define and quantify, for although it is a fairly universal emotion, it is dictated by various internal and external dynamics and is certainly not experienced by everyone in the exact same way. It can be described simply as an undesirable feeling associated with negative affect (Margalit & Efrati, 1996) as well as an awareness of a perceived gap between an actual and a desired social status (Asher, Parkhurst, Hymel & Williams, 1990). The latter definition might be of particular relevance for this research project as it recognizes the importance of both internal (level of awareness) and external (social exclusion/participation) factors. Bauminger & Kasari (2000) also note that loneliness is quite different from a preference for solitude, as solitude can have a positive

connotation and does not imply exclusion per se. Asher et al (1990) hypothesize that loneliness may in fact be an extremely strong motivating factor towards social interest and bonding. Bauminger et al. (1993) found that children with autism were also quite able to understand loneliness and the development of a close friendship as a loneliness protective factor.

Perhaps even more difficult than *defining* difficult constructs like social exclusion, love, friendship and loneliness is attempting to measure their levels within a population as misunderstood and diverse as persons with autism. Baron-Cohen & Wheelwright's (2004) study attempted to track predicted differences in friendship quality between neurotypical adults and individuals with autism. They theorized that both neurotypical men and adults with autism would receive a lower score on the "FQ" (Friendship Quotient) scale – not indicating that they did not value friendships, but that they did not "need" relationships as close and "empathetic" as their high "FQ" score counterparts. The authors define this type of friendship as stereotypically "female" and theorize that autism spectrum disorders could represent some sort of "extreme male pattern" (Baron-Cohen & Wheelwright, 2004).

The authors found that their predictions were generally correct; however, it still seems problematic to try and capture the depth of a relationship (and one's internal emotional responses to those relationships) through a quantitative scale alone. Assigning individuals with autism a low FQ score in itself seems to have the potential to stigmatize more than help. The authors confidently assert that their respondents with autism experience relationships that are neither as close nor as empathetic as those experienced by neurotypical controls – but there is certainly conflicting

research in this area. For instance, an interesting study by Rogers, Dziobek, Hassenstab, Wolf & Convit found that persons with Asperger syndrome in their study of empathy demonstrated levels of affective empathy not radically different than neurotypical controls and in fact, their respondents scored higher on average in some testing domains (2007).

Further Evidence of Both Social Interest and Social Disconnectedness

There is considerable literature available to counter the commonly held belief that people with autism do not desire friendships. Contrary evidence can be found in Jobe & White's 2006 study of loneliness and friendship quality in adults with autistic traits and their neurotypical peers. They found that the respondents in their undergraduate sample with a "stronger autism phenotype" (rigidity, preference for sameness and high attention to details) reported significantly more loneliness ($r=.52$, $p<0.01$) along with friendships that were fewer and shorter in duration. The authors hypothesize that the loneliness experienced by some of their respondents with autistic traits could be due to "lack of social skills and understanding" and not due to lack of social interest: if individuals were content to be alone, they would not be reporting negative affect directly related to loneliness (p. 1). There is conflicting evidence in this area, as Baron-Cohen & Wheelwright (2004) found that respondents with higher "Autism Quotient" scores actually tended to report *longer* relationships. However, it is possible that this finding could be related to the "preference for sameness" discussed by Jobe & White (2006).

Ample evidence exists to confirm moderate to high levels of social and sexual interest in persons with autism. Stokes & Kaur (2005) study of parental concerns found that levels of sexual interest in their adolescents was high, but identified the need for social skills training. Additionally, Newport (2002) found evidence for interest in marriage later in life. Various other studies also exist in the literature to support interest in obtaining or keeping a single friendship (Baumringer & Kasari, 2000; Baumringer, Shulman & Agam, 2003; Koning, Magill-Evans, 2001; Osmond, Krauss & Seltzer, 2004). Chamberlain (2007) also found that children involved in a regular education program with other “neurotypical” peers were considered to be “on the periphery of their classroom social structure” but that they tended to at least be associated with one social group (p. 76) – so it seems that social isolation and/or disinterest is not always the norm and may depend on environmental factors as well as individual differences.

Important to note is that so-called “high functioning” forms of autism (such as Asperger syndrome) can present particular difficulty for individuals as they are often associated with a higher level of awareness; thus, individuals might be *more* aware of their lack of social connectedness (Carrington & Graham, 2001). Bauminger & Kasari (2000) also found that children with *high functioning* autism reported greater levels of loneliness and less “friendship satisfaction”. Thus, the different research findings in this area could be due the diversity of the population being studied; individual differences in age, autism diagnosis, type of autism disorder as well as levels of functioning and personality attributes could account for conflicting results within the literature.

Further evidence of this diversity can be found in Downs & Smith (2004) work. They studied levels of emotional understanding, cooperation and social behaviour in children with high functioning autism, children with ADHD, children with Oppositional Defiant Disorder as well as “neurotypical” children. They found that children with autism who participated in their study did not differ significantly from their “normally developing” peers in their levels of cooperative behaviour and emotional understanding and actually outperformed those peers diagnosed with ADHD and ODD (p. 625). The authors found that the children with high functioning autism were quite capable of inferring emotional states from narratives (“How would Tina feel if...?”). They did note deficits in the identification of emotions (from facial expressions) and ability to demonstrate socially appropriate behaviour, which is consistent with other literature – including neurological imaging studies that show unusual processing of facial expressions in the brain (Schultz, 2005). These findings are interesting as it presents a counterpoint to arguments put forward by several prominent researchers (Baron-Cohen, 1995) that persons with autism lack a “theory of mind” – essentially, the ability to imagine the perspectives of others; the capacity for empathy – which is also an essential part of forming meaningful relationships.

Locke, Ishijima, Kasari, London (2010) suggest that loneliness and exclusion might sharply increase by high school due to classmates changing each period; along with the increasingly complex demands of young adult relationships vs. the relative simplicity of childhood friendships. Locke et al summarize (p.76): “As children enter adolescence, services become fewer and the gap between neurotypical peers and individuals with autism generally widens”. To this end, Locke et al ponder how we

can be certain that childhood social skills interventions currently en vogue are effective without examining the experiences of adolescents and adults who have been exposed to these programs.

Farmer & Farmer (1996) also suggest that because friendship is often defined by shared interests and as interests become exponentially more diverse by high school, this further increases the difficulty of obtaining friendships later in childhood and adolescence. For example: relationships are no longer built solely around a few common interests: lunch time, the playground and school yard games, etc. The importance of intimacy within friendships and sexual relationships increases (Howard, Cohn & Ormond, 2006) - which of course, requires greater emotional maturity and a more sophisticated array of social skills.

Yet, despite a fair amount of research into autism and loneliness, there is very little research on the *nature and quality* of friendships experienced by individuals with autism. Locke et al (2010) suggest that this is due to the old belief that friendships held by autistic persons are either a “rare phenomenon or impossible feat” (p. 75).

Sexuality: Interest and Access

Nichols, Blakely and Smith (2010) examined healthy sexuality and persons with autism by interviewing parents of adolescents/teenagers with autism. Because studies have indicated that individuals with autism have levels of sexual interest comparable to that of the general population (Henault and Atwood, 2002), they emphasize the importance of sexual education. Kaur (2007) found that adolescents and adults with autism obtained less romantic knowledge from their peers and media

than their “neurotypical” counterparts; instead, their knowledge came from parents or from making their own social observations. For this reason, Nichols, Blakely & Smith (2010) believe that parents are the “best sex educators”.

The parents in the Nichols, Blakely and Smith (2010) study shared concerns and confusion; i.e. “that they feel unclear about what healthy sexuality could look like for their child” (p. 78). One parent shared:

I would love for my son to have loving relationships with people in his life that are a substitute for sexual relationships (p. 78).

Other issues raised by parents included worries that their children would have struggles understanding privacy, boundaries, personal space and social cues. All parents in the study expressed concerns about sexual abuse and exploitation due to the increased vulnerability of their children along with fears that their children might also exploit others unintentionally. Another parent shared: “I’m worried that my son is going to be perceived as a stalker when he is just lonely and wants someone to talk to” (p. 80).

The issue of “sexual access” for persons with disabilities is applicable to persons with autism. This matter was discussed in a 2003 conference report by Grossman, Shuttleworth & Prinz. The authors use the example of a person with a speech or communication impairment attending a party: this individual has physical access to the party but “negotiating dates” (p. 92) could prove quite difficult. In this sense, they are “denied access” due to a variety of factors (e.g. social stigma, noise level and being generally misunderstood by others). The authors note that overcoming

these barriers could be particularly difficult for a persons living in a more restrictive home environment such as a group residence or institution. Grossman states (2003):

The notion of development tends to homogenize bodies and minds, sensations and emotions, with the description of one trajectory for all people within a given population. As a result, the sexual identity development trajectories of disabled people are disciplined with silence for their unwillingness (or inability) to conform to this standard (p. 2).

Shuttleworth believes that improving this access could be as simple as increasing the media representation of persons with disabilities as a means of improving “sexual confidence” and shattering negative stereotypes. It is true that the social, romantic and sexual lives of persons with disabilities are very rarely explored in popular mediums like television, film or advertisement. Shakespeare (in Grossman, Shuttleworth & Prinz, 2003) agrees that increasing the profile of persons with disabilities will in and of itself help ameliorate social/romantic isolation and combat the invisibility of disabled person’s sexualities. He suggests that collecting narratives of persons with disabilities in research and academia is one such method to combat the invisibility of sexuality of disabled persons (p. 95).

The Effects of Social Disconnectedness on the Individual

What are the immediate and long term effects of being socially disconnected or isolated? Rubin, Dwyer, Booth, Laforce, Kim, Burgess & Rose-Krasno (2004) found that generally, children without friends experience decreased self-esteem, delayed social skills development and poorer school performance at increased rates.

Furthermore, it seems likely that social isolation will ensure that more advanced social skills are less likely to be learned - potentially leading to greater isolation (and stigma) in the future. Other studies, such as Sandstrom & Zakriski (2004) found that loneliness in both adolescence and college led to greater rates of social anxiety and alienation.

Conversely, the positive effects of social connection in the general population cannot be overstated. One study of 222 undergraduates by Seligman (2002) compared the upper 10% of “very happy” people with their average and very unhappy counterparts. The happiest were the most highly social and had the strongest romantic and social relationships with other people. They also scored the lowest on several psychopathology scales. No other variable (like exercise or external “objectively defined good events”) was identified as being necessary for a high happiness score *except good social relations*. Some animal studies have even found a link between positive social relationships and physical health – such as the startling study by Williams, Pang, Delgado, Kocherginsky, Tretiakova, Krausz, Pan, He, McClintock & Conzen (2009) that found cancer in mice increased markedly when they were socially isolated.

Current Interventions

A review of 16 empirical studies by Hwang & Hughes (2000) found that while early social skills interventions were generally successful, there was limited evidence for the long term maintenance and generalizability of their effects. Improved communication skills, eye contact, joint attention and imitative play were indeed found but not generally replicated outside of the training context. Thus, the authors

conclude that the interventions “promoted more advanced preverbal and verbal communication...in daily classroom activities” (p. 342).

The use of “social scripts” is another method that has been used to increase social skills of children with autism with some success. Krantz & McClannahan (1994) used scripts to encourage the initiation of peer interactions of children with autism. Scripts have also been used to increase imaginative/sociodramatic play (Goldstein & Cisar, 1992) and it was found that over time, children with autism would deviate from the script and initiate more contact with peers throughout the sessions.

Another promising intervention currently being used is the implementation of “social stories” as social skill training (including sex education) for individuals with autism. A social story can be defined as “...a short story with specific characteristics that describes a social situation, concept, or social skill using a format that is meaningful for persons with autism spectrum disorders” (Reynhout & Carter, 2007). In practice, it involves identifying a target behaviour or skill to learn, creating the story/rehearsing the skill (e.g. through role-playing) and then monitoring or measuring the efficacy of the training (Tarnai & Wolfe, 2008).

Swaggart, Gagnon, Bock, Earles, Quinn, Myles & Simpson (1995) found evidence for the effectiveness of social stories in teaching social skills to children with autism. Although there is no current research to suggest the effectiveness of this training with adolescents and adults, it could be the basis of future research.

An interesting study that examines a “peer initiation model” as a means to increase social interactions between young adults with autism and peers without

autism was authored by Haring & Breen in 1992. It is unique in that it explores what peers without autism can do to promote social inclusion of peers with autism. The authors designed a “social support network strategy” wherein neurotypical youth provided support to peers with autism. Frequency of interactions as well as “appropriateness” (i.e. meaningfulness and relevance) of those interactions was found to increase and by the end of the study, many classmates described their peers with autism as friends.

Hwang & Hughes (2000) postulate that early social deficits (such as those described previously) may eventually broaden the gap between children with autism and non-autistic children even more as time goes on - and that it is the development of social/communication skills that will narrow this gap and increase rates of social inclusion. Hwang & Hughes therefore advocate for early “social interactive strategies” interventions – such as those found in Applied Behavioural Analysis therapies that currently dominate autism interventions; e.g., requiring a child to ask for a preferred toy explicitly before it is given.

How are Adults with Autism Faring? Research in their own Words

In terms of research that has been undertaken on this specific topic (social experiences and adults with ASD), the results have been interesting and in some ways, surprising. Sperry & Mesibov (2005) investigated the social experiences of adults with autism in their qualitative study “Perceptions of Social Challenges of Adults with Autism Spectrum Disorders”. The participants (three groups of adults in already established support groups for persons with autism) generated social

questions they encountered as a result of having autism. In the discussions that transpired, several significant themes emerged. These included, but were not limited to: relationships at work, maintaining and developing interpersonal relationships in general, appropriate dating behaviour as well as personal perspectives of navigating the social world as a person with ASD (Sperry & Mesibov, 2005). Although the main purpose of the study was to identify social “challenges”, it is notable that many respondents were able to articulate strategies for “solving” these social questions. For example, respondents provided a multitude of insightful and detailed strategies to deal with issues such as disagreements at work, asking people out on dates and even specific quandaries like assessing personal space and joining in on conversations. One respondent had this to say on the topic of extending a positive conversation with a person of interest:

Well, first of all, to extend a conversation you want to show interest in the other person, it's not too hard; you just want to ask questions. Showing interest, letting them know you are interested in what they have to say is one of the main things no matter what kind of conversation you are having. Extend could be to go more sensitive, or more personal, or more intimate, not just deeper. What kind of extension are we talking about here? (p. 370)

Hurlbutt & Chalmere (2002) authored an excellent qualitative study of three adults with high functioning autism over a 9 month period in order to identify themes and unique life experiences. The interviewers used only two questions: a) describe your life and b) how has autism affected your life? One central theme discussed by participants was the idea of culture. These adults maintained that high functioning

persons with autism identify themselves as being part of a unique culture or community as well as experts on autism with their own valuable knowledge to share – particularly with young people with autism but also with educators and the general “neurotypical” population.

The respondents also identified social supports as being essential to their life and development – primarily family but also social groups (including church communities). They also shared that they felt social skills training (including the use of support groups and “social stories” training) were important educational experiences for persons with autism. They brought up issues with dating, particularly in identifying what body language and other non-verbal cues meant in social situations. One participant stated that he was “unable to understand the difference between friendship and romance” (p. 105, 2002). Interestingly, these social barriers were identified as particularly problematic in the field of employment with a respondent noting that jobs were “80% social skills and 20% work” (p. 108).

Perhaps some of the most intriguing and significant additions to qualitative research in this area have come from an unexpected source: anthropology. Most anthropologists naturally focus on the rich ethnographies of the individual and tend to reject the medicalized view of autism. One such anthropologist (and individual with Asperger syndrome) is Dawn Eddings Prince (2010), who has written a very insightful account of her experiences and view of the world as a person and parent with Asperger syndrome. The following quote demonstrates her perspective that receiving a diagnosis of Asperger syndrome is not synonymous with emotional blankness or social disinterest:

When most people think of autism they think of violent, unreachable people in worlds completely of their own making, worlds without keys, without structure, feeling no empathy, lacking imagination, and unavailable to the deepest of human needs for contact and love. Having autism is the worst fate parents can imagine befalling their children and they dread its impact on their families (p. 58).

Conclusion

The literature related to autism and the social experiences of persons with autism is considerable in some areas but greatly lacking in others. There is a burgeoning literature demonstrating higher rates of social isolation and loneliness in persons with autism, but a deeper analysis of these phenomena is still largely missing. It is clear that so far, most research has been focused on either medical/neurological studies examining difference or on the integration and learning processes of children in classroom settings. There are a few interesting studies investigating interventions specifically targeted at improving social connectedness and social functioning (e.g. Goldstein & Cisar, 1992) but this author could find very little pertaining to older youth or adults across the lifespan. This could be due to the fact that increasing autism diagnosis rates is still a relatively recent development, and could also be due to a medical model lens pervading the majority of research in this area – a perspective that puts greater value in the measurable and the “curable”. There is also much more prestige involved in offering autism “solutions” than in the simple exploration of day to day lived realities. This is not to say that literature examining practical and measurable outcomes as well as neurological/physiological differences is not

valuable; certainly, these studies can illuminate certain aspects of the autistic individual's experience and guide programming and interventions. Still, in this author's opinion, it seems that a greater amount of research investigating the social experiences of older youth and adults in detail, and particularly from the perspective of persons of autism spectrum disorders and not external parties, would add much to the current literature in this area.

III. CHAPTER 3: Research Design

Methodology

In order to maximize the number and depth of participant responses, methodology included the collection of both qualitative and quantitative data with two main approaches: an online electronic survey as well as one-on-one interviews. Although recruitment processes will be described in more detail under the “Population and Sample” section, a brief description of the Ottawa-based community partners utilized in this project will be included here. Causeway Work Centre is a multi-serve non-profit mainly concerned with the economic independence of persons with disabilities and offers a variety of employment programs. Y’s Owl Maclure is a non-profit charity offering a day programs and services to adults with disabilities, with a particular focus on autism spectrum disorders. The Ottawa Independent Living Resource Centre aims to empower all individuals with disabilities by providing workshops, social nights and practical supports such as an employment program. Lastly, the Ottawa Autism Chapter also assisted the researcher – this local chapter of a large national organization supports persons with autism spectrum disorders through several different support groups, meet-ups and social events, as well as referrals. In the case of already established groups like Y’s Owl Maclure’s evening social groups for adults with autism, some participants preferred to complete the interviews in-person with the researcher present. However, most responses were gathered online – about 80% in fact. All the question content and order remained the same regardless of data collection method.

Before the survey questions were solidified, consultation with persons with autism took place over a series of weeks. This meant that a few individuals who

expressed interest through Y's Owl and Causeway Work Centre were involved in several discussions in the formulating and finalizing of the research instrument. At first, this process occurred through informal discussions in person – e.g. in broad terms, what should this survey address? Which social issues are important to you? Later on, one particularly dedicated volunteer provided very detailed feedback on a survey draft and this helped to guide the questions further. Another small group of pilot testers completed the preliminary survey and had suggestions for improving the final survey – e.g. providing a few more answer choices and clarifying the wording of some questions. Volunteers emphasized the importance of allowing respondents to answer based on real-life experiences *as well as* preferences and to allow for respondents to indicate when they did not feel able to answer a question due to lack of real-life experience. Volunteers explicitly stated that a lack of “life experience” might make some of the questions challenging, so answer options such as “not sure” or “don't know” were included in the survey where appropriate.

These steps were added with the practical aim of simply increasing the relevancy of the questions and the data gathered but also to help the project move slightly closer to a participatory action model: a research paradigm whereby participants can be empowered by the inclusion of their ideas and voices into the research process (van de Sande & Schwartz, 2011).

Incorporating participatory action goals into the research required the consultation with community members described above but also involved a perspective shift in formulating the survey questions. The researcher tried to limit assumptions - particularly in the multiple choice LIKERT-style questions – while also

attempting to maintain the simplicity and user-friendliness of the survey. It sometimes proved difficult to do: the researcher found that in trying to be inclusive, this often meant providing a range of complex answer options. One way the researcher tried to mitigate this complexity in the multiple choice section was to use simple and straight forward/literal language wherever possible. Some short explanations and definitions were also provided to help guide participants. For example, ideas like “support” and “connection” are fairly abstract and broad, so a brief descriptive phrase was often included in parentheses.

There were also more subtle challenges in creating the instrument. A question that assumes a person with autism spectrum disorder has no experience with romantic relationships contains considerable bias and could alienate participants, but a question that automatically assumes a respondent has ample experience can also be problematic. There was no desire to contribute to experiences of discrimination or stereotyping in this research project by creating a research instrument or using data collection methods that made too many assumptions about the research participants. Still, this researcher recognizes that despite consulting the community, it is likely that the survey instrument ultimately contains biases from the researcher despite attempts to move towards open-ended and non-judgmental lines of questioning.

Population and Sample

The population participating in this research study were all adults (age 16 plus with a mean age of 31) in the Ottawa area who self-identified as being on the autism spectrum. Participants were recruited through several non-profit organizations in

Ottawa that serve persons with disabilities and persons with ASD in particular. The organizations included: Causeway Work Centre, Ottawa Autism Chapter, Y's Owl McClure & Ottawa Independent Living Resource Centre. Recruitment was achieved through posters advertising the research topic and indicating contact information, a URL for the online survey and a QR code that could be scanned with cell phones. Additionally, the survey received considerable online promotion through an e-mail blast from the Ottawa Independent Living Resource Centre and through the Ottawa Autism Chapter's social media network. Lastly, respondents through Y's Owl were primarily recruited in-person.

The recruitment approach therefore led to a non-probability sampling method. The research also reflects a convenience sample with the potential for some participants to have been recruited through "snowball" sampling: individuals referred to the research by other individuals who engaged in the survey or interview. These methods follow some of the techniques outlined by Fulton, Samonte, Tierney, Connor & Powell (2001) in "Effective sampling of rare population elements". It is unknown which participants were recruited from which organization, or if they were referred by a friend, as this information was not requested on the survey itself.

Instrumentation

A series of broad topic areas were initially drawn from the existing research, such as Sperry & Mesibov (2005), who found that relationships at work, meeting new people and dating issues were common themes identified by participants with ASD. The researcher then compared these topics to themes discussed in consultation with

community members in Ottawa (persons with autism who expressed interest in assisting the researcher) to further develop potential survey questions. Once a draft survey was created, pilot testers from the community completed the survey and gave the researcher more detailed feedback on how to improve the questions. Particular attention was paid to ensure questions were a) as clear and concise as possible and b) that they seemed to be drawing out important information about interpersonal experiences. After this, the survey was finalized and placed online through Fluid Surveys. Some respondents chose to do the survey in person/face-to-face with the researcher – question content and order remained the same.

The final instrument itself was comprised of three parts: the first asked three simple demographic data questions (age, gender and employment status), while the second contained twelve LIKERT-style multiple choice questions and the last part was comprised of 6 open-ended qualitative questions – all on the topic of interpersonal experience.

Data Collection

Data was collected in two main ways:

- a) The anonymous electronic survey data was collected online via Fluid Surveys.

The electronic survey theoretically allowed research participants to have another person help them complete the survey if they required assistance (e.g. either accessing it or understand the questions). This method proved to be the most popular option for respondents, and is also obviously the most private and anonymous. It is also much easier and faster to both submit and collect data online. Besides these clear advantages, the online survey was of

particular use for clients associated with Causeway Work Centre, as the researcher could not interview those participants face-to-face as the lack of anonymity could interfere with current or future worker-client relations.

- b) Face-to-face data collection entailed a series of interviews with volunteer participants recruited through non-profit organizations with client bases that included persons on the autism spectrum (Causeway Work Centre, Y's Owl McClure, Ottawa Independent Living Resource Centre and Ottawa Autism Chapter). They were conducted by the primary/only researcher, who recorded participant answers on an electronic recording device in order to check for accuracy; hand-written notes were also taken.

Data Storage

All raw electronic research data/survey results were initially stored on Fluid Survey (Canadian) servers and later on password-protected flash drives only available to the researcher. Any hard copy data was kept in a locked filing cabinet.

Data Analysis

Analysis of the data for this project was somewhat complex as it included quantitative data (demographic data as well as ordinal/scale data from the multiple choice questions) and qualitative data from the open-ended questions in the latter part of the survey.

Quantitative data was processed using SPSS – e.g. all frequencies, means, tabulation charts and graphs were either made by or from SPSS. Qualitative data

examining the unique social experiences of persons with autism involved transcribing data into NVivo in order to organize statements around particular themes.

IV. CHAPTER 4: Results & Analysis

Introduction

The following section will explore both the quantitative findings (from the multiple choice survey portion of the survey) and qualitative findings (answers to the open-ended questions found in the latter part of the survey instrument). The quantitative portion of the survey contained 11 questions in total, including 3 basic demographic questions (age, gender & employment status) [see appendix for full survey]. After these introductory questions, participants were invited to rate their perceived level of connection to others – including both friends and romantic partners, and to share their social/romantic preferences (e.g. how often they would *like* to see friends versus how often they do). Other multiple choice questions included perceived levels of available social support and shared interests, among others. Quantitative findings will be presented in the form of frequencies, tabulation charts and bar graphs. Similarities or differences between previous studies will be included.

The qualitative section included 6 questions that were fairly complex and open to interpretation. Respondents were asked about the “best places” to meet new people, how they preferred to get to know someone better, their positive and negative social experiences at work and/or school and to consider whether or not they felt they had enough social opportunities in Ottawa. Responses were varied – with some respondents giving more detail than others – but certain dominant themes emerged. These will be discussed in detail and compared to the qualitative literature in this area.

Part A – Quantitative Findings

Introduction

The next section will examine the quantitative findings from the survey, providing a statistical preface to the qualitative data to follow. The analysis will include: a brief breakdown of demographic data, a description of the frequencies for each question (which will also feature several supplemental graphs and cross-tabulation charts) and a conclusion.

Demographic Data

In total, 26 individuals responded to the survey both online (19 responses) and in-person (7 responses). Gender breakdown indicated a ratio of 12 men to 14 women. Participants were quite young with a mean age of 31. The majority of respondents reported being employed (14) while 9 indicated “student” as their primary status (with several individuals indicating both statuses concurrently). Relationship status reported varied (see Table 1) - particularly by gender. 6 female respondents reported living in a long-term relationship (including marriage or common-law) while no male respondents indicated this relationship status. “Single” was the most commonly reported relationship status for all respondents (54%).

Table 1 - Gender & Relationship Status of Respondents

Count		Relationship status						Total
		Single	Dating someone "casually"	In a relationship	In a long term relationship	Multiple partners	Long distance relationship	
Gender	Male	9	1	1	0	1	0	12
	Female	5	0	1	6	0	2	14
Total		14	1	2	6	1	2	26

Multiple Choice Questions

The first Likert-scale open-ended question asked respondents to consider their opinion on the importance of “feeling connected to friends” (Table 2). The majority of respondents (61.6%) rated this type of connection as either “quite important” or “essential – extremely important” (both split evenly at 30.8%). 38.5% reported that connection to friends was “somewhat important” and 19.25% felt they were “neutral – could take it or leave it”. A single respondent reported that this type of connection was “not very important [to me]”.

Table 2 - How important is it to feel connected to friends?

	Frequency	Percent	Valid Percent	Cumulative Percent
Not very important to me	1	3.8	3.8	3.8
Neutral - could take it or leave it	5	19.2	19.2	23.1
Somewhat important	4	15.4	15.4	38.5
Quite important to me	8	30.8	30.8	69.2
Essential - extremely important	8	30.8	30.8	100.0
Total	26	100.0	100.0	

One of the more notable findings from the quantitative data involves questions pertaining to friendship preferences. Respondents were asked to firstly consider a) the number of times per month they spent time with friends (Figure 1) and b) the number of times per month they would *like* to spend with friends (Figure 2).

A cursory glance at the graphs reveals that a large portion of respondents are seeing friends considerably less often than they would *like* to. Participants were most likely to indicate actually seeing friends “infrequently – a few times a year (e.g.

special occasions)” (34.6%) or “regularly – once a week to a couple times per month” (also 34.6%) with a significant portion choosing “semi-regularly – sees a friend/friends at least once a month”. *Only 1 respondent reported seeing a friend/friends “frequently – at least a few times a week”*. This is in stark contrast to *preferred* number of friend interactions per month: in this category, 26.9% indicated that they would like to see friends “frequently” – while 46.2% preferred at least “regular” contact. 5 respondents (19.2%) desired “semi-frequent” contact and 2 individuals (7.7%) preferred “infrequent” meetings.

Preferences for desired amount of time spent with romantic partners was even higher – over 70% of respondents indicated that they would like to see partners frequently (“every day or at least 3-5 days of the week”). It is possible that this is related to qualitative responses which seemed to demonstrate preferences within the sample for a) one-on-one social interactions and b) interactions with familiar persons. This author also suspects the findings are comparable with those of the general population. They are also in line with Henault & Atwood’s 2005 study of adults with autism demonstrating a high level of interest in relationships comparable to the general population.

Figure 1 – Question: How often do you see friends in a 1 month period?

Figure 2 – Question: How often would you like to see friends within a 1 month period?

Looking at overall frequencies, a few other findings stand out. When respondents were asked how connected they felt overall (see Figure 4), the most common answer was “somewhat connected” at 46.2% (12 respondents). The other choices break down as follows: “disconnected” (19.2%), “connected” (19.2%) and “very connected” (15.4%). In some ways this seems to be a fairly positive finding as the majority of respondents reported being socially connected to some degree (80.72%) with only 19.2% reporting a sense of social disconnection. Yet when compared to preferred levels of social interaction with friends (see Figures 1 and 2), it is evident that many respondents are not connecting with others as frequently (and perhaps as closely) as they would like.

Respondents were also asked to consider whether or not they felt they could turn to someone else for support (whether practical or emotional). The results were fairly positive with 50% of respondents stating “yes”, 34.6% reporting that they were “unsure” and only 4 respondents (15.4%) indicating that they did not believe they had anyone to turn to for support. For the questions pertaining to shared interests and perceptions of being understood by others, the answers ranged considerably but generally grouped around middle/moderate answers. 40% of respondents reported that their interests were “sometimes” shared by others – with 16% indicating they interested were “usually” shared, 16% reporting “occasionally” and 28% chose “never” or “rarely”. When participants were asked whether or not they felt understood by others, the answers were again grouped heavily around middle/moderate answers with fewer respondents indicating high or low answers. 23.1% of participants felt that they were understood “most of the time” while only 1

respondent felt they were “always” understood, whereas a full 30.8% said they felt understood “sometimes”. 38.4% believed they were understood by others either “never/almost never” or just “occasionally”, with 1 other respondent stating that they were “unsure”.

Figure 3 – Question: “Overall, how connected do you feel to people?”

Figure 4 – Question: “Do you feel there are people (or a person) you can turn to for support?”

Conclusion

The quantitative data produced by the sample revealed several important findings. The responses established a high level of social interest first and foremost, in that most participants communicated a desire to interact with both friends and romantic partners on a daily or weekly basis. Another fairly positive finding is that most respondents (50%) felt confident that they had another person to turn to for emotional and practical support. It is also of note that there was quite a disparity found between desired contact with friends/partners and actual time spent. The most marked difference is seen in desired contact with friends versus actual (see Figure 3 and 5). The majority of respondents (over 60%) expressed a desire to see friends regularly (at least once a week) or frequently, but most respondents reported actually seeing friends on an infrequent to regular basis. Although this is positive in some

ways because it is clear that there is indeed a desire to connect with others and that some participants are successful in doing so, it still appears that it is occurring less frequently than most respondents would prefer. This corresponds with the question on perceived overall social connectedness, which seems fairly low: a minority of respondents said they felt connected/very connected (34.6%) with most individual indicating they were either “somewhat connected” or “disconnected”.

Part B – Qualitative Findings

Introduction

The quantitative findings, while providing a concise and perhaps easier to understand version of the survey responses, do not supply the necessary depth and detail to understand the viewpoints of the participants. It is only in the qualitative and open-ended portion of the survey that respondents are able to express their social experiences, preferences and ideas in entirely their own words. As a population that is rarely given much voice in academia, this is particularly important. And in light of stereotypes which often typify persons with autism as entirely social disinterested and disconnected, it is even more important.

The quantitative data seemed to establish the existence of fairly high level of interest in both social and romantic connection. In other words, most respondents within the group believed it was important to be socially connected and preferred to see friends and romantic partners on a daily or at least weekly basis. But it is within the qualitative section that respondents were able to describe those social experiences and preferences in greater detail. For instance, where do positive social interactions occur? Who do they occur with? And what is the difference between a negative social interaction versus a positive one? Respondents provided very thoughtful answers and insights to these questions, and their answers will be grouped into sections according to major themes. Below are the survey questions as they appeared online and as they were asked in person:

Q. 13 Which are the best places to meet people in Ottawa – including friends or potential romantic partners? (If you are unsure/don't know, you can indicate this in your answer)

Q. 14 When meeting someone for the first time, how do you get to know them better?

Q. 15 Can you describe your social experiences at school or work?

Q. 16 Are there any social experiences you find particularly negative or overwhelming? (E.g. first dates?)

Q. 17 Are there any social experiences you find particularly positive and enjoyable? (E.g. interacting with people you know versus strangers, interacting online, etc.)

Q. 18 Do you feel you have enough social opportunities in Ottawa? If yes – can you describe? If not – do you have any ideas or recommendations?

Structure & Familiarity

One of the most dominant themes expressed in the open-ended section of the survey was a preference for structured social environments, such as a workplace.

classroom or other familiar environment:

Work provides a structured environment where I find it easier to speak with people and get to know them than in less structured environments like chance encounters in various situations.

At school my interactions with classmates are usually only about school topics. I enjoy helping others with understanding concepts and share what I have learned about interesting topics related to what we are doing in class.

I fixate on the bus and the pool. These areas are places I know a lot about so I like to go there so I know what to talk about.

Concern regarding social situations of a more spontaneous and improvised nature was expressed by several participants. Two sub-themes were frequently discussed under this heading: a) worrying about not having an obvious conversation topic and b) worrying about general behavioural expectations or social roles.

Examples of social roles which respondents found confusing included any occasion that was socially ambiguous, such as a party or even unstructured class time, where

behavioural guidelines are usually unclear and informal. For example, respondents discussed uncertainty around what they should say, how they should say it and to whom. This is eloquently explained by several respondents:

I don't enjoy interactions where topics and expectations are undefined. I feel more comfortable in a classroom than in a cafeteria or another area where there is no clear relevant topics or behavioural expectations...

I enjoy participating in sports or organized activities where it is clear what to do and there is a clear conversational topic available.

I like stuff where people are invited to join in; like my social swing dance group. They welcome everyone. There's a lesson before that allows for light mixing. But I don't like breaking the ice; I find it hard.

I'm OK interacting about structured work topics, but unstructured discussion and socializing are baffling and stressful.

I like interacting in person but I usually say the wrong thing.

Perhaps related to preference for familiar surroundings is a preference for interacting with familiar people. At various points in the survey, participants communicated a greater inclination towards well-known people in their lives, usually family members, long-established friends and romantic partners. This is not a surprising finding, as certainly many people prefer interacting with familiar persons they have established bonds with (Carter & Keverne, 2002). Increased levels of oxytocin (considered to be a “bonding hormone”) have been found in the brains of humans and other mammals during and after interactions with not only familiar sexual partners but friends as well (Donaldson & Young, 2008). Increased levels of familiarity also help to remove the stress and effort inherent in making a good impression and “breaking the ice”. Below is a collection of statements related to preference for familiar persons and/or dislike of meeting new people.

On preferred social interactions:

...Meeting with old friends who know me well (or used to know me well).

...interacting with people I know well.

Small groups 2 to 5 people of whom I know very well...

I like socializing with my mom, people at work, my best friend's mom – ladies I see as a mother figure.

On the negative/overwhelming aspects of social interaction:

The whole meeting the other person is the hardest thing.

Large groups of new people.

Being one on one with a complete stranger is never fun...

Getting together where I do not know anyone.

On social opportunities in Ottawa:

There seem to be many interesting clubs that I would like to join if I can get up the nerve to meet new people.

Crowds versus Small Groups

Generally speaking, situations which commonly present a large number of strangers at one time were often perceived as less desirable. Participants were asked to identify social situations that felt “negative or overwhelming” and parties were often cited due to these challenges:

Parties where there are many people I've never met before, any situation with a crowd of people, noisy environments.

...talking to someone for the first time, getting to know someone new, hosting an event, making small talk or informal conversation.

Parties and large social get-togethers.

Parties (e.g. Christmas parties), pretty much any sort of social engagement, when I have to answer the telephone for work, going out to an event.

Bars were also sometimes mentioned as unlikely places for positive social interactions, including one participant who said: "...the bar scene is kind of a disgusting system to me." And another, who had a more specific analysis of why he did not utilize bars as meeting places:

I'm not good at going to bars, not a good 'picker upper'...drinkers have a totally different language; I feel out of the loop. I don't get the jokes. I don't fit in because I'm sober.

However, many respondents shared a preference for close one-on-one interactions (or small groups) with people they knew well, including this participant:

Small groups 2 to 5 people of whom I know very well, and only occasionally offend or befuddle. We get together a few times a year, and that is very pleasant. One on one time with a knitting/crochet friend is nice too.

Positive, Negative & Mixed Social Experiences at Work and School

When respondents were asked to describe their school and/or work experiences, the answers were fairly diverse. A roughly equal amount of persons (12 versus 9) described their experiences as positive versus negative overall, while the remaining participants provided neutral or mixed answers.

Some examples of positive answers:

Mostly positive – people say hi to me in the hall.

Pretty good...

I enjoy helping others with understanding concepts and share what I have learned about interesting topics related to what we are doing in class.

I see my friends at school on a frequent basis.

I like socializing with my mom, people at work...

Negative and/or “mixed” answers:

Bullying since my first day in middle school, throughout high school. No bullying at work, people are more mature and friendly, plus if it happened I could tell my boss. In middle school I was still a little girl so I believed that telling on bullies is bad, now I know it's not.

Terrible. I was so shy that [nobody] want[ed] to speak with me. I change[d] school so [many] time[s].

I was bullied severely both at school and at all of my jobs. I had one or two 'friends' but we weren't close. *I got along with most people except the bullies.*

I find that a couple of co-workers have negative attitudes toward me.

I try to respect peoples' boundaries at work, but my social experiences usually not too bad.

School – I live in residence. There are a lot of people. I sometimes just hide away in my room because it's all very overwhelming.

Isolated.

I work part time (2 days a week) in a very quiet boutique, I'm thankful not to see too many people in a day. It can be emotionally exhausting.

One respondent was also able to verbalize precisely *why* he thought high school was a difficult social experience for him:

At high school, I felt like a loner. High school is the first time you have to make decisions. There is less structure [than elementary school]...before classes, after lunch...

This insight is in line with research findings from Locke, Ishijima, Kasari & London (2010) that suggest loneliness and exclusion might indeed increase markedly by high school. However, those authors thought that high school constituted a greater social challenge due to classmates changing each period (more new people to adjust to) and the increasing complexity of young adult relationships (e.g. a demand for

deeper intimacy). Locke et al noted a disparity in number and quality of friendships between students with autism and their neurotypical peers, and further surmised that the gap might exist “because of differences in social skills between the groups” (p. 79). But the relatively simple idea that longer and more frequent periods of unstructured time might *in and of itself* be one of the greatest barriers to social inclusion for persons with autism is not discussed. This is definitely a topic that requires greater exploration, as problems with unstructured/free time in school (and in general social situations) was one of the most dominant themes found in the survey responses. Respondents often identified a lack of a specific conversation topic (as discussed previously) and of being unsure of role expectation in general in informal social situations.

Why are unstructured social situations presenting particular difficulty to young adults with autism? The DSM classification notes that children with autism often exhibit a “failure to spontaneously seek to share enjoyment, interests or achievements with other people”, and there is some neurological evidence to suggest this could be hard-wired in the brain – as in Schultz, Grelotti, Klin, Kleinman, Van der Gaag, Maroi & Skudlarsk’s study on deficits in facial perception in persons with autism. Applied behavioural analysis (ABA) techniques are common interventions for children with autism, and they are used specifically to help increase communication skills and the frequency of social behaviours like prolonged eye contact and the initiation of verbal exchanges. It is quite possible that these early interventions are not producing lasting results and that their effects are not being “generalized” to social interactions outside of a direct training context – an idea that is supported by Hwang

& Hughes 2000 empirical analysis of 16 different studies. They found that while most ABA/ABA-style program tended to result in improvements in classroom or training contexts (e.g. increased communication), these behaviours were not necessarily observed in other social situations.

Although this sample is not large enough to make generalizations or comparisons to other populations of persons with autism, it is notable that several respondents shared experiences of bullying, as previous studies have found that persons with autism can experience higher levels of bullying in school. Research in this area is still in the preliminary stages, but one study by Little (2002) found that children with autism spectrum disorders were 4 times as likely to experience bullying in school settings; that is, 55% reported bullying experiences compared to 13% of their neurotypical peers. Similar findings of higher rates of bullying were also found by Carter (2006) and Wainscott et al (2008). Gray (2004) has suggested that the “atypical” interests of persons with ASD and/or intense emotional reactions could be precipitating factors, although more research in this area is required. There is also very little current research on programs or interventions to address this phenomenon, though bullying in general had garnered intense media attention as of late, with a corresponding increase in literature exploring causes and potential interventions.

Making Friends

The second open-ended question on the survey asked respondents to consider how they would “get to know someone”. The question is purposefully esoteric and rather philosophical: it is likely that many people, whether autistic or not, will have difficulty explaining how this complex social process works. This is probably because

a lot of the social interactions that make up “getting to know someone” do not always occur at a conscious level (Greenwald & Banaji, 1995). Yet, many respondents had incredibly thoughtful answers to this question:

I meet up with people with a hobby as my intention, and then let trust and bonding happen as a result of shared experiences.

Generally upon meeting someone there aren't many words exchanged. I get to know people over time in small bits.

Doing activities that I enjoy – common interests lead to friendships.

Discuss common interests, ask about them, empathize. Make small talk – VERY difficult for me.

They usually ask a bunch of questions and I try to remember to ask some back.

One participant had some specific advice to share on the topic of making friends:

Autism Ontario was the first group to get me plugged in. First group to teach me about my disability and connect me to the community... You need to get in contact with people who have things in common. I educated myself on how to make friends with conferences and social learning books.

Suggestions for Improving Connectedness

When respondents were asked to rate their own access to social opportunities and provide suggestions for new opportunities, there was a clear preference for structured social and special interest groups. Several respondents spoke favourably of meet-up groups specifically for persons with autism or Asperger syndrome (e.g. “More Aspie social groups!”) while others lamented a lack of access or knowledge of appropriate groups or services:

It is possible that such opportunities exist but I am not aware of them or they are out of my price range.

...I don't find there are many places to meet girls my age.

I'm not particularly social, but I do wish I found more things that interested me to get OUT and do with others.

I don't know much about the social stuff. I don't have the options so I don't think about it.

I know there are clubs. I just don't know where to find them. I found out about this one through Y's Owl.

Overall it appeared that individuals within the sample had a clear preference for social groups that offered some kind of structure – either because it was centred around a specific hobby and thus provided a clear conversation topic (e.g. the Y's Owl gaming night) or because the structure of the group itself contained enough direction and rules to make behavioural expectations clear and encourage participation from everyone – thus avoiding role confusion or the formation of exclusive cliques. One participant noted that his swing dance group was structured this way (everyone was invited to join in after an initial lesson at the beginning) and this helped to create a welcoming environment. As well, because many respondents indicated that familiarity of surroundings and persons were important to them, groups centred on a common theme within the same environment every week or month could also be another reason that structured groups and clubs are popular choices. This author was somewhat surprised to find this level of enthusiasm for social recreational groups, purely due to my own biases and inexperience with such groups – and this is precisely why it is of the utmost importance that we listen to the opinions and desires of persons with autism spectrum disorders/Asperger syndrome instead of merely assuming which interventions and ideas will be the most beneficial.

There was one individual who felt that perhaps not all of his social needs were being met by such groups, stating: “I've belonged in social clubs, but feel I don't get what I'm looking for.” It would have been interesting to interview this participant further to try and elicit just what it was he felt he was missing. This researcher does not want to hypothesize too much, but it is possible the respondent was referring to levels of closeness or intimacy with other social club members.

Social “Disinterest” or Lack of Access?

Among the rather diverse data, there were only a few statements made indicating a lack of social or romantic interest. Only 4 individuals made reference to a lack of interest in social engagement with family/friends/prospective romantic partners, but it is unclear whether or not this simply meant they felt their social needs were already being met or if they were not interested in social connection in general. Other complicating factors (lack of knowledge/access to social groups, economic barriers and/or social anxiety) could also be at play – these will be examined in greater depth in the “Discussion” section. This is an area that would also require further research. Below are a few examples of these types of statements:

Do you feel you have enough social opportunities in Ottawa? If yes – can you describe? If not – do you have any ideas or recommendations?

I don't know, because I don't seek out social opportunities.

I never do this.

Yes. Because of my family life, I actually spend more time in the company of others than I would like.

I guess so. If there were more, I'm not sure I would go.

I don't know, and haven't tried to find out.

I don't know much about the social stuff. I don't have the options so I don't think about it.

If one were to only look at these answers, it might seem that social “disinterest” was a dominant theme in the findings, but this would be a misleading generalization. Referencing the quantitative data, it was observed that in fact most respondents were, on average, seeing friends much less often than they would like to. Participants were most likely to indicate seeing friends either “infrequently – a few times a year” or “regularly – once a week to a couple times per month” (only 1 respondent reported seeing a friend or friends “frequently”), yet the majority of respondents said that they would prefer to see friends either “regularly” or “frequently”, in that order.

There could be many reasons for these findings. This researcher would suggest that it is possible that data indicating a lack of social connection and social satisfaction could be directly related to the specific population sample captured by the survey. Many of the individuals surveyed would probably be considered persons with “high functioning” versions of autism, including Asperger syndrome (mainly because individuals were recruited from non-profit organizations offering totally optional and “higher level” supports – e.g. assistance in finding employment or specific support groups for persons with autism). The literature has established that persons with “high functioning” autism might actually experience of social disconnect and loneliness at higher rates: Carrington & Graham (2001) suggest that this could be due to more acute levels of self-awareness, while Bauminger & Kasari (2000) found that “high

functioning” autistic individuals tended to report high levels of loneliness and decreased friendship satisfaction.

Online Interaction

Another topic touched upon by many respondents was online interaction (12 individual respondents and 16 separate references). These respondents demonstrated a strong preference for social interaction that took place over the internet as opposed to face-to-face or telephone interactions. The following are a few examples of this preference:

Facebook and Twitter are my friends.

Interacting online is very comfortable for me. Chatting while playing a game is also comfortable and great for bonding. I also just like to listen to people's stories.

Besides being a relatively common answer to the above question (“Are there any social experiences you find particularly positive and enjoyable?”), it was also sometimes mentioned as an effective way to meet new people:

This city is probably the worst for meeting new people. The layout lends itself to exclusive cliques in certain areas. The best thing to do is meet people in [an online] forum and then set up local hangouts, in my experience.

As well as a means of working and going to school:

I am an online student, so my school social experiences are online only.

I work for a virtual organization. I spend most of the day alone, with some contact with others through the use of social media.

What is it about online interaction that appeals to persons with autism spectrum disorders? There are no studies examining this relationship in the literature (that this author is aware of) though it seems to play such an important part in the lives of many of the participants. The internet has been mentioned by advocates who

are members of the community – most notably, Singer (1999) who recommended that persons with autism use the internet as a “prosthetic social device”. By looking at other dominant themes brought up by respondents, it seems possible that the internet might represent an ideal social milieu for persons with autism because it can provide a surprising amount of structure, familiarity and control in social interactions. If one wants to have a discussion about a specific hobby (and having a specific conversation topic was also deemed essential to the respondents), one can find a website and a forum specific to that desire. Engaging in a forum is also not as overwhelming because it does not happen face-to-face in real time; instead, people can take their time to formulate responses at their own pace. In this way, it seems to provide opportunities for persons with autism to meet and discuss issues important to them without having to overcome the barriers presented to them by more unpredictable, spontaneous and informal interactions that happen face-to-face.

Conclusion

Overall, there seemed to be diversity in social experiences and preferences within the data, in a way that is probably quite similar to the general population. That being said, there were also some emergent themes that individuals in the sample seemed to share with each other at a fairly high frequency.

It is also important to note that due to the recruiting techniques, it is likely that most persons responding to the survey would probably be termed persons with “high functioning” forms of autism (including Asperger syndrome), and this needs to be considered when examining the data. This is also important as both Carrington & Graham (2011) and Bauminger & Kasari (2000) found evidence that children and

young adults with such high functioning forms of autism generally reported higher levels of loneliness and less “friendship satisfaction”, so it is conceivable that this phenomenon could also be affecting the data – i.e. this effect could be responsible for the disparity observed between contact with friends and desired frequency of contact with friends, as well as several comments made regarding a perceived lack of social opportunities (e.g. lack of knowledge regarding where to meet people).

It is also significant that many respondents had positive stories – whether regarding experiences at school, work or the enjoyment they have experienced sharing hobbies with close friends (especially online). This author believes that too often studies focus on the disparities in social connection but do not appreciate that what one person considers a positive social interaction is not necessarily shared by everyone.

V. CHAPTER 5: Discussion of Findings

Overview

It seems that through the survey results, three dominant findings emerged from the data. Firstly: that the participants reported varying but generally high levels of social and romantic interest. I.e. most respondents rated social connection as important, and most preferred to see friends and romantic partners regularly or frequently. The second finding is that what that social connection might *look like* could vary greatly both within this group and as compared to “neurotypical” persons. It is not clear whether these preferences are based on traits specific to the individual or related to autism symptomatology, but is likely a combination of multiple factors. That being said, strong preferences for structure (e.g. concerns about having specific conversation topics) and familiarity (desiring the company of close family members, old friends or significant others above less familiar individuals) were often stated by participants. This showed that while social interest was high, context mattered a great deal: for examples, a party, bar or classroom with large numbers of unfamiliar persons and unstructured discussions would most likely not be welcomed by most of the participants from the sample.

The third finding that must be discussed is the apparent disparity observed between desired time spent with friends versus the actual time spent with friends in a one month period (see Figure 3 and Figure 4). Although this was not a universally reported experience, and certainly many respondents described engaging in positive and rewarding relationships on the whole, it is a very important finding nonetheless. This is because it refutes the common assumption that persons with autism can be generalized into one wholly socially disinterested group. On the contrary: the data

seems to indicate that many respondents actively pursue social interactions with people (though perhaps more often with close family members, partners or long-established friends) but that they may simply desire *more frequent* and potentially deeper or more intimate relationships, as most respondents also reported feeling somewhat connected or disconnected from others (see Figure 5).

However, it is perhaps most important to examine ways of *improving* social inclusion and connection for persons with autism than it is to extrapolate potential differences between groups, which might only serve to further alienate individuals. But what do ideal social relations look like for persons with autism? Can (and should they) be better integrated into “mainstream” social networks? Or should individuals with autism spectrum disorders be given the opportunity to create their own communities and spaces?

It is certainly first and foremost a matter of choice, or at least should be. It is clear that some individuals with autism might prefer to engage in wide and varied social circles and pursue relationships in ways similar to their neurotypical counterparts. Other individuals might be more limited due to challenges in verbal communication. Yet others still might find themselves in an awkward “middle ground” sometimes discussed in the literature (e.g. Carrington & Graham, 2001; Bauminger & Kasari, 2000) where individuals are capable but excluded; isolated and very much aware. When considering these questions then, it is also necessary to discuss the importance of wider disability theory and discourses surrounding inclusion and exclusion.

What is the evidence for any “disability culture” existing outside of mainstream culture? One study (Finn and Asch in Nagler, 1993) found that 74% of Americans with disabilities felt a “common identity” with one another and 45% saw themselves as “part of a minority, with a particular group consciousness and specific referent group” (p. 52). Peters (2000) presents some particularly convincing evidence for a disability culture in her paper “Is There a Disability Culture? A Syncretization of Three Possible World Views”. She notes that disability culture meets several important criteria for a separate and distinct culture, including: a common language (not formally – outside of sign language perhaps – but there are certainly many terms specific to certain groups of persons with disabilities), historical lineage that can be traced through text (the portrayal of disability culture exists through several magazines, journals and other types of media), social cohesion (this varies from community to community), political solidarity, acculturation with the family (though not necessarily family-of-origin), genetic links and finally, pride and identity in segregation from the Other. It is important to note that engaging in a culture does not always have to mean segregation or marginalization: it is possible to engage in a variety of cultures and to be accepted, including in Canada – which is often considered to be a “mosaic” structure which recognizes and respects multiple identities.

But Peters believes that persons with disabilities have the choice to engage in a disability culture and that it is highly individual - not necessarily a given. The ability to engage culturally or politically can depend on many intersecting issues including severity of disability and socio-economic status – as well as race and sexual

orientation, for example. This idea is particularly important for the autism community as people on the spectrum are extremely variable in the degree to which their disability may (or may not) affect their ability to function – and this is directly related to employment status and economic position. In other words, if someone is focused on survival needs, it is possible that cultural participation could be considered comparatively unimportant. There are also those who suggest that the concept of neurodiversity itself should *only* apply to high functioning individuals (Jaarsma & Wellin, 2011) as they see lower functioning individuals as incapable of engaging in a culture due to the severity of their disabilities.

When respondents in this sample were asked to provide suggestions for how to improve their social experiences in Ottawa, there were two main types of answers. The first had to do with access: some participants lamented a lack of knowledge regarding opportunities that might exist in their community and beyond. They said they were interested in expanding their social networks, but did not know how. This issue of access to programs (or the existence of those programs and opportunities) is very pertinent for persons with autism, and particularly relevant for this age bracket (adults over age 16) as these are individuals have already passed through various educational/school-related supports. However, supports for *adults* are often much less widely available and perhaps not well-known even when they do exist in the community. It is also possible that there is an even more pronounced services gap for “high-functioning” persons with autism, as it is more likely for such individual to “fall through the cracks” due to their higher level of functioning in other domains. As an antidote to this disconnect, some advocates – most notably Singer, the first person

to coin the term “neurodiversity” (1999) – have recommended the use of the internet as a “prosthetic social device” (p. 62) as a means of connection and expression. Certainly, within this small sample alone there were many references to online interaction as a preferred method of communication and connection. In fact, there were 16 references to online interaction found within the qualitative data in this study – a high number for a study containing just 26 participants.

The second category of answers was more explicit in requesting groups *specific* to persons with autism – some openly asking for “more Aspie groups!” or more social-recreational groups geared towards persons with autism exclusively (e.g. one respondent wanted more outdoor/physical activity-based opportunities). Another respondent articulated the importance of connecting to a wider community of persons with autism:

Autism Ontario was the first group to get me plugged in. First group to teach me about my disability and connect me to the community...you need to get in contact with people who have things in common.

Orsmond, Krauss & Seltzer (2004) found that in their study of 235 of adults with autism, engagement in social/recreational activities outside of the home was associated with higher rates of social connectedness. Certainly, it seems important that persons with autism are afforded the opportunity to connect with other individuals on the spectrum. Such groups provide individuals the opportunity to not only make friends with persons experiencing similar challenges and successes, but also potentially as a way to discover other resources and programs in the community. Social/recreational and support groups can even be considered an empowering

experience for some, as well as a potential site and catalyst for social change and community organizing.

However, we must be very careful, particularly if we are speaking as “neurotypical” persons in privileged positions to make recommendations for a population as diverse and misunderstood as persons on the autism spectrum. We must be even more careful when we suggest that persons with autism might benefit from their own spaces and connection to an autism “community”, to not use this as an excuse to avoid our own responsibilities towards enhancing the wider social inclusion of persons with autism in our communities. The bottom line is that the creation of better programming and social-recreational opportunities for persons with autism (and improved access to those programs) does not mean we do not need to increase social inclusion in our schools, workplaces and wider community. The following section includes comments and recommendations specific to school, work and social services.

At School

Schools are (arguably) the second most important socialization agent in the lives of most North Americans after the family of origin, and certainly a sphere where politics and policy play out frequently. And now more than ever, as children with autism are more frequently integrated into mainstream classroom settings, it seems quite pertinent to examine the social impacts of the school environment on persons with autism. Studies of children with autism in school-settings are dominant in the literature, though the focus tends to be on effective teaching techniques and pedagogies and less on their social integration into the classroom and wider school

culture/environment. As social impairments are so central to the diagnosis of autism, this is curious. Then again, how far can (and should) schools and teachers be responsible for social learning and social inclusion?

But even if schools are incapable or unwilling to ensure social inclusion for children with autism, they must *at least* be responsible for providing safe environments. This study only briefly touched on school experiences of participants by asking respondents to share any positive or negative stories from their time in the school system. Unfortunately, some of these stories did contain instances and histories related to bullying experiences. Little's exploration of bullying experiences in this population found that children with autism spectrum disorders were 4 times as likely to experience bullying in school settings (2002), and higher rates of bullying in this group have also been found by Carter (2006) and Wainscott et al (2008).

Equally troubling is the lack of studies exploring the experiences of students with autism or Asperger syndrome as they transition to high school and post-secondary institutions. Connor (2013) believes this further evinces the skew towards birth to elementary school within the research, and that an important part of the life cycle for persons with autism/Asperger syndrome is ultimately ignored, as though they simply disappear as they reach adulthood. As noted by Grandin (1990), it is of the utmost importance for individuals with high functioning autism and Asperger syndrome to be encouraged and supported to further their education in order to reach greater economic independence. Persons with learning disabilities are increasingly able to receive accommodation and higher levels of support, but what about someone with a "social" disability? Some college officials have argued that it is not feasible to

teach such students the “social survival skills” necessary to thrive in a post-secondary environment (Farrell, 2004).

At Work

The employment status of participants in this study did not seem to reveal much about levels of social connectedness. Deeper statistical analysis would be required to establish any correlations, but, it was clear from the qualitative data that work environments were not considered especially socially important to the respondents. Although a few respondents did say that they enjoyed some of the discussions they had with workmates, nobody discussed work as a place where very close relationships were established or maintained. Coming from a background of employment supports, this author was anticipating that this might be a social domain of greater importance. But as shared interests were found to be essential in feeling connected to others, it seems that workplaces might not be ideal settings for meaningful connections. This might be why special interest groups and clubs, which seemed to be favoured by a majority of participants, seem to present greater social opportunities to individuals with autism. The fact that work relationships did not seem to be considered particularly significant to respondents might also emphasize the importance of *quality* relationships versus a multitude of superficial relationships – even if those relationships are pleasant and cordial.

Read another way, however, it is possible that persons in the sample might desire or benefit from closer work relationships but do not know how to access these types relationships – or how to make the leap from cordial work camaraderie into a deeper friendship. And if shared interests are truly essential to feeling connected, such

relationships might not be desired without some sort of shared hobby or commonality. It is impossible to make assumptions (or any recommendations) on this matter based on the current data, though the intricacies of relationships in the workplace and friendships could represent another interesting topic for future research in this area.

In the Community: Implications for Social Services

Which services or interventions will truly improve the social lives of persons with autism spectrum disorders in a meaningful way? Certainly ABA methods are the dominant choice in most North American contexts. But are these therapies enough to ensure social inclusion? And is it possible that such therapies are perhaps unwarranted and oppressive towards those individuals who function with a more “manageable” level of difference? Baker (2006) argues:

For individuals who are more involved with autism (particularly those who tend toward self-injury), ABA therapy can be tremendously life-enriching. For those for whom autism is a more manageable difference, ABA therapy can represent oppression of essential elements of their personality and thought process that discriminates against all but the more neurologically typical thought and behaviour patterns. The effectiveness of public sector programs depends on accommodation of both (p. 27).

An individual with autism also speaks out on this issue in Sinclair (2005):

We are interested in workshops about positive ways of living with autism, about functioning as autistic people in a neurotypical world and about the

disability movement and its significance for autistic people. We are not interested in workshops about how to cure, prevent or overcome autism (p. 24).

What are the implications for social workers? Awareness of the neurodiversity movement as well as the various local and national autism advocacy groups in Canada should be essential knowledge for any professional working with youth or adult with autism. Knowledge of any other community-specific programming such as social-recreational activities or support groups could also be particularly important as, at least in this sample, these groups were strongly preferred over less structured forms of social interaction. Other studies (Orsmond, Krauss, Seltzer, 2004) have also demonstrated that such groups seem to provide participants with a greater sense of social inclusion.

For social workers and other professionals working with *families* of children with autism or Asperger's syndrome it is much more complicated, as they must also contend with the family's expectations and aspirations for their child – whether that individual is a “child” or an adult. Sinclair (1993) suggested in his seminal work “Don't Mourn for Us” that parents who become interested in curing autism are often mourning the loss of their “normal” child. He argues that parents and relatives should instead accept the autism diagnosis as a pervasive and integral part of their child's identity instead. While this can certainly seem like an insurmountable task in some cases, and one that can require considerable resources and support to achieve, it is a valuable alternative perspective that might also bring hope to families and individuals.

A Note on Wider Structural Factors

It has been well-established that the autistic individual experiences challenges to “normal” social functioning – most likely related to concrete neurological differences. But do individuals with autism experience social exclusion at higher rates due to these deficits in their social abilities or are higher rates of isolation due to greater structural issues and inequalities? A combination of both factors could be at play. Yet, external/societal factors are not often examined within the literature.

A national anti-poverty organization in Australia defines social exclusion as a way to measure levels of advantage and disadvantage among groups (in this case, the study focuses on those below a poverty-line income). They believe that the “social exclusion” construct can be further dissected into the following categories: financial, vocational, educational health and social/relational dimensions, among others (BSL.org.au, 2011). With all of these factors considered, the study of social inclusion/exclusion becomes rather complex. If we add another hypothetical variable – such as autism – it becomes even more confusing. Do people with autism experience reduced access to social/economic/community resources because of difficulties in communicating or social functioning? Or is a state of social exclusion and isolation reflective of a collective failure to include individuals with autism into our homes, schools and workplaces? And – if one is routinely excluded from these domains, how is it possible for one to acquire social skills? There may be a complex interplay occurring between these scenarios. While it is certainly beyond the scope of this paper to answer these questions, these different ways of conceptualizing social

inclusion vs. exclusion will certainly colour future research, practice and policy for persons with autism.

VI. CHAPTER 6: Conclusion

Overview

This study was created with the relatively simple aim of exploring the social experiences of adults with autism. The author hoped that the combination of both quantitative and open-ended qualitative methods would reveal trends and commonalities within the sample as well as unique insights. Based on previous literature establishing higher rates of social isolation in children and adults with autism, the author expected this effect to be mirrored in the population, and it was to a certain degree. The author was also quite confident that the survey would demonstrate fairly high levels of social interest, which was confirmed. Besides these two fairly broad assumptions, the author expected other findings to be fairly individual and diverse and this was reflected most clearly in the variety of school and workplace experiences, which ranged from very positive to instances of bullying and discrimination. Overall reported levels of social connectedness also varied though a majority of respondents reported being only “somewhat connected” or “disconnected” and many respondents indicated they saw friends less frequently than they would prefer.

Methods & Findings

The issue of how to properly investigate constructs like social connection and loneliness was initially quite vexing. Although the survey instrument did contain a question asking respondents to directly rate their perceived level of social connection (with a definition of social connection provided), it seemed rather blunt to ask participants to rate levels of loneliness. Asking this question also seemed to the researcher to be negative and presumptuous; and one of the aims of the study was to

be as strengths-based as possible. Thankfully, discussions with volunteers and pilot testers seemed to steer the survey instrument into a positive direction. Although certainly not without bias by any means, the volunteers aided the researcher in creating a survey that was more open and exploratory than it was “diagnostic”. To this researcher, this meant trying to structure questions that did not assume a particular set of life experiences nor a lack thereof. Volunteers suggested that participants should be able to indicate if they did not know the answer to a question and they supported the inclusion of open-ended questions which allowed respondents to answer without any restriction.

Interestingly, when this researcher was completing face-to-face interviews, several participants would ask whether or not they were answering things “correctly” and they would often question the validity or usefulness of their own answers. This researcher always tried to reassure respondents that *any* answer they were willing to provide was helpful – even telling the researcher they did not know the answer to a specific question provided useful data. For example, several respondents answered that they did not know how they would go about getting to know someone, because they felt they had never been in this situation before. Not all respondents struggled with these types of questions of course; many were able to provide very rich and insightful answers to a variety of social questions, often giving detailed and almost “step-by-step” instructions on how to make friends.

The finding on actual versus preferred amounts of time spent with friends was particularly telling. The research indicated that there was a fairly high degree of social interest within the group but that respondents were still not connecting socially as

often as they would like, and this was most obvious when respondents were asked about friendships. If respondents were in relationships, they demonstrated a fairly high level of satisfaction regarding the amount of time spent with their partner. It must be communicated that not all results were negative. In fact, most respondents stated that they believed they had someone to turn to for support if they needed it, though many still reported feeling socially disconnected on the whole.

Limitations & Recommendations for Future Research

One of the primary limitations of the study is the relatively small sample size (26). Generalizations to the larger population of persons with autism are obviously limited. As well, the sample was also largely recruited from a) an employment service centre b) a social/gaming night and c) a support group for women on the autism spectrum. One might notice that all these groups represent *optional* services and therefore target “higher functioning” individuals: persons who have achieved enough independence or resources to be able to attend and take part. It follows that persons who might be struggling with more basic needs were left out of the study. This could include persons with economic barriers, communication challenges or other significant obstacles.

There were also no comparison groups (“neurotypical” persons without autism), although this is not necessarily desirable, as comparisons can often lead to hierarchies and intentional or unconscious judgments, and the purpose of this research was mostly exploratory; intended to highlight the unique understandings of the

individual rather than try to define a relationship between “normal” versus “abnormal” social experiences.

Another possible limitation is that the researcher used a scale that has not been tested for validity and reliability – it was instead guided by some research on comparable measures and studies as well as the participants themselves. In some ways, this is positive as it perhaps increased relevancy and response rates to the survey instrument. But the question of whether or not it measured what it set out to measure is not entirely clear.

In terms of possible directions for future research projects, it might be relevant to investigate gender differences. This author says “might” because although gender itself was not found to correlate to any other variables, female respondents were much more likely to report being a relationship, and this in itself might be an interesting finding to explore. Another topic that could provide useful insights into the social experiences of persons with autism could be a deeper examination of internet usage/culture and/or gamer culture, as these also seem to be inextricably linked to this population. As noted in the methodology section, the gaming night at Y’s Owl was particularly instrumental in the formulation, data collection and completion of this study.

Additionally, research examining the quality of friendships and relationships for persons with autism could also yield interesting results. This study really only touched upon the surface of social experiences for this population. For instance, although it was established that social interest was high and that most respondents would like to spend more time with friends, what do those interactions really look

like? Baron-Cohen & Wheelwright (2004) have asserted through their research that persons with autism do not desire friendships as close nor as empathetic as their neurotypical counterparts. Is this true? Is it fair or even possible to judge autistic relationships against neurotypical ones? Is it possible that an experience of closeness or connectedness is different from person to person and perhaps quite different for a neurotypical person versus someone with autism? The qualitative section suggests that many participants prefer social opportunities based around specific interests and hobbies, as this provides conversation topics and clearer roles. But to get closer to understanding the social preferences and subjective internal experiences of individuals with autism clearly requires a deeper analysis and perhaps entirely different lines of questioning. It would be particularly illuminating if research in this area could be undertaken and analyzed *by persons with autism*. This researcher suspects (or at least hopes) that this could be a future direction for research in this area in the future.

Further research into the social realities of persons with autism will only become more and more important as time goes on – if rates of (diagnosed) autism are any indication. Perhaps then the most important research to come will look at how this part of the population can be better included in “mainstream” social settings at work, school and beyond. Conversely, future research might instead focus on whether or not having autism constitutes a community or culture and the further development of spaces which are *specific* to persons with autism. This author is not sure which type of research would be more helpful or beneficial, although this is somewhat irrelevant because it is really up to persons with autism to decide this. There is also no

singular voice for persons with autism – it is not a homogenous population and while some people favour “cure”-based research, others are strong advocates for neurodiversity and autistic ways of thinking and interacting as equal (and sometimes better) than their “neurotypical” counterparts. This is why, more than anything else, research in this area must be authored *by* persons with autism and Asperger syndrome.

In this spirit and as a reminder that persons with autism might have different but equally valid viewpoints, this author would like to conclude this thesis with a quote from an individual diagnosed with Asperger syndrome about his own perspective on social interactions and perceptions of persons on the spectrum:

People say autistics are very routine offenders. They’re very picky, generally a little obsessive, compulsive, very fixated on routines, order, structure. I think this is a little unfair, you see. Because when you get right down to it, an autistic may have a favourite way of lining up his clothes, or maybe get pissed off if he doesn’t get meatloaf for dinner on Friday night. But the autistic probably doesn’t try to insert an arbitrary sense of social conventions on others to govern every other interaction in life. When you get right down to it, who’s really pick, the guy who eats his meatloaf on a Friday or the one who expects you to conform to a set of eye-contact, indirect communications and otherwise generally inefficient and often unreliable forms of communication for the sake of smoothing social interactions which relationships between Aspies prove aren’t really necessary? It’s not really necessary to have all of these tricks, it’s just habitual. I guess...I just always find it a little ironic that

the neurotypicals call the aspies routine-fixated. They've got their own.

(p. 123, Connor, 2013)

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