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Informal Caregivers' of Adults with Autism Spectrum Disorder: Experiences of Social Inclusion Policy in the Province of Ontario

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A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree
in Health and Rehabilitation Sciences

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Abstract

Social inclusion for people with Autism Spectrum Disorder (ASD) is a widely accepted social value. Policy implementation impacts on health, experience of inclusion and on individuals and caregivers.

Method. This study used a qualitative directed content analysis to analyse the needs, care, services and policy which influence the care and support of adults with ASD in the Province of Ontario. Caregivers of adults with ASD were interviewed to determine: a) how the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*, is experienced and b) has influenced how they and their loved one with ASD live, c) what their needs are, d) how these needs are being met and e) by whom.

Results. Themes identified in this research aligned with Hall's themes for effective social inclusion. These themes could then be broken down into subcategories, which included: a) health and mental health, b) isolation, c) housing preferences, d) advance care planning, e) suitability of services and supports, f) inefficiencies, waitlists and distrust in the system, and g) financial constraints.

Discussion. Findings suggested that although social inclusion policy in the Province of Ontario is intended to promote social inclusion, there are systemic barriers including: a) inefficient application and funding processes, b) limitations on how funds can be used, c) distinct needs based on age and prior history with institutionalization and d) insufficient qualified service providers to meet the needs of this population.

Contribution to Research. This study has important implications for practice and research, including identifying: a) barriers to effective social inclusion within public policy as perceived by caregivers, and b) priorities and preferences of the target population of the policy.

Lay Summary

The Province of Ontario has developed *The Services & Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008 (the Act)*, to outline what services and supports are available to people with developmental disorders, including Autism Spectrum Disorders (ASD). This policy relies heavily on informal (i.e., unpaid, typically family members) caregivers to support people with developmental disorders. The present study presents a review of the health, inclusion and the history of treatment of people with ASD to provide a context for the study at hand. It then reviewed how the policy was used, what research and informal media such as newspaper articles said about how inclusion is experienced in the community and by caregivers. I then interviewed 4 informal caregivers of adults with ASD, an adult who has ASD and identifies as his own caregiver and a formal (i.e., paid) caregiver to learn about how they experience the Act (2008).

Findings suggested that informal caregivers experienced difficulties in the following areas: a) health and mental health, b) isolation, c) housing preferences, d) advance care planning, e) suitability of services and supports, f) inefficiencies, waitlists and distrust in the system, and g) financial constraints. They also cited concerns with long waitlists and unavailability of suitable services or housing for their loved ones with ASD.

The findings from this study could be useful in helping to inform policy by the perspectives of those tasked with implementing it by identifying what is and is not working for the targeted population.

Keywords

Autism Spectrum Disorder, Health Equity, Social Inclusion, Public Policy, Caregivers of Adults with Autism, Health Equity Impact Assessment, Social Determinants of Health, Subjective Well-Being, Quality of Life, Directed Content Analysis, Mental Health

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Table of Contents

Abstract	i
Lay Summary.....	ii
Acknowledgments (if any)	iii
Table of Contents.....	iv
List of Tables (where applicable)	vii
List of Figures (where applicable)	viii
List of Appendices	ix
Chapter 1	1
1 Introduction To The Study.....	1
1.1 The Scope Of Autism Spectrum Disorder	2
1.1.1 Historic Attitudes Toward ASD	5
1.1.2 Context Of Caregiving	7
1.1.3 ASD In The Global Context	9
1.2 Perspectives On Social Inclusion	12
1.2.1 Impact On The Family	13
1.2.2 Social Inclusion In The Global Context.....	15
1.2.3 Social Inclusion Research	19
1.2.4 Explanatory Model Of Disability	23
1.2.5 Medical Labelling	25
1.2.6 Needs Based Labelling.....	26
1.3 The Research Question	28
1.4 Plan of Presentation.....	29
1.5 Chapter Summary.....	30
Chapter 2	32
2 Literature Review	32
2.1 Literature Review Methodology	32
2.2 Literature Review Goals And Objectives	37
2.3 Health Equity	38
2.3.1 Review Of Health Equity Assessment	44
2.4 Policy Impacting ASD & IDD	53
2.4.1 Human Rights Perspective	53
2.4.2 Life Course Perspective	55
2.5 Autism Spectrum Disorders.....	57
2.5.1 Historical Effects Of ASD.....	57
2.5.2 Cumulative Disadvantages Of Autism.....	59
2.5.3 Cohort Effects of ASD	59
2.5.4 Health Status In Autism	60
2.5.5 Health And Mental Health	62

2.5.6	Education & Vocation.....	67
2.5.7	Social & Community	68
2.6	Social Policy.....	74
2.6.1	Policy-As-Discourse	74
2.6.2	Neurodevelopmental Disorders	77
2.7	Infrastructure of Inclusion.....	79
2.7.1	Administrative & Policy Assessment	84
2.7.2	History of Ontario’s Social Inclusion	87
2.7.3	Inclusion In Ontario Currently.....	92
2.7.4	Self-Determination & Subjective Well-Being.....	102
2.7.5	Implications for Individuals	106
2.8	Chapter Summary	114
Chapter 3	117
3	Methodological & Theoretical Approach.....	117
3.1	Methodology	117
3.1.1	Reflexivity Statement.....	121
3.2	Method – Interview the Stakeholders.....	122
3.2.1	Ethics.....	122
3.2.2	Participants	122
3.2.3	Participant Characteristics.....	124
3.3	Study Methods.....	133
3.3.1	Data Collection	134
3.3.2	Memos and Theoretical Sampling	141
3.3.3	Review Of Techniques to Promote Rigor	141
3.4	Summary of Methods	146
Chapter 4	147
4	Data Analysis	147
4.1	Quantitative Analysis	147
4.1.1	Quality of Life Inventory	147
4.1.2	World Health Organization Quality of Life Index -Brief	153
4.1.3	Personal Well-Being Index – Adult Version (PWI-AV)	155
4.1.4	WHO (Five) Well-Being Index (1998 version) (WHO-5).....	156
4.2	Qualitative.....	157
4.2.1	Interviews	158
4.2.2	Mapping Results	226
4.3	Chapter Summary.....	230
Chapter 5	231
5	Discussion.....	231
5.1	What Do Caregivers Identify as Appropriate Accommodation?	233
5.2	What Are Caregivers’ Experiences of Accessing Formal and Informal Supports for Adults with ASD?.....	235
5.3	What Are Caregivers’ Experiences of Meaningful and Reciprocal Relationships?	242
5.4	What are Caregivers’ Experiences of Acceptance Beyond the Disability?.....	244
5.5	What are Caregivers’ Experiences of Contributions to Society?.....	248
5.6	What are Caregivers’ Experiences of Involvement in Activities?	251
5.6.1	Employment/Vocation	252
5.7	Limitations & Suggestions For Future Research	264

5.8 Use of Caregivers in Policy	270
5.8.1 Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons	271
5.8.2 B) Non-discrimination, full & effective participation & inclusion in society, c) equality of opportunity, d) accessibility	274
5.8.3 e) Respect for difference and acceptance of persons with disabilities human diversity and humanity	277
5.8.4 f) Equality of opportunity, g) accessibility, h) Equality between men and women	278
5.8.5 Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities” (p.5)	278
5.9 Chapter Summary	282
Chapter 6	283
6 Conclusion	283
6.1 Health Equity Assessment	284
6.2	284
6.2 Implications for Inclusion	285
6.3 Future Directions	288
References	289
Appendices	320
Appendix A: Ethics Certificate	320
a. PARTICIPANTS NEEDED FOR RESEARCH IN	321
b. Health Equity Status of Caregivers of Older Adults Who Have Autism	321
Appendix C: Letter of Information and Consent	322
Appendix D: Letter to Agency Administrators.....	327
Compensation: No compensation is being provided for participation.	329
Appendix F.....	335
Curriculum Vitae	336

List of Tables (where applicable)

Table 1. Comparison of Steps in Qualitative Directed Content Analysis to PPM & HEIA. . .	43
Table 2. Ordered Situational Map: Predicted Elements Related to Aging Adults with ASD.	114
Table 3. Regions with the Province of Ontario (Retrieved from http://www.dsontario.ca/agencies on January 8, 2015)	124
Table 4. Demographic Information of Participants	133
Table 5. Subjective Rankings on the QofLI.	151
Table 6. Weighted Rankings by Domain on the QofLI.	153
Table 7. WHOQOL-BREF Transformed Scores and Rankings. WHOQOL-BREF Transformed Scores and Rankings	155
Table 8. PWI-AV Scores by Domain and Overall.....	156
Table 9. WHO-5 Item Rankings, Raw Score and Percentile Rankings.....	157
Table 10. Correspondence Between Hall’s Themes for Effective Social Inclusion (2009) and Corresponding Codes.	158
Table 11. Adults with ASD: Diagnoses and Medication	221

List of Figures (where applicable)

Figure 1. Prisma Diagram of Scoping Review Results.....	37
Figure 2. Determinants of Health According to the Public Health Agency of Canada (2013) (Copied from Agic et al., 2012).....	40
Figure 3. Steps Involved in an HEIA (Copied from Tyler, et. al., 2014).....	48
Figure 4. PRECEDE-PROCEED Model. PRECEDE-PROCEED Model (Green & Kreuter, 2005, copied from http://www.nyc.gov/html/doh/images/cmha/pp_model.gif on April 15, 2017).....	52
Figure 5. Overview of Developmental Services Relationships (Copied from Dubé, 2016.) Legend: Solid arrow indicates direct relationship (application, funding, oversight or service provision); broken indicates possible relationship depending on issue or relationship.	86
Figure 6. Social Arenas Map Reflecting Relationships Consistent with the Act	229
Figure 7. Social Arenas Map: Adults with ASD as Experienced by Caregiver	229
Figure 8. Prisma Diagram of Employment & ASD Research.....	255

List of Appendices

Appendix A: Ethics Certificate	315
Appendix B: Recruitment Information.....	316
Appendix C: Letter of Information and Consent.....	317
Appendix D: Letter to Agency Administrators.....	322
Appendix E: Semi-Structured Interview and Demographic Information.....	324
Appendix F: Themes and Operational Definitions.....	330

Chapter 1

1 Introduction To The Study

This doctoral dissertation is the result of a qualitative directed content analysis examining how social inclusion policy in the Province of Ontario impacts on the health equity of caregivers of adults who have Autism Spectrum Disorder (ASD) and their loved one with ASD. Written in a monograph format, this manuscript describes each phase of the research study as a separate chapter.

My interest in the topic of health equity as it is experienced by caregivers of adults with ASD in Ontario as it relates to social inclusion policy arose from my clinical experience as a board certified behaviour analyst (BCBA) and registered psychotherapist (RP) working with clients who have ASD and their caregivers. I had observed that many of the people I served to address their needs were not only not experiencing inclusion in the community, they were also experiencing health impacts arising from care needs they were neither qualified nor equipped to provide. What I observed was that social inclusion policy did not take into account the waitlists for services to facilitate social inclusion limits access to participation in the community for the person with ASD. Consequently, informal (i.e., unpaid) caregivers, typically parents and siblings, attempt to provide for the needs as they arise. In doing so, they too experience reduced access to the community. As a result of this observation, I completed a literature review search on social inclusion, health equity and ASD. I found there was limited empirical evidence informing how social inclusion policy is defined and how it is experienced by informal caregivers of adults with ASD.

To situate this study in the context of ASD and social inclusion, this chapter begins with an overview of neurodevelopmental disorders (ND) and ASD in Ontario and Canada. Next, I place ASD within the context of caregiving historically and globally. This section includes an introduction to ASD, historic attitudes toward people with ASD and their caregivers, followed by a review of the progression to current attitudes which emphasize inclusion of people with ASD/ND.

The next section of this introduction explores how social inclusion is defined, by whom and the issues which arise from these understandings of social inclusion. I then review health equity, common approaches to studying health equity impacts of policy and programming and how that informed my approach to this research. These approaches have influenced my scoping review found in Chapter 2 and the approach to the research found in chapters 3 and 4. Next, the development of the research question and sub-questions is described. This includes the rationale behind the choice of interviewing informal caregivers of adults with ASD. Finally, the plan of the presentation for the rest of this monograph, including a brief summary of each of the chapters is identified.

1.1 The Scope Of Autism Spectrum Disorder

The *Diagnostic and Statistical Manual, 5th Edition (DSM-V)* uses the term neurodevelopmental disorder (IDD) to refer to disorders characterized as IDD. There are seven classes of IDD, all of which must have an onset during childhood:

- (1) Intellectual Disabilities (i.e., delays in intellectual functioning, impacting on the development of adaptive living skills).

(2) Communication Disorders (i.e., those disorders impacting on language, speech, verbal and non-verbal communication, as well as behaviours which have an impact therein).

(3) Autism Spectrum Disorders (i.e., disorders which are characterized by deficits and deviancies in each of the domains of the triad of impairment; that is, on language and communication, restricted and repetitive behaviour and interests and social interactions and relationships).

(4) Attention Deficit Hyperactivity Disorder (i.e., a pattern of impulsivity and/or inattention which is severe enough that it impedes functioning and/or development).

(5) Specific Learning Disorder (i.e., when one fails to make academic gains which would be expected given one's intelligence; this failure to make gains must rule out environmental causes, such as distraction, injury, malnutrition, illness, etc.).

(6) Motor Disorders (i.e., disorders which impact on the movement, motor skill development, including tics).

(7) Other Neurodevelopmental Disorders (i.e., other disorders which do not meet the diagnostic criteria set out in any of the other classes of neurodevelopmental disorders, yet there are sufficient symptoms and significant impairment to warrant a diagnosis) (American Psychiatric Association [APA], 2013).

Among medical health care practitioners in Canada, the terms developmental disabilities (DD) and intellectual disabilities (ID) are used interchangeably (Sullivan et al., 2011). This is problematic, as it is in conflict with the terminology used in the DSM-5 (APA, 2013), rendering it difficult to consistently compare research conducted by

medical health care providers to that conducted by psychological or psychiatric providers, as well as to that research conducted internationally. For the purposes of this study, the term IDD will be used, as it is the most commonly recognized term for this population, across fields (i.e., psychology, medicine, education, etc.). For the purposes of this research study, the term IDD will pertain to any individual who has a disorder that falls within any of the seven classes of neurodevelopmental disorders.

Defined as an IDD, ASD, is characterized by deficits and deviancies along a continuum of varying severity/intensity that informs a triad of impairment: a) language and communication; b) social skills and interactions; and c) behaviour, with demonstrated restrictive and repetitive interests but often no intellectual disability (APA, 2013). In Ontario, the prevalence of ASD is estimated to be approximately 1 in 94 people (Autism Ontario, 2014). According to the Canadian Survey on Disability (Arim, 2012), it is believed that 29 550 people in Canada who are 15 years old and older have ASD. Of this population, 56.2% live in Ontario.

The Canadian Survey on Disability (Arim, 2012) did not report prevalence of those who were 65 years old and over. Piven and Rabins (2011) estimated that the prevalence of ASD in adults 65 years old and over in the US will reach approximately 700,000 by 2030. Given comparable prevalence in other developed Western countries (Ouellette-Kuntz et al., 2014), this estimate can likely be generalized to other populations, including Canada. Although previously, life expectancies among those who have IDD have been shorter than average, life expectancies among those who have IDD are now increasing such that they are comparable to those who do not have IDD (National Advisory Council on Aging, 2004).

1.1.1 Historic Attitudes Toward ASD

People with ASD, among other developmental disorders, have only relatively recently gained acceptance as people who are more than a threat to society (Donvan & Zucker, 2016). During the early part of the 20th century, commonly accepted terms in the field of psychiatry included “defectives”, “imbeciles”, “morons”, “feebleminded”, etc. in reference to people who had what are now known as developmental disorders (including ASD). The pursuit of eugenics of this population was not uncommon among the psychiatric community, with the *American Journal of Psychiatry* publishing an article advocating for the “mercy killing” of such individuals in 1942 (Kennedy, as cited by Donvan & Zucker, 2016). Although an in-depth exploration of the history of eugenics of people with ASD in Canada is beyond the scope of this paper, it is necessary to acknowledge that it did occur (Springer, 2012). The purpose of mentioning eugenics herein is to assist to illustrate the climate in which older adults who have ASD have lived in, with regards to attitudes and acceptance of them in Ontario.

Until recently, the common approach to serving and supporting individuals who had ASD (among other developmental disorders) was to institutionalize them in settings which offered little to no stimulation. Consequently, it was not uncommon for those committed to these facilities to lose skills they had upon entry to the facility. According to Donvan and Zucker (2016), nine percent of people under the age of thirty-five living in institutions for people with “mental handicaps” had ASD (149). Given the stigma associated with the disorder, those who were not in institutions tended to be kept hidden at home. In the province of Ontario, the shift to community-based care and social inclusion began to become a priority in 1993, when a committee with the Ministry of Community and Social Services conducted a costing review (Vermeulen et al., 1993).

The purpose of this research is to conduct a qualitative directed content analysis of services and supports available to and required among older adults who have ASD and their caregivers in relation to the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2008), S.O. 2008, c.14 (the Act), in the Province of Ontario. This research examined both discourse in the form of documents which have informed policy, as well as interviews with caregivers of adults who have ASD. In order to inform service and supports to this population, it is necessary to consider both sources of data. This research will also reflect on the health and mental health impacts such policy, services and supports have on caregivers who are frequently tasked with facilitating these policies.

According to Foucault (1978), it is important to consider the tactical function of discourse segments as culminating into a particular, changeable social circumstance rather than a static outcome. For this reason, it is just as important to consider the discourse by the overlooked segments of the population as well as the existing, prevailing discourse. This analysis will consider both what is present and absent from the discourse.

Existing services and supports available in accordance with the Act are purported to be evidence-based (Ministry of Community and Social Services, 2008). However, in light of the fact that the research examining aging in people with developmental disorders has largely excluded those who have ASD (Piven & Rabins, 2011), it is clear that the latter population has been overlooked in the research and subsequent policy, service and support development. By considering the overlooked population, as well as the prevailing discourse, a better understanding of the institution and its effects on the various actors within the institution becomes apparent.

1.1.2 Context Of Caregiving

There are a number of misconceptions about ASD which have impacted on how this population and their informal caregivers access services and supports (Donvan & Zucker, 2016). Among them are the idea that ASD did not emerge until psychiatrist, Leo Kanner, identified it in 1947 and that self-professed child psychologist, Bruno Bettelheim, coined the term “refrigerator mother” in reference to parenting thought to have caused ASD. It was Kanner who first postulated that children with ASD had become cold and unresponsive in response to cold, rejecting parenting (Donvan & Zucker, 2016).

In fact, Bettelheim was a lumber merchant and art historian who emigrated to the United States of America (USA) as a condition of freedom from Buchenwald concentration camp in 1939 (Donvan & Zucker, 2016). Once in the USA, Bettelheim took an interest in psychoanalysis, assumed the role of child psychologist and became the director of a practice laboratory geared toward treating children with special needs, run out of the University of Chicago. Although Bettelheim did compare symptoms and characteristics observed in individuals who have ASD to the behaviour of prisoners in Nazi concentration camps he had observed while a prisoner himself (Bettelheim, 1967), it was not he who equated parents of children with ASD to Nazi prison guards (Donvan & Zucker, 2016).

Regardless of the origin of the bias about the parenting of children who had ASD, the impact was felt deeply by these parents (Donvan & Zucker, 2016; Langan, 2011). Consequently, parents of children who had ASD were frequently reluctant to pursue services or advocate for their children. When ASD researchers began publicly decrying the placement of blame for ASD on the parents, profound expressions of relief emerged

from the ASD community (Donvan & Zucker, 2016). In fact, Langan argued that it was this trend which led to the emergence of advocacy for services and supports to people who have ASD by their parents (2011).

Older adults who have ASD, and their families, have experienced dramatic change in terms of societal attitudes and access to services across the lifespan (Donvan & Zucker, 2016). The way in which ASD has been characterized historically has served to create a distinct institution for this population, unique from younger generations who have ASD. Additionally, responses of parents of children with ASD and consequently, how society has responded to the disorder, has created a distinct institution whereby the aging population with ASD have unique care and service needs. In many ways, these norms are at odds with those currently accepted among the general population.

According to Evens (2005), norms are "...prescriptions for addressing the chronic tension between behavior and ideal in the first place. Norms comport values and therefore present themselves as transcendent to and, accordingly, regulative of material behavior." (49). This applies to the case of informal caregivers of older adults with ASD. Parents of children with ASD who are now adults have lived in times in which institutionalization of people with developmental disorders was the accepted practice. They have also now experienced a shift to community-based and socially inclusive services and supports as the standard framework for care and service provision.

A qualitative directed content analysis is pertinent to research about policy as it relates to informal caregivers older adults who have ASD because of the history and nature of ASD. This research must consider the symptoms and behaviours which drive relationships between the individual, informal caregivers, formal caregivers and service

providers, advocacy groups and policy-makers, through service utilization. However, it must also consider the history of the disorder and service provision therein.

1.1.3 ASD In The Global Context

The principles of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006) include:

- “(a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons’
- (b) Non-discrimination;
- (c) Full and effective participation and inclusion in society;
- (d) Respect for difference and acceptance of persons with disabilities human diversity and humanity;
- (e) Equality of opportunity;
- (f) Accessibility;
- (g) Equality between men and women;
- (h) Respect for the evolving capacities of children with disabilities and respect for the right o children with disabilities to preserve their identities” (p.5)

The CRPD also requires state parties to ensure that legislative and administrative measures are taken to ensure that people with disabilities are able to fully realize all human rights and fundamental freedoms.

The requirements placed on state parties are extensive and include (but are not limited to): ensuring training for paid care providers, undertaking and promotion of

research and development geared toward meeting the needs of persons with disabilities, accounting for the protection and promotion of the human rights of persons with disabilities in all policies and programs. Although Article 23 of the CRPD does focus on home and family rights of individuals who have disabilities, the focus is on the rights of the individual to marry and parent, as well as the rights of children who have disabilities. No provision is made for family caregivers of adults who have disabilities. Given that caregivers tend primarily to be family members, most frequently the parents (Lunsky, Tint, Robinson, Gordeyko & Ouellette-Kuntz, 2014), the absence of formal consideration for caregivers may be in conflict with other international positions on human rights.

The global population is aging. In response to this, international institutions, such as the World Health Organization (WHO) and the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) have made recommendations to prioritize policy development, capacity building and research into supporting adult individuals who have IDD as they age (Evenhuis, et. al., 2000; Hogg et. al., 2000; Thorpe, Davidson & Janicki, 2000). The principles guiding the approach to initiatives related to aging among individuals with neurodevelopmental disabilities are based on the principles adopted by the United Nations (UN) General Assembly in the *United Nations Principles for Older Persons* (resolution 46/91) (1991). Resolution 46/91, which is intended to include all aging individuals, proposed five clusters regarding the status of aging people. These include: (a) independence, (b) participation, (c) care, (d) self-fulfilment and (e) dignity. Implicit in the intention to include all people as they age is the inclusion of people with intellectual disabilities and neurodevelopmental disabilities and their aging, informal (i.e., unpaid) caregivers (Hogg et. al., 2000).

In a setting where social inclusion is the end goal of services and supports, these principles can be in conflict with one another. For instance, should care and service provision to adults who have IDD rely heavily on informal caregivers? This could potentially impede an aging parent caregiver's ability to achieve self-fulfilment and participation in social activities commonly accessed by same-aged peers who are not caring for an adult child. In fact, such isolation is commonly cited by aging parent caregivers as a source of stress, loneliness, burden and diminished quality of life (QoL) (Marsack & Church, 2019; Marsack & Perry, 2018; Altieri & von Kluge, 2009; Krauss, Seltzer & Jacobson, 2005; Lee, Harrington, Louie, & Newschaffer, 2008).

Much of the research conducted in response to the prioritization of aging among people who have neurodevelopmental disorders has largely excluded ASD (Piven & Rabins, 2011). Research is emerging which examines the experience of caregivers of older adults with ASD (Marsack & Church, 2019; Marsack & Perry, 2018; Marsack & Samuel, 2017). However, these studies do not focus on health equity status or the impacts of policy in the Province of Ontario.

In an international study seeking to achieve consensus on the priorities associated with planning for frailty among adults who have intellectual or developmental disabilities, Ouellette-Kuntz, Martin, Burke, McCallion, McCarron, McGlinchey, Sandberg, Schoufour, Shooshtari and Temple (2018) solicited input from advocates and researchers affiliated with the Ontario Partnership on Aging and Developmental Disabilities (OPADD) and IASSIDD. Consensus was achieved on using a person-centered approach to planning, with ageing in place being a priority. However, the responses where they had difficulty achieving consensus reflected the following themes:

1) tensions around ageing in place being prioritized because it may not always be possible or desirable, 2) emphasis or lack of emphasis on dignity, risk and choice, 3) importance of documentation and consideration of financial security, 4) inclusion of consideration for the needs of caregivers and 5) a need to increase the evidence base (Ouellette-Kuntz, et. al., 2018).

Unfortunately, Ouellette-Kuntz, et. al. (2018) did not collect data on participants' roles or interest in developmental disabilities. Therefore, they were unable to determine whether the participants were family members, people who had intellectual or developmental disabilities, clinicians or researchers. Because research is increasingly being used to inform policy, it is important to research the priorities of those tasked with implementing and living according to the policy, including the individuals targeted by the policy in question.

1.2 Perspectives On Social Inclusion

What is meant by the term 'social inclusion' of people with ASD/IDD has not been well-defined in the literature (Martin & Cobigo, 2011; Cummins & Lau, 2003; Minnes, Carlson, McColl, Nolte, Johnston & Buell, 2003). The Act (2008) leaves how individuals targeted by the Act (2008) to define social inclusion for themselves, reflecting the egalitarian perspective that every citizen can define for him/herself the degree to which he/she wishes to participate in the community. At the international level, WHO and IASSIDD have tended to define social inclusion as the opposite of social exclusion, relying heavily on evidence of diminished inequities in SDOH to demonstrate the pursuit of social inclusion. As demonstrated by the current study, how individuals define social inclusion and barriers to social inclusion is more concrete and deals with barriers which result in isolation of people with ASD and their caregivers.

This section is devoted to exploring what the literature says about inclusion and how it impacts on the target for inclusion and their family members. To do so, I start by reviewing the literature examining impact on the family, then broaden the scope to examine how international agencies, such as WHO and IASSIDD consider inclusion, how the Province of Ontario does so and what research says about issues related to conclusion. I then explain the choice to adhere to Hall's (2009) themes for effective social inclusion to define what is mean by the term 'social inclusion' for the purposes of this study. Thereafter, I present the plan of presentation for this manuscript. Thus, for the purposes of this study, social inclusion will refer to the degree to which individuals experience: 1) acceptance of the individual beyond his/her disability (or that of their loved one who has a disability), 2) opportunities to pursue and enjoy meaningful and reciprocal personal relationships, 3) involvement in activities, 4) suitable living accommodations, 5) contribution to society through employment or volunteer opportunities and 6) receiving supports as needed (Hall, 2009).

1.2.1 Impact On The Family

In his reflection on the shift from societal attitudes which allow for institutionalization versus inclusion, Foucault (1965) argued that by virtue of one's difference, inclusion within the general population serves the same effect as segregating him/her, as the "otherness" of his/her condition distinguishes one from the general population. The location (i.e., institution or community) has little to do with the experience of being included or excluded. Although this may be true of the individual who has a developmental disorder, it may be less true of his/her informal caregivers.

In the case of institutionalization, a family could maintain an existence relatively comparable to that of the general population. However, in the case of community-based

care which relies heavily on informal caregivers to facilitate the individual's functioning, this becomes less possible due to simple logistics, such as time required to coordinate or provide care. The time spent providing the care diminishes time available to the caregiver to participate in society in a way consistent with the general population, putting him/her in a position of "otherness".

Research examining adults with ASD and their caregivers is limited (Marsack & Perry, 2018). When it is studied, it is frequently included in research about aging in individuals who have intellectual disability. This inclusion tends to arise as a result of their meeting diagnostic criteria for intellectual disability as a corollary effect of their cognitive, functional and social impairments arising from their autistic disorder rather than because the research intended to focus on aging in people who have ASD (Melville et al, 2008). This sort of research, however, is important, as caring for individuals who have ASD across the lifespan is costly.

In a study estimating the cost to care for individuals with ASD across the lifespan, Ganz (2007) concluded that per person, it will cost about \$3.2 million USD, much of this being due to the cost of adult care. His estimate included cross-sectional cost analyses of various age groups across the lifespan. This research took into consideration both direct costs (i.e., the goods and services directly associated with the disorder) and indirect costs (i.e., lost or reduced opportunity to earn income for the individual with ASD and/or caregivers, arising from the disorder). It is important to note that this research was conducted in the USA.

Although an economic analysis of the cost to provide services and supports to individuals who have ASD across the lifespan in Ontario is beyond the scope of this

research, it is likely that, adjusting for the exchange rate, the direct and indirect costs would be similar in Ontario. One estimate has been that the cost to provide daily care and service needs in Canada to an adult with ASD is approximately \$400 CAD per day (Monsebraaten, 2012). However, information about how this was calculated and what was included in the calculation was not provided.

1.2.2 Social Inclusion In The Global Context

A search of the term “social inclusion” on the World Health Organization’s (WHO) website garnered no specific definition of the term “social inclusion” as it relates to adults who have IDD. However, a WHO initiative, Better Health Better Lives: Children and Young People with Intellectual Disabilities and their Families, defines social inclusion of children and youth who have intellectual disability as “ensuring that all children and young people with intellectual disabilities are fully participating members of society, living with their families, integrated in the community and receiving health care and support proportional to their needs” (WHO, 2010). The Social Exclusion Knowledge Network, one of nine global knowledge networks for WHO’s Commission on Social Determinants of Health, defines social exclusion as “consisting of dynamic, multidimensional processes driven by unequal power relationships interacting across four main dimensions – economic, political, social and cultural – and at different levels including individual, household, group, community, country and global”, resulting in “...a continuum of inclusion/exclusion characterized by unequal access to resources, capabilities and rights, which leads to health inequities” (Popay, Escorel, Hernández, Johnston, Mathieson & Rispel, 2008, p.7-8). These definitions are broad and general, in order to account for inclusion on the basis of a number of different characteristics (e.g., race, religion, socio-economic status, etc.).

The concept of social inclusion, as it relates to people who have IDD, has not been well-defined in IDD literature and research (Martin & Cobigo, 2011; Cummins & Lau, 2003; Minnes, Carlson, McColl, Nolte, Johnston & Buell, 2003). The failure to establish consensus of the goals of social inclusion and what constitutes effective social inclusion across people who have IDD, their caregivers, service providers, professionals and researchers obfuscates what must be done in order to facilitate the provision of services and supports to achieve social inclusion. Broadly speaking, based on the goals of social inclusion as a concept, outlined by WHO (2010) and the definition of social exclusion (Popay et al., 2008), a definition of social inclusion as it relates to adults who have IDD might be a process undertaken at the individual, household, group, community, country and global levels. The intention of this process is to address barriers across economic, political, social and cultural dimensions to ensure that all adults who have IDD are fully participating members of society, integrated in the community, receiving health care and support proportional to their needs.

1.2.2.1 Social Inclusion in Ontario

In his work on genealogy of morals, Foucault, 1980 (in Burchell, Gordon & Miller, 1990) emphasized that understanding the reason (or the “why”) is not as important as understanding how practices are implemented. He stated that movements, such as institutionalization, arise out of ideologies and theories in a particular time. For instance, he cited the de-institutionalization movement as arising out of an anti-psychiatry sentiment in much of the Western world in the 1960’s. This was a time when emerging understanding of psychiatric conditions coincided with greater moral awareness of ethics in medical and psychiatric practice and research. In light of abuses and mistreatment (Williston, 1971), the rationale and morals for moving away from segregation toward

inclusion are obvious. What is less clear and more variable is the method for facilitating it. In the province of Ontario, there has been a history of government implementing measures and funding strategies meant to facilitate this move toward inclusion, most recently with the Act (2008).

The province of Ontario funds over 350 agencies for the purposes of providing services and supports to 42 000 adults who have IDD (Ministry of Community and Social Services (MCSS), 2017). The province spends over \$2 billion per year to fund services and supports to facilitate the social inclusion of people who have a developmental disorder (IDD) (MCSS, 2014). These funds are administered through Developmental Services Ontario (DSO), which is a branch of MCSS dedicated to discretionary government programming for people who have IDD.

The funding and service delivery in the provision of care to adults with IDD have been characterized as poorly implemented and lacking a continuity of care, placing families, aging parents in particular, at risk of violent and unmanageable situations (Dubé, 2016; Marin, 2014a; Marin, 2014b). Funding services and supports for people who have IDD is considered a “discretionary program area” (i.e., funding of a particular program is an optional component of fiscal policy), whereas the adults with IDD are eligible for financial support through the Ontario Disability Support Program (ODSP), to a maximum of \$1098 per month. Although means tested and adjusted, ODSP is not a discretionary program. It is mandatory funding, available to anyone who has a physical, mental or developmental disability, intended to supplement lost income or expenses arising from the disability (Government of Ontario, 1997). There are approximately 64 856 recipients of ODSP who have IDD (MCSS, 2014).

In an effort to improve the services and outcomes for those who have IDD, the government of Ontario formed a select committee, comprised of elected provincial representatives. The committee was tasked with formulating recommendations to government, in consultation with people who have IDD, their families, service providers and community-based developmental service agencies. This was achieved through review of documents, public hearings and committee meetings. The final report submitted to the province reflected guiding principles: 1) elimination of waitlists, 2) oversight and system accountability, 3) empowerment of individuals, families and communities, 4) capacity building and 5) development of opportunities for inclusion across sectors and provincial ministries (Albanese, Elliott, Balkissoon, DiNovo, Jones, Maclaren, Martins, Taylor & Wong, 2014).

Although MCSS is the core ministry responsible for administering services and policy for those who have IDD, the committee identified ten ministries which also play a role. These include the following ministries: (1) Child and Youth Services, (2) Health and Long-Term Care, (3) Education, (4) Municipal Affairs and Housing, (5) Aboriginal Affairs, (6) Community Safety and Correctional Services, (7) Training, Colleges and Universities, (8) Economic Development, Employment and Infrastructure and (9) Attorney General. Although the policies and programs of the ministries are often intertwined, the focus of this paper will be on policy administered by MCSS only. This is because MCSS is tasked with the duty to meet the needs of people who have IDD, including ASD, while the other ministries are involved incidentally, by providing services frequently accessed by people who have IDD and their families.

1.2.3 Social Inclusion Research

The majority of the literature on social inclusion of people who have IDD relies on objective measures (i.e., frequency of access to participation in socially inclusive settings/activities) rather than considering the subjective experience of feeling or being included experienced by the person who has IDD (Martin & Cobigo, 2011). Rather than considering the type of life the individual with IDD would want to live, social inclusion policies, research and practices tend to be guided by a reaction to institutionalization (Parmenter, 2014). Failure to consider the perspective of the individual who is meant to be included defeats the purpose of inclusion because it excludes the perspective of the target for social inclusion from the process. Too often, social inclusion policies are implemented as though they are something to be done to or for the target(s) of social inclusion. This is not true social inclusion, as it minimizes the role of the target of social inclusion. In order for social inclusion to truly be inclusive, there must be an opportunity for reciprocal exchanges in interactions and transactions between members of society (Parmenter, 2014). Approaches to social inclusion are not limited to policy implementation but must also be reflected in how those social inclusion policies are informed.

Focusing on objective measures of inclusion implies that those studying or implementing the inclusive measures are better able to determine whether or not the individual has been included than is the individual. This is problematic because variables important to those defining the concept are not always those prioritized by those experiencing the issue. Inclusion ought to reflect reciprocity and interactional relationships rather than merely reflecting a physical presence in the community (Parmenter, 2014, p. 420). In order to achieve this, inclusion must consider the

perspectives of those targeted for inclusion. Otherwise, it is simply a process of those in positions of authority administering policy to those in positions of vulnerability, which in turn would perpetuate institutionalization in practice, if not in location (Harvey, 2005).

When developing a research study, Szatmari (2016) solicited input from parents of children with ASD in order to determine which research questions ought to be asked with regard to developmental outcomes among children who have ASD. Prior to doing so, he had identified variables he considered important to study. These included:

intelligence quotient (IQ), symptoms, socialization, communication, mental health, school placement and achievement as potential areas of focus. All of these variables are valuable in information design and implementation of interventions and supports.

However, his informants cited mental health, adaptive functioning, independence and physical health as priorities (Szatmari, 2016). All of these variables are necessary for living and functioning on a daily basis and would dictate which interventions and supports should be prioritized for an individual. This demonstrates how one's role in relation to an issue can influence one's experiences and therefore, one's priorities in relation to that issue. If the purpose of social inclusion is to address barriers to full participation across dimensions, the target population must inform the process.

Caregivers' assumptions also influence how they interpret the experiences of those who have IDD who are in their care. In their study examining quality of life (QoFL) among adults who have ASD, adults with ASD and their parents rated QoFL of the adults with ASD. Mothers rated their subjective interpretations of their adult children's QoFL, as well as their interpretations of QoFL from the perspective of the adult child. Adults who had ASD rated their own QoFL. Scores by mothers when they considered items from the

perspective of their adult children were more consistent with those of the adults who had ASD than were their scores when they rated items according to their own perspectives. Adults with ASD rated stress and experiences of being bullied frequently as the primary threats to enjoyment of QoFL, whereas maternal reports cited level of independence in activities of daily living and physical health as primary mediators of QoFL (Hong, Bishop-Fitzpatrick, Smith, Greenberg & Mailick, 2016).

Overlooking the perspective of the individual(s) targeted by social inclusion can perpetuate the power structures which enable exclusion to remain in place, thereby usurping inclusion efforts (Silver, 2015). In fact, there is evidence that as institutionalized services and practices have been replaced by community based, inclusive practices, discrimination, isolation and lack of access to social interactions have persisted but are more difficult to identify (While & Clark, 2010; Burrell & Trip, 2011). The way society and place-specific institutions are configured influences beliefs and availability of opportunities (Silver, 2015). For instance, with de-institutionalization of people who have IDD, visibility and incidence of IDD has become more common and familiar to the general population, which in turn has increased societal interest in policy as it relates to this population (Pariseau-Legault & Holmes, 2015).

Since the goal of the Act is intended to promote autonomy and independence among people who have IDD, allowing them more choice, the implicit assumption is that the individual is best able to determine when s/he has been included in a context, to his/her satisfaction. For instance, if the individual attends a socially inclusive recreational event but nobody interacts with him/her or s/he spent the duration of his/her attendance standing in a corner, an objective measure would consider the individual to have been

included. A subjective measure would consider the individual's experience of feeling included. Contrary to the objective measure, a subjective measure considers the individual's perception of the experience beyond taking up physical space in a setting.

Consistent with the discrepancy between objective and subjective measures of social inclusion is the experience of research by the researcher and the participant. This is an interesting consideration in relation to social inclusion policy, as the research forms the evidence upon which policy ought to be based. In her exploratory research of the experiences of research participants who have IDD, McDonald (2012) found that participants consistently reported a desire to be treated with respect and as though their opinions were worthwhile. When participants did report displeasure with their experience participating in research, their displeasure tended to be related to interactions with the researchers rather than with the experience of research participation itself. McDonald suggested that these experiences reflect a need by researchers to better understand the perspectives of adults with IDD.

In terms of defining social inclusion of people with IDD, honouring personal preferences can be challenging, as preferences may not always reflect a socially inclusive mandate. For instance, a common characteristic among people with ASD is a tendency to prefer less stimulating, more isolated settings. Thus, for such an individual, insisting on participation in many social activities may interfere with his/her ability to be autonomous (Roberts, Beadle-Brown & Youell, 2011). Provision of services and supports to people who have IDD in order to facilitate inclusion in stimulating social activities, in such a case, could then compromise the autonomy of the individual.

1.2.4 Explanatory Model Of Disability

Complicating the issue of defining social inclusion is the discrepancy between approaches to defining functioning and disability. The move toward social inclusion and human rights of people who have IDD coincided with the emergence of explanatory models of disability (Shakespeare, 2010). The explanatory model of disability consists of three distinctions: (a) impairment (i.e., characteristics of the individual which hinder performance of certain skills, tasks, movements), (b) disability (i.e., a structural concept accounting for how one's impairment impedes functioning in society arising from how society and resources are structured) and (c) location in society (i.e., one's role in society arising from the interplay between impairment and disability) (Shakespeare, 2010). By distinguishing between impairment (i.e., characteristics of the individual) and disability (i.e., structural elements) the responsibility for impairment leading to disability is shifted from the individual to society, holding society and government accountable for minimizing the impact of impairment on the individual (Bampi, Guilhelm, & Alves, 2010).

The explanatory model of disability has also been criticized because it minimizes the interactions between impairment and disability and the complexities therein (Tremain, 2005). Consequently, the impact of impairment is often underestimated and inadequately accounted for in policy and structural approaches to accommodating impairment (Shakespeare & Watson, 2001; Hughes & Paterson, 1997). It has also been criticized because it imposes a normative ideal, thereby oppressing people who have disabilities by imposing an expectation that they conform to the norm rather than simply function according to their abilities (Yates, Dyson & Hiles, 2008).

Physical disability-centric, the explanatory model of disability is challenging as it relates to inclusion of people who have IDD, as it implies a degree of ability for self-advocacy, which may not be possible for many who have IDD (Pariseau-Legault & Holmes, 2015). In spite of this, it is important to recognize the intersection of de-institutionalization of people who have IDD and the explanatory model of disability. How disability has been understood has informed discourse and social inclusion policy for people who have IDD (Pariseau-Legault & Holmes, 2015).

Consistent with a disability approach, the World Health Organization (WHO) has taken a medical labeling approach, considering the influence of the person's environment in defining disability (i.e., focusing on the interactions between physiological structures and function, activities/involvement and contextual factors such as the community, attitudes of those encountered, etc.) (Salvador-Carulla & Gasca, 2010). Conversely, the health care community has tended to take a needs based/impairment focus, prioritizing the individual's ability to independently and autonomously complete activities of daily living (Luckasson, & Schalock, 2013; Ravet, 2011; Salvador-Carulla & Gasca, 2010). Both approaches are important in the context of social inclusion.

The Act (2008) seems to attempt to account for both approaches, defining developmental disability in such a way as to account for diagnostic language, as well as functioning and capacity. Specifically, the Act (2008) states:

“Developmental disability

3. (1) A person has a developmental disability for the purposes of this Act if the person has the prescribed significant limitations in cognitive functioning and adaptive functioning

and those limitations,

- (a) originated before the person reached 18 years of age;
- (b) are likely to be life-long in nature; and
- (c) affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity. 2008, c. 14, s. 3 (1).

Same

- (2) In subsection (1),
 - “adaptive functioning” means a person’s capacity to gain personal independence, based on the person’s ability to learn and apply conceptual, social and practical skills in his or her everyday life; (“fonctionnement adaptatif”)
 - “cognitive functioning” means a person’s intellectual capacity, including the capacity to reason, organize, plan, make judgments and identify consequences. (“fonctionnement cognitif”) 2008, c. 14, s. 3 (2).”

1.2.5 Medical Labelling

The focus on IDD, from a medical labeling framework, is on the individual’s physiological/psychological/neurological abilities to function within existing social structures or a particular setting within society. From this perspective, social inclusion would focus on the deficits of the individual and provision of supports to minimize the impact of those deficits. From this perspective, the concept of inclusion positions the

individual within a social construction based on their relation to “normality” and perpetuates their ‘otherness’ by creating a system whereby they are reliant on monitoring and reporting (Ravet, 2011) to service providers or funders (in the case of Ontario, this would be MCSS/DSO) for support to function within an inclusive setting. Given the lack of research into the subjective experience of inclusion, this represents an imposition of values-oriented construction about what does and does not represent a desirable way of life and interacting with society. In a framework that assists the individual who has IDD to participate in activities within the general community, the onus is on the individual to fit into the community. In such a case, the individual with IDD is challenged by the information available to others about him/her, thereby perpetually casting him in the role of the “unknown visitor” (Foucault, 1965).

1.2.6 Needs Based Labelling

The needs based approach, which focuses on an individual’s impairment(s) and consequent needs and abilities to determine the approach to support, allows for defining and accounting for the logistics which permit social inclusion to be effective. Consideration for the individual’s ability to perform the tasks which allow him/her to physically function within a socially inclusive setting are also accounted for in a needs-based approach. The focus, which is criticized by rights-based proponents, is on what the individual can and cannot do. Critics of this focus claim that by focusing on ability to determine how to serve and support an individual, exclusion occurs because it suggests that the regular setting is incapable of facilitating inclusion without taking specialized measures (Ravet, 2011). In the case of social inclusion policy designed to account for the services and supports provided to individuals on the basis of their needs, however, this

criticism is invalid because the policy assumes that exclusion occurs in the absence of services and supports informed by needs.

Social inclusion is dependent upon the context of the individual, as demonstrated by Martin and Cobigo (2011), in their retrospective analysis of the subjective experiences of inclusion among adults who had IDD. No differences existed between those who lived in an institution or those who lived in a community-based residence (i.e., a group home). Residential arrangement was not important to the residents. What was important to the participants in their study was the experience of participating and being included in activities. Consistent with these findings, Silver (2015) argued that social inclusion is dependent upon the context of the familial, residential and societal factors of the individual. The context-dependency of social inclusion influences how it is implemented and the success therein (Silver, 2015).

In the absence of a single, clear definition of social inclusion, it becomes necessary to consider how the social actors responsible for creating social inclusion must be examined. In social research, documents such as legislation can be used to define how interactions are structured and implemented (Prior, 2008). A focus on how a legislative document is used or functions rather than on the content of the documents allows for interpretation of the effects of the document (Prior, 2008).

In his synthesis of qualitative studies of the experiences of social inclusion among people who have disabilities, Hall (2009) identified six themes characterizing effective social inclusion. These included some characteristics directly related to the subjective experience of being included in social settings, such as: (1) feeling accepted as someone beyond one's disability, (2) having meaningful and reciprocal personal relationships, (3)

being involved in activities. Others were more reflective of the infrastructure necessary to facilitate effective social inclusion. These characteristics included: (4) having appropriate living accommodations, (5) being employed and (6) receiving supports (formal and informal, as needed). Hall's (2009) research focused on applied concepts which had concrete impacts on people's experiences and ability to participate in the community. As the focus of the research at hand is on experiences and barriers to participation in the community, Hall's (2009) indicators of effective inclusion will inform the definition used for 'social inclusion' for the purposes of this study. In this study, social inclusion will refer to the degree to which individuals experience: 1) acceptance of the individual beyond his/her disability (or that of their loved one who has a disability), 2) opportunities to pursue and enjoy meaningful and reciprocal personal relationships, 3) involvement in activities, 4) suitable living accommodations, 5) contribution to society through employment or volunteer opportunities and 6) receiving supports as needed (Hall, 2009).

This suggests that in order to assess whether or not the Act is achieving the goal of social inclusion, as defined by the individual, it will be necessary to examine both the infrastructure of inclusion and the subjective experience of inclusion.

1.3 The Research Question

The province of Ontario funds over 350 agencies for the purposes of providing services and supports to 42 000 adults who have IDD (Ministry of Community and Social Services (MCSS), 2017). The province spends over \$2 billion per year to fund services and supports to facilitate the social inclusion of people who have a developmental disorder (IDD) (MCSS), 2014). These funds are administered through Developmental Services Ontario (DSO), which is a branch of MCSS dedicated to discretionary government programming for people who have IDD.

The funding and service delivery in the provision of care to adults with IDD have been characterized as poorly implemented and lacking a continuity of care, placing families, aging parents in particular, at risk of violent and unmanageable situations (Dubé, 2016; Marin, 2014a; Marin, 2014b). Funding services and supports for people who have IDD is considered a “discretionary program area” (i.e., funding of a particular program is an optional component of fiscal policy), whereas the adults with IDD are eligible for financial support through the Ontario Disability Support Program (ODSP), to a maximum of \$1098 per month. Although means tested and adjusted, ODSP is not a discretionary program. It is mandatory funding, available to anyone who has a physical, mental or developmental disability, intended to supplement lost income or expenses arising from the disability (Government of Ontario, 1997). There are approximately 64 856 recipients of ODSP who have IDD (MCSS, 2014).

1.4 Plan of Presentation

This dissertation is written in the form of a monograph with a separate chapter for each phase of the research process. To ensure consistency with the approved formatting standards for dissertations using a monograph format, previously granted dissertations from the faculty of Health Sciences using a monograph format and published at the University of Western Ontario thesis repository were referenced. Specifically, Norton (2018) and Titus (2013) informed the formatting for this monograph. Each chapter represents a different phase of this research. Although the process was iterative, the plan of presentation is linear.

Chapter 2, the literature review, initially occurred prior to the development of this study proposal. It was then revised with updated articles after the data collection and analysis of the participant interview data. The literature review chapter describes the search

strategies used for the scoping review, the inclusion and exclusion criteria, the results and the discussion.

Chapter 3, methodology, describes the theoretical and philosophical foundation underlying this study. I begin by outlining the choice of discourse analysis, followed by discussing the fit of this paradigm with the aim of this study. I then go on to discuss the methodological choice of qualitative directed content analysis.

The methods are described in Chapter 4, including the approach used to collect data, recruitment strategies and inclusion criteria.

In Chapter 5, the approach used to analyze the data is described. The participants are introduced, using pseudonyms to protect their privacy. This chapter includes a description of the themes and sub-categories identified.

In Chapter 6, the discussion focuses on the key outcomes of this study as it relates to the research question. I provide a summary of the research and its implications. Finally, I suggest areas for future research.

1.5 Chapter Summary

Historically, approaches to serving and supporting people with ASD have centred on exclusionary practices such as institutionalization, parent blaming and eugenics. Since the early 1970's, provision of services to meet the needs of people with ASD has been recognized as a societal moral obligation in the province of Ontario (Williston, 1971).

How this is implemented, as well as societal values with regard to people who have ASD (among other neurodevelopmental disorders) has changed over the last four decades.

Currently, in Ontario, services and supports provided to people who have neurodevelopmental disorders, including ASD, reflect the value of social inclusion.

This chapter provided an overview of the historical approach to policy and care provision to people who have ASD in Ontario. This was followed by an examination of how the assumptions about people with IDD and the cause of ASD influenced both services and supports available to people with ASD and their caregivers, as well as the advocacy efforts for such services and supports. Finally, this chapter demonstrated how the context in Ontario relates to global priorities.

Inclusion of people who have developmental disorders, including ASD, is a common value both domestically in Canada and internationally. However, social inclusion has not been well defined. For the purposes of this research, Hall's themes for effective social inclusion (2009) is considered to provide the framework most relevant to the research question at hand. Effective social inclusion has been characterized as demonstrating the following themes: 1) acceptance of the individual beyond his/her disability, 2) opportunities to pursue and enjoy meaningful and reciprocal personal relationships, 3) involvement in activities, 4) suitable living accommodations, 5) contribution to society through employment or volunteer opportunities and 6) receiving supports as needed (Hall, 2009). Achievement of these characteristics requires infrastructure and must be informed by the subjective experience of the person targeted for inclusion.

Chapter 2

2 Literature Review

This chapter demonstrates how ASD and developmental disorders have been addressed by policy-makers both internationally and domestically, within Canada. Health impacts of policy can be assessed using a health equity assessment framework such as the Health Equity Impact Assessment tool (HEIA) (Tyler, et al., 2014) or the PRECEDE-PROCEDE Model (PPM) (Green & Kreuter, 2005). Finally, the various approaches to understanding how inequities influence health outcomes, including social determinants of health (SDOH), quality of life (QoL), developmental health outcomes (DHO) and subjective well-being (SWB) is discussed.

2.1 Literature Review Methodology

The HEIA suggests the use of a scoping review of the literature related to the population in question (Agić et al., 2012). A scoping review provides a broad source of information on a particular topic, allowing for maximum insight into the issues at hand. In response to Welch et al.'s concern about a lack of clarity and transparency regarding how health equity reviews are conducted, a description of the search techniques used to review literature for this study follows.

Similarly, the PPM suggests that the first phase is to conduct a social assessment or situational analysis to identify the affected population(s) and stakeholders (Green & Kreuter, 2005). This stage presents an opportunity for the researchers and/or policy makers to signal to the target population a commitment to developing policy/programming which reflects their interests. Conversely, the HEIA suggests that the first step of a health equity assessment entail a scoping review of the literature (Tyler et al., 2014).

To conduct a scoping review of the literature on older adults who have ASD, the PEARL Harvesting database search was used (Sandieson, 2006, Sandieson et al., 2010). This search strategy combines an exhaustive series of search terms using combinations recognized by database search tools in order to maximize the number of relevant articles retrieved. It is hoped that by doing so, relevant articles are not missed simply due to use of different keywords. This is an important consideration, as Welch et al. (2012) demonstrated that because different researchers use different terms to refer to the same or similar topics, it is often challenging to conduct an exhaustive search of issues related to health equity. For the purposes of this research, two scoping reviews were conducted, targeting: 1) health equity research as it relates to caregivers of adults with ASD and 2) social inclusion research as it relates to caregivers of adults with ASD.

Using a PEARL Harvesting search (Sandieson, 2006, Sandieson et al., 2010), the terms “Health Equity” or “Health Equity Impact Assessment” or “Health Equity Assessment Tool” or “Health Impact Assessment” and “Autism” or “Autism Spectrum Disorder” or “Developmental disorder” or “Developmental Disability” or “Neurodevelopmental Disorder” or “Pervasive Developmental Disorder” garnered zero results using PsychInfo, Medline, Scopus and Summon databases. Entering the same search terms in the Cochrane Library database search tool, only one of 30 articles were relevant to health equity. When the reference information of this article was entered into the other database search tools, 18 articles, including the one identified in the Cochrane database were identified. These were hand-sorted for relevance. Six articles were removed from the results due to irrelevance. None of the remaining 12 articles pertained to ASD. Some of these articles, however, did focus on the challenges associated with

conducting a systematic review of health equity. When articles related to health equity research were identified, they were retained to inform the consideration of health equity research.

For the purposes of learning about the health equity needs among older adults who have ASD and their families, a literature search using Sandieson's Pearl Harvesting technique (2006; Sandieson et al. 2010) was conducted on PsychInfo, using the following search terms: "social inclusion", "inclusion", "community integration", "integration", "mainstream*", "autism", "neurodevelopmental disorder" and "developmental disorder", spanning the years from 1979 to 2018.

The scoping review considered data available up to June 29, 2018. This is because there was a provincial election which resulted in change-over of government for the first time in fifteen years in the Province of Ontario. The outgoing party was the party which conceived of, developed and implemented the Act (2008) and DSO funding and services. All data were garnered before the swearing in of the new government. As such, this provided a clear cut off point for consideration of data since the policies and values of the incoming government have had little to no bearing on how the Act (2008) or DSO have been implemented to date.

This search garnered 444 articles. However, when the search terms were limited to those articles related to adulthood (i.e., 18 years and older), only 134 articles were identified. Once the results were filtered to include only peer reviewed articles and to exclude unrelated material (e.g., early intervention, elementary education, kindergarten, preschool, etc.), only 16 articles remained. These were hand-filtered to exclude unrelated

material (i.e., those focused on childhood, early education, unrelated disorders, etc.). Only two articles remained (Mehling & Tassé, 2014; Gray, et al., 2014).

The same search criteria were applied to ProQuest Research Library (373 articles prior to exclusions for unrelated articles; 68 after exclusions were applied; only one article in addition to those identified in the PsychInfo search was added). A broader search of the terms “social inclusion” and “inclusion” was conducted using the Cochrane database. Only one article was identified in the “Developmental, psychosocial & learning problems” category. The other two categories this search retrieved were unrelated (Childhood and Dentistry & Oral Health). The one article retrieved in the related category was not relevant to the topic at hand. It pertained to behaviour problem treatment among youth involved in foster care (http://www.cochrane.org/CD005649/BEHAV_research-suggests-that-treatment-foster-care-can-help-youth-with-behaviour-problems.-more-research-needed ; retrieved on May 17, 2016).

Perhaps the most fruitful search was the one conducted using SCOPUS, which garnered 632 articles before the inclusion and exclusion criteria were applied. Thereafter, 107 articles were hand-filtered for relevance. None of the relevant articles identified were novel to those identified in the previous searches. Admittedly, the search results were limited. However, consistent with a scoping review, searches are broad. Thus, when articles located using the search methods referred to other relevant materials, these were subsequently sought out. Figure 4 presents a Prisma diagram (Moher, Liberati, Tetzlaff, Altman & The PRISMA Group, 2009) of the literature search. In this diagram, the total sum of novel articles identified through all databases are reflected in the ‘Records identified through database searching’ box, whereas policy and grey material are

represented in the ‘Additional records identified through other sources’ box. The vast majority of articles were literature reviews and policy statements. These are reflected among those articles represented in the ‘Studies included in the qualitative synthesis’ box. It is important to also note that the majority of the results focus on people with ASD rather than their caregivers.

Although it guarantees the right to supports to promote the social inclusion of individuals who have ASD or ND/IDD, the Act (2008), itself, does not define social inclusion. This is a consistent conundrum across IDD services, policy and literature. This may be due to a lack of consensus in the literature about what social inclusion involves, as it relates to people who have ASD or ND/IDD (Martin & Cobigo, 2011; Cummins & Lau, 2003; Minnes et al., 2003).

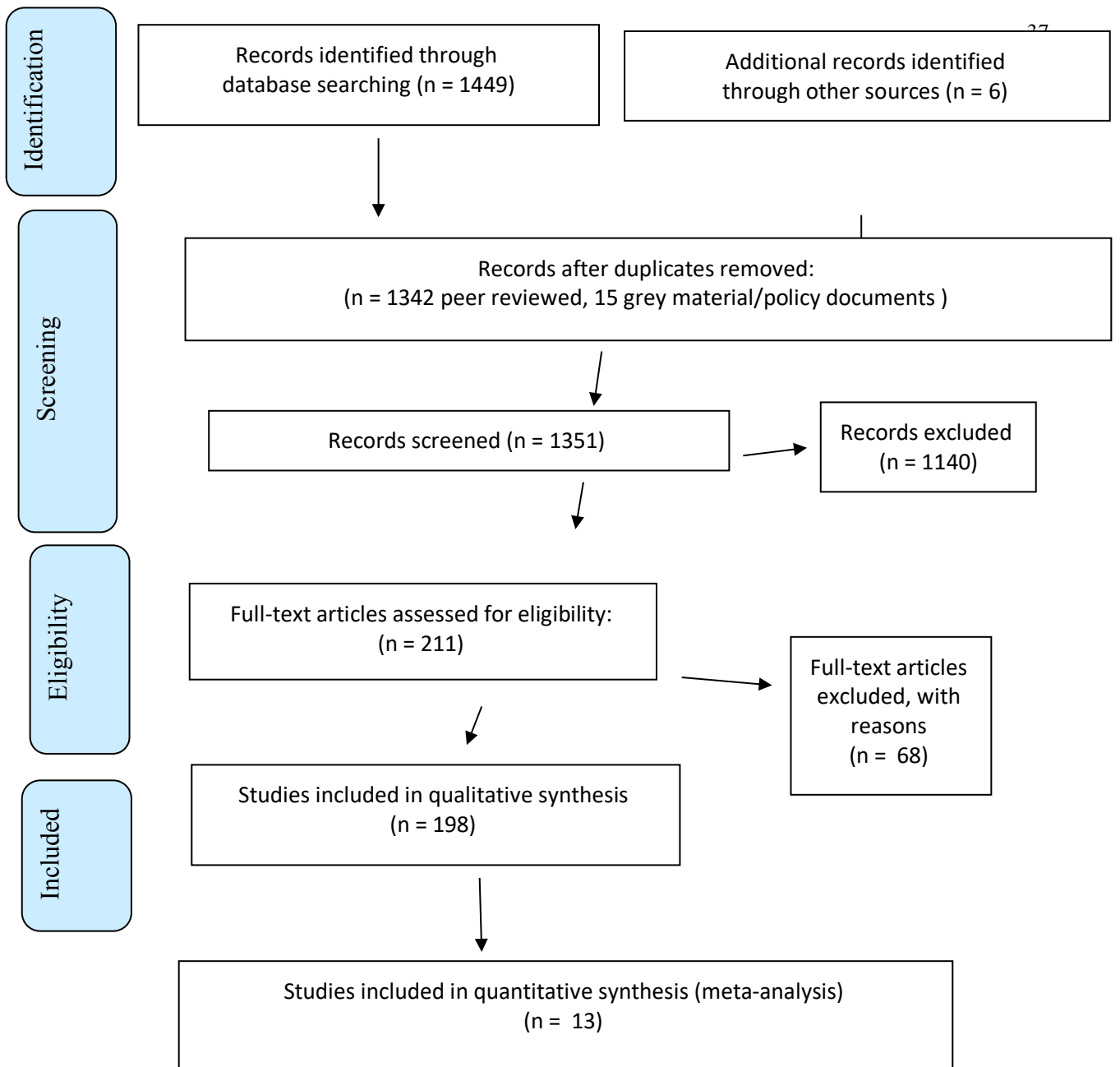


Figure 1. Prisma Diagram of Scoping Review Results

2.2 Literature Review Goals And Objectives

Using the first three steps of the HEIA as a framework for organizing data, this qualitative directed content analysis sought to understand what the needs of adults with ASD and their caregivers are, how adults with ASD and their caregivers are experiencing the available supports, and how this impacts on their health, from the perspective of their informal (i.e., unpaid) caregivers. Table 1 demonstrates how the steps of qualitative

directed content analysis compare with the stages and phases of PPM and HEIA research. This research is located in the position that in the absence of suitable supports and services, the potential for health inequities exists not only for the older adult who has ASD but also for his/her caregiver(s).

2.3 Health Equity

equity is defined as the outcome of reducing health inequalities and differential health outcomes arising from social structure and systemic barriers (Agic, Fernley, MacInnes, Macrae & Katherine, 2012). This is achieved through health service delivery and organization aimed at reducing the overall health disparities across all populations within society, including the most disadvantaged (Agic et al., 2014). Health equity is closely tied to the concepts of social determinants of health (SDOH) and Quality of Life (QofL) (Raphael, 2010), as well as developmental health outcomes (DHO) (Hertzman, 1999, Keating & Hertzman, 1999). A fourth concept, subjective well-being homeostasis (SWBH) refers to the mechanisms which contribute to and maintain a positive self-perception (Cummins, 1995; Cummins, 2010, Cummins, 2015).

Whereas SDOH refers to national differences in health on the basis of demographic characteristics (Raphael, 2006), QofL is a normative concept focusing on judging whether or not an individual or population of people are experiencing good or bad outcomes from a treatment or intervention (Raphael, 2010). DHO, on the other hand, analyzes the effects of SDOH on individual and population human development (Hertzman, 1999). SWBH refers to one's general feeling about oneself, which is fixed on a genetically-determined set-point, on a scale from zero to 100 (Cummins, 2015).

According to the principles agreed upon in the Ottawa Charter, it is the responsibility of society to advocate for and enable access to equitable opportunities to

achieve physical and mental health (WHO, 1986). The Ottawa Charter defines the conditions necessary for this to occur for an individual as follows: “peace, shelter, education, food, income, a stable ecosystem, sustainable resources, social justice and equity.” (WHO, 1986, p.1). Consistent with this, Raphael (2009) identified fourteen social determinants of health, including: 1) Aboriginal status, 2) gender, 3) disability, 4) housing, 5) early life, 6) income and income distribution, 7) education, 8) race, 9) employment and working conditions, 10) social exclusion, 11) food insecurity, 12) social safety net, 13) health services and 14) unemployment and job security. Although conceptualized and grouped slightly differently, the Public Health Agency of Canada (2013) identified similar determinants of health, as depicted in Figure 2.



Figure 2. Determinants of Health According to the Public Health Agency of Canada (2013) (Copied from Agic et al., 2012)

The World Health Organization's (WHO) Commission on Social Determinants of Health has proposed that studying SDOH and using it to inform social policy is crucial to decreasing the disparity in health equity (2008). In Canada, inequities in the SDOH have been increasing since the 1980's. It has been suggested that this is due to an interaction of a number of social and tax policies (Bryant, Raphael, Schreker & Labonté, 2011).

Within the academic research community, the study of QofL has been problematic. Many researchers treat outcomes and impacts of a particular treatment or intervention as though it were inappropriate to assign judgement or value statements about the lives of others (Raphael, 2010, Raphael, Curry-Stevens & Bryant, 2008). This

has made it challenging for researchers to make policy recommendations to impact on QoFL and consequently, on SDOH (Raphael, Curry-Stevens & Bryant, 2008). Particularly relevant to SDOH and people with IDD, an international study examining the relationship between QOFL and self-determination [i.e., making choices and decisions about one's life free of undue influence in a way which influences one's QOFL (Weymeyer, 1996)] demonstrated that the degree of self-determination achieved by an individual was positively correlated with QOFL (LaChapelle, Wehmeyer, Haelewyck, Courbois, Keith, Schalock, Verdugo & Walsh, 2005).

The SDOH align well with the concept of developmental health outcome. Hertzman suggests that developmental health considers various aspects of health as they relate to one's ability to meet developmental milestones consistent with one's developmental age (1999). This is an important distinction because it accommodates the variable and often unpredictable developmental state of one with ASD. By relating one's developmental milestones with one's developmental age rather than chronological age, it is possible to better interpret one's experience. In light of the IDD research which finds that individuals who have IDD have an earlier age of onset for age-related frailty and dementia (Ouellette-Kuntz & Martin, 2014; Brehmer & Weber, 2010; Lunsky & Balogh, 2010), this is an important consideration for approaching research of older adults who have ASD.

The domains considered within developmental health outcome research include: a) cognitive functioning, b) physical health, c) emotional and behavioural regulation, d) prosocial behaviours, e) independence, f) school achievement, g) recreational skills and h) adaptive functioning (i.e., socialization, communication and daily living skills)

(Szatmari, 2016; Hertzman, 1999). It is important to note the absence of symptoms associated with the disorder from this list. This is because developmentally, there is no evidence of an interactional relationship between symptoms and the domains which influence developmental outcome (Szatmari, 2016; Szatmari et al., 2015). One can present with severe symptomatology regardless of whether or not their developmental health outcomes are favourable. Contextual factors also heavily influence developmental health outcomes (Szatmari, 2016). For instance, an accommodating employer may facilitate one's independence, whereas one's independence may suffer if an employer is unprepared to accommodate one's needs.

In terms of meeting one's needs, the concepts of SDOH, QOFL and DHO refer to the degree to which one's needs are met such that it impacts on them physically and developmentally. SWBH refers to the degree to which one is satisfied with one's ability to meet one's needs (Cummins, 2015). It relies not only on the demonstration of links between one's motivation and subjective wellbeing but also on comparison group equality in access to and enjoyment of external resources (Cummins, 2015). Consequently, it is a challenging variable to study, comprised of a number of other variables, to consider. Although it is an important concept to consider in relation to this topic, a fulsome exploration of the study of SWBH is beyond the scope of this paper.

Directed Content Analysis	PRECEDE-PROCEED Model	Health Equity Impact Assessment
Preparation Phase	Phases 1-5 (Social, Epidemiological, Bx & Environmental, Organizational, Admin & Policy Assessments)	Scoping Review Stakeholder Reports of Impacts
Organization Phase	Process Evaluation Impact Evaluation (Behaviour, Lifestyle & Environment)	Mitigation Monitoring
Reporting Phase	Outcome Evaluation (Health & QoFL)	Dissemination

Table 1. Comparison of Steps in Qualitative Directed Content Analysis to PPM & HEIA.

There are some components of both the Health Equity Impact Assessment (HEIA) (Tyler et al., 2014) and the PRECEDE-PROCEED (PPM) (Green & Kreuter, 2005) which exceed the scope of this paper. Specifically, steps 3 and 4 of the HEIA focus on the implementation of strategies to mitigate the impacts of the policy (Tyler et al., 2014).

Similarly, phases 4 through 8 of the PPM focus on the implementation of education, training and intervention, as well as subsequent review of the effects thereof, with a goal of improving QOFL (Green & Kreuter, 2005).

2.3.1 Review Of Health Equity Assessment

For this research, an examination of the Act (2008) and how it is implemented and experienced by older adults who have ASD and their caregiver(s) in the province of Ontario was conducted. The fourth phase of the HEIA (i.e., implement and monitor evidence-based recommendations) was not completed, as it was beyond the scope of this research. Although dissemination of the results of this study will be completed, doing so will not technically fulfill the fifth and final step of the HEIA, as the results to be disseminated will pertain to the results of this study, not the results of implementation of the recommended effects.

The study entailed: (a) a review of the publicly available policies and decision-making documents related to services and supports for individuals who have ASD in Ontario, (b) a literature review considering the health equity status of older adults who have ASD and their caregivers, (c) completion of QOFL and SWBH measures, as well as interviews to establish the needs of this population as reported by caregivers of adults, from the perspective of their caregivers and (d) a review of data mined from Facebook posts on Facebook pages for groups related to adults with developmental disorders or ASD in the province of Ontario.

This section will demonstrate how assessments of health equity can be used to examine the positive and negative unintended health impacts of the *Services and Supports to Promote the Inclusion of Persons with Developmental Disabilities Act (2008)*

(the Act) on older adults with ASD. In order to do so, the following questions will be posed:

- What are the components of a health equity impact assessment?
- Why is a health equity impact assessment necessary in relation to the Services and Supports to Promote the Inclusion of Persons with Developmental Disabilities Act (2008) (the Act) as it relates to older adults who have ASD?
- How can health equity be impacted by the Services and Supports to Promote the Inclusion of Persons with Developmental Disabilities Act (2008) (the Act) as it relates to be people who have ASD be conducted?

Because there has been very little research conducted on older adults who have ASD, it is recognized that much of the literature reviewed focused on ND/IDD and may or may not include participants who had ASD. This should not diminish the value of the research, given that grounded theory research is intended to generate theory based on the reports of those experiencing the situation.

2.3.1.1 Health Equity Impact Assessment

The HEIA was developed by the province of Ontario as a means of conducting an assessment of the unintended health impacts (positive and negative) of any given policy (Tyler et al., 2014). It can be used not only at the design phase of an initiative but also retrospectively to review, evaluate and guide decision-making regarding existing programs and services. One of the benefits of the HEAI is that it allows for evaluation of

a host of programs and services which fall under the umbrella of an over-arching policy, such as the services and supports provided for under the Act (Tyler et al., 2014).

The creators of the HEIA recommend implementing the HEAI prior to launching a program, service or policy, so that efforts can be made to mitigate potential inequities before implementation has occurred. They do acknowledge that it is possible to conduct an HEIA assessment with an existing program, service or policy. However, the ability to mitigate inequities at that time will be constrained by resource allocation (Tyler et al., 2014).

In the HEIA training modules, a link to a WHO (2017) summary of a health impact assessment is provided. This assessment was conducted by external, hired, third-party evaluators. It is unclear whether the HEIA tool referred to was the HEIA created by the Province of Ontario or is another health equity impact tool.

The HEIA training modules, which have a publication date of 2012, cite material demonstrating its effectiveness with publication dates which are later than the HEIA training modules themselves (i.e., Public Health Agency of Canada's "What Makes Canadians Healthy and Unhealthy?" (2013) and WHO (2017) Health Impact Assessment: Evidence that HIA Works. This demonstrates how policy related tools are "living documents" in that they are developed and improved upon as they are being used and challenges are identified.

The HEIA training modules seem to suggest that the WHO (2017) assessment is evidence that the HEIA works. However, the WHO (2017) report does not refer to the Province of Ontario's HEIA tool. It simply indicates the effectiveness of Health Impact

Assessments (HIA). The absence of ‘equity’ from that report reflects that the focus was on health impacts, without necessarily identifying inequalities.

The HEIA is a living document and appears to be evolving, as evidenced by references to later publication dates within documents released prior to the supporting documents. Consequently, for the writing of this paper, it was necessary to establish a cut-off date for reviewing HEIA related documents. Approval to write this paper was provided in November 2016. As work on the paper progressed remaining current as the HEIA project evolved was challenging. In order to render it more manageable, a cut-off date for inclusion of documents was applied. For the purposes of this paper, a cut-off date was applied at February 28, 2017.

The creators of the HEIA suggest that third parties should not conduct HEIAs citing concerns about cost and being removed from the process of policy making as a rationale for this (Tyler et.al., 2014). This is inconsistent with their reliance upon the WHO (2017) report to support claims of the HEIA’s effectiveness as a tool. In the WHO (2017) report, the health impact assessment was conducted by a third-party, independent investigator. Furthermore, if a third party investigator conducts an HEIA at no cost to the policy maker, the prohibitive cost ceases to be a precluding concern. With regard to interviewer effects, whereby participants might be concerned about sanctions placed on them by those in a position of authority, a health equity impact assessment might be more reliable if conducted by a neutral party who has no influence over access to services or resources. There are five steps involved in completion of the HEIA: 1) scoping review of literature related to intended population and the health impacts they experience, 2) analyze existing data to assess unintended impacts on the population; where no data

exists, make note of this and attempt to collect evidence, 3) develop evidence-based recommendations, 4) monitoring effects of implementation of recommendations and 5) dissemination of results. Figure 3 reflects the stages of HEIA (copied from Tyler et. al., 2014).

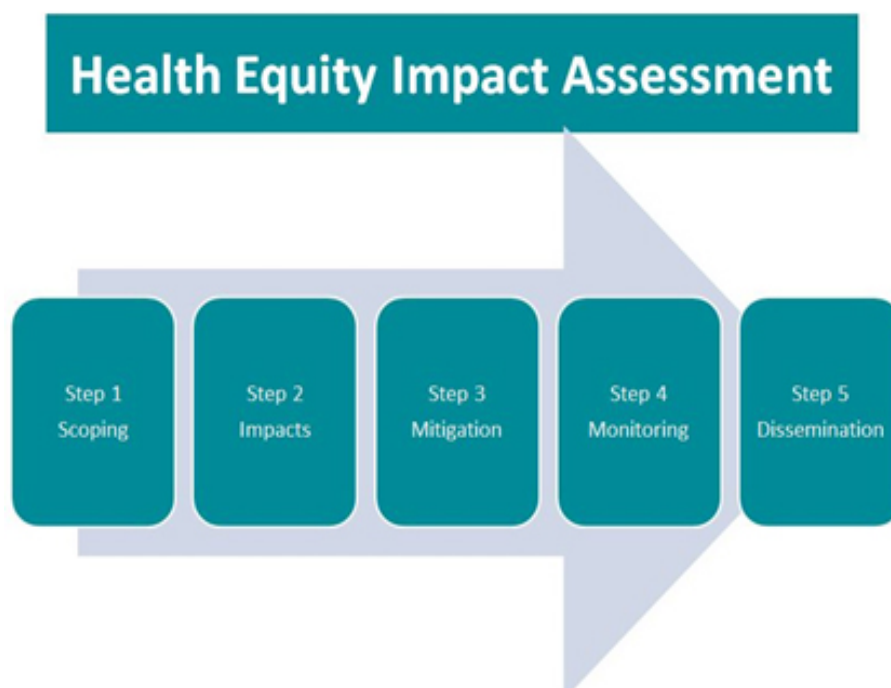


Figure 3. Steps Involved in an HEIA (Copied from Tyler, et. al., 2014).

Policy makers have critiqued health equity research as challenging to use to inform policy due to a lack of consistency or clarity in how health equity is measured (Welch et al., 2010). In their systematic review of health equity research, Welch et al. (2010) found that the methods and criteria used for conducting health equity reviews are inconsistent. Of concern was that of the thirty-four studies they reviewed, only three provided a definition of health equity. In their review, they identified four methods to assess health equity:

“1) descriptive assessment of reporting and analysis in systematic reviews (all 34

studies used a type of descriptive method); 2) descriptive assessment of reporting and analysis in original trials (12/34 studies); 3) analytic approaches (10/34 studies); and 4) applicability assessment (11/34 studies)” (Welch et al., 2010, p. 2).

The authors found that none of the studies reported analytic or applicability approaches in a manner which was sufficient or transparent, making it challenging to determine whether or not they reported credible findings.

The HEIA is not the only framework for analyzing the impacts of policy or program. In fact, the steps involved in completion of the HEIA are quite similar to those of the PPM. The PPM is an 8-step framework for program evaluation, used for planning and evaluating programs (Green & Kreuter, 2005). Figure 1 depicts the phases of the PPM (Copied from http://www.nyc.gov/html/doh/images/cmha/pp_model.gif on April 15, 2017). Whereas the HEIA relies on the SDOH as the benchmark for health equity, the PPM considers QOFL as the outcome in question.

2.3.1.2 PRECEDE-PROCEED Model

Similar to the HEIA, the PPM consists of a review of what is already known about a policy or program and the consumers therein. The model is considered as a two-phase, eight-step process, whereby the first phase (i.e., the PRECEDE phase) is comprised of a series of assessments used to identify the “*predisposing, reinforcing and enabling constructs in educational/ecological diagnosis and evaluation*” (Green & Kreuter, 2005, p.9). The PRECEDE phase allows researchers to examine the various social determinants of health (SDOH), how those determinants arise for the population under study and the strengths of the population or context which can be capitalized upon

in order to address challenges. It is comprised of three major steps: 1) Social assessment and situational analysis, 2) Epidemiological assessment, 3) Educational and Ecological Assessment (Green & Kreuter, 2005).

2.3.1.2.1 PPM Step 1

The first step in the PPM, referred to as a social assessment, is an analysis of the QOFL and health outcomes of the target population. In this case, the QOFL and health research of adults who have ASD and who are thirty-five years old or older and their primary caregivers is the focus of the social assessment. Although the research pertaining to this particular population is limited, there is research on this topic as it relates to adults who have IDD in general, as well as in younger people who have ASD. In the database search, however, no such research specific to adults or older adults who have ASD were identified.

Effective participation of stakeholders requires: a) participation in the initial stages of the planning process, b) sufficient opportunities for discussion and c) mutual respect and trust between stakeholders and policy makers (Green & Kreuter, 2005, p.20). In the case of ASD, this can be a challenge to overcome, as there can be a contentious relationship between people with ASD or their caregivers and policy-makers and service providers arising from the lack or fragmented nature of services available to them (Dawe, Whelan, Farrell, Spoelstra & Coursens, 2016). Reflecting on a combination of professional and personal experiences, (Dawe, Whelan, Farrell, Spoelstra & Coursens, 2016) reported experiences and observations of caregivers “giving up” and learning to deliver the needed services themselves. For policy development and research purposes, this is problematic, as it becomes challenging to assess the true prevalence of those

falling within the target demographic, which in turn makes it challenging to assess need for programming.

2.3.1.2.2 PPM Step 2

The second step, known as the epidemiological assessment considers the health research as it relates to genetics, behaviour and the environment in which the population functions. Whereas the focus of the PRECEDE phase is on identifying the social and epidemiological aspects of the topic, the focus of the second phase of the model (i.e., the PROCEED phase) is an examination of implementation of the policy and administrative constructs as they relate to the development of educational and environmental strategies used in the program (i.e., *“policy, regulatory and organizational constructs in educational and environmental development”* (Green & Kreuter, 2005, p.9). In the case of how the Act (2008) impacts on the health of older adults who have ASD, many of the steps can be filled in based on existing research. There are many steps, however, which require further investigation.

Program and policy evaluation research has been completed using the PPM to examine community development in relation to gerontology research (Lauckner, Krupa, & Patterson, 2011), the field of occupational therapy in relation to mental health (Sedgwick, Cockburn and Trentham, 2007) and physical activity among clients in early learning facilities (Vanderloo et al, 2015). Organizing existing knowledge using this framework can be helpful in identifying areas which require further research. This is necessary because policy and service delivery are being developed and implemented now. However, these policies and services tend to be based upon the research which exists.

According to Szatmari (2016), it is important to include individuals with ASD, as well as their caregivers and service providers in the research and policy making process. This was exemplified when Szatmari (2016) surveyed parents of children with ASD in order to determine which research questions ought to be asked with regard to developmental outcomes among children who have ASD. He had identified variables related to cognitive development, symptomology, social and communication skills, mental health, academic options and achievement as potential areas of focus. His parenting informants, however, cited mental health, adaptive functioning, independence and physical health as priorities.

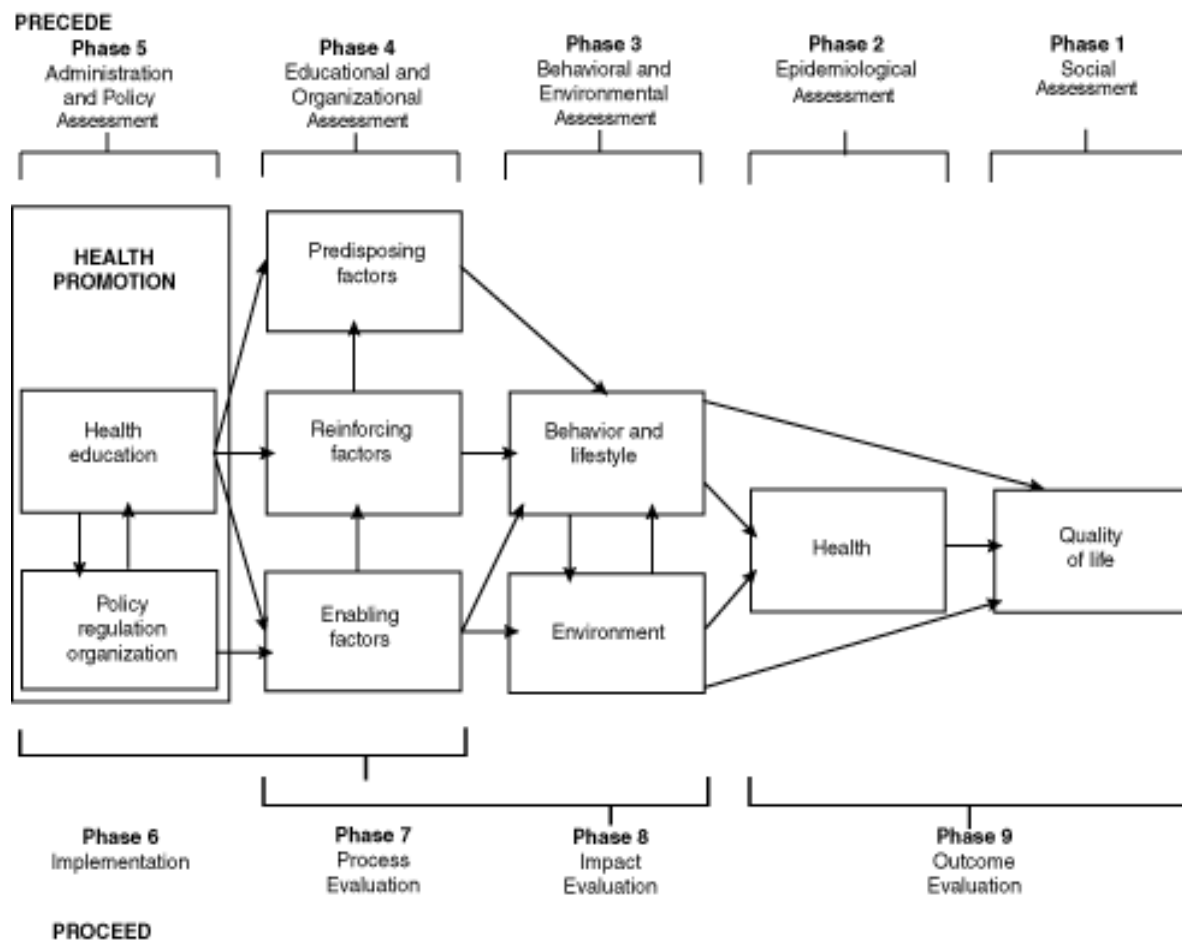


Figure 4. PRECEDE-PROCEED Model. PRECEDE-PROCEED Model (Green & Kreuter, 2005, copied from http://www.nyc.gov/html/doh/images/cmha/pp_model.gif on April 15, 2017).

2.4 Policy Impacting ASD & IDD

This section presents the theoretical and philosophical underpinnings which drive social inclusion of people who have ASD/IDD. It starts out by broadly examining the global approaches to understanding the principles guiding services and supports to people with ND, before focusing more narrowly on the human rights perspective.

2.4.1 Human Rights Perspective

There is evidence that societies have been providing care and residential services to people with IDD since the Middle Ages (Cumella, 2007). However, a turning point in their humane care occurred in 1793, when Phillipe Pinel lead the reformation of care in Parisian asylums so that they were free of abuse, provided treatment plans and offered recreation and vocational opportunities (Scheerenberger, 1983, as cited by Cumella, 2007, p. 354). Humane care of people with IDD became a movement which spread across Europe by educational and religious factions, with countries developing and implementing statutes around their education and care (Cumella, 2007). North American followed suit shortly thereafter.

In spite of efforts to institutionalize humane education and care practices, most countries struggled to provide services, with the majority of people with IDD living in almshouses, asylums, poor houses and with their parents (Campbell & Adel Herge, 2000; Cumella, 2007, p. 354). With population growths and industrialization, it became increasingly difficult and costly to provide care in community based, informal ways. Thus, publicly funded institutions began to emerge in the 19th and 20th centuries (Campbell & Adel Herge, 2000; Cumella, 2007). In Ontario, the first institution for people with IDD was established in 1876 (DSO, 2014a).

Unfortunately, the physical care and treatment of people with IDD were not good. This was due in part to lack of knowledge about how to care for them and in part due to eugenics (i.e., a movement in which the killing and forced sterilization of people deemed disabled, ‘mentally inferior’ or ‘insane’ was encouraged) (Cumella, 2007). Following World War II, eugenics movements lost popularity and consensus on human rights was established internationally, language embedded in the *United Nations Universal Declaration of Human Rights*, pertaining to people with disabilities (Cumella, 2007).

Thereafter, society became increasingly concerned with the humane treatment of people with IDD, with parents of these individuals advocating for care and support within their communities (Campbell & Adel Herge, 2000; Cumella, 2007). Since the late 1960’s, de-institutionalization has focused on establishing placements within the community in the form of group homes and with family members (primarily parents) (Campbell & Adel Herge, 2000). Attitudes and approaches to care and service provision have also shifted from one which resembled an invalid care model to one of “normalization” (i.e., providing skills training to increase one’s ability to lead a lifestyle similar to that of neurotypical peers) (Campbell & Adel Herge, 2000, p. 78).

Ontario had closed all its institutions for people with IDD by 2009. One notable exception was the Penetanguishene Mental Health Centre. When faced with the closure of this facility, advocates for its residents effectively argued for it to remain open (Canadian Newswire, 2008). Subsequently, it was divested by the Province of Ontario, becoming instead a public hospital corporation, sponsored in large part by the Catholic Health Corporation of Ontario (Town of Penetanguishene, 2014).

2.4.2 Life Course Perspective

Given the relatively recent acceptance of eugenics, the living circumstances of older adults with ASD is rather unique in comparison with those born more recently. It is therefore helpful to consider their experience within the context of the life course perspective (i.e., a theoretical framework which defines: a) the course of events followed by a subset of the population and b) how those events have impacted on a particular point in the life course of those in question, within the context of the broader population) (Fuller-Iglesias, Smith & Antonucci, 2009; Alwin & Wray, 2005; Settersten, 2007). The life-course perspective considers social influences (e.g., services, care providers, policies, etc.) which impact on the population in question (Fuller-Iglesias, Smith & Antonucci, 2009). Because care and service provision for people with IDD is legislated and based on social and political values, the life-course perspective is a suitable framework for considering the care and service provision of aging adults with ASD.

The life course is becoming increasingly institutionalized due to various normative social institutions Kohli (1986). For instance, the progression through education is becoming increasingly standardized, particularly with inclusive education practices. Other examples may include entry to the workforce, followed by retirement. There are three key ways in which society formally influences the life course: (a) chronologization (i.e., the effect of age and place in history), (b) institutionalizations (i.e., structuring of the life course through the institutions, legislation, and the state) and (c) standardization (i.e., the normalization of life course patterns arising as an effect of adoption of these patterns as societal institutions) (Fuller-Iglesias, Smith & Antonucci, 2009, p.6).

This progression typically tends to play out primarily in the public domain, through participation in school, the workforce and pensioned retirement. The life-course perspective considers these themes within the context of five main concepts: (a) cohorts (i.e., social change within a historical period will have specific impacts on groups of people depending on their age at the time of the social change/historical period), (b) transitions (e.g., major life events which influence status and roles within society, such as marriage, divorce, child-bearing, etc.), (c) trajectories (i.e., the transactional course of multiple aspects of a person's life, in relation to the individual, as well as to family members; for instance, one's educational trajectory may influence one's marital trajectory, which in turn may influence one's reproductive trajectory, etc.), (d) life events (i.e., significant events which change the course of one's life, for instance, death of a loved one) and (e) turning points (i.e., life events which alters one's life course trajectory entirely, for instance the arrest of one who has a drug addiction, for one to change one's lifestyle) (Hutchison, 2005).

Bio- psycho-social impacts across the lifespan are also considered. Also considered is people's ability to adapt and change over time, depending on their life circumstances (Hutchison, 2005). Cultural, societal and political influences are also accounted for in the life-course perspective. However, due to the heterogeneity of society, it is often difficult to apply a life course perspective objectively to identify societal patterns (Hutchison, 2005).

In the case of aging adults with ASD, their historical and societal context distinguishes them sufficiently from society that it is possible to retrospectively analyze the impact of social policies and attitudes on their current lives. The characterization of

ASD over time has served to create a distinct institution for this population. Responses of parents of children with ASD, as well as societal responses has created a distinct institution whereby care and service needs are unique to the aging population with ASD.

2.5 Autism Spectrum Disorders

This section examines ASD from the lifecourse perspective. It demonstrates how ASD has been understood historically, the effects this has had on the ASD community in terms of access to services, health and mental health, education and vocation. Finally, it will demonstrate how this has informed the current approach to services and supports policy in the Province of Ontario.

2.5.1 Historical Effects Of ASD

Defined as an IDD, ASD is characterized by deficits and deviancies impacting the triad of impairment [i.e., (a) language and communication, (b) social skills and interactions, and (c) behaviour, with demonstration of restrictive and repetitive interests and often does not include intellectual disability (American Psychological Association [APA], 2013] along a continuum of varying severity/intensity. In the province of Ontario, the prevalence of ASD is estimated to be about 1 in 94 people (Autism Ontario, 2014). Prevalence estimates tend to focus on prevalence in children between the ages of six and nine years old (Lunsky, et. al., 2012) and may not apply to the broader population. Piven and Rabins (2011) estimate that the prevalence of ASD in adults 65 years old and over in the USA will reach approximately 700 000 by 2030 (p. 2152). Given comparable prevalence in various developed, Western countries (Lunsky, et al., 2012), it is likely that this estimate of prevalence can be generalized to the populations of these countries, including Canada.

ASD and suspected causes thereof have been poorly understood and frequently ignored in the research (Langan, 2011). It was in the 1980's that the popular theory about the cause of ASD (i.e., that it was caused by "refrigerator parents" who were characterized as cold and rejecting toward their child) (Bettelheim, 1967, as cited by Langan, 2011). Although the origin of this characterization is unclear, the interaction styles between children with ASD and their parents were supposedly described as being similar to how prisoners of the Holocaust interacted with Nazi prison guards (Donvan & Zucker, 2016). These parents were encouraged to institutionalize their children, with the aim of separating the child from alienating parenting situations. However, Kanner (1971) (as cited by Henninger & Tyler, 2014) reported severe skill deterioration when these children left their family homes and were institutionalized.

In response to the stigma and blame, Parents of children with ASD frequently chose to care for their children at home. This often took place with minimal interaction in the community and in the absence of formal supports (Perkins & Berkman, 2012). Consequently, adults with ASD (or those who meet diagnostic criteria but have never accessed a diagnosis) who have never accessed formal services/supports increasingly making initial contact with community service providers, upon outliving their parental caregivers (Perkins & Berkman, 2012). This cohort had limited opportunity to develop skills and function in the community, yet present policy in the province of Ontario requires that they participate in the community in order to access care and services.

As parent-blaming theories have lost influence, parents of children diagnosed with ASD have increasingly become vocal about advocating for inclusion, care and service provision, as well as visibility of individuals with ASD within the community

(Langan, 2011). These parent-advocates have begun to advocate for services to facilitate successful transition to adulthood. As such, those with ASD born after 1990 are likely to benefit from access to greater opportunities for participation in the community and independent functioning through skill development opportunities and participation in education. Older counterparts who entered adulthood at a time when the disability was often hidden from the community are less likely to have had this same benefit (Perkins & Berkman, 2012).

2.5.2 Cumulative Disadvantages Of Autism

The majority of the research conducted in response to the prioritization of aging among people who have IDD has excluded ASD (Piven & Rabins, 2011). Frequently, this research focuses on those who have intellectual disabilities (i.e., impaired functioning in cognitive, functional and social abilities, as well as having an intelligence quotient, or IQ score, which falls at least two standard deviations below 70) (APA, 2013). An intellectual disability, however, is not necessary to achieve a diagnosis of ASD. In fact, only about 41% people who have ASD meet criteria for a diagnosis of intellectual disability [Centers for Disease Control and Prevention (CDC), 2009]. Occasionally, people with ASD are included in research about aging and intellectual disability as a result of the participants with ASD meeting diagnostic criteria for intellectual disability (Melville et al, 2008). Consequently, the needs of adults with ASD may not be reflected in the research. This under-representation in the research is problematic, as the research subsequently informs policy and practice.

2.5.3 Cohort Effects of ASD

There is little research examining the cognitive functioning of older adults who have ASD. Cognitive functioning research as it relates to people with ASD tends to focus

on children, although that of young adults is also increasingly considered (Geurts & Vissers, 2012). Adaptive functioning (i.e., the capacity to perform daily living skills and cope with one's circumstances independently) has been studied in relation to adults aged between 27 and 69 years old who have profound intellectual disability using the Vineland Behavior Scales (VABS) Belva and Matson (2013). Greatest strengths were found in basic hygiene skills (e.g., feeding, dressing and bathing oneself independently), while the areas posing greatest difficulty included completing daily living skills (e.g., preparing meals, budgeting, performing household chores, etc.). Consistent with the suggestion that older adults would have had less access to skill building opportunities, those who were younger (e.g., 30 to 39 years old) achieved better scores than did those who fell into the oldest age range (60 to 69 years old) (Belva & Matson, 2013). Older people would have had less access to community-based intervention programs targeting adaptive functioning skills, thereby limiting the independence they have achieved. This in turn would lead to greater dependence on care and services provided by family and in the community, across the lifespan.

2.5.4 Health Status In Autism

There is an interactional relationship between ASD and older age, resulting in social exclusion and unintentional violation of the individual's human rights (Autism Europe and AGE Platform Europe, 2012). This can arise from the combined impact of: a) discrimination and stigmatization associated with both age and the presence of a disability, b) inadequate access to goods and services appropriate to both the needs arising from ASD and those arising from age and c) life and care settings which are not suitable to the needs arising from ASD and age (Autism Europe & AGE Platform Europe, 2012).

The cumulative disadvantages associated with the presence of an ASD, combined with the interactional relationship between the disorder and aging may also be associated with poor developmental physical and mental health outcomes. To date, although there is some research which examines the resiliency of parents of children who have ASD, no resiliency or developmental health outcome research on individuals who have ASD exists (Szatmari, 2016).

Care provision of aging adults with IDD, including ASD, in general nursing homes is inappropriate, as the staff is not trained in the care of individuals with IDD (Marin, 2014a). As a result of high turn-over rates among staff at assisted living community facilities, such as group homes, the training and care provision is often not sufficient for aging adults with IDD at the latter either (Campbell & Adel Herge, 2007). The research into older adults who have ASD, has been identified as a priority Autism Europe & AGE Platform Europe (2012).

What follows is a synthesis of what is known about older adults who have ASD, as it relates to their health. This section is organized by the SDOH categories identified by the Public Health Agency of Canada (2013). These categories include: a) biology and genetic endowment b) gender c) personal health practices and coping skills, d) health services, e) healthy child development, f) employment/working conditions, g) income and social status, h) education and literacy, i) social support networks, j) social environments, k) physical environments and l) culture. Many of these areas have not yet been researched and others have only scant research related to them.

For the purposes of this study, review of the research as it relates to the SDOH domains have been grouped together in themes. These themes are: a) Health and Mental

Health, b) Education and Vocation and c) Social and Community. Topics which reflect the domains of biology and genetic endowment, gender, personal health practices and coping skills, health services, healthy child development are subsumed under the Health and Mental Health themes. Research covering the employment/working conditions, income and social status, education and literacy domains are subsumed under the Education and Vocation theme. Research that considers social support networks, social environments, physical environments or culture is subsumed under the Social and Community theme.

2.5.5 Health And Mental Health

In their review of the existing literature on adults with ASD, Perkins and Berkman (2012) expressed alarm at how little is known about how those who have ASD fare in adulthood. Life expectancy among this population is roughly three years shorter than that of the general population, among both men and women with ASD (Perkins & Berkman, 2012). However, this population also tends to experience significantly higher rates of death due to epilepsy. Specifically, as intellectual impairment increased, so too did risk of death by epilepsy (Gillberg, Billstedt, Sundh, & Gillberg, 2010; Mouridsen, Brønnum-Hansen, Rich, & Isager, 2008; Pickett, Xiu, Tuchman, Dawson, & Lajonchere, 2011; Shavelle, Strauss, & Pickett, 2001).

Adults with ASD also have an increased risk of death by: drowning, suffocation, respiratory disease (especially pneumonia), nervous and sensory diseases and circulatory disease, cancer (Shavelle, Strauss & Pickett, 2001). This higher rate of mortality associated with diseases might be due to challenges navigating health care and diagnostic services, leading to delayed access to the diagnostic and treatment services (Perkins & Berkman, 2012).

Although not reported specific to people who have ASD, in general, those who have IDD tend to report less effective interactions with their health care providers (Nicolaidis, Kripke & Raymaker, 2014; Lewis, Lewis, Leake, King & Lindemann, 2002). Challenges specific to health care interactions among adults who have IDD include difficulty accessing preventive services (e.g., screenings and vaccinations) (Lewis et al., 2002). They are more likely to receive pharmacological interventions than the typical population (Nicolaidis, Kripke & Raymaker, 2014), often receiving prescriptions for psychotropic drugs, often two or more such drugs simultaneously, without receiving a diagnosis for a related condition (Lewis et al., 2002).

Adults with ASD are more likely to receive psychopharmacology than are adults who do not have ASD (Perkins & Berkman). Therefore, it is necessary to study the effects of long-term use of these medications (e.g., osteoporosis, neural degeneration, etc.), particularly in relation to the other health issues common to people who have ASD (Perkins & Berkman, 2012). Long-term medication use has been associated with osteoporosis (Perkins & Berkman, 2012). In the case of osteoporosis, bone density measures are relatively easy to conduct.

In the case of dementia or Alzheimer's, it is necessary to develop measures and diagnostic protocols which are sensitive to the characteristics common to ASD (Mukaetova-Ladinsky, Perry, Baron & Povey, 2012). Data on the incidence of age-related frailty and dementia are not available specific to people who have ASD. However, adults who have IDD in general tend to develop age-related frailty and dementia more frequently and at an earlier age of onset (Ouellette-Kuntz & Martin, 2014; Brehmer & Weber, 2010; Lunskey & Balogh, 2010).

Health problems common to adults who have ASD have not been well researched (Perkins & Berkman, 2012). However, research does exist with regard to children with ASD. Common health problems among children with ASD include: a) more visits to doctors for preventive, non-emergency and emergency care (Gurney, McPheeters & Davis, 2006), b) gastrointestinal and food sensitivity (Horvath & Perlman, 2002; Molloy & Manning-Courtney, 2003; Valicenti-McDermott, McVicar, Rapin, Wershil, Cohen, & Shinnar, 2006) & c) sleep problems (Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen, & Hansen, 2008). Further research is necessary in order to ascertain whether or not these health challenges continue into and throughout adulthood (Perkins & Berkman, 2012).

In comparison with the general population, adults with ASD are 70 to 75% more likely to have at least one additional mental health problem (e.g., obsessive-compulsive disorder, anxiety, depression, etc.) (Totsika, Kerr, Felce & Hastings, 2010, Ghaziuddin & Zafar, 2008; Simonoff, Pickles, Charman, Chandler, Loucas, & Baird, 2008).

Interestingly, in their study examining the prevalence of social anxiety disorder among adults who have ASD, Bejerot, Eriksson and Mörtberg (2014) found that although adults with ASD scored significantly higher on measures of social anxiety and social avoidance than did the control group, they tended to achieve significantly lower scores than did typically developing adults who had diagnoses of Social Anxiety Disorder. The items most frequently scored more highly by those with ASD tended to focus on making and maintaining friendships and working/functioning in groups. This is worth noting, given that many employment and community-based support opportunities require people to function in groups.

Ability to independently complete activities of daily (ADL) that support personal and independent living were correlated with higher functioning individuals and lower psychopathology levels (Matson, Rivet, Fodstad, Dempsey & Boisjoli, 2009). Although not specific to ASD, it is important to note that comorbid health and mental health disorders tend to be higher among higher functioning adults who have IDD and are living independently than among those living with familial caregivers (Gotham, Marvin, Lounds Taylor, Warren, Anderson, Law, Law & Lipkin, 2015). Because they have fewer developmental barriers across domains, higher functioning individuals who have IDD tend to be eligible for fewer formal supports (Gotham, et al., 2015). Consequently, they may not receive ongoing contact by caregivers who may recognize the emergence of health or mental health issues in earlier stages of onset, resulting in more intense problems before the issue is identified.

One of the challenges to addressing mental disorders in adults who have ASD is that mental health services are frequently not competent to meet the needs associated with ASD. At the same time, services designed to support those with IDD often do not offer services required of higher functioning adults with ASD (Barnard, Harvey, Potter & Prior, 2001; Barnard, Prior & Potter, 2000). Where specialized mental health services are available to those who have ASD, it is frequently limited to providing diagnostic clarity rather than treatment of mental health problems (Ward & Russell, 2007).

When adult children with IDD experience age-related deterioration or frailty (e.g., incontinence, loss of vision, bone degeneration, physical strength decline, chronic illness, etc.), parent caregivers tend to experience higher rates of depression (Lin, Hsu, Juo, Wu, Chu & Lin, 2014). This was consistent across caregivers, even when demographics such

as income, marital status and geographic location were accounted for. The strongest predictor of depressive symptomology among parent caregivers was poor sleep quality of the adult child with IDD (Lin, et al., 2014). This is not surprising, as the age-related deterioration or frailty would increase the physical and mental demands placed on caregivers. If this was occurring at the same time the caregiver's sleep was disrupted due to the wake patterns of the adult child, the caregiver's ability to cope physically and mentally would be challenged.

Consistent with these findings, Ruiz-Robledillo, González-Bono and Moya-Albiol (2014) found a negative correlation between access to formal supports and cortisol awakening responses among informal caregivers of children who have high-functioning ASD. This is important because cortisol awakening response, which is associated with stress responses, is a biological marker of health, which has been studied in-depth (Ruiz-Robledillo et al., 2014). In mothers of adults who have IDD, Pruchno and Meeks (20014) demonstrated that mothers' depressive symptoms increased when their own health was stressed through acute or chronic illness. When their adult children's symptoms or needs posed high rates of stress (e.g., aggressive behaviour, non-compliance, emotional volatility, etc.), mothers depressive symptomologies and reports of stress also increased. Older mothers were also more predominantly represented in the high stress, depressive group than were younger mothers. As demands are placed on informal caregivers, their sleep becomes disrupted and protective physiological responses become over-burdened. These effects appear to increase as the parents and adult child's needs increase due to age.

In a study examining low back pain among formal caregivers of adults with IDD, including ASD, Hsu, Su, Lin, Lin, Chu, Wu and Lin (2015) found when caregivers had formal knowledge of low back pain and coping strategies, they were less likely to report experiencing low back pain. Additionally, when caregivers had access to scheduled breaks, regular exercise or had poor health status, they were more likely to implement coping behaviours than their counterparts. These findings could be generalized to examine back pain among informal caregivers, who do not have access to working conditions regulated by labour laws.

2.5.6 Education & Vocation

Employment among people who have ASD is a poorly researched topic, making it particularly challenging to develop policy to support employment for this population (Shattuck, P., Roux, A., Hudson, L., Taylor, J., Maenner, M. & Trani, J. 2012). In Canada, research of this nature is particularly problematic because of how income supports and employment insurance are structured (Dudley, Nicholas & Zwicker, 2015). Based on research from the United States of America and United Kingdom, however, only about 25% of adults with ASD are employed, are often paid below the national minimum wage and experience more periods of unemployment than do typically developing adults (Dudley, Nicholas, & Zwicker, 2015; Chiang, Cheung, Li, & Tsai, 2013). Based on statistics retrieved from the Canadian Survey on Disability, 2012, Zwicker, Zaresani and Emery (2017) determined that people who have ASD tend to participate in the work force at a rate of 21.5%, which is lower than the participation rates of other people who have IDD (27.1%). Additionally, their mean wage earnings is roughly \$6700, which is \$9800 lower than that of other people with IDD (p.4).

Adults who have ASD and are able to obtain employment experience job precariousness, whereby jobs are often not permanent. When people with ASD have frequent but brief periods of employment, this has been demonstrated to have a negative effect on future employment prospects (Balwin, Costley, & Warren, 2014). Although completion of post-secondary education is helpful, people who have ASD with no cognitive deficits experience high rates of over-qualification for the positions they hold (Balwin, Costley & Warren, 2014).

Those with ASD who are employed report higher QOFL and SWBH than do their unemployed counterparts, as well as demonstrate higher cognitive functioning, higher self-esteem and greater community participation (Walsh, Lydon, & Healy, 2014, Joshi, Bouck, & Maeda, 2012). Although not well research in people who have ASD, among people who had IDD, school-based work experiences (e.g., apprenticeships, internships, work-study) were the most effective strategy for developing work related skills and obtaining employment upon graduation (Wehman, et al., 2012, Kohler, 1993). In spite of evidence of potential poor health, subjective QofL specific to health, mental health, social and environmental domains among adults who have ASD were more strongly influenced by their experience of stress and bullying in the workplace (Hong, et al., 2016). This is particularly concerning considering the high rates of unemployment and under-employment (i.e., insufficient work hours to support oneself) among adults who have ASD.

2.5.7 Social & Community

Adults who have ASD report high rates of social exclusion, regardless of how high functioning they are (Department of Health (UK), Retrieved 2015). The social motivation

theory of ASD proposes that people who have ASD have low motivation to engage in social interactions, arising from a combination of cognitive and biological characteristics leading to behavioural responses. These behaviours in turn have had social consequences (e.g., humiliation, teasing, reprimand, etc.), which in turn diminish motivation for future social interactions (Chevallier, Kohls, Troiani, Brodtkin & Schultz, 2012). Further studies are necessary to support or refute this proposition.

In their study examining how supports influence QOFL, Claes, Van Hove, Vandeveldel, van Loon and Schallock (2012) proposed that staff directed initiatives, such as providing incentives such as obtaining specialized roles or status, recognition and appreciation and empowering clients to participate in decision making processes were related to higher QOFL and sense of security reported by clients. Living independently and being employed were also associated with higher QOFL scores. It is important to note that QOFL was measured as experienced subjectively by participants who had IDD, as well as by the researchers, who completed direct observation (Claes et al., 2012). This is interesting to note in relation to Gotham et al.'s, (2015) finding which suggested that those who lived independently tended to have a higher incidence of health and mental health problems. Although further research would be necessary to draw any conclusions, it is possible that in spite of health and mental health challenges, living independently and the roles associated with doing so are more predictive of subjective QOFL than are health and mental health. The study, however, considered those with IDD, with no mention of ASD (Claes et al., 2015).

In a case study examining older adults who had IDD, Treece, Gregory, Ayres and Mendis (1999) found that older adults wanted more opportunities to make

choices in important areas in their lives. Specifically, participants living in self-contained apartments, shared among four residents, reported never getting to decide with whom they lived or how many roommates they had. They also did not get to choose how to spend their money or what activities to complete within their daily routines (Treece et al., 1999). Consistent with these findings, McDonald (2012) demonstrated that people with IDD recognize when they are being treated respectfully and that these experiences influence their willingness to participate in future activities or tasks. Again, neither of these studies focused on people who have ASD.

In their review of areas which require further investigation, Ward and Russell (2007) argued that because adults with ASD tend to receive care primarily from their parents, further research is required into grief and coping when a parent dies, as well as into subsequent transitions into alternative care arrangements. ASD is characterized in part by intense, stereotyped interests which may not serve a functional purpose. In some instances, these interests may be in objects or concepts which have violent associations (e.g., weapons, vehicle accidents, etc.). Consequently, adults who have ASD are frequently over-represented in hospitals with a corrections orientation (Scragg & Shah, 1994, Hare et al., 2000).

In their study, examining the population of adults who have ASD who commit criminal offenses, Långström, Grann, Ruchkin, Sjösted & Fazel (2008) found that those who were higher functioning were more likely to commit crimes. They speculated that this is because they had more opportunity to pursue activities without supervision or guidance. Interestingly, the demographics of those hospitalized due to commission of violent crimes tended to reflect the demographics consistent with those hospitalized due

to commission of violent crimes who do not have a diagnosis of ASD or any other IDD (Långström, Grann, Ruchkin, Sjösted & Fazel, 2008). The majority had diagnoses or symptoms of other psychiatric disorders (i.e., depressive symptoms, schizophrenia, substance use disorder or personality disorder) at the time of apprehension. Surprisingly, however, is that they tended to be older (i.e., 30 years old or older) (Långström, Grann, Ruchkin, Sjösted & Fazel, 2008). Life transitions have been related to the development of psychiatric symptomology among adolescents who have ASD, arising as they go through or after they have completed major life transitions, such as transitioning from elementary to high school or out of pediatric services to youth/young adult services (Ward & Russell, 2007). Further research would be required to determine whether or not the older age and/or psychopathology found among older adults who have ASD who commit crimes is associated with life transitions.

It has been suggested that the incidence of crime and stereotyped interests in violent objects may be due to difficulty understanding the perspectives of others. This is a characteristic common to those who have ASD (Ward & Russell, 2007) and has been identified as one of the challenges adolescents and adults who have ASD struggle with when pursuing dating (El-Ghoroury, 2012). Further research would be necessary to investigate the possibility that crimes are also associated with difficulty understanding the perspectives of others.

Those who have ASD are also at higher risk of unwanted, sexual contact (Brown, Peña & Rankin, 2016, Irvine, 2005). This is likely due to less knowledge about sex and sexuality, as well as due to a tendency among schools, community services and parents to fail to provide sex education to adolescents who have ASD (Irvine, 2005). In their study

examining the incidence of unwanted sexual contact among college students who have disabilities, students with ASD, as well as those with other disabilities were twice as likely to experience unwanted sexual contact than were those who did not have a disability. Females who had ASD only represented 27.8% of the participants who had ASD. However, they comprised 61.5% of all the participants who had disabilities (Brown, Peña & Rankin, 2016).

Developing and providing suitable care to adults who have ASD has been particularly challenging, due to a dearth of research on older adults who have ASD (i.e., 35 years old and older) (Piven & Rabins, 2011, El-Ghoroury, 2012). Parents of adults who have ASD report a constant struggle to find suitable and competent resources, from providers who understand ASD, as well as ASD as it relates to aging (El-Ghoroury, 2012). Parents also struggle with balancing the need to ensure safety with allowing their adult child to develop autonomy (Eh-Ghoroury, 2012).

Parent caregivers of adults who have ASD report uncertainty in their ability to meet their adult children's emotional and behavioural needs (Washington Barnes, 2014). Washington Barnes reported that they have been unable to pursue career progression, experienced financial setbacks and feelings of isolation arising from caring for their child (Washington Barnes, 2014, Marsack, 2015)

There are two models of residential care: (a) "aging in place" and (b) "in place progression". When one ages in place, one remains in the same residential setting, with community services provided to meet needs as they arise. In place progression refers to a system whereby one moves to more intensive assistance residential settings as one's needs increase (Courtenay, Jokinen & Strydom, 2010).

In their literature review examining care provision to aging adults with IDD who develop dementia, Courtenay, Jokinen and Strydom (2010), found that the majority of studies examined care provision in staffed settings and that families had limited family involvement. The majority of time care providers spent caring for individuals with IDD and dementia was spent assisting them with hygiene tasks. Care providers tended to have minimal training in caring for this population and the timing of training tended to arise after it was needed, rather than prior to delivering a service. This means that care providers must provide care as they learn to do so in the moment.

Quality care in group homes is defined as supports and services provided fall within the accepted professional practices, enhance quality of life and functioning of the care recipient, with an eye to provide a goodness of fit (i.e., care reflects the best possible fit with the individual's needs and interests) (Janicki, p. 773, 2011). Consistent with this, Heller, Miller and Factor (1998) found that when adults with IDD lived in settings which provided opportunities for stimulation and pursuit of varied interests, residents demonstrated better adaptive functioning. This study also found that when individuals lived in general nursing homes not specializing in IDD or hospital settings, their adaptive skills reflected greater decline over time than they did when living in community-oriented settings.

In a study examining the transitions individuals with Down Syndrome face across adulthood, Jokinen et al. (2012), transitions are less stressful when they have been carefully planned. When they are controlled by family members, typically parents, these transitions tend to have more positive results, whereas those which arise out of an immediate need (e.g., death of a parent, unforeseen change to the current living situation),

outcomes tend to be unpredictable. In these situations, control over transitions is generally relinquished from the family to an external source. Changes to staffing in care settings can also lead to poorer results. The authors identified a need for training of staff and care providers to facilitate successful transitions.

2.6 Social Policy

Following the situation and social assessment of phase 1 in the PPM (Green & Kreuter, 2005), the next phase is to conduct an epidemiological assessment. In this phase the health goals and problems are identified. Consistent with this, the step subsequent to the scoping review in the HEIA (Tyler et al., 2014) is to identify who the vulnerable populations in relation to the policy and program are and the related potential health impacts. To explore the policy and literature for this phase, a policy-as-discourse approach was used.

2.6.1 Policy-As-Discourse

The purpose of policy-as-discourse is to explore the various realities, which arise from social interactions and processes (Bacchi, 2000; Shaw, 2010; Wodak & Meyer, 2009). Policy-as-discourse researchers agree that power is at the crux of interpreting social phenomena in relation to policy (Bacchi, 2000; Shaw, 2010; Wodak & Meyer, 2009). Specifically, this line of research takes the position that analysis of how language is used in shaping, implementing, consuming, reporting problems and solving problems within social policy helps to highlight the power structures and ideologies which inform the policy and its interpretation (Shaw, 2010).

Research of this nature takes an interpretive approach to reflect the association between social and political contexts, with the assumption that the transactional nature of these contexts shapes the realities of participants of both contexts (Shaw, 2010).

According to Bacchi (2000), researchers analyzing policy within a discourse analysis framework (i.e., policy-as-discourse) have an agenda for change. Bacchi argues that policy-as-discourse researchers define discourse in ways which reflect their purposes, identifying the factors which hinder change (2000). In the case of this paper, the agenda for change is to identify how social policy influences the ability of aging adults with ASD and their caregivers to access to safe and competent care and services, with smooth transitions when modifications to care and service arrangements must be made.

From this perspective, policy-as-discourse researchers focus on how language and discourse are used to set parameters around what is said and what is acceptable (Bacchi, 2000; Shaw, 2010). In an effort to include the interests and positions of all stakeholders affected by a policy, policy-as-discourse researchers avoid positivist interpretations of social phenomena, preferring to focus on language and discourse (Shaw, 2010). Thus, multiple examples of discourse are considered to be relevant and valuable sources for analysis. Specifically, policy, the position taken by MCSS and existing research have been considered.

Policies themselves, how they are reported on by various stakeholders, as well as how people speak about them and the impact they have on their lives are all relevant sources of information to policy-as-discourse researchers (Bacchi, 2000; Shaw, 2010; Wodak & Meyer, 2009). Similarly, there are multiple ways of conducting analysis of discourse. For the purposes of health equity and policy/program evaluation in relation to it, three main approaches to data analysis can be considered. Specifically, these include: (a) conversation analysis (i.e., a basic analysis of what is said and by whom), (b) linguistic analysis (i.e., how language is organized to convey its intended meaning) and

(c) discourse within post-structuralism (i.e., how society and socio-cultural relationships influence how discourse is interpreted) (Shaw, 2010, 201).

Consideration of all three approaches is necessary, as in order to understand current policy as it pertains to the ethical, humane and suitable care and service provision of older adults with ASD is heavily based on a history of abuse, exclusion and maltreatment of this population. Ontario policy makers advocate for community-based care and service provision, citing that it provides a service delivery modality preferable to institution-based care and services. The section pertaining to transformation to a community-based service model, Developmental Services Ontario states that they... ‘are making it easier for people to access supports within their community and this is part of making a “stronger, more inclusive Ontario”’ (DSO, 2014b).

With the aging nature of the global population, international institutions, such as the World Health Organization (WHO) and the International Association for the Scientific Study of Intellectual Disabilities (IASSID) have made recommendations to prioritize policy development, capacity building and research into supporting adult individuals who have IDD as they age (Evenhuis, et. al., 2000; Hogg et. al., 2000; Thorpe, Davidson & Janicki, 2000).

The principles guiding the approach to initiatives related to aging among individuals with developmental disabilities are based on the principles adopted by the United Nations (UN) General Assembly in the *United Nations Principles for Older Persons* (resolution 46/91) (as cited in Hogg et. al., 2000). Resolution 46/91, which is intended to include all aging individuals, proposed five clusters regarding the status of aging people. These include: (a) independence, (b) participation, (c) care, (d) self-

fulfilment and (e) dignity. Implicit in the intention to include all people as they age is the inclusion of people with intellectual disabilities and neurodevelopmental disabilities (Hogg et. al., 2000).

2.6.2 Neurodevelopmental Disorders

Unfortunately, the bulk of the research conducted in response to the prioritization of aging among people who have IDD has focused on intellectual disabilities, excluding other neurodevelopmental disorders, such as ASD, which has a prevalence greater than does Downs Syndrome and cerebral palsy combined (Perkins & Berkman, 2012; Piven & Rabins, 2011). In fact, based on the definition of intellectual disability (i.e., impaired functioning in cognitive, functional and social abilities, as well as having an intelligence quotient, or IQ score, which falls at least two standard deviations below 70) (American Psychiatric Association [APA], 2013), not all individuals who have a neurodevelopmental disorder will have an intellectual disability. Only 31% of people who have ASD meet criteria for a diagnosis of intellectual disability (Autism Speaks, 2019).

After intellectual disability, which comprises the largest population of individuals with IDD, ASD is the second most prevalent such disorder in the United States of America (USA) (Newschaffer et al., 2007; as cited in Piven & Rabins, 2011). The prevalence of ASD among adults in the USA, is approximately 1% (Autism Speaks, 2019), which is consistent with the prevalence of the disorder in the United Kingdom (UK) (Brugha et al., 2011) and Canada (Geneva Centre for Autism, Retrieved on December 7, 2014). Prevalence estimates in the European Union are slightly higher, at 1.5% (Autism Europe & AGE Platform Europe, retrieved September 14, 2014). According to Brugha et al. (2011), there is no difference in incidence of ASD in

prevalence, regardless of age. In the province of Ontario, the prevalence of ASD is estimated to be closer to the 1.5% reported by Autism Europe and AGE Platform Europe (2014). Piven and Rabins (2011) estimate that the prevalence of ASD in adults 65 years old and over in the USA will reach approximately 700 000 by 2030 (p. 2152). Given comparable prevalence in various developed, Western countries, it is likely that this estimate can be generalized to the populations of these countries, including Canada.

In spite of the prevalence of IDD, the body of research in aging among adults with intellectual disabilities, primarily DS, is far more substantial than that related to any other IDD, with ASD research a distant second (Perkins & Berkman, 2012). Just as their counterparts who have intellectual disability only, people who have IDD are entitled to the same principles as the aging adults who do not have a disability under resolution 46/91 and therefore, their needs as they age warrant identification and consideration. Unfortunately, the majority of the research on ASD is focused on children and adolescents, with an emerging body of research examining young adults with ASD (Piven & Rabins, 2011). The paucity of research on aging specific to adults with ASD, though problematic, creates an opportunity for a number of exciting research possibilities.

In order to prepare to meet the needs of an increasing population of adults with IDD, the following areas have been suggested for research: (a) development of diagnostic criteria and instruments to assess the mental health needs of aging individuals according to their specific diagnosis (Anderson, Humphries, McDermott, Marks & Sisirak, 2013; Autism Europe & AGE Platform Europe, 2012; Henninger & Taylor, 2012; Piven & Rabins, 2011;), (b) development of assessment tools and diagnostic criteria to identify

aging adults who have IDD but have never been diagnosed, (Anderson et al., 2013; Piven & Rabins, 2011;); (c) cross-sectional studies of adults including their medical and psychiatric conditions and descriptions of the services and supports available to them, as well as those accessed, (Anderson et al., 2013; Geurts & Vissers, 2012; LoVullo & Matson, 2009; Mandell, 2013; Piven & Rabins, 2011;); (d) longitudinal life-span trajectories (Geurts & Vissers, 2012; Henninger & Taylor, 2012; Perkins & Berkman, 2012; Totsika, Felce, Kerr & Hastings, 2010) (e) effective interventions geared toward aging adults with ASD (Autism Europe & AGE Platform Europe, 2012; Henninger & Taylor, 2012; Piven & Rabins, 2011;); (f) determine if and how intervention provided to young people with ASD influence outcomes and aging process in adulthood (Henninger & Taylor, 2012), (g) develop new models of care which meet the needs of adults with ASD as they age (Anderson et al., 2013; Autism Europe & AGE Platform Europe, 2012; Henninger & Taylor, 2012; Perkins & Berkman, 2012; Piven & Rabins, 2011; Stoddart et al., 2013) and (h) training in support and research of this population (Autism Europe & AGE Platform Europe, 2012; Hogg, Lucchino, Wang & Janicki, 2000; Kats, Payne, Parlier & Piven, 2013; Moran, Rafil, Keller, Singh & Janicki, 2013; Nicolaidis, Kripke & Raymaker, 2014; Piven & Rabins, 2011; Thorpe, Davidson & Janicki, 2000; Shooshtari, Naghipur & Zhang, 2012).

2.7 Infrastructure of Inclusion

This section examines how the province of Ontario conceptualizes social inclusion for the purposes of the *The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* (2011), *S.O. 2008, c.14* (the Act) (Government of Ontario, 2008). To do this, a summary of the Act and its intent will be explored, drawing from the Act itself, supporting documentation published by the

province of Ontario and placing it within the context of recognized international standards set out by the WHO, the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) and the United Nations. In order to address the concept of social inclusion, the following three questions will be posed:

1. What is the definition of “social inclusion” as it relates to IDD currently used by the government of Ontario?
2. How does this definition align with the definition of “social inclusion” currently used in the literature and by stakeholders?
3. How is effective social inclusion measured?

The focus of this section is on the impact of the use of the concept of ‘social inclusion’ on those who have IDD. This chapter will not attempt to achieve a philosophical understanding of inclusion, nor will it attempt to debate the positive and negative aspects of social inclusion. The intent is to understand what the Province of Ontario envisions when it refers to ‘social inclusion’, how it arrived at this concept and how the effects of social inclusion are measured. In order to do so, it will briefly analyze: a) policy documents reflecting the progression from institutionalization to community-based, socially inclusive service and support provision, b) literature pertaining to social inclusion and c) existing research on social inclusion as it relates to people with IDD.

The *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, S.O. 2008, c. 14* (the Act) is provincial legislation which mandates how people with IDD access services and supports to meet various needs. The Act provides language, which communicates the province’s role and obligations in relation to people with ND/IDD (including ASD).

The Act defines a developmental disability as follows:

“[3. \(1\)](#) A person has a developmental disability for the purposes of this Act if the person has the prescribed significant limitations in cognitive functioning and adaptive functioning and those limitations,

- (a) originated before the person reached 18 years of age;
- (b) are likely to be life-long in nature; and
- (c) affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity. 2008, c. 14, s. 3 (1).” (Ministry of Community and Social Services, 2008).

Further, the Select Committee, comprised of elected provincial representatives, tasked with making recommendations for improving services and supports to people who have IDD to the province of Ontario noted that in many instances, people who have IDD’s which may not include cognitive functioning in the below average range, such as is common in ASD, are often denied services by DSO funded agencies (Albanese et al., 2014). The committee recommended that the requirement for impairment in cognitive functioning therefore be removed from the definition, in order to ensure access to services and supports required by those with IDD whose cognitive functioning is not impaired.

In response to this recommendation, the Ontario government declined to adopt this recommendation, citing section 3.1(c), which allows for clinical judgement of a regulated health professional when a service applicant does not meet criteria, as sufficient to account for these differences in cognitive functioning (Jaczek, 2014). However, funded agencies are often non-governmental organizations (NGO’s) with an established mandate to serve those who have cognitive delays. Consequently, those who

would otherwise meet the definition for eligibility according to the Act (2008) are not eligible for services through the agency funded by resources made available to facilitate the Act (2008).

The decision to focus on clinical decision-making as it relates to the individual with IDD is also problematic because it does not take into consideration the context of the individual. As many adults who have IDD live with their families, it is important to consider the capacity of the family to live with and meet the needs of the individual who has IDD. In their study examining caregiver distress, Weiss and Lunsky (2010) found that where aggressive behaviour and/or negative life events were present, caregivers were more likely to fall within range for distress or approaching crisis. The finding regarding negative life events is particularly concerning, as it reflects the reality that the IDD occurs within the context of a family, where family members fall ill and require care, loved ones die, accidents happen, etc.. In short, foreseeable unforeseen circumstances arise which will present stressors for families to navigate. When this occurs, it is not always possible to obtain the necessary clinical judgement in time to access the supports needed in order to accommodate the life circumstance.

The current values guiding service and support provision to people who have developmental disorders, in Ontario, reflect a neo-liberal orientation, arising out of: (a) a system in which abuses in institutions compromised the safety of the individuals (Williston, 1971) and (b) a need for cost reduction (Vermeulen et al, 1993). In response to an identified budget shortfall, the Ministry of Community and Social Services (MCSS) for the province of Ontario reframed its role as primary service provider to adults and

children who have IDD, as a shared responsibility with families, communities and other government funders (Vermeulen et al., 1993).

A common strategy in the liberal economy is to entrust care of marginalized individuals to the care of the family (Foucault, 1965). This approach represents an assumption that the family has the capacity to meet the needs of the individual, with little regard for the condition of the individual or the family's ability to meet those needs. In circumstances in which the family proves unable to meet the needs of the individual, they are substituted by a contrived family arrangement (Foucault, 1965). This is evident in the use of group homes and the province of Ontario's effort to increase and develop "...innovative housing options as a priority for people with a developmental disability, their families and the government." (Jaczek, 2014, p.4).

Interestingly, in addressing the select committee's recommendations around housing for people who have IDD, the province of Ontario refers to Ontario's poverty reduction strategy. In doing so, there seems to be an implicit recognition that those who have IDD are quite likely to experience poverty. However, there is no accommodation or mention of strategies to address the factors which lead to poverty among those with IDD within the Act, nor within the government's response to the select committee (Jaczek, 2014).

Constraining social forces related to the service, supports and social inclusion of individuals who have IDD may include: behavioural challenges (e.g., aggression, rigid interests, inflexible adherence to routines, etc.), stigma, willingness and ability to participate in socially inclusive settings. Additional constraints, external to the individual who has IDD may include the willingness and competence to provide care and support

among informal caregivers and the community. The degree to which services and supports are necessary may vary according to the individual and the context.

The range of variables involved in analyzing the implementation of social inclusion in Ontario is complex. Analyzing government documents and the attitudes reflected therein, over time, may allow the positioning of the concept of social inclusion as currently experienced by individuals who have IDD and their families within the context of government intent. This in turn may assist in understanding how the government of Ontario defines social inclusion in policy, as well as in practice.

2.7.1 Administrative & Policy Assessment

The Ottawa Charter for Health Promotion (the Ottawa Charter) conceives of health as a construct reflecting not only physical abilities and resources but also the control one has over one's well-being (WHO, 1986). The Ministry of Community and Social Services (MCSS) does not directly provide services or supports. It provides funding and develops policy, which informs services and support. Individual service agencies receive funding based on the type of service/support provided (Dubé, 2016). These service agencies, emerged from grassroots, parent-run efforts in response to concerns about institutional care, and typically reflect a narrow response to local community needs (Dubé, 2016). Consequently, there is limited long-term strategic planning with inconsistent priorities across the province.

The organizational flow of developmental services as outlined in Dubé (2016) is presented in Figure 3. The Ministry of Community and Social Services (MCSS) provides the mandate and criteria all services must achieve in order to qualify for funding of developmental services. The five regional Ministry offices provide direction and administer the funding in their assigned regions, which are broken into nine

developmental service offices. These offices inform their decision making, program and service delivery based on input by the community planning tables, which in turn are informed by the needs of the service agencies. These needs reflect the needs of the individuals within the local communities who meet the eligibility criteria, as outlined in the Services and Supports to Promote the Inclusion of Persons with Developmental Disabilities Act (2008).

Individuals are assessed for eligibility for funding and programs by the Developmental Services Offices. Funding is administered through the “Passport offices” or “Transfer Payment Agencies” (i.e., the offices tasked with administering funding and/or services), whereby individuals receive funding in the form of services offered by eligible service agencies. It is important to note that not all the service agencies are eligible to receive Passport funding.

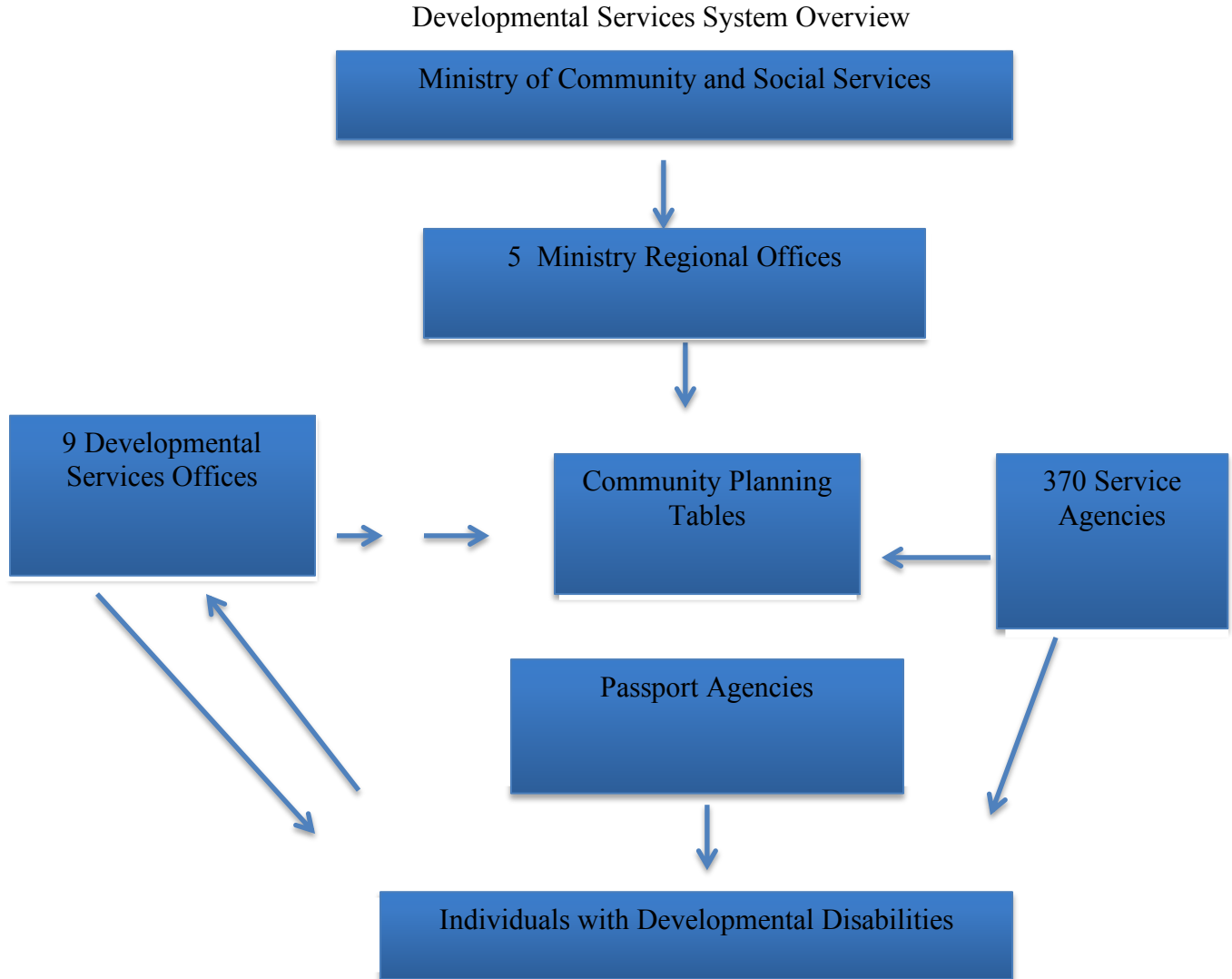


Figure 5. Overview of Developmental Services Relationships (Copied from Dubé, 2016.) Legend: Solid arrow indicates direct relationship (application, funding, oversight or service provision); broken indicates possible relationship depending on issue or relationship.

It is necessary to position the current conditions for older Adults with ASD within a historical context in order to understand how Ontario, as well as much of the Western world has come to embrace de-institutionalization. For the purposes of review, the historical review will often refer to ND/IDD, as ASD itself was not identified until 1943 (Kanner, 1971, as cited by Henninger & Taylor, 2014), It falls within the overarching

category of ND/IDD and therefore ought to be included in the historical consideration of ND/IDD.

2.7.2 History of Ontario's Social Inclusion

The history of social inclusion of individuals who have IDD in Ontario is complex. It seems to have been first recommended by Williston (1971), with institutions for people with IDD being transferred from the Ministry of Health to MCSS in 1974 (Ministry of Community & Social Services, 1987). In 1987, the stated long-term goal was "...to have the community assume ongoing responsibility for service delivery and for the Ministry to divest its direct services." This report also states "individuals know best what their needs are and they must be involved in the planning and choosing the services they require." (p.3). The tone of this document and the recommendations made therein reflect an attitude of respect and concern for the welfare of the individual with IDD, as well as that of their families. This approach to serving people with IDD established an opportunity to implement de-institutionalized mechanisms of governmentality (Foucault, 1978), relying heavily on normalization (Burrell & Trip, 2011) and societal acceptance of the related social roles (Wolfensberger, 2011).

In the province of Ontario, meeting the needs of people who have IDD has been considered a societal moral and ethical obligation since the 1970's (Williston, 1971). In an investigation of abuses and deaths of people with IDD who were receiving institutionalized care in Ontario, Williston stated that access to publicly provided services should not be means tested. He reflected on the social and financial strain the presence of a person with IDD would have on a family, even accounting for the impacts on any siblings in the home whose access to parental support could be negatively impacted.

Based on his review of a number of cases documenting reported abuse, deaths, suicides and injuries to institutionalized patients diagnosed with various IDD's, it is clear that Williston preferred a transition to care based in local community settings to large institutional care. His report included arguments for community-oriented services to facilitate easier access for researchers, professionals and trainees in the relevant professions, while also keeping people with IDD visible in the community. Williston (1971) also demonstrated concern for those families who opted not to pursue institutional care. Specifically, he was supportive of the potential for decreasing the likelihood of stigma for those who opted not to pursue institutional care by increasing visibility of people who have IDD in the community by demonstrating the value that people who have IDD can add to a community through provision of adequate and competent supports.

This was an important consideration, as only 31 years prior to Williston's (1971) report, the *American Journal of Psychiatry* published an article advocating for the "mercy killing" of such individuals in 1942 (Kennedy, as cited by Donovan & Zucker, 2016). Prior to World War II, commonly accepted terms in the field of psychiatry included "defectives", "imbeciles", "morons", "feble-minded", etc. in reference to people who had IDD. The pursuit of eugenics (i.e., the forced sterilization and euthanasia) among those who had IDD was common (Springer, 2012).

The stigma extended to the families of people who had IDD. Specifically, parents were frequently blamed for their children's conditions. For instance, until the 1980's, it was common for experts in the field to characterize parents of children who have ASD as "cold, rejecting parents", some going so far as to equate their parenting styles to Nazi prison guards (Bettelheim, 1967, cited in Donovan & Zucker, 2016). Although an in-depth

exploration of the history of eugenics and stigma of people with ASD in Canada is beyond the scope of this paper, it is necessary to acknowledge the degree to which it occurred in order to provide context for Williston's concerns regarding stigma.

Williston also reflected on the challenges of reintegrating someone who had spent the majority of his/her life in an institution, into the community, demonstrating concern for ensuring that people with IDD and their families were perceived positively by society and service providers. He speculated that removal of numerous people with IDD from society through institutionalization increased the likelihood that those who remained in the community would be stigmatized. He reflected on the unrealistic expectation of institutions assisting their residents to develop functional life skills (e.g., budgeting, maintaining a household etc.), when paying them unrealistic wages (i.e., ranging from four to eight cents an hour for labour performed in the institution). His argument in this regard was that residents would develop unrealistic and unsustainable understandings of the value of money, with no meaningful practice budgeting and using it as would be expected in the community.

Although he did advocate for transition of care to the community, it is important to note that Williston also advocated for maintaining institutions in order to serve a number of purposes. Among those were: to provide overnight respite care to families tasked with caring for individuals who have transitioned to the community, to provide training facilities for family care providers learning to care for their family member who has a IDD and for research purposes. Williston recommended developing plans to ensure that as individuals with IDD became adults, they would be able to transition from the family home, citing burden on the family and accounting for the trauma associated with

the eventual death of parents by ensuring the adult child was established in his/her adult home before this was likely to happen, thereby minimizing the number of major life changes occurring at once. These recommendations, had they been implemented, would have been beneficial in addressing current pressures as they relate to inadequate respite care and emergency care services when informal caregivers or existing living arrangements become impossible.

Although they focused on the transition to community-based care, subsequent documents by the province of Ontario did not reflect the same focus on functionality for the client and family. For instance a document titled *Chronology of the M[ental].R[etardation]. Five Year Plan* (Harper & Baker, 1986) documents a list of events from 1982 to 1983 reflecting meetings which took place with and about families protesting the closure of smaller facilities and subsequent moves of their family members to larger institutions further away. According to the document, this period was characterized by anxiety arising from a “leak” of the plan to transition residents of smaller facilities to the community or to larger facilities farther away.

A subsequent review of the *M.R. Five Year Plan* reflected that the five-year plan had included closure of six smaller facilities and reducing the size of another facility by a quarter (Harper & Baker, 1986). According to this report, the province had functioned on the assumption that the lower functioning residents of facilities would move to larger facilities outside of the community while the higher functioning individuals would move into the community. The report reflected on a number of errors made, with a recommendation that planning in the provision of services and changes therein be

“...done in response to the needs of the clients to be served and not on the basis of any savings expected from closures or phase-down of facilities...” (p.4).

The report also reflected on the overall goodwill of community-based agencies to assist with the transition to community-based services but did note that some agencies chose not to be involved. According to the report, no preliminary efforts to determine whether or not the transition would be received with goodwill and cooperation had been conducted. Consequently, in some cases the volume of institution residents transferred to community-based settings exceeded the capacity of the agencies in the communities, impeding adequate service delivery.

The gaps in services arose from issues such as lack of: awareness of clients’ medical needs, trained staff, crisis support teams, psychological or behavioural professions, formal procedures to cope with substance abuse or “dating”. The latter mention of dating reflects the Ministry’s failure to consider people with IDD as autonomous adults with the urges and needs of any other adult. This report also reflected on the impact of “rumours” on staff and families, citing a need for counseling for staff and need to establish trust between families and the Ministry.

The failure to consider factors such as impact on staff and families, the possibility of engaging in risky or sexual behaviour by the people with IDD, etc., reflects an assumption of moral obligation to transition to inclusive, community-based living for people with IDD without considering the individual person as a whole. It also fails to consider the method by which the transition is achieved. Failure to account for the various diversions, interests and conduct of the individuals reflects an implicit assumption of moral uniformity by the state on the family caregivers and the individuals

receiving care (Foucault, 1965). In this case, the moral uniformity is assumed to be something inconsistent with the expectations for others (i.e., interest in sexuality will be present but the majority will conduct themselves according to implicit moral and cultural standards). Exclusion of consideration for individuals' sexuality, ability to understand unspoken social rules or implied moral and cultural standards reflects a failure to consider individuals who have IDD as whole persons. In order for inclusion to be effective, the target population must be considered within the same context as any other participant in the community in which s/he is meant to be included.

More recently, the Act (2008) appears to provide opportunity for pursuit of interests such as individual sexuality by referencing provision of choice and autonomy to the individual with IDD. However, whether or not funding is made available to an individual with IDD who is seeking support to pursue interests which the state or the funded service agency does not consider to fall within the purview of the Act, is unclear. For instance, if a client were to seek funding in order to pay the admission to a rave, it is unclear whether or not this would be funded. A rave may very well be a socially inclusive setting relevant to an individual's age and stage in life, yet the risks and behaviours associated with raves may be problematic for a funded agency to condone.

2.7.3 Inclusion In Ontario Currently

For about four decades, the province of Ontario has appeared to follow a progression to an increasingly neoliberal style of service delivery to people who have IDD. This is demonstrated through problematization and reform of individual and institutional conduct to render it more efficient and economically competitive, through establishing enterprise and autonomy (Dean, 2010)]. The focus has been on promoting autonomy and independence through participation in the community.

The last institutional care facility was closed in 2009 (Ministry of Community and Social Services, 2012). Developmental Services Ontario (DSO) was launched in late 2011 with the intent of providing care and resources to individuals with IDD (including ASD), as well as to their caregivers. A significant number of these complaints arose from the primary caregivers of individuals who have ASD (Dubé, 2016, Marin, 2014a).

Policies relating to care and services provided to these individuals by virtue of eligibility on the basis of a diagnosis of an IDD, are implemented through Developmental Services Ontario (DSO). Consequently, consideration of service and support provision to adults who have ASD must be considered in the context of the service and supports available to people who have IDD. By November 2012, the Ombudsman of Ontario, André Marin, had launched an investigation into the provision of care and services to people with IDD due to a high volume of complaints from caregivers (Ontario Ombudsman Press Release, 2012). Subsequently, the Ombudsman's office reported over 1 100 complaints in relation to the investigation (Marin, 2014a).

In 1993, the focus of a service standards and costing project was on the discrepancy between the per diem cost of care across community-based group homes (Vermeulen, et al., 1993). The goal of this report was to identify the source of the discrepancy and to align practices across group homes so that they all reflected the lowest per diem. According to this report, in 1990-1991, the funding allocation of a sample of 11 residences for adults and children were analyzed, reflecting that 78-82% of budgets accounted for direct care staffing, 3-14% of budgets accounted for shelter/client needs and 8-15% of budgets accounted for central administration. The range of per diems, not accounting for inflation, were \$70.08 to \$192.85, with an average of \$167.55 (p.3)

(CND). According to the Bank of Canada's inflation calculator, \$167.55 would convert to about \$269.25 (CND) (2017).

During the 1990's, families of adults with IDD formed the Independent Funding Coalition of Ontario (IFCO) out of the recognition that many of the services and supports available to them were not suited to their needs. Consistent with the value of choice and individualization articulated in the Act (2008), the function of IFCO was to promote self-determination and inclusion through purchasing the services and supports which reflected individuals' priorities rather than attempting to fit into a "one size fits all" model (Hasbury, IDD). The IFCO, in collaboration with MCSS established Independent Facilitation Demonstration Project (IFDP) in seven regions of the Province of Ontario. The IFDP's collaborated with communities in six regions to identify ways to support adults with IDD using the IFCO model (Hasbury, IDD). One project has been running since the 1990's, citing its success as due to: "strong, creative, local working relationships..." (Hasbury, IDD, p.A-14). In another case, the project was terminated because it was unable to generate the support necessary. The IFDP goal was to engage 1100 new people in independent facilitation services by March 31, 2018 (Hasbury, IDD). According to MCSS estimates, there are approximately 42 000 people eligible for developmental services in the Province of Ontario.

Responding to the concerns identified in the Ombudsman's Annual Report (Marin, 2014a), the Developmental Services division of MCSS invested in the Ontario Independent Facilitation Network (OIFN), a network of individuals with IDD, their family members, caregivers and community stakeholders interested in assisting in the

facilitation of independent living. Passport funding is used in this model to fund housing alternatives to groups homes, congregational housing and living with family.

In collaboration with seven regional independent facilitation organizations OIFN has developed independent facilitation demonstration projects (IFDP). The IFDP's have three goals: 1) increase the number of people who are meeting their needs through independent facilitation, 2) evaluate outcomes and impacts of independent facilitation and 3) increase sustainable models of independent facilitation (Hasbury, IDD).

Seven themes were identified by people with IDD and their family members/caregivers (Hasbury, IDD). These themes included: home, relationships, choice and control, purpose, work, valued sense of self and money. The Act (2008), refers to Person Directed Planning (PDIS) (i.e., a service that assists persons with IDD 'in identifying their life vision and goals and finding and using services and supports to meet their identified goals with the help of their families or significant others of their choice' (part 1, section 4.2).

Increasingly, MCSS has been seeking to fund what they refer to as "Person Directed Individualized Support (PDIS)", whereby the individual with IDD and his/her "natural support" lead the planning process, rather than following a process developed by a service provider (Martin, Grandia, Ouellette-Kuntz & Cobigo, 2016). Where no "natural support" exists, people with IDD have the option of spending up to \$2500 of their Passport funding to employ a "person directed planner" (Hasbury, IDD, p.A-15). Similar approaches are referred to in the literature as Person Centred Planning (PCP) (i.e., the individual provides input about how s/he wishes to live, his/her priorities and what is important to him/her. The support team then works with the individual and/or his/her

caregivers in order to develop a model of care and service consistent with those priorities and interests) (Hasbury, IDD).

However, Martin, Grandia, Ouellette-Kuntz and Cobigo (2016) suggest that PCP models are lead by the service delivery agent. The distinction between PDIS and PCP would be that the person assisting the individual who has IDD to lead the process would be a family member, friend or other person designated by the person with the IDD in the former. In PCP, the person assisting the leadership process is an employee of the service agency. However, it is unclear whether or not this distinction is consistently applied across the research and service communities. Given the option exists to use public funding to purchase services of a planner, the distinction may not even be relevant, since the focus of both PDIS and PCP are to allow the person with IDD and/or their families to determine their goals and priorities. In their respective reviews of the research on PCP, Mansell and Beadle-Brown (2004) and Ratti, Hassiotis, Crabtree, Deb, Gallagher and Unwin (2016) reported that one of the challenges in reviewing this literature was that different researchers used different terms to describe similar processes and similar terms to describe vastly different processes.

In their participatory action research study funded by MCSS, Martin, Grandia, Ouellette-Kuntz and Cobigo's (2016) aimed to identify components of successful PDIS processes within service agencies located in the Province of Ontario. Participating agencies were asked to identify cases where PDIS had been successful. Participants in the study reported that PDIS was empowering to the individual with IDD, with the effect of goal setting being promoted and facilitated. Elements which predicted success, as identified by participants included "the right people, the right attitudes and the right

actions” (p. 561). The actions referred to included: capacity building, evaluation of actions and responsiveness to the changing needs and interests of the individual were also identified as important to the effectiveness of the PDIS process. No information was provided about the goals of individuals with IDD, nor was any information provided about how outcomes of those goals were measured. No information was provided in this study about the intellectual functioning of the people with IDD or the degree of impairment that they experienced. It is also unknown whether or not any of the participants had ASD.

Similarly, in a study conducted in the Province of Ontario, Gosse, Griffiths, Owen and Feldman (2017) compared outcomes of adults with IDD living in multi-bed residential settings who were assigned to either PDIS groups or traditional planning (i.e., support staff organize meetings to determine individuals’ goals and the individual and/or his/her family members may or may not be included but the process is primarily staff driven). Participants were described as having mild to moderate intellectual deficits. No information about their diagnoses or whether or not they had ASD was provided.

In the PDIS model, a planning facilitator assisted the individual with IDD to organize meetings. People with IDD who participated in the PDIS group tended to report more empowerment, had larger informal support networks and those in the PDIS network had designated tasks with accountability measures built in. When those from the traditional model were put into PDIS models, their support networks also increased (Gosse, Griffiths, Owen & Feldman, 2017).

The PDIS model does require more time for meetings. As service agency staff attend these meetings, more funds used to attend these meetings results in less money to

fund direct services and supports. To mitigate the financial impact of the increased time demands required for an effective PDIS, Gosse, Griffiths, Owen and Feldman (2017) suggested that unpaid members of an individual's support network (e.g., family members, friends, community members) could participate in tasks/activities in the community in place of paid support workers to prevent increased costs to the service agency. This study only examined the access to supports available in the traditional and PDIS groups. It did not examine the satisfaction with the two groups among the individuals with IDD nor their informal caregivers/supports. No clear description was provided of goals or outcome measures nor of how the groups compared in these regards.

In their focus group study of 120 participants who have ASD, their service providers and family members, Miller, Matthew, Nonnemacher and Shea (2018) examined experiences using funded PCP models of service delivery among adults who have ASD in the state of Pennsylvania. Consistent with Medicaid requirements that all funded programming for people with developmental disabilities reflect a PCP model of service delivery, including long-term care plans as alternatives to institutionalization (Centers for Medicare and Medicaid Services, 2015), the state of Pennsylvania established a state-level Bureau of Autism Services, creating Medicaid-funded programs specific to people with ASD. Ensuring that focus groups of adults with ASD were kept private from those of their family members and caregivers, Miller, Matthew, Nonnemacher and Shea (2018) conducted focus groups to determine the effects of PCP-modeled service plans on service recipients. Among their findings, adults with ASD identified as benefits associated with participating in the PCP process included: a) an opportunity to recommend training opportunities for direct service staff, citing concerns

that they tended to have expertise working with children with disabilities but not with adults and b) community engagement opportunities arising from their involvement in the PCP process. This article offered an important contribution to the PCP research in that it identified the priorities of adults with ASD based on their experiences of the services they used, as well as the experiences of their family members and service providers. However, no outcome data was provided.

In the academic research community, there is inconsistency with regard to the merits of PCP models of service delivery. In their critical review of PCP, Mansell and Beadle-Brown (2004) identified that there is very little research demonstrating the effectiveness of PCP compared to other approaches to planning service and care of people with IDD. Their primary criticisms of PCP models include: a) where PCP models are prioritized, a minority services users actually access a PCP process, b) when PCP models are accessed, PCP goals tend to be recorded but not necessarily implemented (i.e., what the authors referred to as an “implementation gap”), c) clients and their independent representatives (i.e., advocates for their interests who are not affiliated with the funder or service providers) are not included in the process, d) long-term goals are often excluded and e) quality assurance and goal attainment criteria are often omitted or are not written in a way which is measurable.

Finally, Mansell and Beadle-Brown (2004) noted that funding constraints were a recurring barrier to implementation. They suggested that it is unlikely that planning models will make any difference to the individual’s life if the funds are not available to implement the plan. This study also examined people with IDD. There was no mention as to whether or not any of the studies examined people with ASD.

In their systematic review of PCP, Ratti, Hassiotis, Crabtree, Deb, Gallagher and Unwin (2016), selected 16 articles from a total of 5833 to review on the basis that they were the only ones which provided outcome data. The focus of the studies included: a) training individuals with IDD, their families/caregivers and staff in the PCP process, b) retrospective reviews of documents to determine effectiveness and c) a quality of PCP documents and outcome comparison. None of the studies reviewed were randomized control trials and only six provided comparisons with other models.

Consistent with Mansell and Beadle-Brown's (2016) finding that PCP plans lacked measurable outcomes, Ratti et al. (2016), reported a lack of clear descriptions of the interventions and their components. A further criticism was that only one study provided data on adherence to the PCP plan. Although Ratti et al., (2016) reported inconclusive findings, they did suggest that the PCP process increased the ability of those supporting individuals with IDD to identify areas of need in a person's health care and living circumstances. The studies examined considered people with IDD. The authors did not mention whether or not any of the studies considered people with ASD.

In 2012, the cost to provide care in a group home setting was approximately \$400 (CND) per day (Monsebraaten, 2012), which converts to \$423.76 in 2017 (Bank of Canada, 2017). It is important to note that although MCSS cited cost reduction as a focus for this document, it also included within the appendix (Appendix III) recognition of the importance of ensuring quality assurance measures, direct service intervention, the intensity of which is based on individual need and a balance between clinical intervention, support, supervision and monitoring on an ongoing basis (1993). Costs accounted for included: direct personnel/service staff, direct management/supervision,

non-personnel operating (i.e., supplies), transportation, facility and indirect management (e.g., administrative, education and development, salary, etc.). Referring to a package of material developed by the state of Ohio, which had gone through similar restructuring of IDD services, responding to budget cuts, it is noted that "...a distinction between 'Cadillac' and 'Chevrolet' client care should not exist."

In August 2016, the office of the Ombudsman for the province of Ontario released a report in which it stated that the move toward deinstitutionalization of people who have developmental disorders has resulted in "institutionalization by default", whereby due to lack of adequate housing and care, individuals find themselves hospitalized, placed inappropriately in long-term care facilities, imprisoned, etc. (Dubé, 2016, 50). Among the complaints, caregivers, primarily family members, report that the bureaucracy involved in accessing services and supports prevents addressing and resolving situations where health and safety are at risk (Dubé, 2016, Marin, 2014). In the worst cases, individuals with IDD are being arrested or hospitalized in psychiatric wards for lack of other safe alternatives (Dubé, 2016, Marin, 2014a, Marin, 2014b).

It is important to note that the focus of these complaints and subsequent investigations has been mostly on young people transitioning into adulthood. Older adults with IDD, many of whom have transitioned from institutional settings into community and/or family-based care, access the same services and supports as those transitioning into adulthood. However, by virtue of their age, they are less likely to have family caregivers to advocate for them simply because their parents are more likely to have age-related diminished capacity, require care themselves or they may be dead.

The needs of older adults who have IDD can often be greater than those of young adults with IDD, simply because in addition to the needs arising as a result of their disorder, they also have needs arising from the physical and neurological effects of aging (Campbell & Adel Herge, 2000; Gilbert, Lankshear & Petersen, 2008; Grant, 2007; National Advisory Council on Aging, 2004; Salvatori, Tremblay & Tryssenaar, 2003). Older adults with IDD, many of whom have transitioned from institutional settings into community and/or family based care, access the same services and supports as those transitioning into adulthood. Because their needs can often be greater than those of young adults with IDD, this is not suitable.

2.7.4 Self-Determination & Subjective Well-Being

Consistent with the challenges associated with normalization (Wolfensberger, 2011), Ontario's social inclusion efforts seem to have confused the concept of autonomy with the concept of independence. Throughout the Act (2008) and explanations thereof (Ministry of Community and Social Services, 2013; Ministry of Community and Social Services, 2009), reference is made to independence, not autonomy. The language throughout also suggests the emphasis of the values guiding the Act are on providing the individual with "choice" and "flexibility". These concepts are consistent with autonomy, not independence.

Autonomy refers to an individual's ability to live and act according to his/her free choices and values (Deci & Ryan, 2008). Independence, on the other hand, refers to freedom from the control or influence of others (Oxford Dictionaries, 2016). Whereas it is possible to live autonomously while funded by an external agency, it is not possible to live independently when dependent upon access to the supports and services required to facilitate independence funded by an external agency. By virtue of the existence of

legislation that provides services and supports to facilitate one's functioning and legislates where and how those services and supports will be funded and delivered, independence is not attainable.

A degree of autonomy, on the other hand, may be achievable. However, to do so depends upon the caregivers' ability and motivation to facilitate or allow that degree of autonomy to be achieved. When receiving care, services or supports, it is also possible to live autonomously but one's independence is influenced by the amount of support delivered by providers of care, services and supports. It may be that accessing support outside of the family is beneficial to development of autonomy.

In their study examining the emotional well-being and self-concept of adolescents who had IDD, Majorano, Brondino, Morelli and Maes (2017) demonstrated that although these adolescents had lower levels of self-concept and perceived quality of relationship with their parents and teachers than did their typically developing peers, emotional autonomy was more closely related to self-concept. However, parent-child relationships had less of an influence over self-concept and loneliness in teenagers with IDD than did teacher-student relationships.

Although the study conducted by Majorano et al. (2017) focused on adolescents, the findings suggest that developing relationships with others in the community may have protective factors to the self-concept and experience of loneliness experienced by people who have IDD. Consistent with Majorano et al.'s (2017) findings, Saldaña, Álvarez, Lobatón, Moreno and Rojano (2009) demonstrated that when adults with ASD had a broader support network, beyond family caregivers, they tended to report better perceived QoFL and achieved better QoFL scores on objective measures. If social inclusion of

people who have IDD is to be effective, it must address the barriers that exist across dimensions in order to facilitate full participation, with a range of people, in society.

Self-determination theory (SDT) posits that humans have three universal needs: 1) relatedness (i.e., a need and desire for interaction, connection with and to care for others), 2) competence (i.e., a need to control outcome and experience mastery over a skill/knowledge) and 3) autonomy (i.e., a drive to be the causal agent in achieving a life which is in harmony with one's sense of self) (Deci & Ryan, 2008; Deci & Ryan, 2000). It is important to note that Vansteenkiste, Lens and Deci (2006) specify that self-determination and autonomy do not equate or necessitate independence from others. The emphasis is on the individual's ability to live according to one's values and to pursue one's interests, not on freedom from control by external forces.

In its efforts to create a climate and mentality that affords autonomy and inclusion to people with developmental disorders, the Province of Ontario has inadvertently marginalized the caregivers tasked with delivering and coordinating the care necessary to make social inclusion a successful movement. Legislating concern for the health, happiness and wellbeing of citizens by modern government requires recasting the knowledge and technical means appropriate to the new governmentality (Dean, 2010). In the case of caring for adults with IDD, this can be seen in reports by parental caregivers who frequently cite loss of a sense of self (Marsack, 2016), physical burden (Marsack, 2016), financial burden (Altiere & von Kluge, 2009; Montes & Halterman, 2008), social exclusion (Siklos & Kerns, 2006; Smith et al, 2012), vocational limitations (Marsack, 2016) and time burden (Krauss, Seltzer, & Jacobson, 2005).

SDT has been criticized because the evidence used to support autonomy as a basic need is lacking. Specifically, Cummins (2015) argued that whereas the evidence supporting competence and relatedness are directly related to these concepts, the evidence supporting autonomy refers to the motivating properties of “freedom of action” being greater than those associated with being controlled. However, this observation is not made in the context of basic needs (deCharms, 1968, as cited in Cummins, 2015).

Cummins (2015) challenged the assumption that competence, relatedness and autonomy were basic needs, as the evidence to support them relies on the inter-relatedness of a combination of behaviours which must be present simultaneously. For instance, autonomy in the absence of competence will not serve a person in achieving his/her goals. Likewise, low competence creates a greater need for relatedness, leading to a diminished fulfillment of a need for autonomy. Finally, Cummins (2015) challenged the definition of autonomy as a basic need because the evidence used to define and demonstrate its relevance to SDT lacks coherence and conflicts with the concept of relatedness.

Although the shift to social inclusion has the potential to allow for the promotion of greater autonomy of the individual who has IDD, it frequently relies heavily on family, primarily parental, caregivers. The role of caregiver and case coordinator has been shifted to the family. Duties which previously had been carried out by employees paid by institutions, with specialized training sought out on the initiative of the employee are now completed by family members who may only be aware of, let alone interested in, the care of people with a particular IDD out of necessity. For parental caregivers of adults who have IDD, this increase in duties comes at a time when, by virtue of their own age, they

themselves are developing increased health needs, frequently with diminishing financial resources due to retirement from income earning employment.

2.7.5 Implications for Individuals

In their case study involving participants who had lived in a variety of institutional settings before placement in shared assisted living apartment with two other residents, Treece, Gregory, Ayres and Mendis (1999) found that an absence of autonomy across choice of: residence, housemates, personal finances and daily routine were the primary barriers to life satisfaction for participants. Although more likely to enjoy higher rates of employment when living with familial caregivers, marriage and independently living, higher functioning adults who have IDD tend to have higher rates of unemployment, comorbid health and mental health disorders than did those living with familial caregivers (Gotham, Marvin, Lounds Taylor, Warren, Anderson, Law, Law & Lipkin, 2015). This is surprising because they achieved a greater degree of independence, suggesting that they have fewer developmental barriers across domains of inclusion. However, as such, they are also less likely to qualify for the shelter of direct care.

According to Gotham et al. (2015), when people with IDD achieve independence, they fare more poorly than do those who are lower functioning than they are because they have access to fewer supports. This has problematic implications for the Act, which strives to facilitate independence, as it suggests that the goal of such a policy would be to strive for a variable which is correlated with lower life satisfaction. It is particularly problematic if intelligence scores fall in the low average or higher range of functioning, as these individuals are less likely to qualify for DSO supports.

Those who were employed reported high rates of workplace discrimination, suggesting that integration into the vocational setting had not been achieved (Gotham et

al., 2015). Social policies act primarily on the population (Foucault, 2008). That adults who have IDD are being discriminated against in the workplace suggests that the population which requires intervention may not be the people who have IDD but their typically developing colleagues.

Among the services and supports offered by agencies funded through DSO are job preparation services (Parents Supporting Adults on the Spectrum [PSAS], personal communication, 2017). However, these services focus primarily on preparing resumés and cover letters, as well as developing interview skills. They do not tend to provide assistance locating employers who are willing to hire people who have IDD (PSAS, personal communication, 2017).

This research raises a social-moral issue. In creating a system whereby clinicians are gatekeepers to services and are tasked with defining what services and supports exist, rationing those resources, society has transposed its responsibility for vulnerable members of the population (Pellegrino, 1986). It is not enough for society to adopt an inclusive policy if members of society, such as employers, are not prepared or competent to include the targets of inclusion. The requirement of a clinician to ration finite services and supports creates an inequality in freedom and power (Pellegrino, 1986). A more inclusive approach to addressing barriers to employment and the over-representation of people with IDD living in poverty might be to target potential employers for service and support delivery.

Potential employers are in a position of power to include individuals who have IDD but doing so may come at a cost to them. Rather than solely relying on the clinician-client relationship, a service which assists employers to develop strategies to meet the

needs of employees with IDD, could place some of the responsibility for rationing resources on a broader range of members of society. The same could be true of community recreation opportunities, whereby supports can be offered to the general recreation sites to facilitate more inclusive services. In doing so, the location or site of inclusion is supported to serve those seeking to participate, relieving the individual person of dependence on access to funding. If this were done, community participation of individual people would not be constrained by waitlists for access to the necessary funding.

The goal of social inclusion is rooted in mediation of the health inequities arising from barriers across economic, social, political and cultural dimensions (WHO, 2010). Thus, a consideration of the effects of social inclusion on people who have IDD must consider their health status. In their meta-analytic review of the research on adults who have ASD, Nicolaidis, Kripke and Raymaker (2014) found that adults with ASD frequently experience a higher rate of accidental death than does the typical population. This tends to be associated with seizure disorders, drowning, suffocation and other accidents. Adults who have IDD also have a higher rate of gastrointestinal disorders and challenges related to feeding and nutrition. Although some of these challenges are related to food sensitivities and preferences, they also had less access to nutritious diets. Additionally, they had a higher rate of obesity and metabolic syndrome. They tended to have a higher rate of mental illness, sleep disturbances and reported higher rates of victimization for violence and abuse (Nicolaidis, Kripke & Raymaker, 2014).

People who have IDD tend to have less effective health care interactions with their health care providers (Nicolaidis, Kripke & Raymaker, 2014; Lewis, Lewis, Leake,

King & Lindemann, 2002). They have difficulty accessing preventive services, such as screenings and vaccinations (Lewis et al., 2002). However, they are more likely to receive pharmacological interventions than the typical population (Nicolaidis, Kripke & Raymaker, 2014), often receiving prescriptions for psychotropic drugs, often two or more such drugs simultaneously, without receiving a diagnosis for a related condition (Lewis et al., 2002).

Although poorer health status is concerning, it must be considered within the context of the individual and his/her priorities. In their study examining QofL, Hong et al. (2016) found that adults with ASD tended to rank good subjective QofL as it related to health, mental health, social and environmental domains. Their subjective experience of QofL was more strongly influenced by their experience of stress and bullying in the workplace (Hong et al., 2016).

The shift from corporal punishment to incarceration resulted in disciplining the soul, rather than the body (Foucault, 1979). As demonstrated by the health challenges experienced by both individuals who have IDD and their caregivers, the shift in serving and supporting people who have IDD from institutionalized settings to community-based, socially inclusive settings appears to have come at the expense of harming the body, with the intent of enriching the soul. Good interventions act on the population, with the objective of everybody having equal access to consumer goods (Foucault, 2008).

In the case of social inclusion, consumer goods would be access to the community, recreational and vocational activities, housing and health care. It is important to note that equal is not synonymous with identical. Equal, in the case of society, suggests that everybody gets equal access to what they need (Roberts, J. (2004). *ED-D 568*:

Special Education: Program, Practices and Policies [Course lecture] Victoria, B.C.: University of Victoria.). Policy which relies on one member of society to sacrifice his/her health or well-being in order to care for and facilitate access to what another member requires does not achieve equality and potentially substitutes the exclusion of one member of society with the exclusion of a different member of society.

In the case of social inclusion policy which relies heavily on inexperienced parent/family caregivers to meet the needs of people who have IDD, the same potential for abuse, harm and violation of rights exists. They are simply redistributed over the individual with IDD, their family members and those living within their local community, rather than over the individual, residents and staff of the institution. In their exploration of quality of care, Matthias and Benjamin (2003) found that there was no difference between quality of care or prevalence of abuse between care delivered by agencies or by self-employed care providers. The predictors of abuse included quality of family relationships (i.e., advocates were available to ensure safe, quality care), care delivered in the language spoken by the care recipient and cultural factors.

Perhaps the challenges accessing services and supports suitable to their needs experienced by people who have IDD and their caregivers in the Province of Ontario is due to inappropriate focus in policy. The focus of the policy is on facilitating social inclusion. However, there is a lack of clarity around how social inclusion is defined, except that the ultimate goal is to achieve social inclusion to eliminate health inequality (WHO, 2010; Popay et al., 2008). If the ultimate goal is to achieve health equity, rather than focusing on provision of services and supports to facilitate social inclusion, perhaps

social policy in Ontario ought to focus on achieving health equity or on improving social determinants of health among people who have IDD and their caregivers.

Functional approaches to reasoning and decision-making common to other fields are seen as a way to apply theory or phenomena to particular examples (Cohen, 1935). Arguing that vague, broad sweeping policies with concluding outcomes, such as social inclusion, are not sufficient in evaluating public policy and the effects of services and supports, Luckasson and Schalock (2013) proposed applying a functionality approach to clinical practice and service delivery to people who have IDD. The model they proposed is comprised of three components: 1) the input component (which considered individual human functioning, 2) the throughput (which is comprised of systems of support through which the desired outcome can be facilitated, including skills, knowledge, assistive devices, personal characteristics, social supports, policies, professional services, etc.) and 3) the output component, which is comprised of socio-economic status, health status and subjective well-being (i.e., satisfaction with life, happiness, QoL domains, absence of negative affect and a sense of self-efficacy).

A functionality approach to IDD allows for an assessment of an individual's needs across settings and activities, rather than relying upon a diagnosis or description of the person's functioning. This allows for provision of support according to needed supports rather than according to eligibility defined by broad descriptions. As a functionality approach focuses on how the individual is functioning in order to achieve wellbeing, it is possible to respond to the individual's evolving needs rather than simply removing a support when the outcome demonstrates that the targeted goal has been achieved (Luckasson & Schalock, 2013). From a clinical practice perspective, the benefit

of the functionality approach is that it allows clinicians the opportunity to assess the outcome of a support and to build on that outcome, rather than offering a prescribed service/support, terminating service and redirecting the client to a different service when the outcome has been achieved (Luckasson & Schalock, 2013).

Situational maps serve to identify the actors and elements involved in a broader situation (Clarke, 2005). They are also helpful in identifying how the discourse of various actors construct their situation. Table 2 presents an ordered situational map depicting the actors and elements related to the Act (2008) as it relates to adults who have ASD.

<p>Individual Human Elements/Actors</p> <ul style="list-style-type: none"> Adults who have ASD Informal Caregivers of Adults with ASD Other family members Formal Caregivers Service supervisors <p>Collective Human Elements/Actors</p> <ul style="list-style-type: none"> Community/Neighbourhood Employers Health Care Providers Social Service Providers Advocacy Groups Community recreation services <p>Discursive Constructions of Individual and/or Collective Human Actors</p> <ul style="list-style-type: none"> Stereotypes Gender ratios and prevalence Self-determination & autonomy Definition of social inclusion Concepts of citizenship Funding policies <p>Political/Economic Elements</p> <ul style="list-style-type: none"> Policy – UN, Federal, Provincial Attention ASD receives in the media Increasing costs and demand for public sector services Aging population Aging caregivers, decreasing ability to provide care/support Debate around housing & care formats 	<p>Non-Human Elements Actants</p> <ul style="list-style-type: none"> Communication technologies for non-verbal Adults who have ASD Transportation Activities/Services Living Accommodations Living Structure <p>Implicated/Silent Actors/Actants</p> <ul style="list-style-type: none"> Community members & neighbours Possible employers Employment agencies <p>Discursive Constructions of Nonhuman Actants</p> <ul style="list-style-type: none"> Social inclusion as preferable to institutionalization ation of social inclusion arising from lack of opportunity and supports <p>Sociocultural/Symbolic Elements</p> <ul style="list-style-type: none"> Pop culture representations of ASD Opportunities for inclusion ideals vs realities Attitudes in General public
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Temporal Elements	Spatial Elements
Age of the individual and informal caregivers = varying needs	Housing, neighbourhoods, communities
Structural lag - lifespan opportunities	Urban/rural/suburban
Major Issues/Debates (Usually Contested)	Transportation
Transitions to care as age-related needs progress	Related Discourses (Historical, Narrative and/or Visual)
Access to suitable housing	Refrigerator Mother
Access to behavioural challenges	Rainman/"idiot savant"
need to press assault charges &/or seek psychiatric hospitalization to access support when caregiver safety is at risk)	Distinction and relation to other neurodevelopmental disorders
	Eligibility criteria for services focused on intellectual deficits
	Other Key Elements
	Mental health outcomes of individuals with ASD
	Mental health outcomes of informal caregivers
	Physical health outcomes of individuals with ASD
	Physical health outcomes of informal caregivers

Table 2. Ordered Situational Map: Predicted Elements Related to Aging Adults with ASD.

2.8 Chapter Summary

The components of the HEIA and PPM, although presented in markedly different styles, with emphasis on different areas, are: 1) to review what is known about the policy/program in question and the social variables interacting with the population it targets, 2) to identify the impacts of the policy/program on the population targeted, as well as on stakeholders, 3) identify mitigating factors, 4) implement and monitor a strategy to mitigate the impacts and 5) review the effects of the strategy. It is necessary to assess the impact of the Act on older adults who have ASD for a number of reasons.

They and their families have had a range of experiences across the lifespan which could render their needs unique to the rest of the population of adults with ASD.

The HEIA could be conducted in consultation with people who have ASD and their caregivers. Much of the research already exists, although it tends to be stratified based on how the researchers opted to approach their topic. Keywords, such as health equity, QOFL, SWBH and DHO are all used in research related to ASD and health outcomes. Broad, systematized literature search and review methods can be helpful in identifying resources to inform this research. However, even using these methods does not garner a fulsome search of existing research. It is often necessary to supplement such a search with references cited in the materials retrieved from the search. Although informative, research conducted internationally can often be irrelevant to the circumstances in a region under study, as policies, funding and support strategies will be unique to the region in question. Stakeholders must be included in the HEIA and PPM processes, in order to accurately reflect their interests.

This chapter presented two processes frequently used to analyze the health equity impacts of policy and programs. Although the PPM and the HEIA bear many similarities in terms of the considerations made, for the purposes of examining the unintended health impacts of social inclusion policy in the province of Ontario, among older adults who have ASD, the HEIA may be a more suitable model to use. The HEIA was developed by the Province of Ontario, with the intent of identifying unintended health equity impacts of provincial policies. It makes sense to use the evaluation strategy recognized by the province in order to evaluate policy implementation and program delivery funded by the province. Although it also lends itself to serving this purpose, the PPM is a more complex

model, which includes steps and phases which exceed the scope of the research in question.

Chapter 3

3 Methodological & Theoretical Approach

This chapter explains the approach used to conduct this research. The goals of the research, which was conducted from a constructivist paradigm, were to analyze the needs and work performed by caregivers of adults who have ASD. To do so, the following three questions were posed: 1) “What is the policy that drives service and support provision to adults with ASD, how are they implemented, and by whom?” (2) “How are the needs of adults with ASD and their caregivers being met and by whom?” and (3) “What needs are not being met, and how does policy account for these needs?”. After identifying the approach used to conduct this research, this chapter then lays out the framework for this study. It identifies the research questions, methodology and definition of social inclusion used to complete this study. The overarching themes used in this study are informed by Hall’s (2009) themes for effective social inclusion.

3.1 Methodology

Consistent with the PPM and HEIA, the first phase of a qualitative directed content analysis is to prepare by identifying what is and is not known about the question at hand (Assarroudi, Nabavi, Armat, Ebadi, & Vaismoradi, 2018; Hsieh & Shannon, 2005). For the purposes of this study, a scoping review of the literature was conducted, followed by interviewing caregivers of adults with ASD. Operational definitions created for the codes are identified (Hsieh & Shannon, 2005). A table of the themes identified and their operational definitions is provided in Appendix F. Data which do not reflect the identified codes are further identified and analyzed. Where necessary, researchers can

then create a new category or subcategory of an existing category (Hsieh & Shannon, 2005).

In this particular study, many of the themes identified and reflected in Appendix F became subcategories of broader, more general categories, which arose once the data from grey material were considered in relation to the data provided by participants during interviews. Many of the overarching themes aligned with those of Hall's (2009) themes for effective inclusion.

As such, these themes were used as an overarching framework from which to analyze what participants reported more in-depth. This made it possible to get more specific about participants' experiences, as they provided more context for understanding how policy documents and media interacts with their individual circumstances. For instance, although a need for and right to suitable housing are addressed in both policy and media, the rationale for the differing opinions on what constitutes suitable housing is explained from a variety of viewpoints among the participants, based on the needs of their loved one, their own health needs, personal biases and assumptions about societal attitudes. Given that much of what the participants reported aligned with Hall's (2009) themes for effective social inclusion, these themes are used to define social inclusion for the purposes of this study.

A strategical model of discourse analysis [i.e., one which considers the strategies in which production, comprehension and reproduction of communication have been used (Van Dijk & Kintsch, 1983) is pertinent to research about the inclusion of older adults who have ASD because of the history and nature of ASD. Research of this nature must consider the symptoms and behaviours which drive relationships between the individual,

informal caregivers, formal caregivers and service providers, advocacy groups and policy-makers, through service utilization. However, it must also consider the history of the disorder and service provision therein.

Legislated reliance on family to provide the care required by people who have ND represents an assumption that the family has the cognitive, emotional and physical capacity to meet the needs of the individual. In circumstances in which the family proves unable to meet the needs of the individual, they are substituted by a contrived family arrangement (Foucault, 1965). This is evident in the use of group homes and the province of Ontario's effort to increase and develop "...innovative housing options as a priority for people with a developmental disability, their families and the government." (Jaczek, 2014, p.4). However, the supply of groups homes and other suitable housing options is inadequate, thereby emphasizing the reliance upon informal caregivers to facilitate and render successful inclusion legislation.

The ontological nature of a directed content analysis assumes that there is a social situation in which conflict exists, arising from a constraining social force, which interacts with an overarching social structure (Evens, 2005). Ontology refers to the nature of knowledge and reality, whereas epistemology focuses on the basis of knowledge (i.e., hard, real, transmittable in concrete vs abstract form, or whether it is more subjective, based on personal insight and experience (Dieronitou, 2014; Cohen, Manion and Morrison, 2006). From an epistemological purist lens, knowledge is viewed as a subscription to the humanistic sciences model interpretivism/constructivism.

There is debate around whether or not content analysis lends itself more to qualitative or quantitative analysis in text analysis (Dieronitou, 2014). Qualitative

analysis reveals content which can be used beyond simply measuring the frequency of occurrences and can expose meaning and unmeasurable characteristics (Dieronitou, 2014). As such, content analysis approached qualitatively can provide a relational analysis, building on relationships between concepts (Assarroudi et al., 2018; Busha & Harter, 1980). In doing so, it can allow the question at hand to be deconstructed, revealing the power relations, through analysis of the social relations, cultural values and beliefs associated with the question at hand (Dieronitou, 2014). For this reason, a qualitative directed content analysis lends itself well to the research question at hand.

The current values guiding service and support provision to people who have developmental disorders reflect a neo-liberal orientation, arising out of: (a) a system in which abuses in institutions compromised the safety of the individuals (Williston, 1971) and (b) a need for cost reduction (Vermeulen et al, 1993). In response to an identified budget shortfall, the Ministry of Community and Social Services (MCSS) for the province of Ontario reframed its role as primary service provider to adults and children who have what are now classified as neurodevelopmental disorders (ND), as a responsibility to be shared with families, communities and other government funders (Vermeulen et al., 1993). People who have ASD fall within this population.

Constraining social forces related to the service, supports and social inclusion of individuals who have ASD may include: behavioural challenges (e.g., aggression, rigid interests, inflexible adherence to routines, etc.), stigma, willingness and ability to participate in socially inclusive settings. Additional constraints, external to the individual who has ASD may include the willingness and competence to provide care and support among informal caregivers and the community. The degree to which services and

supports are necessary may vary according to the individual, as well as to the situation in question. Regardless, adults who have ASD will require support in order to be included effectively in society. A number of forces combine resulting in informal caregivers being the ones most frequently tasked with providing that support.

3.1.1 Reflexivity Statement

I am a registered psychotherapist and board certified behaviour analyst who has been working with people who have ASD and their families for over 18 years. In this role, my clients have made known to me their needs and how they use their strengths and resources to achieve their goals. My clinical training helps me to focus on the application of research. However, it also may result in a tendency to focus on individuals rather than systems. My clinical work has taken place in both public and private sectors, though predominantly in the public sector in Ontario. As such, I do have a strong understanding of the system in which this research is located. In order to pursue this degree, I did leave the public sector and am not currently serving people who have ASD. I therefore do not consider this work to represent a conflict of interest with my clinical work. The focus of this research is on caregivers' experiences, which I have reported as they spoke of them. Analytic memoing was used to track concepts and insights as they emerged from the data. The analysis therein has been objective and relies on the available literature, accepted coding practices in qualitative directed content analysis and consistency/inconsistency of issues raised by participants. Following Assarroudi et al (2018) criteria for establishing rigor in a content analysis further ensures findings in this research are free of bias and consistent with reliability and validity standards.

3.2 Method – Interview the Stakeholders

3.2.1 Ethics

The research proposal was submitted to and approved by the study advisory committee. It was then submitted to the Health Science Research Ethics Board at Western University. Ethical approval for this study was applied for and approved by the Western University Health Science Research Ethics Board (HSREB) (Appendix A) prior to beginning this study.

3.2.2 Participants

This study focused on caregivers of adults (i.e., people over 18 years old) who have ASD. Although the focus was on informal (i.e., unpaid) caregivers who are typically family members, a formal (i.e., paid) caregiver participated in the study, as did an adult who has ASD and identifies as his own caregiver. In consultation with the supervisor, it was decided that these participants fell within the requirements outlined in the submission to and approved by HSREB. As they could offer a perspective not necessarily available to informal caregivers, it was decided that the data provided by these participants could serve to substantiate the data provided by the informal caregivers.

3.2.2.1 Recruitment

In light of the relatively small population of adults with ASD, maximum variation sampling, drawn from people living in urban, suburban, and rural settings in Ontario, was used to compare participants' diverse experiences. Participants were recruited from across Ontario. Given the limited population of adults with ASD, it was necessary to sample from across the province to achieve saturation.

As the study focused on the impact of service and support policy within Ontario, participants were recruited from within this province only. With one exception, all participants had diagnoses of the person they cared for who has ASD confirmed by psychologist. The one exception was a paid caregiver, who spoke broadly about his clients who have ASD.

Recruitment materials were provided to the Ontario Partnership for Aging and Developmental Disorders (OPADD), Partnership for Aging and Developmental Disorders, ASD Ontario, ASD Canada, Kerry's Place, Geneva Centre, and all nine regional providers of DSO listed on <http://www.dsontario.ca/agencies> as of February 9, 2018.

Independent service agencies listed as DSO partner agencies within the province were also contacted. Table 3 presents how the province is broken down into nine regions for the purpose of DSO service provision.

3.2.2.2 Consent

Written consent was obtained from each participant. Most participants emailed signed consent forms to the researcher, but two (an informal caregiver and the formal caregiver) did not have printers and could not do so. In these cases, the researcher mailed hard copies of the letter of introduction and consent to the participants along with a stamped and addressed envelope to sign and return the consent forms. Prior to beginning interviews, the researcher reviewed the consent form and explained it to each participant, ensuring his/her understanding and answering any questions before obtaining verbal consent to proceed with the interview.

Region	Communities Served
DSO Central East	Durham, Haliburton, Kawartha Lakes, Northumberland, Peterborough, Simcoe, York
DSO Central West	Dufferin, Halton, Peel, Waterloo, Wellington
DSO Eastern	Ottawa Region, Prescott-Russell, Renfrew, Stormont, Dundas & Glengarry
DSO Hamilton-Niagara	Brant, Haldimand-Norfolk, Hamilton, Niagara
DSO North-East	Cochrane, Muskoka, Nipissing, Parry Sound, Timiskaming
DSO Northern	Algoma, Kenora, Manitoulin, Rainy River, Sudbury, Thunder Bay
DSO South-East	Frontenac, Hastings, Lanark, Leeds & Grenville, Lennox & Addington, Prince Edward
DSO South-West	Bruce, Chatham-Kent, Elgin, Essex, Grey, Huron, Lambton, Middlesex, Oxford, Perth
DSO Toronto	Etobicoke, North York, Scarborough, Toronto

Table 3. Regions with the Province of Ontario (Retrieved from <http://www.dsontario.ca/agencies> on January 8, 2015)

3.2.3 Participant Characteristics

Participants self-identified to the researcher through contact information provided in the recruitment materials which were provided to service agencies, in classified ads and on a Facebook post. An ethics review was completed and approved by Western University prior to recruitment.

Six participants were recruited:

1. Four informal caregivers (i.e., unpaid, typically familial) of adults with ASD,
2. One formal caregiver (i.e., paid personal support worker), and

3. One adult who reported having ASD and identified himself as his primary caregiver.

Of the informal caregivers, two were parents and both were women. One caregiver (45 years old) cared for a 21-year-old son and 16-year-old daughter, each of whom has ASD. All participants lived in urban settings. One participant identified as part White and part Métis, while another who identified as White reported that her children's father was Black. All other participants identified as White.

Abigail

Abigail is the 33 year-old younger sister of a 37 year-old man who has ASD. In addition to ASD, the brother is diagnosed with: intellectual disability, cerebral palsy, depression and anxiety. Recently, his health care providers have queried a possible diagnosis of schizophrenia. Abigail reported that the complexity of her brother's health needs have "left him in a void" because there are some services which are funded only if the needs are associated with a health issue, while others are funded only if associated with a developmental disorder. Her brother lives with his mother. Although Abigail was pursuing her career in another city, she left that role and returned home to assist in the care of her brother following ongoing and intense behaviour incidents (e.g., assaulting her mother, property destruction, etc.). When these incidents arose, she reported that her mother would lock herself in the bathroom and phone the police and Abigail for assistance. Abigail stated that though she needs to be close to her family so that she can help in the care and support of her brother, she prefers to live on her own, feeling safer this way.

Abigail described her brother as weighing 220 pounds and aggressive. Specifically, he has thrown his mother off the front porch and regularly assaults her. Abigail reported that her brother has broken her glasses and bitten her. She reported feeling “flinchey” and speculated that her fear of her brother manifests itself as anxiety disorder. She currently takes medication for anxiety and speculated that her mother’s health and mental health have diminished as a result of her brother’s needs, stating “I have watched my mother’s mental health deteriorate and I could definitely benefit from counseling”.

Louisa

Louisa is the 68 year-old sister of a 55 year-old man who has ASD and lived primarily in institutions since diagnosis. She reported that he was removed from an institution in 1998, following discovery that he was being abused. He will not discuss the abuse that he experienced. Since that time until recently, he was cared for by their parents until their deaths. He then lived with Louisa until she and her husband were no longer able to care for him and their son who also has ASD. Since then, Louisa reported that he has been “default re-institutionalized” (i.e., he lives in the “developmental disorders” ward at a psychiatric hospital due to lack of housing options appropriate to his needs).

In addition to caring and advocating for her brother, Louisa and her husband care for her 19 year-old son who has ASD who she described as 6’2” and 250 pounds. She reported that their son has a diagnosis of ASD and developmental disability, stating that “he can walk and talk quite well”. She reported that her son once grabbed her by the head, pulling it backward and attempting to slit her throat. She was able to reach the phone and call police for assistance. She reported that “due to son’s name trying to kill

me, the incident is always in the back of my mind. It is hard to accept that it will never go away and that it has altered and probably shortened my life and lifestyle. It is very hard not to be resentful. On the other hand, it has given me a unique insight to empathize with other parents in the same situation.”

Emiline

Emiline is a 71 year-old woman who is the sole caregiver for her 78 year old brother. She described herself as follows: “I’m not well myself. I’m just finished; my whole life has been filled with caregiving. I have a son with cerebral palsy; I’m a single sole support parent. I have another son who’s out of the country and my mother had Alzheimer’s. I took care of her. So I just said I can’t, I don’t have the wherewithal, I’m not well myself. I have a heart condition; I have many things wrong with me.”

She reported that she was not aware of whether or not he had ever been “formally diagnosed with Autism” but did recall that the diagnostic process was intensive and involved a psychiatrist and team of health professionals spoke about how her brother’s developmental difficulties were due to poor parenting by her mother. She reported that this was very traumatizing for her family, her mother in particular. Although she was seven years old when this occurred, she stated that she recalled it very well as an upsetting and disruptive time in her family.

She recalled that the professionals told her parents her brother’s symptoms were due to parenting but that he could not tell them anything specific about his diagnosis “...because the information was confidential between the doctor and the patient”. She reported that she recalled hearing the psychiatrist telling her parents “...usually, it’s the mother to blame if there’s anything wrong with the child.” She reported that these

conclusions had an effect on her family which was “awful, it was awful”. She declined to discuss specific impacts. Although he has not had a subsequent diagnosis, his current health team is treating him as though he has ASD. She described her brother as being at the high functioning end of the ASD spectrum, stating that he had gained admission to an undergraduate journalism program but “it didn’t last”. He also worked for an accountant and then at a shoe factory.

Throughout his adulthood, he has lived independently, though reclusively, in an apartment, choosing to forage for food in dumpsters. Knowing this, Emiline would often seek him out by driving around, searching local dumpsters. Neighbours, including some restauranters, who were aware of his tendency to seek food from their dumpsters would leave food for him in/near the dumpsters he was known to frequent. When unable to find her brother, Emiline stated “I would just drive around and look for him and I would drive around wherever there was garbage, like at the back Loblaw’s, or like around the area that he lived and sometimes I could find him that way.”

In 2016, he experienced intense and regular bouts of diarrhea. He fell and broke his hip in his apartment, unable to reach a telephone to call for help. A neighbour who would hang food in sealed containers in a bag on his apartment door became concerned when a bag of food she had left for him remained on his door for three days. She shouted through his apartment door to ask if he was alright. He stated he was not and provided this neighbour with Emiline’s contact information. Once he had been treated at the hospital, he was discharged to a group home which was inhabited by people who were recovering from drug addiction.

Emiline reported that while he was at the hospital, he was treated poorly. According to her, this included an incident in which a social worker admitted to fraudulently obtaining his signature consenting to discharge from the hospital and placement in a group home one hour away from where he and Emiline lived. Emiline reported that the social worker admitted to Emiline that she knew he was not competent to consent and that Emiline had power of attorney for decision-making purposes when she solicited his consent. According to Emiline, he was regularly victimized, frequently having his belongings stolen from him while at the group home.

Emiline reported dissatisfaction with the services provided at the group home. She reported that when group homes have less than eight residents, the group home is not required to be accredited. The group home her brother was living in was not accredited. While at the group home, he had diarrhea regularly but nobody reported it to Emiline nor did they seek help. Emiline stated that she reported this to the pharmacist tasked with filling the prescriptions for her brother's diarrhea. According to Emiline, the social worker assigned to his care stated that she was unable to assist him, stating "it's my job to keep him out of the hospital". It was the pharmacist who referred her to a physician located an additional 45 minutes from the group home. This physician contacted MCSS and advocated for his placement in a nursing home.

Emiline reported that the nursing home, although not a suitable placement for him, is "the best thing that's happened to him" because "they try". She visits him five days per week, paying someone to visit him the other two days per week to ensure that his needs are being met and so that he is able to leave the facility for walks. Since being placed in the nursing home, Emiline's brother accessed dental care for the first time that

Emiline is aware of. She reported that the dentist told her that her brother does not have teeth. This is something neither she nor her brother knew. According to the dentist, Emiline's brother had been relying on his jaw bone to chew his food.

He also accessed a colonoscopy for the first time once placed in the nursing home. As a result of this, it was discovered that he had polyps and precancerous cells. Prior to admission to the nursing home, he had also been diagnosed with and treated for diabetes. However, once he was placed in the nursing home, he started having seizures so was referred to an epilepsy clinic. At this clinic, the doctors found that there was no evidence of diabetes. However, it was also discovered that he had had several strokes which had gone undiagnosed.

Theresa

Theresa is the mother and sole caregiver for a son (21 years old) and daughter (17 years old), both of whom have ASD. Her son is on a waitlist for housing in a group home and has been living in the psychiatric ward of a local hospital for the last 5 months due to increasingly aggressive and uncontrollable behaviour since he transitioned out of high school. Although he is able to communicate effectively, she reported that her son has the "maturity of an 11 or 12 year old". He was diagnosed at 10 years old, at which point he was described as having behaviour and cognitive functioning consistent with a diagnosis of Asperger's Syndrome but his social, as well as his language and communication skills were more impaired.

Mitch

Mitch is a 23 year-old man who has ASD. Although he described himself as currently functioning as though he has Asperger's Syndrome, he reported that he was

much lower functioning as a child. He did participate in the provincial Intensive Behaviour Intervention (IBI) program for children with ASD. In addition to his diagnosis of ASD, he has a diagnosis of depression, anxiety disorder, obsessive compulsive disorder, is blind in one eye, has one kidney, has a health condition he chose not to disclose and takes Zoloft (i.e., an anti-depressant) and Risperidone (i.e., an anti-psychotic medication frequently used to treat schizophrenia, bipolar disorder and irritability in people with ASD). He lives with his parents in an upper-middle class area of an urban area.

He reported feeling isolated due to lack of opportunities to work, stating that he works “when I can get a job”, describing a variety of short-term contracts he has fulfilled. He opted not to pursue formal post-secondary education, stating that his experience with the education system has been traumatic and characterized by bullying by peers and teachers, including one incident in which he reported he was assaulted by a teacher. He described himself as a self-advocate and politically involved, expressing dismay with the recent election results, stating “I’m pretty terrified”. When asked why this was so, he stated that the recently elected premier “wants people like me dead”.

Bart

Bart is a personal support worker who serves people with developmental disorders. He reported that agencies such as his employer have increased their costs to consumers by 15% in order to accommodate recent increases to minimum wage. He stated that he takes one sick day per month in order to recover from the demands of his job, stating that his work is emotionally and physically demanding. He estimated his physical health to be about a 6 or 7 on 10 a point scale, where 10 is excellent health and 0

is very poor. He reported that he has tears in his shoulders resulting from the physical demands of his work. He estimated his mental health to be about 3 or 4, where 10 is excellent mental health and 0 is very poor, stating that he is sometimes too exhausted to play with his daughter.

Having worked in his role for ten years, Bart was able to reflect on various needs of his clients. Although the breadth of his understanding of their needs was broad, the depth of this understanding was somewhat limited. For instance, he reported that “waitlists are horrendous” but did not know the specific duration people waited on waitlists or how that duration varied depending on the nature of the service they were seeking. When asked what his clients do when he is unable to attend their appointments, he stated “they just make do” but did not know what specifically they did to coordinate care or occupy their loved one with ASD.

Table 4 reflects participants’ demographic information. Relationship refers to the relationship the caregiver has to the person with ASD. Ages of the caregivers and people with ASD are reported in years. Overall, QoFL scores reflected in this table are based on scores achieved in the QoFLI (Frisch, 2005) and the Overall personal well-being scores were obtained from the PWI-A (International Well-being Group, 2013).

Participant	Relationship	Marital Status	Income	Age	Age of Person with ASD	Overall QoFL Scores	Overall PWI Scores
Abigail	Sister	Single	Low Income	33	37	Very Low	20

Louisa	Sister Mother	Married	2 Income Middle Class	68	19 55	Low	40
Mitch	Self- caregiver	Single	ODSP & contract work	23	23	Average	69.38
Theresa	Mother	Single	ODSP	45	19 16	Very Low	62.5
Emiline	Sister	Single	CPP & OAS	71	78	N/A	N/A
Bart	Personal Support Worker	Married	Working class	N/A	Varied	N/A	N/A

Table 4. Demographic Information of Participants

3.3 Study Methods

This constructivist qualitative directed content analysis used multiple sources of data including: interviews, standardized measures of quality of life and subjective well-being, public policy documents and news reports to gain a broad perspective and understanding of the issues identified in this study. The reader is reminded that the study design is iterative, and as a result is difficult to describe in a linear fashion in a manuscript. For clarity, the method is presented starting with a description of the participants and their individual circumstances. This provides the foundation for the following reporting of standardized measures results, as well as how the policy documents, services and supports, as well as the narrative in the media influence participants' perspectives and

experiences. Comparison between participants allows for identification of recurring themes, as well as outlying experiences and perspectives.

3.3.1 Data Collection

Each participant completed a semi-structured individual interview and demographic questionnaire (see Appendix E) along with Frisch's (2005) Quality of Life Inventory, WHO's (1996) Quality of Life – Brief (WHOQOL-BREF) instrument, and Personal Well-being Index – Adult version (PWI-A) (International Wellbeing Group, 2013). Study findings are organized to reflect the overarching themes characterizing effective inclusion identified by Hall (2009): a review of infrastructure regarding how inclusion in is achieved (i.e., in Ontario), followed by a review of the subjective experience of inclusion as reported by caregivers of adults with ASD (and, in this case, a self-advocate who is an adult with ASD).

The formal caregiver did not complete quantitative measures, which focused on variables that could be influenced by participants' lives outside the workplace; hence, it was difficult to interpret if and how the needs and access to supports for his clients with ASD would influence the formal caregiver's QoL and SWBH. One informal caregiver did not complete the measures, citing concerns that they were diagnostic in nature. She did, however, complete the semi-structured interview. Participants' data were de-identified, associating their responses with participation numbers. For the purposes of reporting the findings in this study, these participation numbers were then assigned pseudonyms.

The semi-structured interviews ranged from one hour to one and a half hours in duration. The questionnaires were administered in a follow-up phone call. Where consent

was provided to do so, interviews were recorded. Recordings were transcribed by a professional transcribing service, which had signed a confidentiality agreement. In two cases, interviews were not recorded. In these instances, the interviewer read back what the participant said to him/her throughout the interview to ensure accuracy of what she recorded by hand.

Although participants were asked to participate in two interviews, the burden was reduced for participants through flexible scheduling (i.e., their choice of date and time). Participants were also offered the opportunity to conduct interviews in person or over the phone. All participants opted to complete the interviews over the phone.

3.3.1.1 First Interview

A constructivist approach was used to inform the design of the interview questions. Specifically, "...eliciting the participant's definitions of terms, situations and events and try to tap his or her assumptions, implicit meanings and tacit rules." (Charmaz, 2006, p. 32). Interviewing caregivers about their experiences, perspectives and observations of the Act and the associated services and supports, as well as how they access them is the most direct way to access their understanding and experiences of this topic.

Interviews were semi-structured and recorded using an encrypted, digital recorder. Semi-structured interviews allowed for the opportunity to explore identified concepts in depth. The recordings were transcribed for analysis.

3.3.1.1.1 First Interview Content

The first interview, which lasted between 60 and 90 minutes, was divided into two parts:

- 1) gathering background information including the diagnosis, strengths, needs and

characteristics of the loved one with ASD and 2) gathering information about their experiences caring for a loved one with ASD, their own needs, needs within the family and those of the person with ASD, how they experienced accessing what they needed and their experience using the services and supports related to the Act (2008).

The background was explored as part of the first interview, including demographic information, diagnoses the loved one with ASD might have, any diagnoses or health considerations impacting on the caregiver, as well as information about any medications the loved one with ASD might be taking. This was important to provide a context for the caregivers' observations and experiences in order to help determine if those providing care to someone whose developmental and/or health needs are greater than others whose needs are not as intensive. It also helped to identify any health barriers the caregiver might be experiencing themselves which could impact on their experience of the Act and related services and supports.

The next part of the interview got more specific, focusing on identifying their knowledge of the Act, the services and supports available to them and how they access them. This then lead to exploration of what needs are being met and what needs are not being met. To ensure a clear understanding of what participants were saying, the primary researcher would repeat back her understanding of what they were telling her throughout the interviews, seeking clarity where necessary.

3.3.1.1.2 Transcription and Coding of the First Interview

The first interview was transcribed and analyzed by hand. Prior to formally analyzing the transcripts, I read them to familiarize myself with the content. At that time, any observations or insights I made were recorded in a notebook. For the purpose of

analyzing transcripts, they were printed out, with notes made directly on the transcripts and recorded in a notebook.

3.3.1.2 Completion of Measures

With the exception of one participant, the formal (i.e., paid) caregiver and one informal caregiver, all participants completed the second part of the study, which was completion of standardized measures of quality of life and subjective well-being. In consultation with the dissertation supervisor, it was decided that the formal caregiver would not complete the measures because he did not live with the people he provided care to. Additionally, as he is compensated for the care work he provides, it was decided that his experience of caregiving would impact differently on experiences of quality of life and subjective well-being than it would on those providing uncompensated care. One informal caregiver declined to complete the second part of the study, citing concerns that the questionnaires were too ‘diagnostic’ and she was uncomfortable with sharing that degree of privacy.

Participants were offered to complete the measures during a second interview or to have the measures mailed out to them for individual completion on their own time. With the exception of Mitch, these statements were written by participants, at their convenience. In the case of Mitch, the interviewer administered the questionnaires over the phone and recorded his answers, seeking confirmation from him to ensure accuracy. This accommodation was made at the request of the participant, who preferred to complete questionnaires this way.

3.3.1.3 Data Analysis

All of the data elements were analyzed and coded by the primary researcher. The researcher coded each segment of each data element by hand. The coding process

resulted in a sorting and consolidation of the data. Qualitative data analysis was an iterative process, consisting of reading and re-reading the interview transcripts to identify emerging themes. Maximum variation sampling can provide a better understanding of how policies are implemented across rural, suburban, and urban settings.

Data were coded by a two-cycle method. The first coding cycle focused on identifying and understanding various elements of the problem and identifying predetermined codes. The second cycle focused on establishing patterns and theoretical coding to develop a theory about how issues identified in the policy literature interacted with human elements, culminating in the experiences of the individuals under study.

In qualitative directed content analysis, it is common to review textual data and highlight parts which may form predetermined codes consistent with an existing theory or prior research findings (Assarroudi, et al., 2018; Hsieh & Shannon, 2005). Predetermined codes arise from categorization codes emerging from the literature (in this case, that depicted in the Prisma diagram). These codes are then applied to data, noting where data does and does not fit the categorization (Assarroudi et al., 2018). Descriptive coding was used to code the policy literature, as it is useful in describing the foundations upon which policy makers and service providers make decisions (Saldaña, 2016). However, descriptive coding is limited in its usefulness in analyzing participants' interview responses. Therefore, in-vivo and process coding were used to analyze data collected in interviews with participants. This approach facilitated a clearer understanding of individual experiences as well as the process that led them to have and interpret their experiences as they did (Saldaña, 2016). Analytic memoing was used to track concepts and insights as they emerged from the data.

3.3.1.3.1 In-Vivo Coding

In-vivo coding is used to “ensure that concepts stay as close as possible to research participants’ own words or use their own terms because they capture a key element of what is being described” (King, 2008). It was useful in this study because not only does it allow the researcher to focus on what participants are saying and how they use language in reference to their experience, it also can be used to analyze how specific words or phrases are used in other materials (King, 2008). For this reason, in-vivo coding was suitable for this study, which examined not only participants’ experiences, but also policy documents and grey literature.

Policy documents and grey literature were also coded using in-vivo coding. In-vivo coding is useful for initial analysis of data but can be challenging to reliability and validity due to over-generalization in later stages of research (King, 2008). For this reason, it was used to conduct an initial analysis of all sources of data. To prevent over-generalization, process coding was then used. Analytic memoing was used to track concepts and insights as they emerged from the data.

3.3.1.3.2 Process Coding

Once initial coding was completed, process coding was performed to establish patterns and theoretical coding. This allowed for identification of how issues in the policy literature interacted with human elements, drawing together the participants’ experiences and perspectives with the policy documents and grey literature (Saldaña, 2016). Analytic memoing was used to track concepts and insights as they emerged from the data.

3.3.1.4 Coding Policy Documents & Grey Literature

Retrieval of policy and media documents (i.e., grey literature) was completed prior to interviewing participants. An initial list of themes was identified in the grey literature by the researcher. A table presenting the themes and their operational definitions appears in Appendix F. Following the interviews, it became evident that these themes often represented subcategories of broader, more general categories raised by participants.

Identified codes included housing preferences, waitlists for services and funding, isolation, health and mental health, financial constraints, and distrust in the public support services system. Once coding was completed, patterns were categorized into overarching categories. The literature was then reviewed to identify commonalities between the themes identified in this study with that already existing in the literature. The themes and subcategories most closely reflected congruence with Hall's (2009) themes for effective social inclusion (i.e., a. acceptance beyond one's disability, b. meaningful and reciprocal personal relationships, c. involvement in activities, d. appropriate living accommodations, e. being employed and f. receiving formal and informal supports). Table 10 reflects how the coded themes were aligned with Hall's (2009) themes for effective social inclusion. Because the themes identified in this study aligned with those identified by Hall (2009), Hall's themes were used as a framework for analyzing subcategories identified in this research. Hall's (2009) themes comprised the overarching themes for this study, then where issues identified by participants were more specific within those themes, their reports are reflected in subcategories within the relevant theme.

3.3.2 Memos and Theoretical Sampling

Throughout the analysis of data, memoing was an important role in the method. Additionally, theoretical sampling took place, probing participants' responses during the first interviews with questions about how their responses related to their experience and understanding of social inclusion policy and the services and supports they accessed or require. Frequently, participant data was then cross-referenced with existing literature and other sources of data collected (e.g., grey literature and policy documents). The memos were analytical in nature, reflecting the primary researcher's insights and observations about the data. This helped to identify similarities and differences between participants' responses and other data.

3.3.3 Review Of Techniques to Promote Rigor

Transparency in the congruence between the philosophical stance, study methodology and study method determines the rigor of a qualitative study (Norton, 2018). The approach described by Hsieh & Shannon (2005) relies on following three distinct phases in conducting research: 1) Preparation phase (i.e., gather the thinking skills, data collection, etc.), 2) Organization phase (i.e., organizing data in a way which is informed by data analysis and 3) Reporting phase (i.e., all steps of the study and findings are reported) (Hsieh & Shannon, 2005). However, Assarroudi et al. (2018) suggest that taking a more thorough approach to delineating these three phases ensures greater rigor. They rely on a sixteen-step model which builds on the three-step model used by Hsieh and Shannon (2005).

3.3.3.1 The Preparation Phase

This phase, consistent with that of Hsieh and Shannon (2005) focuses on gathering what is known about the problem at hand, identifying and ensuring the necessary skills are available. However, Assourroudi et al. (2018) conceive of this phase as having seven unique steps which must be completed: 1) the acquisition of general skills necessary for academic work (i.e., development of critical analysis skills, self-appraisal, creative thinking, scientific writing, data gathering, etc.), 2) selection of the appropriate sampling strategy (i.e., sampling which facilitates access to maximum variations across the population in question), 3) deciding on the analysis of manifest (i.e., transcribed interview text) and/or latent content (i.e., researchers' interpretations of available text and participants' non-verbal communication, such as silences, pauses, deep breaths, etc.), 4) developing an interview guide (i.e., open-ended questions based on the study's aims which can be supplemented with directed questions informed by existing theory and prior research), 5) conducting and transcribing interviews (i.e., using the interview guide to conduct interviews), 6) specifying the unit of analysis (i.e., interview transcriptions and notes) and 7) immersion in data (reading and reviewing transcribed interviews several times to extract meanings).

This study was completed as the final requirement for completion of a doctoral degree at Western University. In order to qualify for completion of this stage in the doctoral program, one must complete a comprehensive exam and gain approval for one's proposed research study from an advisory committee comprised of doctoral researchers with expertise relevant to the field of study. In doing so, the requirement of acquisition of general skills necessary for academic work have been fulfilled.

Maximum variant sampling was used to recruit participants for this study, soliciting participants across the Province of Ontario. Unfortunately, the only participants recruited were self-selected participants who had all accessed recruitment materials from a self-advocacy page on Facebook. In order to accommodate this weakness in the study, a broader range of data sources were used, including policy documents and grey literature. This provided more opportunity for variations in perspectives to be explored. Both transcribed interview text and latent content were considered in the data analysis. As such, the first three phases of Assarroudi et al's (2018) model to ensure rigor in qualitative directed content analysis have been satisfied. Where weakness arose, it was accounted for by increasing the range of data sources, which in turn ensured that themes and subcategories identified represented a broader range of perspectives and experiences. An interview guide was developed based on a literature review of health equity and social inclusion, as well as on what is already known in the ASD literature as it relates to adults with ASD and their caregivers. This satisfied step four of Assarroudi et al.'s (2018) model of rigor in qualitative directed content analysis. Interviews were conducted and transcribed, with a unit of analysis identified (i.e., the Act and related services and supports as experienced by informal caregivers of adults with ASD). Immersion in the data then took place, analyzing data from various angles in an effort to identify what participants were reporting, where and when it took place, why it happened the way it did. Once all seven phases of the first stage were satisfied, the research entered the organization phase.

3.3.3.2 Organization Phase

In Assarroudi et al.'s (2018) model ensuring rigor in qualitative directed content analysis, there are eight phases: 1) developing a formative categorization matrix (i.e., identification of main categories and subcategories derived from the existing theory or previous research), 2) theoretical definition of the main categories and subcategories (i.e., definitions are accurate and objective), 3) determination of the coding rules for the main categories (i.e., coding rules are based on theoretical definitions, 4) pre-testing of the categorization matrix (i.e., independent and tentative coding of text, identifying challenges in the use of the coding and differences in interpretations of the unit of analysis), 5) choosing and specifying the anchor samples for each main category (i.e., samples which offer explicit exemplification of the category are selected), 6) performing the main data analysis (i.e., data are reviewed and summarized), 7) inductive abstraction of main categories from preliminary codes (i.e., codes are grouped and categorized according to their meanings, similarities and differences and 8) establishment of links between generic categories and main categories (i.e., comparison between categories is constantly performed throughout the study).

In lieu of developing a formative categorization matrix, an ordered situational map (Clarke, 2005) was used to depict the actors and elements related to the Act (2008), presented in the Chapter 2 of this manuscript. This was selected because it allowed for depiction of a broader range of relationships which arise in relation to the Act (2008) and caregivers of adults who have ASD. Social arenas maps depicting: a) the supports and related actants as the Act (2008) intends them to be experienced by people with IDD and their caregivers, and b) as experienced by caregivers of adults with ASD in this study

were also created. These maps allow for demonstrating relationships, which are frequently interactional with other relationships rather than linear. For this reason, these maps seemed better suited to reflect the problem at hand than would a categorization matrix.

Main categories and subcategories were developed, informed by Hall's (2009) themes for effective social inclusion, as well as a review of the policy documents informing social inclusion in the Province of Ontario, satisfying the second (i.e., theoretical definition of main and subcategories) phase of the organization phase. Coding rules were determined based on theoretical categories and are provided in the coding manual in the appendices. Pre-testing of the categorization matrix was informally achieved by attending a housing coordination presentation, the audience of which were parents of adults with a variety of IDD's. Their comments and questions throughout the session, as well as in personal communication thereafter was consistent with the themes identified. Anchor samples were selected and the main data analysis was conducted with findings recorded. This data is summarized, with codes being grouped and categorized according to their meanings, similarities and differences herein. Links between main themes and subcategories are demonstrated in a linear fashion, with more detail provided as necessary throughout the results section of this document. As such, this study satisfies Assarroudi et al.'s (2018) criteria for rigor throughout the organizational phase.

3.3.3.3 Reporting Phase

The final phase, reporting phase entails one phase, which is provide a detailed description of the data analysis process. Findings are presented in a systematic way, demonstrating the process followed. Trustworthiness is enhanced through the delineation of the three

phases (i.e., preparation, organization and reporting). The latter has been accomplished in this section, while the following section provides a detailed description of how analyzed data were interpreted.

3.4 Summary of Methods

The link between qualitative directed content analysis and the research method used in this study has been discussed throughout this chapter. As a review, steps identified as indicators of rigor in qualitative directed content analysis have been followed, with explanations provided for deviations from the standards (i.e., use of an ordered situational map and social arenas maps in lieu of matrices) and how a weakness in maximum variation sampling was accounted for. The processes that were followed to generate codes, themes and subcategories was also described.

Chapter 4

4 Data Analysis

This chapter discusses how data were analyzed. Although quantitative analysis is given a separate section, it is important to note that the interpretations possible from this data are limited due to the small sample size, which made it impossible to achieve power. The quantitative analysis is presented first, followed by the qualitative findings.

4.1 Quantitative Analysis

Quantitative data collected through questionnaires were analyzed for descriptive purposes. Descriptive statistics such as the mean and standard deviation were calculated for each quantitative measure to determine the overall importance and relevance of items for participants and to uncover any differences in overall QofL and subjective well-being. Due to the small sample size, it was impossible to achieve statistical power for within- and between-groups analyses. The data were therefore insufficient for mixed methods research. However, descriptive data provided further information for analysis related to individual participants' responses to interview questions and could be compared with standardized norms for individual measures. Emiline declined to complete the questionnaire portion of the study, expressing concern that it seemed "too diagnostic".

4.1.1 Quality of Life Inventory

The Quality of Life Inventory (QofLI) (Frisch, 2005) measures 16 domains considered measures of health equity in SDOH and DHO research: health, self-esteem, goals and values, money, work, play, learning, creativity, helping, love, friends, children, relatives, home, neighbourhood, and community. The instrument provides an overall score, reflecting a weighted satisfaction rating in each domain of QofL and an overall weighted satisfaction rating, achieved by dividing the sum of the weighted satisfaction ratings by the domains ranked by the participant on the degree of importance she or he ascribes to each domain. QofL raw scores can also be converted to T scores with a mean

of 50 and standard deviation of 10, as well as percentiles. This allows individual scores to be interpreted relative to the standardization sample. The QofLI consists of 32 questions and takes approximately 5 minutes to complete (Frisch, 2005) or slightly longer for individuals with ASD, depending on the respondent's ability.

This measure was selected because: a) it allows participants to reflect on each domain of QofL, indicating the degree of importance individuals place on each domain, as well as their satisfaction with their experience of each domain and b) it has been standardized and validated against the WHOQOL-BREF. Other measures, such as the CarerQofL (Brouwer, van Exel, van Gorp & Redekop, 2006) could have been used. The CarerQofL allows caregivers' to use a three-point Likert scale (i.e., "no", "some", "a lot of") to rate the following areas: a) fulfillment received carrying out caregiving tasks, b) relationship problems with the care recipient, c) subjective mental health problems, d) difficulty achieving balance between caregiving and other domestic tasks, e) financial problems arising due to caregiving tasks, f) assistance received carrying out caregiving tasks and g) problems with own health (Brouwer, van Exel, van Gorp & Redekop, 2006). The focus of the CarerQofL is to examine cost and effects of informal caregiving. Although relevant to the purposes of this study, an economic evaluation of informal is beyond the scope of this study, which focused on subjective experiences of caregiving and health impacts thereof. Additionally, it was decided that the CarerQofL did not allow analysis of a sufficient range of domains related to QofL, and therefore health equity. The QofLI was deemed more relevant to the study at hand because it considers all domains of QofL and allows participants to indicate, not only their subjective experience of

satisfaction with each domain but also the degree of importance they place on each domain therein, resulting in a weighted score of each domain and overall QoFL.

Additionally, the QofLI has been validated against the WHOQOL (Frisch, 2005). As this study is relying on WHO's definition of health, it is important to use measures which are consistent with tools recognized by the WHO as measurement tools for the variables in question. Another strength of the QofLI is that allows participants to reflect on the degree of importance they place on each domain, as well as their satisfaction with the domain, providing a weighted satisfaction rating within each domain of the measure. Originally, the QofLI was norm-referenced across 798 individuals in 12 US states. The sample was reflective of racial and ethnic diversity based on the 1990 US Census.

The QofLI provides raw scores, weighted satisfaction ratings, and conversion scores reflecting the respondent's opinion of the importance of a given aspect of his/her life in comparison to his/her satisfaction with that aspect. Reliability is high (0.73, $p < .001$) with an internal consistency of 0.79. Validity for this measure was compared to and reflected a significant correlation with the Satisfaction with Life Scale (SWLS) ($r = .56$, $p > .001$) and the Quality of Life Index scores ($r = .75$, $p > .001$). Table 3 depicts the scores in each thematic group and overall QofL ranking achieved by each participant in the study, as well as the mean, standard deviation (SD) and range of scores achieved by participants.

The QofLI is useful for planning and evaluating potential impacts of interventions on respondents. Two participants in this study, a parental caregiver and a sibling caregiver, achieved raw QofLI scores of -2.94 and -0.125, respectively, placing them in the Very Low category for overall QofL with scores ranking in the first and third percentiles; in other words, 1% and 3% of the population achieved a score higher than

that achieved by these participants, respectively. Another parental caregiver achieved a raw score of 1.33, ranking in the 17th percentile and Low range for QofL.

The participant with ASD achieved a raw score of 1.07, ranking in the 23rd percentile and the Average range of QofL. The results in Table 5 indicate each participant's subjective ranking of overall QofLI, whereas Table 6 reflects the weighted satisfaction scores for each domain as ranked by each participant. Both participants Bart and Emiline were excluded from these tables as they completed only the interview and did not complete the measures.

The QofLI also provided respondents in this study opportunities to identify barriers to satisfaction with QofL in each of the 16 domains. Barriers to satisfaction with their circumstances in each domain as described by participants in the QofLI are also reported here. They are reported by domain, with an effort to remain consistent with the themes identified.

Participant	Raw Score	t-score Range	Percentile Rank	Ranking
Abigail	-2.94	8	1	Very Low
Louisa	1.33	40	17	Low

Theresa	-0.25	28	3	Very Low
Mitch	1.07	43	23	Average
Mean	-0.1675			
Raw Score				
SD	1.95			
Range	.94-1.33			

Table 5. Subjective Rankings on the QofLI.

Participants				
Areas of	Abigail	Louisa	Mitch	Theres
Life				a
Health	-6	-4	2	-9
Self-Esteem	-6	4	6	2
Goals & Values				
Goals &	1	2	6	4
Money	-6	1	0	-3
Work	-6	2	-6	-6
Play	-3	2	6	0
Learning	-3	2	6	6
Creativity	-6	4	4	6
Helping	2	4	6	6
Love	-6	-4	6	0
Friends	-4	-1	6	4

Children	-6	4	-6	6
Relatives	4	-1	4	0
Home	-6	2	6	-6
Neighbourhood	-6	1	6	-6
Community	-6	2	4	-6

Table 6. Weighted Rankings by Domain on the QofLI.

4.1.2 World Health Organization Quality of Life Index -Brief

The World Health Organization Quality of Life Index – Brief Version (WHOQOL-BREF) (World Health Organization, 1996) was created to address researchers’ concerns that the original 100-item version (WHOQOL) was too lengthy for use in research studies incorporating other surveys or questionnaires. Out of respect for the caregivers’ time, the WHOQOL-BREF was used instead. Including 26 items, the WHOQOL-BREF retained items from 24 facets in the WHOQOL-100 to assess four dimensions of QofL: physical health, psychological health, social relationships, and environment. Two items from the overall QofL and general health facets of the WHOQOL-100 were included in this measure. This measure is a tool recognized by WHO. As this study relies on the definition of health used by WHO, using a measure which is recognized by WHO is important to ensure validity.

Participants rate items on the WHOQOL-BREF on a 5-point Likert-type scale (i.e., 1 = Not at all, 5 = Completely; 1= Very poor, 5 = Very good; 1= Very dissatisfied, 5

= Very Satisfied; 1 = Not at all, 5 = An extreme amount). The WHOQOL-BREF was tested for reliability across a sample of participants in 23 countries ($n = 11,830$), reflecting physical and mental health conditions consistent with the demographics and prevalence in those countries (Skevington, Lofty, & O'Connell, 2004). Participants were recruited from standard living situations, assisted-living areas, residential care centres, hospitals, and rehabilitative care settings. Internal consistency was assessed using Cronbach's alpha (physical health: $\alpha = 0.7$; psychological health: $\alpha = 0.81$; social relationships: $\alpha = 0.68$; environment: $\alpha = 0.80$).

Validity measures demonstrated that QofL was most strongly associated with health ($R^2 = 0.42$; overall health: $R^2 = 0.41$; overall health + overall QofL: $R^2 = 0.52$).

Raw scores are then transformed to render the scores consistent with the original WHOQOL-100. These scores can then be ranked as follows: scores lower than 45 are ranked as "Low", scores ranging from 46 to 65 are ranked as "Moderate" and scores exceeding 65 are ranked as "Relatively High". Table 7 reflects the scores achieved by participants on the WHOQOL-BREF. Participants Bart and Emiline were excluded from this table, as they did not complete this measure.

Transformed Scores	Participants			
	Theresa	Abigail	Louisa	Mitch
Physical Health	19	31	63	81
Ranking	Low	Low	Moderate	High
Psychological	31	19	63	69
Ranking	Low	Low	Moderate	High
al Relationships	31	0	25	56

Ranking	Low	Low	Low	Moderate
Environment	19	19	50	63
Ranking	Low	Low	Moderate	Moderate

Table 7. WHOQOL-BREF Transformed Scores and Rankings. WHOQOL-BREF Transformed Scores and Rankings

4.1.3 Personal Well-Being Index – Adult Version (PWI-AV)

The PWI-AV (International Wellbeing Group, 2013) uses a 10-point response scale format to analyze respondents' satisfaction with and perceived control over seven life domains: standard of living, health, achieving in life, relationships, safety, community-connectedness, and future security (i.e., 1 = No satisfaction at all, 10 = Completely satisfied). This measure is considered a reliable and valid measure of subjective well-being homeostasis (International Wellbeing Group, 2013). Examples of questions posed include: "How satisfied are you with your standard of living?" and "How satisfied are you with what you are achieving in life?". These scores are combined to calculate an overall score, intended to reflect one's overall life satisfaction.

The maximum variation in subjective well-being has been found to be 3.2 percentage points, with Cronbach's alpha between 0.70 and 0.85 and moderate inter-domain correlations ($\alpha = 0.30-.55$) and item-total correlations ($\alpha > 0.50$). The PWI-AV has also been measured for validity against the Satisfaction with Life Scale (0.78). The normative range for Western populations is reported to be 70 to 80 points (International Wellbeing Group, 2013). The range for participants in this study was 20 to 69.38 points. Table 8 reflects how these scores were allocated by domain and overall.

PWI-A Domains	Participants			
	Abigail	Louisa	Mitch	Theresa
Standard of Living	30	40	35	50
Health	10	40	50	50
What You are Achieving in Life	40	30	100	70
Personal Relationships	0	30	100	30
How Safe You Feel	0	20	0	80
Feeling Part of Your Community	0	40	100	70
Future Security	0	30	20	70
Spirituality or Religion	30	60	100	50
Overall Life Satisfaction Score	20	40	69.38	62.5

Table 8. PWI-AV Scores by Domain and Overall

4.1.4 WHO (Five) Well-Being Index (1998 version) (WHO-5)

The WHO-5 (Psychiatric Research Unit, 1998) is a 5-item scale (0 = At no time, 5 = All of the time) that measures respondents' experiences with happiness (e.g., mood, energy, and interests). In a systematic review of the literature on research using the WHO-5, Winther Topp, Østergaard, Søndergaard, and Beech (2014) found that this measure demonstrated strong validity across several studies. Again, it is a measure of well-being, recognized by WHO, rendering it a suitable measure for this study, which relies on the definition of health used by WHO. Table 9 reflects scores achieved by participants for

each item. Scores which fall below 13 suggest poor wellbeing (Psychiatric Research Unit, 1998).

Item	Participants			
	Abigail	Louisa	Mitch	Theresa
I have felt cheerful and in good spirits	0	2	3	1
I have felt calm and relaxed	0	2	3	1
I have felt active and vigorous	0	1	3	0
I woke up feeling fresh and rested	0	1	2	0
My daily life has been filled with things that interest me	1	2	4	0
Raw Score	1	8	15	2
Percentile	1st	32	60	8
	Percentile			

Table 9. WHO-5 Item Rankings, Raw Score and Percentile Rankings.

4.2 Qualitative

This section presents the qualitative results, with a discussion of the themes and subcategories that were identified. To facilitate analysis of data, analytic memoing was used and coding was an iterative process, cross-referencing what participants reported with policy documents and grey literature to ensure rigor. In the discussion section, these results are discussed within the context of existing empirical research. For the purposes of identifying themes, Hall's (2009) themes for effective social inclusion informed the coding and development of subcategories. Assarroudi et al (2018) take the stance that rigor is enhanced by establishing links between themes and subcategories. Overarching Hall's (2009) themes were corresponding codes which arose throughout every theme and subcategory identified. Table 11 reflects how these corresponding codes relate to Hall's

themes. These corresponding codes emerge implicitly in statements made by participants and in their interpretations of their experiences quoted herein.

Hall's Themes for Effective Social Inclusion	Corresponding Codes
Feeling Accepted as a Person Beyond One's Disability	Isolation
Having Meaning & Reciprocal Personal Relationships	Isolation
Being Involved in Activities	Isolation
Having Appropriate Living Accommodations	Housing Preferences
Being Employed	Isolation Financial Constraints
Receiving Formal & Informal Supports	Waitlist for Services, Distrust in the System

Table 10. Correspondence Between Hall's Themes for Effective Social Inclusion (2009) and Corresponding Codes.

4.2.1 Interviews

All informal caregivers completed a semi-structured interview lasting approximately 1 hour in addition to questionnaires. Participants were given the option to complete questionnaires over the phone as an interview with the researcher or to have questionnaires mailed to them for completion at their convenience. Informal caregivers (n

= 4) opted to have the questionnaires mailed; the participant with ASD chose to complete them over the phone, such that the interviewer read the items to him and recorded his responses. In this case, the participant was asked the same questions as the informal caregivers, but they were re-worded to reflect that he was meeting his own needs rather than those of another person.

The formal caregiver did not complete the questionnaires, which covered material that would be influenced by one's living circumstances. Because this caregiver did not live with a person with ASD and was paid to be involved with people with ASD, for the purposes of this research, the results of these measures would not be applicable to him. The questionnaires pertained to QoFL and personal well-being. The paid caregiver had chosen to work with people with developmental disorders and possessed the necessary training and credentials to do so. His QoFL and personal well-being would likely be more influenced by his family situation and job satisfaction and presumably not comparable to those of unpaid caregivers who may have no prior training in caring for a person with ASD and who provide care in addition to their own jobs and/or personal pursuits rather than professionally.

In addition to the questionnaires, participants were asked to discuss their experiences accessing services and/or providing care to the individual. In the case of the formal caregiver, he was asked about his experience providing care along with his understanding of services, funding, and policy. He was also asked how his clients used available services and supports and what he believed was needed by his clients and their informal caregivers.

There was a significant amount of overlap between themes. For the purposes of clarity, efforts have been made to keep them distinct. However, in many instances, the overlap is unavoidable. Themes identified were consistent with Hall's (2009) themes for effective inclusion. These themes were considered broader, overarching themes under which subcategories were subsumed (i.e., health and mental health, isolation, housing preferences, advance care planning, suitability of services and supports, inefficiencies, waitlists and distrust in the system, health and mental health, isolation, financial constraints) which emerged consistently across participants. In several instances, these subcategories overlapped with one another. For instance, some participants associated mental health needs experienced by themselves and/or their loved ones as arising from lack of access to services and supports due to inefficiencies in the system. In presenting the data, efforts have been made to reflect these overlaps within the most relevant overarching theme. Where overlaps between themes have occurred (e.g., experiences of being isolated from the community impacting on one's ability to experience acceptance beyond a disability, as well as hindering development of meaningful and reciprocal relationships, as well as involvement in activities), efforts have been made to locate these themes sequentially within the body of the text.

The two most common themes to arise were: 1) accessing appropriate living accommodations and 2) accessing formal and informal supports. No participant felt that the living accommodations they and their loved one were access were suitable to the individual with ASD. However, there was inconsistency as to what they believed would constitute appropriate living accommodations.

4.2.1.1 Appropriate Living Accommodations

Housing suited to their loved one's abilities and needs was a primary concern for all caregivers, as it was for Mitch. He lives with his parents in a house in a neighbourhood he described as "very nice", stating he would not be able to live there if he lived on his own. He reflected that the ODSP funding he receives would not be sufficient for him to live in his own apartment, speculating that to do so, he would need to move to a small town where living expenses would be lower.

Contemplating getting his own apartment, he stated that he did not believe his funding was sufficient to get his own apartment, he replied: "I'd have to live in small town Ontario like [names four cities] where things are a lot cheaper". He relies on his parents for assistance with managing his finances and for is able to pick up contract work in their businesses from time to time, so leaving the city he lives in would not be an option.

In completion of the QofLI, he reflected on his circumstances in the Housing domain: "Where I live is great but I would prefer to live on my own" and in the Neighbourhood domain: "This is not really a problem. I mean, it's a great neighbourhood. If I had to live on my own, I couldn't afford to live here and would be in a much worse neighbourhood.". He further explained that the housing options he had been presented with did not meet his needs, expressing concern about the location:

They're trying to get me like on a waiting list for like community housing and I don't want to live in community housing. I live in a very nice house in a nice neighbourhood and for me Community Living is not exactly in the best neighbourhood and so, I'd rather not live in community housing

Reflecting on what he would need to be comfortable in an alternate housing option to that of his parents' home, he stated:

I think living at home just for now. Like I don't know what my plan is five years or ten years down the line, I really don't know. So it's going to have to depend on some of the stuff I'm going through right now and yeah.

Theresa reported that her son has been in a hospital psychiatric ward for 4 months due to aggressive behaviour at home. She concluded he could no longer remain in the home for her safety and that of her other child living at home:

... I think the fact right now, the hardest thing for us is the residential or housing, him not – that's why he's in the hospital, because there's nowhere in the community for him to go. I would say that's [son's name] biggest need that's being unmet at this point in time, is funding, because if he had the funding, we wouldn't need him to be living somewhere else, and if we couldn't get the funding, definitely housing for him. They've talked about group homes. They've talked about treatment facilities and there's just so many waitlists.

When asked what her ideal housing arrangement would be for her son, she replied: "Mine would be in a group home, but with direct, one-on-one, when it comes to the behaviours, and for him to get, whether it be counselling or psychotherapy or something, to deal with the trauma and address his behaviours."

Both sibling caregivers whose brothers had been raised primarily in institutions reported that efforts had been made to have them live in less exclusive, community-based

settings. However, both efforts were unsuccessful, resulting in eventually requiring them to move into nursing homes despite having some capacity for independence. In the case of Emiline, her brother had been living independently prior to breaking his hip. However, upon breaking his hip, he was hospitalized. Eligibility for physical rehabilitation was contingent upon having a confirmed address upon release from the hospital. However, Emiline did not feel she was physically or mentally able to care for him in her home.

In describing the process of pursuing physical rehabilitation for her brother when he broke his hip, Emiline described her experience getting her brother into a nursing home as follows:

The social worker in the hospital, the social worker who came to see him in the group home, they all knew what they were doing was wrong but they couldn't do anything because their job was to keep him out of the hospital. The thing is, what happens is, people end up staying in the hospital until a nursing home spot comes up and they don't want to do that. So they send them to these second or third class, what they call group homes but they're not, they're just very poorly run, I don't know what they are, they're terrible. They should be, they do criminal things there. It's terrible. It was just terrible. Horrible.

According to Emiline, the source of the difficulty accessing suitable housing arises as an effect of Ministry regulations which seem to prioritize discharge from hospitals, relying upon informal caregivers to achieve this goal:

So the person who helped me was this doctor, a compassionate doctor who saw what was going on and said 'well, if he would have just been kept in the [hospital], it's the way the Ministry sets it up is they say he couldn't go to rehab.

Emiline explained that there were two consequences to her brother resulting from this regulation. Her brother could only access rehabilitation if Emiline guaranteed that he had a home once discharged from the in-patient rehabilitation program. In cases when informal caregivers are unable to provide in-home care to the person in question,

admission to a nursing home is necessary. However, the wait-times to access nursing home placements is so long that it prohibits access to shorter term in-patient rehabilitation, access to which is dependent upon having somewhere to go upon discharge:

It's terrible. It was like a circular, there was no way out. There was no way to do it...And the only place would be the nursing. And the nursing homes, you can't, there's no guarantee that you can get in at the end of the four or five months.

Although it was clear that living arrangements was a concern for all participants, there were different priorities and preferences communicated. For instance, Louisa expressed a desire for transitional housing where her son could learn skills to allow him to live independently prior to actually living independently:

Right now he lives the – my favourite line, he lives in a glass bubble. We know what he needs in our home. The school, the same situation. They know, right? In a glass bubble. But when he hits reality, he's going to need supports with him. And he's going to need a bit of practice at this, you know what I mean?

She went on to describe an arrangement that she thinks would be ideal for him:

What I'd like to see in our community, you might call that a halfway house, right? Where he could go for a weekend, to a little apartment. You know, maybe other guys there or something like that. Almost like a – maybe a transition house, I don't know. But haven't found any online but he could practice because you know, with ASD, it takes a lot of build up right? To get them to certain places. Especially with ASD. ...

Her reflections on the wait for services and supports to coordinate the ideal living arrangement were punctuated by frustration: “There’s all those things you know. And I’ve got 10 years to wait. Grr. I don’t think so!”

Some participants took exception to group homes. For instance, Abigail stated: “We don’t trust group homes so he’ll move in with me when mom can’t care for him any longer. I’ve been shaping my career and income expectations around that.”. Others reported a sense of stigma around group homes. For instance, Louisa stated:

My brother would do all right in an apartment out in the community with a worker. You know. He would do all right. But he would need that worker each day and overnight. So, providing that kind of service and a one-on-one, that’s going to be extremely expensive. So, I can see the small settings, like two or three. Even that, I’m not real keen on. But a group home is – it’s ... you know, people walk by and go ‘Oh, that’s a group home.’ You know. Or communities say, ‘We don’t want it over here.’ You know, ‘It’ll bring down the value of our homes.’ That’s why I think ... an apartment building, when new buildings and complexes are built, there should be a certain percentage, say 10 percent, set aside within that whole building for individuals who have special needs. You know, they shouldn’t be housed, congregated. They shouldn’t be segregated. They should be out and about.

Alternatively, Theresa explained that her son could live on his own if they could afford the cost to provide him with an apartment:

We’ve heard that, you know, the government’s putting money into it now, now it’s still a waiting game as to, because if he had the funding there would be no need for him to be in the hospital because I could get him the services he needs. That’s the unfortunate part. I’m not working, we’re relying on the system, because we can’t afford, if we had the money, he wouldn’t be in the hospital. There would be a place for him to go. It’s unfortunate, because we have no choice but to rely on the system that operates in Ontario. This is where we’re at with that system.

Later, she identified suitable housing for her son as her family’s greatest unmet need:

As far as them [needs] being unmet, I think the fact right now, the hardest thing for us is the residential or housing, him not – that’s why he’s in the hospital, because there’s nowhere in the community for to go. I would say that’s [son’s name]’s biggest need that’s being unmet at this

point in time, is funding, because if he had the funding, we wouldn't need him to be living somewhere else, and if we couldn't get the funding, definitely housing for him. They've talked about group homes. They've talked about treatment facilities and there's just so many waitlists.

When asked what her ideal housing arrangement would be, Theresa stated:

“Mine would be in a group home, but with direct, one-on-one, when it comes to the behaviours, and for him to get, whether it be counselling or psychotherapy or something to deal with the trauma and address his behaviours.”

Housing suited to their loved one's abilities and needs was a primary concern for all caregivers. Mitch also cited housing as a concern. Consistent with Mitch's sense that he could live on his own but is not prepared for managing many of the related tasks, Louisa reflected on her son's needs. She speculated that although he would be competent to live independently, he would require a period of sheltered skill development which requires more independence than is available to him while living at home:

What I'd like to see in our community, you might call that a halfway house, right? Where he could go for a weekend, to a little apartment. You know, maybe other guys there or something like that.

Almost like a – maybe a transition house, I don't know. But haven't found any online but he could practice because you know, with Autism, it takes a lot of buildup right? To get them to certain places. Especially with Autism...there's all those things you know. And I've got ten years to wait.

Theresa reported that her son has been in the hospital for four months, in the psychiatric ward due to aggressive behaviour at home. She concluded that for her safety and for that of the other child living at home, he could no longer remain in the home:

...I think the fact right now, the hardest thing for us is the residential or housing, him not – that’s why he’s in the hospital, because there’s nowhere in the community for him to go. I would say that’s son’s name’s biggest need that’s being unmet at this point in time, is funding, because if he had the funding, we wouldn’t need him to be living somewhere else, and if we couldn’t get the funding, definitely housing for him. They’ve talked about group homes. They’ve talked about treatment facilities and there’s just so many waitlists.”

When asked what her ideal housing arrangement would be for her son, she replied: “Mine would be in a group home, but with direct, one-on-one, when it comes to the behaviours, and for him to get, whether it be counseling or psychotherapy or something, to deal with the trauma and address his behaviours.” There was no consensus on group homes as a suitable living arrangement.

Although she did not express dissatisfaction with her own housing circumstances during the interview, Theresa did cite concerns both with her housing and the neighbourhood she lives in as barriers to satisfaction section in these respective domains: “[Due] to my job being raising my children on ODSP, we currently live in geared to income housing in a bad area of th[e] city -> owning my own home is a dream.” And “As stated above, living in rent geared to income we live in a bad area of the city.”

Consistent with this finding, Abigail did not express concerns with her family’s home, except to say that she preferred to live away from her mother and brother for her own safety. However, on the QoL, in the barriers to satisfaction, she cited concerns both with her own housing, as well as that of her brother:

Our housing situations are not good – I live in one of the places I can afford and that is close to my brother. I am not in my home by choice & prefer to live elsewhere. The same goes for my brother. He lives where he does because he receives support.

None of the participants in this study mentioned the IFCO, OIFN, IFDP or any of the housing initiatives that the province is pursuing. They did not indicate any awareness of these projects. In an effort to address the need for suitable housing options, the regional DSO offices created housing coordinator positions in 2017. None of the participants indicated any awareness of this role within their local DSO provider, nor did they communicate accessing any services fulfilled by the housing coordinator role.

4.2.1.2 Receiving Formal & Informal Supports

This section is broken down into the subcategories which arose from participants' comments. These include: a) advance care planning, b) suitability of the supports available, c) infrastructure and system effectiveness and d) health and mental health.

4.2.1.2.1 Advance Care Planning

Louisa focused more on her son during the semi-structured interview than her brother.

Although she is involved in her brother's care and advocated for more suitable services, her priority was caring for and procuring suitable services for her son. In her words, "I'd like to go to my grave knowing [his care is] going to be set up before I die. Or it's happening already. [long pause] Oh dear."

Mitch also expressed concern about how his parents' mortality would impact on his circumstances. When asked about concern he has for the future, he replied: "Yeah, you know, I'm concerned about, you know, how I'm going to function after my parents are gone cause they're not going to live forever. That's one of my biggest concerns." In response to a question about whether or not he discusses his concerns with his parents, he

replied: “Not as often as I probably should but it’s a topic I don’t really to think about especially after the last few years I’ve had in my family with death.”

Echoing this sentiment regarding an urgency to resolve care issues prior to one’s own death, Emiline cited an incident in the nursing home where an employee of the nursing home treated him roughly. The employee, following confirmation of the incident by a colleague who witnessed the event, was terminated. However, Emiline stated that although her brother is capable of recognizing when he is being maltreated and reporting it to her, he may not advocate for himself in the same way when she is no longer able to do so: “He knows, my only worry is if anything happens to me then he’ll, you know, I’ll just have to accept the fact that he’ll die.”

4.2.1.2.2 Suitability of Supports

Theresa also reported concern about the care her son was receiving in the hospital, citing concerns about the staff lacking the required expertise to care for him in a way which reflects his needs:

...You can see the wear and tear you’re having on the nurses, because [son’s name] is high maintenance behaviour and you can see the nurses that are getting up with it. They don’t want to deal with them, because they’re becoming ignorant to me and [son’s name] other family, visitors that go up. They’re becoming ignorant because they don’t want to deal with it, all because of the fact there’s nowhere in the community to put him. [clarification sought about ignorant behaviour by nursing staff in psychiatric ward]...[son’s name] is a huggy person. Well, you’re in a mental health ward, you’re not allowed to hug, he gets hand props. So one

of the nurses at the beginning, the first [son's name] says "oh, this is my mom", she's like "oh hi" and she's all nice. Each time since then, her demeanor's changed. There are certain nurses up there, you walk in and you can tell. There are nurses that won't give me any information. I've got ten pages of stuff, I've actually tried to contact the patient care manager on the advice of the hospital social worker, and she's not getting back to me. They are not trained in the hospital to deal with people with ASD. They don't know how to deal with [son's name]. It's like they get frustrated because he is – yes, he's 21, he's a big guy, but he's a kid. He is totally a kid. He's a kid in a grown man's body.

Although he can communicate effectively, she reported her son has the "maturity of an 11- or 12-year-old." He was diagnosed with ASD at age 10, at which point he was described as having behaviour and cognitive functioning consistent with a diagnosis of Asperger's syndrome but exhibited more impaired social, language, and communication skills.

Abigail expressed concern that policy, services and support do not seem to be informed by knowledge of the needs of those they target:

Well, I mean, if they actually knew what it is like, what it takes, I don't know, maybe then they would make better decisions, inform their decision making with experience...My brother is 220 pounds and very aggressive. He has ASD but also has an intellectual disability, depression, anxiety disorder and cerebral palsy and now we're wondering if he has schizophrenia, so he needs a lot of help. He's on SSRI's, antidepressants

and PRN's which he has to take two times a day...his health needs are complex and I feel like we're left in a void.

Contemplating what he would need to live independently, Mitch stated he did not know but also identified a need for assistance with financial management:

Honestly, I don't know. In all realness, I really don't know. There's a lot of stuff I'd have to work on before I could be successful living on my own. And not just with financial literacy, I'm not good with taxes, like I struggle with math and science so that's a big part of that.

In relation to the services and supports available to him through DSO, he reported feeling that they did not reflect his needs or interests:

...they were trying to get me on a bunch of lists for stuff I wasn't wanting and so it was really, was sort wait for things I'm really not ready and so it's, yeah, it's really like, and then they've been pretty useless since...They were trying to get me on a waitlist for different education programs and formal education was never my forte. I did finish high school but it took me eight years instead of four years....

It was unclear which education programs he was referring to. However, he also reported dissatisfaction with Community Living:

Well, for a while I was getting services from Community Living Toronto and Ontario but then they kind of, I'm not too happy with them honestly, and I haven't been for a while. They were giving me services and then all of a sudden they just like went ghost on me. Like they're not

responding to my calls, my text. I've gone in and when I go in it's almost like they don't want to deal with me.

He also reported a similar experience with DSO: "They kind of just ghosted me like at Community Living as well." In both cases, it seems as though the agencies had exhausted the options available to him without identifying any which reflected his strengths, priorities and needs.

He reported that one of his unmet needs is money to cover his medical expenses. When his funding is insufficient to cover his medical expenses, he relies on money earned from sporadic, casual work opportunities: "Like I said, I have to spend out of pocket from other money I've earned." He had difficulty identifying or predicting expenses he would encounter living on his own, focusing more on how he currently uses his funding (i.e., on food, clothing, and non-academic professional development training programs).

Mitch is quite high functioning, so services which meet the needs of people with intellectual deficits will not necessarily align with those of his own. He reported a need for assistance with higher order skills such as financial planning and budgeting, envisioning how he wants to live, how that can be achieved and developing a plan to achieve that. Although he has potential to live independently, he does have needs which, if met, can facilitate doing so.

Reflecting on how he uses his funding, he explained: "I'm using some my ODSP. I used it \$700 of my ODSP to pay rent to my parents out of the \$1100 and then I have to use the rest for groceries, my cellphone, my clothes and that's not enough really". I just get the money and then I deal with what I need, like whatever it is that I need and that's

it. He uses his Passport funding in order to achieve his career goals and participation in the community:

I use it for my acting school, I use it for when I go and work out at the gym, and yeah, and that's been really great. So it's been like \$4500 a year and they just upped me another \$500 to \$5000 a year.

Louisa reported her brother was removed from an institution in 1998 following discovery that he was being abused, but he will not discuss the abuse. Their parents then cared for him until they passed away, at which point he lived with Louisa until she and her husband were no longer able to care for him and their son who also has ASD. Since then, Louisa reported that her brother has been “default re-institutionalized” (i.e., living in the developmental disorders ward at a psychiatric hospital due to lack of housing options appropriate to his needs).

Only one participant reflected on her active pursuit of information from the local service agencies. Louisa reported:

I call regularly to the Passport manager. Not to the frontline girl. Not doing the frontline stuff anymore. I want to talk to whoever's in charge. And – and she's ... and it won't take very long before I get a call back. ... I shouldn't have to do this, you understand? I mean not that I'm too proud or someone special. I should not have to chase up a service that he's going to have to have to survive out there.

She also expressed frustration with spending priorities within the province:

... our health unit has a brand-new, shiny building. Community Living has renovated their building and built on. That place is a shiny new spot. All those things in our community, billions – I should say millions of dollars spent, and our family is waiting 10 years to get support and a place for our son to live. And they have their fancy new place? This is not balanced. ... It's not that they don't deserve it. There's lots of dedicated men and women out there working in the disabilities sector, working hard. And it's not that they don't deserve it, but not at the expense of families

that are waiting. So we get into their shiny new building, do our ... we get to get told, 'Yeah, 10 years.' [pause] But we were comfortable. Bright, shiny new building, little electric fireplace. And here we sit trying to plan for our children. What are we going to do?

Louisa also reflected on the challenge of planning for her future and that of her son. Citing the impact of her son's aggression toward her, she expressed frustration with all the unanswered questions and variables she needs to coordinate while also coping with her trauma:

How do we plan? You know. If you think about my trauma and all that stuff, you know, on top of this I have my doubts about where you – you know, first of all, trying to navigate the system and then try to figure out, what is the plan for my son? And when is that going to happen? And how much is the money going to be?

4.2.1.2.3 Infrastructure & System Effectiveness

At some point during three of the interviews, participants spontaneously thanked the researcher for conducting this research, making a statement indicating that it was much needed. Comments ranged from a desire for increasing understanding among the general population about the needs of adults with ASD and their families (e.g., "Thank you for doing this. It's about time that the adult sector got a little more attention. I think people think, well they get the money, they get the ODSP. You know. They get that – you know, they'll be fine. It doesn't change after you're eighteen, you're still Autistic.") to a desire for the research to be done to inform policy (e.g., "I'm alright I guess but I guess I really just wanted to thank you for doing this research. It needs to be done. I honestly don't think anyone in this government has ever known somebody who has ASD."). The

sentiment that policy makers do not understand what is needed or what caring for someone who has ASD was echoed by other caregivers, such as Louisa:

I also work with some politicians. Just before this election, we attended a rally. And, we were going to have a debate, until the parties pulled out. And, I knew it's the politicians that make changes and they need to be aware of what we're going through. I would tell them openly, you need to do at least one week of working with our kids. Volunteer and work with them and get a feel of what this is like...

...it's only about making it real. Because everybody talks about it from here and policy and in the perfect world and if everything works right, but on the ground, it's not like that at all.

Another perception communicated was that the needs of adults with ASD and/or IDD are not adequately addressed because the political motivation among the general public is lacking: "...it's, some people just don't know. People just don't know. And it's not that they don't want to know but everything is else is put in your face. Again, mental health, Indigenous, victims of domestic violence, but not developmentally disabled and the families are taking care of that, so nobody else has to think about it."

Reflecting on the challenges associated with going out in the community, Abigail explained that because funding is so limited, the turnover rate among respite care workers is high enough that the caregivers rarely learn to understand her brother's bids for communication:

Yes, he's really aggressive and he has motor movements which make people uncomfortable. They don't really know how to act around

him, which upsets him and then starts getting loud and aggressive. My mom and I know how to work with him to keep things from escalating but we never get enough time with the workers to teach them how to do it, so we end up being the only ones who can go out anywhere with him.

Passport funding excludes therapeutic services such as speech and language pathology, occupational therapy and applied behaviour analysis (Developmental Services Ontario, 2014b). Consequently, when clients have communication or behavioural barriers, they do not have access to services to mediate those challenges, requiring those who are familiar with the client to develop their own strategies.

He had an SLP until he was 10 but has had nothing since then.

Nothing's been tried except for a picture board my mother and I made for him. We don't know what we're doing though, so it's all just been trial and error, seeing what works. It would be nice if someone who knew how to do it could even just show us how to make it better for him. He's on a waitlist to be assessed by an SLP but it could be at least four and possibly five years...he really doesn't have another way of communicating. My mother and I can understand him because we've known him all our lives but it's not like he can talk to the cashier at a store even. He gets frustrated and lashes out and strikes out. It comes from being misunderstood. Really, any sort of support would be nice right now but communication is huge. I feel really guilt-ridden saying this...The policies are incredibly ill-informed. The expectations they have of families are just insane. It's discriminatory, you know? My brother is forced to go everywhere with his

mom and me. It's not good for his development. It's infantilizing to have to rely so much on his mom. Especially for a grown man.

Louisa expressed frustration with the process required to coordinate services. She indicated that she no longer tolerates this process, taking her concerns directly to the relevant manager: "I call regularly to the Passport manager. Not to the frontline girl. Not doing the frontline stuff anymore. I want to talk to whoever's in charge. And – and she's...and it won't take very long before I get a call back....I shouldn't have to do this, you understand? I mean not that I'm too proud or someone special. I should not have to chase up a service that he's going to have to have in order to survive out there."

Additionally, she expressed consternation with the funding priorities of the government in delivering services and supports in the community:

...our health unit has a brand new shiny building. Community Living has renovated their building and built on. That place is a shiny new spot. All those things in our community, billions – I should say millions of dollars, spent and our family is waiting ten years to get support and a place for our son to live. And they have their fancy new place? This is not balanced...It's not that they don't deserve it. There's lots of dedicated men and women out there working in the disabilities sector, working hard. And it's not that they don't deserve it, but not at the expense of families that are waiting. So we get into their shiny new building, do our...we get to get told, yeah, ten years [pause] but we were comfortable. Bright, shiny new building, little electric fireplace. And here we sit trying to plan for our children. What are we going to do?

The inconsistency of funding within and between electoral terms was also cited by participants as having a negative impact on their ability to meet the needs of their loved one with ASD and for themselves: “How do we plan? You know. If you think about my trauma and all that stuff, you know, on top of this I have my doubts about where you – you know, first of all trying to navigate the system and then try to figure out, what is the plan for my son? And when is that going to happen? And how much is the money going to be?”

Several participants commented that one of the challenges they face when planning for their loved one’s care was that services and supports available, as well as funding structures, are subject to change depending on which political party is in power. Reflecting on the issue of unsuitable placement in a hospital rather than a placement which would allow more autonomy and independent functioning consistent with her loved one’s ability, Louisa discussed her loved one’s current situation:

I’m sorry. Brother’s name is still in the hospital in the developmental wing. We got a – here we go again, June election coming, so they did a big thing about getting people out of nursing homes, out of hospitals where they didn’t belong. Brother was right up there on their list...They’ve come back on board after telling me they couldn’t take him. They’ve come back on board and said ‘yeah, yeah’. But you’ve got government saying, I don’t know, \$50 000, \$75 000 here, take care of him. They’re not going to say no... And I’m going, praise God. He’ll have his own little separate spot. Because he’s so Autistic, right? He’ll have his own little spot in that house and a 24-hour worker. I’m going praise God.

But what he had to go through. What our family had to go through... And I'll bet you that if it wasn't an election year it wouldn't happen. Not at all.

Related to this uncertainty is the duration of waitlists and the potential for skill development or loss of skills of their loved one with ASD: "Ten years or more...and I'm saying God, will I survive it? Will he survive it? And what shape is he going to be in when we get there?" Participants were not solely focused on their own needs. They made a point of highlighting the needs of other families in similar circumstances:

And these other families that have to go into crisis or do go into crisis and get their spots, what kind of shape is that individual going to be in, in order to make it the best independent situation for them? They're already damaged and in crisis. That's not right. Families shouldn't have to go into crisis in order to get a place for their children to live. That's the reality of the system right now. It's not good.

In her efforts to advocate for services, one participant stated that service providers at DSO and the Passport funding offices have instructed her to embellish her needs in order to expedite access to funding and/or services:

I've actually had professionals say to me – now we're Christians, we have ethics, we have – you know, strong faith. I've had them say to me, Participant's name, just exaggerate a little bit more. Just lie, just tell them a little bit more. And then I think to myself, you want me to lie, that's what you want to do? That would be us stepping on other people. It's not right... I could probably do a song and dance, blah blah blah, and get our scores higher. It probably wouldn't get me immediate one but – unless I

flip out or something. But – nobody should be forced to do this kind of thing. No family should be put in such a position that you have to claw, you know, or lie. It's not right. I won't do it.

Another option that participants have been presented with include trying to expedite access to services and supports sooner by moving to other communities in the hopes that the waitlists will be shorter in those communities:

I've been approached by people saying "well, why don't you extend the area, outside of the community that he can go to?" Well, number one, he's autistic, he knows this place, right? This is his home. Why would I be having it any other place? And besides, those other places, this is a province-wide ten years or more. And that's a low estimation, ten years. If you saw that program on whatever W whatever, or read the papers, twenty years or more.

The regions within the province are made up according to population size. Moving to another region is an ineffective strategy because municipalities in which populations tend to be smaller fall within regional catchment areas which are geographically larger than those in which populations density is greater. Population sizes and wait times are comparable across the province.

As policy makers move increasingly toward evidence based policy and programming, it may be necessary for academic and research institutions to examine their communication and public relations in terms of how they influence potential participants. Some of the approaches used in academia might be off-putting to the general public, thereby creating bias in terms of who is reflected in the research that gets done. For

instance, Emiline took exception to the section in the information and consent form where it stated that there were no known benefits to participation, citing the importance of hearing caregivers and expressing concern that the language in the form could be off-putting to some potential participants:

...the second page, under benefits I think there are benefits to participating in this study. It's an opportunity for caregivers to be heard and to hopefully influence future improvements in care for people who have ASD and those who care for them...I think there is benefit...To say there is no known benefits, well you could also say, there may be some benefits. I just think a more positive way of saying that because it's saying, why are you doing this if there are no known benefits. There could be some supposed benefits, that's what I'm trying, I think it's important because this is very hard work for the people who you're interviewing because it's very painful to talk about. Maybe that's one of the reasons you're not getting a lot of response.

4.2.1.2.4 Health & Mental Health

Concerns about health and mental health were not limited to only the person with ASD. Participants also reported concerns about their own health and mental health, often citing concerns about their ability to support their loved one given their own condition. Abigail is the 33-year-old younger sister of a 37-year-old man with ASD. Her brother has also been diagnosed with an intellectual disability, cerebral palsy, depression, and anxiety. Recently, his health care providers have queried a possible diagnosis of schizophrenia.

Abigail reported that the complexity of her brother's health needs have "left him in a void" because some services are funded only if the needs are associated with a health issue, whereas others are funded only if the needs are associated with a developmental disorder. Her brother lives with their mother:

My brother is plugged into the Ministry of Community and Social Services and Ministry of Health and Long-Term Care because of his cerebral palsy. He gets Passport funding but that's only enough for a support worker a couple of hours a week, two times a week... They do more of the person-to-person support, activities of daily living, you know, ADL. He's not being supported. It's more just relief for my mother for a couple of hours so she can take care of what she needs to do like if she needs to go to the doctor for her own health.

She also reported concern about her mother's well-being, as the primary caregiver. When asked what it would take to meet their family's needs, she replied:

It would take a pretty big intervention. Mom sees her health and her life destroyed by care work... A few times, mom has had the flu and I've had to be there. I have to be there and I have a hard time explaining to employers that I just have to be there.

Within the Health/Mental Health subcategory, another trend emerged, whereby participants cited concern for their safety arising from aggression perpetrated by their loved one with ASD. Abigail reported that her brother has also broken her glasses and bitten her. She speculated that her fear of her brother manifests itself as anxiety disorder.

She takes medication for anxiety and noted that her mother's health and mental health have diminished as a result of her brother's needs, stating:

“I have watched my mother's mental health deteriorate, and I could definitely benefit from counselling.”

She stated that although she needs to be near her family so she can help in the care and support of her brother, she prefers to live on her own and feels safer this way.

Abigail reported concern about her mental health and physical health:

Four out of seven days a week, I'd say my health is pretty bad. There's about three days a week where I feel energetic and positive but there's always issues on a weekly basis...Like he pushed my mom down the front porch. He didn't do it to be mean, I don't think. He gets frustrated and he doesn't know. He doesn't know that he can hurt her really badly. My glasses have been broken, we get bitten. I'm flinchey and mostly afraid of getting hurt but I can't show it when I'm around him. It comes out in anxiety.

In addition to caring and advocating for her brother, Louisa and her husband care for their 19-year-old son with ASD, who she described as 6'2" and weighing 250 pounds. Despite a diagnosis of ASD and developmental disability, the young man can reportedly “walk and talk quite well.” However, he can be violent. She explained:

Due to [my son] trying to kill me, the incident is always in the back of my mind. It is hard to accept that it will never go away and that it has altered and probably shortened my life and lifestyle. It is very hard not

to be resentful. On the other hand, it has given me a unique insight to empathize with other parents in the same situation.

Although reluctant to characterize her son as ‘aggressive’ or ‘violent’, Louisa did make a point of placing a limit on her tolerance for this behaviour: “If he attacks me again, I won’t have him come back in this house. We’ll have to do something, because I don’t want that kind of pattern to stick in his head, right? I can get things by attacking people...if it happens again, for my own health, for my relationship with my husband, he will not come back here.”

In her role as an advocate for parents of adult children with developmental disorders, Louisa finds strength supporting parents who have had similar experiences. She explained that it is relief to know that she is not alone in this experience and takes pride in being able to support other parents: “I’ve had parents call me crying because [pause] their son or daughter has taken a round out of them. They didn’t want to call the police. You know? They – you know?”

Consistent with this, Emiline reported mental health concerns related to trauma. When asked how many days her health had not been good over the last thirty days, Emiline replied: “It’s always not good. The doctor said I might have PTSD which is just a fancy word, which he said is just a fancy word, how did he put it? Remembering something too well.”

Echoing this sentiment, Louisa explained that she has learned through her advocacy work that families of people with ASD are experiencing exhaustion physically and mentally from the need to advocate for their loved one’s needs:

I can safely say that there's a lot of folks that are just sick and tired of this whole fight. They're beaten down with life itself and then life with kids with special needs. You know. And they just don't want to play anymore.

She argued that the struggles are not just limited to those who experience financial constraints:

It's a tough journey, you know. It's even a tough journey for those that have a lot of money. ... Trying to figure out the future for your child. And you've got to take off those rosy glasses sometimes and face the realities and do something."

She explained the effect of the ongoing nature of the stressors associated with caregiving had on her:

Once you have a child with special needs, it's a growing thing, right? For me it was a growing thing. Like, you know, I noticed I was tired and was cranky. ... These things irritated me or – you know. It accumulates and accumulates until you go 'That's enough.

Abigail reflected on the anxiety she experiences related to supporting her brother financially.

My mental health is very close to poor. I don't know if I can sustain this. One day per week when I just had a really bad visit with my brother and I expect to turn to my own work and I just can't. Usually, I just end up

obsessing and budgeting to pay out of pocket. Usually, it just comes back to money. I would say we're working class mostly but we're really poor.

In their analysis of uncompensated caregivers across 20 WHO member nations, Shahly, Chatterji, Gruber, Al-Hamzawi et al. identified that few resources are dedicated to sibling caregivers' health and mental health (2013). Their research examined caregivers of people with physical and/or mental conditions. The impact of caregiving duties to siblings was greatest on those caring for somebody with a mental condition (Shahly et al., 2013). Parental caregivers also experienced significant impact (Shahly et al, 2013). Consistent with this, when asked what needs go unmet for her, Theresa also reflected on the impact of the pressures she faces:

Sanity! No, I'm joking. Just support My thing as far as [son's name] is, I would have liked to have had him be able to stay home and have had respite. That would have been, that's how it would have looked to me in the grand scheme of things, because I knew that there would be a waitlist for the group home, it would have been to have [son's name] stay at home with supports in our home. But I know that's impossible.

She responded to the question of her unmet needs first by focusing on those of her son.

if he was in a group home or a treatment facility, we, we know he's getting help he needs, but being in the hospital, we don't know that, and they don't necessarily treat him the best up there, and so I feel like I'm obligated to go up there every night to make sure things are going ok.

She then reflected on her unmet needs.

As far as my needs being met, myself. I, myself, now, am having, I'm seeking a counsellor out just to kind of bounce off my frustrations and stuff like that, to keep my sanity. I, myself, am bipolar and through since, February have had a rough time with my issues, so I am now seeing my doctor on a regular basis as well...Because of the stress and the fact that I've lost 38 pounds, between the stress and me losing so much weight, the medication I'm on went into toxic levels, so that's why I was having the episodes.

She also expressed concern about her daughter:

And my daughter's never dealt with depression or anything like that. She's going through it, it's affecting the whole family, it's not just affecting [son's name], it's affecting the whole family.... She's never had to use anxiety medications before, and she's using anxiety medications as well.

Her son's mental health was also a concern. Specifically, she indicated that she is concerned that his ongoing hospitalization is having a negative effect on his mental health. In the absence of ASD-specific services, his mental health is negatively affected.

He's not getting help. If he was getting help, that would be different. They're just medicating him and lately, with the ASD he has a speech and language delay so he doesn't fit in with the mental health and that's a problem. When you're on a mental health ward, they deem everyone

mental health and ASD should supersede the mental health issue and it doesn't. I've told them, even at the hospital because of the lack of services, you guys are going to see more people with secondary conditions like ASD coming through the mental health wards because there's nowhere for them to go.

Respondents had another opportunity to reflect on their health and mental health within the QofLI. The following comments were made by participants within the section of the QofLI pertaining to barriers to health. Abigail reflected: "Over-worked, no insurance coverage, no access to therapy or other supports". Consistent with this report, Mitch cited "Cost of medical supplies" as a barrier to enjoyment of his health. Louisa reflected on the impact of her own age-related health concerns: "My arthritis gets in the way (knees especially) of healthy living.", while Theresa reflected on the impact of the stress of her son's hospitalization has had on her own pre-existing mental health concerns: "Being bipolar in control for 12 yrs but since [my son] has been in the hospital it has become out of control -> migraines and chronic pain."

In keeping with the theme of mental health, the QofLI also includes a section to reflect on barriers to satisfaction with one's self-esteem. In this section, Abigail reflected on the impact public policy in relation to her family has had on her sense of self-worth: "The message I take away from the province's failure to provide support to my family is that we are not worthwhile; we are not deserving of an adequate standard of living or a just life – this has really impacted my own sense of worth."

Similarly, Theresa reflected on the impact of advocacy, with little results: “-> the constant need to advocate on behalf of [my son] and being ignored or shut down affects how I feel about myself in turn.”.

Louisa reported self-blame in relation to her son’s assault on her: “Feelings of guilt that I ‘caused’ the attack, should have seen it coming?” [in reference to an incident where the participant’s son attempted to slit her throat with a knife]. Mitch reflected on physical features he would like to work on: “Like to lose more weight and gain more muscle.” All participants reported that the individuals with ASD for whom they cared had additional diagnoses. Table 9 reflects the age, health needs, and medications consumed by adults with ASD.

Participants often discussed the impacts of prior maltreatment in various settings. For instance, Louisa reported that her brother had been abused while living in institutions. He refuses to talk about it and has won settlements for the abuses, which are being used to fund his care. During a stay in his initial placement upon deinstitutionalization, he was heavily medicated to manage his behaviour, resulting in health effects to him:

“These places aren’t ready for institutionalized individuals. There were not ready. And I was trying to guide it and all that stuff, but you only have so power, right? So, what they ended up doing was increasing his medication, increasing them and increasing them and exchanging them and eventually, most of his teeth fell out. His nerves became so bad that he could hardly hold a cup...but [husband’s name] finally got hurt... The community Living said ‘I can’t do this.’ And I’m going ‘what?’ What are

my options? He ended up back in the hospital here at [community of residency]

Reflecting on the lack of suitable placements for people like her brother, Louisa explained:

We have a developmental wing and we have a psychiatric wing. He went to the psychiatric wing first, because of the behaviours. Right? And I'm going 'what?' He's – he's not a psychiatric patient. He's developmentally delayed...He was trying to help other people that were there. Not have outbursts and he had to go to whatever room when they put that special jacket on him. He was totally out of place there...But these places were not well prepared. And my brother had suffered.

Louisa stated that her brother had been abused by peers while living in institutional settings. She pointed out that when her brother was removed from an institution, he was placed in group home placements offered through Community Living that were not suited to his needs.

Emiline's brother had also experienced abuse in institutions. She speculated that the system was ill-prepared to support a person who had survived abuse:

You know, the government did spend a lot of money getting places ready for these folks when they were shutting down these huge institutions. I know that. But these places were not well prepared. And my brother had suffered.

Regulated health professionals within the system had also reportedly offered advice and acted in ways suggesting they had concerns about how more difficult situations are handled.

Louisa built on this, explaining that,

My brother's] psychiatrist said, 'You should sue the pants right off them'. Because he was on medication that he shouldn't have been on. Eleven different medications over a certain time frame. [The psychiatrist] said, 'You need to find a lawyer', a law group that'll you know – because we couldn't afford it. You know, they would do the case and then when they won, they would take their fees, however that works. But that's pretty bad when a sister sits there and I'm only basically the only one left in the family and here's a psychiatrist saying that to you? How do you get faith in – and that was Community Living [that] said we should sue the pants off them. And then it's like, well, I could do that. I just can't go that route.

Louisa went on to explain that the issue was not compensation. Her concern was accessing care for both her son and her brother. She was concerned that suing would create tensions among the service community, which in turn could impact on the care and service both her brother and son would receive: "He has gotten some money from the different lawsuits from the different institutions he was in. But I have to live here, right? And I need Community Living. You go suing their pants off, I wonder how long my waitlist will [be] for this if I – and if I did it, it would not be a quiet little thing."

Participants Abigail, Theresa and Louisa made a point of specifying weight and size of their loved ones with ASD. Throughout their interviews, they referred to various

incidents in which they or other loved ones had experienced aggression perpetrated by the adult with ASD. For instance, Louisa referred to a phase in which her son had episodes of violence, but she was careful to refer to the aggression objectively. She caught herself describing him as aggressive before rephrasing her statement as follows:

[He] is – had episodes of violence ... when I talk about [son's name] being [pause, takes a deep breath] aggressive or violent, there was one specific incident. You've got to understand the thinking, right? [pause] [He] went through a time where he wanted his dad to get rid of me. Okay.

This incident occurred at a time when the family was trying to teach her son to complete more household chores to increase his independent functioning, suggesting the implementation of behavioural strategies was not adequately supervised by a behaviour analyst:

And this is about the time we started the token system. So that [he] could have balance and learning his chores and all that stuff. And he actually attacked me. I was doing the dishes, he took a kitchen fork and stabbed me in the neck a few times. He actually held my head back and stabbed my throat. And it wasn't until I could sort of twist that fork into his finger that he stopped.

She then reflected on the impact that this had on her career, as well as that of her husband, who was out of town, on business at the time of the incident:

... I mean how do you keep your brain together – there was an ambulance, there was the police, there was all kinds of stuff. And my

husband flew back home from work and all that stuff. That was – I had to take a year off for stress.”.

Not surprisingly, this incident also required the family to commit to counselling in order to work on their relationships: “You know, just to get my head around this whole situation, get [son’s name] on the right path. Get that relationship going again. All that stuff. You know.”

Louisa reflected on trauma, citing her own experience with it:

And as I’m learning about trauma – tell me about trauma. Anybody ever try to kill you? ... That’s a whole different ballgame for trauma. And I’ve come through it. ... I’ve gotten educated on it, done a lot of counselling, all that stuff.

Louisa reported that through her recovery, she encountered other parents who had similar experiences:

And I found my own parents’ group. I’m not alone. These kids take things into their own hands and they actually go that length. Whether it’s someone at school or whether it’s, you know, a parent or whatever. This is another part of ASD that people don’t see. You know? And frankly, I wish more parents would speak up.

Although she cited a desire for more parents to articulate their experiences with aggression, she was also concerned about how doing so would impact on the opportunities available to her son within the community:

But that's another thing I have to think about, too. Because we live in this community, I can't go blabbing that everywhere. Because he needs to be hired, have a little job, get an apartment. ... But you know, you've got to think about that, too. What would my neighbours think? You know, if they thought he was violent.

Louisa reflected on her experience of aggression and the need for addressing behavioural concerns:

If he attacks me again, I won't have him come back in this house. We'll have to do something, because I don't want that kind of pattern to stick in his head, right? 'I can get things by attacking people'. ... If it happens again, for my own health, for my relationship with my husband, he will not come back here.

Louisa also stated that in her volunteer social support work among families of people who have ASD, she regularly gets phone calls from family members seeking moral support relating to experiences of aggression: "I've had parents call me crying because [pause] their son or daughter has taken a round out of them. They didn't want to call the police. You know? They – you know?"

This was a challenging topic for her to discuss openly, as evidenced by the emotion in her voice, pauses and unfinished thoughts. In spite of the trauma she associated with the experience, Louisa also attempted to find positive meaning from it. In the barriers to satisfaction section of the QoFLI, she reflected on her experience with aggression in the Additional Problems/Concerns section:

Due to [my son] trying to kill me, the incident is always in the back of my mind. It is hard to accept that it will never 'go away' + that it has altered & probably 'shortened' my life + lifestyle. It is very hard not to be resentful. On the other hand, it has given me a unique insight to empathize with other parents in the same situation.

In order to access adequate supports, it is necessary for informal caregivers of people with ASD to articulate their experiences with violence and the related trauma it causes within the family. Caregivers also expressed concern that the impact of doing so can have on public perception of people with ASD could serve to further isolate their loved ones with ASD.

Three of the four informal caregivers also cited effects of aggression committed against them by their loved one with ASD as a source of both physical and mental health injuries. Mental health needs of caregivers arising from the care needs of their loved ones with ASD were cited by all participants. Anxiety and depression were cited by three participants, with Theresa also stating that her pre-existing bipolar disorder which had been managed and under control, has intensified and no longer responds to the medication she was on, requiring increased dosage, during her son's hospitalization. Three participants cited concerns about their own experiences of trauma associated with aggression by their loved one with ASD. Participants Abigail, Louisa and Emiline all reported reticence to request help and feelings of guilt expressing their own needs arising from their caregiving duties.

It's just painful. It's painful to talk about and most of us, just, it fills our day so much that we don't want to, you know, I can't talk, it's very

hard for me. I can't really talk about this with my friends. They don't want to hear about it. It's too depressing. It's too distressing. And it's scary. So you know, it's too much. You know, people are built a certain way and we can only take so much.

Caregivers also age as their loved ones with ASD age. Consequently, they also develop their own age-related health needs. Abigail cited concerns about her mother's health and stated that as her mother's ability to meet her brother's needs decreases, Abigail's obligations to provide more intimate care to her brother increases, thereby creating a discrepancy in the sibling relationship.

You know, my mom has been really careful to protect his dignity. She tries to do more of the more personal care tasks because I'm young and the opposite sex but as mom gets older, she has low bone density and can't do as much as she used to. I'm taking on more of the caregiving role. It's awkward, you know? It's changing the relationship for the worse...he wants his privacy but there are just things he can't do on his own. He's the older brother but I've been taking care of him all my life. Since my mom can't help him as much as she used to, I'm doing more of the more intimate jobs like helping him in the shower. It changes things. He doesn't like it and I don't like it either but it needs to be done...I'm his little sister. He's 37 and I'm 33, so he's always been the big brother. We're supposed to be companions. It changes the dynamic.

4.2.1.3 Having Meaningful & Reciprocal Relationships

Maintaining relationships was an issue identified by all participants as a challenge. In the Love domain of the QofLI, Louisa reflected on the impact of caregiving on her marital relationship: “Maintaining a relationship with my husband is a challenge due to our ‘focus’ on [my son and brother]. We have to deliberately schedule time for ‘us.’”.

During her interview, Louisa expanded on this, highlighting how one’s marriage can easily become overlooked when caring for a person who has ASD:

And then, to keep a relationship going with your husband. You know, you can get so focused or he can get so focused on his thing. You know, he does [names a couple of charitable causes related to disabilities] and he’s [cites another voluntary role related to disabilities] and – you know. When this child has gone, you know, he’s settled, not gone, but you know, settled, there’s going to be him and I looking at each other over the breakfast table. What are we going to talk about? We’ve got to make sure we make our memories, right? For him and I. So, we have date nights, man. Nothing comes in place – interferes with that....

So you see, you’ve got to deliberately do these things, otherwise when you’re sitting at that breakfast table and there’s no kid there, what are you going to talk about? You know? I’m sure we’ll still be advocating, but you have to have a personal relationship, right? And there are rules for date night, by the way. No talking about the kid. No talking about ex-

relationships and – what’s the other thing? Work. Because my husband and I are still working. We need to work for a bit more.

I have to carve out these times, you know? And do it deliberately. You can’t just keep rolling and rolling and rolling with the ASD, with the [unintelligible] you have to stop and realize that there’s life after this.

Throughout the interview with Louisa, she only referred to her son, husband and brother when speaking about familial relationships. During the interview, she stated:

“We don’t have a – we haven’t our family around, but they all have their own issues. And it’s not been a great relationship with [pause] brothers and sisters and all that stuff. It’s hard to help people understand, right? Advocating, trying to educate, trying to pave the way, smooth the way. Not the easiest.

In the Children and Relatives domains of the QofLI, in the barriers to satisfaction, the reflected on the challenges of maintaining relationships: “Due to time restraints, fatigue & stress, maintaining relationships with my sons and grandchildren is almost impossible.” And “Ditto” (participant drew an arrow up to her statement about children – i.e., “due to time restraints, fatigue & stress maintaining relationships with my sons + grandchildren is almost impossible.”), respectively. During the interview, Louisa touched on the challenge of involving relatives and community in the care of a child with behavioural challenges:

There’s really nobody we can call in the community and say, come on over, you know. I mean – the other families are [long pause] they have

their own stuff. And frankly, [son's name] is being kind of [pause] sulky since he has violent spots, you know. So, you've got little kids that are scared. You've got parents that are going 'are you kidding me?' You know? And you've got some places that are just not suitable, like family suitable. It's not an option to call up my sister-in-law and say 'can you come over for a few hours?' Not an option. And we're not alone, because you know, when you have a kid with special needs, it's not a [pause] you can't get away as much as you can, you know. And [pause] people are people, you know? We're all in different spaces. Not the Brady family.

In relation to her satisfaction in the Friends domain of the QofLI, Louisa reflected: "Hard to maintain friendships with non-special needs parents. They don't often understand so you end up 'educating' them etc."

During his interview, Mitch indicated satisfaction with his social support network, citing parents of people who have IDD that he knows from his advocacy work and teammates on sports teams as his source of friendship. Consistent with this, on the QofLI, in the barriers to satisfaction section, he cited "None" in the Friends domain. He did, however, cite dissatisfaction in the Love domain, stating: "Dissatisfied because I just broke up with my girlfriend.". Building on this theme, he reflected on his dissatisfaction in the Children domain:

Very dissatisfied. I mean, I would like to have children and I don't have any way to support them right now and I don't have any of them, so I guess that is what is keeping me from being satisfied.

In relation to Relatives, he stated: “Christian Conservative, racist, homophobic relatives.”, while he stated “Not applicable” in the Additional Problems/Concerns domain.

Abigail also reflected on how her family’s circumstances have impacted their involvement in the neighbourhood: “We are isolated & focused on just getting by that we haven’t had time to meet neighbours. We live in a place we can afford, not a place of our choosing”. Finally, she reflected on her family’s experience in the community: “The community at large was not designed for families like our[s]. My brother is clearly not welcome here, and we feel unwelcome in public spaces.”

Whereas Abigail and Theresa’s caregiving takes place in households headed by a single parent who left the workforce to meet the needs of their loved ones with ASD, Louisa lives in a two-income household. She also expressed greater satisfaction with her housing circumstances but indicated feeling isolated from her community.

In terms of barriers to satisfaction in the Housing and Neighbourhood domain on the QoFLI, Louisa stated: “Maintaining our home is a challenge due to time & money spent on [son’s and brother’s names].”. Referring to her neighbours, she stated: “They don’t understand & keep away. So we end up advocating continuously”. Although she is actively involved in advocacy and communicates a good deal of satisfaction with the relationships she has formed from this, she expressed less satisfaction with her experience of the community at large: “We have a strong commitment to the ‘special needs’ community but not for the rest of our community.”

Similar to Louisa’s experience of her community, Abigail reflected on how the aggression impacts on perceptions her relatives have of her brother:

When I do talk about it with my cousins, some are a little bit afraid of him but others just don't understand. Like how we always eat with spoons because of an incident when he stabbed my mom with a fork. His aggression has been escalating since he was twenty.

All participants cited a sense of isolation experienced by a lack of access to suitable supports to allow their loved one with ASD to participate effectively in the community. For instance, Abigail discussed the challenge of inconsistent access to supports, as well as the limitations imposed by funding criteria. She would prefer accessing services which promote skill development, which in turn could facilitate more functional participation in the community over the long-term:

We only get a few thousand dollars per year, so it's not enough to design a life around it. It's so short-term. You get somebody for a bit, but then when the funding runs out and you have to wait for the next year to get more...It's so piecemeal. I compare it more to babysitting, more to keep the caregivers going. There's very little in it for him. There's no skill development, no incentive for people who do this kind of work to keep coming back.

Abigail also expressed concern about the challenge of maintaining trusted formal care providers arising from limited funds available to pay them. She also reflected on her worry about the potential for abuse and poor quality of care:

He had some workers who had to go because the income is so low. I don't blame them. I mean, they have to live too. It's just that it's very hard to find people who you can trust. You hear all these stories of neglect and

abuse. You have to be very careful about who you hire. He can't communicate that sort of thing so you'd never know.

Theresa reflected on lack of opportunity to recuperate or pursue her own interests.

I don't get a break. I've literally had a break from [my son] twice in a matter of seven years, other than him being in the hospital. And him being in hospital, I'm there 6 days a week. There's only one day that I don't go and see him in the hospital, and in my replacement, my sister goes, his aunt goes to see him that one day that I don't go.

She expanded on this in the QofLI in several domains. For instance, reflecting on her satisfaction in the Play domain, she stated: "There is only one day a week for 4 hours I get away from the city to try to relax, however, I have my 16-[year-old] Asperger's daughter in tow.", while in the Love domain, she stated: "I have chosen to stay single until my children are grown and on their own in whatever way they can be -> with their behaviours I was always afraid of rejection."

Abigail reflected on the isolation experienced by her family in a number of ways. For instance, her brother has difficulty with communication but has not had access to a speech and language pathologist (SLP) since he was ten years old:

He had an SLP until he was ten years old but has had no access since then. Nothing's been tried except for a picture board my mother and I made for him. We don't what we're doing though so it's just trial and error, seeing what works. It would be nice if someone who knew how to do it could even just show us how to make it better and easier for him.

He's on a waitlist to be assessed by an SLP but it could be at least four years and possibly five. Not being able to communicate prevents him from feeling included and having any independence from us...He doesn't have a way of communicating. My mother and I understand him because we've known him all our lives but it's not like he can talk to the cashier at a store even. He gets frustrated and lashes out and strikes out. It comes from being misunderstood. Really, any sort of support would be nice right now but communication is huge. I feel really guilt ridden saying this.

Abigail expressed feeling that she and her mother are isolated as a result of the financial impacts arising from her brother's needs:

Mom sees her health and her life destroyed by care work, not having any support around has been really isolating. I think she would benefit from counselling. My dad's not involved. He couldn't take it. He left. He helps her out financially but we're really poor. I don't blame him. It's really hard. It's just that there's so much that we need. You know, like it would be nice to go out for a movie once in a while or a nice dinner but there's no money for that.

Associated with the lack of involvement by her father, Abigail also cited a sense of isolation by Friends and Relatives in the respective domains of the QofLI section on barriers to satisfaction within domains: "I have no time to socialize though I would like to. Most of my friends have been lost over the years. There is also a disconnect between us because they can't relate to my situation."

4.2.1.4 Contributions to Society

Theresa also reflected on the isolation of parenting a child, as a result of reactions of friends: “I have very few friends and those that I do have are the only ones that have seen my children at their worst.” and relatives: “Due [to] [my son’s] explosive behaviours, there have been rifts within our family including verbal and physical.”. In the Children domain, she had an opportunity to reflect on her satisfaction parenting her children: “Due to [son’s name]’s behaviour at 5 when I had my daughter I opted to have my tubes tied -> I was on my own with an undiagnosed autistic child and a brand-new baby.”

Reflecting on her satisfaction with her involvement in the Community domain, she stated: “Due to my heightened anxiety currently, I haven’t really involved myself in the community in any capacity”. Within the Creativity domain of the QofLI, she stated: “[I] have absolutely no interest in being creative as I was in the past”.

Her son also experiences isolation and frustration with his inability to pursue his interests.

He wants to get his licence and have his own car. I would love to see that for him. He wants a girlfriend, he gets depressed about the whole thought because he’s not a social person, so he doesn’t get out and meet people, but he’s always saying wanting a girlfriend. He wants to have a family eventually, that kind of stuff. He himself has dreams and he’s expressed them many times, to people that he’s worked with whether it be with the behaviourist or just his support worker, he’s expressed that he does, he’s depressed, and he talks about wanting to die and stuff like that.

He does have things he wants to do with his life, I think he just gets frustrated because they're not happening in the way he wants them, or fast enough.

Abigail further reflected on her experience of isolation, as well as that of her family: "My brother, mother and I are isolated within our family due to a lack of free time, as well as understanding.". Building on this, in the Helping domain of the barriers to satisfaction section of the QoFLI, she stated: "I have been forced to let down friends & other relatives to support my sibling."

Another source of isolation for Abigail related to her romantic life. She recounted an experience of a romantic partner ending the relationship upon realizing that Abigail would always have to prioritize her brother's needs, rendering parenthood challenging:

I will never have kids. I can't. I remember when I first realized that. It was when my boyfriend, we're not together anymore and I don't blame him. It's just that it's my life. He said to me that we can never have kids because we'll always be taking care of him, my brother, and there will never be enough time, energy or money for there to be both. It will always be him.

Although she did not state emotions associated with her isolation from relatives and friends, this was evident in what she said:

It's just that sometimes, when I'm with my friends, it's rare that I get to go out with them but when I am, when I do see my friends and how

they're living, it's not really envy but it's frustration that I'm unable to do it.

Consistent with this reflection, in the barriers to satisfaction section of the QofLI, she stated in the Love domain: "No time to date – it is also difficult connecting due to the general lack of understanding around intellectual disability & my brother's needs + my role in his life.". She further reiterated her perspective regarding her reproductive options in the barriers to satisfaction section in the Children domain of the QofLI: "Not an option given my care duties toward my brother."

Isolation arising from her care obligations have also influenced her career. She explained that a few times, she has had difficulty explaining to employers that "I just have to be there" for her mother. In response to the question 'have you ever lost a job because of it [care obligations]?', she stated:

I don't think so but definitely have been in situations where I wonder if I would have advanced in my career if I could have been more flexible...Right now, I'm working and saving to up to pay out of pocket...I've been shaping my career and income expectations around that. That's why I went back to do my Masters and now why I'm doing my PhD. I have to keep advancing and increasing my income potential...I work about 60 hours per week. I'm very eager to save as much as I can. I have to. I have to support my mom and my brother. I figured it out and I spend about \$10 000 a year on support.

Building on this, she cited barriers to her satisfaction with Learning on the QofLI: "I am struggling to make ends meet and outside of school, paid work & care-work, cannot

pursue former interests (read a novel, etc.)”. Similarly, she cited in the Leisure domain: “I have no leisure time” and the Creativity domain: “Life has been crisis-driven and this forces me to be pragmatic, with little time for fun activities or personal development” in the barriers to satisfaction sections of the QofLI.

Also isolating were the experiences of adults who have ASD and are unable to access employment. Theresa reported that her son accessed job training through co-operative education placement opportunities when he was in high school and wants to work:

He wants a job, and when he was in school, that’s what he did in his school, he had a co-op, at least one co-op every semester from grade 11 on, because he did five years of it, so he had, I think it was in total, seven different job placements he’s done to get experience. Everything from a dog grooming place to a gardening place to a nursing home. He has experience in various facets of employability, but he needs to deal with these behaviours before he can go out and do it, that kind of thing.

Louisa - I didn’t know where to go to talk to someone who might know. You know what I mean? In the same boots as me. You know? There wasn’t anybody. I looked for groups, I – you know, not just online because I don’t want to do everything online. And I have sat with other parents, you know, other parents with teens who said to me, ‘oh, is it ever good just to talk to someone who understands what it’s like to have an autistic kid who’s turning, you know, and the hormones are hopping and

the moods are swinging.’ You know what I mean?...Yeah, just because it’s such an isolating experience as it is.

This is an important finding, as Marsack and Samuel demonstrated that informal social supports had a mediating effect on quality of life and the experience of burden reported by parents of adults with ASD (2017). Advocacy also requires strong literacy and communication skills, which many informal caregivers do not have. Abigail, who has post-secondary education, reflected on the challenge of connecting with others, in spite of having strong literacy skills and being proactive in the community:

It’s like – it’s depressing, you know, it’s really discouraging. We’re really a proactive family that – you know, we don’t have a lot of money and stuff, but we would have a few connections and we’re pretty vocal about, you know, not just what we need but about the system and stuff. But there are other people out there that, you know, may not have the education or not the drive or they may be beaten down, way lower income, or some from high income, I’ve spoken with those individuals.

Based on participants’ experiences of services, Figure 4.1 presents a social arenas map, depicting the supports as they experience them. Contrary to Figure 1.1 in which the central arena is social inclusion, participants identified the adult with ASD as the focus. Of note is that clinicians with expertise in ASD are removed to the side of the map. This depicts the lack of access the adults with ASD and their caregivers have to them when adequate funding is not available. The size of the circles reflects the degree of involvement of the entity in question, as perceived by caregivers.

As DSO/Passport funding cannot be used to access clinical services, such as occupational therapy, psychotherapy, applied behaviour analysis, etc., these services tend to be limited to those families who are able to fund them privately.

Although Abigail had been pursuing her career in another city, she chose to leave her position and return home to help care for her brother following ongoing and intense behaviour incidents (e.g., assaulting their mother and destroying property). When these incidents arose, she reported that her mother would lock herself in the bathroom and phone the police and Abigail for assistance.

The absence of supports may not only be limited to aggressive behaviour management. Lack of stimulating and meaningful activities, resulting in isolation may contribute to the problem of aggressive behaviour. Theresa reflected on how leaving school, with no formal programming or employment options for her son may have elicited aggressive behaviour.

Last year, he was turning 21 and for the school program he was in was over, and we just found that once he finished school, there was nothing for him to do, so he started getting bored, he would reclude himself to the house and play video games, those were the only friends he had because he wasn't out in the community anymore. He started getting depressed, and he's had numerous hospital visits, and this one is his longest stay.

In reflecting on the source of the problem, Theresa speculated that her son's challenges and consequent hospitalizations are related to a lack of suitable programming.

In my opinion, this all comes down to the fact that there's not programming, there wasn't programming for him and for the fact that he's on this waitlist and we're not receiving any sort of funding...his behaviour became uncontrollable. He was becoming very physically aggressive. When he ended up going into the hospital in February, it was because he had put his hands on me to the point that he scared me that he might hurt me very badly, that's why he's there, and we've been looking for a behavioural treatment facility and we were told in May that it was a 2-3 month waitlist and then in June we were told now it's going to be a year. They're expecting us to keep him hospitalized until they can find him a bed.

Participants also reflected on their satisfaction with their QofLI as it relates to their ability to pursue their goals and live according to their values. Abigail reflected on the effect of her family's financial circumstances have had on the goals she had set for herself, indicating that she has had to focus on providing the necessities, rather than pursuing her own interests: "My own goals relate to basic survival, they have been severely curtailed.". Similarly, Louisa also reported that the time spent conducting advocacy work has had an impact on her ability to pursue her own goals: "Time spent advocating for [my son] and my brother interfere with my goals (personal)"

4.2.1.5 Acceptance Beyond One's Disability

Mitch, who has chosen to pursue a career in film cited the challenge of precarious income as a barrier: "Not working, couple projects got cancelled", again citing the cancellation of projects as a barrier to satisfaction in the Work

domain of the QofLI. During the interview, he revealed that he had been bullied extensively by peers in his school and explained that some of those peers continue to harass him now. He explained how this experience has impacted on his experience of his community:

It's just like I constantly feel like, cause there's still some boys from elementary school who are still sometimes coming after me and I feel like I constantly have to watch my back, especially at night. I feel like I have to watch my back if I'm walking down the road cause I sometimes like to go for a late night walk because I have insomnia from different issues that I have and so I try to go for walks, try to get myself sleepy and then I constantly feel like I have to watch my back and watch over my shoulder to make sure no one's following me or anything.

During the interview, he reflected on a preference for people who are older or younger than he:

The thing is I don't hang out with people my own age. That's one of the things that's weird about me. I either hang with people who are older than me or younger than me. Like my best friend is three years younger than me. So I'm twenty-three, he's twenty and then my next best friend is thirty and I'm twenty-three. I just don't like people my own age. I just have never liked people my own age.

He also reported a preference for socializing with people whose country of origin was not Canada, citing countries of origin of numerous friends before going on to state:

So, I don't really hang out with a lot of kids born in this country. I more hang out with people who were immigrants like myself because we understand the struggle coming to a new country and making it in the new country. And going to a new country where don't know anyone or anything and that's kind of the people I tend to hang around with. I'm not really into Canadians. It's not that I live in Canada, I more hang out with people who are from other countries like myself.

Reflecting on his experience of the community, on the QofLI, Mitch reported: "There's lots of homelessness, drug activity, prostitutes.". During the interview, he shared that he is actively involved in social media: "Yeah, I do a bunch of live streams, I post a bunch from there" and advocacy work:

All the advocacy work I've gotten to do, [identifying information omitted], I'm probably going to be doing another bunch this year after the election to try and fight tooth and nail to keep our services and maybe even get more services.

With regard to how he is perceived in the community, much of Mitch's reflections are based on his interpretations of the media: "Doug Ford said he wants to freeze ODSP and OW and Passport funding". Many of the attitudes he ascribed to society in general seemed to be sourced from mainstream media:

Like I said a lot of my friends, and they're all immigrants, and that's the other thing I despise about Donald Trump is he considers, basically he's always said immigrants are terrorists so according to him me and all my friends are terrorists and just want to cause harm in this country which

is far from the truth. And it just doesn't feel good being discriminated against just cause you're not from this place. It's hard enough coming from a land like half way around the world and not knowing anyone, not knowing the language, not trusting anything and it's this big scary thing. You don't know who to trust. I mean all my friends have gone through it and I think that's why we gravitate toward each other because we all have that same experience.

However, when asked if he remembered coming to Canada, he replied: "vaguely", replying that he had been five when he immigrated to Canada, two years before being diagnosed with ASD. He explained that once he started school, his teachers urged his parents to pursue a diagnosis and stated: "I'm glad that I got diagnosed 'cause it's opened a whole bunch of doors for me that I never thought would be open."

He also reflected on statements which had been made by Doug Ford regarding conditions in a group home: "He doesn't think that people with ASD and other disabilities should be living in houses and shouldn't be allowed in society".

The comments made by Doug Ford which Mitch was referring to were made in relation to a group home specializing in people aged 12 to 16 years old who have IDD, including ASD and mental health issues. The group home had relocated to a location in Doug Ford's ward when he was acting as a municipal councilor. At that time, attempting to address concerns raised by some of his constituents regarding frequency of screaming, police attending issues at that house, Doug Ford has been characterized by the media as stating the group home "ruined the community" (Shepherd, 2014). Community residents in attendance at the meeting were characterized as: "Some 60 angry and anxious residents

packed last week's meeting organized by Ford's office expressing fear and concern over frequent police and paramedic calls to the address and taking issue with the centre staff parking on the street" (Shepherd, 2014).

Comments by residents in attendance at this meeting were recorded by Shepherd, 2014, including:

"This is not a place for mental people. This is a residential area. Why don't you build a house out on a farm?" one man said.

"What do I say to my three kids under the age of seven when one of these kids freaks out?" asked one woman, who declined to give her name.

"When my child says, 'Mommy, why are there police here again?' What do I say?"

David Melgarejo lives next door.

"The solution is for them to move out. Locate the facility in another place. This is a community for people, not for that. I have nothing against the kids. If the kids need help, they need help," Melgarejo said in an interview. (Shepherd, 2014)

According to the newspaper article, the staff for the centre in question highlighted that the stress associated with the transition to the new location had resulted in higher than usual behavioural challenges among some of the residents (Shepherd, 2014). The director of the group home was cited as responding to the upset among community members:

Dannell reiterated that police calls to the address have been more frequent than usual, saying the special needs-youth face transitional stress and challenges in their ability to manage different and new situations.

“Moving has certainly increased the stress of some of our clients,” she said. “All the emergency services calls were made in the context of lending support and safety to our program. Understand these are mental health issues. Calls are made with respect to further supporting issues around mental health.”

Dannell had explained at the meeting the calls to police or paramedics are to support the youth facing a mental health issue. Youth are not criminals, as one man asked, nor are they sex offenders, as Ford asked. (Shepherd, 2014)

In light of the fact that changes to routine can be challenging for people who have IDD, particularly ASD whereby behavioural inflexibility is a characteristic of the disorder (Green, Sigafoos, O’Reilly, Pittuch, Didden, Lancioni & Singh, 2007), it would be reasonable to expect that a major transition, such as moving homes would be disruptive to residents of this group home. However, this is a foreseeable challenge and funding to the group home could have been such that it would allow for staffing with those with expertise in teaching coping skills for major transitions, as well as managing behavioural challenges such that they are less likely to require police or paramedic intervention.

According to media, Doug Ford is quoted as follows:

"You've ruined the community," Ford is quoted by the Guardian as telling the facility's staff.

"You can't destroy a community like this. People have worked 30 years for their home...My heart goes out to kids with ASD. But no one told me they'd be leaving the house. If it comes down to it, I'll buy the house myself and resell it." (Lum, 2014)

When the researcher contacted the city of Toronto seeking transcripts from this meeting, no minutes or transcripts were taken from this meeting. However, minutes from a subsequent executive committee meeting in which the city of Toronto committed to working with the group home in question to address concerns were available.

It is important for the public to have access to full transcripts of these meetings, as mainstream media often only provides snippets of statements, allowing the point speakers have made to be misinterpreted by the public. This can have detrimental effects on members of the public. For instance, Mitch expressed intense fear arising from Doug Ford's election and rightfully so, as he interpreted statements released from the media as meaning Doug Ford did not believe people with ASD should be allowed to leave their homes and that he wants them dead.

Reflecting on his satisfaction with his community, when asked how satisfied he feels with his community, he replied:

Very. It's been really amazing because like I said I was freaking out when Doug Ford got elected and a lot of parents instantly rushed to phone me or text me or to message me on Facebook if I'm okay, which I clearly

was not okay, but checking in on me which really meant a lot 'cause it made me feel like family and like a part of the community. And for me the ASD community and the sports community are really the only communities where I feel like that.

Exploring his experience of other communities, he reported:

I don't feel as welcome in those other communities and that's why I mainly stick to the sports community and the disability rights community cause those communities have made me feel like family and not ostracized me and have accepted me and taken me in.

When asked which communities ostracized him, he replied:

I'd say the school community, like definitely the education system really ostracized me and especially [school name]. It was, [school name] was not a good time at all. It was probably one of the darkest times in my life...I was severely bullied not only by students but by teachers. I was physically assaulted and physically beaten by one of my supply teachers at [school name]. And when we called the police and went above the superintendent's, to like the head, head person at the school board, nothing was done. The police did zilch, the school did zilch, the school board did zilch and that really made me feel ostracized. And also like in elementary school my teachers were good to me but the other students not so much. Students my own age were not good to me but students who were younger than me, and the students who were older than me were great. Just my own age were not good to me. And that made me feel ostracized.

Not all responses in the barriers to satisfaction section of the QofLI were grim. In the Play domain, Louisa replied: “I ‘play’ in my gardens. Very satisfying!”, while Mitch reported: “No problems there!”. During the interview, Louisa reflected on the importance of ensuring caregivers take time for themselves:

I journal for myself, for my own personal sanity. That’s another thing you have to watch, you know, taking care of myself. Yeah. It’s beyond these – you know, this kind of thing could become such a focus in a person’s life – it probably sounds like that with me. But I do take care of myself. I have my own little personal trainer. I’ve squeezed together enough money, I’ve got a little bit of a pension. And you know, each week I do my training program for me. Because everything else seems to be for disabilities or [son’s name] or, you know what I mean. So I have to consciously make sure I get my rest, eat well, do my training, you know, take care of me. And I’ve never had to do that so hard in my whole life. It’s a challenge.

Louisa identified barriers to satisfaction on the QofLI in the Learning and Creativity domains as: “Too tired & stressed from advocating + worrying about where my son will live after I am gone. And greatly disappointed that my brother has been by ‘default’ re-institutionalized” and “Being tired + stressed interferes with my creativity although at times it ‘boosts’ my creativity in solving problems”, respectively. In the same domains, Mitch identified as barriers to satisfaction with Learning “Multiple learning disorders, especially math and science” and in Creativity “none”.

Participant ID	Age of Person with ASD	Diagnoses	Medication	Medication Administration Training Received
Abigail	37	ASD Intellectual Disability Depression Anxiety Disorder Cerebral Palsy Querying Schizophrenia	SSRI Antidepressants PRN (2x/day)	Pharmacy information pamphlet
Louisa	19	ASD Developmental Delay Scoliosis	N/A	N/A
Louisa	55	ASD Missing several	Unknown	N/A, Administered at the Nursing Home

teeth				
Emiline	78	ASD Blind in one eye No teeth	Unknown	Unknown, Administered at the Nursing Home
Mitch	23	ASD Clinical depression Anxiety Obsessive- Compulsive Disorder 1 Kidney Blind in one eye	Zoloft Risperidone	Pharmacy Information Pamphlet
Theresa	21	ASD Attention Deficit Hyperactive Disorder (ADHD) Oppositional Defiant Disorder (ODD)	Citalopram (40 mg 1 time daily) Divalproex (500 mg, 2 times daily) Sodium (1000 mg 1 time	Administered by hospital staff while stay at the hospital When living at home, administered by Theresa, who

Depression	daily)	learned to do so
Anxiety	Vvanyse (30 mg 2 times daily)	using Pharmacy Information Pamphlets
	Lorazepam (1 mg 2 times daily)	
	Methothreza pine (25 mg 1 time daily)	
	Quetiapine (15 mg daily, 100 mg at bedtime)	
	Haloperidol (5 to 10 mg every 6 hours as needed)	
	Methothrepr azine (25 to 50 mg every 6 hours as needed)	

Table 11. Adults with ASD: Diagnoses and Medication

Theresa, discussed the impact of leaving the workforce on her own sense of isolation in completion of the QofLI: “-> have not been able to reach my goal of being gainfully employed as I have put that on hold to raise my children on my own.”. In the Additional Problems of the QofLI, she reflected on the impact of delayed access to intervention services, stating:

Due to the fact that [my son] was diagnosed in 2007, 6 months prior to his 11th birthday, and at that time the age of qualifying for [applied behaviour analysis and intensive behavioural intervention (the latter is a therapy funded by the province for children up to 6 years old before the age restriction was lifted in 2008)] was only up until age 6, [my son] never received the proper behaviour therapy. We used community agencies as ‘Band-aids’ to dealing with these behaviours. That is, in my opinion, precisely why we are now still dealing with behaviours. I was employed after going back to school, until [my son’s educational assistants] went on strike. Due to the fact that I had to be accessible in case [my son] exhibited behaviours, I ended up having to give up on my career, because at that point I knew my kids could be my only job until they were successful to their greatest capacity. And making the only decision I felt best has lead to loneliness, boredom and isolation. In addition to living below the poverty line, in a rented home, in a bad area of the city.

Conversely, Mitch made a statement (i.e., “very satisfied”) which was inconsistent with his interview, in which he had stated that he was frustrated with his inability to gain steady employment.

In the Helping domain, Louisa identified “Again, being tired, stressed & having time restraints due to caring [son’s name] and [brother’s name] reduces my time to help others. Balance is very hard to achieve.”. In spite of this, Louisa also reported being actively involved in both advocacy and facilitating support groups for parents of children with ASD and/or IDD, citing two support groups she facilitates, referencing another one she had applied for funding to start and an advocacy movement she was actively involved in to raise awareness of the rights of people who have IDD. Similarly, Theresa stated that advocacy comprises a major portion of her identity: “Everybody who knows me, including people from different agencies I’ve dealt with since [son’s name] was like 18 months, everybody knows that I’m an advocate and unfortunately, my health comes last, I come last.”

Mitch, who also is actively involved in advocacy for people who have disabilities, reported being “very satisfied” in the Helping domain of the QofLI.

4.2.1.5.1 Involvement in Activities

Theresa acknowledged that she left the workforce when her son was a child in order to meet his needs:

... I haven’t been employed for 10 years, and I had to stop working primarily because at the time, my son’s EA’s were on strike, therefore I had to be within half an hour’s distance in case his behaviour, if he acted up, because the teachers weren’t qualified to deal with him. I ended up quitting my job through that. I’ve been out of work for 10 years. Move to Results Chapter

Reflecting on the challenges associated with going into the community, Abigail explained that because funding is so limited, the turnover rate among respite care workers

is high enough that caregivers have rarely learned to understand her brother's attempts to communicate.

Yes, he's really aggressive and he has motor movements which make people uncomfortable. They don't really know how to act around him, which upsets him and then [he] starts getting loud and aggressive. My mom and I know how to work with him to keep things from escalating but we never get enough time with the workers to teach them how to do it, so we end up being the only ones who can go out anywhere with him.

Passport funding excludes therapeutic services such as speech and language pathology, occupational therapy, and applied behaviour analysis (DSO, 2014); therefore, when clients have communication or behavioural barriers, they do not have access to services to mediate those challenges, requiring those who are familiar with the client to develop their own strategies, without the input of clinicians qualified to develop effective and efficient programming. Abigail continued,

He had an SLP until he was 10 but has had nothing since then. Nothing's been tried except for a picture board my mother and I made for him. We don't know what we're doing, though, so it's all just been trial and error, seeing what works. It would be nice if someone who knew how to do it could even just show us how to make it better for him. He's on a waitlist to be assessed by an SLP but it could be at least 4 and possibly 5 years. ... He really doesn't have another way of communicating. My mother and I can understand him because we've known him all our lives but it's not like he can talk to the cashier at a store even. He gets frustrated and lashes out and strikes out. It comes from being misunderstood. Really, any sort of support would be nice right now but communication is huge.”

Theresa also reflected on the need for therapeutic intervention. Citing behavioural challenges she suspects are associated with trauma her son developed as a result of bullying, she stated health professionals have recommended behaviour therapy, which also is not funded through Passport funding.

He needs intensive behavioural therapy. That's what the doctors are recommending, that's what everybody's recommending. He has anger issues, and he dealt with trauma when he was a child that he's never dealt with, and that's some of the stuff that he needs help with.

Theresa also reflected on the effect that the isolation associated with his unemployment and inability to access services is associated with behavioural challenges he experiences.

All it has been up until now is just been medication. And he gets bored up there, so he gets himself into trouble, and then he goes back on lock down. It's like, a cycle for him. When he gets bored, he's already established 'when I get bored, I get myself in trouble'. That's the problem. He needs to be in some kind of programming so that he's not getting bored and causing trouble...He can get argumentative, he has threatened the nurses and stuff like that, so he has anger management issues and that's what he needs help with. He's admitted he needs help but he keeps saying 'nobody's helping me, nobody's helping me'. He's just as frustrated with the whole process as well.

In relation to her perspectives on public policies which inform the services and supports her family accesses, Abigail stated:

I feel really guilt-ridden saying this. [long pause, deep breath] The policies are incredibly ill-informed. The expectations they have of families are just insane. It's discriminatory, you know? My brother is forced to go everywhere with his mom and me. It's not good for his development. It's infantilizing to have to rely so much on his mom. Especially for a grown man.

Building on this, she responded to the Additional Problems/Concerns section of the QofLI, stating:

Poverty is my biggest concern. It is hard maintaining full-time employment because my role in my brother's life is not recognized. The costs associated with his support are not often covered, so this lowers my income. The health impact on myself also threatens my ability to work full-time. Without counselling & support, and as a result of burn-out from care-work, my own mental & physical health (sleep, cardio, etc.) are poor. I fear I have been disabled by care-work & that this will only entrench the poverty experienced by my family. My mother is already disabled from this role & she is unable to work.

4.2.2 Mapping Results

Whereas Assaroudi et al. (2018) recommend the use of a formative categorization matrix to depict the process of developing categories, social arenas mapping was used for the study at hand. This is because the relationships between and across entities related to the service and support provision to adults with ASD are interactional, not linear. A formative categorization matrix does not allow for depiction of these interactions as clearly does a social arenas map.

Based on language used in MCSS documents and the Act (2008), Figure 6 presents a social arenas map depicting the social arenas interacting with the lives of adults who have ASD in Ontario. Proximity of the circles/arenas to the adult with ASD represents direct influence that arena has over a person's life. For instance, there is greater overlap by family and caregivers who are tasked with day-to-day physical, emotional and financial support, while there is less overlap with WHO and IASSIDD, which are influential in that they achieve international consensus on research, service and rights priorities but not direct, physical influence on individuals. ASD clinicians are on the periphery, beside funding because neither the mandatory nor discretionary funding cover ASD-specific clinical services. Excluding exceptional circumstances, these services may be available to an adult with ASD but they would typically be paid for privately.

Figure 6 reflects a social arenas map depicting the relationship between entities involved in the provision of services and supports to adults with ASD if implemented consistent with the values outlined in the Act. The size of the circles reflects the degree to which each entity informs or is involved in the Act, while the location and overlapping of circles in the figure reflects interactions between entities. Conversely, Figure 7 reflects a social arenas map as experienced by caregivers. International agencies, such as WHO and IASSIDD are not featured in Figure 7, as caregivers in this study did report having direct involvement with them.

Community is depicted as also being removed from the focus of the map. This is because community is often perceived as a barrier by participants, due to attitudes and inability to access community due to behavioural challenges. It interacts with the concepts of deinstitutionalization and mandatory funding, as full participation in the

community is the intended outcome of social inclusion policy, however it is not depicted as interacting with adults with ASD or their caregivers, as attitudes and logistics within the community were perceived as barriers to their inclusion experiences.

Clinicians specializing in ASD are depicted as peripheral and unconnected to the figure. This reflects participants' reflection that these services are not covered by Passport funding. Families, advocacy groups and rights movements are depicted at the top of the figure, reflecting their involvement in the lives of adults with ASD and the advocacy necessary to achieve their rights. The funding initiatives, community and de-institutionalization appear together in the lower portion of the figure. They appear together, reflecting that funding and support within the community were necessary in order to achieve de-institutionalization. Clinical ASD and IDD researchers appear as interacting with the Ministry and the independent facilitation projects. This reflects the research which informed Ministerial decision-making.

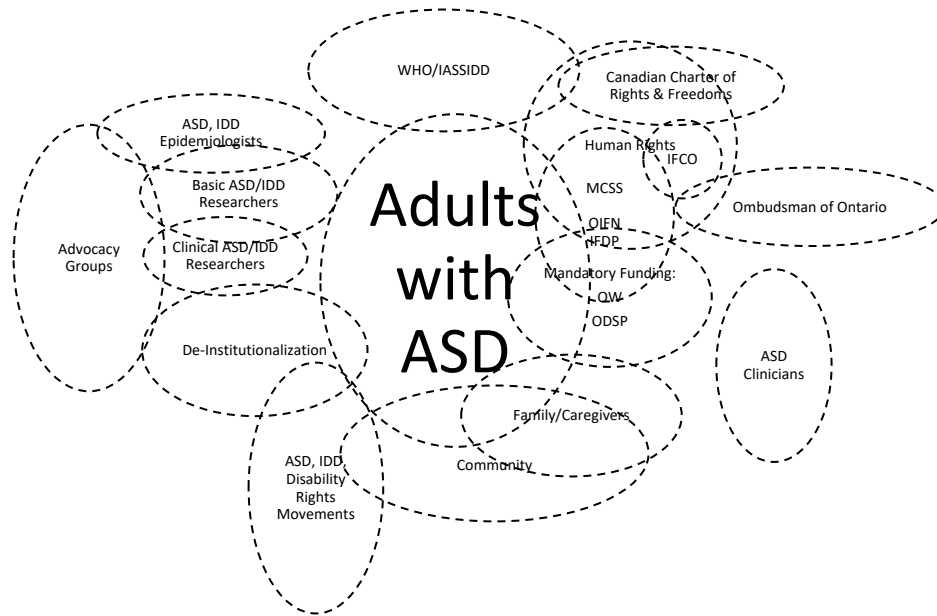


Figure 6. Social Arenas Map Reflecting Relationships Consistent with the Act

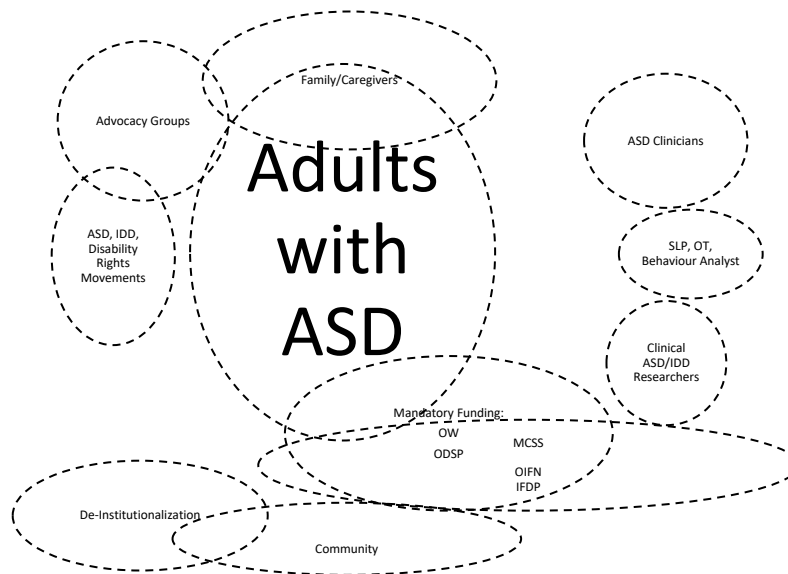


Figure 7. Social Arenas Map: Adults with ASD as Experienced by Caregiver

4.3 Chapter Summary

In this chapter, the results of the study were reported. Although there were insufficient participants to achieve power, the quantitative data provided descriptive statistics relating to the QoFL and subjective well-being reported by participants. The qualitative analysis was informed by Assarroudi et al's (2018) criteria for rigor in qualitative directed content analysis. Themes identified were consistent with Hall's (2009) themes for effective social inclusion, with subcategories identified within several of these themes. Overarching the themes were codes which arose across all themes (i.e., isolation, housing concerns, financial constraints, waitlist services and distrust in the system). These are conveyed implicitly by participants.

Chapter 5

5 Discussion

This qualitative directed content analysis has advanced the knowledge of how informal caregivers of adults with ASD experience social inclusion policy in the Province of Ontario based on data up to June 28, 2018. At the same time, it has confirmed the existence of a gap between the identified importance of social inclusion of adults with ASD within the community and delivery of services and supports to facilitate this. It has also identified health, mental health impacts which threaten the health equity not only of adults with ASD but also that of their informal caregivers. Participants were from across the Province of Ontario and received services (or were on waitlist for services) in their respective communities. Bringing their experiences together and analyzing them in relation to public policy in the Province of Ontario, as well as the grey literature has led to a substantive understanding of their experiences, assumptions about them and their loved ones with ASD communicated by community members and implied in how public policy specific to people with IDD is implemented in the Province of Ontario.

To set the context for the rest of the discussion, this chapter begins by revisiting the goals of the Act and how this relates to what participants reported. This discussion will be framed using Hall's (2009) themes for effective social inclusion. The first section will reflect on the results as they relate to literature focusing on appropriate living accommodations among adults who have ASD or IDD. There was no consensus on preferred housing options for adults with ASD across the participants. The second section will explore the theme of receiving formal and informal supports. In general, participants

provided the majority of supports their loved one with ASD received. There was a sense among all participants that formal supports received were either not suited to the needs of their loved one with ASD or the participants' families or that services were unavailable. The third section reflected on meaningful and reciprocal relationships. All participants reported a sense of isolation from the community, frequently citing a lack of a social support network, with difficulty connecting with those who are unfamiliar with the support needs of adults with ASD.

Complimenting the discussion of meaningful and reciprocal relationships, the subsequent section will discuss acceptance beyond one's disability. Participants reported a sense that their loved one with ASD and/or themselves were isolated from the community and their family and friends due to the needs arising from caregiving duties. Frequently, they cited the people they encounter in their advocacy work as their source of connection and reporting a sense that they do not connect with others outside of the advocacy community. The next section discusses contributions to society made by adults with ASD and their informal caregivers. All participants reported a sense of isolation and lost opportunities to contribute to society for themselves and their loved one with ASD. Related to this is the final section, which focuses on involvement in activities. Participants cited that their involvement in activities is frequently limited to advocacy work and that care work limits their ability to become involved in a broader range of opportunities.

Gaps were identified by caregivers in each of Hall's (2009) themes for effective social inclusion: 1) acceptance beyond one's disability, 2) meaningful and reciprocal personal relationships, and 3) involvement in activities, 4) appropriate living

accommodations, 5) employment, and 6) effective supports (formal and informal as needed) were identified through analysis of social inclusion policy and experiences of adults who have ASD and their caregivers. These themes will be considered as they relate to the social determinants of health identified by the Public Health Agency of Canada: a) biology and genetic endowment; b) gender; c) personal health practices and coping skills; d) health services; e) healthy child development; f) employment/working conditions; g) income and social status; h) education and literacy; i) social support networks; j) social environments; k) physical environments; and l) culture (2013). Recommendations are then made to mitigate these gaps and help to minimize the discrepancies experienced in terms of health equity.

5.1 What Do Caregivers Identify as Appropriate Accommodation?

Safe housing suitable to one's needs was identified as a major source of concern. Three of the five familial caregivers identified inadequate access to such housing in institutionalization by default (i.e., hospitalization in psychiatric wards and in a nursing home, despite needing neither psychiatric hospitalization nor nursing care) as a need for their families. Inability to participate in the workplace and consequent low income was also cited as impacting on satisfaction with housing, as participants reported concern about the safety of their neighbourhoods.

Access to suitable housing arrangements, as well as a lack of consensus on what constitutes suitable housing were also identified as issues faced by participants and their loved ones with ASD. Additionally, sentiment within the community reflected a potential lack of tolerance for behavioural disturbances. This speaks to the need for adequately

funding housing and care arrangements to mitigate the potential for these issues. It also supports the argument raised by participants for funding clinical services, such as behaviour therapy.

Just as one's physical environment (i.e., housing, neighbourhood, geographic location, etc.) are social determinants of health (Public Health Agency of Canada, 2013), appropriate living accommodations is a theme for effective social inclusion (Hall, 2009). Due to financial circumstances arising from care demands placed on them, two informal caregivers reported living in housing they were not pleased with, in neighbourhoods where they did not feel safe. Mitch reported that although he currently is satisfied with his neighbourhood, he is only able to live there because he lives with his parents. If he were required to rely only on his ODSP and DFO funding, he would not be able to afford to live in his current city, where his informal social supports are all located.

Two participants reported that their loved ones with ASD were living in hospitals due to lack of access to appropriate housing alternatives, while a third reported that her loved one was living in a nursing home despite not requiring nursing services, for the same reason. This is a concerning trend among people with ASD, as when they are in these institutional settings, they are removed from the community and losing access to opportunities to use their skills. Consequently, their condition deteriorates such that they are unable function at the levels of independence achieved prior to hospitalization, thereby increasing the level of care and support required of a more suitable housing arrangement (Lunsky, in Goldenthal, 2012). It may also warrant economic analysis to determine whether or not a more suitable living and support arrangement may be less expensive than the cost to provide care in hospitals and nursing homes.

Placements in hospital wards and nursing homes are additionally concerning as it renders the hospital spaces inaccessible to those for whom such a placement is necessary. Further, participants expressed concern that the hospital wards were not suited to the needs of their loved ones. Specifically, they were often placed in psychiatric wards where the strategies used were not consistent with their needs.

There was no consensus across participants about what would serve as appropriate housing. Some participants reported a preference for group homes, while others reported strong distrust thereof, citing concerns about exploitation by staff and other residents, as well as neglect and stigma around groups homes within the community. In keeping with this, various options are being explored by DSO in order to provide flexible housing that is responsive to individual needs (Ministry of Community and Social Services, 2018).

5.2 What Are Caregivers' Experiences of Accessing Formal and Informal Supports for Adults with ASD?

Employment and working conditions are important social determinants of health. For adults with ASD, accessing formal and informal supports, a tenet of effective social inclusion (Hall, 2009), may influence one's ability to participate in the workforce. In this study, Mitch, the self-caregiver with ASD identified sporadic employment as a barrier to his satisfaction with QoL. Louisa stated that despite extensive job training during secondary school, through completion of seven job placement opportunities, her son has not been able to access employment support necessary to maintain a job since leaving secondary school.

Similarly, Theresa's son participated in job placement opportunities during secondary school but has not accessed employment or community engagement opportunities since leaving secondary school. Theresa speculated that it was the lack of stimulation and frustration with not being able to work which lead to his increased behavioural challenges, which in turn prompted his hospitalization.

Other informal caregivers cited limitations on how provincial funding can be used as a barrier to accessing the community and/or employment opportunities. Abigail stated that her brother had not had access to speech and language pathology services since he was ten years old. She speculated that this contributed to his degree of isolation and lamented the lack of access to services which facilitated more skill building. Similarly, Theresa believed a lack of skill building, coupled with counselling and behavioural intervention to address prior trauma would allow her son to function in a supervised independent living arrangement.

Specifically, behaviour therapy and speech and language pathology (SLP), required to develop the skills necessary to participate in these settings, cannot be paid for using funding available to adults with ASD. In Abigail's case, the lack of access to an SLP has necessitated that she and her mother learn how to upload new vocabulary into her brother's augmentative communication device (ACD) through trial and error. For the most part, he does not use his ACD when communicating with Abigail and their mother, as they understand him. However, his paid support workers experience such a high turnover rate and such infrequent contact that they are unable to learn his communication strategies, resulting in a lack of stimulation for her brother. This is an important challenge to address, as effective communication is crucial to interacting with others in the

community. In Theresa's case, her son has the skills to related to performing jobs and has experienced success in the past. Effective participation in paid employment could reduce his dependency upon funding and improve his living circumstances. He could benefit from assistance navigating the job search and learning a new job.

Socioeconomic status is a social determinant of health itself. It also influences one's physical environment, which in turn is a social determinant of health. Supporting conditions for effective and ongoing participation in the workforce may influence health outcomes among adults with ASD. An international research group specializing in ASD research identified a need for research into transition to adulthood and meaningful employment among adults with ASD (Nicholas et al., 2017). The support needs to facilitate effective employment associated with ASD are lifelong and may change over time as an effect of aging and changes to physical capacity to perform one's job. More research into the job support needs and effective employment strategies among adults with ASD across the lifespan is needed.

Turn-over of paid service providers and the duration of waitlists to access services and supports were identified as major barriers to effective participation in the community by both adults with ASD and their informal caregivers. Reports by participants suggested a heavy dependence by the province of Ontario upon informal, unpaid caregivers to make social inclusion policy possible. In the absence of adequate services, supports and funding to make the Act feasible, service and support provision remains institutionalized, as the government maintains power over the lives of adults with ASD and their families.

Both informal caregivers of people with ASD who had lived in institutions prior to de-institutionalization reported that their loved one had experienced abuse in those

settings. They both reflected on the ongoing nature of the trauma experienced by their loved ones related to the abuses they experience:

So now, the big institutions have closed, ok? We've got all the horror stories. My brother personally won't talk about it. He shakes his head and says no. He can talk, like, conversation, but he won't talk about what happened.

Similarly, they both speculated that the effects of the abuse contributed to their difficulty adapting to group home settings and subsequent placement in nursing homes, characterized by Louisa as “re-institutionalization by default”:

So, I brought him up here with me to [city of residence] in 1998 and he went to a couple of different placements. First of all was Community Living, ok? These places are not ready for institutionalized individuals. They are not ready. And I was trying to guide it and all that stuff, but you only have so much power, right? ... His nerves became so bad that he'd hardly hold a cup... He ended up back in the hospital here in [city of residence].

Given the changing attitudes toward institutionalization and people with IDD over time, research is necessary to examine the cohort effects among adults with ASD. Specifically, it may be that those who were not institutionalized and did not experience abuse may have different care and support needs than do same-aged peers who were abused. Exploration of independence and adaptive living skills may also be influenced by where and how people with ASD lived and were educated. For instance, those who were institutionalized may not have had the opportunity to learn basic food preparation and

house-keeping skills, whereas those who remained in the family home may have had more exposure to these opportunities. As such, the latter cohort might be capable of functioning in more independent living arrangements. Examination of the long-term effects of intervention programs and education programs is also necessary in order to determine how best to prepare people for living and participation in the community.

Research examining the long-term effects of trauma arising from maltreatment among people with ASD is necessary. Mitch reported experiences of bullying by both peers and teachers during his participation in elementary and secondary school, attributing his current diagnoses of depression and anxiety disorder to these experiences. He also reported that former classmates continue to harass him when he encounters them in the community. Similarly, Theresa speculated that her son continued to suffer from trauma due to bullying when he attended elementary and secondary school. Identifying the threat of harassment and assault of adults with ASD within the community is crucial in order to develop effective social inclusion strategies.

As parents of adults with ASD experience their own age-related declines, sibling caregivers of adults with ASD may also take on care duties associated with their parents' care needs (Coyle, Kramer & Mutchler, 2014). In the present study, the youngest sibling caregiver had established a care plan with her mother for when her mother is no longer able to care for her brother. Conversely, two other sibling caregivers, who were about 30 to 40 years older than she and whose brothers with ASD had been institutionalized, did not have established care plans in place when they took over care for their brothers.

When it does take place, long-term care planning is often not discussed with siblings intended to take on informal caregiving duties (Heller & Caldwell, 2006; Bigby, 1997;

Freedman, Krauss & Seltzer, 1997). When siblings do know that they will be taking over caregiving from their parents, they often maintain low involvement in advance care planning activities (Heller & Kramer, 2009). One of the challenges with this is that when the time comes for siblings to take over informal caregiving, they may have established their own lives without accounting for caregiving. By engaging in advanced care planning, siblings are able to account for their own lives and interests, which has been demonstrated to render them more effective as informal caregivers (Heller & Kramer, 2009).

In a study of the health habits of adults who were caring for children and aging relatives, healthy behaviours (e.g., selecting nutritious food options, exercising regularly) were significantly lower and were more likely to engage in unhealthy behaviours such as smoking and not wearing seatbelts when riding in cars than were controls who were only caring for children (Chassin, Macy, Seo, Presson, & Sherman, 2010). Further research is necessary to determine how sibling caregivers are impacted by the care duties associated with caring for their adult siblings with ASD and their aging parents.

Abigail reported that her brother who has ASD also has a diagnosis of cerebral palsy. Emiline also reported that she has a son who has cerebral palsy. According to Christensen, Braun, Doernberg, et al. (2013), children with cerebral palsy have a higher prevalence of ASD than do those who do not have ASD. Additionally, those who have ASD also tend to have a higher prevalence of epilepsy (Christensen et al., 2013). Other health concerns experienced by loved ones with ASD cited by participants included: a kidney condition, precancerous polyps and a schizophrenia query.

People with ASD are commonly diagnosed with comorbid psychological and psychiatric conditions, such as depression, anxiety disorder, schizotypal disorders and schizophrenia (Picoito, Santos & Rita, 2018). Not only do adults with ASD tend to have a high prevalence of psychiatric disorders, they also tend to be prescribed and taking more than one psychotropic medication at a time (Buck, Viskochil, Farley, Coon, McMahon, Morgan & Bilder, 2014; Nicolaidis, Kripke, & Raymaker, 2014; Perkins & Berkman, 2012). Frequently, they are prescribed these medications without receiving a diagnosis for a related condition (Lewis et al., 2002).

In a longitudinal investigation of the use of psychotropic medication among teenagers and adults with ASD, Esbensen, Greenberg, Seltzer, Mailick and Aman (2009) found that over the course of 4.5 years, psychotropic prescription increased from 70% to 81% of participants. In a study examining the effects of withdrawing psychotropic medications from people with IDD, de Kuyper and Hoekstra (2018) demonstrated that it was possible to fully terminate use of antipsychotic medication among participants deemed eligible by their physicians to attempt withdrawal of medications. Where the possibility of behavioural challenges was a risk, candidates were excluded from participation. The heavy medication of people with ASD, particularly where no related diagnosis exists, potential health impacts thereof and the possibility of withdrawing the medication support an argument for provision of behaviour analytic services to adults who have ASD.

Additionally, ASD has been shown to be comorbid with metabolic disorders, seizure disorders, gastrointestinal disorders, sleep disorders and hormonal dysfunction (Bauman, 2010). Consistent with these findings, all caregivers in the study reported that the adults

with ASD they cared for had more than one diagnosis and most were taking more than one psychotropic medication prescribed to them by a physician or psychiatrist. However, in cases where informal caregivers were responsible for administering the medication, no caregiver had had any training in the administration of the medication, contraindications or side effects beyond what was provided in the information sheet accompanying the medication when prescriptions were filled at the pharmacy.

Several participants commented that one of the challenges they face when planning for their loved one's care was that services and supports available, as well as funding structures, are subject to change depending on which political party is in power.

5.3 What Are Caregivers' Experiences of Meaningful and Reciprocal Relationships?

All informal caregivers cited a lack of friendships and supportive relationships among extended family members. Having meaningful and reciprocal personal relationships is a tenet identified as a theme of effective social inclusion (Hall, 2009). Although Mitch, a self-caregiver with ASD, reported that he enjoys such experiences among his sports league and the disability advocacy community, he does not have such relationships with people outside these arenas. Similarly, all participants reported lacking friendships.

Abigail for instance cited a difficulty connecting with friends and cousins, as their lives are completely different from her own. Similar to Dillenburger, McKerr, Jordan, Devine & Keenan's (2015) finding that the general public lacked understanding about what was needed to facilitate social inclusion of adults with ASD, Abigail explained that

even her closest relatives do not understand the measures her family takes to support her brother, with some fearing him because of previous aggressive behaviour.

Participants Louisa and Theresa both reported that their relationships with relatives were fractious due to a lack of understanding about the behaviours and care needs related to ASD, indicating an inability to rely upon extended family for assistance.

Both Mitch and Louisa cited participation in advocacy and support groups as their primary source of social support. Louisa frequently cited her connection with other parents having similar experiences as an important source of support.

While access to informal social support may be positively correlated with higher QoFL and burden scores, formal social supports may not interact with these variables in the same way (Marsack & Samuel, 2017). Consequently, it is important for informal caregivers of adults with ASD to have opportunities to access and maintain their own informal social support network.

Health equity is often measured by examining QoFL. As demonstrated in this study, those participants who reported having the least access to informal social supports had the lowest QoFLI and WHOQOL-BREF scores, they also achieved the lowest PWI-A scores, falling within range of scores predictive of clinical depression. This is particularly worthy of note among caregivers of adults with ASD, who are undergoing their own aging processes. As people age, their informal social support networks tend to diminish due to death and naturally arising barriers to maintaining relationships (e.g., decreased mobility, illness, etc.) (Carstensen, Schaie & Lawton, 1991). Further research is necessary to determine whether or not the impact of isolation from informal social supports on informal caregivers will increase as they age.

It is worth noting that three of the four informal caregivers reported feeling that they were unable to pursue romantic relationships because of the caregiving demands that they encounter. The one informal caregiver who was married reported that it was necessary to make a concerted effort to ensure that she and her spouse maintain their relationship. One of the challenges identified was that the amount of advocacy effort required to meet the needs of the person with ASD dominated one's identity.

Louisa also reported that caregiving needs can dominate one's marital relationship. Similarly, Abigail and Emiline indicated that the demands placed on them as a result of the demands associated with ASD prevented them from pursuing and maintaining long-term relationships. Reproductive choices were also influenced by the expectations placed on them in caring for their siblings with ASD.

5.4 What are Caregivers' Experiences of Acceptance Beyond the Disability?

One of the tenets identified as a feature of effective social inclusion is feeling accepted by others and the community as a person beyond one's disability (Hall, 2009). Consistent with this, Public Health Agency of Canada identifies social support networks and social environments as social determinants of health (2013). However, all participants in this study cited feelings of exclusion and/or rejection of themselves and their loved ones with ASD within the community.

Mitch, who identifies as a self-caregiver who has ASD, reported instances of not feeling accepted by the community, citing fears associated with public statements made by a municipal politician. In relation to the incident in question, community members articulated their frustrations with incidents they had witnessed in their neighbourhoods

related to a group home serving youth with ASD. In fairness to the group home, however, the incidents arose over the course of transition to a new facility. Difficulty adapting to this transition by the residents of the group home should not have been unforeseen.

According to the DSM-5, difficulty coping with changes to routine and with transitions are both features of ASD (APA, 2013). As such, difficulties related to the transition should have been predictable and provided for in terms funding to adequately staff the group home to provide required supports over the course of adapting to the new location in order to mitigate upset among the residents of the group home. A more graduated transition plan may also have been implemented to allow residents of the group home an opportunity to acclimatize to their new surroundings.

By redefining their role as a partner in supporting people with IDD rather than as a primary care or support provider, the province articulated an expectation that the community would act as a partner in supporting people with IDD. As demonstrated by the incident which lead a number of community members to seek intervention by their municipal representative, failure to provide adequate funding to service and support agencies tasked with caring for people with ASD can have a negative impact on the community's perception of people with ASD. Consistent with this observed impact of lack of information about ASD and/or IDD among community members, all informal caregivers reported feeling stigmatized and excluded when they were in the community with their loved one with ASD.

This included when pursuing legally protected rights, such as voting. Louisa cited her participation in the We Matter advocacy initiative which was created specifically to raise awareness about the voting rights of people who have IDD. She reported her own

experiences whereby her loved ones with ASD had initially been denied the right to vote and/or to avail themselves of the necessary accommodations at their local polling station by polling officials staffing the station until she showed them where the Election Act (Province of Ontario, 1990) and the Canada Elections Act (Government of Canada, 2000) guarantee the right to vote to people with ASD and other IDD.

According to Prince (2004), 93% of Canadians with disabilities are legal voting age, 4% of whom have IDD. Motivated by a desire to effect change and improve accessibility, voter turnout and engagement among Canadians with disabilities is increasing, whereas among Canadians who do not have disabilities, voter turnout and engagement are decreasing (Prince, 2007; Prince, 2004). Further research is necessary to identify how voting can be facilitated to increase accessibility to people with ASD, as well as to identify the training needs among polling officials to ensure that they accommodate these rights appropriately.

Louisa also reflected on the need to temper advocacy efforts with a need to live and function within the community. She noted that many of the challenges experienced by her brother in accessing a suitable living arrangement were cause for litigation, which in turn could help to fund the required services and supports. However, she also reported concern about how both her loved ones would then be treated by service providers if she pursued this course of action.

Similarly, Louisa and other participants who reported experiencing aggression by their loved one with ASD also cited concerns around identifying the challenge of coping with aggressive behaviour publicly. Specifically, they were concerned that doing so would influence how their loved one was received within the community. For instance,

Louisa reported concerns about employment prospects for her son if she were to advocate vociferously to meet his needs in relation to preventing aggressive incidents. Very little research exists to reflect on the experiences specific to caregivers of adults with ASD. However, what little research does exist demonstrates that parental caregivers of adults with ASD do feel isolated from the general community (Marsack & Church, 2019; Marsack & Perry, 2018; Marsack & Samuel, 2017). In her review of caregiving to the elderly, those with acute illnesses and those with disabilities in the Province of Ontario, Aronson (2004) reported that participants experienced shame and embarrassment about how their circumstances which had changed as a result of their caregiving. The participants in her study were predominantly caregivers of people who had previously not required care, whereas the caregivers in the present study have required care specific to their disorders across their lifespan.

The literature examining informal caregiving to adults with ASD in Canada has focused on parents' experiences of self-efficacy following training and degree of distress experienced across the lifespan, the degree of distress experienced by maternal caregivers seemed to be influenced by: the caregiving demands themselves, maternal appraisals of their ability to meet those needs, availability of external resources and subjective appraisal (Weiss, Wingsiong & Lunsky, 2014). Implicit in this is the recognition that maternal caregivers do experience distress associated with caregiving. The response to this is to train parental caregivers, thereby enhancing their self-efficacy beliefs in dealing with the circumstances which cause distress through training (Weiss, Tint, Paquette-Smith & Lunsky, 2015).

Parental caregivers in the present study, as well as in Marsack and Church (2019) reported feeling excluded by caregiving demands, which they felt were inconsistent with their stage in life (Marsack & Church, 2019). Given that the bulk of the research around caregivers has focused on capitalizing on their ability to contribute, with little regard for the impact caregiving duties have had on their own lives (Aronson, 2004; Heaton, 1999), further research is necessary to determine the extent to which the use informal (i.e., unpaid, typically familial) caregiving is reasonable and does not interfere with caregivers' rights to self-determination. As the caregivers in the present study cited experiences of exclusion, it is important to recognize when the focus on facilitating informal caregiving through programs targeting enhancing capacity may exclude informal caregivers from the community and society.

5.5 What are Caregivers' Experiences of Contributions to Society?

Employment and working conditions are social determinants of health identified by the Public Health Agency of Canada (2013). Being employed is also a tenet of effective social inclusion (Hall, 2009). In a study examining predicted and identified barriers to effective participation in the workforce, Lorenz, Frischling, Cuadros and Heinitz (2016) found that adults working in employment situations tailored to meet the needs of people with ASD experienced process-oriented challenges (i.e., difficulty working within the practices of the employer, adapting one's lifestyle to the employment schedule, etc.). Conversely, adults with ASD working in non-specialized jobs reported challenges related to communication (Lorenz, Frischlin, Cuadros & Heinitz, 2016). Participants in the Lorenz, Frischlin, Cuadros and Heinitz (2016) study were self-selecting, recruited from online chat rooms for people with ASD, suggesting strong

literacy and written communication skills, as well as an ability to search and locate relevant supports. Both process-oriented and communication barriers could be mediated with support from the outset by paraprofessionals with expertise in the related areas (i.e., behaviour analysts, occupational therapists, SLP) could facilitate effective work environments. Further research would be necessary to demonstrate how this might be achieved.

Informal caregivers of adults with ASD cited impacts of caregiving on their own ability to pursue employment. Louisa reported that she had delayed retirement in order to offset the impact of working a reduced workload so that she could meet the case coordination needs associated with caring for her son and brother. Theresa, whose two children have ASD, left the workforce in order to meet their needs. Similarly, Abigail reported that her mother had left the work force “because they just couldn’t handle him in school.”

Although the Act provides a good framework for what should be happening in the community, it does not contain language which allows for supporting the community in facilitating positive and effective inclusion of people who have ASD. In their study examining the influence of community service participation, Lawson, Cruz and Knollman (2017) demonstrated that participation in shared activities with people who have disabilities, including ASD, increases positive attitudes toward people who have disabilities by those who do not have disabilities. This research, however, included participants who were students studying in primarily helping profession fields. Research is necessary to determine whether or not these findings generalize to the overall population.

The majority of research examining social inclusion focuses on people who have IDD, with a primary focus on those living in residential care settings and their paid caregivers. Experiences of those living and participating in the community who do not have disabilities are not well reflected in the literature (Amado, Stancliffe, McCarron & McCallion, 2013). In light of the incident which led to the comments by community members and their municipal representative cited by Mitch, as well as Mitch's interpretation and internalization of those comments, a better understanding of the attitudes and experiences of social inclusion among community members who do not have disabilities and are not paid to care for people with disabilities is necessary. Such research may help guide awareness and education initiatives directed toward the community in which people with ASD (and other IDD) are being included.

Consistent with the attitudes expressed by community members in the incident involving the group home, informal caregivers in the present study consistently stated that they do not feel welcomed by the community and that their loved one with ASD was rejected by the community. This finding is not consistent with findings of a study examining attitudes toward people with ASD within the community (Dillenburger, McKerr, Jordan, Devine & Keenan, 2015). In the present study, Emiline reflected on the challenge of generating support for issues relating to the care of adults with ASD and how it relates to their own needs:

Well, that's what people don't realize. How many, what's happened is when families can't care for their loved ones, even if they're young, they end up in nursing homes. People don't know that. That's why nursing homes are so full. It's not just elderly.

In their study, self-selecting participants reported positive attitudes if someone with ASD moved into their neighbourhood, married a close relative, worked as a colleague or was their boss (Dillenburg, McKerr, Jordan, Devine & Keenan, 2015). Overall attitudes toward inclusion and providing necessary supports to facilitate it prevailed. However, 58% of participants also reported that they did not know ASD was a lifelong disability (Dillenburg, McKerr, Jordan, Devine & Keenan, 2015).

In order to generate political will to provide efficient access to the services and supports required to function effectively in the community, awareness of what is needed is necessary among the general public. Relying exclusively on public policy to facilitate inclusion may be an inadequate approach to service and support provision for people with ASD. Health promotion efforts targeting what individuals, employers and business owners can do to make the community more inclusive and accessible to people with ASD may be helpful in creating a more inclusive community.

5.6 What are Caregivers' Experiences of Involvement in Activities?

Two participants identified leaving or reducing their own participation in the workforce in order to meet the needs of their family member with ASD. Another participant, identifying as having ASD and caring for himself identified precarious employment as a challenge. Three participants also identified lack of employment or otherwise meaningful engagement opportunities for their family member with ASD as a cause of frustration and behavioural challenges by the person with ASD.

Consistent with this experience of diminished participation in the workforce, a feeling of exclusion within their communities was reported by caregivers for themselves,

as well as for their family members with ASD. Caregivers also reported strained relationships with and an inability to access support among extended family members and friends. They also identified difficulty relating to and not having sufficient opportunity to spend time with friends or pursue their own interests.

In a mixed-method study examining the experience of parents of adults with ASD, Marsack and Perry (2018) demonstrated how parents' finances and personal health affected them. Parents reported feeling excluded from same-aged peers who were experiencing an 'empty nest' (i.e., the experience of having raised and launched adult children who are competent to care for themselves). Parents of adults with ASD expressed feelings of exclusion and isolation, citing lost opportunities to pursue their own interests, concerns about their mental and physical health. Additionally, they reported concerns associated with caring for partners in addition to caring for their adult child with ASD (Marsack & Perry, 2018). Consistent with these findings, participants in the present study reported that caring for and advocating for their loved ones with ASD represented excessive proportions of their lives.

5.6.1 Employment/Vocation

Ability to participate in the workforce was frequently cited by participants as a barrier to experiencing inclusion for themselves, other caregivers and their loved ones with ASD. Participants also speculated that behavioural challenges escalated following high school departure due to a lack of employment or meaningful activity. The scoping review described at the outset of this manuscript identified literature as it related to inclusion and health equity. Few of the results from this search were articles specific to employment.

This is an interesting observation in itself, as it suggests that inclusion research rarely considers employment as a means of achieving inclusion.

As employment related issues were raised by all participants, additional exploration of these issues was merited. To further inform the findings of this study as they relate to caregivers' experiences of employment, further literature review, using the search terms "employ*" or "vocation*" or "work*" and "Autism" or "autism spectrum disorder" or "ASD" or "Aspergers" was entered into the PsychInfo and Cochrane databases. Of all the databases used in the scoping review of this manuscript, PsychInfo garnered the most journal articles once inclusion and exclusion criteria were applied. The Cochrane database only includes studies which meet their evaluation criteria for methodological rigour. Therefore, these were the databases used to inform the employment portion of the discussion section.

Once inclusion criteria were set, the PsychInfo search yielded only: a) book chapters (1), b) book review (1), (c) dissertation/thesis (10), (d) journal article (22) and publication (1). When hand sorted for relevance, 23 articles remained. Several of these articles were literature reviews and meta-analyses of the existing research. As such, the articles cited in the references section of these articles were also reviewed for additional input. The following section discusses how findings in this study relates to the existing literature. Figure 8 reflects the results of this search

In their review of the literature about the conditions which promote successful employment experiences by people with ASD, Dudley, Nicholas and Zwicker (2015) found that the majority of the literature was based on research conducted in the USA and United Kingdom (UK). They argued that this is problematic as Canadian employment,

labour policies, disability funding and support policies are unique to Canada.

Consequently, much of the existing literature will be limited in its relevance to Canadians who have ASD in terms of their participation in the Canadian workforce.

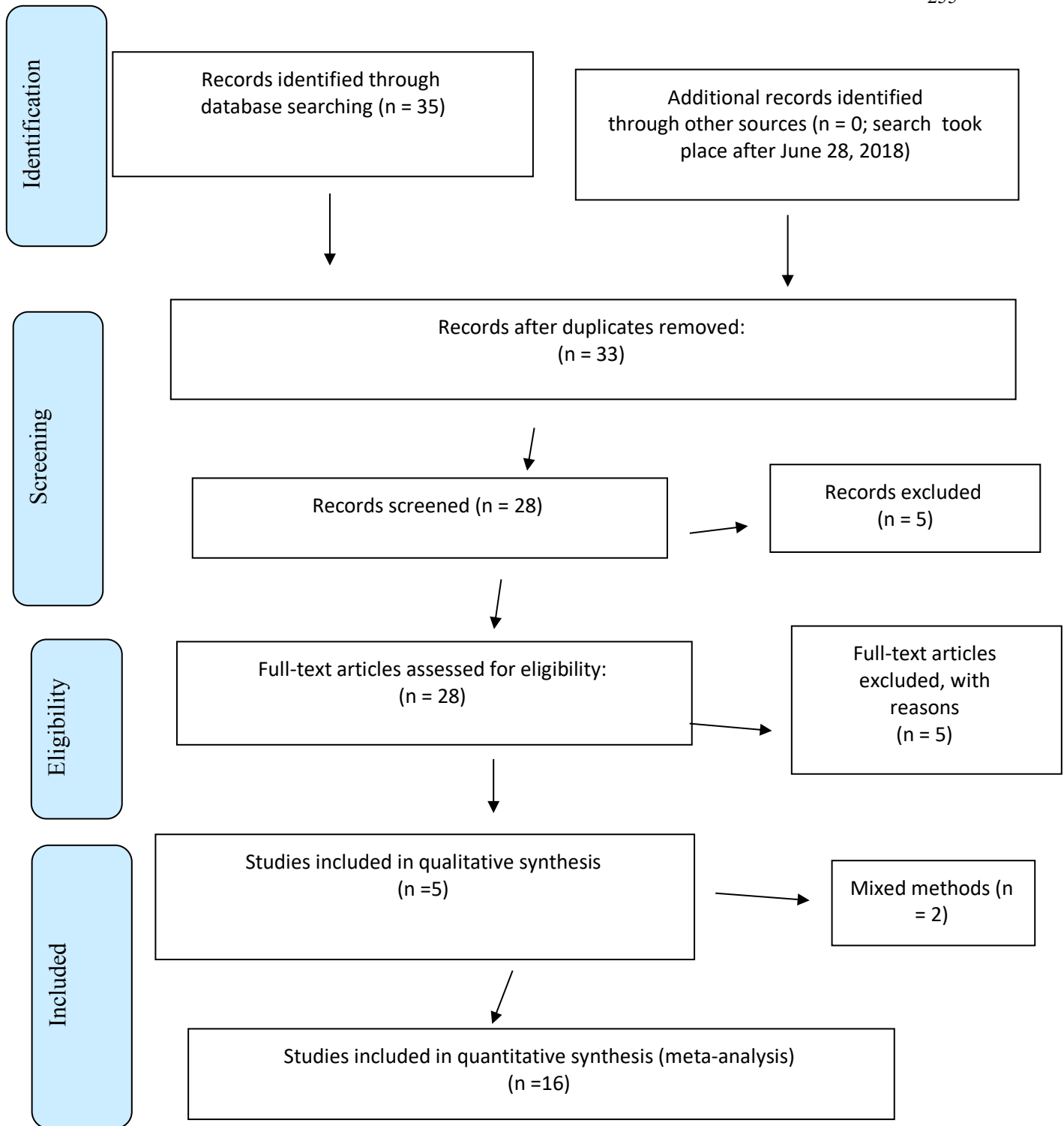


Figure 8. Prisma Diagram of Employment & ASD Research

5.6.1.1 Employment of Caregivers

Theresa reported leaving the workforce to care for her children when they were elementary school due to a feeling that the school could not manage her son's behaviour.

Similarly, Abigail reported that her mother had done the same, motivated by the same concern. Additionally, Abigail reported that her own career development and goals were built around the need to provide for her brother. She also reported that she works approximately 60 hours per week in order to meet her family's needs in the present and to save to meet those needs over the long-term. Saving for the latter is motivated by her recognition that her mother's ability to care for their son while Abigail is at work will not last indefinitely as her mother's own age-related needs intensify. Louisa reported that she had postponed retirement in order to make up for time lost from work due to case coordination needs for both her brother and her son.

These findings appear to be consistent with that in the literature regarding parental workforce participation of children with ASD. In their study using logit and tobit modelling to estimate parental labour force participation and parental hours of work and earnings in the USA, respectively, Cidav, Marcus and Mandell (2012) demonstrated that mothers of children with ASD earn 35% less than do mothers with children who have other health limitations and 56% less than do mothers whose children do not have health limitations (p.620). Additionally, they are 6% less likely to be employed than mothers whose children do not have health limitations (p.620).

In two-parent households, it was 15% more likely that one parent would not work among parents raising a child with ASD than among two-parent households with no health limitations. Earnings for mothers of children with ASD were \$5921 lower than those of mothers with no health limitations (p.621). No statistically significant differences in earnings were observed between fathers of children with ASD, children with other health limitations or children with no limitations. The mean age of the children in this study was

10.45 for families of children with ASD, 1.34 in those with children with other limitations and 8.82 in families whose children had no health limitations (p.620). It would be necessary to conduct similar modelling across one's lifelong career to gauge the lifelong impact of caregiving.

In their mixed-methods study examining the experiences of parental caregivers of adults with ASD, Marsack and Perry (2018) demonstrated that parental caregivers do experience challenges in the workplace arising from their caregiving duties to adults with ASD. In particular, as they get older, the challenge of explaining their caregiving duties to an adult is something which caregivers reported as a challenge.

Consistent with this finding, Abigail reported having difficulty explaining absence related to caregiving duties, while Louisa reported that she had initially had difficulty accessing accommodations in the workplace to facilitate case coordination for her brother and son.

In her review of how the health care system in the Province of Ontario meets the needs of elderly people, those who have acute illnesses and disabilities, Aronson (2014) argued that Canada's tendency to favour a mixed economy (i.e., legislated reliance upon informal, volunteer and paid caregivers) for caregiving predominantly places the burden of care on unpaid, typically familial caregivers. The caregivers in her study predominantly cared for people whose caregiving needs took place over a briefer period of time than those in the present study. Long-term impacts of workplace exclusion in order to deliver unpaid care needs associated with a developmental disorder to be studied further.

5.6.1.2 Employment/Vocation Literature – Outcome Studies

In a content analysis of the literature examining employment and ASD in competitive, supported or sheltered workshops, Scott, Milbourn, Falkmer, Black et. al. (2018) found that people with ASD have strengths and abilities which can serve them well in the workforce. In particular, the articles they reviewed focused on job performance but did not consider contextual factors, such as the work environment, barriers to success in the workplace or employment conditions.

On the most basic level, there is some evidence that attitudes toward people with ASD can influence their employment outcomes. In their analysis of parents' expectations of young adults with ASD preparing to transition into adulthood, parental assignment of household chores and responsibilities pertinent to adulthood to their child with ASD (Holmes, Kirby, Strassberg & Himle, 2018). Whereas parents of girls with ASD were more likely to enroll them in preparatory courses for entry to the workforce, parents of boys with ASD were more likely to speak with their child about entering the workforce (Holmes, Kirby, Strassberg & Himle, 2018).

In their study examining employment characteristics of young adults who had recently transitioned from high school in the USA, Chiang, Cheung, Li and Tsai (2013) demonstrated that employment rates differed significantly by gender among recent graduates of high school who had ASD was statistically significant. Accounting for discrepancy in incidence ratios between males and females, Chiang, Cheung, Li and Tsai (2013) demonstrated that males with ASD who had recently graduated from high school were 11% more likely than females to be employed (p. 1837). Communication skills and social interaction skills also were strongly correlated with employment prospects

(Chiang, Cheung, Li & Tsai, 2013). It could be that discussing employment expectations with young males better prepares them for the workforce than does enrollment in preparatory courses. Alternatively, it may be that data provided for females was negatively skewed because more of them are participating in preparatory courses and are therefore, less available to participate in the paid workforce. Further research would be necessary to determine the causes of gender differences in workforce participation among adults who have ASD.

In their examination of employment among young adults with ASD upon leaving school, 53% of those with ASD, while 98% of those with disorder and 62 to 80% of those with other IDD had ever had employment (Roux, Shattuck, Cooper, Anderson, Wagner, & Narendorf, 2013). Such disparate findings suggest a need for further investigation to identify factors which preclude, exclude and include people with ASD in the workforce. In their work examining the effect of vocational services, Chen, Sung and Pi (2015), analyzed employment outcomes and service use by adults with ASD. They found that those of transition age (i.e.. transitioning out of child and adolescent services and/or education services, into adult services) tended to receive more assessment, post-secondary training, vocational training and unspecified training than were adults who were already in the adult service system. This makes sense, as the services often require assessment to determine eligibility.

In my experience, service agencies tend to take the position that it is also good clinical practice to reassess a person as they achieve adulthood to obtain a current reflection of their functioning, strengths, interests and needs. The services those already accessing adult services tended to include: transportation, job search assistance and job placement

assistance and diagnosis and treatment of impairment (Chen, Sung & Pi, 2013). Older adults, such as those accessing services, may have already had assessments, as evidenced by their currently accessing services contingent on assessment results.

The effects of job placement assistance, counselling and guidance have been demonstrated to be steady across age groups, with those who received such services being more likely to attain and retain employment than those who did not access these services (Chen, Sung & Pi, 2013). Post-secondary training, other occupational training and counselling services were also associated with better employment outcomes across age groups (Chen, Sung & Pi, 2013). These results were pertinent to those living in the USA.

Assuming Chen, Sung and Pi's (2013) findings that assistance locating, attaining and retaining jobs best predicts employment outcomes in adults who have ASD can generalize to Canada, it is important to examine what vocational supports are available to Canadian adults with ASD. In Canada, researchers found that across the country, there were inconsistencies in service agency staff awareness of programs offering vocational support to adults with ASD within their organizations, with 40.14% stating no such service exists and 32.11% reporting they were unsure whether or not such a service exists (Nicholas, Zwaigenbaum, Zwicker, Clarke, et al., 2018, p.696). This could reflect the fact that people with ASD do not necessarily have cognitive deficits. Many of the service agencies funded to provide these sorts of supports are agencies which specialize in disorders characterized, in part, by a cognitive deficit. It is reasonable then to assume that employees at such agencies may not have expertise in the supports necessary to support a person with an IDD that is not necessarily characterized by a cognitive deficit.

5.6.1.2.1 Transition, Post-Secondary Training/Life Skills

Theresa reported that it had been her son's high school special education resource teacher who told her about how to apply for DSO services and Passport Funding. Similarly, Mitch was unsure about how he came to work with DSO but believed it had been his high school guidance counsellor who had coordinated the application for him. In their study, Chiang, Cheung, Li and Tsai (2013) demonstrated that participation in career counselling during high school and school's involvement in coordinating post-secondary vocation opportunities (i.e., either post-secondary training or employment) were significantly related to post-secondary employment outcomes.

Both Theresa and Louisa cited a lack of cognitive and physical stimulation as being the cause of the behavioural challenges their son's encountered. In both instances, participants believed their sons would be able to develop the skills necessary to work in the community and live independently but that they would require support learning to do so. As Nicholas et al. (2018) demonstrated, those with higher cognitive functioning often have poorer employment outcomes. This may be due to ineligibility due to a lack of cognitive deficit.

Support through the job seeking and interview process, as well job assistance were positively correlated with performance outcomes (Nicholas et al., 2018). It then becomes necessary to look at what works in preparing people with ASD for job entry and retention. In the cases of the youngest adults with ASD in the present study, both informal caregivers reported that they were preoccupied with playing video games. It may be that capitalizing on this interest can be an effective way to help adults with ASD to develop job search, attainment and retention skills, as well as the skills necessary to

teach the job. Studies examining the effects of video modelling (i.e., using video to demonstrate effective completion of a task or performance of a skill) has demonstrated that this approach is effective in teaching interview and vocational skills among people who have ASD (So, 2017; Taylor, McPheeters, Sathr, Dove, Veenstra-Vander Weele & Warran, 2012; Allen, Wallace, Greene, Bowen, and Burke, 2010; Burke, Anderson, Bowen, Howard & Allen, 2010). Although promising, further research is necessary to explore other options, as well as challenges which may arise through the use of video modelling for vocational skills and job search skills.

5.6.1.2.2 Employer Perspectives

In their cross-Canada study examining factors which contribute to success in the workforce, Nicholas et al (2018) demonstrated that those in the community were more likely to appraise vocational support services more consistently with families and individuals who have ASD than were the employees of the service agencies which provide the vocational support services. Adults with ASD also reported experiences of bullying, poor treatment in the workplace and workplace cultures rendering employment untenable.

Consistent with MCSS (2014) select committee observation and subsequent recommendation to remove cognitive functioning from eligibility criteria for services and supports provided in the Act (2008), this study also demonstrated that it was most challenging to access services for adults with ASD who did not have a comorbid intellectual disability (Nicholas et al., 2018). Part of this could be due to the wide range of cognitive functioning possible among people with ASD being in conflict with mandates by service agencies to deliver services to people with IDD.

Many of the services available may not be suitable to the needs of the person who has ASD but no cognitive deficit. This could account for Mitch's experience of being "ghosted" (i.e., agencies ceased to reply to his initiations for interactions) by his regional Community Living and DSO service providers. He reported having extensive conversations with staff from these agencies but found that the training, services and supports they were offering him were not suited to his interests or needs. Predictors of more positive outcomes in the Nicholas et al (2018) study included: vocational skills development, earlier exposure to jobs, accommodations in the workplace to remove barriers to successful job performance, promotion of workplace culture which is positive toward and knowledgeable about ASD and how it will affect the person in the workplace (Nicholas et al., 2013).

As people with ASD gained employment, they often encountered job disincentives, such as loss of funding due to employment status when funding entitlements are greater than income earned (Chen, Sung & Pi, 2013). A Canadian study examining the effects of wage subsidies to incentivize employment of people with disabilities and assist employers to support them have had inconsistent results (Jongbloed, 2010). Subsidies targeting wages, when applied in conjunction with tax exemptions for making accommodations, accessing consultation and supports from service agencies and staff recruitment, retention and training grants are most effective (Jongbloed, 2010). This research looked at people with disabilities generally. It did not focus on people with ASD or those employing people with ASD.

5.7 Limitations & Suggestions For Future Research

This study examined a small sample size. With the exception of one participant who identified as part Métis, all participants were White and lived in urban locations. One participant reported that her children's father was Black. It will be important to achieve more racially diverse samples in future research.

Recruitment efforts were extensive, with minimal uptake. All participants found recruitment information on Facebook pages dedicated to advocacy for people with developmental disorders. This suggests that they actively pursue supports and information about developmental disorders.

It will be important to replicate this study with a larger, more varied sample size in terms of race, gender, socio-economic status, and drawn from urban, suburban, rural and remote locations. It will also be crucial to identify strategies to recruit informal caregivers who are not accessing support services and who are less likely to pursue supports on social media. Only one participant identified as having ASD.

Research examining how public policy impacts on the targeted population is important. Further research is necessary to examine how adults with ASD, as well as those with other IDD, experience social inclusion policy and the way it is implemented. Additionally, it will be necessary to analyze how social inclusion policy impacts members of the community in which social inclusion occurs, as well as how to increase the public awareness and acceptance thereof.

Participants also identified trauma arising from bullying and abuse as impacting on the mental health and independence of the adults with ASD. Further

research is necessary to identify the long-term effects of people who have ASD and were bullied in childhood and/or adolescence. Additionally, it is necessary to determine how institutionalization impacted on independent functioning and housing placement options among adults with ASD, as well as how this differs from adults with ASD who were not institutionalized.

Gender is a social determinant of health which impacts on informal caregivers of adults with ASD is gender. The prevalence of ratio of ASD between males and females is 4:1 (APA, 2013). All informal caregivers were female, whereas the adults with ASD for whom they cared were male. Several of the informal caregivers reported incidents of aggression emitted by the adults with ASD for whom they cared. They also tended to reference the size/weight of the adult with ASD, with all references to size and weight being taller than 6 feet and weighing over 200 pounds. Given that women tend to be smaller than that, further study needs to look at the safety and danger to female caregivers in relation to the size of those for whom they care when there is a history of aggression.

In a meta-analysis of caregiving, Pinquart and Sorensen (2006) demonstrated that women tend to take on unpaid caregiving roles more frequently than do men and when they do so, they tend to seek social support less frequently. Consistent with this finding, the informal caregivers participating in the current study reported limited access to social support. Additionally, the women caregivers reported higher levels of burden, poorer health and lower subjective well-being and health ratings (Pinquart & Sorensen, 2006). Given Marsack and Samuel's (2017) finding that access to informal social supports is positively correlated with

QoFL scores and negatively correlated with measures of burden, this is not surprising.

Three of the informal caregivers reported impacts on their ability to participate in the workforce arising from caregiving responsibilities associated with ASD. Although beyond the scope of this research, informal caregiving to adults with ASD should be analyzed in relation to the issue of pay equity. The interaction between pay equity, employment conditions, health status and gender among informal caregivers of adults with ASD should be further examined.

The Act (2008) is intended to promote social inclusion of people who have IDD, and aims to provide them with choice, fairness and access to the community. One of the ways it achieves this is by relying on informal caregivers to provide care and support to their loved one who has IDD. Participants in this study indicated experiences of being excluded from their community as a result of their caregiving duties. In general, caregivers in this study focused on the needs of their loved ones. They indicated that they were unable to focus on their own needs as they had to prioritize those of their loved ones. Consequently, many of the recommendations to address the needs of informal caregivers in this study target enhancing the independence of those they care for.

Participants in this study identified circumstances which prevented them from pursuing both employment and leisure opportunities. Additionally, many cited experiences of alienation from family and friends arising from their caregiving roles. They also reported their own health and mental health concerns, some of which they attributed to their caregiving duties. Measures should be taken to ensure that their needs are met while fulfilling their caregiving role.

Appropriate housing arrangements for their loved one with ASD were also cited as a major challenge faced by participants. The major barrier participants indicated was waitlists which can be ten to fifteen years in duration. To mitigate the impact of long waitlist durations for housing independent of the family home, funding and programming should be made available to adults targeting skill development, such as daily living skills and employment skills. Further research is necessary to determine whether or not doing so will increase their independence, thereby decreasing the intensity of support required to meet their needs once housing becomes available. Therapies such as speech and language pathology, which targets language and communication skills and behaviour analysis which targets both skill development across all domains of functioning and behavioural challenges, can also facilitate this skill development.

Awareness and promotion of adults with ASD as valuable contributors to society, in the workforce, volunteer roles and leisure activities is necessary. These campaigns should target community members in an effort to assist them to see themselves as stakeholders and participants in inclusion efforts. Reactionary reporting by journalists contributed to one participant's perception that people like him were rejected by Ontario's leadership and electorate. Examining how media influences public perception of ASD, caregiving thereof and the experience of caregiving is also necessary.

Participants in this study and the adults for whom they care had a high prevalence of mental health challenges, with limited access to mental health services. Psychotherapy specializing in people with ASD or IDD and their caregivers may help to address these difficulties. Given that participants indicated having little time to attend to their own health and mental health care, frequently citing time lost from work to coordinate

services for their loved one with ASD, it is necessary to analyze approaches to address this time constraint.

Although the Act guarantees the right to supports that promote the social inclusion of individuals with developmental disabilities, the Act (2008) does not define social inclusion explicitly. The overarching goal of social inclusion of people with IDD, and by extension people with ASD, is to address barriers across economic, political, social, and cultural dimensions to ensure that adults with ASD/NDs can participate fully in society and become integrated in the community, receiving health care and support proportional to their needs.

Social inclusion in the context of individuals with ASD has not been well-defined. Research on social inclusion has tended to focus on objective measures, such as the number of opportunities for inclusion, rather than on the subjective experiences of those meant to be included. Positions taken by international organizations such as WHO and IASSIDD have tended to define social inclusion as the opposite of social exclusion, relying heavily on evidence of diminished inequities in SDOH to demonstrate the pursuit of social inclusion. As demonstrated by the current study, how individuals define social inclusion and barriers to social inclusion is more concrete and deals with barriers which result in isolation of people with ASD and their caregivers. For instance, inadequate or inappropriate housing options and lack of opportunity to develop skills which facilitate interactions within the community, among those who are not necessarily familiar with how to respond to a person presenting with the skill deficits in question.

Another challenge is that social inclusion policy requires those who are meant to be included to define the terms of inclusion, without considering the logistics related to

those with whom they are being included. Failure to consider inclusion from the perspective of those with whom the individual is mean to be included is exclusionary in itself. Defining social inclusion for oneself is also challenging without information about what is possible and what will be welcomed by those among whom one seeks to be included. Initial research examining person-centered or person-directed planning suggests that it may be helpful in assisting individuals with IDD and their caregivers to identify what is possible and develop a plan for living according to one's priorities and values.

Based on MCSS reports (Harper & Baker, 1986, MCSS 1987, Vermeulen et al., 1993, Jaczek et al., 2014), policy makers in Ontario apparently expected that transitioning to community-based care, as supported through social inclusion initiatives, would reduce the costs associated with serving and supporting people with NDs. Further research is necessary to determine the cost-benefit of increasing funding to provide services which facilitate participation in the workforce, as well as independent functioning across the lifespan. It may well be that doing so will decrease the cost of long-term care, as well as the cost to provide health care to caregivers as their burden would decrease with increased independence of their loved one with ASD. An additional benefit to this would be that employed adults with ASD could contribute to the tax base rather than relying on the tax base.

It is important to note that each of the recommendations for future research relies heavily on access to organized care and service provision. The nature of the complaints by users of developmental services in Ontario, as well as observation by the Ombudsman of Ontario that systemic constraints and poorly conceived implementation have hindered client access to care and services (Marin, 2014a). Thus, it is first necessary to establish

how policy pertaining to care and service provision to aging adults with IDD influences development and implementation of, as well as access to that care and service. As public policy decisions often prioritize economics, research which examines the cost to provide services and supports which facilitate independence, as well as participation in the workforce not only by the person with IDD but also by their informal caregivers is important.

5.8 Use of Caregivers in Policy

At the outset of this manuscript, the principles of the CRPD were laid out to provide a context for understanding the rights of people with disabilities as agreed upon internationally. The previous section has synthesized how findings in this study relate to policy in the Province of Ontario and the literature.

The following section will use the CRPD guidelines to demonstrate how the findings of the research at hand relate to them. This is an important consideration because the approach the Province of Ontario reflects the values of the CRPD, a document that member nations of WHO have adopted to guide their approach to supporting people with IDD. As the uncompensated people tasked with providing the majority share of caregiving to people with IDD, it is reasonable to assume that these principles apply not only to people with IDD but also to their informal caregivers.

5.8.1 Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons

In reviewing the grey material related to an unfortunate incident in the Municipality of Toronto, it was evident that community members held varying values and concerns where inclusion of people with ASD who are engaging in challenging behaviour are concerned. In the absence of sufficient public sector services to meet the demand associated with people with ASD/IDD, legislation which relies on the family and community to provide care assumes competence and willingness of the family and community members to do so (Heaton, 1999). Consistent with Heaton's position that informal caregivers are considered by policy-makers as "...unpaid care-givers who provide care out of love and filial piety.", Passport funding in Ontario prohibits using the funds to compensate parental, spousal or relational caregivers who often fulfil tasks similar to those compensated, formal caregivers perform. It can, however, be used to purchase "caregiver respite services and supports", which comprise a section of the definition of 'services and supports' in the Act (2008, subsection 4(1)). Accounting for caregivers in this way indicates not only an expectation that they will provide the care but also recognition that the provision of care will have effects on caregivers which will impact their ability to sustain caregiving duties (Heaton, 1999).

In their cross-sectional study of participants providing care to adults family members with various physical and mental conditions in 20 countries, Shahly, Chatterji, Gruber Al-Hamzawi et al (2013) significant negative impacts on mental and physical health of caregivers were identified, with distress, and embarrassment about one's circumstances

being the most commonly identified burdens. In the present study, caregivers expressed concerns about their capacity to provide care, the impact doing so has on their health and well-being. The participants in the present study cited caregiving duties had mental health impacts similar to those identified in Shahly et al.'s (2013) findings.

Abigail – “My mental health is very close to poor. I don't know if I can sustain this. One day per week when I just had a really bad visit with my brother and I expect to turn to my own work and I just can't.”

Emiline – “...So I just said I can't, I don't have the wherewithal, I'm not well myself. I have a heart condition; I have many things wrong with me.”

The assumption is that these caregivers are competent, physically and mentally to provide the care. In such an arrangement, policy views formal care as a “...means of preventing the caring relationship from breaking down...” (Heaton, 1999, p. 766). This is evident by experiences reported by informal caregivers in the present study:

Abigail – “My mom and I know how to work with him to keep things from escalating but we never get enough time with the workers to teach them how to do it, so we end up being the only ones who can go out anywhere with him.”

Louisa – “And these other families that have to go into crisis or do go into crisis and get their spots, what kind of shape is that individual going to be in, in order to make it the best independent situation for them? They're already damaged and in crisis. That's not right. Families shouldn't have to go into crisis in order to get a place for their children to live. That's the reality of the system right now. It's not good.”

Inability or refusal to provide care by informal caregivers can put them in a situation where their loved one with ASD must live in an unsuitable setting while they wait for an alternative arrangement to become available in the community. Informal caregivers in this study expressed concerns about the loss of skills associated with this, as well as the degree of crisis the family would be in by the time access to more suitable arrangements would become available. In one case, Emiline reported that when her brother was placed in a group home for recovering addicts, he was victimized by other residents and neglected by staff such that his chronic diarrhea went untreated for months before she was able to access a colonoscopy for him.

Caregivers in this study also expressed resentment that they were put in a position where they have to consider sacrificing their values in order to advance the cause of their loved one with ASD:

I've actually had professionals say to me – now we're Christians, we have ethics, we have – you know, strong faith. I've had them say to me, Participant's name, just exaggerate a little bit more. Just lie, just tell them a little bit more. And then I think to myself, you want me to lie, that's what you want to do? That would be us stepping on other people. It's not right... I could probably do a song and dance, blah blah blah, and get our scores higher. It probably wouldn't get me immediate one but – unless I flip out or something. But – nobody should be forced to do this kind of thing. No family should be put in such a position that you have to claw, you know, or lie. It's not right. I won't do it.

An alternative to this consideration of the informal caregiver is one which acknowledges that informal caregivers have their own needs. However, such consideration for informal caregivers tends to be limited to the care of children (Heaton, 1999). It is important to note, however, that in some jurisdictions, it is becoming increasingly common for informal caregivers to be recognized as service users equal to the client with IDD (Heaton, 1999). The Act (2008) seems to do this by accounting for caregiver respite within the definition of services and supports.

5.8.2 B) Non-discrimination, full & effective participation & inclusion in society, c) equality of opportunity, d) accessibility

It is important to ensure that legislation does not implicitly exclude one population from the community in order to facilitate the inclusion of another population.

This research has demonstrated that caregivers of people with ASD are less likely to be employed but more likely to be single heads of households. Informal caregivers tend to contribute on average 16.6 to 23.6 hours of caregiving duties on a weekly basis (Shahly, et al., 2013). The caregivers in the present study also cited caregiving, case coordination and advocacy as consuming significant amounts of their time every week. In conducting this research, it became evident that there is an assumption within policy that informal caregivers will only be providing care to the one individual. This may be true of caregivers of children and teenagers with ASD. However, as the care recipient ages, so too does the caregiver and other family members.

Participants in the present study identified numerous health effects experienced by themselves and their loved ones with ASD. All participants identified health effects they experienced as caregivers. For instance, the formal caregiver stated that he had physical

injuries arising from his care duties and also found that he tended to burn out so occasionally took unpaid sick days in order to prevent the latter. Informal caregivers cited burn out and mental health as major sources of concern in relation to their health.

Emiline also cited care duties related to caring for her mother who had Alzheimer's and her son who has cerebral palsy as compounding factors which rendered her exhausted and incapable of caring for her brother. She also reported having a heart condition herself. Compound caregiving (i.e., caregiving demands placed on a caregiver caring for more than one person) has been associated with three adverse outcomes: 1) reduced contact with and access to a social support network, 2) difficulty prioritizing caregiving demands and 3) compromised stress resilience (Perkins, 2010).

In the present study, Emiline, Louisa and Theresa are responsible not only for the care of an adult with ASD but also have caregiving duties to another person with ASD or another developmental disorder. All three participants also reported that their parents had died of conditions which required informal care. In Abigail's case, there could come a time when she is caring for both her mother and her brother. The participants in the present study are at risk for adverse outcomes arising from compound caregiving. In a study examining compound caregiving, Lunskey, Robinson, Blinkhorn and Ouellette-Kuntz (2017) found that almost half of their participants in their study examining the experience of parental caregivers were compound caregivers, caring for more than one person. They too found that compound caregivers reported significantly higher rates of burden and family distress than did those caring only for an adult child with IDD (Lunskey, Robinson, Blinkhorn & Ouellette-Kuntz, 2017).

The informal caregivers were all female in this study, while the self-care provider with ASD was male and the formal caregiver was male. Men who are caregivers of adults with ASD are less likely to leave the workforce for caregiving duties (Cidav et al., 2012).

Women who do participate in the workforce earn less than do women who are not caregivers of adults who have ASD, less than do men who are caregivers to adults who have ASD and men whose children do not have ASD (Cidav et al., 2012). This research was conducted among parents of children with ASD and has not examined whether or not these discrepancies continue as children transition into adulthood.

Female participants in the present study indicated a need to leave the workforce and to delay retirement in order to account for time lost from work in order to coordinate care. Parental postponement of retirement has been demonstrated to be a common practice among parents of adults with IDD, both to help save for future care needs and to offset the cost of time lost from work for provision of care (Parish, Seltzer, Greenberg & Floyd, 2004). In the current study, only one participant cited a need to postpone retirement. She was female. Further research may be necessary in order to determine the impact legislation which positions the family as caregivers has on women's ability to participate in the workforce.

There is some evidence that employment outcomes for males with ASD are better than for females with ASD (Holmes, Kirby, Strassberg & Himle, 2018). To account for this finding, it is necessary to look at the nature of support given. Research has demonstrated that parental caregivers are more likely to discuss participation in the workforce with their sons who have ASD, whereas parental caregivers of females with ASD are more

likely to enroll their daughters in courses in preparation for participation in the workforce.

5.8.3 e) Respect for difference and acceptance of persons with disabilities human diversity and humanity

These principles of the CRPD as applied to an assessment of the Act (2008) may be limited by the understanding policy-makers have of IDD. For instance, recommendations to the Province of Ontario by the select committee included removing stipulations that cognitive functioning be considered within the eligibility criteria (MCSS, 2014).

Although the policy-makers suggest that language allowing diagnosing health professionals to account for need when a cognitive deficit is not present, the literature has demonstrated that those with higher IQ's tend to fare more poorly and tend to have access to fewer supports than do those with cognitive deficits (Nicholas et al., 2018).

Abigail expressed concern that the policies did not reflect the capacity of families to provide the degree of care required by people like her brother: "The policies are incredibly ill-informed. The expectations they have of families are just insane. It's discriminatory, you know?" She reflected on the limitations care work has placed her mother's ability to pursue a career, as well as on her own ability to pursue a career, marry and have a family.

Inability to use Passport funding to access skill building services was experienced by participants as hindering access to the community: "My brother is forced to go everywhere with his mom and me. It's not good for his development. It's infantilizing to have to rely so much on his mom. Especially for a grown man."

Similarly, both Louisa and Emiline reported that their brothers, who had been abused in the institution system, were not well-suited to the services and supports available to them. Although both acknowledged that the placements their brothers are currently in are not ideal, they are satisfied with these placements having experienced the alternatives.

5.8.4 f) Equality of opportunity, g) accessibility, h) Equality between men and women

As has been demonstrated, both female informal caregivers and females with ASD experience lower rates of employment and lower incomes outcomes than do their male counterparts. In the present study, all informal caregivers were women, two of whom had left the workforce in order to provide care for their loved one with ASD, one who framed her entire career around planning for taking over caregiving duties for her brother when her mother is no longer able to provide care and one who has delayed retirement in order to coordinate care. Aronson (2014) has demonstrated that informal caregivers tend to be women, while Cidav et al. (2012) demonstrated that even when men are caregivers, they experience lower impact to their incomes than do women.

5.8.5 Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities” (p.5)

Children with disabilities evolve into adults with disabilities. The distinct focus on the evolving capacity of children’s abilities, without considering the evolving capacity of adults’ abilities, could contribute to perpetuating the lack of awareness that the community has about ASD persisting throughout adulthood. The capacities of people

evolve across the lifespan, even into and throughout adulthood. The challenge for informal caregivers is to create sufficient awareness to generate political will amidst competing priorities:

Louisa – “...it’s, some people just don’t know. People just don’t know. And it’s not that they don’t want to know but everything is else is put in your face. Again, mental health, Indigenous, victims of domestic violence, but not developmentally disabled and the families are taking care of that, so nobody else has to think about it.”

One of the considerations which also must be explored further is the impact current challenges to developmental services have on other systems. For instance, nursing homes are often a placement option exercised when a person with ASD lacks suitable housing, regardless of need for nursing care. Advocates in the ASD community point out that the insufficient access to suitable housing accommodations for their loved ones with ASD causes them to compete with those in need of nursing home placements:

Emiline – “Well, that’s what people don’t realize. How many, what’s happened is when families can’t care for their loved ones, even if they’re young, they end up in nursing homes. People don’t know that. That’s why nursing homes are so full. It’s not just elderly.”

Caregivers in the present study expressed the view that these placements are not ideal for the adults with ASD if they are not in need of nursing care, particularly if they are younger than the normative population of these facilities, as they are under-stimulated and the staff lack expertise in supporting people with ASD.

The CRPD places an onus on state parties to ensure that legislative and administrative measures are taken, ensuring that people with disabilities are able to fully

realize all human rights and fundamental freedoms. This is based on the value of ensuring egalitarian treatment of people regardless of disability. However, the CRPD does not use language to protect the rights of informal caregivers.

That the findings of Shahly et al's (2013) research suggests that these findings are consistent across WHO member nations, regardless of economic development status of the nation suggests that existing principles rely heavily on informal caregivers to their detriment. As has been demonstrated in the research at hand, informal caregivers also experience exclusion from society, employment and income disparity as a result of the disability which requires them to provide care beyond that which is typically expected of the general population. The consequences experienced by informal caregivers are sufficient to “..threaten the continued integrity of their caregiving capacity...” (Shahly et al, 2013).

This research has also demonstrated that the care provided by informal caregivers is frequently assumed in language around caregiving in legislation (the Act, 2008; Heaton, 1999). In the case of the Province of Ontario, this seems to have been part of an intentional repositioning of the government as primary care provider to one of collaborative partner, alongside the community, family members, volunteers and service agencies (Vermeulen et al., 1993).

The requirements placed on state parties are extensive and include (but are not limited to): ensuring training for paid care providers, undertaking and promotion of research and development geared toward meeting the needs of persons with disabilities, accounting for the protection and promotion of the human rights of persons with disabilities in all policies and programs. Quality Assurance Measures (QAM) articulated

in subsections of the Act (2008) do require that service providers of service recipients funded for developmental services access training. However, this is limited to paid caregivers. Furthermore, it is limited to people actively receiving services.

Although Article 23 of the CRPD does focus on home and family rights of individuals who have disabilities, the focus is on the rights of the individual to marry and parent, as well as the rights of children who have disabilities. Family members who provide care to adults who have disabilities are not accounted for within the language of this section. The failure to formalize consideration for informal caregivers may be in conflict with positions taken on human rights (Lunsky, Tint, Robinson, Gordeyko & Ouellette-Kuntz, 2014). For instance, United Nations (UN) General Assembly in the *United Nations Principles for Older Persons* (resolution 46/91) (1991). Resolution 46/91, which is intended to include all aging individuals, proposed five clusters regarding the status of aging people. These include: (a) independence, (b) participation, (c) care, (d) self-fulfilment and (e) dignity protects the rights of people as they age (Hogg et al., 2000).

Informal caregivers of adults who have ASD may include ageing parents and/or siblings. Caregivers in this study cited experiences of feeling a lack of dignity associated with seeking services and supports. In many cases, participants cited the difficulty associated with admitting the intensity of the challenges they are facing and limitations placed on them and their loved one with ASD in terms of accessing and participating in the community. Caregivers also indicated their own mental health and physical health needs which arose as a result of providing care, as well as needs which were going unmet in order to provide care.

5.9 Chapter Summary

This chapter examined the findings of the present study in relation to the existing literature, tying the findings to policy at the provincial level, as well as to international principles. Many of the findings were consistent with existing caregiving literature, demonstrating the health, mental health and burden effects of caregiving. It then demonstrated how policy in Ontario relates to the effects. Finally, in recognition of the fact that the principles of the CRPD align with the values reflected in the Act (2008), the discussion demonstrated how the findings of the present study align or conflict with the principles in the CRPD.

Chapter 6

6 Conclusion

This qualitative directed content analysis identified the policy which informs care and service provision to adults who have ASD and their caregivers. It explored how informal caregivers experienced the Act, what they did in order to meet the needs of their loved one's and what impacts caregiving has had on them. It did so by first exploring common tools used to evaluate the health equity impacts of policy on the intended population, then demonstrated how qualitative directed content analysis is a research strategy which complements the approach of these assessment strategies.

The life course perspective was used to consider the history of ASD, demonstrating how this has influenced how people with ASD are understood currently. A literature review was conducted to situate this study within the context of social inclusion and health equity. An exploration of the policy documents which legislate the services and supports people with ASD access, grey material was also reviewed, demonstrating attitudes toward people with ASD which exist in the community in an urban centre in the Province of Ontario. Stakeholders were then interviewed about their experiences as informal caregivers of adults with ASD.

A scoping review was conducted using the Pearl Harvesting strategy to ensure an exhaustive list of search terms is considered. Although it did prove fruitful, the Pearl Harvesting strategy may exclude literature related to the issue if the correct terms are do not appear among the key words. For instance, although participation in the workforce is evidence of inclusion and also is a determinant of health, very limited employment and vocation research came up in the Pearl Harvesting searches of both inclusion and health

equity, requiring a further literature review to be completed in order to consider participants' reports related to employment within the context of existing literature.

6.1 Health Equity Assessment

The HEIA is an assessment tool to identify the unintended health equity impacts of public policy. Step one of the HEIA is to conduct a scoping review of the population/problem the policy is intended to address. Chapters 1 through 3 provided a scoping review of the Act and literature about social inclusion of adults with ASD or IDD. Step 2 of the HEIA is to identify the potential impacts of the policy. Chapter 4 identified potential impacts of the Act on adults with ASD and their caregivers, as reported by their caregivers. The third step of an HEIA is to make recommendations to mitigate negative impacts of the policy.

The third step of an HEIA is to identify ways to reduce the potential negative impacts of the policy in question and amplify the positive impacts. To do so, this chapter will consider the Act, the decision-making and implementation thereof, as well as the experiences and perceptions reported by caregivers. The final two stages of the HEIA, monitoring (i.e., monitoring the effects of the recommendations on health equity of the population targeted by the policy) and dissemination of these results, are beyond the scope of this study.

The goal of the Act (2008) is to promote social inclusion among people who have IDD. However, as reflected by Vermeulen et al. (1993), social inclusion in the province of Ontario was influenced by a budget shortfall. How the Act is implemented reflects decisions made whereby the budget shortfall prompted the province to reframe its role as

the primary service provider to adults and children with IDD to a partnership role with families, communities and other government funders.

6.2 Implications for Inclusion

The way the Act and related services and supports are implemented assumes adults with IDD (and by extension, ASD) will primarily be cared for by informal, typically familial caregivers. The expectation that adults must rely on their families undermines the goal of social inclusion among two groups of people. Specifically, it requires adults with IDD (and in the case of this research, with ASD) to rely on familial caregivers. This is not consistent with how the majority of adults live in Ontario. By requiring them to live in a way which is defined by their need of familial support, the funding formula for services outlined within the Act perpetuate their “otherness” by forcing them into roles informed by their disability. It also requires informal, familial caregivers to deviate from living in a way which is consistent with those who do not love a person who has ASD (or other IDD). Informal caregivers in this study consistently reported that they regularly forego pursuit of their own needs, interests and careers in order to accommodate the Act’s goals for social inclusion of the person with IDD. Consequently, the Act and inadequate funding of related services and supports to facilitate independence and autonomy among people with IDD (and therefore, ASD) creates circumstances both for adults with ASD and their informal caregivers which cause them to experience exclusion in the community, workforce and among their extended families.

This study set out to identify: a) how the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008, is experienced and b) has influenced how they and their caregivers live, c) what the needs of their

caregivers are, d) how these needs are being met and e) by whom. The themes that were identified in this research included: a) housing preferences, b) waitlists for services and funding, c) isolation, d) health and mental health, e) financial constraints and f) inefficiencies in the public support services system. Social inclusion policy in the Province of Ontario is intended to promote social inclusion. However, there are systemic barriers which hinder this from happening. These include: a) inefficient application and funding processes, b) limitations on how funds can be used and c) insufficient access to service providers, preventing adults who have ASD and their caregivers from participating in the community.

Although it guarantees the right to supports to promote the social inclusion of individuals who have developmental disabilities, the Act (2008), itself, does not define social inclusion. In general, the goal of social inclusion of people who have IDD is to address the barriers across the following dimensions: economic, political, social and cultural, to ensure that adults who have IDD are able to fully participate in society and are integrated in the community, receiving health care and support proportional to their needs. In Ontario, social inclusion as public policy appears to have been motivated by the potential to cut costs, shifting the duty to provide care to families and communities.

This study has demonstrated that social inclusion, as it relates to people who have ASD, has not been well-defined. The focus of research on social inclusion has tended to be on objective measures, such as number of opportunities for inclusion, rather than on the subjective experiences of those meant to be included. Positions taken by international organizations such as WHO and IASSIDD have tended to define social inclusion as being the opposite of social exclusion, relying heavily on evidence of decreased inequity in

social determinants of health to demonstrate the pursuit of social inclusion. In the spirit of promoting autonomy and respecting the individual, the Province of Ontario, has left social inclusion to be defined by the individuals who have IDD and their primary caregivers.

The Act relies upon family caregivers. However, as demonstrated by participants in the present study, this can have health and mental health consequences to the caregivers. Reviews by the Ombudsman of Ontario have demonstrated that individuals who have ASD, and their families are not adequately supported. According to these reviews, the inadequacy of supports has resulted in dangerous situations for both individuals who have ASD and their caregivers. These reports suggest that this situation often results in “institutionalization by default”, citing the inappropriate placement in long-term care facilities, hospitals, prisons, etc. (Dubé, 2016; Marin, 2014a).

Caregivers reported experiencing isolation and dissatisfaction with their experience of the community. Participants in this study identified circumstances which prevented them from pursuing both employment and leisure opportunities. They also reported their own health and mental health concerns, some of which they attributed to their caregiving duties.

The Act (2008) aims to achieve choice, fairness and inclusion of people who have developmental disorders. However, the language and procedures in the Act (2008) rely on informal caregivers to make this happen, implying that by virtue of being related to the person with ASD, they are entitled to less choice. As a result of long waitlists and lack of access to suitable supports, informal caregivers in this study reported a lack of choice and inclusion for themselves and their loved ones with ASD, as well as

opportunity costs due to inability to participate fully in the workforce both among informal caregivers and people with ASD.

6.3 Future Directions

The first step in effecting change is to create awareness that current approaches do not reflect the best interests of those targeted. In the case of how the Act (2008) is experienced by informal caregivers and people with ASD, participants reported incidents in which the effect of the Act (2008) and barriers to accessing related services and supports served to isolate both informal caregivers and adults with ASD from the community. Publishing this study can contribute to creating awareness of factors the complexity involved in meeting the needs of adults with ASD and their informal caregivers. It is through discourse and sharing experiences that policy-makers and service providers will identify which issues should be targeted.

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Appendices

Appendix A: Ethics Certificate



Date: 8 January 2018
To: Ken Kirkwood
Project ID: 110458
Study Title: Health Equity Status of Caregivers of Older Adults Who Have Autism
Application Type: HSREB Initial Application
Review Type: Delegated
Full Board Reporting Date: 23JAN2018
Date Approval Issued: 08/Jan/2018 14:49
REB Approval Expiry Date: 08/Jan/2019

Dear Ken Kirkwood

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

Document Name	Document Type	Document Date
17-11-21 Newspaper ad Clean	Recruitment Materials	17-11-21
17-11-21 Recruitment Letter For Administrators Clean	Recruitment Materials	17-11-21
17-11-27 Control Group Newspaper ad Clean	Recruitment Materials	17-11-27
17-11-27 Control Group Recruitment poster 16-02-13 Clean	Recruitment Materials	17-11-27
17-11-27 Recruitment poster	Recruitment Materials	17-11-27
18-01-02 Semi-Structured interview	Paper Survey	18-01-02
18-01-05 Autism LOI	Written Consent/Assent	18-01-05
18-01-05 Control Group Letter of Information and Consent	Written Consent/Assent	18-01-05
76	Paper Survey	1996-12
Personal Wellbeing Index	Paper Survey	2013-05-06
QOLIF FRISCH	Paper Survey	1994 (Received 18-01-05)
WHO5_English	Paper Survey	1998 (Received 18-01-05)

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Page 1 of 2

Date: 8 January 2018

Nicola Geoghegan-Morphet, Ethics Officer on behalf of Dr. Marcelo Kremenchtzky, HSREB Vice-Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Page 2 of 2

Appendix B: Recruitment Information**a. PARTICIPANTS NEEDED FOR
RESEARCH IN****b. Health Equity Status of Caregivers of Older Adults Who Have
Autism**

We are looking for volunteers to take part in a study of the service and supports available to people who meet the following criteria

You are:

A caregiver who is not paid to care for someone 35 years old or older,
who has Autism
Speaks English

If you are interested and agree to participate you would be asked to:
complete two 1-hour interviews.

Your participation would involve 1 to 2 sessions,
each session will be about 60 to 120 minutes long.

For more information about this study, or to volunteer for this study,
please contact:
Heather Church
Health Sciences

Primary Investigator: Dr. Ken Kirkwood

Appendix C: Letter of Information and Consent



Health and Rehabilitation Sciences

LETTER OF INFORMATION AND CONSENT

Health Equity Status of Caregivers of Older Adults Who Have Autism

Name of Principal Investigator: Ken Kirkwood, Ph.D

Co-Investigators

Heather Church, M.A., CRPO

Contact Information

Conflict of Interest

No known conflicts of interest exist.

Introduction

You are being recruited for participation in this study because you are somebody who cares for a person who has Autism who is 35 years or older.

Background/Purpose

The purpose of this study is to learn about what is and is not working in Ontario in the care and service provision to older adults who have Autism. The researcher is seeking to learn what needs caregivers of older adults with Autism have, how these needs are met, by whom and what needs or questions are going unmet.

Study Design

You will participate in two interviews. In the first interview, you will be asked questions about what you do to care for an older adult who has Autism, your own health needs and your living arrangements. In the second interview, you will be asked questions about your health, daily living and well-being.

Procedures

You will book an appointment with the researcher to complete an interview about the experience of being an adult who has Autism or caring for an adult who has Autism. You will suggest times and locations for the interviews which are convenient to you. With your consent, interviews will be audio recorded (i.e., your voice is recorded, not your

image). If you do not wish to be audio recorded, you may decline consent to be recorded. The interview can be conducted without being recorded.

Visit	Procedures
Initial Interview	Complete a questionnaire about what you do to care for the person who has Autism, your living arrangements and lifestyle. Estimated duration: 1 hour
Interview 2	You will be asked a number of questions about your health and well-being. Estimated duration: 1 hour

Voluntary Participation

Participation in this study is voluntary.

Withdrawal from Study

If at any point during the study, you wish to withdraw from the study, you may do so by notifying Heather Church. You may also choose not to answer some questions. If you decide to do this, you may simply say “pass” and the interviewer will move on to the next question.

If you choose to withdraw from the study, no more data will be collected. The data collected up to that point will be used in the study and kept on file for seven years, at which point it will be destroyed according to standards required in the Health Act.

Risks

Participants may experience discomfort or distress as a result of discussing their needs.

Benefits

There are no known benefits to participation in the study.

Alternatives to Being in the Study

Participation in the study is not required. It is important to note that the researcher is independent of and not affiliated in any way with any service agencies. Participation will not in any way influence access to services.

Confidentiality

Unless required by law, information provided during the interview will be confidential. There are limits to confidentiality. If there is reason to suspect that the participant or other is at risk of harm, the researchers is obligated to report this to the police. The Human Subjects Research Ethics Board (HSREB) at Western University may require access to the study records for monitoring purposes.

Data collected for this study will be stored in the researcher's locked office, in a locked filing cabinet for seven years, at which point it will be destroyed according to guidelines in the Personal Health Information Protection Act. Qualified representatives of the following organizations may look at your medical/clinical study records at the site where these records are held, for quality assurance (to check that the information collected for the study is correct and follows proper laws and guidelines).

Examples include:

Principal investigator, Dr. Ken Kirkwood and the members of Heather Church's dissertation committee

Representatives of the Western University's Health Sciences Research Ethics Board that oversees the ethical conduct of this study.

Costs

Participants will be asked to complete an interview with the researcher. This should last about an hour. There are no known monetary costs associated with participation in this study.

Compensation

Participation in this study will not be compensated.

Rights as a Participant

You do not waive any legal rights by agreeing to participate in this study. You may withdraw in full or in part from this study, at any point during the interview. If you are not comfortable answering a question, you may decline to answer.

Questions about the Study

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics. The REB is a group of people who oversee the ethical conduct of research studies. The HSREB is not part of the study team. Everything that you discuss will be kept confidential.

Scope of the Study

This study is a one-time study, completed over the course of two interviews which will be conducted at times which are convenient to you. Upon completion of the two interviews, you will not be contacted by the researchers for participation in subsequent studies.

Consent

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time.

I agree to take part in this study.

I can be contacted by the researcher for the purpose of participating in this study at the following phone number: _____

CONTACT FOR FUTURE STUDIES

Please check the appropriate box below and initial:

I agree to be contacted for future research studies

I do NOT agree to be contacted for future research studies

Print Study Participant's Name

Signature
(YYYY)

Date (DD-MMM-

My signature means that I have explained the study to the participant named above.
I have answered all questions.

Print Name of Person Obtaining Signature

Signature of Person Obtaining Signature
YYYY)

Date (DD-MMM-

Appendix D: Letter to Agency Administrators

Recruitment

HEALTH EQUITY
CAREGIVERS OF
HAVE AUTISM

**Name of
Investigator: Dr**

Co-
Heather Church,
RP, BCBA



Western

Cover Letter

STATUS OF
OLDER ADULTS WHO

**Principal
Ken Kirkwood**

Investigators:
Ph.D Candidate,

Contact

Information

Conflict of Interest: No known conflicts of interest

Introduction

You are receiving this letter because you manage/administer a program which serves among its clientele, adults who have Autism Spectrum Disorder (ASD)/Autism. We are conducting research examining the health equity of older adults who have Autism and their informal caregivers. We are asking that you post the enclosed poster in areas of your facility where staff who have direct contact with adults who have ASD/Autism and/or clients themselves may access them.

Background/Purpose

The purpose of this research is to identify the unintended health effects of the services and supports available to older adults who have ASD/Autism and their caregivers.

Study Design

This study is a mixed methods (i.e., quantitative and qualitative) study.

Procedures: Self-selecting participants will complete two one-hour, semi-structured interviews and complete three standardized instruments designed to measure quality of life and subjective wellbeing.

Voluntary Participation: Participation in this study is voluntary. Your clients should not feel compelled to participate in this study as a condition of service from your agency.

Withdrawal from Study: Participants may withdraw from the study at any time with no penalty to them. In cases where verbal communication skills prevent such withdrawal, behavioural cues (e.g., protesting, refusal to participate, walking away, etc.) will be considered withdrawal from the study. Data obtained up to the point of withdrawal will be used in the study but no further data will be collected.

Risks: Some participants may find it upsetting to reflect on their situation. To mediate this, information about available resources will be provided. As with any study, there is a risk of privacy breach. Measures consistent with those required in the Personal Health Information Privacy Act (PHIPA) will be implemented to prevent privacy breaches from occurring. Beyond this, there are no known risks to participation in this study.

Benefits

Although there are no direct benefits to participation in this study, doing so will contribute to the knowledge base on serving and supporting adults who have ASD/Autism and their caregivers.

Reminders and Responsibilities

Clients should not feel compelled to participate in this study. You are being asked to make recruitment information about this study available to those who might wish to participate but to allow those who wish to do so to be self-selecting.

Alternatives to Being in the Study

Some clients may wish to decline to participate in the study. This should be their right to opt to do so.

Confidentiality

Unless required by law, we will protect the confidentiality of our participants within the legal limits. In cases where we suspect someone is at risk of being harmed, we are required to report this risk to the police.

Costs: There are no financial costs associated with participation. Participants will be asked to provide two hours of their time to the researchers.

Compensation: No compensation is being provided for participation.

Rights as a Participant: Participants have the right to withdraw or decline to participate in the study at any given time.

Questions about the Study: For further information about the study, please contact Heather Church:

Appendix E: Semi-Structured Interview and Demographic Information

Health Equity Status of Caregivers of Older Adults Who Have Autism

Primary Investigator: Ken Kirkwood

Co-Investigator: Heather Church

HESICOAA Original Version 17-11-13

Appendix A

Semi-Structured Interview Questions – Informal Caregiver

1. Tell me about the Autism-related services you/your family receive.
2. How do you access these services?
3. What is your understanding of the policies which influence the services and supports you receive/the person who has Autism receive?
4. How did you become aware of these services
5. Tell me about the process you completed in order to access the services
6. What needs do these services fulfill?
7. What needs go unmet for you? For the person with Autism? For other family members?
8. How do you fulfill the needs which go unmet?
9. Tell me how you meet your/his/her needs when you are sick/unable to do so?
10. What long-term plans have been made for when you are no longer able to care for yourself/care for him/her?
11. What are your hopes for your future? For his/her future?
12. Is there anything which concerns you about your future? His/her future?
13. Tell me about the experience receiving education/services as a child for the person who has Autism.
14. Would you say that in general your health is: (a) Excellent, (b) Very good, (c)

Fair, (d) Poor?

Health Equity Status of Caregivers of Older Adults Who Have Autism

Primary Investigator: Ken Kirkwood

Co-Investigator: Heather Church

HESICOAA Original Version 17-11-13

15. Thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was physical health not good?

16. Thinking about your mental health, which includes stress, depression and problems with emotions, how many days during the past 30 days was your mental health not good?

17. During the past 30 days, for how many days did poor physical or mental health keep you from doing your usual activities (e.g., self-care, work, recreation)?

Health Equity Status of Caregivers of Older Adults Who Have Autism

Primary Investigator: Ken Kirkwood

Co-Investigator: Heather Church

HESICOAA Original Version 17-11-13

Appendix B

Demographic Questionnaire - Caregiver

1. What is your relationship with the person who has Autism?

2. How old is the person who has Autism who you care for? _____

3. How long have you been caring for him/her?

4. Do you live with the person who has Autism? ___ Yes ___ No

5. If yes, who else lives with you?

6. If no, where does the person who has Autism live?

7. What city/town/village do you live in? If you live in a remote area, how far is the nearest community to you?

Health Equity Status of Caregivers of Older Adults Who Have Autism

Primary Investigator: Ken Kirkwood

Co-Investigator: Heather Church

HESICOOA Original Version 17-11-13

8. How old are you? _____

9. Do you provide care to anybody else? ___ Yes ___ No

10. If yes, what sort of care do you provide to this person?

11. What is the nature of the care you provide to the person who has Autism

Domain Specific Tasks

Physical Care

Domestic

Financial

Social

Community

Health Equity Status of Caregivers of Older Adults Who Have Autism

Primary Investigator: Ken Kirkwood

Co-Investigator: Heather Church

HESICOOA Original Version 17-11-13

Involvement

Transportation

Medical/Dental

Other

12. How long have you been providing care to the person who has Autism?

13. Are you currently employed outside the home? ___ Yes ___ No

14. If yes, is it full-time___ or part-time___? How long have you been working?

15. What is the highest level of education that you have attained?

16. Are there any other informal (i.e., unpaid) caregivers who support the person who has Autism? ___ Yes ___ No

17. If yes, how many people are informal caregivers? _____

18. What is the relationship of the informal caregivers to the person who has Autism?

a. _____

Health Equity Status of Caregivers of Older Adults Who Have Autism

Primary Investigator: Ken Kirkwood

Co-Investigator: Heather Church

HESICOAA Original Version 17-11-13

b. _____

c. _____

d. _____

e. _____

19. Is the person with Autism supported by any formal (i.e., paid) caregivers?

___ Yes ___ No If yes, what is the nature of the support?

20. How does she/he access the support?

21. Were you involved in arranging formal support? ___ Yes ___ No

22. If yes, how did you become aware of this support and how to access it?

Health Equity Status of Caregivers of Older Adults Who Have Autism

Primary Investigator: Ken Kirkwood

Co-Investigator: Heather Church

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23. What was the eligibility criteria required to access support? How was this demonstrated?

24. What do you do when you are not supporting him/her and/or not working?

25. Do you live in urban, rural or remote Ontario?

26. If the person who has Autism receives formal supports, where are the services provided in relation to where he/she/you live?

Health Equity Status of Caregivers of Older Adults Who Have Autism

Primary Investigator: Ken Kirkwood

Co-Investigator: Heather Church

HESICOAA Original Version 17-11-13

27. What is your cultural/ethnic background?

28. What is the cultural/ethnic background of the person who has Autism?

Appendix F

Operational Definitions and Code Manual for Grey Material

Theme	Definition
Changing System	Uncertainty about the system and what to expect from it due to ongoing, expected, real or perceived changes to how services, supports and opportunities are delivered, eligibility criteria and funding models.
Engagement/Employment	Opportunities for a person with a developmental disorder or Autism to be involved in community-based, academic, recreational, professional activities or tasks.
Funding	Money, stipends or grants provided on the basis of eligibility due to having a diagnosis or a developmental disorder or Autism.
Health	Any physical and/or mental health, presence/absence of good health, strategies to achieve health, illness, pain, medication.
Housing	Where a person lives regardless of the model of accommodation (e.g., with family, independently, group home, congregational, institutional).
Identity	How an individual perceives oneself and how s/he wishes to be perceived by others.
Isolation	Set apart or segregated from others, real or perceived lack of opportunity for engagement with others.
Programs	Formal services or supports, provided free or at cost in which people who have developmental disorders/Autism participate. May or may not be specialized to people with developmental disorders/Autism.
Transition from School	The process followed to leave the public education setting once no longer eligible for these services. Typically occurs between the ages of 18 and 21 years old.
Waitlists	Lists maintaining names and data about individuals seeking to participate in or receive programming, services, supports or funding until space/funding become available to them.
Overgeneralization of values	The tendency to apply one's values as they relate to people who have developmental disorders without knowing the strengths, needs or context of the individual(s) in question

Curriculum Vitae

Name: Heather Church

Post-secondary Education and Degrees: Trent University
Peterborough, Ontario, Canada
1997-2001 B.A.

University of Victoria
Victoria, Ontario, Canada
2004-2006 M.A.

The University of Western Ontario
London, Ontario, Canada
2014-2019 Ph.D. in progress

Honours and Awards: Business Excellence – Professional Services Nominee
West Ottawa Board of Trade
2018

Great Ideas For Teaching (*GIFT*)
Teaching Support Centre
2018

Graduate Student Funding - \$17 000/year
Faculty of Health Sciences, The University of Western Ontario
2014-2015, 2015-2016, 2016-2017, 2017-2018

FHS Travel Award - \$250
The University of Western Ontario
2017-2018

Student Researcher on a SSHRC Initiative in the New Economy – Collaborative Research Initiative (Winne, P. H., Azevedo, R., Hadwin, A. F., Kumar, V., Lajoie, S., Nesbit, J., Perry, N. Co-Applicant/Investigator). *The Learning Kit: Theory and cognitive tools to enhance learning skills and support life-long learning.* -\$2 998 983
 University of Victoria
 2005-2006

Graduate Tuition Fellowship - \$2500
 University of Victoria
 2004-2005, 2005-2006

Trent Study Abroad Scholarship - \$1800
 Trent University
 2000-2001

Related Work Experience

Course Instructor
 Carleton University
 2018-2019

Course Facilitator
 Algonquin College
 2018-2019

Teaching Assistant
 The University of Western Ontario
 2014-2015, 2015-2016, 2017-2018

Disability Counsellor
 Algonquin College
 October 2017-May 2018

Research Assistant
The University of Western Ontario
2016-2017

Project Coordinator & Manager
The University of Western Ontario
2015-2016

Course Instructor
The University of Western Ontario
2014-2015, 2015-2016, 2016-2017

Reviewer
Canadian Association on Gerontology (CAG)
2015

Course Instructor
Seneca College
2010-2011

Teaching Assistant
University of Victoria
2004-2005, 2005-2006

Project Manager
University of Victoria
2005-2006

Research Assistant
University of Victoria
2005

Rsearch Assistant

University of Victoria
2004-2005

Research Assistant
Trent University
2000-2001

Publications:

Marsack, C.N., & Church, H. (2019) Impact of caregiver burden on quality of life for parents of adult children with ASD. *American Journal on Intellectual and Developmental Disabilities*.

Church, H., & Marsack, C. (2017). Health equity predictors among aging parental caregivers of adults with ASD. *Innovation in Aging*, 1(1), 445-445.

Church, H., & Dyson, L. (Under Review). Family Functioning and Quality of Life in Families of School-Age Children with Autism: a comparison with families of children who do not have Autism, *Focus on Autism and Other Developmental Disabilities*

Gress, C. L. Z., Hadwin, A. F., Page, J., & Church, H. (2008). A Review of Computer-Supported Collaborative Learning: Informing Standards for Reporting CSCL Research, *Computers & Human Behavior* (Special Issue).

Morris, R., Church, H., Hadwin, A. F., Gress, C. L. Z., & Winne, P. H. (2008). The use of prompts, roles, and scripts in collaboration. *Computers & Human Behavior* (Special Issue).