Perceived Outcomes and Expectations for Disclosure of an ASD Diagnosis in Community Recreation Contexts:
An Instrumental Case Study

by

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ABSTRACT

Children with Autism Spectrum Disorder (ASD) identify community leisure and recreation activities as their highest priority when setting personal participation goals, yet they participate in significantly fewer community-based activities than their typically developing peers. Decreased community participation has been mostly attributed to the influence of family and child factors such as financial resources of the family, and/or the childs emotional and social function. Contextual factors in community settings, including attitudes of community members and organizational practices and policies, have been infrequently evaluated. In a related study investigating parental decisions regarding disclosure and non-disclosure of an ASD diagnosis to others, parents report apprehension to disclose their childs ASD diagnosis within community-based programs, often due to preconceived ideas about Autism and stigma. This study is the first to investigate the expectations and perceived outcomes of disclosure of an ASD diagnosis from the perspective of community recreation programs. An instrumental case study approach was used for this study. Consistent with case study methodology, multiple data sources were used. Semi-structured interviews were conducted with six staff who worked for a large organization that provides a number of community recreation programs. These staff represented a range of seniority from senior leadership to new summer program staff. Interviews were audio-recorded, transcribed verbatim, and checked for accuracy. Registration documents for programs at the same organization were also reviewed. Thematic analysis of these data was conducted, providing the opportunity to identify, analyze, and report patterns found within the interview transcripts. Analysis revealed three themes associated with disclosure in community settings: (1)Perceived Informational Needs (2) Perceived Disclosure Outcomes, and (3) The Expected Disclosure Process. Our study helps address this critical research gap to inform more effective practices and support services for families and address programming and societal level education and intervention to improve social participation for children with ASD. These outcomes may ultimately contribute to improved quality of life for these children and their families, and healthy communities overall.

PREFACE

This thesis is an original work by Rinita Mazumder. The research project, of which the thesis is a part, was given research ethics approval from the University of Alberta Research Ethics Board, "At Whose Discretion? Assumptions and Expectations for Disclosure of an ASD Diagnosis in Community Recreation", No. Pro00074185, Date: July 5, 2017.

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DEDICATION

I would like to dedicate this work to my family; my parents, Shapna and Asit Mazumder, and my older brother Robin Mazumder. From day one you have each taught me in different ways what hard work and perseverance looks like. It is what has gotten me this far, and what continues to drive me forward.

For that, and so much more, I am grateful.

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To my fellow graduate students and friends here in Edmonton and across the country, thank you for constantly cheering me on and helping me stay motivated. My graduate school experience has been enriched with all of you to lean on and learn from. Finally, to my partner, Carson. Your unwavering support has made this undertaking that much more achievable.

As a final note, I would like to acknowledge the language used throughout this work. I have used person-first language (e.g. children with disabilities or children with ASD), as it reflects the language used by the literature I have referenced and the language used by my participants. With that said, I believe it is important to acknowledge that many self-advocates prefer and use identity-first language (e.g. disabled child or Autistic child).

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Chapter 1

Introduction

"In the end, we can construct sensible, complex, fascinating, and indefinite accounts of reality that simultaneously evoke wonderment and unease about what it means to be part of our social world."- Maria Mayan

1.1 Background

How we disclose information about ourselves to others can be tricky. It may become extra challenging when a parent has a child with a disability and needs to decide to share or not share certain information about their child. Some parents are in favor of disclosing their child's diagnosis, and some are in favour of maintaining non-disclosure. Many fall in the middle, where disclosure is context-dependant. This is understandable, as we live in a society ripe with misconceptions and preconceived notions of certain conditions and disabilities. But, we also live in a society where information sharing has become open and accessible and is expected most of the time. It is clear that making decisions around disclosing your child's diagnosis can be challenging with many considerations. Will the information change how their child is treated? Will the information enhance inclusion? Will the information prevent their child from being included? These questions are very pertinent to community recreation contexts. This case study will, in hope, promote conversation about language and disclosure processes within community recreation contexts, and support parents in understanding what information organizations may ask for, and why they seek the information.

1.2 Purpose of Study

The overall purpose of this study was to examine the perceptions and expectations that community recreation organization staff have of parents to disclose their child's diagnosis of Autism Spectrum Disorders (ASD). This study complements other studies by members of our research team that explored parents perspectives on diagnostic disclosure to others. Many parent's expressed their apprehension to disclose their child's diagnosis in community settings. The parent perspective is one side of the story, which is why I wanted to better understand the expectations and assumptions of staff for this type of disclosure. Gaining a deeper understanding of these expectations and perceived outcomes can facilitate dialogue around the varying expectations, assumptions, practices and policies of community organizations related to disclosure. Additionally, it can allow us to obtain more information on how to positively support families and provide more inclusive opportunities to children with ASD. The specific objectives of this study were to:

1. Investigate the expectations and assumptions of program staff to have parents disclose their childs ASD diagnosis;
2. Better understand the perceptions of the outcomes of disclosure/non disclosure of an ASD diagnosis;

3. Understand how organizational language use and structural practices play a role in disclosure.

1.3 Overview of Thesis

The entirety of this thesis is comprised of six chapters. Following this introduction, chapter two explores the literature related to core constructs that informed this study: participation of children with ASD, stigma and ASD, and diagnostic disclosure. Chapter three outlines the methodological approach and methods used for the study. Chapter four reports the results of the qualitative case study. Chapter five discusses and reflects on the limitations and broader implications of these results. And finally, chapter six includes my reflection of the research process and concluding statements. Appendix A includes a scoping review of the literature related to stigma and stigmatization of children with ASD and their families, which was conducted in the development of this project. It was published in the Review Journal of Autism and Developmental Disorders. The last two appendices include the information and consent forms, and the interview guide used in this case study.

Chapter 2

Literature Review

This chapter provides a background on the relevant literature pertaining to: 1) social participation of children with ASD, 2) stigma, and 3) diagnostic disclosure. Implications of the literature will be highlighted in relation to the rationale of the study.

2.1 Social Participation

"Through active participation, young people are empowered to play a vital role in their own development as well as in that of their communities."

- UN World Programme of Action for Youth

2.1.1 Why social participation?

The International Classification of Functioning, Disability and Health (ICF) defines participation as, "involvement of persons in life situations" (World Health Organization, 2001). For adults with Autism Spectrum Disorders (ASD), social participation is conceptualized as engagement with social skills groups, support groups, and social networks where there is a focus on engagement with peers and where the individuals gain a sense of community (Tobin, Drager, & Richardson, 2014). In the context of school-aged children, social participation can be “any activity outside the home...outside the school environment, such as playing on a sports team or attending social outings with friends” (Taheri, Perry, & Minnes, 2016, p. 436). In general, social participation related to the context of community recreation is involvement in meaningful social activities and relationships.

The World Health Organization identifies participation, including social participation, as vital to health, development and quality of life (Currie et al., 2012). It is regarded as a fundamental right for all individuals and youth (United Nations Department of Economic and Social Affairs, n.d.). Social participation has been linked with improved emotional, social and academic outcomes for children (Kasari, Rotheram-Fuller, Locke, & Gulsrud, 2012), improved quality of life, and improved overall functioning in adulthood (Tobin et al., 2014). Therefore, it is incredibly important to make sure that all children, regardless of ability, have access to social participation opportunities.

2.1.2 Social participation and ASD

In recent decades, the prevalence of ASD has steadily increased to current rates of 1 in 66 children in Canada (Government of Canada, n.d.). This complex, neurodevelopmental disorder is characterised by deficits in social development and communication, as well as repetitive and restricted behaviours (American Psychiatric Association, 2013). These characteristics may limit participation in meaningful social activities and relationships for children with ASD, and can make it more difficult to develop meaningful social connections and participate in group activities. Children with ASD do participate less than other children across contexts (Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013; Taheri et al., 2016); and are bullied and socially excluded at higher rates than their typically developing peers (Cappadocia, Weiss, & Pepler,

2012) and peers with intellectual disability (Zeedyk, Rodriguez, Tipton, Baker, & Blacher, 2014). In fact, despite participating less than other children in community-based leisure activities (Orsmond et al., 2013; Taheri et al., 2016), children with disabilities, including ASD, identify participation in community leisure activities as their highest priority (Vroland-Nordstrand, Eliasson, Jacobsson, Johansson, & Krumlinde-Sundholm, 2016).

2.1.3 Community Contexts

Community programs are a common venue that provide opportunities for social participation. The ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) obligates Canada to take action to ensure that "community services and facilities...are available on an equal basis to persons with disabilities" (United Nations Human Rights Office of the High Commissioner, n.d., Article 19). As mentioned, children with ASD participate at lower rates across contexts, including in community-based settings (Orsmond et al., 2013; Taheri et al., 2016; Solish, Perry, & Minnes, 2010; Minhas et al., 2015). Decreased community participation has been mostly attributed to the influence of family and child factors such as financial resources of the family, the childs self-perception of competence, the childs emotional and social function (King et al., 2003). Contextual factors, including attitudes of community members, have been less frequently evaluated (King et al., 2003). Therefore, it is important to identify these contextual factors and investigate the improvements that can be made to social participation of children with ASD.

2.2 Stigma

2.2.1 Invisibility and Judgement

It is well known that children with ASD experience stigma, perhaps due to the invisibility of ASD compared to other disabilities (Nowicki & Sandieson, 2002; Chambres, Auxiette, Vansingle, & Gil, 2008). Indeed, families and caregivers of children who live with other "invisible" disabilities like epilepsy (Benson et al., 2016), mental health disorders (Kaushik, Kostaki, & Kyriakopoulos, 2016), and Attention Deficit Hyperactivity Disorder (Wiener et al., 2012), report feeling societal stigma, marginalization, and social exclusion. Gray notes that "it is [a] combination of pervasive disability and apparent physical normality that gives the stigma experienced by families with autistic children its unique quality" (D. E. Gray, 1993, p. 114). The invisibility of ASD in conjunction with challenging behaviors leads others to make assumptions about a child misbehaving and in turn make judgements about parenting abilities (Broady, Stoyles, and Morse, 2017; Farrugia, 2009; Gray, 2002(a); Munroe, Hammond, and Cole, 2016; Neely-Barnes et al., 2011). Parents share how they are constantly judged and misunderstood by others in various settings (Broady et al., 2017), and that the resulting judgement can be embarrassing and contributes greatly to perceptions of stigma (Gray, 2002(a); Minhas et al., 2015).

2.2.2 Labels

The preconceived social perceptions of how a "normal" looking child should behave are further complicated with the pervasive assumptions made around the specific label of ASD or Aspergers. Parents of children with ASD and adolescents living with ASD report public social stigmatization specifically related to the diagnostic label of ASD or Aspergers (Jones, Gallus, Viering, & Oseland, 2015; Mogensen & Mason, 2015; Russell & Norwich, 2012), and higher levels of affiliate stigma than caregivers of children with an intellectual disability or physical disability (Werner & Shulman, 2015). Parents express how it is easy to refrain from sharing a diagnosis because of the negative preconceived perceptions that are associated with the ASD label, and fear of their child experiencing discrimination (Russell & Norwich, 2012).

A larger encompassing label that is often used in relation to children with ASD is the term “special needs”, which is regarded as a euphemism; a phrase that can be used to replace words that might be regarded as offending. However, euphemisms can often not be effective (Gernsbacher, Raimond, Balinghasay, & Boston, 2016). In relation to stigmatizing language, Gernsbacher et al. (2016), observed that individuals labeled as having “special needs” were regarded more negatively than individuals labeled with a “disability” or individuals labeled with a “specific disability” (assigned labels in vignettes: is blind, is deaf, is Autistic, has epilepsy, has Down syndrome, has ADHD). For parents of children with disabilities, the euphemism “special needs” was found to be no better then the term “disability”. The National Center for Disability Journalism (National Center on Disability and Journalism, 2015, p. 23) advises against using the term “special needs” as it is “euphemistically stigmatizing”.

2.2.3 Social Isolation

Parents report experiences of social isolation resulting from two different causes: social isolation due to rejection from others, and social isolation due to their own avoidance of social situations. Parents felt rejected from various sources, including schools, other parents, and family members (Broady, Stoyles, & Morse, 2017). Parents refrain from putting their children in mainstream education and avoid sending their children to public environments or out for social celebrations because of the way they may be treated (Minhas et al., 2015). Parents believe that the public held negative beliefs about their children, including that they would not be a good friend, and that their children were socially isolated because other children thought they were weird (Kinnear, Link, Ballan, & Fischbach, 2016). As a result, some caregivers describe changing their social practices (Blanche, Diaz, Barretto, and Cermak, 2015) or avoiding certain social situations (Gill and Liamputtong, 2011) as a strategy to avoid stigmatization.

2.3 Disclosure

Disclosure /dis'kloZHer/noun

the action of making new or private information known

2.3.1 Disclosing a Diagnosis

For many parents of children with ASD, choosing if, to whom, when, and how to disclose their childs diagnosis of ASD is a major life decision. Parents struggle with whether disclosure will increase understanding, compassion and inclusion, or result in increased exclusion, stigma, and bullying. Disclosure is a central issue in how one articulates and navigates disability, and although not well understood, the growing body of literature gives insight to the perspectives of those with lived experience of ASD, and those who interact with individuals with ASD (e.g., doctors, police, fellow students).

2.3.2 Outcomes of Disclosure

Existing research suggests that disclosing one's diagnosis of ASD can have both positive and negative outcomes. It has been suggested that disclosure of an ASD diagnosis may improve understanding, and subsequently increase peer acceptance of a child with ASD (Chambres et al., 2008; Humphrey & Lewis, 2008; Dowjotas, 2009). For example, in two studies, attitudinal responses of peers to a new student who demonstrated signs of ASD were measured (Campbell, Ferguson, Herzinger, Jackson, & Marino, 2004; Campbell, 2007). It was shown that a combination of descriptive and explanatory information resulted in more positive attitudes from peers than if only descriptive or only explanatory information was given (Campbell et al., 2004; Campbell, 2007). However, it has also been speculated that peers misunderstandings and assumptions of ASD, and exploitation of their social naivete, may contribute to social isolation and bullying of children with ASD (Nowicki & Sandieson, 2002; Humphrey & Lewis, 2008). A scoping review related to the outcomes of disclosure or non-disclosure of an ASD diagnosis to others found a disconnect in perspectives of disclosure between persons diagnosed with ASD versus others (Hodgetts, Labonte, Mazumder, Frison, & Phelan, In preparation). In contrast to the findings of Campbell (2004) in which disclosure increased peers' perceptions of children with ASD, persons with ASD, including teens (Mogensen & Mason, 2015), college students (Knott & Taylor, 2014; Van Hees, Moyson, & Roeyers, 2015), and adults (Johnson & Joshi, 2016), reported apprehension to disclose due to perceived negative outcomes from disclosure, such as stigma and social exclusion.

Chapter 3

Methods

> *"Qualitative researchers aim not to limit a phenomenon - make it neat, tidy, and comfortable - but to break it open, unfasten, or interrupt it so that a description of the phenomenon, in all of its contradictions, messiness, and depth, is (re)presented."*
>
> *- Maria Mayan*

This chapter gives a description of the methods used in the current study. The section begins with the qualitative methodology, philosophical alignment, and approach to interpretation. The discussion of methods continues with an explanation of participant selection, data collection techniques, and the analytic approach. The chapter finishes with a reflection on validity, reliability, and ethical considerations taken in to account for this study.

3.1 Methodological Approach

3.1.1 Qualitative Inquiry

In the *Handbook of Qualitative Research*, Denzin and Lincoln (1994), describe qualitative methodology as a naturalistic approach where researchers study a topic or entity in it's natural settings, and attempt to make sense of it based on the meaning that people bring to that specific phenomena. The intent of qualitative research is to gain an understanding of how people make sense of reality (Merriam, 2009), which is not a fixed or measurable phenomenon as is assumed in quantitative, or positivist research (Merriam, 2002). Merriam (2002) outlines four important characteristics of qualitative research. The first is a focus on understanding the meaning of the experience, or as Merriam (2002, p. 5) states, "how do people make sense of their experience?". Second, the researcher acts as the primary instrument of data collection, meaning that the individual researcher is the central means of collecting and organizing the data (Merriam, 2009). Third, the research process is inductive, which identifies the process of gathering data to build concepts or theories, rather than deriving a hypothesis (Merriam, 2009). Finally, the fourth characteristic of qualitative research is that the inquiry is richly descriptive; words are used instead of numbers to convey what has been learned about the issue (Merriam, 2009)

3.1.2 Social Constructivism

Markula and Silk (2011, p. 25), describe a paradigm as

> "an overarching set of beliefs that provides the parameters - how researchers understand reality and the nature of truth, how they understand what is knowledge, how they act and the role they undertake, how they understand participants and how they disseminate knowledge - of a given research project."

In essence, a paradigm acts as the net that holds our ontological, epistemological, and methodological assumptions together.

A social constructivist approach was taken to investigate and understand the experiences of staff related to the assumptions and expectations for disclosure of an

ASD diagnosis. Social constructivism is situated within a relativist ontology, which is related to “what we know about our world” (Mayan, 2009, p. 24). Studies in this orientation assume that our realities are socially constructed, and that there is no one observable reality, but instead, multiple interpretations or realities of a single event (Merriam, 2009). In addition, the social constructivist perspective falls under a subjectivist epistomology, which is related to “how we can know” (Mayan, 2009, p. 24). Denzin and Lincoln (2005) discuss this epistomological assumption as the realities of individual experiences being co-constructed between the researcher and participant. This in turn provides a stronger understanding of the experience by allowing interpretation of differing perspectives.

3.1.3 Case Study Research

Case study research is used to develop an in -depth understanding of an issue or problem using a specific case (Creswell, 2012). The unique defining characteristic of case studies is that the research is conducted within a bounded system (Stake, 1995; Merriam, 2002). This bounded system is delimited by both place and time (Stake, 1995). For example, a case can be a person, a program, a group, an institution, a community, or a specific policy (Merriam & Tisdell, 2016). In this study, the case is identified by a specific organization. By focusing on one specific unit, researchers are able to describe the phenomenon in depth (Merriam, 2002).

The specific interest of a case study can come in two forms: as an intrinsic case study or as an instrumental case study. An intrinsic case study is undertaken when the researcher solely wants to know more about the specific case; whereas an instrumental case study is utilized to provide insight in to a certain issue (Stake, 2000). For this study, an instrumental approach was chosen to gain a deeper understanding of the process of disclosure within the organization (or case), without the intention of generalizing the results to other organizations, as “the purpose of case report is not to represent the world, but to represent the case” (Stake, 2000, p. 245).

3.1.4 Qualitative Description

Mayan (2009) maintains that if a case study approach is chosen, a method through which to understand the case must also be decided upon. To be able to provide a description and summary of the case I have drawn on Qualitative Description as described by Sandelowski (Sandelowski, 2000). The word “description” would lead one to believe that we have strayed from the interpretive nature of this study, however, as Sandelowski (2000, p. 335) notes, “all inquiry entails description, and all description entails interpretation.” As a researcher who is looking to describe the experiences of community recreation staff, I am in turn representing certain features of it, and in doing so the event becomes slightly transformed. Sandelowski (2000) raises the point that qualitative description is not highly interpretive in that the event is being described within a conceptual or philosophical framework, but that the “description in qualitative descriptive studies entails the presentation of the facts of the case in everyday language” (Sandelowski, 2000, p. 336). The intention to represent the unique experiences of community recreation staff is strongly upheld by utilizing qualitative description, as using this method of interpretation has allowed me to stay close to the data, a factor that both Sandelowski (2000) and Mayan (2009) deem important to qualitative description.

3.2 Current Study

3.2.1 Participant Selection

By definition, convenience sampling was used to choose the organization that is bounded within the case (Merriam, 2009). By using a professional connection to the organization, I was able to connect with them to inquire about participation in the study. To choose the participants, a combination of purposive sampling and network sampling was used. As there are many employees of the organization, the intention was to interview individuals working at different levels of administrative and front-line positions, to gain a better understanding of the different experiences at each level.

The supervisor and manager, who were my initial points of contact, oversaw a wide variety of community-based recreation programs, including registered and drop-in programs. She requested that we limit the case to one program, their extensive program of registered summer camps. The manager emailed the inclusion coordinator, who then got in touch with me regarding participation. To recruit potential camp counsellors and front-line inclusion staff, the manager distributed copies of the information letter via email and at a staff training day. Interested participants then contacted the researchers directly. A summary of the pseudonyms and roles within the organization of the six participants are provided in Table 3.1.

Participant	*Pseudonym*	*Role in Organization*
1	Maya	Supervisor
2	Eva	Manager
3	Katherine	Inclusion Coordinator
4	Liz	Camp Counsellor
5	Omar	Camp Counsellor
6	Alice	Front-line Inclusion Staff

Table 3.1: Study Participants

3.2.2 Data Collection

Multiple data sources are often used in case study methodology (Stake, 1995). Semi-structured interviews were used as the primary method of data collection for this study. Semi-structured interviews contain a combination of structured questions and less structured questions. This type of questioning allows flexibility in how the conversation evolves, while allowing the researcher to target some more specific topics (Merriam, 2002). The interviews were conducted with participants to better understand the assumptions and expectations that staff have for parents to disclose their childs diagnosis of ASD. The interviews each lasted 25-30 minutes. Three interviews took place at the organization's main office, two in the Supporting Kids Inclusion and Participation (SKIP) Lab at the University of Alberta, and one was conducted over the phone. Questions for the interviews were carefully constructed to avoid indication of blame or assumptions of stigma, while still obtaining rich data. All interviews were voice recorded and transcribed verbatim, with the exception of identifying information, by a professional transcription service.

Policy and practise documents can also offer certain insights to a phenomenon, making them a mode of information gathering and worthwhile addition to data examination (Merriam, 2002). Pescolido (2008) describes how these documents can shape opportunities for inclusion, and contribute to discourse related to inclusion and stigmatizing attitudes and practices. Registration forms, a family information letter, a general inclusion statement from the organization, and inclusion directives for the organization were included in the analysis to better understand the inclusion practices of the organization and use of language in asking for information from parents.

3.2.3 Data Analysis

Data analysis followed the six phases of thematic analysis techniques and processes as described by Braun and Clarke (2006), including: (1) familiarization with the data, (2) generation of initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report. Thematic analysis is most often used to identify, analyze, and report patterns from a data set (Braun & Clarke, 2006). The interviews were initially read and reviewed manually for data familiarization, to understand the experiences as a whole, and note key emerging ideas. Then, using NVivo qualitative analysis software, line by line coding of the transcripts was executed and significant ideas were highlighted. Using mind mapping techniques, themes were generated from groupings of the initial codes. A second reader (S.H.) independently read and coded each transcript and confirmed emerging themes.

Braun and Clarke (2006) suggest that researches should decide whether to represent their themes at a semantic (explicit) or latent (interpretive) level. Cohesive with the choice to interpret the data using Qualitative Description (Sandelowski, 2000), a semantic approach to analysis was undertaken. With thematic analysis at the semantic level, themes are identified based on what was said or written, without examining underlying ideas and assumptions. As such, the analysis progressed from a description of the data through generation of initial codes, to interpretation, where themes emerged through an attempt to speculate the significance and implications of pattern in the data that emerged through coding. Member checking was attempted with all participants via email. It was successful with three of the six participants. One participant who had moved to a new position within the organization participated in this process and two participants were no longer employed by the organization.

3.2.4 Quality Criteria

Qualitative research does not follow the same practices of rigor that positivist quantitative research does, including validity, generalizability, and reliability (Mayan, 2009). Instead, researchers Guba and Lincoln (1981) introduced a different conceptualization of rigor, and referred to it as trustworthiness. From their initial proposed criteria of credibility, fittingness, and auditability (Guba & Lincoln, 1981); a variety of different definitions and criteria have been proposed (Thorne, 1997; Finlay, 2006). Mayan (2009) suggests and reinforces that one should choose a set of criteria that best fits the research that is being done. Mayan (2009) goes on to share how a colleague of hers likens the wide variety of criteria to an "assortment of board games":

> "A researcher may choose from a variety of games (qualitative research designs/theoretical position/perspectives/methods) but then must apply the rules or strategies (criteria) of each game to lead them through the game (research). If you apply the rules of Monopoly (e.g. autoethnography) to Risk (e.g. grounded theory), you had better not be a gambling person. But if you apply Monopoly rules to Monopoly, the outcome is likely to be more favourable." (Mayan, 2009, p. 105)

Criteria were followed for both case study research and thematic analysis techniques used in this study. Stake (1995), who's case study approach was practised, outlines a "critique checklist" (Stake, 1995, p. 131), which is list of 20 items used for assessing a good case study report. See Table 3.2.

In addition to this extensive list, a more compact criteria list as outlined by Creswell (2012, p. 265) for case study research was drawn upon. See Table 3.3.

For the data analysis stage of the research, a unique set of quality criteria were incorporated. Braun and Clarke (2006) provide quality criteria for a rigorous thematic

Number	*Criteria*
1	Is the report easy to read?
2	Does it fit together, each sentence contributing to the whole?
3	Does the report have a conceptual structure (e.g. themes or issues)?
4	Are its issues developed in a serious and scholarly way?
5	Is the case adequately defined?
6	Is there a sense of story in the presentation?
7	Is the reader provided some vicarious experience
8	Have quotations been used effectively?
9	Are headings, figures, artifacts, appendixes, and indexes used effectively?
10	Was it edited well, then again with a last minute polish?
11	Has the write made sound assertions, neither over- nor under representing?
12	Has adequate attention been paid to various contexts?
13	Were sufficient raw data represented?
14	Were data sources well chosen and in sufficient number?
15	Do observations and interpretations appear to have been triangulated?
16	Is the role and point of view of the researcher nicely apparent?
17	Is the nature of the intended audience apparent?
18	Is empathy shown for all sides?
19	Are personal intentions examined?
20	Does it appear that individuals were put at risk?

Table 3.2: Stake (1995) “Critique Checklist”.

Number	*Criteria*
1	Is there a clear identification of the ”case” or ”cases” in the study?
2	Is the ”case” used to understand a research issue or used because the ”case” has intrinsic merit?
3	Is there a clear description of the ”case”?
4	Are themes identified for the ”case”?
5	Are assertions or generalizations made from the ”case” analysis?
6	Is the researcher reflexive or self-disclosing about his or her position in the study?

Table 3.3: Creswell (2013) Criteria for evaluating a “good” case study.

analysis including: thorough transcription of data, theme generation that is inclusive and comprehensive, and clearly explained assumptions and approaches. Another common strategy that was employed to ensure credibility in the research, was a member checking process as previously mentioned. Also referred to as respondent validation, the process is used to make sure that the interpretation of the participants experiences “ring true” (Merriam, 2009, p. 217). Participants are given the opportunity to recognize their experience in the interpretation and are able to ask for changes that better represent what they had shared (Merriam, 2009).

3.2.5 Ethical Considerations

Ethical approval was obtained from the Research and Ethics Board at the University of Alberta. Participants were informed of the purpose of the study and that they had the right to withdraw from the study at any time without consequence. Results of the interviews have been reported with participant confidentiality, with all identifying information of the individual and the organization being anonymized. The administrator who gave the approval for her staff to participate in the interviews wanted confirmation that the name of the organization would not be included in any publications or presentations. Steps to minimize risk were also taken in to consideration. There was the chance that participants could experience social risk if they were worried about sharing certain information about the organization’s practices; to address this, interview questions were carefully constructed to avoid indications of blame or assumptions of stigma.

Chapter 4

Results

Aligning with the objectives of the study, the results reflect the experiences that staff have had with disclosure and non-disclosure of an ASD diagnosis in their community recreation contexts; in this case, a wide variety of community-based summer camps that took place in settings throughout Edmonton. Three major themes related to disclosure in community recreation settings emerged through our analysis. These themes, with their respective sub themes are outlined in Figure 4.1.

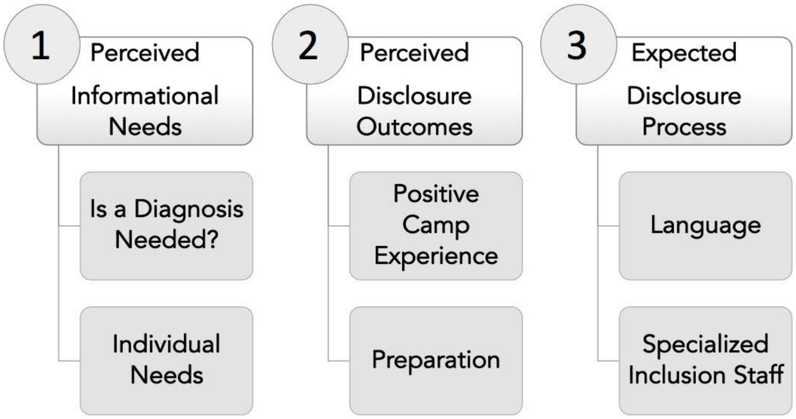


Figure 4.1: Themes with respective sub themes.

4.1 Emergent Themes

4.1.1 Perceived Informational Needs

The first theme is related to the type of information that staff spoke about needing or wanting from parents. They shared their opinions about whether knowledge of a child's diagnosis is necessary, and on how non-diagnostic information about the child's preferences and strategies that have worked previously, can help staff be more supportive of children with ASD.

Is a Diagnosis Needed?

Camp counsellors shared their perspectives of the type of information they believed was necessary to help facilitate effective participation of children with "special needs", including ASD, in their camps. There was consensus across staff members that the precise diagnosis (e.g., ASD) is not important, and often not helpful. Rather, as one of the camp counsellors, Omar, stated, it is the "in-between stuff that really matters the most." Staff spoke about how a diagnosis doesn't highlight the uniqueness of each child, especially in terms of how to best support them. Alice, one of the front-line inclusion staff, found that,

> "the diagnosis itself isn't as important...because, I don't know, I think the label of the diagnosis, I mean when it comes to anything, automatically gives like stereotypes, okay this and this and this is how its gonna be and its never like that. Everyone is so different, so its more so like the individual characteristics and needs of each kid. If we are aware of that like I dont know that the label itself really has anything to do with it."

Similarly, one of the camp counsellors, Liz, shared,

> “like, if I just had a diagnosis, that doesnt really help me very much, right. You kind of need to know because I mean even if you have a diagnosis, right, theres still differences there, right.”

Senior administrative staff agreed that a diagnosis alone would not be sufficient to support many children, but did comment that they thought a diagnosis is beneficial to help staff who wanted to do independent research to better understand the condition.

Individual Needs

This sub-theme relates to both individual family needs related to sharing diagnosis, and individual child needs to best support their participation. Staff at the supervisory and management levels commented that they do not want to force parents to share their child’s diagnosis; rather, it is each family’s choice of whether to share information. Camp counsellors and front-line inclusion staff shared how there are some forms of information they find particularly helpful. When parents do want to disclose, information that helps camp counsellors and front-line inclusion staff support participation includes behaviour support strategies that are used at home or in other contexts, and the child’s likes and dislikes. Omar, a camp counsellor, shares how,

> “...their likes and dislikes to me [are] huge. If they like playing a game, I want to play that game, because I know that theyre going to be fully involved and fully included in that game. Whether they want to be the referee or they want to be one of the actual participants in the game, if theyre loving it, Im loving it. If they really dont like getting messy with crafts, Im going to stay away from messy crafts.”

4.1.2 Perceived Disclosure Outcomes

Participants shared their perceptions of the outcomes of disclosure for staff, for programming, for peers, and for the children with ASD. They talked about how their intent behind asking for disclosure often relates to providing a positive camp experience for all campers and for preparing staff.

Positive Camp Experience

The first sub theme related to perceived disclosure outcomes is a "positive camp experience". Staff shared how they perceived that information allowed them to provide the support needed to make the child with ASD's camp experience positive. The inclusion coordinator, Katherine, shared how,

> "...[they] want to make sure that that childs camp experience is the best that it can be and, typically, the more information that we have with that participant, the better we can make their camp experience."

Eva, the camp manager says how they,

> "try to let [parents] know that we are an inclusive program in that...this just will help us and basically, we want to make sure that their childs camp experience is the best that it can be."

Eva continues on to point out that disclosing support needs helps both the camper and the staff to have a positive camp experience,

> "...with having all of that information, we are able to then ensure that the participant has the best camp experience as well as for our leaders...depending, if [front line inclusion staff] can't be at every single camp where there is a participant who has an inclusion need or ASD...we want

> to ensure that [general front line staff] have as much information, and feel comfortable and confident handling that situation and making sure that they can make it a welcoming environment."

Preparation

Both senior level management staff and camp counsellors indicated that information that is disclosed is often important to help staff prepare for a camper with ASD. The three upper level staff members (Maya the supervisor, Eva the manager, and Katherine the inclusion coordinator) spoke about how the disclosure of information can help direct how they support their camp counsellors. This support is especially relevant for staff who are not very experienced working with children with disabilities. The inclusion coordinator, Katherine, shares how she thinks that,

> "...for our leaders, especially because they are like a bit younger and I mean they do have a lot of experience in recreation and in childrens programming but not so much with children with disabilities or ASD. It helps in a way to prepare them and I think like it alleviates a lot of anxiety because its – like usually I get like phone calls on the first morning of camp. Theyre like oh this child – this parent just came in and they told me this and theyre like, Im really nervous to like work with them. Like where do I start?"

Camp counsellors and front-line inclusion staff, especially, notice when fellow staff who are less experienced with children with ASD become nervous once they learn that a child with extra support needs is registered in their camp,

> "some of the people who I work with this year who, you know, are pretty new, maybe just starting camps or maybe they only worked at Green

> Shack before or something like that. It can definitely be overwhelming especially on like the first couple days, right. Its overwhelming just having like 20 new kids and then if youve got like other needs kind of on top of that, that makes it tricky."

Alice, the front-line inclusion staff, spoke about her experience the previous summer as a camp counsellor. She outlined how her success as a camp counsellor was dependent on having information about special needs ahead of time:

> "like had half the stuff not like been pre-told to us, I guess, last year, I don't know if we would've done as well as we do. Because I mean we would be blindsided with a lot of stuff, so I think like kind of having that filter helps quite a bit."

She goes on to speak to the other side of preparation, how sometimes the "worst case scenario" is disclosed. Knowing only this information can lead to apprehension on how to support the child and being "scared of the information". Alice stated how,

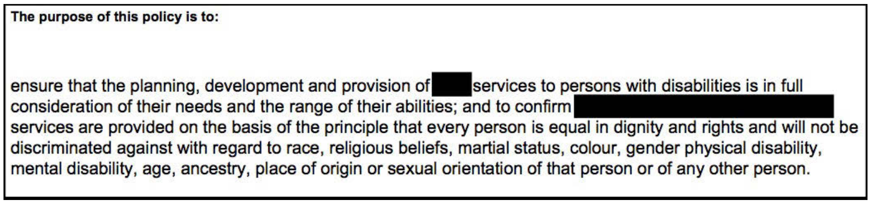
> "a lot of times people disclose the worse case scenario and sometimes you don't always run in to that, so like overall I think disclosure is a good thing, but sometimes when people disclose the worse case scenario, you kind of prepare for that and sometime you don't always need to and it could hinder things in some ways."

4.1.3 Expected Disclosure Process

The final theme, expected disclosure process, is related to the manner in which parents are expected to share information about their child. This includes the type of language used to ask for or elicit information, and the incorporation of a specialized inclusion coordinator and front line inclusion staff within the summer camp programs at this organization.

Language

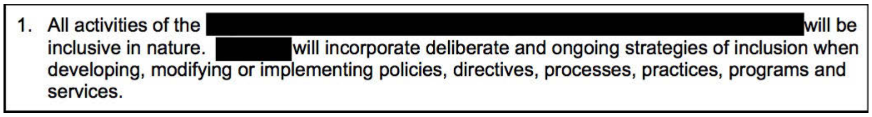
Data collected through the interviews with staff and the variety of practise and policy documents revealed how the language used may have an impact on the disclosure process. Guiding the practices and registration documents of the organization are a set of inclusion policies and directives, as seen in Figures 4.2 and 4.3.



The purpose of this policy is to:

ensure that the planning, development and provision of [redacted] services to persons with disabilities is in full consideration of their needs and the range of their abilities; and to confirm [redacted] services are provided on the basis of the principle that every person is equal in dignity and rights and will not be discriminated against with regard to race, religious beliefs, martial status, colour, gender physical disability, mental disability, age, ancestry, place of origin or sexual orientation of that person or of any other person.

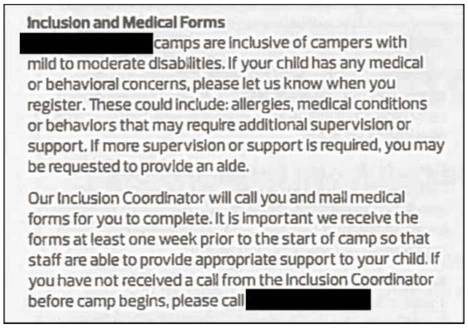
Figure 4.2: Overarching Inclusion Policy Directive for Organization (1).



1. All activities of the [redacted] will be inclusive in nature. [redacted] will incorporate deliberate and ongoing strategies of inclusion when developing, modifying or implementing policies, directives, processes, practices, programs and services.

Figure 4.3: Overarching Inclusion Policy Directive for Organization (2).

In addition, Figure 4.4 is an excerpt from the camp's brochure that is available to the public, which outlines the organization's specific day camp inclusion policy.



Inclusion and Medical Forms

[redacted] camps are inclusive of campers with mild to moderate disabilities. If your child has any medical or behavioral concerns, please let us know when you register. These could include: allergies, medical conditions or behaviors that may require additional supervision or support. If more supervision or support is required, you may be requested to provide an aide.

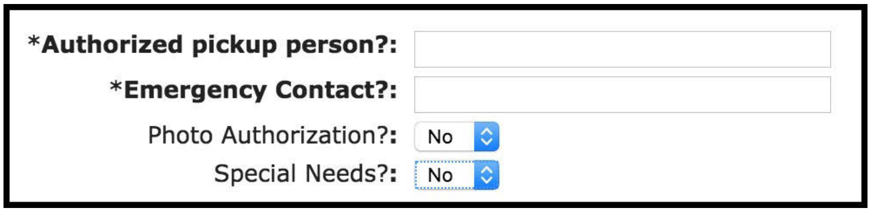
Our Inclusion Coordinator will call you and mail medical forms for you to complete. It is important we receive the forms at least one week prior to the start of camp so that staff are able to provide appropriate support to your child. If you have not received a call from the Inclusion Coordinator before camp begins, please call [redacted]

Figure 4.4: Daycamp Inclusion Policy.

From the interviews, the inclusion coordinator, Katherine, explains what happens when a caregiver or parent uses the online registration portal:

> "so when they fill out their registration form online, there is a section for inclusion needs or special needs and so its just basically a yes or no button I think and it clumps like medical needs with like any like disabilities or other needs. So, its very general."

Figure 4.5 shows an image of the online portal drop down menu, which uses the language "special needs".



***Authorized pickup person?:**

***Emergency Contact?:**

Photo Authorization?: No

Special Needs?: No

Figure 4.5: Online registration portal.

Katherine notes that the language that is used - "special needs" - is quite general. As such, it can be interpreted differently by each parent who is registering their child. Alice, one of the front-line inclusion staff shared how,

> "if they just see it as special needs, they may be like no, no, no, my kid (with ASD) does not have special needs. So I almost want that piece to be verbal, 'does your kid need any support in any way?'"

Along with an online portal, parents and caregivers have the option of registering by phone. With this method, any question or prompt related to "special needs" is dependent on whoever answers the phone. Katherine shares how this important support question could sometimes even be missed,

> “so they can register as well through phoning into [organizations call] service and so, I guess thats subject to whether or not the [secretary] answers that question and I dont know for them if they dont have training, it might be awkward to ask that or they might not feel comfortable.”

To help ensure that families whose children do have extra support needs are not missed (for example, if they do not understand the prompt, or if it differs from language they would use to describe their child), Katherine shared how a follow-up request for information is sent as part of a camp information letter:

> “so before like camp starts about a week or two prior all of the other coordinators send out parent letters that have information on like field trips and what activities to expect and what to bring and they also put my name in the bottom and say, again if your child has any – and then – so that sometimes gets a lot of parents to phone if they miss that like that prompt a lot.”

The letter goes out to all caregiver’s of children attending the camps. Figure 4.6 shows the section of the letter that asks for more information about any child who has extra support needs. Note the shift from “special needs” on the online portal, to “inclusion needs” in the family letter.

If your child has any inclusion needs, such as behavioural concerns (i.e. ADHD, ASD, etc.) or medical needs (i.e. allergies, asthma, etc.), please contact our Inclusion Program Assistant, [redacted] to fill out the appropriate forms.

Figure 4.6: Letter to families.

Even still, Katherine, the inclusion coordinator shares how parents are sometimes confused by the language that is used:

> “...like even when I phone parents, Ill say oh you indicate your child has an inclusion need. Theyre like, ‘What does that mean?’ And then Im like a special need, a medical need, behavioral need kind of thing.”

Eva, the camp manager, spoke about how parents are often more ready and willing to disclose their child’s ASD diagnosis when their child has participated in previous camps and they have already been through the registration process,

> “I know for like some participants that have registered with our camps in previous summers, they have learned like the language in that process. So, they are pretty like willing to disclose.”

Having gone through the process already could play a role in understanding what the organization is asking for, but for first time participants, there may still lie some apprehensions to disclose or share information.

Specialized Inclusion Staff

The organization in this case study has a unique structure in their staffing. Along with the camp manager and camp counsellors, there are three inclusion-specific individuals on staff. There is one inclusion coordinator and two front-line inclusion staff that float between camps based on need.

Specific to the inclusion coordinator role, the program manager, Eva, pointed out an important aspect of the position related to communication with families:

> “she is able to build that rapport with the parents...she definitely has that open communication ...because its that one consistent person who is able to communicate and talk to the parents about their child and I think that also helps with the parents feeling more comfortable. Like that they are

> connecting with one person, they dont have to continuously repeat their story over and over again."

Katherine, the inclusion coordinator, echoed this sentiment, "leaders will see the kids through multiple weeks so developing that rapport is everything and kind of makes it so much easier to connect with them."

Along with the inclusion coordinator, there are two front-line inclusion staff who have a background in supporting children with disabilities. The inclusion coordinator is responsible for allocating the front-line inclusion staff accordingly depending on the amount of support needs each camp has each week. These front-line inclusion staff can be re-assigned to different camps as needed. Camp counsellor, Liz, says how, "if there is a camper that [the inclusion coordinator] kind of feels is going to need a lot of extra support then we will get a third leader [front-line inclusion staff] to come in."

Omar, the other camp counsellor who was interviewed, points out that the main camp manager has so many other things that they need to support staff about, that getting extra support from them regarding behavioural support can be challenging. He shares the benefit of a dedicated inclusion coordinator,

> "...because you have somebody that is trained in a lot of different inclusion needs. They are there to support you with just those children, not with any like general things because the other bosses... have so many other things going on and she can just focus on helping those kids have the best week that they possibly can. So, I think its really helpful to have somebody to call..."

Alice, who supported camps as a front-line inclusion staff shared how she had worked as a camp counsellor the year before, and could see the benefits from both roles. She shared how, "last year I felt like just as a [camp counsellor], I felt well prepared to deal with those needs and I think it's definitely because of that [coordinator] position." Alice also discussed how having the inclusion coordinator position allowed the staff (both camp counsellors and herself and other front-line inclusion staff) to better understand the kids they would be supporting before camp started because the inclusion facilitator had already been in contact with the child's parents. They especially appreciated this support from someone who had an understanding of how to support inclusion.

Katherine, who sits in this unique role as the inclusion coordinator, shared how other programs do not have a role like this to support families and staff, and how, "[she] thinks that it is probably a huge gap that [they] can probably fill."

Chapter 5

Discussion

This chapter will discuss the implications of the results in relation to the larger body of literature related to participation, inclusion, disclosure, and stigma. This chapter will also cover the limitations to the research and future directions for this field of study.

5.1 Implications

5.1.1 Language Use

This study, at a surface level, exposes some of the challenges that come with the type of language we use in communication. In this context, we are solely taking the language at face value, and in a literal manner, as compared to a discourse analysis, which is the approach to “analyzing written and spoken language use beyond the technical pieces of language, such as words and sentences. Therefore, discourse analysis focuses on the use of language within a social context” (Salkind, 2010). While there may be no “right answer” of what language to use, it has been suggested that the term “special needs” can result in negative impressions from others (Gernsbacher et al., 2016). The way diagnostic information is asked in the registration portal may offend caregivers who do not identify with this term. It was also apparent that there lacked consistency in language across documents and by program staff, which could potentially confuse parents or caregivers registering their children in the summer camps. While I acknowledge that it can be difficult to choose one statement, while also acknowledging that identification with different terms can be individualistic (e.g. child with Autism, Autistic child, etc.), maintaining consistency with the language the organization uses may benefit families and ultimately improve understanding.

5.1.2 Power Imbalance

Inquiring in to the type of information that staff and the broader organization expect helped delineate the importance of information related to individualized behavioural supports over a specific diagnosis. While communicating this preference may be beneficial for parents who are apprehensive to share a diagnosis, the underlying assumption that information will be shared can not be ignored. I highlight this point solely as an acknowledgement of the power that an organization can have in the giving and taking of information. An imbalance of power may exist, and in that, defines who owns the information and at whose discretion information is shared. Individuals with ASD advocate for selective disclosure based on whether the receiving body will be supportive (Mogensen & Mason, 2015; Knott & Taylor, 2014). In the grounded theory study conducted by members of our research team that explored parent's perspectives of disclosure, parents reported being uncertain of how a disclosed diagnosis would follow their child in the years to come. As consumers of the services, parents may feel pressured to share information, and are not always informed of what will happen with the information they share or why they are asked to share it. The results of this study reinforce that having information such as a child's likes and dislikes, or tips for areas in which the child needs extra support, such as socializing or transitions between activities, can be more useful than diagnostic information. It is important to highlight that it is a parent's choice to share or not share information about their child; but in the same respect it is important for organizations to be transparent with parents and caregivers about the kind of information they need, why they are asking for it, and what will be done with the information.

5.1.3 Inclusion?

The organization in which this study took place has overarching policy directives that prescribe all activities to be inclusive. In this study, the adoption of staff whose roles are inclusion-specific was identified as a critical component of the organization's ability to be inclusive of children with ASD who need additional supports in their camps. Having an inclusion coordinator and front-line inclusion staff provided much needed and appreciated support to the camp staff to improve the camp experience for everyone. Camp counsellors and front-line inclusion staff commented on how the coordinator's presence and knowledge made supporting children with extra support needs manageable. As previously stated, children with ASD engage in social participation, including in recreation programs, at much lower rates than their typically developed peers (Orsmond et al., 2013; Taheri et al., 2016). The inclusion coordinator and inclusion staff appear to be a beneficial organizational practise to help support participation of children with ASD in their camps.

5.1.4 Theoretical Considerations

While the participants did not directly identify stigma as a factor related to their assumptions and expectations for disclosure, a theory of stigmatization can be considered in relation to the results. Potentially stigmatizing behaviours will be identified and understood within the context of a theoretical framework of stigma.

In their work, *Four Manifestations of Stigma*, Pryor and Reeder (2011) depict four interrelated “types of stigma. These types of stigma include: (1) Public Stigma, which represents peoples social and psychological reactions to someone they perceive to have a stigmatized condition. Public stigma may be related to innate beliefs and reactions, but is also informed by the presence of a diagnostic label, perceived severity of a condition, and media portrayals of that condition; (2) Self-Stigma, which reflects the social and psychological impact of possessing a stigma; in other words, of internalizing stigma; (3) Stigma by Association, which refers to social and psychological reactions to someone associated with a stigmatized person. For children, this may include parents and other family members, other caregivers, peers, or even professionals or programs that support people with the stigmatized condition. Finally, (4) Structural Stigma is defined as the legitimization and perpetuation of a stigmatized status by societies institutions and ideological systems. This type of stigma may include attitudes and practices of professionals or leaders, as well as other organizational practices and policies.

Of interest, in the context of this study, are the depictions of Public Stigma and Structural Stigma. Both administrative and front-line staff spoke about “fear”, “uncertainty”, and “the need for preparation”. These sentiments may reflect the preconceived notions that the general public may have of individuals with ASD, and a lack of knowledge of the defining features of the condition itself. This aligns with parent reports of social stigmatization (Jones et al., 2015; Mogensen & Mason, 2015) and negative preconceptions (Russell & Norwich, 2012) related to a diagnosis of ASD. Stigma may also be unconsciously represented in the organization’s public information booklets (Figure 4.4), which indicate that children with mild to moderate, but not severe, disabilities are welcome to participate. However, they do not define mild versus moderate versus severe, interpretations that may differ between staff members and families.

Inclusion means that all people, regardless of ability or health care needs, have the right to equal access of employment, education, participation in recreational activities, and in general that they "be respected and appreciated as valuable members of their communities" (Institute for Community Inclusion, n.d.). In Figures 4.2 and 4.3, it notes that services from this program be in "full consideration of [the participants] needs and the range of their abilities." In keeping with the dialogue about who can access their programs, it is important to note the misalignment of language between the over arching policy directives and the camp inclusion statement seen in Figure 4.4 and as mentioned above.

5.2 Limitations and Future Directions

This study examined the experiences of staff from one single organization in the greater Edmonton area. While the information garnered from this research is very informative, it will be important to extend the body of research to other organizations to be able to identify different or similar experiences. To address this limitation, this study will be continued by researchers in the SKIP lab between different types of organizations or community programs. In addition to interviewing staff from other organizations, an ethics amendment has been made to also invite parent participants whose children have participated in the community program from which staff are interviewed. Integration of data from the variety of data sources (staff, parents and documentation) will support more thorough within and cross case analysis of the experiences of and processes of disclosure in community settings in a larger collective case study.

Throughout the interviews, we alternated between talking about disclosure of a diagnosis and talking about the sharing of behavioural support information, which was also referred to as "disclosure". It will be important in future interviews with this study to clarify and be consistent that we are defining disclosure related to one's diagnosis; differentiating that from the sharing of behavioural support information or the child's likes and dislikes.

A final and significant limitation to the interpretation and understanding of these results is the absence of any direct data related to stigma. The proposed study was conceptualized within a stigma framework, with the intention of unpacking the impact of stigma on the disclosure process and organizational processes. It is of concern that conversations about stigma were not elaborated on in interviews, and that there lacked commentary related to the influence of stigmatizing behaviours on inclusion and participation; this resulted in a sizable silence in the data. Stigma is inherently a very complex and difficult construct that is so deeply rooted in our society; it is something that is not easily talked about. Participants were understandably reluctant to talk about or elude to stigma and discrimination, and the manner in which the questions were asked only elicited theorizations of how stigma could be impacting the process. However, participants did talk about staff feeling anxious, overwhelmed and blindsided with having a child with ASD in their camp, indicating that some preconceived notions of what ASD meant were present. The lack of representation of this topic in the results does not mean that the experiences of families and children who have had negative encounters should be ignored. It would be a dis-service to families and children accessing these programs, to say that stigma does not exist within the context of community recreation settings. As previously mentioned, stigma can be a difficult topic to broach, but this is not representative of the family and child experience.

Chapter 6

Reflection and Conclusion

This final chapter will include my personal reflections on the research process and concluding thoughts.

6.1 Researcher Reflections

> *"It is a conscious experiencing of the self as both inquirer and respondent, as teacher and learner, as the one coming to know the self within the processes of research itself."*
>
> *- Lincoln, Lynham, and Guba*

Reflexivity is the process of attending to how and why we make certain decisions and interpretations throughout the research, and being critical of how the researcher role interacts with each aspect of the research journey (Mayan, 2009). An important ethical practise in qualitative research is the practise of reflexivity, and in general reflecting on the choices that were made along the way.

6.1.1 Lessons Learned

Among the many words that I “identify” with: sister, friend, partner, daughter, partaker in activities of the outdoors, consumer of anything and everything related to chocolate...I can happily and confidently add researcher to the mix. The research journey is an elaborate one, filled with ups and downs, and lefts and rights. Partaking in qualitative research has challenged me in numerous ways. It has provided me with insights of my strengths and weaknesses, not only in an academic setting, but apart from it as well. I have learned what it means to immerse yourself in something, resulting in both feelings of love and hate. I was ultimately challenged over the last two years in three distinct ways: (1) the manor in which a research study adapts and changes, (2) conducting interviews and grasping how to do qualitative analysis, and (3) facing personal assumptions head on.

6.1.2 Flexibility

“It’s okay”, she said, “things will probably change a few times”. At first these comments from my supervisor were alarming, and quite frankly, unsettling. “But I have put so much work in to making this choice, how could it change?”, I would ask myself naively. As I look back on the academic journal I kept over the last 2 years, it is almost alarming to see how much my knowledge and understanding of the research process has developed. The largest takeaway from this experience is that things will change. In the final stages of writing and reflecting, I really do believe that developing and executing sound research means being flexible and adaptable to those changes. Early on, as a newcomer to qualitative research, I was introduced to Maria Mayan’s (Mayan, 2009) *Essentials of Qualitative Inquiry.* She outlines and reiterates Janice Morse’s ideas around methodological coherence (Morse, 1999), and the practise of using an “armchair walkthrough” (Mayan, 2009, p. 13). Having this base and simple explanation was imperative in understanding the importance of congruence between my epistomological and ontological assumptions, the theoretical position, my research questions, and the methods I would choose. Now, despite having this outline, finding and maintaining methodological coherence is ultimately a challenge. However, I am happy that I remained patient with the changes, and learned to respond in an adaptable way, for it has resulted in what I believe to be a cohesive research study.

6.1.3 Being a Qualitative Researcher

In recent job interviews, for the first time since starting my degree, I have been challenged to say aloud that, "I am a qualitative researcher." While I would categorize myself wholeheartedly as a novice qualitative researcher, I am one none the less. Data collection for this study was the first time I have ever conducted an interview. I prepared myself as much as possible by reading up on how to build an interview guide, what kinds of questions to ask, and how to interact with participants. I asked questions to anyone who would answer them and when the time came (which was much quicker than I had expected), I began conducting my interviews. The first thing I thought upon replaying the recording when I got back to the office was "wow, that's what I sound like, why has no one ever told me this?", "I am only half way through and I have said 'um' 15 times", but more productively, "this is such a cool way to answer my research questions and understand the practice of disclosure in our communities!" Practically speaking, it was the beginning of learning how to listen, how to identify patterns, and dissect what was important and what was excess information. It has changed how I take in and process information, and has reiterated the importance of understanding experiences more thoroughly.

Previous to this research, I had never been in a position to interview another person. Collecting data through interviews is truly an art form. I am sure it is a skill that continues to evolve and grow, and can never really be perfected. The organization I worked with truly does strive to be inclusive, however, with that comes the need to present themselves behind a certain image, which is understandably the case for many large organizations. In building the interview guide, we tried so hard to not make any accusations or blames of stigmatizing behaviour, that, in turn, my data did not reflect stigma to the extent we "know" it is present. However, I believe that it is possible to discuss tough subjects in ways that do not lay blame, without sacrificing the loss of important information. In the future, when I am building interview guides and conducting interviews, I look forward to finding different and unique ways of addressing tough subjects.

6.1.4 Researcher Assumptions

I will be honest. Previous to grad school, I had never consciously had to acknowledge my assumptions related to any specific life experience. I would consider myself to be a very socially conscious individual, but I have indeed never been challenged to identify and acknowledge my assumptions in practise. Acknowledging our assumptions allow us to pay attention to all of the data and to develop logical arguments to support our conclusions about something. When we do not, we are at risk of being partial to or preferring one side of an argument or idea. With my background as a front-line inclusion support staff in summer camps, it was imperative to remain neutral and not impose any previous positive or negative experiences with community-based camps or organizations. Additionally, I tired my hardest to remain neutral in relation to language use and reflect the language used by the organization as well as the body of literature related to disability and ASD. Acknowledging these assumptions has challenged me to reflect on previous experiences and understand how they can impact the actions we take in research, including analyzing and reporting the results. Moving forward, it is a something I hope to continue incorporating in my research practices.

6.2 Conclusion

The purpose of this study was to gain a better understanding of the expectations that community recreation staff may have for parents or caregivers to disclose their child's diagnosis of ASD to the camp. These expectations were a reflection of the staff's perceived needs for disclosure, their perceived outcomes of disclosure, and the identified processes for doing so. The outcomes of this study have provided insights on the expectations that this recreation organization has related to disclosure and non-disclosure of an ASD diagnosis. Our findings contribute to a deeper understanding of what kinds of information staff perceive to be most helpful to supporting children with ASD. More specifically, information related to behavioural strategies and a child's likes and dislikes were perceived to be more important that a child's diagnosis. Our findings also suggest that the organization may benefit from training for all camp staff to mitigate some of the fear and uncertainty camp counsellors have when supporting kids with ASD. Finally, the organization may want to reconsider the language used in asking for information from parents and the consistency in terminology when communicating with parents and caregivers.

Appendix A

Stigma Scoping Review

Stigmatization of Children and Adolescents with Autism Spectrum Disorders and their Families: A Scoping Study

Autism Spectrum Disorder (ASD) is a complex, neurodevelopmental disorder characterised by deficits in social development and communication, as well as repetitive and restricted behaviours (American Psychiatric Association, 2013). As described by the diagnostic label, these characteristics fall on a spectrum and can present in a variety of ways. Often though, the individual living with ASD will present as having a normal physical appearance, leaving contrasting abnormal behaviours perplexing to onlookers. It can be difficult for some people to accept or understand that a child has ASD because of their normal appearance (Moyson & Roeyers, 2011). People who do not know that a child has ASD will tend to judge certain ASD related behaviours as being problematic, yet are more lenient when they are told the child has ASD (Chambres et al., 2008; Huws & Jones, 2010). Individuals with ASD and their families experience judgement from others based on these behaviors and preconceived negative stereotypes about normality and abnormality. This stigmatization can present in different forms including: self-stigma, public stigma, stigma through association, and structural stigma.

In his seminal work, The Theory of Social Stigma, Erving Goffman defined stigma as a social identity that is perceived to negatively deviate from societal norms and values (Goffman, 1963). His work was instrumental in providing an initial conceptual framework for the analysis of stigmatizing conditions. Goffman recognized that stigma is enacted within social contexts, and that perceptions of stigma can profoundly impact the quality of life and wellbeing of not only the person with disability, but also of close friends and family, known as courtesy stigma (Goffman, 1963). While Goffman's work remains one of the dominant theoretical foundations for examining and understanding stigma, more recent scholars have expanded on the concept of stigma (Farrugia, 2009). For example, Pryor and Reeder depict four interrelated types of stigma in their *Four Manifestations of Stigma*(Pryor & Reeder, 2011). These types of stigma include: (1) Public Stigma, which represents peoples social and psychological reactions to someone they perceive to have a stigmatized condition. Public stigma may be related to innate beliefs and reactions, but is also informed by the presence of a diagnostic label, perceived severity of a condition, and media portrayals of that condition; (2) Self-Stigma, which reflects the social and psychological impact of possessing a stigma; in other words, of internalizing stigma; (3) Stigma by Association, which refers to social and psychological reactions to someone associated with a stigmatized person. For children, this may include parents and other family members, other caregivers, peers, or even professionals or programs that support people with the stigmatized condition. Finally, (4) Structural Stigma is defined as the legitimatization and perpetuation of a stigmatized status by societys institutions and ideological systems. This type of stigma may include attitudes and practices of professionals or leaders, as well as other organizations practices and policies. Bos, Pryor, Reeder, and Stuttenheim (2013), use Pryor and Reeders (2011) articulation of the manifestations of stigma to theorize on the interrelatedness of the different forms of stigma, explore how stigma is rooted in social interactions, describe advancements in how we measure stigma, and provide recommendations for research related to stigma reduction.

There is currently a body of literature related to stigma and stigmatization of children and individuals living with other conditions including: mental health disorders, epilepsy, Attention Deficit Hyperactivity Disorder (ADHD), and intellectual disability. Individuals and their families living with these conditions report feeling societal stigma, marginalization, and social exclusion from the community, extended family members, and friends (Benson et al., 2016; Kaushik et al., 2016; Wiener et al., 2012; Ali, Hassiotis, Strydom, & King, 2012). Children with ASD are at a particularly high rate of experiencing stigma, even when compared to other disability groups (Cappadocia et al., 2012; Kinnear et al., 2016). ASD is diagnosed based on pervasive impairment in social interactions, social communication, and the presence of socially atypical behaviors (American Psychiatric Association, 2013). Some scholars have proposed that these pervasive social impairments without a visible disability make the experience of stigma different for ASD than other disabilities (D. E. Gray, 1993). Currently however, there is no review of the existing literature around the stigmatization experienced by children with ASD and their families or caregivers. Therefore, the purpose of this scoping review is to (1) synthesize the existing literature related to stigmatization of children with ASD and their families, and (2) identify gaps in the literature to inform future directions in the field.

A.1 Method

A scoping review was conducted as outlined by Arksey and OMalley (Arksey & O'Malley, 2005). This type of review process allows us to thoroughly examine, map, and identify gaps in the current existing literature regarding the broad topic of stigma and ASD, as opposed to empirically answering a well-defined research question and assessing the quality of the literature, like in a systematic review (Arksey & O'Malley, 2005; Levac, Colquhoun, & O'Brien, 2010).

Arksey and OMalleys (2005) five-stage methodological framework was utilized: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarizing, and reporting the results. In addition to this framework, recommendations to clarify and enhance each stage as suggested by Levac et al. (2010), were also taken in to consideration. Suggestions made by Levac et al. (2010) incorporated in to this study included: collectively developing the data charting form and determining which variables to extract to answer the research question, and breaking down step five of Arksey and OMalleys (2005) framework (collating, summarizing, and reporting) into three distinct steps of analysis (a descriptive numerical summary analysis and a qualitative thematic analysis, reporting of the results, and consideration of the meaning of the findings).

A.1.1 Identifying the Research Question

The scoping review addresses the following question: What is known from the existing literature about the stigma and stigmatization associated with children and adolescents with autism spectrum disorder and their families?

A.1.2 Identifying Relevant Studies

Inclusion and exclusion criteria were defined for the study. Inclusion criteria were: (1) a focus on stigma and/or stigmatization; (2) a focus on children or youth with a diagnosis of ASD (including previous terms used prior to the DSM-V, such as Aspergers) and/or their families or caregivers; (3) publications in English; and (4) peer-reviewed literature. Studies that were related to: (1) diagnoses other than ASD; (2) a focus on adults with an ASD diagnoses; (3) families of adult-aged children; and (4) stigma in the workplace related to adults, were excluded.

A.1.3 Study Selection

Four electronic databases, ERIC, MEDLINE, Child Development and Adolescent Studies, and CINAHL, were searched using search terms autism, autism spectrum disorders, ASD, or Aspergers, AND stigma or stigmatization. No date parameters were set and an initial search took place in January 2017 resulting in 107 peer-reviewed studies. All articles were screened by title and abstract, based on the clearly defined inclusion and exclusion criteria. Forty articles potentially met the inclusion criteria based on abstract and title and were read in full. Nineteen of these articles clearly met inclusion criteria based on full text. Four articles were unclear, so a second researcher independently screened these four articles based on the established inclusion and exclusion criteria, and an agreement was made for inclusion of all four based on full text. From this first search, twenty-three articles in total met the inclusion criteria based on the full text and were included in the study. A second search was conducted in December 2017 with date parameters set to the year 2017, which identified four potential new articles based on title and abstract. Upon reading in full, two of these articles also met inclusion criteria. Therefore, a total of twenty-five articles were identified for inclusion in this review.

A.1.4 Charting the Data

The final twenty-five articles were read in full and data were extracted in the following fields: author, year of publication, location of study, title, participant information, study objective, methodology, outcomes and interpretation of methods, and main findings related to stigma. See Table 1.

A.1.5 Collating, Summarizing, and Reporting the Results

Information from the twenty-five articles were collated and analyzed thematically to map areas of interest related to stigma and ASD. Initial analysis of the data resulted in five themes: (1) Judgement, (2) Diagnostic Label, (3) Social Isolation, (4) Social Well-Being, and (5) Fear of Discrimination. These themes were organized using Scapple, an online mind mapping application. Data charts were read and compared to the studies main findings to better formulate these themes and the information was further charted. Data were then thoroughly examined again by two reviewers; a process that revised our findings into four themes and two subthemes that better represent the data. The four final themes are: (1) Social Perceptions of ASD, which includes two subthemes (i) Invisibility & Judgement and, (ii) Diagnostic Labels; (2) Social Isolation; (3) Well-Being & Response to Stigma; and (4) Stigma Reduction.

Table 1. Data Charting

AUTHOR LOCATION	TITLE	SAMPLE	METHODOLOGY	OUTCOMES/ INTERPRETATION	MAIN FINDINGS RELATED TO STIGMA
Blanche et al. (2015); USA	Caregiving experiences of Latino families with children with Autism Spectrum Disorder	n= 15 Latino parents of children with ASD	Semi-structured interviews	Thematic analysis	Theme of 'dealing with stigma and social isolation' emerged from data; stigma led to changing social practices leading to social isolation
Broady et al. (2017); Australia	Understanding carers' lived experience of stigma: the voice of families with a child on the autism spectrum	n=15 carers' of children with high functioning autism (HFA)	Semi-structured interviews	Thematic analysis	Four domains of stigmatizing experience: (1) lack of knowledge, (2) judgement, (3) rejection, (4) lack of support
Corcoran et al. (2015); USA	The lived experience of US parents of children with ASD: a systematic review and meta-synthesis	n=14 papers	Meta-synthesis of literature	Identification of themes using meta-synthesis framework	One of six major themes was stigmatization
Daniels et al. (2017); USA	Autism in Southeast Europe: A survey of caregivers of children with Autism Spectrum Disorders	n=758 caregivers of children with ASD	Surveys	Affiliate Stigma Scale	29% report worrying if others knew child had ASD; 41% report other people would discriminate against them; 42% report having child with ASD has negative impact on them
Farrugia, D. (2009); Australia	Exploring stigma: medical knowledge and the stigmatization of parents of children diagnosed with ASD	n = 12 parents of children with ASD	Semi-structured interviews	Discourse analysis Deviant case analysis	Enacted stigma from friends affecting social circles; enacted stigma from public (staring, judging looks); invisibility of disability plays role in greater stigmatization; blamed/judged for bad parenting because of child's behavior

Gill & Liamputong (2011); Australia	Being the mother of a child with Asperger's Syndrome: Women's experiences of stigma	n=15 mothers of children who have Asperger's Syndrome (AS)	Semi-structured interviews and narrative review of diary entries	Thematic analysis	Invisibility of disability with Asperger's leads to more stigma; mothers avoid social situations to lessen stigma; dialogue around learning to adapt to stigma
Gillespie-Lynch et al. (2015); USA	Changing college students' conceptions of autism: an online training to increase knowledge and decrease stigma	n = 365 college students	Surveys Qualitative coding of open ended questions	Demographic survey, pre-test measures, autism training, identical post-test measures	Gender differences in stigma rating; autism in immediate family changed ratings of stigma; autism knowledge increase post-test and stigma decreased in post –test
Gray (1993); Australia	Perceptions of Stigma: the parents of autistic children	n = 32 parents of children with ASD	Semi-structured interviews	Thematic Analysis	55% identified as being stigmatized; parents report higher social withdrawal from social contact with outside world; discrepancy between normal physical appearance and reality of disability plays role in negative public encounters; courtesy stigma experienced by family
Gray (2002); Australia	Ten years on: a longitudinal study of families of children with autism	n= 28 parents of children with ASD	Semi-structured interviews	Ethnography	Majority of parents still experienced stigma but impact of stigmatization declined for some over the years; some parents expressed continuation of stigma but how it mattered less to them
Gray (2002); Australia	'Everybody just freezes. Everybody is just embarrassed': felt and enacted stigma among parents of children with high functioning autism	n=53 parents of children with high functioning autism (HFA)s	Semi-structured interviews	Thematic Analysis	Parents felt others were critical of their parenting skills; embarrassment was a common manifestation of felt stigma; visibility and symptoms of the condition plays a role in stigma

Jones et al. (2015); USA	‘Are you by chance on the spectrum?’ Adolescents with autism spectrum disorder making sense of their diagnoses	n= 10 adolescents diagnosed with ASD	Semi-structured interviews	Phenomenological Analysis	All adolescents referred to social stigma of ASD, and describe struggling with how they and others with ASD are perceived in light of their diagnosis; feelings of frustration around social stigma experienced
Kinnear et al. (2016); USA	Understanding the Experience of Stigma for Parents of Children with ASD and the Role stigma plays in families' lives	n = 502 parents of children with ASD	Computer assisted telephone interview Surveys/Scales	Constructed Scales: child’s autism related behaviors; parent’s perceptions of public stereotypes; frequency of rejection; assessment of difficulty of stigma in parent’s lives; difficulty of raising a child with ASD	95.6% of parents reported that stigma was difficult in their lives from a little to extremely; stigma plays a significant role ($\partial = 0.282$, $p<.001$) in predicting how challenging life is for parents.
Milacic-Vidojevic et al. (2014); Serbia	Tendency towards stigmatization of families of a person with ASD	n = 181 participants from the general public in Belgrade	2 Questionnaires	Family Stigma Questionnaire (FSQ) and Level of Familiarity Questionnaire (LFQ)	Parents are blamed for onset of condition; individuals with least education of ASD demonstrated higher tendency towards stigmatizing behaviors
Minhas et al. (2015); Pakistan	Parents’ perspectives on care of children with autistic spectrum disorders in South Asia – Views from Pakistan and India	Study 1 n=15 parents of children with autism spectrum disorder in Pakistan Study 2 n=5 studies previously conducted in India	Semi-structured interviews and narrative review of previous studies	Thematic analysis of interviews Secondary narrative analysis of 5 previous studies	Parents found challenging behaviors were socially embarrassing and contributed to stigma towards their children and families; worry about mistreatment in the community; afraid to put children in mainstream education due to teachers’ attitudes; parents fear sending their children in to public or for social celebrations

Mogensen & Mason (2015); Australia	The meaning of a label for teenagers negotiating identity: experiences with ASD	n = 5 teenagers with ASD	Participatory action research informed by phenomenology and ethnography Range of communication options given - face to face interview, drawings, photos, emails	Thematic analysis of interview transcripts, e-mails, and photos of a communication board	Participants were reluctant to disclose diagnosis due to stereotypes and negative public attitudes attached to the diagnosis in society; two participants feared sharing diagnosis with friends would result in being treated differently; one participant comfortable with sharing diagnosis, and being different helped him socially
Munroe et al. (2016); UK	The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an Autism Spectrum Disorder: an interpretive phenomenological analysis	n=6 African immigrant mothers of children with ASD	Semi-structured interviews	Interpretive Phenomenological Analysis	One of four themes identified was the pain of stigma and rejection
Neely-Barnes et al. (2011); USA	Parenting a child with as ASD: public perceptions and parental conceptualizations	n = 11 parents of children with ASD	Focus group interviews	Interpretive qualitative analysis	Difficult for people in public to "see" autism and they endure criticism because their child does not "act normal" (invisibility of ASD); public views them as bad parents
Obeid et al. (2015); USA	A cross cultural comparison of knowledge and stigma associated with ASD among college students in Lebanon and the US	n = 675 post-secondary students from Lebanon and US	Pre-test and post-test questionnaires about knowledge and attitudes towards ASD Intervention: Autism training program	Social Distance Scale; Autism Awareness Survey; Broad Autism Phenotype Questionnaire	Stigma lower at post-test relative to pre-test for both groups of students; women endorsed lower levels of stigma than men

Ranson & Byrne (2014); Australia	Promoting peer acceptance of females with high functioning autism in a mainstream education setting: a replication and extension of the effect of an anti-stigma program	n = 273 7th, 8th, and 9th grade female students	Pre-test and post-test (one week and one term) of ASD knowledge and attitudes	Autism Knowledge Questionnaire; Adjective Checklist; Shared Activities Q; Similarity Ratings Form; Perceived responsibility Q	Positive influence of anti-stigma on knowledge and attitudes, and to a lesser extent behavioral intentions
Russell & Norwich (2012); UK	Dilemmas, diagnosis, and de-stigmatization: parental perspectives on the diagnosis of ASD	n=8 parents not seeking a diagnosis; n= 9 parents of children diagnosed with ASD	Semi-structured interviews	Thematic Analysis	Parents fear child will be discriminated against; parents may shy away from diagnosis because of negative perceptions
Staniland & Byrne (2013); Australia	The effects of a multi component high functioning autism anti stigma program in adolescent boys	n = 395 7th, 8th, and 9th grade male students	Pre-test and post-test (one week and one term) of ASD knowledge and attitudes	Autism Knowledge Questionnaire; Adjective Checklist; Shared Activities Q; Similarity Ratings Form; Perceived responsibility Q	The anti-stigma program improved knowledge and attitudes but did not improve behavioral intentions towards peers;
Thibodeau & Finley (2017); USA	On Associative Stigma: implicit and explicit evaluations of a mother of a child with autism spectrum disorder	n=95 undergraduate students	2x3 between subject design: audio recorded vignette pertaining to a mother of a child with ASD or severe asthma	IAT (Implicit Association Test) score, social distance, stereotyped attitudes	Implicit evaluations of mother of child with ASD were less positive than implicit evaluations of mother of child with asthma
Werner & Shulman (2013); Israel	Subjective well-being among family caregivers of individuals with developmental disabilities: The role of affiliate stigma and psychosocial moderating variables	n= 176 family caregivers of individuals with ASD, ID, PD	Self-report questionnaire	Demographics, social well-being, affiliate stigma, positive meaning in caregiving, caregiving burden, self-esteem, social support	Affiliate stigma a predictor of subjective well-being for parents of children with ASD; greater levels of stigma associated with lower subjective well-being for ASD and not ID or PD

Werner & Shulman (2015); Israel	Does type of disability make a difference in affiliate stigma among family caregivers of individuals with ASD, ID, or PD?	n = 170 family caregivers of individuals with ASD, ID, PD	Self-report questionnaire	Affiliate stigma scale	Higher levels of affiliate stigma for parents of children with ASD compared with ID or PD
Woodgate et al. (2008); Canada	Living in a world of our own" The experience of parents who have a child with autism	n= 21 parents from 16 families of children with ASD	Open ended, in depth qualitative interviews	Hermeneutic Phenomenology	Parents expressed feeling social isolation and stigmatization

A.2 Results

A.2.1 Overview of Results

The twenty-five articles included in the study were published between the years 1996 and 2017. Figure A.1 shows the detailed flow of our study selection and results. Articles that were excluded focused on adult populations with ASD and workplace stigma, or individuals with diagnoses other than ASD.

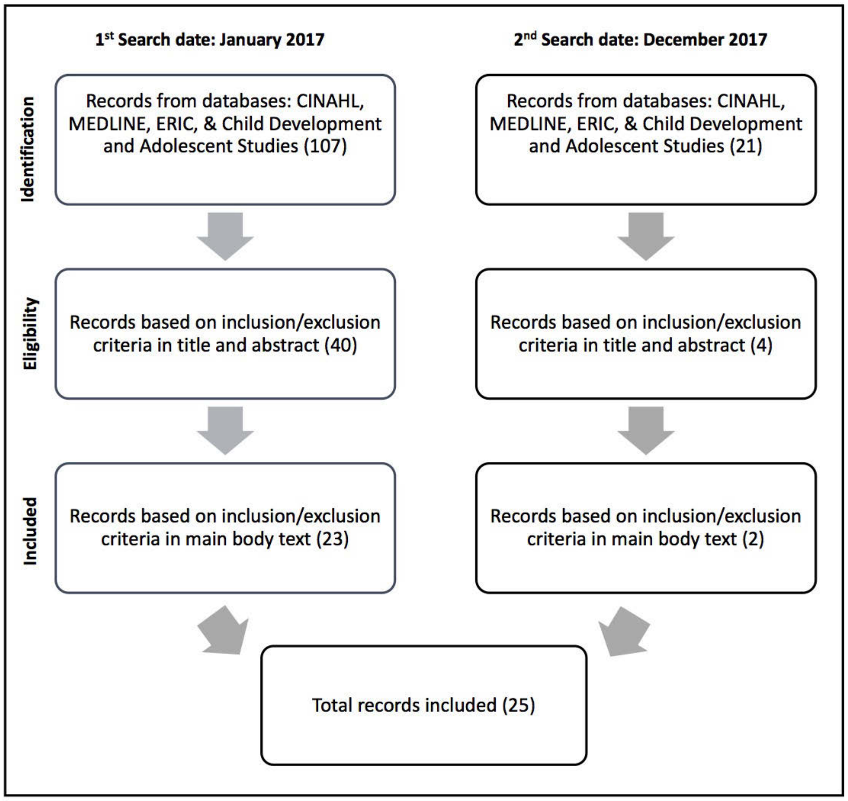


Figure A.1: Flowchart of study selection.

The final studies selected used a variety of methods including qualitative (n=12; 48%), quantitative (n=9; 36%), mixed methods (n=3; 12%), and one meta-synthesis (4%). Majority of the studies were conducted in the USA (n=9), and Australia (n=8), with two studies each from the UK (n=2), and Israel (n=2), and one study each from Hong Kong (n=1), Serbia (n=1), Pakistan (n=1), and Canada (n=1). Participants included those with lived experience of ASD, including: parents or caregivers of children with ASD (n=17 articles), and adolescents with ASD (n=2 articles); and those without identified lived experience with ASD, including: university undergraduate students (n=3 articles), and adults in the general public (n=2 articles).

A.2.2 Thematic Analysis

Four major themes were identified, including: (1) social perceptions of ASD (with two sub-themes: invisibility and judgement, and diagnostic labels), (2) social isolation, (3) well-being and responses to stigma, and (4) stigma reduction.

Social Perceptions of ASD

The first theme relates to how others see people with ASD and perceive the diagnosis, and how people with ASD and their families perceive that others see them and the diagnosis of ASD. Two distinct subthemes emerged that both directly relate to the primary theme.

Invisibility and Judgement. Social perceptions and preconceived notions of individuals with ASD and those with whom they are associated are apparent in society, specifically around what it means to behave "normally". Parents report how it can be "difficult for people in the public to see Autism, (and how) all the public sees is a child acting out" (Neely-Barnes, Hall, Roberts, & Graff, 2011). Gray notes that "it is [a] combination of pervasive disability and apparent physical normality that gives the stigma experienced by families with autistic children its unique quality" (D. E. Gray, 1993, p. 114). The invisibility of ASD in conjunction with challenging behaviors leads others to make assumptions about their child misbehaving and in turn make judgements about their parenting abilities (Broady et al., 2017; Farrugia, 2009; D. E. Gray, 2002; Munroe, Hammond, & Cole, 2016; Neely-Barnes et al., 2011). From vignettes depicting a mother of a child with ASD and a mother of a child with asthma, the mother of the child with ASD was evaluated as being less valuable, illuminating the presence of associative stigma (Thibodeau & Finley, 2017). Parents share how they are constantly judged and misunderstood by others in various settings (Broady et al., 2017), and that the resulting judgement can be embarrassing and contributes greatly to perceptions of stigma (D. E. Gray, 2002; Minhas et al., 2015). One mum reports negative judgement from her childs school, "school is judging me, like I am some sort of crackpotI have been through hell at this school with them pointing their finger"; three parents share how people in the general public, who, based on observing them and their child, comment, "control your (child)" or "that child just needs a good smack on the bum"; and finally from their own finally members, "my family judges me all the timecommenting on how 'some people shouldnt be parents" (Broady et al., 2017, p. 228).

Diagnostic Label. The preconceived social perceptions of how a "normal" looking child should behave are further complicated with the pervasive assumptions made around the specific label of ASD or Aspergers. Parents of children with ASD and adolescents living with ASD report public social stigmatization specifically related to the diagnostic label of ASD or Aspergers (Jones et al., 2015; Mogensen & Mason, 2015; Russell & Norwich, 2012), and higher levels of affiliate stigma than caregivers of children with an intellectual disability or physical disability (Werner & Shulman, 2015). Parents express how it is easy to refrain from sharing a diagnosis because of the negative preconceived perceptions that are associated with the ASD label, and fear of their child experiencing discrimination (Russell & Norwich, 2012). Adolescents living with ASD share mixed feelings about carrying an ASD label. In relation to sharing their diagnosis, some teens reported reluctance to share because of the negative stereotypes the public carries, which are directly related to negative experiences including being stigmatized and treated differently than non-diagnosed teens (Mogensen & Mason, 2015). However, for some teens, a diagnosis improved understanding of themselves and helped them find belonging (Jones et al., 2015); with one teen reporting how he liked sharing his diagnosis because he was proud of being different and unique (Mogensen & Mason, 2015).

Social Isolation

Social isolation was reported from two different perspectives: parent reports of their own experiences, and parent reports of their childs experiences. Parent reports of their experiences exposed two different causes of social isolation: social isolation due to rejection from others, and social isolation due to their own avoidance of social situations. Parents felt rejected from various sources, including schools, other parents, and family members (Broady et al., 2017). Parents refrained from putting their children in mainstream education and avoided sending their children to public environments or out for social celebrations because of the way they may be treated (Minhas et al., 2015). Parents believed that the public held negative beliefs about their children, including that they would not be a good friend, and that their children were socially isolated because other children thought they were weird (Kinnear et al., 2016). One parent made clear that the school is stigmatizing their son, "the resource person said I should not expect other kids to buddy with himthey are saying, 'why would another kid want to play with your kid" (Woodgate, Ateah, & Secco, 2008, p. 1078). Additionally, parents felt isolated from extended family members who lacked an understanding of their childs behaviors (D. E. Gray, 1993; Kinnear et al., 2016; Munroe et al., 2016). Caregivers described changing their social practices (Blanche, Diaz, Barretto, & Cermak, 2015) or avoiding certain social situations (Gill & Liamputtong, 2011) as a strategy to avoid stigmatization. One mother shared, "you tend to limit your activities as well, either consciously or subconsciously, because its just hard to really, to go out and to be judged" (Munroe et al., 2016, p. 809). However, this created feelings of guilt for some of the mothers because they worried they were limiting their childs life experiences (Munroe et al., 2016).

Well-Being and Responses to Stigma

The combination of social stigma experienced by individuals with ASD, the affiliated stigma experienced by families, and the resulting social isolation can greatly influence their well-being. Werner & Shulman (2013) highlighted that greater levels of stigma were associated with lower social well-being for caregivers of children with ASD, which was notably lower than for caregivers of individuals with an intellectual disability or physical disability. Parents report feeling helpless (Daniels et al., 2017), and how the stigma associated with having a child with ASD has a negative impact on them (Daniels et al., 2017) and their families (Corcoran, Berry, & Hill, 2015). Peer rejection and negative stereotypes, along with the potential consequences of stigma including isolation, exclusion, and loss of employment, were related to the parents ratings of how difficult stigma has been in their lives, and how challenging it can be to raise a child with ASD (Kinnear et al., 2016). However, Gray (1993; 2002), showed that responses to stigma and how it affects well-being can change over time. In 1993, Gray interviewed parents and asked them about their experiences of raising a child with ASD (D. E. Gray, 1993). Ten years later he performed a follow up study with the same families and found that stigma did not affect them to the extent it had initially. Parents reported that over time they had developed better coping strategies (D. Gray, 2002). Parent reports in more recent studies also show that the ability to cope with stigma changes over time, and knowing that society wasnt going to change meant that they needed to adapt to the stigma and "stare it in the face" instead of allowing it to anger them (Gill & Liamputtong, 2011, p. 718).

Stigma Reduction

A lack of ASD knowledge and education feeds negative perceptions (Broady et al., 2017) and leads to greater levels of public (Farrugia, 2009; Gill & Liamputtong, 2011; Neely-Barnes et al., 2011) and affiliated stigma (Milacic-Vidojevic, Gligorovic, & Dragojevic, 2014). Parents of children with ASD (Woodgate et al., 2008) and adolescents living with ASD (Jones et al., 2015) report that educating others about ASD could help mitigate enacted discrimination. A subset of the literature has begun to investigate the outcomes of stigma reduction programs for both adolescent and young adult populations (Gillespie-Lynch et al., 2015; Obeid et al., 2015; Ranson & Byrne, 2014; Staniland & Byrne, 2013). Staniland & Byrne (2013) developed an anti-stigma program to promote acceptance of peers with ASD in adolescent boys. Results from their study showed improvements in knowledge and attitudes, but did not show any change in behavioral intentions of non-autistic peers towards their peers with ASD. Ranson & Byrne (2014) updated the protocol and implemented the program in a group of adolescent girls. Similarly, knowledge and attitudes were improved, but in this group the researchers also saw improvements in behavioral intention.

Working with US college-aged students, Gillespie-Lynch et al. (2015) reported lower stigma ratings on the Social Distance Scale, where students are asked how willing they are to engage with a certain type of person at varying levels of intimacy. In a replication study executed by Obeid et al. (2015), researchers found that, after a similar autism training program, students in both Lebanon and the US reported similar improvements on the same measures. Both studies also reported increased knowledge and understanding of ASD (Gillespie-Lynch et al., 2015; Obeid et al., 2015).

A.3 Discussion

This scoping review examined the existing literature related to the stigmatization experienced by children and adolescents with ASD and their families or caregivers. Overall, the findings from this study situate closely with Pryor and Reeders (2011) *Four Manifestations of Stigma*, centralized around public stigma. From the results of this study we can see the impact that the invisible nature of ASD and the diagnostic label of ASD have on public perceptions and public stigma, the social behaviors and self-stigma that result from this judgement, the negative effects of stigma on well-being, and positive developments around education and awareness that can help those who stigmatize and those targeted by stigma. This study helps reinforce the multi-dimensional nature of stigma and our understanding that stigma can be experienced in different ways, affecting different facets of daily life. We discuss the implications of these results in relation to sensitivity and education and highlight gaps in the literature with suggestions for future research directions.

A.3.1 Potential Implications

Our findings highlight the impact that stigma has on the lives of individuals living with ASD and their parents or caregivers. Increased understanding of the perceptions and implications of the stigma experienced by people living with ASD has implications in professional practice, for building educational initiatives, and in supporting policy development. Professionals who display sensitivity, openness, and have inclusive practices may be better equipped for supporting families and children who are navigating services and able to build stronger relationships to best support their well-being.

The results from our review show that both caregivers and those living with ASD report difficulty in navigating spaces with others who lack knowledge of the developmental disability. This lack of knowledge includes a misunderstanding of the different behaviors children and adolescents with ASD may display. This has generally been reported to lead parents or caregivers of children with ASD to feel judgement and exclusion. Furthermore, people living with ASD report feeling stigmatized about their capabilities, which can lead to more severe levels of social isolation and decreased well-being. For these reasons, a fear of sharing a diagnosis or disclosing the label of ASD or Aspergers because of the way it may be perceived is understandable.

People living with ASD and their support networks report high levels of social isolation and judgement based on stigma. The potential benefits of stigma reduction strategies on decreasing these negative outcomes reinforces the importance of developing educational tools and specific interventions targeted at all individuals. Regardless of the setting (e.g., professional settings, community contexts, schools, targeting the general-public), these strategies should focus on improving acceptance and inclusion of children with ASD and their families. Importantly, this type of education would help raise awareness of stigma and social isolation experienced by people with invisible disorders, such as ASD. Similarly, youth with epilepsy maintain the invisibility of their disorder by not disclosing to others because they have experienced social exclusion and judgment based on stigma (Benson et al., 2016; Lewis & Parsons, 2008). Youth with epilepsy expressed the need for educational strategies to improve understanding and accepting attitudes (Lewis & Parsons, 2008). In addition to educational initiatives, it is paramount to improve inclusive practices and supports in our communities. These types of structural reforms are not easy to implement, but must be identified as a priority to move towards a culture of equal access, understanding, and acceptance of people with ASD.

A.3.2 Research Gaps and Future Directions

Stigma research related to ASD is a growing field. While many steps have been taken to increase the scope of research in the field, it is important to recognize the gaps in the literature and highlight areas for further research. Many of the studies in this scoping review were from the viewpoint of the parent (n=17), which gives valuable insight to the lived experience of caregivers and parents; whereas only two studies have examined experiences of stigma from the perspective of adolescents, and the voice of younger children are completely missing from the picture. Including the voice of children as participants in research can be difficult. Directly involving children who may have limited verbal communication skills can add further challenges. However, it is possible. An emerging body of literature outlines the importance of hearing childrens voices, and delves in to the methodological creativity required to engage participants, and more specifically children with ASD (Danker, Strnadova, & Cumming, 2017; C. Gray & Winter, 2011).

A small subset of the stigma literature (n=4) is related to the development and assessment of educational programs that are intended to reduce stigma. These studies have opened a door to better understanding how increasing knowledge of ASD can influence more inclusive practices and behaviors that can decrease stigma. Outcomes of evaluations of educational programs targeting stigma reduction are encouraging, but there is a lack of cultural diversity within the educational initiatives and within their target populations. In line with considering targeted stakeholder groups, many (n=6) of the studies in this scoping review represented non-Western cultures, taking into consideration that stigma contains a cultural context so addressing the roots of stigma and providing education and sensitivity training must be individualized in relation to each culture. A better understanding of how these promising interventions may generalize across cultures is warranted. For these programs to be effective, Bos et al. (2013) highlight the need for stigma reduction programs that identify specific manifestations for change in other words, they should be directed towards a certain component of the stigma framework (self, affiliated, public, or structural stigma). Bos et al. (2013) also advise on the importance of targeting the level of intervention, whether it is intrapersonal, interpersonal, at the community level, or at the institutional level, and that this should be clearly identified at the initiation of the program.

It should also be noted that majority of stigma literature in ASD is related to public stigma, self-stigma, and stigma by association. Structural stigma, the fourth category described by Pryor and Reeder (2011) has not been addressed. Because this form of stigma incorporates attitudes and practices of professionals and organizations, it is imperative to gain a clearer understanding of how structural stigma implicates individuals living with ASD. In addition to outcomes related to well-being, it is important to understand how it shapes opportunities for inclusion. Do structural policies play a role in the participation and inclusion of children and adolescents with ASD? Do the attitudes of individuals in organizational roles have implications in policy related to inclusion? By intervening at the structural level, would we see dynamic changes in public stigma and self-stigma?

A.4 Conclusion

Participation and inclusion are paramount to an individuals sense of self within a community. Stigmatizing behaviors deeply affect children and adolescents with ASD and diminish an individuals capacity to feel like a part of their community. Education around what stigma is, how it is experienced, and how the general-public contribute and perpetuate stigma is an important first step in developing awareness and knowledge around developmental disabilities including ASD. It is clear that there remains a need for stigma reduction. Professionals supporting people living with ASD and their caregivers need to advocate for these changes both structurally in professional organizations as well as privately with the general public.

Appendix B

Information and Consent Form

On the following three pages you will see the Information and Consent form that was used for all six interviews. The information pages outline the purpose of the project, a description of the research, benefits and risks, a confidentiality notice, and contact information. The consent forms were used to gain informed consent for the use of the information and experiences that participants shared with me.

Information and Consent Form for Participants

Study Title: At whose discretion? Assumptions and expectations of ASD diagnostic disclosure in community recreation

Investigators:
Rinita Mazumder
MSc Rehabilitation Science Student, University of Alberta

Sandy Hodgetts, PhD, OT
Assistant Professor, Department of Occupational Therapy, University of Alberta

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David Nicholas, PhD, RSW
Associate Professor, Faculty of Social Work, University of Calgary

Introduction:
Choosing if, and then to whom, when, why and how to tell a child's diagnosis of autism spectrum disorder (ASD) to other people is a major life decision for parents. In community recreation programs, disclosure of a diagnosis can have different outcomes for programming and the child's program experience. Little research has been done to look at policies, practices and perceived outcomes of disclosing ASD diagnoses in community recreation programs.

Purpose:
This study will explore the assumptions and expectations made around disclosing or not disclosing a child's ASD diagnosis in community recreation programs.

Description of the Research:
You are invited to participate in an interview because you are a programming leader directly involved with the registration and inclusion of kids with ASD in your programs. We want to learn about your experiences with a child's diagnosis of ASD being disclosed or not disclosed to you and your program leaders.

The interview will last about an hour. It will take place at a time and place convenient for you. We will ask you questions about your experiences with disclosure or non-disclosure of an ASD diagnosis, as well as your perceived outcomes. We will audio record the interview. Later, a professional transcription company who has signed confidentiality waivers will transcribe word for word, but all information that could identify you, the recreation program, or your workplace will be removed from the transcript.

Following data analysis you will be contacted to check the information we have included in our summarization to make sure that the words expressed truly represent your experiences. You can ask for your data to be withdrawn at any point up to and including this member checking process. After this point it will not be possible to withdraw your information.

Possible Benefits:
Your taking part in this study will help us to understand this important process in our communities. Findings may help with future research on services for children with ASD in community recreation. Findings may also help parents with their decision to disclose or not disclose their child's diagnosis of autism.

Possible Risks:
There are no projected long-term risks or discomforts. Please be aware that all identifying information about you, your program, or your workplace will be removed from the data.

Voluntary Participation:
Participation in this interview is voluntary. You can stop at any time by telling the interviewer. You do not have to answer any questions that you don't feel comfortable answering. You can request the audio recorder be shut off at any time.

Confidentiality:
Your identity will be kept private if you take part in the interview. We will remove your name and any other potentially identifying information from the typed records of the interviews and in reports about the research. We will replace your name with a pseudonym that is known only to the researchers. Your code will be kept in a secure and locked filing cabinet or in a computer that can only be entered through a password. The interview transcripts will be kept in secure locked storage for a minimum of 5 years' post study completion.

The results of the study may be printed in a newspaper or journal but you will not be identified. The results from this study may be used in future research and for teaching purposes but your rights will be protected in the future as they are now.

What costs are there to you if you participate in this study?
We do not expect you to have any expenses as a result of taking part in the study. You will receive a $25 gift card for your participation. You will receive this gift card even if you withdraw early from the interview.

Contact Information:
If you have concerns about your rights as a study participant, you may contact the University of Alberta's Research Ethics Office at (780) 492-2615. This office has no affiliation with the study investigators.

Please contact the project lead if you have any questions or concerns.

CONSENT FORM

Title of Project: At whose discretion? Assumptions and expectations of ASD diagnostic disclosure in community recreation

Locally Responsible Investigator: Rinita Mazumder

Do you understand that you have been asked to be in a research study?	YES ☐	NO ☐
Have you read and received a copy of the attached Information Sheet?	YES ☐	NO ☐
Do you understand the benefits and risks involved in taking part in this research study?	YES ☐	NO ☐
Have you had an opportunity to ask questions and discuss this study?	YES ☐	NO ☐
Do you understand that you are free to withdraw from the study at any time without having to give a reason?	YES ☐	NO ☐
Has the issue of confidentiality been explained to you?	YES ☐	NO ☐
Do you understand who will have access to your information?	YES ☐	NO ☐

Who explained this study to you? ____

I agree to take part in this study	YES ☐	NO ☐
I agree to be audio recorded during my involvement in the research interview	YES ☐	NO ☐
I agree to allow the use of my sound recordings for presentations	YES ☐	NO ☐
I agree to allow the use of my sound recordings for teaching purposes	YES ☐	NO ☐
I agree to be contacted for future research related to this study	YES ☐	NO ☐
I agree to be contacted for future research not related to this study	YES ☐	NO ☐

Signature of Research Participant ____

(Printed Name)
____Date:____________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee ______________________________ Date ______________

Appendix C

Interview Guide

On the following page you will see the semi-structured interview guide used for the interviews. Before beginning the interview I verbally outlined the project, went through the information and consent forms, gained informed consent, and then turned on recording devices before beginning.

Sample Interview Questions

Thank you for agreeing to participate in this research project and to talk with me today. I would like to talk with you about your experiences of including children with disabilities, specifically autism spectrum disorder, in your recreation programs. Although I would like this to be more of a conversation than an interview, I do have a few questions written down to make sure I cover everything. If you feel uncomfortable with any of the questions, you can choose not to answer that question and you do have the right to stop the conversation at any point.

1. Do you have many families and children with ASD accessing your program(s)?
2. Is it mandatory for parents to disclose diagnosis upon registration?
    - At what point during registration are parents asked to disclose?
    - To whom are they expected to disclose?
    - If it is not mandatory at registration, is it mandatory at any other point?
3. What do you believe is the outcome of disclosing this information?
4. How does disclosure have bearing on programming?
    - If it helps, in what ways does it help?
    - If it acts as a barrier, in what way does it act as a barrier?

*These questions will be informed and tailored by each organization’s policy documents

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