READING, SEEING AND HEARING VOICES:

WHAT CAN AUTISTIC PEOPLE TEACH SOCIAL WORK?

by

Tobi McEvenue, BFA, OCAD University, 2006, BSW, Ryerson University, 2013

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ABSTRACT

Reading, seeing and hearing voices: What can autistic people teach social work?
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Tobi McEvenue
Program of Social Work,
Ryerson University

Social workers are prominent in the lives of autistic individuals in their capacity as intake workers, group facilitators, and counsellors. There are few examples of literature written by social workers regarding working with autistic individuals and groups, and even fewer studies which surface the voices of autistic individuals. Preliminary Grounded Theory research was conducted using asynchronous online interviews with three adult autistic participants to explain how they experienced the process of social work interventions in their lives. The emergent themes from this study include "I wouldn't want a cure", neurotypical assumptions of ability and disability, fluid and intersecting identities, help-seeking and autonomy, cautionary self-advocacy, neoliberal service provision and creating ineligibility, multiple categorizations and "body control", "I don't even really know what a social worker is supposed to do", and critical social work facilitation. This preliminary grounded theory research may form the basis of a future larger, grounded theory study.

Keywords: autism; social work; online research; advocacy; disability; queer

ACKNOWLEDGEMENTS, DEDICATION

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Chapter 1: Introduction

This MRP is about the experience of autistic people, and social work services they have received. Knowing the power of language, before I proceed I must first position how I speak about this work, in my life and in the research study.

Why I Do Not Use "Person-First" Language

I would like to share that there are a variety of ways that individuals may choose to identify themselves. There may be some who prefer to self-identify as "Aspie", "person with autism", or autistic. There is no general consensus on terminology, and in fact, how people identify, or do not identify with particular identities and/or communities is contested (Baggs, 2010; Bascom, 2011; Sinclair, 1999).

My personal and familial connection to autism, and my professional complicity in the autism discourse, has ignited my passion to explore counter-narratives about autism. My encounters with the professional lexicon used to identify autistic individuals took place in social work spaces, a vocabulary called person-first language, which instructs society that"…disability should be spoken of as something that comes along 'with' people… [and] conceives of disability as a troublesome condition arbitrarily attached to some people, a condition (unlike gender, race or ethnicity) that is only significant as a remedial or managerial issue" (Titchkosky, 2001, p. 126). According to person-first language, disability, or autism is at once something which afflicts individuals, and is not understood as a part of identity. While formerly working in a social work capacity at an agency funded to provide services to autistic people and their families, my first education was the political importance of "person-first" naming .I was taught to refer to service users as "people living with ASD", and not as "autistic people".

The uptake of person-first language, as directed by the Ontario Ministry of Citizenship in the 1970's, was considered an effort to affect the ways that society considers and treats disabled people by substituting hateful or discriminatory identifiers with the reminder of the humanity of the person being identified as such (Titchkosky, 2001). By placing "person" before the disability identifier, the aim was to diminish the harshness of the label by underscoring the common tie between non-disabled people and disabled people. While I support and celebrate each individual's choice to identify themselves as they so choose, I situate my understanding of the issue alongside autistic self-advocates as I use the term "autistic" (Bascom, 2011; Sinclair, 1999). Using this language aligns myself with the understanding that autism is not a disease, or something that can be eradicated or cured. Using this language allows people to understand that autism is a difference and a state of being.

Why Autism and Social Work?

Autism is understood scientifically as a disorder displaying any mixture of impaired social and communication skills, and repetitive actions and interests (Davidson, 2007), as a disease, or a social and economic epidemic. Close to 1% of Canadian children are diagnosed with autism per year, while services cost over a billion dollars per generation (Autism Ontario, 2008; NEDSAC, 2012). The wide-spread adoption of evidence-based approaches to early interventions is deeply rooted in the medical model of disability (Holmes, Murray & Perron, 2006; Mesibov & Shea, 2011).

Scholarship which interrogates consultation with autistic people and their families, and the applicability, feasibility, and desirability of these evidence-based programs is conspicuously absent. There are studies regarding the needs of autistic adults within ill-equipped Ontario social service systems (Stoddart et al, 2013);other literature notes that social workers should familiarize

themselves with the early warning signs of autism in pre-school aged children, to improve

children's developmental outcomes (Dababnah, 2010). However, there is a dearth of critical,

anti-oppressive social work literature discussing autism. There also are few studies conducted

that bring autistic voice, experience and knowledges to the forefront to inform social work

practice and the discourse of autism. For these reasons I have sought out the stories of autistic

adults to share what their experience of social work practice was in their past, or is currently.

The Purpose and Objectives of This Study

I have used grounded theory methodology to conduct qualitative research online with

self-identified autistic adult participants living in Ontario. As a strategy used to create

"substantive theory" (Glaser & Strauss, 1965, p. 5), this research is not merely a contribution to

legitimizing evidence-based quantitative research. The utilization of qualitative, grounded theory

research may assist in surfacing counter narratives which challenge damaging positivist

discourses in autism research (Clarke, 2005). It was my objective to aid in the development of a

theoretical model of social work practice informed by "best practices" based on lived

experiences, prioritizing autistic voices as a contrast to quantified, evidence-based social work

practice. While theory and models of practice already exist which explain social phenomena

related to disability and to queerness, the application of theory to explain the intersections of

disability, queerness, and autism have not been explored (Creswell, 2007). As such, I have

conducted grounded theory research in order to surface the voices of autistic adults to explain

how they experienced the social phenomena of social work counselling and interventions in their

lives.

My own interest in this research stems from finding counter discourses of autism online,

written by autistic people, and subsequently not finding any "evidence" in scholarly journals to

support the opinions and claims. Supporting my methodology with legitimacy, I have included information from blogs and essays written by autistic people in my literature review, and have sought out counter-narratives to the discourse of autism.

Moving beyond a survey model for online qualitative research, I created an online, confidential asynchronous interview tool, resembling a chat forum. Three adult autistic participants responded and engaged in an online interview process over a longer period of time, ranging from 3 hours to fifteen days. The data collection, analysis and participant characteristics will be discussed in the methodology chapter. The uniqueness of the online interview tool yielded interesting findings, both related to my interview questions and to this method of data collection. The findings chapter of this MRP will describe the participant's experiences of social workers in their lives, highlight emergent themes and will problematize the multiple relations of power inherent in that relationship, and in the social work profession's proximity and complicity in systems of power which operate in normative society.

Due to the few participants recruited for this study, substantive theory could not be developed as expected from a grounded theory approach (Corbin & Strauss, 1990). However, in the discussion chapter of this MRP, I will provide preliminary concepts and connections, as well as future directions and recommendations for further study.

Chapter 2: Literature Review

The topic of Autism Spectrum Disorders (ASD) is subject to considerable debate, whether it be about the diagnosis itself, causation, services and interventions, or identity politics. The literature available on this topic is immense, and the narrative arch of how I have come to understand and demand the inclusion of autistic voices guiding research, and producing counter-narratives to the deficit-based discourse of autism will be accordingly wide. In order to adequately cover the epistemology of ASD, I must start with the positivist determination of the diagnosis, and society's response. This investigation will lead into the politicized, and often mercurial, worldviews of parents of autistic children and their service providers, and autistic self-advocates who align themselves with the neurodiversity movement.

The Science of Autism Spectrum Disorder

Autism is understood scientifically as a disorder displaying any mixture of impaired social and communication skills, and repetitive actions and interests (Davidson, 2007), as a disease, or as a social and economic epidemic. While many theories proliferate the scientific autism literature, one theory that has gained avowal in the scientific community is the "theory of mind". Theory of mind can be described as a person's ability to understand or intuit what other people may be thinking, and has laid the foundation for much autism research to follow (Baron-Cohen, Leslie & Frith, 1985). Research has been conducted to indicate that autistic children, youth and adults struggle with theory of mind. This research suggests that in time autistic youth and adults can learn to link cause and effect social relations from rote memory and pass false belief tests; however, they fail simple moral judgement tasks (Begeer, 2007; Moran et al., 2011). The failure to anticipate moral judgement in test scenarios elicited the authors to suggest that "…unlike even typically developing infants, they failed to spontaneously anticipate another's

person's actions…" (Moran et al, 2011, p. 2688). The language used to describe adult autistic participants in this study is infantilizing and paternalistic, and how the consistent use of this language throughout studies such as this dubiously affects autism discourse will be considered later in the discussion section of this study.

Following up from inferences in theory of mind and the overrepresentation of males with an autism diagnosis, the "extreme male brain" theory was developed (Baron-Cohen, 2002). This theory suggests that the prevalence of autism diagnoses in males is linked to the psychometric differences between males and females when systemizing and empathizing is measured. Baron-Cohen (2008) suggests that males in general, and autistic males in particular tend to display measures of systemizing, which is considered to be a method of cognition which orders and comprehends scenarios based on rational, *if x, then y* thought, and comprehends events in search of lawful truth. He suggests that this gendered trait lends to the autistic person's difficulties with understanding emotionality and multiple perspectives on events involving social interactions. His research implies that on average non-autistic females are less inclined to exhibit systemizing preferences over empathizing preferences. The social construction of the essential male and female brains via positivist, scientific truth-seeking extends to further studies, which imply that a key component of autism is a failure to empathize with others, thus underscoring the essence of the extreme male brain (Hobson, J., Hobson, P., Harris, &Garcia-Perez, 2009). Not surprisingly, positivist critique of this research does not engage with the problematic, essentializing gender discourse expounded in this study, rather it takes issue with methodological design and test-retest reliability (Bumiller, 2008; Fisch, 2013).

Consequently, an additional study looking into the extreme male brain theory solicited head, bust, waist, hip, wrist, and ankle measurements along with digital photographs of autistic

people in their underwear. This study posits that females with ASD display masculine physical characteristics, while males with ASD display feminine physical characteristics (Bejerot, Eriksson, J., Bonde, Carlstrom, Humble, & Eriksson, E., 2012). This purported gendered presentation of autism has also been linked to the exposure of fetuses to testosterone and steroids in amniotic fluid while in the womb (Baron-Cohen, Knickmeyer, & Belmonte, 2005; Cheslack-Postava & Jordan Young, 2012).The research infers that ASD may be less an issue of masculine phenotypes in both genders and more an issue of "gender defiance disorder" (Bejerot, Eriksson, J., Bonde, Carlstrom, Humble, & Eriksson, E, 2012, p.116). Given that the results fit with the extreme male brain theory in that there is an increased presence of testosterone in women and a reduction of such in men, the researchers suggest that autism is associated with androgynous physical characteristics (Bejerot et al, 2012). The linking of this finding to other research implicating the large number of children with gender identity disorder and ASD being "…male-to-female boys" emphasizes the preoccupation in this study with enforcing gender norms on bodies (Bejerot et al, 2012, p. 121).

While there are tensions in the scientific community regarding the validity of this research, "the crucial issue is not the critique of the social construction itself but how such essentialist constructions [of gender] affect people as they form their identities, seek support and attempt to find a place in their social worlds" (Bumiller, 2008, p. 672). The categorization of autism as a form of gender defiance disorder is an alarming, marginalizing approach for scientists to take in understanding and defining autism, and later on in this paper I will call upon queer and disability theory to further understand how autistic identity is being constructed.

The Social Construction of Autism as Epidemic

Much of the scientific research on autism suggests that many countries in the world are experiencing an autism epidemic. For instance, the current estimates of the incidence of new autism diagnosis in some parts of Canada is one in ninety four individuals (NEDSAC, 2012). As such, the social and political response to autism is multi-storied and peppered with literal and figurative autistic identity interventions.

It is not difficult to find literature regarding the discourse of the autism epidemic and the scientific interest in finding a cure for such. The majority of information available is quantitative, positivist research, all of which constructs the way that society identifies, characterises and marginalizes autistic people. The epistemology of autism is concretely linked to the socially constructed notion that disability/autism is a blight on humanity that science must work to change, or eliminate altogether. Interventions aimed at eradicating autistic symptoms in children and adults have gone to dangerous, even unconscionable lengths both historically, and in present day. A tragic example of the lengths that science and caregivers will go to cure autism can be seen in the positivist studies which suggest that higher levels of toxic metals in the blood and urine of autistic children may cause of autism (Al-Farsi et al, 2013). Accordingly, chelation therapy has been prescribed by physicians to remove the heavy metals and toxins from the blood, a therapy which has caused the death of children in the recent past (Adams et al, 2013; Brown, Willis, Omalu, &Leiker, 2006).

This medically and scientifically sanctioned autism intervention is reminiscent of Garland-Thomson's (2012) discussion of "eugenic logic", the thrust of modernist science to prevent or cure disability in order to erase societal impurities, and which closely coincides with the medicalization of disability. The impulse of parents, professionals and salespeople to

vanquish autism, thereby extracting the otherwise imprisoned neurotypical (NT) child underneath, is precisely what drives critical disability studies and disability advocates to distraction. This is also why I rail against person-first language.

Devastating additions to the list of dubious practices undertaken in the search to cure autism include the practice of chemical castration, bleach enemas coined as "Miracle Mineral Solution" (MMS), and hyperbaric oxygen therapy (AutismOne, 2012; Willingham, 2013). All three of these options take a biomedical approach to autism, and all with an insidious measure of cruelty. For example, the downloadable MMS instructions on the AutismOne website instruct parents and caregivers to administer the bleach enemas and bleach baths to their children every other day, and to note that the "immune system wakes up and sometimes we find the body detoxing an old suppressed cold, flu or rash. It is common to find that the child gets a fever. This is very good" (Rivera, 2012, p 6). Rivera (2012) further explains that children often cry, laugh or behave oddly for no apparent reason when beginning the MMS therapy, and suggests that her approach and solution is not snake oil, rather a scientific approach to combatting autism. The individual pursuit of parents and caregivers to cure their children, while likely driven by love for their child, is misguided. Sinclair (2003), an autistic self-advocate, suggested that parents let go of the dream of the child they thought they were having, and instead asks them to

> Take a look at your autistic child sometime, and take a moment to tell yourself who that child is not. Think to yourself: "This is not my child that I expected and planned for. This is not the child I waited for through all those months of pregnancy and all those hours of labor. This is not the child I made all those plans to share all those experiences with. That child never came. This is not that child." Then go do whatever grieving you have to do-- away from the autistic child--and start learning to let go (p 3).

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Evidence-Based Practice and Identity Construction

While Sinclair's (2003) message to parents also provides insight into how to parent an autistic child, there is significant uptake of different therapeutic approaches with which to intervene on autistic behaviours. The wide-spread adoption of evidence-based approaches to early interventions are deeply rooted in the medical model of disability, and came about at the time in which health and social services were struggling under funding constraints. Socially constructed and developed in part to legitimize professions, including the social work profession, the advent of evidence-based therapies placed the psychology profession favourably in the minds and budgets of government and corporate interests preoccupied with the marketization of the human services sector in the 1990's (Mesibov & Shea, 2011; Smith, 2011). The literature suggests that services provided to autistic people and their families should be based in scientific evidence, and models of service provision are produced accordingly which determine what access and what kinds of services are considered appropriate for practice.

One such model of service that has been advanced is home-based intensive applied behavioural analysis (IABA), which is more cost effective for governments to implement as no program space is needed and parents are part of the delivery of the program, thus reducing staffing costs. In one such qualitative study which measured stress in families delivering evidence-based IABA programs, parental stress reportedly decreased both when the families believed that the program was effective (regardless of the outcome of therapy), and when they had access to social and familial supports during the program (Hastings & Johnston, 2001). An additional, mixed methods study followed families to determine if an empowerment or acceptance model is more appropriate to support parents of autistic children (Weiss, Cappadocia, MacMullin, Viecili, & Lunsky, 2012). This study suggested that if stress factors were too severe,

and if the family did not have the financial and social resources to deal with persistent ASD

behaviours in their child, the likelihood of having positive outcomes from mobilizing resources

to change the problem were poor. This study offered up the option of "acceptance-commitment

approaches" to intervene where empowerment approaches cannot; however, it was suggested

that chronic problems cannot be helped by said techniques. Both of these studies suggest that the

support for families of autistic children is highly reliant on having the financial and familial

means to be self-sufficient neoliberal citizens.

One study (Dingfelder & Mandell, 2011) which measured the capacity of community

agencies to deliver best-practice applied behavioural analysis (ABA) programs found that certain

social service agencies failed to adopt evidence-based models due to a lack of local expertise and

conformance to specific ABA programs. After conducting an investigation, this study found that

agencies in a geographical area were failing to deliver the same evidence-based, ABA programs.

They ascertained that the onus was on an under-skilled, front-line workforce unequipped and

uninterested in delivering autism interventions along best practice guidelines (Dingfelder &

Mandell, 2011). This study emphasized the complexity of applying evidence-based therapies

across the board to agencies and schools with different purposes, however, it placed the blame,

for the failure of said institutions to successfully implement the evidence-based programs, on the

workers, teachers and therapists working in these environments. The assumption that the

evidence-based ABA model utilized in the studies was appropriate and applicable to the autistic

children and families is problematic. The literature states that the social construction of the

autistic person developed out of a relatively small number of case studies, all of which were

conducted on White, Anglo children without the input of autistic people themselves (Waltz,

2005). As such, the epistemology of autism is heavily informed by observations which construct

the autistic person as White, and one who requires special intervention and care, and not one who has autonomy, emotions, or skills. I consider this omission to be of vital importance for research. These studies ignore the possible experiences of racism, heterosexism, sociocultural differences, and structural and physical barriers that individual children and their families may experience.

The literature suggests that the scholarship of disability studies and postcolonialism studies must interrogate how race specifically impacts and creates disability in terms of access to healthcare (Mandell, Listerud, Levy & Pinto-Martin, 2002; Sherry, 2007). In a quantitative study which investigated the age at which White and Black children eligible for Medicaid received a diagnosis of Autistic Disorder in the U.S., the study found that White children received diagnosis nearly a year and a half earlier than did the Black children (Mandell et al, 2002). Indeed, this study suggested that the causes of this may be supposed differences in attitudes towards accessing health care, the support and advocacy that the families have access to, and the attitudes of health care professionals. The study did not cite racism or colonialism as the cause for this discrepancy in access to health care, and instead pushed back some of the reasoning onto the individual families. The small amount of empirical research available regarding race and autism deals specifically with statistics, and does not delve into the interlocking oppressions which further marginalize racialized autistic people.

The Role of Social Workers in the Literature

There exists a dearth of critical literature written by social workers regarding autism. In one large, mixed methods study involving autistic adults, their caregiver(s) and autism service providers, recommendations for multi-service integration, knowledge dissemination and services based on evidence were considered crucial to support autistic adults in Ontario (Stoddart et al, 2013). This study was conducted as an introductory study and needs assessment for the province

of Ontario's autism services. It outlined the how the province's programs lag behind other sector supports, and in turn do a disservice to both autistic children, adults and their caregiver(s).

Two of the few pieces of literature written by social workers state that delivering social skills programs to adolescents in clinics, at school and at home in an effort to generalize learned social skills in the community at large, is of vital importance (Dababnah, Parish, Turner Brown & Hooper, 2010; Duncan & Klinger, 2010). It is noted that companion pathologies such as depression and anxiety disorders, often linked with autism, can use social skills interventions to combat compulsive and aggressive behaviours (Dababnah et al, 2010). The suggested response in the aforementioned scenario is for social workers to act as "first responders", in essence, to police the bodies of autistic individuals and their families such that the neoliberal response to autistic identity is one of conformance and evidence-based intervention. The situated identity of the autistic person is one to be feared and controlled, and to further illuminate this point, the author states that "insight- oriented therapies are not recommended with this population" (Dababnah et al, 2010, p 31). This author advocates for therapies which focus on the offending behaviour or speech deficits to be worked on in a multidisciplinary team involving social workers, speech language pathologists and behaviour therapists (Dababnah et al, 2010; Mandell et al, 2002). The suggestion that social workers support autistic people as part of a multi-disciplinary team is a theme in the literature.

Evidence-Based Autism Interventions and Autistic Voices

An interrogation of the applicability, feasibility, consultation with shareholders (namely autistic people and their families), and desirability of these evidence based programs was conspicuously absent in the literature. Despite this failure to obtain consent and collaboration from autistic people themselves in the design of evidence-based autism intervention such as

ABA, the demand for this expensive brand of therapy persists. The efficaciousness of evidence-based early autism intervention calls for multidisciplinary team involvement including behaviour therapists, speech and language pathologists, psychologists, occupational therapists and social workers (Levy, Mandell, & Schultz, 2009; McConachie & Robinson, 2006). Despite these findings, the literature shows that less than half of families surveyed have a social worker, or primary worker who follows them throughout their service navigation (McConachie & Robinson, 2006). It is interesting to note that those families who chose not to access the evidence-based program, and/or partake in the research study were also considered to fall in the "more deprived" category of the Townsend Index of Material Deprivation, as opposed to those who did participate in one or both. The Townsend Index was developed as a way to measure relative poverty and access to resources in geographical areas of England (Phillimore, Beattie & Townsend, 1994). While this study did make note of this correlation, they did not move to interrogate why this might be the case. These researchers did not consider how their surveillance of services accessed by autistic children and their families might only capture those families who can afford to access said services, or on how these services might fail to support the more deprived families who "opted out" of service. There was no discussion of how the provision of services provided by a neoliberal government may not fit the needs of persons who may be wary of further involvement in systems of surveillance, of persons whom are already over-researched. Once more, I see evidence that autistic individuals and their families are being questioned, not the evidence-based programs.

Alongside the emphasis placed on the importance of evidence-based service delivery to autistic people stands the concept of recovery. Members of the Autism Self-Advocacy Network (ASAN) have come forward to criticize governments and insurance providers for reducing or

pulling away services that have allowed autistic individuals to cope and manage in a society not built with autism in mind. It has been suggested that, while recovery from autism is not supported by science, proponents of a recovery model may remove the supports put in place which allow autistic people to develop "…the myriad of coping strategies and mitigating measures that many…use in order to be successful" (Ne'eman, 2010, para. 7). These supports, such as Individual Education Plans (IEP), or other accommodations within schools and the workplace, may cease to be utilized if certain recovery-framed benchmarks are reached. This takes place even when the space for autistic people to operate using their individually devised success strategies is what may always have been required, not therapeutic intervention. This removal of support and accommodation speaks once more to the notion that autism is an affliction that can be recovered from, or that a person can operate in a neurotypical fashion with only initial accommodation.

The Discourse of Autism and Family Responses

The strain placed on families of autistic children has been well-documented in the literature. The knowledge produced by scientific studies about autistic people ensures autistic individuals are subjected to being "normal", or neurotypical (NT) and neoliberal formulas instruct parents and caregivers to seek out independent solutions to their personal problems. The veneration of evidence-based ABA programs as canon in early autism treatment is an example of how the power of scientific truth claims operates in the discourse of autism. Foucault (1980) wrote that "'Truth' is linked in a circular relation with systems of power which produce and sustain it, and to effects of power which it induces and which extend it" (1980, pp. 132-133). The insistence on conformity, behaviour modification and biomedical intervention proliferating the discourse of autism is an example of how the power of truth in discourse operates in society.

Organizations such as Families for Early Autism Treatment (FEAT) in California serve as a prime example of parent advocacy groups who are steeped in the discourse of autism as something to be "fixed", and this is seen by their insistence on making Applied Behavioural Analysis (ABA) something that should be funded by government and/or insurance plans (Orsini & Smith, 2010, p. 41).The crux of their argument is that it is a human right to access to ABA as a medically imperative therapy, and that it should be available to every autistic child and their families. However, this argument follows the medical model and discourse of autism and harbours some serious shortcomings on the human rights angle.

The failure of parent and caregiver advocacy groups in Canada to have the government fund behavioural interventions in the public school system provides an example of how the discourse of autism operates as it relates to the economic costs of autistic citizenship and personhood. This is seen in the case of Auton vs. British Columbia, which displayed how "…none of the evidence about the efficacy or medical necessity of …ABA dealt with the serious ethical issues that arise when powerful behaviour therapies are applied to clients who can't consent" (Orsini, 2012, p. 814). Framing the access to medically-necessary therapy as a human right systematically denies the human right of the child/youth in consenting to this service and in so doing denies autistic children and youth human agency and the right to identify as autistic citizens.

One study found that there was a vast difference between samples of online blogs written by parents with autistic children and of blogs written by autistic people themselves (Clarke & van Amerom, 2007). While the parent's blogs contained recurring themes of parental stresses, the desire for finding appropriate therapies or a cure for their children, the blogs written by autistic people told a different story. These blogs registered a whole range of experiences from

anger and frustration with families and professionals seeking a cure for who they are, to exasperation with charitable organizations contributing to the discourse of autism as a devastating epidemic.

Neurodiversity: Autism Re-framed

Autistic identity, as stated at the beginning of this review, is a hotly contested topic. The neurodiversity movement, whose membership is comprised primarily by people with Asperger Syndrome, or "Aspies", and autistic people considered to be "higher functioning", gained momentum throughout the 1990's (Ortega, 2009; Sinclair, 1999; Ward & Meyer, 1999). The term "neurodiversity", while criticized by some in the autism movement, is used to define appreciation for forms of difference that are based upon a person's neurological make-up (Orsini & Smith, 2010). The movement considers autism to be a particular human condition, and a specific kind of neurological presentation which should not be pathologized.

The adoption of neuroscience as a means to explain and define autistic identity is seen by the neurodiversity community as a celebration of the autistic brain's difference from neurotypical brains. However, this embrace of positivist science to buttress the identity of a community can be problematic. Ortega (2009) notes that there are tensions within the autism self-advocacy movement not unlike issues which arise within identity politics, specifically knighting a few high functioning autistic people to speak on behalf of all autistic people and thus ignoring difference is a prevalent issue within the movement (Ortega, 2009; Sherry, 2007). That said, some self-activists have argued that they are better positioned to inform policy and approaches regarding autistic people than their "neurotypical" counterparts. In sum, if someone is going to speak for autistic people who have yet-to-be-discovered means of communication, those in the neurodiversity movement would suggest that at minimum they themselves should be consulted.

The use of metaphor by the neurodiversity community to express "cerebral subjectivity" at times leads to both the notion that human behaviours are not socially determined and context-specific, and the marginalization of individuals and groups. Cerebral subjectivity refers to the lexicon used by the neurodiversity movement which reflects the interactions and intersections of neuroscientific ways of knowing, or brain-centric language, in our everyday lives (Ortega, 2009). Using metaphors involving the autistic brain as representative of the whole person works to promote autistics while demoting "neurotypicals", thus contributing to identity politics. Ortega (2009) additionally states that members of the anti-psychiatry community caution against the strong reliance on positivist neuroscience to define one's humanity, as this underlines the construction of disability and autism linkages to the medical model.

It is important to note that the binaries emphasized within autism discourse, those of pro-cure parents and professionals, and anti-cure neurodiversity self-advocates, are not the only perspectives. Indeed, the tensions within these camps reveal that there are differing autistic cultures, all of whom have independent perspectives on how being autistic affects living (Krcek, 2013).

There appears to be an erasure of issues of race in the discussions of autistic identity, or at least, a misunderstanding. In one study (Orsini, 2012), a participant suggested that racism and the Black/White binary is similar to the autistic/neurotypical binary. Curiously, the aforementioned participant qualified this statement by explaining that they have an autistic child and are a professional of health disparities research. It is important to note that the participant commenting in this study was not autistic, but a parent of an autistic child. Sherry (2007) states clearly that "postcolonialism should not be understood as simply a metaphor for the experience of disability; nor should the terms 'colonialism' or 'disability' be rhetorically employed as a

symbol of the oppression involved in a completely different experience" (p 10). This parent's insistence on the legitimacy of their allegiance and credibility to make that statement is problematic, especially given that a non-autistic parent is informing autistic identity and speaking about phenomena (racism, colonialism and disablism) that she may be twice removed from.

The inappropriate use of metaphor has also been appropriated by the neurodiversity community. One metaphor used amongst self-advocates, finding their geographical communities in cyberspace, is that the online autistic community is a "new immigrant group online, sailing to strange neurological shores on the internet" (Ortega, 2009, p. 432). While the words used to describe how it feels to find community in a surprising space draws in individuals, the movement must be careful not to race to assume the experiences are the same, thereby appropriating other people's historic oppressions.

Judy Singer, autistic self-advocate, issued a warning to the neurodiversity movement, asking them to avoid "its eternal victimhood, its infantilism, its demand for unconditional love and acceptance without concomitant adult self-reflection, self-criticism, a measure of stoicism, and a willingness to see light and dark in oneself as well as in 'the Other"(Singer, cited in Ortega, 2009, p 441). This is a strong reminder and lesson for groups engaging in strategic essentialism to push social justice mandates. Fellows and Razack (1998) stated that it is imperative to remain mindful of how each human may play a part in the marginalization and oppression of another human in any given context, and that groups and individuals must not be blind to their potential complicity in their "race to innocence" (p. 1). The caution here relates to those voices which are silenced, and those rights that are trounced when select sections of marginalized groups coalesce to speak for the whole.

It is difficult to wade through the process whereby individuals come to engage with the idea of neurodiversity. Given that I personally subscribe to the notion that each and every thing is socially constructed, coming to identify and understand oneself based on neuroscience, as neurologically diverse, is in itself a social construction. Switching out this new, grassroots, scientific identifier for the older, top-down, diagnostic identifier is another way to strategically essentialize general experiences of being autistic in order to galvanize a community and alter the discourse of autism.

There exists an overwhelming amount of positivist, quantitative research conducted on and about autistic people, and emphasis on evidence-based research and interventions. The subsequent social responses which construct autism as an epidemic are unsurprising, and that socially constructed phenomenon has spurred the theoretical development of the autistic self-advocacy and neurodiversity movements. While the empirical literature I have included is by no means exhaustive, I have selected some of the studies which are considered foundational for evidence-based, scientific epistemology of autism. There are many different professional fields devoted to researching how they can best support autistic people with their unique "autistic presentations", such as speech language pathologists, occupational therapists, behaviour therapists, play therapists, social skill interveners, among others, and I have not selected empirical research from these disciplines given the scope and topic of this MRP. The lack of critical interpretive research regarding autism is obvious, and so in my next chapter I will discuss the theoretical framework for my research, which is guided by tenets of Critical Disability Theory, Queer Theory and informed by the Neurodiversity movement.

Chapter 3: Theoretical Framework

For this study I will draw on some elements of Critical Disability Theory (CDT) and Queer Theory (QT) as a theoretical lens through which I will critically examine the tensions in historic and present day social work practices with autistic adults. Ultimately, I will be using these theories to complement or inform the neurodiversity movement.

The discourse of autism and much of the empirical research about autism is heavily influenced by the medical model, the social construction of disability as an affliction in need of cure or containment, and the complicity of social work in supporting this discourse through the endorsement of interventions on autistic people, in lieu of social world interventions. It is for this reason that I draw on CDT and QT as the theoretical framework for this study. The biomedical understanding of disability is deficit-based, determines identity by the classification of abject bodies, and marginalizes disabled people such that a culture of normalization can be maintained. As a response to such, the social model of disability was developed. The notion that disability is a socially constructed phenomenon as opposed to a biomedical fact emphasized tensions in the social response and discourse of disability (Molloy & Vasil, 2002; Nadesan, 2005).

Before I proceed, I must discuss the emergence of Disability Theory and the social model of disability, as they influence the neurodiversity movement and contribute to the counter discourses of disability and autism. Disability Theory emerged as a response to the Western, medical model of disability which maintains a fearful and pitying response to disability in society. It interrogates the academic, political, systemic and interpersonal relations of power which socially construct and represent the meaning and embodiment of disability (Molloy &Vasil, 2002). Erected to combat damaging discourse and identity formations, disability theory

is modelled after the experiences of self-advocating disabled people whose lives are interpreted as pitiable by "the temporarily able-bodied" (Singer, 1998, p. 12). This socially constructed view affects every facet of social living, including access to employment, housing, nutrition and healthcare, among others. Disability Theory shifts the focus from the personal, deficit-based view of disability and emphasizes the social complicity and construction of the ablest environment. Owing a debt to the feminist movement, it endeavours to move disability issues from the personal to the political, and maintains that the modernist conception of disability as an individual barrier is instead a barrier caused by disabling social and physical structures (Sherry, 2004, 2007).

The social model of disability posits that disability is created by systems that pose barriers to access, both physical and social (Connell, 2011). This model suggests that by removing physical barriers to participation, access and opportunity, and eliminating social stigma, hate and abuse, the emphasis is placed on society and structures to change, as opposed to disabled people. The social model of disability defines impairment "…as a form of biological, cognitive, sensory or psychiatric difference [observed] … within a medical context, and disability [as] the negative social reaction to those differences" (Sherry, 2007, p. 10). This understanding of impairment and disability has been criticized for the nullifying effects of the uptake of disability as a defining feature of the social model, thus relegating impairment to the rudimentary, foundational understandings of the disability studies discipline (Connell, 2011). The "demotion" of impairment and the binaries of disabled/non-disabled within this model lead to the reimagining of the social model of disability into critical disability studies.

Critical disability studies look closely at the idea of social embodiment as a fluid relationship which contributes to the creation of impairment and disability in context (Connell,

2011; Garland-Thomson, 2005). The notion of social embodiment connotes that there is no fixed category that bodies fit into, and that identity is connected to various and alternating conceptions of embodiment. This definition suggests that the body is implicated in social exchanges that are called disability, and social exchanges affecting bodies in different contexts are called impairments (Connell, 2011). Indeed, Sherry (2007) writes that the vacillating positioning about and around binaries can result in identity that is neither here nor there, undeterminable, and may produce a challenge to dominant power relations.

Critical disability studies seek to relocate impairment within the model as a critical site for marginalization and interlocking oppressions. Some of the issues at play where the social model of disability cannot do justice involve the idea of "disability nationalism" (McRuer, 2010, p. 613). The creation of exclusive groups within disability, or in this case, neurodiversity, for strategic advocacy initiatives or community development connects to the neoliberal, postcolonial approach which enforces binaries via competition, and the illusion of inclusion within the discourse of nationalist capitalism. In this way, the combination of academia and disability rights advocacy has created the prevailing notion that accommodation means social equality. This has implications for all of society, not just for research as explained by Reyez-Cruz (2008):

> The academia that we know today continues to be a site where that knowledge is produced and legitimated, a place where those with access to it can insert themselves in the reproduction of the kind of capital that allows a few to say what counts as valid for the rest of us. The knowledge produced here for the most part does not profoundly shake the ways things are. And it is used by professionals, policy makers, politicians, bureaucrats, and the like to silence anyone who attempts to walk and talk outside their assigned place (p. 653).

Ultimately, the initial construct of disability studies with its binary distinctions of disabled and non-disabled, and the strategic essentialist moments of community development to advocate for equal rights, did a disservice to different and fluid identities within the spectrum of disability and impairment.

Some critical disability theory academics have weighed in on this process and have emphasized how this exchange creates and sustains a damaging social identity through a process called "enfreakment" (Waltz, 2005, p. 422). This process occurs in all social spaces, where the accessibility of scientific canon, such as the Diagnostic Statistical Manual IV and V, makes it easy for researchers, professionals, the media, friends and family to pathologize individuals who present outside of the norm (Perlin, 1992). This process is made more insidious given that the historical and present day social constructs of autism are built on a few case samples of White, Western, Anglo children (Waltz, 2005). These case examples deny autistic voice and narrative, and promote the identity construction of the diagnostician as truth within the medical model. The epistemology of autism, fundamentally constructed by these case examples, makes problematic the role of social workers, and as such social workers must navigate the different discourses that affect the way they work with autistic people.

Drawing discursive connections between outwardly different theories is one way that social workers can acknowledge how autistic individuals are socially impacted by language. Despite independent scholarship and research, Disability Studies and Queer Theory are linked through discourse and experience. Sherry (2004) wrote that

Disability Studies and Queer Theory problematize the public and the private, the social and the biological, difference, stigma and deviance, and the construction of identities….[They] challenge universalizing norms that marginalize those who don't

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conform to hegemonic normalcy… [and] engage with the lives of people who can experience high levels of discrimination, violence and intolerance (p. 769).

Indeed, the use of metaphor in both disability and autism literature bears a strong resemblance to Queer Theory literature regarding discussions of the perils of disclosure, and experiences of coming out of the closet (Davidson & Henderson, 2010). The early psycho-pathologization of homosexuality as sexual abnormality within the medical model contributed to the development of the theme of "passing" in Queer Theory scholarship, and can also be seen in the neurodiversity literature (Davidson & Henderson, 2010; Sherry, 2007). There is a consistent thread in both Queer Theory scholarship and autistic self-advocacy/neurodiversity writing regarding efforts to appear heterosexual, neurotypical, or "normal". Discussing this phenomenon witnessed in autistic autobiographies, Davidson & Henderson (2010) wrote

AS [Asperger Syndrome] authors describe having learned to fit in through extensive, life-long study of neurotypical 'natives.' They have discovered, for example, which autism-associated behaviours to suppress (e.g., echoing others' speech or walking on tip-toes) and which neurotypical behaviours to mimic (e.g., smiling or making eye contact) in order to present a more or less acceptable front. For many on the spectrum, the hard-won ability to pass means their autism is an invisible condition (p. 151).

As with the discourse of passing, Queer theory also has applications related to the neurodiversity movement, specifically pertaining to the areas of alliance and disclosure. Queer theory takes aim at the discourse of heteronormativity, and strives to trouble the socially constructed binary notions of sexual identity by inferring that there exists multiple and fluid sexual identities in the social world (Sherry, 2004). Both queer theory and the neurodiversity movement hold in common the issue of when, how or whether to disclose identity (Davidson

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&Henderson, 2010).Indeed, one autistic self-advocate stated that "for those…on the autism spectrum who manage (or struggle) to 'pass' in employment or other public social situations, disclosure is often as complicated and risky as coming out is for GLBT people" (Schwarz, 2004, p. 168).

Another element of queer theory that lends itself well to my research includes the issue of ally work in research with autistic adults, where I identify as a neurotypical person. Queer theory allows myself, as a social work researcher, to work in a fluid manner, to occupy the grey space of not knowing, and to work honestly with autistic adults throughout this process (Reynolds, 2010). In so doing, I invite feedback on my working process with the participants in order to acknowledge and disrupt the relations of power that exist. This is important for social work research, as well as social work practice, as it emphasizes the impact that both actors have on each other's lives openly and accepts that this process can be messy.

Engaging in qualitative research to surface knowledge of autistic adults and utilizing Critical Disability Theory and Queer Theory as a theoretical framework allowed myself as a neurotypical researcher to engage with the participants with curiosity, openness and great care. Remaining reflective of what and whom I represent as a neurotypical social worker could not be forgotten throughout the research process, and I consider the use of CDT, QT and the neurodiversity movement a fitting challenge to the professionalization and structures enforced in academic research and the social work profession. The absence of social work research focusing on autism spectrum disorders within combined CDT and QT frameworks is evident, and it is my hope that more research is conducted which considers the intersectionality of these disciplines and theories to highlight the social phenomena and experiences of individuals.

The purpose of this Grounded Theory study is to present exploratory, mid-level theory and a social work model of practice which is reflective of participant responses to three major research questions: How did the presence of social workers in your life feel? How would you describe the support you received, or are receiving, from a social worker? If you would like support, what kind of support would you like to receive from a social worker? The data provided by the three online participants supported the understanding of how the phenomenon of social work was experienced by the participants as children and adults. It is my hope that this study may contribute to critical understandings of social work practice with autistic individuals.

I have used the concept of neurodiversity to link the lenses of Critical Disability and Queer Theory in order to fill in gaps found in both theories as they relate to autistic individuals. For instance, Critical Disability Theory does not specifically acknowledge the experience of autistic individuals and the uptake of Queer Theory to further understand the intersecting complexities inherent in living as neurodiverse can be operationalized for inquiry through any number of approaches to research, such as Narrative, Phenomenology or Discourse Analysis. In this way, the use of Grounded Theory utilizing CDT and the neurodiversity movement is important as a way to develop more robust theory (Creswell, 2007).

Chapter 4: Methodology

Introduction

When searching for information on Autism Spectrum Disorder (ASD), I was given access to hundreds of newspaper articles, research studies, journal articles and books. I came to acknowledge that the majority of information available is quantitative, positivist research, all of which constructs the way that society identifies, characterises and marginalizes autistic people. Indeed, a review of the literature suggests that countless autistic children and adults have been subjected to a preponderance of positivist, evidence-based studies which utilize random control trials, and pre-post tests to determine the effectiveness of autism treatments and interventions (Begeer, 2007; Lovaas, 1987; Moran et al., 2011; Wood et al, 2009). Some qualitative research has been conducted, however this has not been done from a critical, interpretive perspective; rather, the qualitative pieces have been secondary to qualitative studies (Nicolaidis et al, 2012). In the cases of studies coming from a more critical perspective, research has not privileged the voice of autistic people, often instead seeking knowledge from parents of autistic children (Clarke & van Amerom, 2008) or from a combination of autistic people, parents of autistic people, and service providers (Stoddart et al, 2013). As with much of social work research, there exists a dearth of Canadian-based social work studies in this area. Given the emphasis of positivist, evidence-based study on this over-researched population, I consider it important to highlight the missing voices of autistic people in the literature, and suggest that a qualitative, critical interpretive study that focuses on the experience and voice of autistic people is crucial.

There are numerous approaches to inquiry within the qualitative research tradition. Some of the qualitative research undertaken with autistic populations took the form of qualitative content analysis used on pre-existing blogs or autobiographies written by autistic people (Clarke

& van Amerom, 2008; Davidson & Smith, 2009), while grounded theory has been used to determine how autistic individuals experience the online communication medium (Benford & Standen, 2009). Narrative approaches to inquiry can bring autistic voices to the centre of knowledge creation by focusing on the lived experiences unique to each individual, while phenomenology can explore the essence of the lived autistic experience. However, narrative approaches focus more on each individual story as opposed to what is common across individuals, and phenomenology's focus on meaning does not fit with my research question regarding the participant's experience receiving social work services. Initially it may appear then that I defaulted to grounded theory as the best approach to my inquiry, given the limitations of other approaches; however, below I discuss why grounded theory methodology appeared to be the best fit for my purposes.

While many approaches to such an inquiry can surface complicated experiences and socially constructed problems, and focus on emergent themes directly from the data, grounded theory methodology, particularly through its analytical process, takes the inquiry to another level, seeking explanations of concepts and connections to inform theory and frameworks (Jones & Alony, 2011).Grounded theory methodology is also beneficial to social work as it was established initially to create new theories emerging from different social contexts which are less abstract than that of the grand theories, and thus are more likely to be readily applicable to different social work practice situations (Glaser & Strauss, 1967; Oktay, 2012).Using this approach allowed me to interpret a potential model of social work practice which includes best practice ideas emerging directly from the data the participants provided. Grounded theory methodology is also considered a fitting methodology for social workers given their mutual fundamental building blocks of pragmatism, and symbolic interactionism (Oktay, 2012).

Additionally, grounded theory methodology provides a logical structure which is readily understood and followed in a systematic way, which is important to me, as a graduate student undertaking empirical research for the first time.

Grounded Theory as Methodology

In addition to the reasons noted above, Grounded Theory was especially chosen as the methodology for this study because it is important for me to conduct research in a way which allows theory to emerge from the data, and not have a pre-determined theory imposed on the findings (Corbin & Strauss, 1990; Glaser & Strauss, 1967). This inductive process allowed me to centre the participant voices, with their experience as the knowledge which informed the theoretical findings. I began interviews asking more generalized questions in order to allow the participants to direct the interview by their specific experiences of process as evidenced here:

Q. Because this study is focusing on experiences of/with social workers in the past or present, could you share with me what your experiences have been like? A. What exactly do you want to know?

Q. I am interested in hearing your experiences with and ideas about the social work profession. This could include your perception of what they do, what approaches they take, or general feelings you have about accessing social work. I know that's broad, but I am interested in any and all responses.

This participant initially felt overwhelmed by the openness of the interview question, requesting specific guidance to frame their answers. Beginning with the more open question allowed me to tailor any follow up questions uniquely for each participant, based on their responses, but also allowed participants to form their own ideas about concepts in their response, when they did not seek more detailed follow up questions.

By asking more general, open questions, and thus not using pre-determined concepts unless requested by the participant, this research resists other research and service practices that label and categorize autistic people. This iterative development of interview questions to understand how the participants experienced the process of social work practice in their lives allowed me to develop more pointed questions which also aided with axial coding (Creswell, 2007). Following up from previous responses in the transcript, I was able to direct my questions to glean further understandings of process when I asked

Q. You mentioned a distinction between "things that can help you in certain areas" and not wanting a "cure". Can you please tell me a little bit more about how you understand the difference?

To further surface the voices of participants, and thus avoid pre-determined concepts in my research, the online transcripts created by participants in response to my questions (which I discuss later) limited the potential of researcher error or bias which can occur when an interview is transcribed. The availability of these online transcripts also allowed me to use participant's words verbatim in my responses and follow up questions. In doing so, I had the opportunity to reflect on the responses from participants, before formulating follow up or subsequent questions. This process ensured that my questions were iteratively driven by the data, and in my analysis, that I had understood their meaning as they intended.

A grounded theory approach to data collection and analysis, involving constant comparative analysis, open coding, axial coding and use of in vivo labels to determine themes in the data was conducted (Corbin & Strauss, 1990; Glaser & Strauss, 1967). Constant comparative analysis was practiced in all three interviews; as such my first interview questions and their responses were analyzed prior to conducting the second and third interviews in order to discover

emergent themes in the data to further investigate in subsequent interviews. I chose to approach open coding by highlighting emerging themes and in vivo phrases whenever possible in the data that spoke to experiences related to social work in addition to unique emergent details applicable to my research question. The axial coding phase involved the contraction or expansion of all similarly worded emergent themes and contexts which described similar phenomena in order to narrow down the most salient findings pertaining to my research question.

Grounded theory methodology lends itself to the utilization of creative methods of data collections, as "…an important component of the method is to build change, through process, into the method" (Corbin & Strauss, 1990, p. 5).While the principle of online qualitative data collection is not new, my approach to such is somewhat novel. I enlisted the help of my partner, a website and app developer, who was able to build a website and confidential chat environment wherein myself and each participant were able to engage in an online interview. In order to maintain confidentiality and adhere to Research Ethics Board protocols, a confidentiality agreement was drawn up and signed by this individual.

For each participant, the process of the interview looked different, and the design of the chat environment lent itself to fluidity in use due to the notification system. The online chat environment was simply a place to house the interview questions and participant responses which were essentially e-mail responses, while in effect, it resembled a chat room. In this way, participants had the choice of synchronous (online messaging simultaneously) or asynchronous (messaging over an extended period of time) interviews, depending on their comfort level. The participants who chose asynchronous interviews were sent an e-mail notification and link to the e-mail they signed up with, letting them know that I had asked them a question. The participants were able to click the link located in the e-mail to take them directly to the question posed. If at

that time the participant desired to view previous responses, the entire transcript would be available for them to view on the same page as their newest question. As such, the participants were able to add to previous responses they had left, or simply answer the next question.

The unique data collection strategy of both synchronous and asynchronous online interviews allowed for timely and on-going data analysis as no time was needed for transcribing. Indeed, throughout the interview process I was enabled by this design to analyze the data entered in asynchronous communications, as two out of three participants elected to conduct the interviews over time. This added benefit allowed me to easily consider which research questions were irrelevant for participants as I was still conducting an interview, and assisted me to reconfigure my interview approaches with participants. According to Corbin and Strauss (1990), this adds rigor to the grounded theory approach as the process of continuous data analysis during the data collection process opens up avenues of new discovery in the data to explore in future interviews. Throughout my research process, I was able to hone in on certain emerging details, as will be discussed in my findings chapter, that were unexpectedly connected to my general research question, and found consistent threads in all three interviews as a result.

The creation of the online qualitative interview tool served a dual purpose. As previously mentioned, it allowed me to easily conduct data analysis as the interviews took place over time, as well as track the interview flow. In addition to these purposes, the use of the online interview tool also provided a research opportunity accessible to online autistic communities that already exist, conducted in what is, for some autistic individuals, a preferred and comfortable medium (Bascom, 2012; Benford & Standen, 2009; Clarke & van Amerom, 2008; Sinclair, 2012). I chose to meet the online autistic community where they are at, in lieu of insisting on in-person social communication, as some autistic people report that neurotypical speakers have a tendency to

speak quickly, use idioms and fill silence needlessly, while autistic adults report to say precisely what they mean, and do not assume that their word will be conflated with something different (Brownlow, 2007; Dekker, 2000). The use of online correspondence allows for differing communication styles to flourish without elements of neurotypical communication style that can frustrate autistic people. While there has been criticism around appropriate social environments for relationships and communities to flourish (Barak, Boniel-Nissim, & Suler, 2008), Davidson (2008) suggests "…that interaction in virtual worlds enables recognition of complex Other ways of understanding and expressing experience that hold potential for 'real world' outcomes"(p. 792).

Conducting grounded theory research to uncover the stories of autistic adults who received social work services as children and youth is important due to the lack of social work research and knowledge in this area. The textual data, collected over time in a confidential, online chat format, provided ready-made transcripts from individual participants. Given that I was only able to secure three participants for this study, the knowledge saturation expectation of grounded theory research could not be reached (Corbin& Strauss, 1990). However, the interview data can be used as preliminary findings, guiding theory informing social work practice with autistic people.

From my personal connection to ASD, and my professional complicity in the discourse and physical delivery of services to this community, I am committed to co-facilitate and support research and self-advocacy efforts aimed at highlighting the voices of autistic individuals. I have been intentional, both epistemologically and methodologically, in conducting online, grounded theory research with autistic adults to glean an understanding of the impact that the social work profession has on the well-being of autistic person's lives. My interest in autistic identity was

initially piqued by viewing the preponderance of autism blogs written by autistic people, and the incredible work that was being done by this community, for this community. I maintain that conducting grounded theory research to investigate the experiences of autistic adults who received social work services in their lives is important due to the lack of social work research and knowledge in this area. As the literature implies that social work is an integral part of best practices in autism service delivery, I consider it imperative to have social work informed by autistic narratives such that the profession does not perpetuate neurotypical, heteronormative, and oppressive practices. With this knowledge, perhaps a new model of service can be co-created.

Conclusion

Having noted my methodological approach, and the rationale for this approach, I now shift attention to the results of my inquiry. In the following chapter I explore the themes that emerged through the open and axial coding, which I conducted through the constant comparison method. In doing so, key themes emerged across all participants related to their experiences of the social phenomena of accessing social work services.

Chapter 5: Findings

This research study sought to uncover the experiences that autistic adults had of social work practice. Throughout the process of conducting this research, many explanatory themes emerged. In keeping with academic rigor, I utilized an in vivo approach to data analysis and coding, making an effort whenever possible to use the participant's own words to delineate themes. To highlight participant voices, I have cited in vivo themes in quotation marks, such as "I wouldn't want a cure", while themes that I labelled are without quotation marks. The emergent themes dealt primarily with experiences of identity interventions enacted by the social world and the social work profession. The data invariably related back to socially constructed norms erected in neoliberal, heterosexual, neuro-typical and Western society, reinforced and maintained by the social work profession.

The emergent themes in this study are organized according to in vivo participant accounts wherever possible and are positioned in such a way as to describe how elements of social work practice contributed to the social construction of the participants in this study. Moving from the participant's expectations and experiences of social work practice to the participant's acknowledgement of the social and systemic power dynamics involved in the social work profession, the emergent themes construct an alternate vision of how social work may be practiced according to the expressed needs and desires of the participants. The theme "I wouldn't want a cure" was prevalent throughout all three participant accounts, and outlines the understanding of autism as identity, not disease or affliction. The theme of neuro-typical assumptions of ability and disability explains how neuro-typical privilege reinforces social work and societal claims to knowledge of autistic individual and group needs. The theme of fluid and intersecting identities is a theme which considers the acknowledgement of, and dedication to

social work understanding of the non-hegemonic identities of individuals. The theme of help-seeking and autonomy shows how participants understand the link between asking for needed and appropriate help as an extension of their autonomy, as opposed to accepting supports that may not be what was asked for, and serve to undermine autistic identity and autonomy.

Cautionary self-advocacy as a theme discusses the importance of the uptake of autistic voice and insight in order to maintain autonomy, but at the same time itemizes the challenges encountered by autistic individuals when self-advocacy is considered a primary goal in social worker/autistic adult relationships. Neoliberal service provision and creating ineligibility discusses how the services available to autistic adults are ill-suited to their needs, identities and experiences, in part due to the effect of neoliberalism. The theme of multiple categorizations and "body control" discusses how social workers can be implicated in systems which are erected to enforce neuro-typical, heteronormativity through information dissemination and gatekeeping to programs which control certain 'autistic behaviours'. "I don't even really know what a social worker is supposed to do" is a theme which discusses the participant's perception of the role of social work, and their uncertainty regarding social work utility in their lives. Finally, the theme of critical social work facilitation discusses participant's positive experiences of social workers in their lives, and what characteristics, actions and supports they found to be the most impactful for them.

The three participants recruited for this study differed in many ways. Sam (name changed to protect identity) identified as autistic/on the autism spectrum, Caucasian, financially insecure, undergraduate student, Catholic, gender queer and preferring the pronoun *they*. Throughout this MRP, I will italicise references to Sam using the pronoun *they* for clarity. Tonia identified as an autistic female, and as a psychiatric survivor. The final participant, Rae, identified as an autistic

female parent. *All participant quotations were entered verbatim as written by participants in their transcripts to emphasize that participant voice was surfaced and valued. As such, normative forms of speech, spelling, capitalization, punctuation and grammar were not imposed.*

"I wouldn't want a cure"

I started off this research study requesting that the participants share with me how they currently choose to identify. While this was a question asked early in the transcript to ensure a record of the one eligibility criteria I had for participation, the participants provided me with different reasons for why and how they identify with their diagnoses, all of which connected with the assertion that autistic identity is political, not curable. The theme "I wouldn't want a cure" contains many expressions of this position, where participants question why and how social work is practiced, and question the use of person-first language and autism interventions.

Social work practice involving a combination of knowledge of autism spectrum disorders, as well as flexibility and acceptance of different communication styles, is an accommodation that makes social relations accessible for autistic individuals. Relating the differences between an accessible social work intake experience and other social work experiences, Tonia explained:

> "It was okay. She didn't force me to make eye contact, which is important. (I've had 'anti oppression counselors try to coerce me into making eye contact even though I told them "I'm autistic, I don't make much eye contact, it's a normal thing for me". They still insisted on trying to 'fix' it)."

The attention paid to "fixing" an autistic person's behaviour, such as the insistence on meeting the social worker's gaze, is a prime example of the neuro-typical (NT) inability to consider that an autistic person may not want to make eye contact. Additionally, Tonia expressed

the need for social workers to educate themselves about autism in order to help the many autistic adults who may be either seeking or mandated to seek social work services when she stated:

"…recognition of autistic adults as existing…and [emphasis on] ways in which SW can be part of creating an inclusive society for autistic people rather than trying to simply change the autistic person."

Person-first language was identified as being part of what keeps the medical disease model of autism prevalent in social discourse. Reflecting on how she chooses to identify as autistic, Tonia expressed her issues with person-first language, noting:

"Having to insist on person first language suggests that autism/disability is SO bad that we have to purposely try to erase its existence."

While this was a common theme in all three interviews, this was the only instance where the term "person-first" language was used directly as an example of how politically correct taxonomy can do harm.

Rae likened her experience of coming to identify as autistic as an awareness and understanding of who she already knew she was. Describing the feelings she went through upon receiving a diagnosis of Autism, Rae stated:

"…things about my life made more sense. I didn't have to try to change myself anymore. I'm autistic and always will be…I wouldn't want a cure or anything."

While not every autistic individual may claim this, the participant's desires to both name, and maintain their autistic identity is the critical message for social workers, and professionals in the autism industry.

Frequent use of "we" instead of "I" throughout the interviews did connote a sense of community among the participants; however, it is important to note that these are individual

responses, and cannot be generalized to the whole autistic population. For instance, Rae shared that

> "…social workers need to know that most of us don't think we are broken and need
> fixing."

Rae's statement, while generalizing, is an accurate account of the attitudes and opinions of the autistic people she knows in her own community and it is reflective of her own opinion, and so substituting the "we" for the "I" is appropriate for her purposes. Her assertion that there is not a core, underlying problem to be solved about her identity speaks to how she understands the struggles in her life. This is seen as Rae explains how struggles in her life as a result of unfit and unsafe environments can be handled with accessibility and accommodation:

> "There are things that can help people communicate like speech therapy or AAC
> [Augmentative and Alternative Communication] and there are things that can help us
> with movement and sensory issues like O.T. [Occupational Therapy]. There are many
> therapies that try to make us N.T. [Neuro-typical]. We are fine the way we are."

The clear delineation between changing "the way we are" and "things that can help people" is understood as the difference between needing a wheel chair and having a wheelchair – the person remains intact, but their living mobility changes. The space where "things that can help people" melds with undesired interventions and therapies is where the neuro-typical assumptions of ability and disability begin.

Neurotypical Assumptions of Ability and Disability

Concretely linked to the theme of "I wouldn't want a cure", the data displayed many instances where social workers and human service professionals exercised neurotypical (NT) privilege, or rather, operated with assumptions of the abilities and disabilities of autistic people

based on how their NT selves operate in NT society. Tonia provided literature discussing NT privilege, with the caveat that the theory is fluid and in constant construction, and posted a link to an essay on NT privilege in her transcript for me to read and better understand her meaning. Accordingly, the definition of NT privilege is "…having a neurology that roughly corresponds to societal expectations" (Bev, 2009). The essay provided a detailed list of examples of NT privilege in stark difference with experiences of oppression of neuro-diverse individuals.

Describing the NT impulse to "fix" autism in an attempt to render the autistic individual neurotypical, NT privilege thereby assumes this to be the best option, and it is enforced via the sanctioned service options provided to autistic individuals and their families, developed by NT individuals and groups. Reflecting on the phenomenon of assumed and enforced neurotypicality, Rae stated:

"People think we need social skills lessons but if you put autistics together with other who have a same strong interest, there aren't the social problems."

Rae suggested that autistic individuals are capable of engaging and enjoying the social company of like-minded individuals, and that autistic individuals have the right to pick and choose whom they wish to share their time with. Contrary to NT thought, autistic people can enjoy interactions with others on their own terms, and do not require coercion to speak on topics and in ways that are not genuine and unfamiliar.

Guidelines for NT social workers working with autistic individuals to unseat their assumptions of ability and disability were shared by all three participants. Discussing her past experience with social workers Rae shared that it is important not to

"…assume someone wants help in a certain area. The autistic may be fine with it even if someone else would not be."

This suggestion highlights the impossibility of a person, NT or otherwise, to understand or intuit what another person wants and needs for themselves.

Social workers may fall back on scientific determinations of autistic phenotypes which categorize autistic people on a spectrum of mild to severe, mild typically being understood as having a developing communication system and severe being completely non-verbal. This NT assumption falls in line with the province of Ontario's neoliberal service delivery which funnels individual funding for Intensive Behavioural Intervention (IBI) to those children under age six who are considered to have moderate to severe autism, or autistic disorder (Surrey Place Centre, 2014). This funding structure ensures that children who may benefit from access or accommodation to different supports are not receiving the funding for such, and the social safety net sanctions IBI in lieu of considering social change, or individualized options based on the needs and desires of the autistic person. Funding interventions and therapies based solely on changing the autistic child's behaviours to mimic neurotypical behaviours ignores the necessity of investing in the alteration of disabling social and educational environments to accommodate autistic individuals. By failing to support the permanent accommodation of autistic people in social, occupational and educational environments, the funding for children under six years of age appears to be focused on a child-only cure agenda.

Considering her lack of access to support as a child, and her struggles with becoming suddenly and unpredictably non-verbal, Rae stated:

> "you can have a non-verbal autistic who needs less support than a verbal autistic and vice versa (the way everyone thinks it is). It is hard being verbal but non-verbal in certain situations. I am non-verbal for the most part a meetings."

She explains that these periods of becoming non-verbal can be incomprehensible to her NT social worker whom she queries does not always understand what she can and cannot do. She states:

> "I'm not sure that he completely understands how hard it is for me to actually do things at times…things like actually leaving the house, speaking up, advocating for myself."

The NT assumptions of ability and disability are reportedly not believed or understood by her NT social worker, and this complicates the relationship. Rae becomes responsible for ensuring that her social worker believes her. Other NT assumptions during social work exchanges can look like not following up with an autistic person to clarify their meaning, or simplifying an experience having come from a position of "knowing". Reflecting on an experience with a social worker, Tonia stated:

> "She was a bit condescending, though, and tried to fill in places where she didn't understand with her own ideas."

Treating Tonia as though she may not understand things, and subsequently failing to ask for her own clarification is an exercise of power over her in this situation, and is a symptom of neoliberal service provision which will be discussed in a later section.

Autism affects each individual differently, and as such, pseudo-scientific categories and hierarchies are readily used within the social service sector as a means to determine which level of autism presentation gets funding for interventions and therapy (Surrey Place Centre, 2014). Explaining how categories of disability/autism are placed on a hierarchy which measures the degrees to which an autistic person is further from neurotypicality, Tonia explains:

> "Having the label Asperger's can mean I get slotted into the 'high functioning' category, meaning that people don't take my need for help in some things seriously. By the same

token, the people who get considered 'low functioning' get considered as incompetent. Functioning labels don't end up meaning a whole lot…Who's 'higher functioning'? What is 'functioning' defined as, and who gets to decide? (It's usually not the autistic person)."

These categories, based on case study observations, rely heavily on the medical model of autism, and fail to take into account the intersectionality of multiple oppressions. Sam highlights this phenomenon as *they* outline how autism is perceived by a society that cannot comprehend it:

"I think for a wide variety of reasons, including access to the clinic (Clinic?), upper middle class folks tend to have their kids diagnosed as autistic. I also think that racialized others tend to have disruptive behaviour constructed as more intransigent than white folks. In this sense, I don't think that one can argue for a universal autism."

Providing this example, Sam draws attention to one facet of NT assumptions of ability and disability, that racism is linked to how human behaviours are perceived, and the response of differentiated healthcare access for marginalized individuals and families.

Sam reported that the NT assumptions guiding autism intervention are also impacted by heteronormativity. Linking *their* experiences of the application of the medical model of autism by *their* social workers, family and related professionals in their youth, Sam stated:

"It was like if they made me straighter, they would make me more ambitious, if they made me more ambitious, i would be less autistic."

The conflation of queerness and autism with failure, and heterosexuality and neurotypicality with ambition speaks to the kinds of attacks on identity that certain autism interventions can exact, most of which social workers conduct intake for.

Fluid and Intersecting Identities

The emphasis placed on not being pigeonholed by social workers and society as one identity was a persistent thread, and the cause of much anxiety. Reflecting on the difficulties *they* experienced as a child and youth being in and out of care, supported by social workers, teachers, psychiatrists and others, Sam stated:

"I think that gender, sexuality, disability, class, and mobility all made it really difficult to position in a way people understood--the queer radicality, not wanting to change my queerness and not wanting to change my disability and not wanting to betray my class, and not apologizing for any of it, had a kind of mutually reinforcing fuck you quality."

The combination of multiple intersecting identities created a situation where those people in Sam's life who represented power and control were unable to understand *them,* and as such many attempts were made to work on *them* instead of with *them.* Sam's experience of consistently being categorized for easier NT and heteronormative comprehension and consumption caused *them* distress and anxiety:

"…i needed to be controlled, my body taut like an elastic snapped back, and caused damage. this was the first time that i was told i was autistic, but also told that i was not to come out, that i was not sure of my sexuality, that the depression and the anxiety were not controlled--it was as if there was one thing and one thing only."

Placing the change effort on the autistic child, the focus of interventions is often to eliminate undesired behaviours that are not socially acceptable, or not considered functional. In some ways, the eradication of behaviours deemed by neuro-typical, heteronormative society as being without function can have damaging effects on the identity formation of children and adults alike. Sam's appraisal of the interventions on *their* autism, as directly connected to

interventions on *their* queerness, is drawn to the discourse of masculinity. McInnes and Davies (2008) wrote that masculinity defies liminality and fluidity, and restricts multiple and unclear ways of identifying by erecting strict binary divisions around how human beings may identify. Considering Sam's experience, I was drawn to the thread of masculinity tied to autism intervention. Sam considers that the attempts made to categorize *them* were pointedly heteronormative in scope and gendered in practice when *they* state:

"I think that…historically autism has been thought to be overwhelmingly masculine, and about non-normative identities, that there is an overlap in making gender roles more rigid (The desire to make spectrum kids good boys often emphasizes the boy quality of that equation.)."

Sam's physical assertions of queer identity were seen as a site of intervention, a site to fix, by the workers in *their* life. Attempts *they* made at self-expression and identification as a queer child were systematically undermined in high school, as explained by Sam:

"my support worker was…completely lost. She took the nail polish off my nails, she taught me how to dress, she made sure i made my classes, she asked questions and still, she had no ideea--the beatings, the death threats, the pushing against, the profound isolation."

While Sam did not specify which worker(s) made attempts to change *their* physical appearance for reasons discussed later in the findings, Sam suggested that *their* treatment was connected to the "discourse of the sissy". This discourse Sam discussed briefly emphasizes"…performative moments of declaration, in social contexts, in which young men and boys are othered because of their non-conformance to the standard performances of masculinity" (McInnes & Davies, 2008, p 107). Sam's multifaceted experience of intervention on identities is

a prime example of the need for social workers to develop an understanding of multiple and intersecting identities.

The issue of willingness to learn and come from a position of not knowing is recurring in the data, and in Sam's case, this issue is characterised by inappropriate referrals and social workers who were not up to the task of supporting *them*:

"i often had counselors who didn't understand sexuality or gender issues."

Tonia shared that in addition to identifying as autistic she also identifies as a psychiatric survivor. Although identifying as a psychiatric survivor is different than identifying as queer, Tonia's experience of intervention on her autistic identity and body created her intersecting identity. Discussing people whom she considers safe to share her story with, Tonia stated:

"I also identify as a psychiatric survivor…I've been forcibly medicated as a 12 year old, and I do not want to put myself in situations where it's likely that I am the person in the room/space with the least power."

The use of medication as an autism intervention or management tool on children and adults alike is seen by Tonia as an assault on autonomy, and it is an important viewpoint for social workers who support autistic clients to consider, and ask questions.

Tonia expresses that she most readily identifies as autistic, in lieu of her diagnosis of Asperger's Syndrome, and noted that some members of the ASD community prefer to identify with Asperger's Syndrome as opposed to autism. Tonia provided a link to a blog questioning how members of the Asperger community take issue with recent DSM V changes, which eliminate the separate diagnosis of Asperger's Syndrome and group it with Autism Spectrum Disorder. Expressing her dislike of this trend, Tonia stated:

"I use autistic instead of Asperger's -- it's embarrassing to be associated with elitists."

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In her view, placing individuals on the autism spectrum in a hierarchy, with Asperger's Syndrome as superior, does a disservice to neurodiversity and disability communities.

Help-Seeking and Autonomy

The theme of "help-seeking" suggested that there is a strong link between autonomy and choice, and the supports provided by social workers and the social safety net. Emphasis is placed on how participants have been disabled by socially constructed barriers, and not necessarily by being autistic. Reflecting on her experiences of disablement in society, Tonia explains:

"To say I am disabled -- in other words, that I have been dis-abled by the environment -- helps to situate my issues in a sociopolitical context. If I have been dis-abled, I can also be abled when the accommodations I want and need are put into place."

She explains clearly the requirements for her to live safely and securely in society, namely that she is able to name and choose the help she wants, and that her choices are acted upon. Ultimately, she explains that autistic autonomy is at the heart of reducing socially constructed barriers, not necessarily interventions on identity to enable her to live within an unchanged society. This is important for the social work profession to acknowledge given that social workers are often the gate-keepers of autism intervention programs, and they often co-facilitate social skills groups and parent education workshops about autism spectrum disorders. The power to disseminate information about autism to parents of autistic children and to autistic children can determine what decisions are made about support services and how autism is understood.

Interventions on identity focus on autistic deficits and attempt to educate autistic children through intervention and therapies to reduce the aspects of their identity that identify them as different. There are distinctions between therapies which are deficit based, and supports which

are focused on allowing autistic individuals to live more comfortably and more easily with socially constructed disablements. Discussing the distinction between deficit-based autism interventions and help-seeking for disablements, Rae explained:

"There are many therapies that try to make us N.T. [neuro-typical]. We are fine the way we are. We need a way to communicate, however that may be. We need help to move the best we can so we don't hurt ourselves- I lose balance and walk into things etc. We need things like ear plugs for loud noises if that bothers us. Those are things that help us but aren't trying to make us less autistic."

Rae's assertion that some autism interventions may be harnessed to support autistic people to better cope in a society that is disabling is dependent on certain factors. Discussing how she chose to implement Applied Behavioural Analysis (ABA) with her autistic daughter, Rae indicates that she conducted first-hand accounts of autistic individuals who had experienced ABA in order to ascertain its possible worth in her daughter's life. Rae stated:

"some autistics say no ABA at all but it really can be done in such a way as not to be abusive or make someone feel badly about themself or that they need to be fixed."

Rae chose to closely monitor the in-home ABA program she was implementing for her daughter, and insisted that certain practices such as the prohibition of "stimming", a term used to describe repetitive motions made by the body to calm oneself or communicate, be omitted. She indicated that, for her, the exercise of stimming in stressful or overwhelming situations has a calming effect, and communicates how she is feeling, and that disallowing this communication is wrong. By advocating based on her own experience and providing her input into the programs her daughter is being exposed to, Rae consciously frames the discourse of autism intervention into one of accommodation and learning opportunities made accessible.

Cautionary Self-Advocacy

The prevalence of self-advocacy as a theme was apparent in the data across participants. Participants framed the topic of self-advocacy as at times as an important mental health exercise, as an integral part of what they wish social workers would do, and as a tool that is sometimes used inappropriately with deleterious results, albeit unintentionally. Tonia frames her advocacy experiences related to her work with support dogs, and the tensions located both within the disability community and greater society to find the use of support dogs socially acceptable. Discussing a situation where her advocacy within the disability community created difficulty for her within it, Tonia stated:

"…pressure coming from inside the community to behave in ways that are more acceptable to mainstream society, even if what was being done by the non-mainstream people isn't actually harmful…It's a community policing itself."

She recognized that the disability community she was a part of was placing strict adherence guidelines on her community lest they lose what privileges they had to operate within NT space with support animals. Tonia's experience of being silenced within her community for sharing opinions that were considered too much of an affront to normative society culminated in her taking a temporary break from her efforts. She shared that:

"Advocacy is sometimes a wellness thing for me, but sometimes I thing that will cause problems if I do it."

The pressure placed on autistic individuals and members of disability communities to advocate for accessibility and accommodation is huge, albeit incredibly important. Her example of internal community censure brought to light an element of advocacy that she considered

chiefly important for social work practice. Sharing her opinion of the importance of social justice and change, Tonia stated:

"…teaching people about advocacy/self-advocacy can be a good thing, but it's at least as important to stand beside them to demand rights and fairness."

Saying this, Tonia rightfully places part of the responsibility to make change on society, specifically social workers.

The reasons that people access social work support are legion. So too are the reasons that autistic people access social work support. Rae shared that she attends social work appointments regularly because she feels she has to in order to handle issues in her life involving financial dependence and patriarchy. Responding to my follow up question regarding what kinds of things her social worker does not understand that she finds difficult to do, Rae stated:

"Things like actually leaving the house, speaking up, advocating for myself."

This quotation takes self-advocacy and being an ally out of the group advocacy context, and inserts it into an intimate context. It is important to note that Rae has shared that she does not understand what social workers do, and that she is not certain how she benefits from going every time outside of honouring a routine. Rae shared that she feels stuck in a situation that is controlled by a system which would make it very difficult for her to safely remove herself from without living in poverty and potentially losing access to her disabled daughter. Rae's comprehension of what her social worker does either for her or with her is muddled by requirements which outstrip a client/social worker relationship, and call for social work ally advocacy and social change. It is difficult, then, to comprehend how the social work emphasis on self-advocacy will help in the face of patriarchal notions of marriage and financial control.

The insistence on the importance of independence from systems can use self-advocacy as a tool in progressive, neoliberal social work. Taking aim on recovery and independence models of social work service delivery as a case for social work inaction, Tonia states:

"Self advocacy can be used in ways that hurt people (e.g. telling them that it's better to be 'independent' or do things on their own rather than provided needed assistance, and calling it 'self advocacy'. Refusing to help is not teaching self advocacy -- it's leaving people to flounder and then blaming them for their lack of progress!)"

Meeting a person where they are at, asking about what their needs are, or how you might assist them was seen by participants as a crucial component to social work practice with autistic individuals, and sadly one that gets lost in the plot of neoliberal service delivery and NT assumptions.

Sharing an experience of attending an amusement park trip with a small group of people along with social work staff, Tonia requested the company of a social worker for the rides, given her feelings of disorientation when she takes them on her own. Despite having advocated for herself in order to have her needs accommodated, the social worker repeatedly told her that she didn't understand, because Tonia appeared to be enjoying herself on the rides. Expressing her frustration with her self-advocacy not being heard, Tonia stated:

"I couldn't get through to her that it was the riding *alone* that was the issue and that as long as I wasn't forced to ride anything that would freak me out, I'd have a good time."

This element of self-advocacy, where a person expresses what they require to participate in an activity, sits uneasily with the idea of independence, and this example illustrates a neoliberal, NT outlook on service provision. The idea that an activity such as this which provides quality of life experiences would not be as readily supported as an activity implicated as part of

the social determinants of health indicates the recidivist attitudes in service provision, and a general leaning towards independence narratives.

Neoliberal Service Provision and Creating Ineligibility

The participant's shared experiences of social work practice which uncovered issues related to accessing appropriate services, finding support to accommodate them while accessing services and finding the need for social work services which acknowledged intersectionality, the experiences of trauma and anxiety, and fluidity of approach.

Neoliberal service provision took shape for some participants in the form of group service with insurmountable, inaccessible eligibility criteria. Discussing her experience of navigating the system to find a group dealing with anxiety, Rae stated:

"I was interviewed by a social worker for intake (at least I got myself that far).She didn't really seem to understand how hard it was for me to get there just for that and then I was supposed to be joining a group for anxiety… I don't understand how they expected me to go to a group especially unsupported…No good for me, so I have never been."

Rae's experience of intake with this social worker was indicative of a lack of understanding of necessary accommodation, and an approach of inflexibility which in turn orchestrated her ineligibility.

In a similar experience, Tonia shared that it was incredibly difficult for her to attend mandatory group counselling/therapy dealing with trauma due to relations of power from social worker to clients, over-crowding and poor group facilitation.

"She forced people to elaborate on their answers when they didn't want to talk…And somewhere in there, she told us it was important for this to be a 'safe space'.All of the groups I went to were WAY overcrowded. They just kept putting more and more people

in the rooms. The 'therapy' group I mention had about 20 people in it. You can't do therapy with 20 people and expect it to be effective. That's way too many, IMHO [in my humble opinion]."

Tonia's negative experience in the trauma group highlights similar issues as Rae experienced, in that their ineligibility was in part due to social worker misunderstanding, or an attempt to make an individualized service work in a group without the necessary education or supports to sustain it. Relating her experience of cancelling the trauma therapy group, Tonia stated:

"…No follow up. I called them to say that I wouldn't be back and that the program wasn't for me. I had to leave a message since nobody was answering the phone. They didn't contact me again. I'm not upset about that, though. (I didn't want to hear from them)".

With this passage, Tonia shared that there was no feedback mechanism to determine why the group was not for her, nor was there a person on the end of the line to communicate to about what she felt was problematic about the program.

The social workers described by both Rae and Tonia indicated that social workers were either part of the intake and eligibility (gatekeeper) process for service, or the intake and service. The role of gatekeepers to social service programs is a common role for social workers to occupy, and Sam pointed out one of the primary issues with this role in a neoliberal, recidivist system when *they* said:

"…often social workers appear as gatekeepers, but that gatekeeping is told via negation-- what they cannot do for you as opposed to what they can. (I cannot help you fill out forms, I cannot help you find housing, I cannot help you find the hospital chaplin, I cannot help you with the job program, etc)."

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Not providing services that are needed by autistic individuals, but instead leading autistic individuals to needed services for self-referral, navigation and intake is part of a neoliberal service system that confusing, and sets up autistic individuals to fail.

Multiple Categorizations and "Body Control"

The theme of "body control", as stated by Sam, explains the social construction of the power placed in social workers and the mental health system to control unruly behaviour by enforcing norms. Body control may look like many things, such as forcing children and adults to take medication to control behaviours, implementing ABA or IBI programs, social skills groups, or institutionalization, to name a few. Explaining her experiences of being, in her words, "psychiatrized" as an autistic person and self-identified crazy person, Tonia links autistic behavioural presentation with approaches to mental "illness":

> "But the things that get called 'symptoms' or treated as problematic in autistic people (and they may be things that the autistic people themselves find problematic) are things that get people psychiatrized.Hand flapping or pacing? Give them a psych drug to 'reduce agitation'. Not wanting to hang with other people and want to do things alone instead? Send them to a social skills class/therapy group."

Explaining this trend, Sam outlined *their* elementary school experience as being a series of events wherein *they* was exposed to a litany of assessments, and perceived deficit interventions:

> "[I] spent most of elementary school in twice or thrice yearly meetings with psych offices, OT workers, and the like--a variety of suggestions, testing and more suggestions. Including but not limited to games on Tuesdays at lunch with balls, and missing art class for speech therapy."

Sam relates *their* experiences in these therapeutic environments as a "stifling" of who *they* were, all of which *they* named as examples of body control. *They* disclose later that effects and subsequent unsuccessful attempts to categorize and control *their* body and selves never amounted to any closure for *them*, or those who worked to control *them*:

"[I] spent time in and out of hospitals, of clinics, got diagnosed and undiagnosed and rediagnosed. I think at the end of it i have 25 or 26 different diagnoses, some leaning more to personality disorders. I think most of it rests on the failures of control."

"Failures of control" is discussed as a multi-faceted issue wherein society, groups and individuals are equally implicated in creating anxiety and trauma due to efforts to enforce one neoliberal, heteronormative, NT way to be. Discussing how it is difficult for her to express certain ideas and to be assertive in different situations, Rae stated:

"We need social workers to understand that because we have hidden our traits, either from being trained to or because of fear, that we have severe anxiety and/or even PTSD from it… Know that many of us will agree with you just to keep the peace and we think it is what is wanted. Part of that may be due to the way we have been brought up, anxiety, fear, training etc."

Rae highlighted that the complexity of her life in some ways is connected to her autistic identity, and existing in a social space that is neither comfortable nor safe for her to just be. She draws attention to the potential for her social worker to glance over her autistic history, and requests that they instead be cognizant of the tenuous hold she has on her autistic identity in a social work space when making demands and/or assumptions.

"I don't even really know what a social worker is supposed to do"

Rather uniformly, "I don't even really know what a social worker is supposed to do" was prevalent in the data. All three participants experienced confusion related to what the role and purpose of social work was, as well as with power dynamics.

Rae shared that she sees her social worker regularly, and has done for a number of years. She expressed her uncertainty about the mechanics of social work when she stated:

"I don't even really know what a social worker is supposed to do...I went to him a few years ago for my anxiety and we didn't seem to do anything… We talk a bit, mainly him asking me questions and me answering…He is good though. He keeps a supply of fidget toys in his office."

The unintelligibility of what her social worker does beyond accommodate her sensory needs with fidget toys speaks to how she perceives how social work is being practiced with her. Reflecting similar issues with understanding what a social worker's role is, Sam stated:

"…when I was a kid, i never made the professional distinction between social workers and other para-professionals… I think that there is a flattening of role, and a positioning of authority and lack of autonomy that occurs when one goes into a c(C)linic--so it doesn't matter if the nurse, the social worker, the speech pathologist,…,the teacher, the educational assistant, etc tend to be clumped around each other…trying to make sure that… you are controlled--…from the beginning i am never quite sure what the purpose of the social worker was or is."

Sam's childhood appraisal that there exists a collaborative effort to control non-normative bodies within and without institutions is supported by *their* adult experience in

institutions, where social workers that he was assigned were not equipped to work with *them*. Their failures to comprehend and/or accept *them* as *they* were are evident when Sam wrote:

"[During my] time at the hospital when I was in my late 20s and early 30s…they either did not know how to deal with autism, or assumed i didn't have it…"

Indeed, Sam's childhood adult estimations of social workers and those who work in health and social service professions were perceived based on how they exercised their power, and of what use they were to *them.* Sam explained this deduction thus:

"…people tend to be split into two--when you are very young, people who were kind or respectful…and when I was much older, people who were useful, [and people who were]… useless…If I spend a lot of time thinking about social workers--i think about the job clubs or meetings about minutiae. If I can be frank, I think they would have ended up in the useless category."

Sam's perspective of the work done by social workers based on experience is troubling in that it paints a picture of a profession without utility for *them* that is depoliticized and representative of systems used to enforce norms.

Critical Social Work Facilitation

The elements of this theme provide pointers to social workers about what works for some autistic individuals, and can be a starting point for practicing a different kind of social work beyond the constraints placed by neoliberalism and NT society. Participants were able to share experiences of social work that they considered positive and helpful, in addition to providing their own thoughts on what may have made their experiences more effective. As I asked Rae to explain her experiences with social workers in the past, and at present, she explained that her journey to find a social worker who will work with her on her terms has been difficult, and

despite the fact that she questions the usefulness of her appointments with her current social worker, she is not looking for another:

"There is no point since they don't know much about autism when you ask them, and neither do any of the other professionals like psychiatrists. There are few exceptions…"

Rae later qualifies this statement, explaining that she finds her social worker makes the environment accessible for her when she wrote:

"I don't think I really get anything out of it but at least he understands asperger's (for the most part) unlike most social worker, therapists, etc… He is good though. He keeps a supply of fidget toys in his office even."

In addition to having environments and items which accommodate autistic individual needs on hand, participants indicated that social workers with strong listening skills and an ability to assume a position of not knowing is integral to working with autistic individuals, and everyone else. Tonia expressed this sentiment when she wrote:

"Being heard is important. Not being fixed".

Rae emphasized the importance of social workers approaching autistic individuals with an openness to trusting their own insight and acting directly on what they have said, not on how social workers interpret what has been said. Rae emphasized this when she stated:

"We need them to believe us when we say we have a problem. We really need to be listened to and believed no matter where we fall on the spectrum."

Rae shared that autonomy is paramount, as is social worker openness to learning from autistic individuals on their own terms. Operationalizing this may mean that social workers must work to understand how the autistic person they are working with understands their own world, and then consider how NT society impacts and socially constructs it.

One element of social work service provision that was discussed by two participants was the possibility of widening the scope of social work practice to include specific, tactile areas that autistic adults advocate for help learning. Tonia suggested:

"…if there was such thing as a social worker who worked with someone on learning to drive, taking the time the person needed and doing it in a way that respected the person's ideas and self described limits, I might be interested for myself (I don't drive and my ability to get places is limited)."

Tonia considered the physical way that a social worker might be able to help her overcome a barrier in her life, and considers that a niche project that could be worked on within a social work relationship. Rae also highlighted that supports in specific areas that were troubling her related to new technologies and accessibility could also be a role in a trusting, social work relationship when she wrote:

"If we were rich I could hire a support person who could come in at least once a week to teach me things- I struggle with [certain things others take for granted]".

While the traditional role of a social worker does not extend to teaching specific skills, the participants expressed that this was an element of their lives where they are asking for support, and there is no response.

Reflecting on what qualities *their* self-described "autism specialist" emulates, Sam shared that:

"he was the advisor for…the only group in my life that thought of autism as a way of being, of not teaching social skills."

Sam placed value on approaches to support which involve a fundamental understanding

of autism as identity, not disease. Sam discussed abilities and characteristics of the support

person in *their* life that worked best for *them* as *they* explained:

"there was solid talk about how i felt, but also intensely pragmatic matters, often in the

same session… he is also good at working on budgets or negotiating bureaucracy. He's

good about not getting paid on time. He's good at the linguistic cant of autism. HE is

good at autonomy."

The features expressed by Sam that *they* considered valuable in a support person involved

the ability to be flexible with the goals and tasks at each meeting, knowledge of a variety of

complicated and/or bureaucratic systems and a willingness to assist, and an openness to straying

from guidelines and meeting a person where they are at. Sam additionally expressed that *their*

support person maintained support and genuine caring for *them* beyond meeting times when *they*

wrote:

"The last time I was severely ideating he took the bus to my best friends house to make

sure i was safe."

Sam evaluates the support *they* receive based on emergent needs which cannot always be

anticipated. *They* envisioned that social workers can be part of a solution to the problem of silos

of service and fragmented system access for marginalized people, including autistic people and

provided the following suggestions:

"…acknowledge the autonomy of clients.…[and] work on being explicit and clear about

roles and positions…think of the social workers as gatekeepers…find a way to priortize

access… to shrinks, gps, people who work with paper work, adminstrators, experts in

granting or bursaries or loans or social assitance, nurses, housing experts--make the social

worker the front end worker for all those services--make the intake interview last an hour

or two, make it all about what people need."

Sam suggested a ubiquitous social work presence, charged with the role of making social

and health services accessible and flexible for all autistic and marginalized people. Calling for a

revitalized case management system, Sam suggested that social workers strive to simplify

connections to desired services, or help create connections to areas that are not readily prioritized

in the current system.

Additional Findings: Research Design and Process

I approached this research with an awareness that I must be creative with my research

design and fluid with my process, in order to provide the participants with the time and

flexibility they may require to participate. Given that the literature discusses the uptake and

accessibility of online communication for autistic people, as well as expressed difficulties with

NT approaches to social communication, it was incumbent upon me to incorporate an online

research methodology (Bertilsdotter-Rosqvist, Brownlow,& O'Dell, 2013; Bowker & Tuffin,

2004; Davidson, 2008; Seymour, 2001).

For each participant, the process of the interview looked different, and the design of the

chat environment lent itself to fluidity in use due to the notification system. The online chat

environment was simply a place to house the interview questions and participant responses

which were essentially e-mail responses, while in effect, it resembled a chat room. In this way,

participants had the choice of synchronous (online messaging simultaneously) or asynchronous

(messaging over an extended period of time) interviews, depending on their comfort level. The

participants whom chose asynchronous interviews were sent an e-mail notification and link to

the e-mail they signed up with, letting them know that I had asked them a question. The

participants were able to click the link located in the e-mail to take them directly to the question posed. If at that time the participant desired to view previous responses, the entire transcript would be available for them to view on the same page as their newest question. As such, the participants were able to add to previous responses they had left, or simply answer the next question.

New Data Collection Methods: Some Reflective Considerations

While this research methodology and data collection method was ultimately well-suited to the task, there were some learning moments before, during and after its development. The steps taken, to ensure that this data collection method was sound and ready for participant use was not an experience I had undertaken before. While my partner was accustomed to producing "tools" and "products" for his clients according to their specifications, both of us were speaking a different language regarding our understanding of the other's professional backgrounds. Working alongside someone with technological expertise to inform my research ethics protocol and to produce a web-based environment exactly corresponding with all the areas specified in my research ethics protocol was a challenging way for both of us to work.

Despite the challenges of working across and alongside our different professions, I consider it to be of importance for social workers to engage more in the use of technology and use it as a tool to more accessibly support their research aims, and meet participants where they are at (Csiernik, Furze, Dromgole, & Rishchynski, 2006). Two of the three participants chose to conduct the interview asynchronously, over an extended period of time. As the interview process progressed, I became aware that the length of time I had estimated originally in my ethics protocol was quickly being overextended. Due to this, I changed my Research Ethics Protocol to reflect the changes in length of time to conduct interviews from up to four days to up to 15 days,

and contacted the Ryerson Research Ethics Board accordingly. While the Research and Ethics Board approved this change without issue, I felt that it was important to make explicit the amount of time the data collection portion of this study was taking such that this is considered a learning experience for future online data collection models.

One of the participants preferred to book a time with me to conduct the interview online synchronously, and that interview lasted just over three hours. This method of data collection allowed for pauses in communication while the other person considered their response or next question; however, I was cognizant of how much time I was using of this particular participant. I checked in with the participant when I stated:

Q. I know I have had you online for a long time. I am almost done, I have three more questions. Is that ok?"

Prior to the interviews during the introductory phase over e-mail and at different times throughout all three interviews, I reminded participants that they had the choice to step away and reply at their convenience if too much of their time was being taken, or refuse to answer questions they were uncomfortable with. One participant took one to three days to respond per question asked, and at times I would prompt the interview by asking about their comfort with the previous question, or the interview in general:

Q: Hello again, I don't want to nag - this is just me checking in to see where you are at, and whether or not you wish to continue to respond?

A: You are not nagging at all. I am just trying to be really careful with my answers, working slowly through what I think, and trying to work against a history. I want to give answers that are useful, and not to waste your time

Q: I truly appreciate your diligence and attention. You have provided me with an incredible wealth of information already, and in no way are wasting my time.

A: Thank you, i am not good at concision.

The online data collection tool was efficient and easy to use, outside of the unforeseen challenge of having too little space in the text boxes for full-bodied answers. Two of the participants wrote to me via e-mail to share that they thought that the system was not accepting their responses, and I was able to troubleshoot with them, learning that the data encryption code made typed responses significantly longer, and so the text boxes could only hold one small paragraph at a time. This posed a small accommodation issue with one participant, who stated:

"I think I continue to write answers that are too long for the form…i am never very good at concision."

I was able to explain to this, and another participant that it may be easier to write up their responses in a word document if they are long, and then cut and paste small sections of these responses into the online chat forum, given that the system allows multiple responses for the same question. This proved to be a solution for the participants, albeit something I had not anticipated. If I were to conduct research like this in the future, I would ensure that the developer implemented more space in each text box. While this was something that my partner is able to do, the process of the interviews required a quick response so that the participants did not lose interest, and so I decided to come up with a solution with the participants in lieu of waiting for a technical solution.

This data collection method created transcripts for me to readily use for data analysis, and also allowed for the full written meaning of participants to come through on the transcripts without losing threads in the data (Oliver, Serovich, & Mason, 2005; Tilley, 1998). Being able to

follow the history of the conversation I was having with participants made it easy to conduct

comparative analysis with the two other interviews I conducted without a large time lapse for

transcribing. I found the evolution of these interviews quick and pointed, and having the time to

consider questions along with the history of what had been said a valuable way to ensure that I

was able to stick to my interview question while following the participant's answers.

This data collection method seemed to suit the participant's lifestyles and honour their

timelines. One participant appeared to respond to my question(s) at a certain time every few

days, while another participant replied to my questions very late at night, or in the early morning.

As previously mentioned, my third participant decided to do the interview at one time, which she

scheduled. The control the participants had in choosing when and where they would have their

interview with myself and this study was very important to me, and I was able to have the

flexibility to chat at a select time, or over time given my present student schedule (Elwood &

Martin, 2000). It was not difficult for me to be sitting by my computer during this time, and so I

was readily available.

Two of the participants shared that they preferred conducting the interviews over time to

give them time to consider how they would like to respond. In addition to this, the participants

were clear with me about how they understood, struggled, or did not understand my questions.

When I asked one participant how they came to identify as autistic, one participant responded:

"I don't understand the question. I was diagnosed with autism by a psychiatrist and a

psychologist."

My use of language here was unclear, and the participant shared with me how I needed to

ask more concrete questions.

Expressing their reasons for taking their time responding to questions, one participant said:

"These quesitons are difficult and i am quite busy, so I might be a little foot draggy."

While this participant prefaced the response with the difficulty of the questions, it was more the weight of the questions they had difficulty with, and not the concepts. The responses provided by this individual were in depth, detailed and intensely critically aware. I found it helpful to have access to the internet during the interview in order to look up definitions for vocabulary that was used, or concepts espoused to further comprehend their meaning.

Indeed, this method of data collection allowed participants to add links to grey literature they had either read or authored to further explain their meanings. While the majority of these additional sources was inadmissible for this study due to issues of participant confidentiality (from the other sources) and my ethics protocol not including secondary data, it was still a unique experience, and I saw it as a method of upsetting dominant knowledge construction.

Chapter 6: Discussion

Social workers are prominent fixtures in lives of autistic children, youth and adults in their capacity as intake workers, group facilitators, counsellors and educators. Despite these roles, there exists an alarmingly small amount of literature written by social workers regarding working with autistic individuals and groups. Informed by a theoretical framework of Critical Disability Theory, Queer Theory and the concept of neurodiversity, I conducted grounded theory research online. I engaged in three qualitative interviews with adult autistic participants, asking them questions about their experiences with social workers. This is considered preliminary grounded theory research, as it is not possible to reach saturation with only three participants. It is my hope that this research may form the basis of a larger, grounded theory study to determine what autistic adults can contribute to social work practice. This chapter will discuss the limitations of this study, future research opportunities, how I conducted my research process, substantive outcomes and proposed best practices including the formation of social work knowledge, how identities are socially constructed and the complicity of social workers in this construction, and will plot a tentative course forward for the future of social work with autistic communities.

Limitations of this Study

While I do not identify as a neuro-typical person, I also do not identify as an autistic person. My role as a social worker/researcher and outsider conducting this study posed a considerable limitation on this study, and I had to be reflective of the power dynamics throughout the research process and while writing this MRP (Stone & Priestly, 1996; Walmsley, 2004). By surfacing the voices of the participants, utilizing their text from the transcript verbatim and unaltered and using in vivo emergent themes, I attempted to create a mitigating online

environment for participants to share their experiences (Corbin & Strauss, 1990; Oliver, Serovich, & Mason, 2005;).

This study would have benefitted from having a longer period of time for recruitment and data collection. Due to the time constraints built into a graduate school calendar, I was only able to recruit for a month and a half and conduct data collection for one month. It was my experience that at least one of the participants would have benefitted from contributing for longer than 15 days, but my own deadlines and research ethics protocols made this impossible. Alternatively, having a year for recruitment and data collection would have likely garnered more responses and interest in the study, and saturation may have been reached (Corbin & Strauss, 1990; Glaser & Strauss, 1967). Additional time and additional participants would have provided me with the opportunity to more thoroughly engage in constant comparative analysis, search for contrasting themes in the data, and explore novel experiences of phenomena more fully. The participants provided me with thick, rich data, and moving beyond a preliminary study to further engage with participants is an interest of mine.

Opportunities for Future Research

There were many possibilities for further research exploration. Some of the possible directions include a study related to finding autistic identity and community supports online pre and post-diagnosis, the experiences of heteronormativity and masculinity in autism intervention, the politics and experiences of online disability advocacy group members, and the experiences of racialized autistic individuals who received autism intervention(s). All of these topics came up in the data, however they were not part of the scope of this preliminary research.

The sharing of knowledge and growing communities of autistic people online is apparent in the literature (Bertilsdotter-Rosqvist, Brownlow, &O'Dell, 2013; Molloy & Vasil, 2002), and

this impacts the formation of autistic identity. Given the differences between the medical model of autism and how autism is discussed in blogs and forums online by autistic communities, research concerning the messaging and uptake of information from medical and social service persons as contrasted with online autistic sources is of interest to me.

Issues involving autistic LGBTQQ2S (lesbian, gay, bisexual, trans, queer, questioning, two-spirit) individual experiences with heteronormative, masculine approaches to autism intervention and behaviour modification is an area which requires critical, interpretive study. While the literature discusses the further pathologization of autistic individuals as being linked to "gender defiance disorder" (Bejerot et al, 2012, p.116), an interrogation of the therapeutic approaches to such claims is needed. In this area, it is crucial to conduct research utilizing a Critical Disability Theory and Queer Theory framework, such that social justice aims be realized.

The social processes, politics and impacts of online autistic advocacy groups was an unexplored theme in the data that warrants further investigation. Research regarding how different local, national and international autistic self-advocacy groups self-govern, make decisions, recruit members and launch advocacy campaigns could assist in the emergence of counter-narratives to the medicalized autism discourse.

The experiences of racialized autistic individuals who received autism interventions in the past is also an interest of mine for future study. Although I sought to find literature on this topic, I was unable to locate helpful information in this regard beyond literature expressing that White, Anglo families in the United States receive an autism diagnosis for their children one and a half years earlier than do children from Black families (Mandell, Listerud, Levy, & Pinto-Martin, 2002). None of the participants in this study identified as racialized individuals, however

two of the participants did not identify with any particular race or ethnicity. One participant did identify as Caucasian.

Research Process

I conducted the online interviews one after the other, after data analysis was completed on the prior interview in order to maintain methodological congruence with Corbin & Strauss' (1990) idea of constant comparative analysis and grounded theory research. The unique method of data collection allowed me to ask contemplative and mindful questions in order to follow up with participants for further clarification of their meaning and ask for follow up from previous points given that the transcript was available on screen for us both to see when we were chatting. This aspect of the data collection was important as it ensured that participants were always given the opportunity to recommit to, or redact the answers that they had provided (Seymour, 2001). Additionally, this feature in the data collection was responsive and accommodated two of the participants, who both expressed that they required more time to respond to interview questions (Bertilsdotter Rosqvist, Brownlow & O'Dell, 2013; Jones & Alony, 2011). This accommodated and responsive research design and process was a requirement for the participation of two out of three participants, and so I argue that this method of data collection is integral to ensure the voices of consenting autistic adults are surfaced in research and policy.

Throughout the research process I was able to remain reflective and responsive as a researcher, evidenced by requesting the Research Ethics Board for additional time for my participants to complete their interviews given my observation that some participants were taking longer than I anticipated to respond to questions (Stone & Priestly, 1996; Waltz, 2005). Doing so accommodated the participant's need for time to share their knowledge with me, and made the process, for individuals whohad agreed to provide me with their experiences and time voluntarily

in their free time, less of a burden. Grounded theory provided me with the flexibility to alter the research design to fit the requirements of participants while the research was in process (Corbin & Strauss, 1990). This was an important consideration as my novel research design was constructed in such a way as to be more accessible for participants to contribute. Given that this study was not based on probability theory, this fluidity of design is fitting and appropriate for the task.

The data provided by the participants was rich, and described processes of social work from being on a spectrum of helpful and knowledgeable, to complicit in marginalizing relations of power. Within this spectrum, I located several properties that I organized into a coding paradigm which allowed me to further understand causal conditions for the central phenomenon, the participant's experiences of the process of social work practice in their lives (Creswell, 2007). This process of axial coding allowed me to assemble the categories from the coding paradigm into a story line according to the interconnected parts located in the data (Creswell, 2007). Given the small amount of participants in this study, I was not able to delineate a substantive-level theory; however, I was able to construct propositions in the form of a potential best practices social work model (Creswell, 2007).

Substantive Outcomes: Proposed Best Practices

Informing social work knowledge.

The data suggested that there is a requirement for social workers to become more knowledgeable of autism on two different yet intersecting fronts. It was suggested that social workers must be open to learning from the autistic adults that they are working with in order to be open to different communication styles, and requirements for accommodation (Bertilsdotter Rosqvist, Brownlow & O'Dell, 2013; Davidson, 2010, Molloy & Vasil, 2002). The need for

accommodation and the deemphasizing of autistic intervention was particularly prevalent in the data, which is a theme found in the literature (Ne'eman, 2010).

The framing of the need for more ASD specific knowledge in the data provides a framework for what should be known (Stoddart et al, 2013). Indeed, the fact that the participants were contributing to this social work study on social work knowledge about autistic individuals, is one part of what they would have social workers know. The participants were able to share information with me to read via links in the transcript to further illustrate their meaning, but this also served to populate my reference list with grey literature that they provided. Providing participants the opportunity to share knowledge with me online is a unique way to subversively infuse the epistemology of autism into their transcript; however, this did leave me with a quandary regarding how I could reflect this information given the format strictures of writing this MRP (Reyes Cruz, 2008). Ultimately, I chose include this information in my Findings chapter in order to properly give credit to how I engaged with and learned about this new information, but it may have also fit well within the literature review section. This knowledge changes what myself, as a social worker, now knows, as well as any reader.

Socially constructed identities

The discussion around identities and diagnosis linked back to the literature involving the tensions of strategic essentialism within the diagnosis of Autism Spectrum Disorder, with some participants preferring to identify as autistic, and one as identifying on the autism spectrum. All three participants preferred a general diagnostic identifier as a means to be more inclusive of others, while not allowing themselves to be pinned down by labels and categorizations, thus becoming scientifically understood, as though there is a scientific way to understand a person (Fellows & Razack, 1998; McRuer, 2010; Reyez-Cruz, 2008). Indeed, participants chose to

situate themselves and their identities in ways which implicated society and social workers in their disablement (Connell, 2001; Sherry, 2007).

Queer identity was one particular area of struggle for Sam, who succinctly linked *their* struggles with social work, education and healthcare professions as a child with queer theory. The participant's view that *their* unruly body was controlled from different angles as social workers, psychiatrists and other workers toiled to make *them* "normal" is connected to the NT, heteronormative preoccupation with knowledge construction and intelligibility (Davidson & Henderson, 2010; Schwarz, 2004; Sherry, 2004). This participant succinctly expressed that attempts made by social workers and others to ascertain or categorize what sort of human being *they* were resulted in the receipt of over 20 psychiatric diagnoses. I argue that the unintelligibility of Sam by social workers, psychiatrists, educators and others contributed to *their* "categorical" oppression. Sam's identity as queer and autistic, among other identities, actively resists heteronormativity, neurotypicality and embraces liminality.

Alongside this struggle, locating Sam within the discourse of Asperger syndrome as well as the discourse of special needs creates additional areas of intervention where categories, occupations and language are legitimated in a neoliberal context (Molloy & Vasil, 2002). The data supports that it is important to consider the complicity of social workers who maintain these systems of body control, by gatekeeping inaccessible and unaccommodating networks, counselling individuals and families to expect less, not different, and allowing neoliberal systems to dictate the choices for the autistic individuals they work with. The impact of this control resulted in anxiety and trauma for the participants in this study. Orlie (1997) considers the existence of common evil to be that which "…does not originate in sin, and in its most usual

forms it is not pathological, though it may be manifested in practices that pathologize others" (p 23).

Identities and social work complicity

Social workers must consider their complicity in maintaining these systems of control, and work with the contradictions of their role creatively to change circumstances. The idea of body control, categorization and control of knowledge coincides with social worker's drive to collect data on individuals in an effort to know, or comprehend who they are. Rossiter (2011) considers the way to move forward in social work alongside marginalized individuals and groups is with "unsettled practice" (p 982), whereby social workers place ethics before knowing. Understanding this implies that social workers allow themselves to consider each person they encounter as utterly unique, incomprehensible, and unknown, such that knowledge about that person stems only from what is given by that person, and not how you perceive them to fit into a pre-conceived notion or category. Similar notions emerged from the literature and data, urging social workers to ask what is needed, to be led to their answers by autistic people and not preconceived solutions and therapies (Bascom, 2012; Clarke & van Amerom, 2007; Fellow & Razack, 1998; Ne'eman, 2010). Rossiter (2011) states that "ethics cannot be a 'competence' or a naive appeal to 'evidence'—it is a commitment to struggle with the vast historical legacy of totality—a struggle that requires constant judgements of the conflicts between ethics and justice" (p 990). This understanding and way to approach practice suggests that different approaches need to be taken with the autistic community.

The growing urgency for autism services to be grounded in evidence from NT research on autistic subjects, and the heteronormative applications of autism interventions in schools as indicated in the data suggest that the urge to know, comprehend and somehow become an expert

in autistic identity is a focus in social work practice. Rossiter (2011) asks social workers to remain open to learn, which will in turn demand that we never fill in the blanks of what has remained unsaid, nor do we insist that all the knowledge to be had is located in the responses to our questions. This eliminates the urge to develop expertise, as in this configuration an expert is an impossibility.

The Way Forward?

Working in tandem with Rossiter's (2011) suggestions, the data constructs an alternate vision of what social work practice needs to look like to better support autistic adults. This vision involves a post-modern conception of case management, where social workers have priority access to the social safety net, and are able to work with autistic adults in a way that access and accommodations are developed to secure the futures and good lives of those in need. Despite the fact that this conception places a great deal of power with the role of social work, and cannot lay claim to innocence (Fellows & Razack, 1997; Rossiter, 2011), allowing the process to be driven by the autonomously provided needs of autistic individuals in an effort to co-construct the services provided is one step towards having a more responsive system. Alongside this conception of a reformatted social work is the suggestion by two participants that social workers extend the reach of their jobs to include instruction on how to perform specific confounding tasks which present a barrier to autistic adults in NT society. This tactile support from social workers would serve as an avenue whereby social workers respond to the needs voiced by the autistic individuals they work with in lieu of passing off this role to someone else in society.

These recommendations speak to the need for social workers to step away from their professionalized silos of service provision and in-office counselling, and instead co-create what their service looks like anew, with every unique individual they encounter. Indeed, two of the

participants expressed confusion and uncertainty pertaining to exactly what their social worker(s) provide them in both a counselling and intake capacity, and suggested also that at times they pose a barrier to service through assumptions or misunderstandings. Reconfiguring what social work service looks like, to be truly flexible and responsive within reason, is what the participants suggested would provide the best support. I argue that in lieu of being prescriptive and reductionist, social work practice which is creative, fluid, accommodating and queer is what is needed.

Chapter 7: Conclusion

In this grounded theory study I endeavoured to learn from autistic adults how they experienced social work in their lives. In order to conduct this qualitative research, I created an online interview tool such that participants could engage in the interview process at their convenience, or over time. As a result of this unique approach, different findings emerged pertaining to both the major research questions as well as the novel data collection method.

The findings of this study suggest that interventions supported by the helping professions, including social work, are at odds with the participant's assertions of autistic identity and pride, and the NT social work role emphasizes the medical model and discourse of autism through acts of commission and omission. The social work acts of commission link specifically to instances where social workers acted, or were complicit in actions which caused trauma or negative experiences to occur for autistic individuals. Social work acts of omission involve situations where social workers remained ignorant of autistic adult voice and autonomy, or did not seek out information to disconfirm their own ideas and assumptions of what autistic people want or require for support. These acts silence autistic voice and maintain the status quo, which is at odds with the social justice aims of the social work profession (CASW, 2005). This corresponds to the idea of heteronormative, neurotypical privilege, which is exercised by society in general, and social workers in particular, in order to maintain social norms and outliers in lieu of changing society to be more inclusive.

This research contributed a sense of multiple and intersecting identities, as shared by participants. The interplay of many identities within participants created narratives marked by social work and healthcare professional misunderstandings, which in turn caused trauma to some individuals, as the pathologized path to label, categorize and know a person fails to ask the

autistic individual who they are first. This lesson enabled myself, a social worker, to better know my own power and complicity in these systems of knowledge creation, and to move forward with an enhanced duty to ask, and not tell, people what they need.

This study was limited by my role as a social worker/researcher and outsider, the time constraints on recruitment and data collection, and by having only three participants. Due to this, this grounded theory study is a preliminary study as the expectation of saturation could not be reached (Corbin & Strauss, 1990). Despite these limitations, I was able to complete three online qualitative interviews with participants over a period of time that was required by the participants to accommodate their needs and daily activities. Through the practice of constant comparative analysis, and the mixture of in vivo and interpretive emergent themes, the credibility and rigor of the research study was maintained (Corbin & Strauss, 1990). Emergent recommendations for change include a conception of social work practice resembling postmodernist case management, where service is co-constructed and determined by the autistic individual's expressed needs and desires. In the future areas of research to consider may include an exploration of the social construction of online autistic identity pre and post-diagnosis, experiences of heteronormativity and masculinity in autism interventions, the experiences of online self-advocacy disability support groups, and the experiences of racialized autistic individuals who received autism interventions. I consider the expansion of the use and development of online synchronous and asynchronous qualitative interview tools for use with autistic populations, as well as other populations to be of importance in social work research. It is imperative to promote the voices of autistic individuals in order to aid in the production of counter narratives of autism, and possibly affect the way that social work is practiced with autistic individuals.

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