BARRIERS AND FACILITATORS TO ACCESS AND CARE IN SERVICES FOR CHILDREN WITH AUTISM SPECTRUM DISORDER IN NEWFOUNDLAND

By

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ABSTRACT

This thesis uses thematic analysis and a Complex Cultural Nesting theory to assess the perspectives of parents of children with autism spectrum disorder as well as the service providers as they try to navigate through the healthcare and education system in Newfoundland, Canada. These journeys were explored through interviews with a range of participants in a one to one setting, thus providing rich and specific experiential data. The main barriers discovered were frustrations in the diagnostic process, difficulty accessing and understanding services within the healthcare and education systems, and struggles with the applied behavioral analysis therapy. Main facilitators included having a knowledgeable and supportive family physician, family support, and service provider communication and collaboration. Major recommendations focus on increasing the number of experienced providers in the province and increasing specific autism training for service providers (in the healthcare and education system).

Keywords: Autism, Barriers, Facilitators, Parents, Service Providers, Education, Healthcare

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List of Abbreviations

Applied Behavioral Analysis [ABA]

Atlantic Canada Children's Effective Service Strategies in Mental Health [ACCESS-MH]

Autism Society of Newfoundland and Labrador [ASNL]

Autism Spectrum Disorder [ASD]

Diagnostic and Statistical Manual of Mental Disorders— 5th edition [DSM-5]

Individual Student Service Plan [ISSP]

Individualized Education Plan [IEP]

Instructional Resource Teacher [IRT]

Inter— Professional Collaboration [IPC]

Occupational Therapy [OT]

Relationship Development Intervention [RDI]

Speech Language Pathology [SLP]

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Chapter 1: Introduction

1.1 Background

"My journey through autism has been one of climbing the tallest mountains, screaming at the top of my lungs, with nobody around me listening." A quote from *Maureen* when she was asked to describe her journey with a child with autism spectrum disorder.

Today's youth live in a complex world facing many challenges each and every day. Although the topic of mental health has become less taboo in recent years, it remains a prevalent health crisis, with the reality that only one in five children who require neuro-developmental services actually receive them (Canadian Mental Health Association, 2016). As of 2015 approximately one in seven Canadians utilize health services for mental illness and neuro-development disorders each year, with the largest relative increase during a 14-year surveillance period appearing to be amongst young adolescents aged 10-14 (Public Health Agency of Canada, 2015). As was noted by Raphael, Stevens and Pederson (2006), children impacted by mental illness, in combination with low socio-economic status, are among the most vulnerable of all Canadians. Variables such as having an older child or mother, lower income and disruptive behaviors predicted an increase in the unmet needs of the family (Hodgetts, Zwaigenbaum & Nicholas, 2015).

There are a number of key underlying issues that demonstrate serious gaps in the research associated with child and youth neuro-developmental services. At this time there is no monitoring of the markers of mental health nationally, or provincially here in Newfoundland and Labrador (Canadian Institute of Health Research (CIHR), 2013). As such, the research into children's neuro-developmental services lags behind other research activities in health care (Public Health Agency, 2015). Over the last decade, several Canadian reports such as *Reaching for the Top* (Leitch, 2007), and *Out of the Shadows at Last: Transforming Mental Health, Mental*

Illness and Addiction Services in Canada (Kirby & Keon, 2006) have been released. They

consistently identify that the treatment of mental health and neuro-developmental conditions has

not only been scarce, but also poorly coordinated. It is also important to note, that not only youth

are being impacted by this poor coordination of care; but caregivers as well. The caregivers of

the youth with neuro-developmental conditions are weighted with a substantial amount of

financial and emotional burden (Schulze & Rössler, 2005). There is a significant gap

demonstrated in the lack of "intermediate steps" being made available to the youth. As the

system currently exists, there are two extremes: sitting at home without any support or guidance,

and going to the hospital in a crisis.

1.2. Larger Project — Atlantic Canada Children' s Effective Service Strategies in Mental

Health project (ACCESS-MH)

In Atlantic Canada, across the country, and throughout the world, children with mental

health and neuro-developmental disorders currently receive treatment through a host of service

providers. This spectrum ranges from health care professionals to educators and community

services. With an improvement in the diagnostic process of neuro-developmental conditions in

childhood there is a greater recognition of the profound burden these disorders impose on the

individuals themselves as well as their families. With this overwhelming realization and the fact

that research in mental health and neuro-developmental conditions currently lags behind other

research activities within health care, there is a demand for increased exploration and research.

This thesis is a part of a larger project; Children's Effective Service Strategies in Mental Health

(ACCESS—MH). The larger project has interdisciplinary teams in four Atlantic Canadian

provinces. These teams are investigating barriers and facilitators of care provision across

multiple mental health and neurodevelopmental disorders including Autism Spectrum Disorders

(ASD). For my project I looked specifically at children with ASD and the experiences of their

families and services providers. The results of the research from this larger project will hopefully generate and disseminate knowledge related to identification, evaluation, and implementation of innovative models of community-based services for individuals with mental health concerns and neuro-developmental disorders.

The ACCESS-MH team has collected data from participants involved in all aspects of mental health and neuro-developmental systems and have completed interviews with parents, youth, teachers, primary health care providers, and community members (Tilleczek, Bell, & Lezeu, 2014). The research team consists of five individuals with varying expertise including; health economics, clinical psychology, operations research, and research with youth (Tilleczek, Bell, & Lezeu, 2014). The anticipated goals of the research projects that make up the larger ACCESS-MH project were the development of an informative web portal, interactive workshops with primary health providers, social care practitioners, other service providers, policy makers, advocacy groups, researchers, and families (CIHR, 2013). It is anticipated that the findings of all the smaller projects would gather data on what works, as well as identifying ways of ensuring better coordinated and efficient care (CIHR, 2013).

1.3. Barriers and facilitators to accessing care for children and youth with autism spectrum disorders.
This thesis focused on one component from the larger ACCESS-MH project: Autism Spectrum Disorders (ASD). The main focus of the thesis was to identify the barriers and the facilitators to care for children with ASD and their families. Qualitative interviews were conducted with both parents and service providers to gain their perspectives on the care provided to children with ASD and their families.

Throughout this thesis the term "service providers" will be used to group health care and educational professionals involved in the care of children with ASD. Interviews were conducted with a pediatrician, a speech pathologist, and an occupational therapist (health care) and with

teachers, a guidance counsellor and Instructional Resource Teachers (IRTs) (education).
Interviews were also conducted with five parents of children with ASD. The data for this project
were collected through the semi- structured interviews with both groups (service providers and
parents). The data was then used to generate themes and future recommendations.

With this type of information, it is necessary to identify where the significant access
issues occur and identify which currently existing models of interventions within the region are
functioning efficiently. From this a better understanding of the impact that ASD has on families
can be developed, as well as the realities for the service providers involved in potential treatment
plans.

1.4. Context

A recent study showed a combined prevalence of 1 in 66 Canadian children were
diagnosed with ASD in 2015. Of the six participating provinces and one territory, Newfoundland
and Labrador's ASD prevalence rate was the highest. The overall prevalence of ASD in NL was
1 in every 57 (The Public Health Agency of Canada, 2018). Due to the increases in rates of ASD
on the island of Newfoundland, specifically on the Avalon Peninsula, there is a significant need
for a provincial ASD registry and for further research to occur in regards to this population
(Pelly, Vardy, Fernandez, Newhook and Chafe, 2015). In the last decade estimates from
individual epidemiological studies have indicated prevalence rates as high as 2.64% (Kim et al.,
2011). Although the increase is evident, the exact nature of this for the increase is unclear
(McPartland, Reichow & Volkmar, 2012).

The Diagnostic and Statistical Manual of Mental disorder, Fifth Edition (DSM-5) uses
the following criteria for assisting clinicians in the diagnosis of ASD:

1) Persistent deficits in social communication and social interaction as seen through

    difficulty with social-emotional reciprocity, nonverbal communicative behavior used in

social interaction and difficulty with developing, understanding and maintaining

relationships (American Psychiatric Association, 2013).

2)   Restricted, repetitive patterns of behavior. This can be seen in stereotyped, repetitive

movements, use of objects or speech. Can also be seen in their ability to be inflexible

when adhering to routines or patterns. Hyper or hypo-reactivity to sensory output can also

be noted here (American Psychiatric Association, 2013).

3)   Symptoms must be present during the early development period. These may not fully

manifest until triggered once limited capabilities are exceeded (American Psychiatric

Association, 2013).

4)   Symptoms cause clinically significant impairment in important areas of current

functioning such as social and occupational (American Psychiatric Association, 2013).

Furthermore, the DSM - 5 ranks the severity of ASD into three different levels. Level 1 is

labeled "requiring support", level 2 is "requiring substantial support" and level 3 is "requiring

very substantial support (DSM - 5, 2013).

1.4.1. Location for Research.

The data for this thesis was collected on the island portion of Newfoundland and Labrador

(NL). NL has an area of approximately 111, 390 square kilometers with a population density of

1.4 per square kilometer (Government of Newfoundland and Labrador, 2018). Due to the

vastness of the province individuals attempting to access health or social services may have to

travel anywhere from five minutes to 15 hours to avail of appropriate services. Access to care is

challenging based on where the individual resides within the province. NL served as a unique

location for the current study. Within NL as there is one main urban Centre which houses the

majority of the services for children and youth.

1.5. Definitions

Throughout this document, the main research question regularly referenced will be: What were the main barriers and facilitators encountered by families and services providers when accessing services for individuals with autism spectrum disorders in NL? Within this question, it is important to define the terms barriers, facilitators and service providers. In general, a barrier can be defined by the Oxford Dictionaries (n.d.) as a circumstance or obstacle that keeps people or things apart or prevents communication or progress. Goins, Williams, Carter, Spencer and Solovieva (2005) described several different types of barriers that were prevalent in their research that were also was similar to the ACCESS-MH project. Entry barriers referred to individual characteristics that may affect access to needed health care (Goins et al., 2005). Some entry barriers may include financial constraints, geographical distance, and psychosocial barriers such as embarrassment or fear of attaining help or care. Structural barriers were also noted and included disruption or hinder in the service delivery system and/or the environment itself (Goins et al., 2005). A facilitator, for the purpose of this document, can be defined as something or someone who aids an individual in accessing care or services (Gulliver, Griffiths & Christensen, 2010).

1.6. Purpose

The purpose of this study was to identify barriers and facilitators to the access of care for children and youth in NL diagnosed with ASD. More specifically, it was hoped both parents and services providers' perspectives and experiences could provide us with information about barriers and facilitators that they experienced on their journeys. As well, it was hoped that the experiences and perspectives of parents and service providers could help identify which models used in the provision of care for individuals with ASD within NL are functioning efficiently.

Although there is no cure for ASD, there are a number of treatment options available that help address the various deficits experienced by children with ASD. Such treatment options include behavioral therapy, caregiver education, and school-based interventions, all of which involve a number of different service providers. Previous research suggested that the provision of care for children with ASD was largely uncoordinated and resulted in poor outcomes, lengthy queues and inefficiencies within the system (CIHI, 2013). Previous research underscores the importance of conducting research from a broad, well-rounded sample of parents and service providers to gain an in-depth understanding of the experiences of both groups. With these realities in mind there were several other supporting research questions that helped guide my research.

1) What were the main barriers encountered by families and services providers when accessing services for ASD in NL? Were they encountered at individual, community and societal levels?

2) What were the main facilitators encountered by families and services providers when accessing services for ASD in NL? Were they encountered at individual, community and societal levels?

3) Did the families and service providers encounter similar and/or different barriers and facilitators when accessing services for ASD in NL? Why was this and what did it suggest about the current points of access for the systems of care for ASD in NL?

Over the last several years there was increased research studies exploring the gaps in services for children and youth with neuro-developmental disorders. Specifically, one study examined the experiences of patients and service providers when accessing services and examined reasons why barriers may exist (Lai & Weiss, 2017). To this researcher's knowledge there have been no published research studies outlining both the barriers and facilitators to access

to care for children with ASD in NL. Therefore, there is a gap in our knowledge about the barriers and facilitators of services to individuals with ASD and their families residing in NL. This study is unique in that it offered the perspectives of parents of individuals with ASD as well as the perspectives of individuals who provided health and educational services to individuals with ASD and their families.

The focus of this research was to document the experiences of parents and services providers and analyze their experiences and perspectives of how treatments were accessed (parents) or provided (services providers) across two government sectors: health and education.

1.7. Theoretical Approach

The Complex Cultural Nesting theory as described by Tilleczek links the history of becoming, to the time of currently being and then a further connection to society via a sense of belonging. This theory depicts the reality at which social influences occur in the lives of youth (Tilleczek, 2014).

The value in having a theoretical approach when conducting research is in its potential to frame or make sense of the issues, conduct analysis and shape your findings. As Creswell (2012) notes, the important thing to acknowledge about a theoretical approach is that you may think you are going to utilize one type of theory, but once the findings come about, this specific theoretical framework might not work in terms of making sense of the findings. If this is the case, there is no harm in developing your theoretical framework to help explain and justify your findings.

As it stands, the larger ACCESS-MH project approaches the research with a cultural nesting theoretical framework (Tilleczek, 2014). This type of framework sheds light on how both persons and the people closest to them are inseparable from historical and current social systems (Tilleczek, 2014). Tilleczek's complex cultural nesting theory was built upon Bronfenbrenner's framework of human development. Bronfenbrenner's theory encompasses five concentric

systems: chronosystem, exosystem, macrosystem, mesosystem and microsystem (1979). This theory acknowledges that sociological theory has much to contribute by way of understanding social relationships and social relations. The person is always a social person and it must be further examined what it means to understand complex social relations over time in shifting global/local contexts (Tilleczek, 2014). The theory focuses and highlights both society, narrative and biography as critical dimensions of young lives (Tilleczek, 2014).

The microsystem is described by Bronfenbrenner as a pattern of activities, roles and interpersonal relations that people experience in a given setting (Tilleczek, 2014). A youth is not involved in one, but several different microsystems at once, which develops the heart of day-to-day human interaction and social relationships.

In this study, the people themselves are at the core of the framework, expressing and describing his/ her own thoughts. This individual is referred to in this document as the participant. It will be clarified at the time of discussion whether this individual is a parent of a child or youth with ASD or if it is a service provider providing care or interacting with a youth with ASD. The next context involves a variety of family, coworkers, peers, teachers, counsellors, doctors etc., who are in constant contact with the parent. These individuals and context make up the microsystem which Bronfenbrenner describes as the context which involves interpersonal relationships with the individuals who are most immediately impacting the individual (Bronfenbrenner, 1979).

The mesosystem surrounding this includes the family interacting with the service providers, as well as the community and health care providers interacting amongst themselves (Bronfenbrenner, 1979). In this study, the mesosystem includes teacher and guidance counsellors within the schools as well as interactions between general physicians, pediatricians, therapists and Applied Behavior Analysis (ABA) workers. The exosystem is the next social level of which

the individual has no direct connection to. However, decisions made at this level such as policies or regulations may have an indirect effect on the individual (Bronfenbrenner, 1979). In the case of this study, the exosystem would be including certain provincial government departments such as Education and Early Childhood development. The chronosystem involves the timing of lives with a concentration on the timing and history in the specific context of the developing individual and their constantly changing environment (Bronfenbrenner, 1979). For the purpose of this document, the chronosystem refers to the time at which the parent's child wasn't necessarily diagnosed with ASD, but from when they noticed their child may need to access some sort of service or support for their mental health until the time of the interview. In the case of the service provider, the chronosystem would be a reflection of their time spent with working with different individuals with ASD, from the time they started practicing/ working, up until the point at which the interview occurred.

1.8. Thesis Outline

This thesis is divided into five chapters, references and appendices. The first chapter provided as an introduction, the context and the scope of the thesis. The second chapter is a comprehensive review of the literature to date. The review shows that although there is an increase in the research being carried out in regards to the requirement and need of Canadian mental health services, there is still very little qualitatively approached research exploring the access to care for children with ASD in the Atlantic Canadian provinces. The third chapter provides a detailed outline of the methods which have been employed for this study. Chapter four reports the findings generated from the patient journey interviews. The final chapter discusses the key findings and compares and contrasts the finding from data collected during this thesis to existing research literature. As well, the final chapter provides key recommendations as they relate to policy options with the hope of improving services and outcomes for families of

children with ASD. The appendices include the supporting data and documentation used in the

writing of this thesis.

Chapter 2: Literature Review

2.1. Scope of Literature Review

The focus of this chapter is to identify and explore the research that currently exists relating to the lived experiences of individuals and families ASD. More specifically, this review focuses on the literature addressing the barriers and facilitators experienced by the parents trying to access care for their child. Similarly, I reviewed the barriers and facilitators of the service providers providing care to the youth with ASD. PubMed and PsycINFO were used to generate a thorough search of the existing literature to identify any qualitative research on children with ASD. During the review of literature stage, there was a needs assessment by Autism Society of Newfoundland which helped present the most current up to date literature pertaining to this study (CIHI, 2013). Initially a search was done to gain a general background on the research conducted within the last ten years on general barriers and facilitators to accessing services for mental health. Further to this, a more refined search was made in order to focus in on the content for this particular study. There were several inclusion criterions used for this search. Specifically, the terms *ASD, youth, parent, services, providers, barriers,* and *facilitators* were used. Specific combinations of terms used in the search always involved the terms *autism* and then were specified by using *youth + barriers*. In a second search I used *autism + parents + services + barriers*. In additional searches I used similar keywords but replaced *barriers* with *facilitators*. Further boundaries were placed on the literature by narrowing the search history to produce outcomes from 2005 and later. When looking for articles pertaining to the service providers involved in the care of children with ASD, combinations such as *service providers + autism + youth + barriers* was used. In narrowing this search even further, a search of *occupational therapy + autism + youth + barriers* was used. A similar search was done for pediatricians,

developmental pediatricians, speech language pathologists, teachers, IRTs and guidance counsellors.

Articles predominantly from the last seven years were selected based on their specific relation to research on the parent/family experience of access to care for children with ASD. For the service providers portion articles addressing the experiences from occupational therapists, speech language pathologists, developmental pediatricians, family doctors and teacher were included s as these were key members of the team that work to create a treatment plan for children with ASD. Of the selected articles, the majority of studies took place in the United States, New Zealand or Australia. However, the above mentioned Needs Assessment took place in Newfoundland, Atlantic Canada. These articles will be reviewed below to help identify gaps, barriers, and facilitators that have been previously identified in this area of research.

The review will begin by defining and exploring the current prevalence of ASD. The chapter will then explore some of the current interventions and treatments available, as well as current support services. There will be a summary of the qualitative literature as it pertains to the two separate groups of parents/family and service providers. Finally, the gaps in the research will be acknowledged to emphasize the value and necessity for this particular study.

2.2. Autism Spectrum Disorder

2.2.1. What is ASD?

ASD is unique as it refers to a range of disorders that impacts and affects brain functioning. As a result, aspects such as an individual's communication and social interaction abilities are impacted (APA, 2013). In present day, ASD has been coined the umbrella diagnosis by the DSM-5 (APA, 2013). Similarly, this is also the term most commonly used by the public to refer to any of the disorders that fall within the spectrum (Audas et al., 2015).

Although there is often disagreement among professionals regarding the proper classification of ASD, it is generally understood as a neurodevelopmental disorder that affects primarily communicative and social skills (National Institute of Neurological Disorders and Stroke, 2014). Due to more recent advancements in the knowledge which surrounds ASD, parents are noticing signs at an earlier age, and professionals are able to start diagnosing children as early as two years of age. Unfortunately, on average, children in Newfoundland are still not being diagnosed until four years of age, leading to an adverse impact on the individual's therapeutic process (Audas et al., 2015).

2.2.2. Symptoms.

As stated above, ASD is a neurological disorder that affects brain functioning, specifically, communicative and social skills (National Institute of Neurological Disorders and Stroke, 2014). As such, ASD is outlined by three core symptoms of social issues, communication issues and repetitive behaviors (American Psychiatric Association, 2013).

Social symptoms can become evident at just a few months of age. Initially, between 8 and 10 months, a lack of expected social behaviors such as decreased interest in communication might indicate a social symptom of ASD. As the child continues to age and enters into other environments such as preschool, these symptoms may become more profound as the child may avoid group play and might not have the interest or ability to to engage in imitative behaviors (Audas et al., 2015).

This type of social difficulty might also result in difficulty communicating with friends and family. This communication struggle may be verbal or non-verbal, but can be seen through things such as a delay in their use of babble and gestures as a small child. Because not all children with ASD have identical symptoms, some children may have verbal skills, but might

struggle in the correct use of words, the construction of their sentences and their interpretation of verbal and body language (Audas et al., 2015).

Finally, the last core symptom of ASD is repetitive behaviors such as rocking, arranging objects or repeating words (American Psychiatric Association, 2013). These behaviors may manifest in excessive knowledge or interest in a certain subject, or might simply be demonstrated through an extreme obsession with a certain object.

2.3. Treatment Options for Children with ASD

2.3.1. Early Intervention.

Due to the increased knowledge surrounding ASD, professionals and the general public have become aware that early intervention is critical in order for a child to achieve their own individual potential. Studies have shown that with early intervention there have been significant improvements in language and social skills, IQ, development and an overall decrease in autistic symptoms (Audas et al., 2015). It has been noted that children who start treatment earlier will have more success with the treatment interventions. Rogers (1996) has suggested that preschool years is a critical period for a child accessing ASD interventions.

In most cases, children are not able to avail of government funded services until the child has a formal diagnosis of ASD (Barton, Dumont- Mathieu & Fein, 2012). Despite the understanding of the effectiveness and necessity of early intervention, many children are not identified until they are four. The age at which the child is diagnosed is one of the determining factors in the number of hours of ABA Therapy that the child is eligible for in some jurisdictions. If a child is diagnosed at age four, they are eligible for 15-25 hours of ABA therapy which, depending on the jurisdiction, may increase based on the severity of child's disorder and needs (Corsello, 2005). Unfortunately, there are often barriers to accessing this type of service for

many children. Part of the current research looked at whether or not children are in fact availing of their ABA service, at what age, for how many hours, and also the effectiveness of the therapy as well as the process to obtain access to this therapy.

Most of the research pertaining to the preschool aged group is focused around diagnosis, whether it be from a behavioral or a medical perspective. With this in mind, one of the primary focuses of research is the necessity to both assess and evaluate diagnostic models to ensure that they are an integral part of best practices (Audas et al., 2015). There are a number of services that identify the need to both create and adapt models that will identify children at an earlier age. One article in particular, Corsello et al., analyzes the effectiveness of standardized diagnostic tools for children under the age of 3. Similarly, another article analyzes current practices trying to develop effective diagnostic tools for children under the age of two who are suspected to have ASD (Zwaigenbaum et al, 2009). More recently the research of Hathorn et al., in 2014 did an evaluation of contemporary diagnostic tools in Scotland. In this study they determined that persons who received formal training in the diagnostic tools were more likely to use these diagnostic tools for their clients, and as such, would have a higher rate of success in diagnosing the child at an earlier age (Hathorn et al., 2014).

Although there is considerable research supporting the effectiveness and importance of early intervention, there is also recent research indicating not only the importance but the critical consideration that needs to be taken by how messages regarding early intervention are communicated to families of children with ASD (Edwards, Brebner, McCormack & MacDougall, 2016). Associated with these findings was also the idea of a critical need for allied health professionals to be communicating openly and clearly with the parents about the anticipated outcomes of early intervention programs (Edwards et al., 2016).

One of the main therapies for children with ASD is ABA therapy. In Newfoundland a child in preschool is allotted 20 hours per week of ABA therapy, which decreases to 15 hours upon entry into Kindergarten, and further to 10 hours in grades 1-3 (Audas et al., 2015). This ABA therapy is no longer offered or funded once the child reaches the end of grade 3. ABA therapy will be further described in the upcoming section. Unfortunately, the access to this therapy for these above listed hours is often much more difficult than just being granted the hours. This thesis will outline some of the barriers to this therapy such as therapist recruitment and retention as it has notably not been discussed in the literature reviewed.

2.3.2. Interventions.

This section outlines three types of interventions: behavioral interventions, developmental interventions and cognitive behavioral interventions. Although this is not an exhaustive list, these were selected based on their frequent appearance in the literature.

2.3.2.1. Behavioral interventions.

Beginning with the most common form of treatment for ASD, behavioral interventions focus on the social behaviors of the child. Linking back to one of the primary symptoms of a child with ASD, by addressing and providing therapy to help improve the child's social behavior, this intervention helps enable the child to understand what is expected of them socially, and how to use the social skills they are learning automatically in a real life social setting (Cleveland Clinic, 2014). The therapy used to address these social interactions must be continuously modified to suit the child as they advance and progress.

ABA therapy is a common example of a type of operant conditioning that must be modified and adjusted as the child advances through their given program. A trained therapist observes and documents how the child reacts or behaves to a certain task. A program is then

developed appropriate to each child's specific reaction and needs. The foundation of the program created is to address troubling behaviors presented by the child by focusing on three steps: an antecedent, a behavior and a consequence- which is evoked through a reward/punishment method (National Autistic Society, 2014b).

2.3.2.2. Developmental interventions.

Developmental interventions focus on targeting core deficits as opposed to specific behaviors. Deficits can occur in different areas such as logical thinking, affection and communication (National Autistic Society, 2014b). There are different initiatives that exist, of which several will be discussed in the following sections.

2.3.2.2.1 The Early Start Denver Model.

The Early Start Denver Model (ESDM) is a developmental, relationship-based intervention delivered to children ages 3 and under, which fuses approaches validated by both the science of ABA and child development (Rogers et al., 2012). More specifically, the ESDM is an evidence- based model which focuses on being applied early in life, is implemented throughout the child's day and is tailored to the individual child's strengths and needs, targets the core features of ASD while addressing functional and adaptive skills and finally it involves caregivers in the decision-making process for the child (Rogers & Dawson, 2010).

One of the defining principles of the ESDM is that cognition and language are grounded in bodily actions which are both social and playful in nature and occur through the interaction and participation of meaningful social exchanges during daily routines (Bruner, 1975). Another important principle came from the work of Dawson and colleagues (Dawson et al., 2005; Dawson & Bernier, 2007) which suggested a notion that ASD could be linked to a biological deficiency in experiencing social engagement resulting in consequences on brain development.

In addition to these two defining principles which are derived from developmental science, the EDSM is also comprised of the naturalistic application of principles from the ABA program (Rogers & Dawson, 2010)

2.3.2.2.2 The Relationship Development Intervention.

The Relationship Development Intervention (RDI) is a parent-led approach that aids in the flexibility of thought, emotional regulation and perspective taking (National Autistic Society, 2014c). RDI is a broad ranging program which can be useful for persons from age two and onward (Gustein & Sheely, 2002). The end goal of RDI is to view the person as a real person whose communication and humour have become more creative and less scripted, the individual will have better peer acceptance and will become a better collaborative and valued member of a team and also that the individual's actions will be governed more by other's needs and feelings versus the script that previously mediated their actions (Gustein & Sheely, 2002). RDI manuals can be implemented by parents, adolescents/adults, teachers, special educators and therapists, making the intervention quite accessible (Gustein & Sheely, 2002).

2.3.2.2.3 Developmental, Individual Differences, Relationship-Based Model.

The Developmental Individual Differences, Relationship-Based Model (DIR) was developed by Dr. Stanley Greenspan and Dr. Serena Weider as an interdisciplinary approach that includes the emotional development of the child as its primary focus (Greenspan, Wieder & Simons, 1998). The treatment takes into account the child's feelings, relationships with caregivers, and developmental level as well as the child's ability to process and respond to sensory information and from. The goal of the treatment is to help the child develop and achieve different emotional milestones that were missed earlier in development, but are critical to continued learning for the child (Greenspan, Wieder & Simons, 1998).

The Developmental part of the framework aims to help children develop the capacity to both attend and remain calm and regulated, engage and relate to other individuals, initiate and respond to different types of communication, engage in shared social problem-solving, use ideas to communicate needs, and finally, to attempt to build bridges between ideas in logical ways (Greenspan & Wieder, 2008).

The Individual Differences section of the framework focuses on the unique biologically-based ways a child takes in, regulates, responds to and comprehends sensations like sound and touch, and then sequences actions and ideas based on these individual differences (Greenspan & Wieder, 2008).

The Relationship-Based part of the model focuses on the relationships to individuals involved in the child's life and how therapy can be geared towards the child's individual differences so that growth and progress in mastering essential foundations of building and interacting with others can be obtained (Greenspan & Wieder, 2008).

Floortime is a vital component of this DIR Model, which focuses on improving developmental milestones that Greenspan felt was essential for children to master in order to attain healthy emotional and intellectual growth (Greenspan, Wieder & Simons, 1998). This specific technique is used to both follow the child's natural emotional interests and at the same time challenge the individual towards a greater mastery of emotional, social and intellectual capacity (Greenspan & Wieder, 2008). This technique may occur on while sitting on the floor, hence its name, however, it can include interactions in other places (Greenspan & Wieder, 2008).

2.3.2.3. Cognitive- behavioral interventions.

This intervention is a psychotherapeutic approach that addresses the relationship between behavior, thoughts and emotions. Cognitive- Behavioral Interventions hope to improve

behavioral actions by focusing primarily on emotional regulation and impulse control (American Psychiatric Association, 2013).

Scientific data support a goal-oriented intervention strategy in changing brain activity, and as such, improving overall function. This is not restricted to ASD, and is broadly used to treat a number of forms of mental illnesses (National Alliance on Mental Health, 2012).

2.3.3. ASD support services in Atlantic provinces.

Vohra, Madhavan, Sambamoorthi and St Peter (2014) present a clear demonstration of the significant barriers experienced by caregivers of children with ASD in terms of access to services as well as the reality of facing adverse family impact. In some of the Atlantic provinces, support is provided for those living with ASD and their families/ caregivers (Audas et al., 2015). For example, in Newfoundland, the Department of Health and Community Services offers an Intervention Services Program that features both a Direct Home Services Program and a Community Behavioral Services Program. These two complementary programs are designed to aid children from birth until their school years and beyond. These services change in both structure, delivery and availability as the child gets older, but services are offered up until their early teen years.

The Direct Home Services program therapy consists of ABA therapy and is offered by Child Management Specialists across the Regional Health Authorities. Included with this is a program developed specifically to target a smooth transition into school (Audas et al., 2015). Once children begin school, they become eligible for the other complimentary program, Community Behavioral Services Program. This program is offered by the Behavioral Management Specialists to individuals with an IQ of 70 or lower who demonstrate behavioral issues (Audas et al., 2015).The Department of Education and Early Childhood Development will

individually assess any child with a neurodevelopmental disorder, and the child's progress will be monitored through the course of their schooling education.

Money to hire a non-trained caregiver- can sometimes be made available to families who require support in the form of respite care. In cases where the child's condition places an extra financial burden on the family, a Special Child Welfare Allowance can sometimes be provided (Audas et al., 2015).

In other Atlantic provinces, such as Nova Scotia, there are similar initiatives. For example- Early Intensive Behavioral Intervention Programs are being offered throughout the Health Authorities. Professional development opportunities are being offered to resource teachers, learning centre teachers and school psychologists (Province of Nova Scotia, 2018). The implementation of a full-time provincial ASD consultant and providing schools with ASD specialists. Support is being provided through the Direct Family Support program for youth with severe acting out behaviours. Support is offered to Regional Respite Services programs in the different regions of the province so that families can help plan respite care for their children (Government of Nova Scotia, n.d.).

2.4. ASD and the impact it has on Parents and Families.

When it comes to children with ASD, an inevitable piece of the puzzle are the parents and caregivers of the individual. There are several facets to be considered when trying to understand the journey of a parent/ family when trying to obtain a diagnosis of ASD, accessing services for a child with ASD, and the impact having a child with ASD has on a family.

In one article the idea of hope, social relations and depressive symptoms in mothers of children with ASD was examined (Ekas, Pruitt & McKay, 2016). Being the parent of a child with ASD may negatively impact maternal health outcomes (Ekas et al., 2016). These

researchers used an online study to have mothers of children (ages 2-13) who had been diagnosed with ASD to fill out a questionnaire assessing hope, loneliness, perceived social support from friends and family, as well as, depressive symptoms. This study followed a quantitative methodology, evaluating the topics of hope, social relations and depression. Ekas et al., (2016) found that mothers who reported having hope also expressed having less loneliness and lower depressive symptoms. The study also showed that hope was associated with increased family support, which was directly associated with less loneliness and fewer depressive symptoms (Ekas et al., 2016).

In a study conducted in the United States researchers did an examination of the role of particular risk factors in quality of life satisfaction among families of children and adolescents with ASD (Gardiner & Iarocci, 2015). This study was one of the first of its kind to focus specifically on the impact on families of having a child who has ASD versus a combination of mental health or other neuro-developmental disorders. In this study communication skills were not significantly related to family quality of living in either of the correlation or regression analyses (Gardiner & Iarocci, 2015). Communication skills in fact are more impaired in those with comorbid intellectual impairment (Gardiner & Iarocci, 2015).

Gardiner & Iarocci (2015) found daily living skills not to be significantly predictive of the psychological distress or parenting stress once you included a behavioral problem in the model. Instead, this research showed that when certain adaptive functioning domains were included in the model, daily living skills were in fact presenting as an important predictor of family quality of life (Gardiner & Iarocci, 2015). In this study it was not the socialization deficits that exerted the greatest impact on family quality of life, but instead the difficulties with personal (e.g., eating, dressing, hygiene and toileting), domestic (safety awareness, tidying, and food

preparation) and community skills (rule following, telling time and understanding money) were the factors that were most important (Gardiner & Iarocci, 2015). Although socialization and communication skills are significantly impaired in children with ASD, these are the skills that require less tangible assistance from family members, and as such, have significantly less impact on how the family functions (Gardiner & Iarocci, 2015). Moreover, both communication and socialization skills, including how the child interacts and plays with others and copes in certain situations, is often times the focus of intervention programs, and as such, the families might feel less responsibility to perfect these obstacles (Gardiner & Iarocci, 2015). Conversely, the daily living skills of toileting, eating, dressing and hygiene are not as frequently targeted resulting in an increased expectation and stress on the parents to improve upon these specific skills (Gardiner & Iarocci, 2015).

2.4.1. Financial strain on a family with a child with ASD.

Unfortunately, the healthcare system has struggled to keep pace with the alarming rise in the prevalence of ASD (Zablotsky, Kalb, Freedman, Vasa & Stuart, 2014). With this comes the reality that parents/ families face obstacles in accessing and receiving adequate care, with many family experiencing financial hardship (Zablotsky et al., 2014). This hardship is a result of parents seeking treatment wherever they can, pursuing private medical interventions and therapies which are not being funded or covered, resulting in significant financial stress and even at times bankruptcy (Sharpe & Baker, 2007). In a quantitative study conducted in 2015, a comparison of mean factor scores indicated notable differences in doctor satisfaction, timeliness of care, and impact on the family's financial situation. Due to the fact that primary care physicians are often lacking the specialized training required to assess, diagnose and treat ASD, the individuals who have this skillset often have extensive wait times (Zablotsky et al., 2014). As such, parents might receive suboptimal treatments and referrals for their children by less

qualified professionals or individuals who do not appreciate the significant impact that raising a child with ASD can have on a family. Suboptimal treatments can often leave parents relying on their own resources to coordinate care which can be financially draining (Zablotsky et al., 2014).

Families with children who have special health care needs have been found to reduce their working hours, or completely stop their paid employment as a result of factors related to the child's care needs (Zablotsky et al., 2015). A study conducted by Okumura, Van Cleave, Gnanasekaran and Houtow (2009) found nearly 25% of their sample reported that individuals raising children with special health care needs have reported needing to cut back or quit work as a result of their child's health care needs. The Okumura et al., study further showed that the younger the child, in combination with more substantial functional limitations, is associated with having increased loss of work (Okumura et al., 2009). They determined this by conducting a national survey which included specific factors such as the child's age, family levels (family composition and education within the family) and finally the presence of a medical home (having a personal doctor or nurse, receiving family centered care, having no problem receiving a referral, and receiving effective care coordination when needed) (Okumura et al., 2009). Although this study did not outline specific conditions that were included under the umbrella of special needs, it did a sufficient job of outlining the struggles that a parent may face when trying to support a child with special needs and still be employed. Furthermore, it was determined that families with children having ASD specifically incurred increased health-related costs in comparison to families with children having other special health care needs (Zablotsky et al., 2015). The impact on the financial situation was assessed in the study by addressing four questions about the perceived impact of the child's health care needs on the family's financial situation (Zablotsky et al., 2015). A statistical analysis revealed that the parents of a child with

ASD described lower doctor satisfaction, lower scope of insurance coverage, increased delays and a greater financial impact (Zablotsky et al., 2015).

As outlined by Zablotsky et al, Okumura et al; Sharpe & Baker, there is research that examines the health care needs of children with ASD being a financial burden, and the impact it has on a parent's involvement in the labor force throughout the world, there is yet to be research conducted on the realities of this proposition here in Canada, and more specifically in Newfoundland.

2.4.2. Evaluating interventions.

The critical role of parent and family in both the diagnostic process as well as the intervention process is an emerging theme in a significant portion of the literature. There are parent-led interventions such as the Positive Parenting Adaptive to ASD model which has resulted in reports of greater feelings of self-efficacy when it comes to interacting with a child who has ASD (Poslawsky et al., 2015).

Another example that was evaluated for its effectiveness and proven to result in increased parental interaction and better progress from children is the ESDM (Rogers, Estes, Lord, Vismara, Winter, Fitzpatrick, Guo & Dawson, 2012). This model demonstrated increased improvement when implementing a greater number of intervention hours (Rogers et al., 2012). Rhea Paul describes the ESDM as a long standing beacon of empirical rigour and developmental sensitivity (2011). The book released by Rogers and Dawson outlining the details of their program for children and toddlers with ASD has been defined as a book which evidence based, accessible and a solid comprehensive overview of strategies to implement with young children with ASD (Paul, 2011). The University of Washington conducted a study that prospectively examined evidence for the lasting effects of an early intervention based program implemented

during the ages of 18-30 months of age (Estes, Munson, Rogers, Greeson, Winter & Dawson, 2015). The study provided evidence that gains made from early interventions are maintained 2 years later (Estes et al, 2015). In comparison to the "usual treatment" in the greater Seattle area, the children whom availed of the ESDM had notable improvement in the core ASD symptoms in the follow up assessment (Estes et al, 2015). This study's results also indicated the need for further research so that the results being founded with the ESDM at an early age can be extended to a more diverse range of families and communities to assess the effectiveness of early ASD interventions (Estes et al, 2015).

In 2007 Gutstein, Burgess and Montfort performed an evaluation on the effectiveness of the RDI program which supported it as a promising program for remediating critical experience-sharing difficulties of children who were on the spectrum. Data for this evaluation was obtained through observation (ADOS), objective findings (school placement) and parent perception, but limitations of the study such as a lack of a control/ comparison group, left an urgent need for future research in this area (Gutstein et al, 2007). To date there has been very little further research exploring the effectiveness of RDI, and although the intention is great, more investigation is required before it can be developed as a formal approach (National Autistic Society, 2014c).

In 2008 researchers looked at an early intervention program offered by Autism New Zealand, a group providing support, training, advocacy and resources on ASD. This program was put in place for the parents of children with ASD and aimed to provide parents the skills required to increase their child's communication and help manage challenging behavior using different behavioral techniques; both of these factors being indicated as significant difficulties for children with ASD (Birkin, Anderson, Seymour & Moore, 2008). The main focus of the study surrounded

the theme of access. They found that approximately 15% of eligible families accessed the program. Birkin et al., used two studies to draw conclusions that there were both family-influenced factors as well as program- influenced factors that affected the accessibility of this early intervention program for parents. Factors such as access to services, levels of caregiver stress, family functioning, previous experiences of education, family support, scheduling, cost, venue accessibility, transportation and childcare availability were all significant elements of access for these parents (Birkin et al., 2008). As can be deduced from this study, there are very clear factors that can prevent parents from accessing different types of services for their child with ASD.

Parents of children with ASD living in the US, Canada, Australia, New Zealand, England and Ireland were approached and were directly asked whether they liked or disliked the treatments their child was using. The majority (70%) expressed that they "disliked" the services they were accessing. Although there were no universally liked or disliked services, themes that emerged from the study was effectiveness of treatments, relationships with professionals, access to treatments, costs, medication concerns and stress (Mackintosh, Goin- Kochel & Myers, 2012).

In the Mackintosh et al article, the authors bring to light the reality of treatments that are accessed by families who have a child with ASD. Sometimes these services are school based, others may be community based. Other services require transportation to and from the session, some can be conducted within the home. Some treatments may be government funded, or free of charge and others may be quite expensive. Not all desired services are available within a reasonable distance for all families. All in all, these parents/caregivers/ families are faced with the daunting task of arranging all the different treatment options. Once the child starts therapy, they are often enrolled in numerous treatments and interventions all happening at the same time

(Mackintosh et al., 2012). All of these aspects play into the emotions, frustrations and experiences lived by these parents. After a primary and secondary analysis of the questionnaire responses, the authors brought to the forefront six key themes that kept emerging: effectiveness of treatment, relationships with professionals, access to desired treatments, costs (including money, effort and time), concerns about using medications, and stress (Mackintosh et al., 2012).

Although these researchers used a different methodology, the Mackintosh study was essentially looking to develop the themes anticipated to arise in the patient journey interviews being conducted in the ACCESS-MH project. Through an online questionnaire, the parents of children with ASD were asked approximately 100 multiple choice questions and several open-ended questions providing them the opportunity to express their preferences regarding the treatment they were accessing.

The Mackintosh article provided a very coherent depiction of the thoughts and feelings of the participants' responses. The breakdown of the findings six main themes helped generate a lot of open-mindedness and possible outlook moving into our own study. The themes that emerged were: effectiveness of treatments, relationships with professionals, access to treatments, costs, medication concerns and stress (Mackintosh et al., 2012).

Although parents/ caregivers play a significant role in the journey of a child who is in the process of being diagnosed or has already been diagnosed with ASD, they are not the only key players. As is stated by the Canadian Institute of Health Research (2013), children with mental health disorders and ASD receive treatment and support through a myriad of service providers including family physicians, occupational therapists, speech pathologists, and educators, to name a few. The following section will review the literature that exists surrounding the service

providers involved in the coordination and implementation of care for children and youth with ASD.

2.4.3. Perspectives of services providers.

Although there is no cure for ASD, there is quite an intricate team of health-care and educational professionals (family physicians, developmental pediatricians, speech language pathologists, occupational therapists) that work together to help manage its symptoms (National Institute of Neurological Disorders and Stroke, 2014).

The first point of contact for the parent seeking answers to mental health and/ or behavioral health changes is most often the community-based primary health care professional (Audas et al., 2015). Although there are currently several readily available screening tools in place in Atlantic Canada, there are still several barriers to screening for ASD in the primary care setting. Firstly, there is an increase on the demand of the providers' time when needing to screen for multiple disorders (Barton, Dumont- Mathieu & Fein, 2012). It has been recommended that designation of certain staff member to assist in the screening might help mitigate those difficulties, however, shortages of staff and frequent turnovers complicate the development of consistent screen procedures (Barton et al., 2012). Sometimes it is as simple as the primary care physician not having enough information regarding the availability of validated screening tools, or they feel it is not their role and that there are sufficient surveillance practices in place to detect ASD in other settings (Barton et al., 2012). Such validated tools may include but are not exclusive to the Modified Checklist for Autism in Toddlers, Early Screener for Autistic Traits or the Infant Toddler Checklist (Barton et al, 2012).

The importance of the family physician in the role of moving towards an ASD diagnosis in young children is outlined in yet another systematic review (Lee, Thomas & Lee, 2015). With

the very clear rise in ASD, it is commonly encountered by family physicians in a clinical setting. As mentioned previously, the management of ASD is complex and requires a committed multidisciplinary team effort with a focus on the continuity of care (Lee et al., 2015). Often times as a first point of contact, family physicians are key in a timely diagnosis, and play an important role in the management and follow up of these children (Lee et al., 2015). Lee et al., also acknowledges the role of a family physician providing recommendations for interventions for life skills (2015). In order to diagnose, family physicians must have experience in the area of both young children as well as ASD, they must use validated assessment tools, and must have the time needed to make a diagnosis and the follow up required (Barton et al., 2011). If the family physician does not fall under this above listed criteria, it is still critical for them to be able to identify developmental delays of any sort, know where to refer, and then participate in the follow up care of the child.

Occupational therapists play an important role within the healthcare team when it comes to offering services to children with ASD. Occupational therapists play a role in the medical diagnostic and early intervention teams who are trained to enable activities of daily living that are crucial for surviving but are often difficult for children with ASD, such as, self care, sleeping, and feeding (Hebert, Kehayia, Prelock, Wood-Dauphinee & Snider, 2014). Occupational therapists can also support children with ASD by collaborating with the parents and other team members to help minimize maladaptive or unwanted behaviors (Hebert et al., 2014). From the literature it is known that there is no reliable biological marker for ASD (Volkmar et al., 2004). Therefore, this means that ASD screeners must instead focus on specific observable behaviors to identify children at risk.

Research has shown that persons who have ASD show signs of atypical development in language, social communication and cognitive development (Barton et al., 2012). Based on the signs and symptoms someone with ASD may present, it can be seen that an interdisciplinary professional team is both recommended and required to address the different needs of the child. Hebert et al., (2014) determined that up until 2014 there was no pre-existing research on the inter-professional collaboration (IPC) between speech language pathologists and occupational therapists. To address this gap they held semi-structured focus group with 21 participants, both speech language pathologists and occupational therapists, keeping the focus- groups discipline specific, to try to determine any emergent themes. Both disciplines acknowledged the value of IPC, and were able to address barriers and facilitators to reaching optimal collaboration (Hebert et al., 2014). It was agreed between the two groups that the key ingredients to IPC were: shared objectives, shared strategies, joint treatments and on-going collaboration (Hebert et al., 2014).

Health professionals do not stand alone in these efforts. One study conducted a systematic review which revealed that twenty-eight empirical articles indicated parents perceiving teachers to play a vital role in the inclusion of their children with ASD (Falkmer, Anderson, Joosten & Falkmer, 2015). The school was considered key in creating an environment that enabled inclusion through methods of positive peer relations, support from staff and prevention of bullying (Falkmer et al., 2015). Parents and school professionals are critical stakeholders in the creation, implementation and monitoring of a process called the Individualized Education Plan (IEP) for children with ASD (Tucker & Schwartz, 2013). This IEP is used to establish measurable annual goals for the child with special needs, as well as, to state the special education and any related services or supplementary aids that the school will be providing for the child whom the IEP is being created.

For children with ASD, the extent to which teachers and parents are able to successfully communicate and problem solve when presented with a student concern may be as important as any direct intervention (Azad, Kim, Marcus, Sheridan & Mandell, 2016). Communication has been widely recognized both as a facilitator of collaboration and a source of conflict when it falls through (Azad et al., 2016). White (2014) took data from the Department of Education in a mid-western US state to analyze and assess the different types of complaints associated with ASD that were filed with the department. Once 97 documents were selected, the author underwent an inductive content analysis methodology (White, 2014). One of the main themes that emerged was the idea of parent participation (White, 2014). In approximately one third of the sample, complaints were associated with the lack of input from parents and lack of participation in many facets of the special education process (White, 2014). This lack of participation lead to a breakdown in home-school communication in regards to the detail of the individualized education plan, committee meetings and procedural safeguards (White, 2014).

Another source of stress within the education realm is the parents reporting low levels of perceived disability-specific staff knowledge regarding ASD (Tucker & Schwartz, 2013). In the above research conducted by White (2014), a common complaint was concern about the training and qualifications of teachers, paraprofessionals and the school staff in addressing and serving students with ASD. There are often general in-services and training offered within the schools, but these sessions are often not documented or monitored (White, 2014). It is also important to consider that persons that may interact with these children outside of a classroom setting: bus drivers, hall monitors, cafeteria service persons have not received any sort of training to manage or interact with children with ASD (White, 2014).

2.5. Gaps in the Research

There are several key themes that have emerged through the review of the literature as seen above. In regard to the perspective of the parents/ primary caregivers, there has been research in other parts of the world discussing the emotional and social impact that a diagnosis of ASD has on a family as well as the financial strain associated with caring for a child with ASD. Another common topic of research is the evaluation of different interventions being used in different parts of the world. When reviewing the literature on service providers the main themes discussed were the struggles in diagnosing ASD, specifically for the primary health care providers. There is also some preliminary research existing around the idea of collaboration of care between providers, specifically between the occupational therapist and speech language pathologist involved in the intervention implementation for the child with ASD. Finally, the review highlights the multifaceted team that supports a child with ASD, and as such touches on some research discussing the role of teachers with a child with ASD as well as their level of knowledge and expertise in the area.

In addition to what has been reviewed, there is an obvious need for more research on how having a child with ASD effects caregivers, the impact on the caregivers' labour force participation, the stress and mental health struggles, impact on the family, evaluation of the wait times for both diagnosis and services, the coordination of care between health professionals (involving the developmental pediatrician, occupational therapist, speech language pathologist, psychologist, family physician and how this translates into the schools), and the supports offered within the schools and community supports that are available for these children, here, in Newfoundland. There is also currently a lack of qualitative research addressing the experiences and journeys of these caregivers.

There are several methodological limitations that have come to light in the studies that have been reviewed. One of the limitations of the above Ekas et al., (2016) study that was acknowledged was the fact that the study relied on self-report of all measures at a single time point. Another limitation as discussed in the Ekas et al., (2016) article was the characteristics of the study sample. The persons interviewed identified as highly educated, middle class, married and Caucasian. The reality of this type of sample is that it only addresses one very specific type of cohort, leaving a significant gap when it comes to other demographics.

2.6. Chapter Summary

At first glance there appears to be quite a depth of research pertaining to ASD. However, when typing in search terms such as youth, child, barriers and facilitators in relation to ASD, gaps in the literature became more apparent. The largest gap presenting itself in the form of the lack of research relating to child and youth, as well as their caregivers of accessing services in general, but especially in Atlantic Canada. This study will use themes arising from the patient journey interviews to shed light and offer some insight to the gaps that have been outlined above.

The next chapter explores both the methods and the methodology used in this study. There is a review of how the study was designed and conducted, helping to demonstrate and ensure rigor, credibility and trustworthiness.

Chapter 3: Methods

3.1. The Research Question

The research questions explored in this thesis was:

Were there barriers/facilitators encountered by families and service providers when accessing services for ASD in Newfoundland? What are the main barriers/ facilitators encountered by families and services providers when accessing services for ASD in Newfoundland? Are these barriers/facilitators encountered at individual, community and societal levels?

There were several supporting questions that focused to this question as follows:

1. Do families and service providers encounter similar and/or different barriers and facilitators when accessing services for ASD in Newfoundland?

2. If so, what does this suggest about the current points of access for the systems of care for ASD in Newfoundland?

3.2. Ontology

This thesis explored and described subject experiences of participants. The experiences were examined in this across both parent and service provider groups as they expressed their views on the individual journeys of youth and families who are trying to access ASD services as described their unique experience. For example, the diagnostic for some parents was described as very lengthy and dragged at process, while some parents described the process as being "prompt" and "efficient". These differences in perspective illustrate the varying perspectives on the realities of services for children with ASD in Newfoundland. As a result of the diversity in expressions of experience, the findings must be interpreted in nuanced ways to help begin to understand the multiple realities of accessing care and services for ASD in Newfoundland.

3.3. Epistemology

Social constructivism guided the investigation and analysis. The interpretive epistemology activated the possibility of interpreting participant's experiences that have been co-constructed (Guba, 1981). Individuals draw upon experiences that have meaning to them in order to create their reality. These experiences were communicated through interviews and I co-interpreted them by outlining recurrent themes and reflecting on how the current literature supports or challenges these themes. Through the process of meeting with both service providers and parents who are trying to provide or access services within the province, we discussed and negotiated the issues and how these issues may be interpreted by a researcher. Based on the recurrence of similar and different themes within and across both groups I was able to grasp a better understanding of the experiences and provide a co-construction of meaning suggested recommendations. These recommendations are outlined in Chapter 5 and were derived directly from the participant interviews and also layered with interpretation and context provided by current literature and my own position or standpoint in the researcher as outlined below.

3.4. Researcher's Standpoint

In 2013 I completed a course offered by Eastern Health to qualify me to be employed as an ABA Home Therapist. However, I never had the opportunity to work within the program, or witness any of the ABA therapy occurring with a child. To date I have never been personally affected by a person who has ASD. As a researcher, I will state that the research and findings of this study come from a place of genuine interest and care for youth and families who have tried to access support for ASD.

An understanding of researcher reflexivity and standpoint is key to understanding how the findings of a study are collected and interpreted (Creswell, 2012). In order to engage the participants in a reflexive manner, researchers must continually question what we know, how we

know this, and the relationship we have with this knowledge so that different forms of data can be collected to adequately answer our questions (Lapan, Quartaroli & Riemer, 2011). Reflexivity also required the researcher to call into question the cultural, historical and political nature of what influences both the expectations and the assumptions of the research (Lapan, Quartaroli & Riemer, 2011). For example, I did this by assessing who it was I was speaking with and what their role in the journey was (parents versus service providers, public versus private sectors of services). In addition, reflexivity was practiced by assessing and reassessing my role in the system. There was concern that as a result of my training under the ABA program that I would demonstrate some bias or insider knowledge to the service provider voice. However, with countless efforts of inward reflection, because I never had the opportunity to work with a family, or be a part of the process of implementation of ABA therapy, I felt as though I truly had no additional insight to the service provider aspect. Perhaps the knowledge of the intention of how the program was to be implemented could be a bias, but the process of implementation as a service provider and the response of a child and a family to the ABA therapy was something that I had never been privy to until being guided by my participants in this study.

3.5. Data Collection

I was personally responsible for the recruitment, data collection, and analysis of the 11 interviews. I followed exactly the process designed by the CIHR Access Mental Health Project (ACCESS-MH) team for the ethical collection of the interview data. This included the ethics, consent, journey interview tools, journey mapping board, interview prompts, field note guides, and protocol for interviewing (See Tilleczek, Bell, Munro and Gallant, 2017 for detailed methodological description). A workshop was held in May 2015 in the lab of Co-PI, Dr. Kate Tilleczek's Young Lives Research Laboratory to train the team and graduate researchers in all components of the interview process that was designed there. All interviews were transcribed at

the Young Lives Research Laboratory by hired transcribers. There were two different forms of data collection for this current project: a demographic face sheet (see Appendix A) and an individual journey mapping interview. The demographic face sheet was developed for the ACCESS-MH study. For the purpose of this particular thesis, only portions of the journey mapping interviews were analyzed. For the purpose of narrowing this thesis, the face sheets were not used in the analysis process, but the data remains a part of the larger ACCESS-MH project.

The use of field notes was incorporated in order to summarize mental notes which were collected before, during and after the interaction with the participant. These notes were later used to help jog the researcher's memory of moments of observation or interaction (Bailey, 1996). At times the field notes were used as a supplementary source of information. However, these field notes were mostly used for gaining focus and perspective before entering or after coming out of the interview. For several of the interviews the participants were emotional, upset and frustrated. These field notes provided the opportunity to express how the participant's emotions impacted me as an interviewer, and allowed me to decompress and express how the interview impacted me. The field notes provided me the opportunity to briefly reflect on what was discussed, let go any thoughts and opinions and then move forward without emotion or bias. These field notes were not used in the process of analysis as they didn't appear to have any significance on the specific themes that were extracted from the interview.

When the participant arrived, an overview of the procedure was explained and a review of the consent form was conducted. On their own time, they were provided the opportunity to read through the consent again, and once informed consent was provided both verbally and written, they were provided the opportunity to work through the demographic face sheet. It was described to them that this face sheet was additional information, and they were welcome to fill out as little or as much as they felt comfortable sharing. From this demographic form,

information regarding such things as their cultural and socioeconomic status could be objectively identified.

After all of the written paperwork was completed, the interviews were conducted and usually lasted anywhere between 30 and 120 minutes. These interviews were audio recorded. The interviews were guided through a series of pre-created prompts. The prompts were organized through four different "phases": early signs; entering/ not entering the system; exits and return through the system; recommendations and directions. These prompts were not routinely followed, and were more so used as a tool for focusing/ refocusing the participant on the focus of the interview. As every participant is a unique individual, each interview took on its own form and as such was guided in different ways. The underlying focus of all interviews was to address any barrier and/or facilitators that they had encountered in their journey through the system, the resources in place to help deal with these issues and whether or not they were accessible/ helpful or not. All supporting documents, such as consent forms, used during the actual interview process can be found in the Appendices (see Appendix B,C,D)

3.6. Sampling Strategy

The sampling strategy was purposive and designed by Dr. Kate Tilleczek and the ACCESS-MH team. The ACCESS-MH team outlined an Atlantic Sample Frame which included a number of parents and service providers that must be interviewed from each province, within a certain age group. Due to the fact that the goal of this research was not to generalize the findings to a population, but instead to obtain insight into a specific individual an experience, then the appropriate method of sampling is purposeful selection so that the individuals selected can maximize understanding of the phenomenon (Onwuegbuzie & Leech, 2007). The following three main considerations were fulfilled in implementing a purposeful sampling strategy: who is being selected for the study, what type of sampling will occur and what will the sample size be

(Creswell, 2012). In addition, the size of the Atlantic Canadian sample relied on saturation, defined as the point at which no new information or themes are being observed in the data (Guest, Bunce & Johnson, 2006). This was also the case in my sub-sample of Newfoundland and Labrador parents and service providers. All participants were recruited from the island portion of the province due to the fact that funding was not sufficient to travel to Labrador to conduct research.

I selected two categories of participants from the larger ACCESS-MH sample of youth, parents and service providers and chose only those dealing with ASD from one province (Newfoundland). The criteria adhered to when undergoing selection of the sample was: each parent/guardian participant had legal authority to care for their youth with such a current diagnosis or self-identified as ASD. The criteria for the healthcare service providers was: health care professionals who provided preventive, curative, promotional or rehabilitative health care services to individuals, families, or persons in an administrative role, such as manager, with respect to these services. The community-based service providers were selected from the criteria that they were professionals who worked in a community organization or school and who provided services to individuals, families, or communities or persons in an administrative role with respect to services associated with children with ASD. All participants were required to be fluent in English, be over the age of 19 and were both willing and able to participate in an interview. There was no additional exclusion criteria other than the above stated aspects. My sub-sample of 12 participants were selected because they met all the criteria for one of the particular groups, therefore forming a homogenous sampling (Suri, 2011).

3.7. Recruitment Strategy

I was responsible for the recruitment of the parents and service providers in this thesis. Recruitment was organized and supported by the project's principal investigators who were

coordinating the larger ACCESS-MH project as a whole. The interviews gathered and used in this thesis are a small portion of interviews that form a much larger set of Atlantic Canada data that has been gathered in the CIHR-funded ACCESS-MH project (http://access-mentalhealth.ca/). Once participants expressed interest, the project manager for the ACCESS-MH project connected with the participant so that a time and location for the interview could be set up. At this point, the following documents were passed on to the participant: a more in-depth explanation of the project, a copy of the consent form, as well as, a copy of the potential guiding questions for the interview. The interview process that was carried out for sampling was congruent both with the purposeful convenience sampling style, and the expected sampling style of a methodology that was carried out in the ACCESS-MH project (Tilleczek, Bell, Munro & Gallant, 2017).

Originally there was a connection made with a developmental pediatrician, the manager of senior therapists in the ABA Analysis therapy program, and a primary school teacher. The goal in making these three different connections was to tap into the healthcare, education and community sectors of youth ASD. It was from these three contacts that access was gained to other key participants and stakeholders who were interested in supporting and promoting the research that was being conducted. After the initial recruitment blitz occurred, re-evaluations of any gaps in recruitment were made. Through snowball processes, purposeful convenience sampling continued to recruit other doctors, managers, teachers and parents. When snowball sampling is employed in the study of social systems and networks, this particular method can deliver a unique type of knowledge (Noy, 2008). This is supportive as to why snowball sampling was valuable in the recruitment of participants for this particular study.

3.8. Sub-Sample for Thesis

Eleven interviews were conducted with twelve participants. Two of the participants chose to be interviewed together. The seven service providers included a pediatrician, occupational therapist, child management specialist, speech language pathologist, two instructional resource teachers and an early childhood educator from varying locations across the island. Recruitment in the service provider group ceased after this point as there was a good representation of service providers and data saturation was met such that similar themes of barriers and facilitators were reoccurring. A similar process was carried out for the parent participants. There was a total of five parents interviewed. Three of these parents had a child who had been diagnosed with ASD within six months of the interview, and two parents had a child who had been diagnosed with ASD as long as six years prior to the interview. Uniquely, one of these parents had two children who were diagnosed with ASD. There was quite a wide range of experiences on the frame of their journeys and also due to their geographic locations and their financial resources. After five interviews various themes were developed from the data and a clear understanding of the data in the light of the research questions emerged. As such, the saturation of data was obtained (Creswell, 2012). Furthermore, Sandelowski argues that a sample size must be small enough that the information obtained can be effectively managed, but large enough to provide a well understood experience (Sandelowski, 1995). As the researcher, I used this premise to guide my sampling, as I relied on my researcher experience and by assessing the data as it unfolds, I was able to analyze in relation to the goal of the research and determine if the number of participants interviewed was sufficient.

3.9. Data Analysis

For the 11 interviews used for this thesis, the initial data analysis began with reading of the transcribed interviews several times. With each review of the transcription, initial notes were

made along with reference to any corresponding field notes. From these notes, the next step was formulating themes in the process identified below. The goal of the data analysis was to generate a thematic analysis for each parents and service provider and then to examine these themes across the whole parent group, service provider group and finally between groups. The main barriers and facilitators that emerged from these themes are included in the results section and summary. These main barriers and facilitators laid the groundwork for dominant themes that are both articulated and described in the Results section.

3.9.1. Thematic Analysis.

Thematic analysis was selected as it offers an accessible and theoretically flexible approach to analyzing qualitative data (Braun & Clarke, 2006). Thematic analysis acts as an accessible and systematic approach for generating codes and themes from the qualitative data collected from the interviews (Braun & Clarke, 2006). The first step to the thematic analysis for each of the participants was a general read of the transcription to re-familiarize myself with the interview. This process also helped view the interview as a complete journey versus a step- by-step question and answer process. Upon the second reading of the transcript, highlighting occurred, indicating important aspects of the informant's story, whether it be specific experiences, thoughts, feelings or opinions about the healthcare or education system expressed as barrier and/or facilitators and/or any recommendations they made to improve the system (access or care). Braun and Clarke (2006) refer to this as codes and are used as the building blocks to support emerging themes. As previously mentioned (Chapter 1) barriers were defined in the literature as circumstance or obstacles that prevent communication or progress in access to care. In determining what to highlight in the data, I reviewed the literature about existing barriers and compared it to what the participants shared. I highlighted quotations or areas of the interview that participants seemed to become emotional about and/or or tended to expand upon organically. For

example, family support was discussed by every parent as being a key facilitator to both accessing care, receiving proper care and making gains within treatment.

Following the highlighting process, a final overall read of the transcript led to the writing of summary notes for the transcripts. Summaries included direct quotes from the participant and/or a sentence or two communicating the experience the participant described. These summaries were than taken and formulated into a participant specific word document titled *Coding Document* (See Appendix K). Once the interview was thoroughly reviewed, highlighted and the summaries extracted and organized in individual documents for each participant, the document was printed. It was from this printed final document that the process of the thematic analysis was completed.

The completion of the thematic analysis began with the summaries which were organized as the emergent themes of the data and were used to provide a framework for organizing and reporting on the observations made by the researcher (Braun & Clarke, 2006). A theme was described by one or two words such as: diagnostic process or community services. A different colour was chosen for each different theme. Once a colour was applied, the participant documents were reviewed and highlighted to indicate which themes were present across the different interviews (could be easily viewed once the colour coding took place). It is important to note that at this stage it became evident that the two separate groups (service providers and parents) were to be treated separately as the themes generated were different.

All themes extracted were done so based on the relevance to the guiding research questions. Excluded were the themes that did not add clarity to the research question. Themes only briefly mentioned by few participants (for example, longing for normalcy) were removed at this point in analysis.

The recurring themes are presented in the Results Chapter. However, as a pre-organizing heuristic for the reader, the recurring themes for the parents were: the diagnostic process, access to healthcare and community services, ABA and the education system. For service providers, the recurring themes were: diagnostic processes, access to healthcare and community services, ABA and the education system. Some of these themes were expected from the research outlined in the interview guide provided by the ACCESS- MH project (Tilleczek et al., 2014). There were several additional themes that emerged. In a situation whereby a summary could fit under more than one theme, it was colored by both colors and considered in the analysis under both sections. Through the use of both newly created documents, it was simple to generate a clear and comprehensive picture of how different pieces of the individual's journey fit together as they encountered, negotiated or ran into each barrier or facilitator. A composite list was created of themes that were found in multiple participant documents (thematic coding). Each noted theme was linked to a specific reference made by the participant and/or exemplified by a direct quote.

3.10. Methodological Congruence

According to Burns (1989), there are four areas required to ensure methodological congruence in qualitative research. These are: document, procedural and ethical rigor and auditability. There are a number of strategies employed to address methodological congruence in this thesis which are explained in the following subsections.

In addition, this study followed several guidelines for rigour. Firstly, the participants fit within the inclusion criteria such that they were a parent of a child/youth who has been or is in the process of being diagnosed with ASD or they are a community or medical service provider who interacts or provides service with a child who has been or is in the process of being diagnosed with ASD. Another guideline to certify rigour is ensuring proper development of

chronology, describing clearly what the participants said and how they said it as per proper thematic analysis (Creswell, 2012).

3.10.1. Document rigor.

Burns defines document rigor as the presentation of all study elements in a clear and organized manner (1989). This thesis outlines the study purpose, research question, significance, and literature review in two clearly outlined chapters: Introduction and Literature Review. The methodology and the methodological tools are clearly stated and described in the Methodology chapter. Included in this methodology section are the ethical considerations in which the ACCESS-MH project was implemented so that this study could be approved by the 5 different universities Research Ethics Boards as per the university of each of the 5 different PIs. Elements such as analysis, findings and recommendations are presented in the subsequent chapters. The Appendix section houses samples of any forms, processes, or documents that was used throughout the study process. Throughout the process of the study there was significant training, monitoring and supervising provided by my supervisory committee, as well as member of the ACCESS-MH team.

3.10.2. Procedural rigor.

Following Burns (1989), the way to help ensure procedural rigor is to execute the research process as intended. This can be carried out by the researcher recording the steps they have taken so that it can be compared to the initial intent, thus confirming the accuracy. The project uses the tool of field notes throughout the data collection process so that the process of the interviews could be documented and reviewed to identify if any circumstantial specialties or deviations occurred from the planned procedure. As mentioned above, there was training put in place before any researchers went into the field. Through these training sessions there were very detailed workshops on qualitative research, patient journey mapping and the process and

procedure of the qualitative interviews I would be conducting. These workshops provided extreme focus and attention so that I could feel confident and well equipped in my ability to conduct this qualitative interview combined with the patient journey mapping processes. I was the sole collector of data for my portion of the project. This helps ensure that consistency was kept, and procedure was followed.

The interviews used a semi-structured format. However, each participant may have their own interpretation of the questions, their own direction of their story and the interviewer went with the flow of each participant, allowing them to travel through their journey as naturally as possible. In each interview I asked general questions that provided each participant the opportunity to touch on each of the major themes highlighted in our semi-structured interview protocol. As a result of the interviews being so diverse, the information uncovered has an increased sense of trustworthiness in the depiction and accuracy of participant voices. The participants were chosen based on a specific criterion for this study. Their experiences can be viewed as sufficiently credible as each participant either had a child with ASD or were directly involved in a service being offered to a child with ASD or their families. Burns speaks to the importance of appropriately entering into the community you are exploring (1989). After receiving training to become an ABA home therapist, becoming a member of the Research on Autism Exchange Group and being a developing member of different programs for children with ASD, I was accepted by my participants as a sincere and involved member of their community. As such, it helped them develop a sense of true appreciation for this study.

3.10.3. Ethical rigor.

Ethical rigor was carried out through the entirety of this research study. All five universities participating in this ACCESS-MH project received full Research Ethics Board approval. As a student doing a project under the ACCESS_MH study, this specific project also

received ethics approval from the Research Ethics Board. All participants involved in the study were well informed regarding the protocols, procedures and goals of the end results. From the first point of contact there was a sincere emphasis put on the participants' rights to participate or withdraw at any point throughout the study process. These rights were both verbally communicated as well as presented in a written document.

3.10.3.1. Harm and/or potential risks to participants.

Due to the content of this study, there were psychological risks involved for some of the participants. For the parents reflecting on a potentially very difficult experience and journey it was possible that they have felt anxious, embarrassed and upset and as such, may have wanted to stop the interview, or simply avoid answering a particular prompt or question. For the participants that were service providers, they described not having the same kind of psychological/emotional risk, as most of them were speaking about general experiences and broader circumstances. The service provider participants may have felt frustration with their experiences, but it was not likely for them to feel the same type of vulnerability or personal involvement as the parents. In either case, all participants were clearly notified that they could at any point cease the interview without any reason or questions asked.

Throughout the duration of my study, no participants asked to be excused from the study, or requested for the interview to end. It was quite evident that throughout some of the interviews, some participants became quite emotional. However, all participants embraced their emotions and proceeded with the interview.

3.10.3.2. Informed consent.

Informed consent was initially provided through a written email acknowledgement. Further to this, once a meeting time was established and booked, informed consent was again provided verbally, and through a written and signed consent form. Consent was necessary for all

aspects of our study: conducting the interview, audio recording the interview, and consent to utilize the photographs taken of the patient journey mapping. This consent was also required in order for the information collected to not only be used by the larger ACCESS-MH project, but also for this Master's thesis. All participants that were interviewed for this specific part of the study were able to provide their own individual informed consent, no assent forms were necessary. As mentioned in the above section, all participants were clearly explained their right to withdraw at any time or to not answer any questions they were not comfortable with. This information was not only covered in their signed consent form, but also was reiterated verbally.

3.10.3.3. Anonymity and confidentiality.

At the beginning of the interview, as well as at the conclusion of the interview, the time was taken to explain to the individuals that all identifying information would be "washed out" of the interview during the transcription process. Meaning, anything that might identify them for who they are, where they're from, the names of the services they accessed or provided would be removed and replaced with a pseudo name. The idea of participant confidentiality was ensured through all different stages of the study process from recruitment, to data collection and analysis right through to the dissemination of the results. All of the information collected from the participants are being stored in a secure, locked location where it is filed by an alphanumeric code that was generated by the research team. This research team are the only individuals who have access to the identifying information of the participant.

Due to the location of the study taking place in a smaller population size, extensive measures have been taken in order to help protect the participants' anonymity. All information pertaining to the parents or service providers place of work were removed and replaced with a pseudonym to protect the anonymity of the participants. All individuals have been provided a

pseudonym to be referred as in the analysis process. The generating of these pseudonyms were done at random, and as such, may not be a true representation of the individuals' true gender.

3.10.3.4. Storage of data.

All recorded information is kept and stored as stated in the ethical protocol designed at Tilleczek's Young Lives Research Laboratory. This includes any images taken of the patient journey mapping boards which are encrypted and labelled with the above mentioned alphanumeric combination. These interviews have been saved on an external hard drive which is password protected. All consent forms, demographic face sheets, and the physical hard drive containing the interview data are being housed in a secure storage location which is the Young Lives Research Lab at the University of Prince Edward Island. This information will remain safely stored for a minimum of 15 years after the completion of the project.

3.11 Trustworthiness of Data Collection and Analysis

Trustworthiness is the key component used to evaluate the merit of qualitative inquiry (Morse, Barret, Mayan, Olson & Spiers, 2002). Instead of using reliability and validity, Guba substituted in the "parallel concept of trustworthiness" (Guba, 1981). This concept contained four key aspects: credibility, transferability, dependability and confirmability (Guba, 1981).

3.11.1. Credibility.

A qualitative study can be deemed "credible" when it presents accurate interpretations or descriptions of a human experience so that a person experiencing a similar experience would immediately recognize the descriptions being given (Sandelowski, 1986). In this study, there were several things done to help create credibility within the study. Firstly, all procedures, protocols and interview questions were taken from the larger CIHR-funded ACCESS-MH project of which was generated based in the most current and appropriate literature for child/youth mental health research.

As deemed by Guba and Lincoln (1985), credibility also requires adequate submersion into the research setting so that recurrent patterns can be identified and verified, while the informants become accustomed to the researcher (Sandelowski, 1986). I attempted to reach this idea of "prolonged engagement" by involving myself in research groups related to ASD. Over the last five years, I tried to develop a knowledge base so that I could understand the references being used to help provide services to persons with ASD within my province. I also developed a gymnastics program, and worked closely with children with ASD and their families to involve them in this program. Each of these different points of submersion and contact helped to deepen my relationship both with children and youth with ASD, but also with the community as a whole, making my interactions and interviews with members of the community more comfortable and familiar.

In addition, a final point of credibility can be referenced in terms of the researchers themselves. For this study, the primary author is a graduate level student situated at an Atlantic Canadian University. This graduate student has been provided close guidance by two co-supervisors as well as one committee member. The committee consists of credentialed academics such as professors, doctors and researchers in the areas of developmental pediatrics, sociology, psychology, health economics and health care.

3.11.2. Transferability.

Transferability is the ability of the findings from a study to be fit into contexts outside that specific study situation (Sandelowski, 1986). Findings in qualitative research, like this study, are not generalizable. The themes found in this study are connected to a specific population of individuals who are either availing of healthcare/ community services being publically administered within Atlantics Canada, or are working in one of these services/areas. The themes discovered in this study are a representation of individual's experiences who were willing and

able to participate in this study. As such, the views of said participants may not be an all encompassing representation of all individuals who are looking to access services for children and youth with ASD, or the service providers offering these services. In order to help satisfy this aspect of trustworthiness, an extensive background for the study was provided in the first two chapters: Introduction and Literature Review.

3.11.3. Dependability.

Dependability is often referred to as the ability to repeat a study in a similar fashion and still obtain similar findings (Sandelowski, 1986). In order for this to be possible, exact methods of data collection, analysis and interpretations must be clearly described (Sandelowski, 1986). This has been ensured by including a detailed explanation of the protocol for all the above mentioned aspects which can be found in the ACCESS-MH manual, and also in this chapter. Consistency in the protocol has been further reached by one single student carrying out the collecting of data, the transcription of data, and the analyzing of data. "Auditable" is the term coined by Guba to describe the situation in which an additional researcher could clearly follow the decision trail which was used by the investigator in the particular study (Sandelowski, 1986). This idea of an audit trail not only enhances the study's dependability, but also its confirmability (Sandelowski, 1986).

3.11.4. Confirmability.

According to Guba, neutrality was not viewed as researcher objectivity, but instead as data confirmability (Sandelowski, 1986). An audit trail is crucial to help ensure confirmability also. By an external auditor attempting to follow through the raw data, the data analysis, the findings, the field notes, and any methodological tools used, they can help ensure that the findings from the study are in fact a result of the participant's experiences and not the ideas and characteristics of the researcher (Sandelowski, 1986). This audit would be most beneficial

occurring from the start of the project, however, the auditor runs the risk of being "co-opted" into the study and therefore ends of losing their objectivity (Sandelowski, 1986). This audit trail, as well as detailed methodological descriptions and figures outlining data analysis can all be found in this methodology section.

Triangulation of methods, data sources and theoretical perspectives can also be key in helping establishing the confirmability of the study. Guba (1981) states that a researcher should provide documentation from at least two sources for every claim or interpretation that he/she makes in order to support the researcher's analysis and findings. This mindset was taken into consideration and applied in the data analysis and discussion of findings sections to further promote confirmability in the study. The section labeled Researcher Standpoint also helps to improve the reader's interpretation of how the data collected in this study has been impacted or shaped by my beliefs in regards to ASD services.

3.12. Summary of Methodology and Methods.

Through the use of individuals interviews with both the parents of a child with ASD or a service provider who could provide care to a youth with ASD, I was able to address the following research question: What are the main barriers and facilitators encountered by families and services providers when accessing services for ASD in Newfoundland and Labrador? The researcher was able to provide questions and prompts to help engage the participant to share their experience and journey through the system. Through a detailed thematic analysis, as was described in Figure 1, a comprehensive and detailed account of each participant's story was carried out. This process ensured the researcher reviewed the transcripts several times for both individual participant analysis, as well as overarching themes between participants.

The following chapter has been divided in order to organize the information in appropriate order for the reader to explore. The first section is a review of the thematic analysis

of each participant journey. The themes have been depicted and arranged to help support and answer the main research question regarding the lived experiences of accessing services for children and youth with ASD.

Chapter 4: Findings

This chapter produces a summary of the thematic analysis of the Participant Journeys. The themes offer the reader insight into the journeys of both the families and the service providers by summarizing the experiences pertaining to the struggles or supports that were offered while trying to access services or help provide services to children with ASD. After this foundation is built, the reader will be better situated to read and understand the emerging themes that were extracted from the journeys.

There are a wide variety of contexts from which the barriers and facilitators presented themselves in the findings. The main facilitators expressed by the parents for accessing care for the children were: advocacy for their child, money to pay for services which are not funded or immediately available, living in St. John's (urban vs rural), support from family and friends, experienced and flexible health professionals, coordination of care between health care professionals, and community service providers and the school system. The main barriers expressed by these parents were: lack of financial supports, not enough mental health care providers, not enough support to service the needs of the children, not enough information about their services, idea of "inclusion" of children with ASD into regular stream schools, education of the support workers (in community centres and in schools), co-morbidities such as anxiety, and parents' careers. These barriers and facilitators will be organized into tables in the upcoming synthesis.

4.1. Coding Document

In an attempt to organize the emergent themes in the thematic analysis, a coding document was created. This section will reference the coding document and focus on an overview of the barriers and facilitators that the participants experienced, as well as the

emotions, challenges, and feelings these participants felt while accessing or delivering care. It is the details from these journeys which accentuate and define the significance behind the findings.

All twelve participant journeys are briefly discussed within this section. Of the parents who were interviewed, some had a child who had been diagnosed with ASD within the six months of the interview, and there were parents whose child had been diagnosed with ASD as long as six years prior to the interview. There were quite a wide range of experiences simply based on the time frame in which their journey took place, but also due to their geographic location, and their financial resources.

The service providers were interviewed from varying locations ranging from the main urban center to several rural areas, and were represented by pediatricians, occupational therapists, speech language pathologists, child management specialists, senior therapists, teachers, and student assistants.

All of the participants in this study accessed or provided care within Newfoundland; there was no outside of province treatment sought for these individuals.

4.2. Composite Barriers and Facilitators.

Eight tables have been used to generate a visual organization of the barriers and facilitators expressed by the participants. The tables are initially divided by reoccurring themes dictated by the participants and then further divided into barriers and facilitators. Under each category of barrier and facilitator are the specific examples that compose the overall theme. Section 4.2.1. will address the major themes as described by the service providers, while section 4.2.2. will demonstrate the major themes as mentioned by the parents of the children and youth with ASD.

In some situations, in both the group of the service providers, as well as the parents, there were themes that arose that seemed to be paradoxical to one another. For instance, *Jill, Maureen*

and *Patricia* were parents that described the diagnostic process to be "extremely long and dragged out", identifying it as a significant barrier to accessing care. While two of the parents expressed that they received a diagnosis very promptly and efficiently.

4.2.1. The Parents.

4.2.1.1. The Diagnostic Process.

Table 1. Most Prevalent Barriers and Facilitators to the Diagnostic Process

Barriers	*Facilitators*
missed signs by public health nurse	Advocacy
lack on information/ resource	past experience
delay in diagnosis	family
family physician	
referral to specialist	
information overload	
family	
impact on the labour force	

Throughout the diagnostic process for the parents there were several barriers described by the majority of the participants. First, several parents made reference to the missed signs by primary health care professionals such as family doctors and public health nurses. The parents identified these professionals as being the individuals that are assessing the children at an early

age, they should be the ones educated and experienced enough to recognize signs and symptoms, and then have the necessary information to provide to the parents on what to do and where to go. For the majority of the parent participants, this was a missed stage. In fact, in all the participants journeys their first point of contact, whether it be a family physician or public health nurse, every one of the professionals expressed little to no concern regarding the child having ASD. Even after a referral to a general pediatrician the same thing happened. For each parent there was a different response, "boys develop slower than girls…", "give them a chance to get a little older." "it'll work out, don't panic…". As such for the majority of the participants, they described their child's diagnosis as a delayed, meaning it was diagnosed later than what they had hoped, and later than what they felt it should have been.

This delay in diagnosis was also further emphasized by the tremendous waitlists described in the previous sections by the service providers, as well as the lack of service providers. There were several common themes discussed by the parents and the providers which will be more focused on in the Discussion and Recommendations chapter. Parents did put a significant emphasis on the journey of seeking support from their primary care provider and waiting on a diagnosis from another healthcare professional. Of the participants, there was only one that expressed that the process of diagnosis was timely and effective. The remainder of the participants described their stories of diagnosis as a process of "devastation", "desperation" and then the reality of "all your dreams, and all your hopes and all what you envisioned in life was kicked out of you, right there." Many parents did not get the answer they were looking for in the beginning with their primary care provider, so they often sought a second, third and even sometimes a fourth opinion. In rural settings, it was common for no consensus to be met, families to be frustrated and leave for the urban centres to seek more answers.

One facilitator expressed by the parents was the power of advocacy. Many of the participants expressed that they would never have had the success that they did if they did not advocate for their child. Several of the parents focused in on the idea of advocacy. They used examples of physically having to sit on doctors' office doorsteps to get them to see their child. One parent reflected on an instance when she triggered her son to have a meltdown as she felt as though the pediatrician was getting ready to "push her out the door again." This parent wanted so badly for the doctor to see the extent of the behavioral episodes that her son was having, and although she had to negatively trigger him, she explained that this was her way of advocating for her child. It wasn't until this "meltdown" that the doctor even considered testing the child for ASD. Another parent shared memories of her journey of having to continually ask for a second opinion, keep seeking out different doctors, and even travel to a more urban centre until she felt that her child was receiving the diagnostic procedure that was required. Another example of a parent advocating for her child is within the school system. Almost all the parents made reference to needing to make an initial connection with the teacher, and then advocate for the child to receive the necessary support they required both in the classroom and around the school. Some even admitted to lying from time to time as they realized that assistance would only be provided for specific circumstance, but they felt their child "required the assistance" and as such, lied about the child's tendencies to get support.

The issue arises when a parent doesn't understand the power of advocating, is too timid and shy to undergo such lengths to speak up for their child, or simply just does not have the education to know what the child needs, or what the child is entitled to for their special needs. This outlines a very interesting point for discussion in the next chapter.

In all of the interviews hosted for this thesis, the children ended up being diagnosed by a developmental pediatrician. The experience with the developmental pediatrician, although

incredibly long to gain access to them, was efficient and effective once they had the opportunity to have an appointment with them.

After the process of being diagnosed, which for some participants took 6 months, and for other participants, over two years, many of the parents "blindly went through it all." There were so many questions, and not a lot of support available to help them. This lack of information was another theme that was seen to come up in both research groups and will be discussed further. The combination of a lack of knowledge as well as a delayed diagnosis resulted in many parents having to pay out sizeable fees for private therapies.

Depending on the parent, there were a rollercoaster of emotions experienced during their journey of their child receiving a diagnosis, and their continued journey of raising a child with ASD. Many parents shared emotions. Stupidity: for not knowing what was wrong with their child. Hopelessness: for the diagnostic process, and the lack of belief that their child would succeed. Embarrassment: to have a child with ASD who has very atypical behaviors. Relief: at first that it wasn't ASD, and then relief once it was diagnosed as ASD, confirming that the parents weren't "crazy". One parent described "when you have a diagnosis, then you know what the challenges are going to be, and you know then you can start to begin reading up on it and you know what to expect and you can work on it." Frustration: with the process of diagnosis and trying to avail of services. Worry: about the realities of what the school system will bring. And finally guilt: that the ASD was caused by something the parent did, wondering if they had done something differently could they have avoided this outcome.

All parents spoke of the value and role of their family during their journey. In the majority of the participants the partners of the individual as well as their extended family were a good means of support. The families that expressed having a larger basis of support from family and friends appeared to share their journey through a more optimistic lens. One parent who

explained that she was always very upfront with any individual who may encounter her child in regards to his ASD also expressed having increased support from schools, providers and other individuals from the general public. Whereas the individuals who shared the diagnosis with their family, but tried to keep it from friends and outside members expressed more displeasure with how the general public reacted to "outbursts" from her child.

Aside from the support from the families, an important theme that arose for all of the participants was the effect that ASD has had on their families. For example, one participant's first child was born with ASD, her second child born with no neuro-developmental disability that they were aware of. The role of the sister growing up has always been such a huge part in the success and modeling to the older brother with ASD. Although the sister has always appeared to love her brother, and has enjoyed being part of the "games" that are played to redirect him or distract him, the mother expressed sincere guilt for the role that the sister has had to play in the brother's life, and feels as though the daughter has been used in a way that a child should not have to experience resulting in her missing out on many opportunities.

4.2.1.2. Accessing Healthcare/ Community Services.

Table 2. Most Prevalent Barriers and Facilitators to Accessing Healthcare/Community Services

Barriers	Facilitators
waitlists to services	services offered by hospital
geographical restrictions	coordination of care
lack of education/information for parents	family
coordination of care	variety of services offered

family	support groups
finance	
impact on the labour force	

Waitlists arose yet again as a barrier discussed by the parents during this leg of the journey. The parents at this portion of the interview were referencing the waitlists that were faced while trying to avail of publically funded therapies. One parent stated she was told it would be approximately 18 months waiting for occupational therapy, but it turned out to be more like 24 months. Similarly, three other parents experienced "lengthy waitlists" while waiting to gain access to the local occupational therapist. Other therapies such as publically funded speech language pathology also had "long waitlists". Another service that parents reported having significantly long wait times for was psychology. Within the local hospitals there was a reported 2.5 year-long waitlist to get an assessment and speak with a psychologist. Parents expressed this as being absolutely devastating as a psychologist should be able to play a significant role in the management of emotions and mental health of the child and their family once the child has received a diagnosis of ASD.

The factor of waitlists has been very closely linked to geographical location many times throughout this document. Individuals in rural settings expressed "there are not a lot of services in this rural area." As such these individuals are travelling hours, sometimes days to get to a more urban centre, whereby these individuals are still battling the same waitlists that the individuals in the urban centre are facing.

One of the financial barriers emerged for the parents when they were desperate to start therapy, could not wait for the child to come off of the wait list and started paying for private

therapies. Every parent interviewed for this thesis, regardless of who they are, what their profession was or where they lived geographically, expressed the therapies being "financially draining" and "expensive" to keep up with. Parents expressed being "physically, mentally and financially drained." One parent also quoted that "the average family is in debt 25 to100K because of Autism." During the course of paying for therapies and other associated costs with ASD parents described missing out on the opportunities for vacations and trips, and some even made mention to having to refinance their house in order to help pay the bills for the therapy.

Although ABA therapy is funded by the government, parents expressed this therapy as being one of the more financially draining aspects of having a child with ASD. The therapy itself is funded, however, the therapy props, additional hours and childcare requirement must all be paid out of pocket. For many parents this either means they are paying out "$25,000 a year for childcare alone…" or are quitting their jobs or taking a leave of absence and decreasing their family income, in order to be at home with their child during their ABA therapy. For parents who felt they could afford it, they offered to pay an additional stipend on top of the salary being paid by the government to help entice a qualified and reliable individual to commit to the therapy with their child, again, putting further financial strain on the family.

Of the parents interviewed, the majority of the them were either on a leave of absence from their job, had quit their job or had been forced to take some time off based on feeling so "burnt out" from trying to manage work life with their home life. This can pose several difficulties within a family. Firstly, as mentioned above, with only one parent working there is a significant decrease in family income. However, not working can also play on parents' opinion of their own self worth and how they view their own success as an individual. The parents that worked for companies that offered them "flexibility" and "understanding" in terms of their schedule when it came their children reported feeling very "lucky" and "grateful" for their jobs

and reported being "scared to quit" as they might never get that same flexibility with another company.

As described by the service providers above, parents admitted to not having enough knowledge or education on the different therapies that their children should be availing of. Once diagnosed parents described "going blindly through it all", not knowing who or what to waitlist for. For parents who had the opportunity to share their journey with others, or for the few that had a second child with ASD they described "I then knew to waitlist for everything, even if he ended up not needing it, at least the process would be started."

When referencing the continuity of care and the communication amongst service providers, the majority of the parents felt as though there was good communication from one provider to the next. The barrier expressed by the parents to communication appeared to be from the service providers to the parents. Parents expressed not having enough information on what was happening with the child, and felt "frustrated" with the lack of coordination of information from the provider to the parents.

Of the parents interviewed in this thesis there was a paradox that existed in terms of the number of services available for their child with ASD in the community. Some parents expressed availing of all types of therapies: art therapy, music therapy, equestrian therapy, sports offered by Special Olympics, services from the local Autism Society. While other parents expressed that other than publically funded therapies (occupational and speech therapy) they were not aware of the outside therapies that were available for their child, connecting back to the gap being illustrated as a result of the lack of information and education being provided to the parents. One parent said "I even asked the developmental pediatrician for alternative services, but she didn't recommend or offer any."

The concept of daycare facilities also came up in paradox from the point of view of the parents. Some of the parents indicated that there is a gap in the services offered in terms of daycares. Some parents explained that they felt there "weren't enough specialized daycares". Another parent expressed displeasure with how the workers at a daycare reacted and responded to the child once they had a diagnosis (of ASD). "Before there was a diagnosis the daycare never used to call about anything. As soon as a diagnosis was given to my child, they would call for every last thing." The parent felt as though the daycare was labelling and singling out the child for having a diagnosis with ASD, and as such removed the child from the daycare. In paradox, one parent spoke to a specialized daycare in the region. At this daycare, once the child was accepted into the program, the parents were not responsible for applying for any additional supports. All supports required by the child were offered and funded by the daycare.

4.2.1.3. Applied Behavioral Analysis Therapy.

Table 3. Most Prevalent Barriers and Facilitators to Applied Behavioral Analysis Therapy

Barriers	*Facilitators*
senior therapist	senior therapist
recruitment and retention of home therapists	effective therapy
finance	funded
lack of information/support	family support
invasive to individuals home	
not suitable for everyone	

limited hours/ years to access service	
impact on the labour force	

One of the most significant barriers expressed by parents in terms of ABA therapy was the costs associated with this therapy. In addition to the cost of therapy (for childcare, therapy props and any additional hours), recruitment of a home therapist, as well as the retention of a home therapist seemed to be the most constant barriers for all the parents. Every participant defined the process of hiring a home therapist as "stressful." The home therapists are difficult to find, as there is no "central pool" to pull them from. The parents are responsible for finding, hiring and maintaining the therapists for their child. Some parents felt that there should have been more support offered to them in the hiring process of the home therapists. For most parents it was their first experience in hiring anybody, they didn't have the experience or the information needed to comfortably carry out this process. However, the longer the parents wait to hire, the less service their child receives. The child only has access to services for a fixed number of hours, and only for a certain number of years. Not accessing ABA services as soon as possible was disadvantageous to the child, as was outlined by the parents.

ABA therapy itself was described by *Jill* to be "fairly effective." *Jill* also felt it was "very slow progress in the beginning" but that over time "you're starting to see more gains." Other parents like *Maureen* felt that the program itself had "a lot of people who are certified, but they have absolutely no idea what they are doing…" resulting in stunted progression for their child.

Another barrier as discussed by *Maureen*, *Jill* and *Patricia* was the systematic determination of how many hours a child is eligible to receive, and for how many years this

therapy can be availed of. To the parents, children do not "grow out of ASD in grade three." As

such, the therapy should not just cease to be funded at this point.

4.2.1.4. The Education System.

Table 4. Most Prevalent Barriers and Facilitators to the Education System

Barriers	Facilitators
training/ education levels of staff	communication with teachers
not enough support workers	inclusion
designation of student assistants	
inclusion	

For many parents, the entrance into the school system was dreaded. *Jill* describes "I feel

like I'm gonna face the biggest challenge now, with the school system. I feel like it's going to be

a huge challenge." Parents were worried about the amount of support their child would be able to

have access to within the schools. When the child reaches school age, they are no longer eligible

for the speech language pathology within the hospitals, because there is a therapist in the school.

They have decreased ABA therapy hours, and ABA is not able to be implemented into the

school. The parents can bring forth recommendations to the teachers and principals, providing

suggestions for the child's individual ISSP, but home therapists and senior therapists are not

allowed to go into the school or make recommendations to the teachers in regards to these

children with ASD. All of these limitations and changes have the potential to pose a huge barrier

for these children. Some parents did recognize that these limitations could be seen through a

positive lens. For example, *Madeleine* suggested that the limited support forced the child to cope

on his own. However, most parents argued that the majority of these children might not have this ability, and the lack of support just results in a downward spiral of poor behavior and acting out for the child.

All five parents reported having varying experiences with the teachers. Each year something different would occur. For the most part, parents felt as though communication with the teachers was good. However, this communication always had to be initiated by the parent, otherwise the teacher would not seek out the individual. At the beginning of the school year each of the parents made a point to make a connection, and establish an open communication relationship with the teachers to try to help ensure the success of their child. Tools such as notebooks were used to write home to parents about the child's individual successes and failures for that day.

A very interesting barrier that arose while speaking with the parents of children with ASD was the accessibility and realities of a child receiving a support worker, IRT or student assistant within the classroom. All support within the schools require an application process. Once the school is granted hours with certain support workers, the school is then responsible for assigning these hours to the teachers/ classrooms and children in need. This process appears to make logical sense. However, parents reported what was actually happening was that children with a diagnosis of ASD were used to apply for student assistant hours for the school, but if the child was high functioning, the school was using these granted hours in another classrooms. The parents figured out that this was what was happening, and they were "infuriated" by the school placing a "scarlet letter" on the chest of their child, and using it to the benefit of others.

Finally, the last recurring barrier as mentioned by the parents regarding the education system was the general lack of education of the individuals (teachers, assistants) that were working with these children with ASD. "Our school system is not equipped to teach him

properly because they don't know how. And it's not a reflection of his teachers, it's a reflection on the system and the inability of the system to cope." Parents expressed sincere concern for the lack of professional development opportunities for teachers working with children with ASD. The parents feel as though there are not enough specialists involved in the school board when it comes to ASD. ASD is such a complex and varied spectrum that there should be many more experts involved in the educating of the professionals that are working with these children in schools.

For some parents, inclusion is the answer. For other parents, it is not. Some parents acknowledge the value in having their child model "typical children behavior", while being a learning opportunity for "typical children" to also learn to accept, work and learn with children of varying abilities. Completely contradictory to this effect, some parents believed that inclusion was just not the answer. Some believed that forcing the child to exist in an environment that they can't excel was only detrimental to their own child and the other children in that environment.

4.2.2. The Service Providers.

4.2.2.1. The Diagnostic Process.

Table 5. Most Prevalent Barriers and Facilitators to the Diagnostic Process

Barriers	*Facilitators*
availability of persons able to diagnose	communication between service providers
information overload	parent support
wait times	advocacy
parent support	

costs associated in receiving a diagnosis	

The diagnostic process was discussed in every interview held with service providers. Depending on the specific role of the provider, the view of the diagnostic process varied. At the beginning of the interview the providers often mentioned the intake process the child must undergo before gaining access to their service. Depending on which service provider was being interviewed determined whether or not the child had already been diagnosed with ASD. For example, when talking with a pediatrician, the child accessing their services usually had not yet received a diagnosis (at least not in the beginning), whereas, the occupational therapist from the local hospital cannot be seen until the child has already received a diagnosis of ASD. Regardless of which service provider was being interviewed, the first barrier discussed was the number of service providers that had the ability, education and experience to provide the child with the original diagnosis of ASD.

For example, one avenue for diagnosis is through a developmental pediatrician. Participants indicated that on the island there are very few developmental pediatricians, most of whom are located in the urban cities. As such there are significant wait times to see a developmental pediatrician. Secondary to a developmental pediatrician, other participants described a team called the "8-hour team" which hosts a series of assessments to diagnose ASD. There are only three of these teams across the entire island, and again, predominantly existing in the urban centres. These teams are comprised of several health professions that use different tests, such as the North American Gold Standard -Autism Diagnostic Observation Schedule to assess behavior and the individuals functioning to help with the diagnosis of ASD. The health professionals on these teams depends on who is available and trained in the various areas. Could include; developmental pediatrician, pediatrician, speech, psychology, OT and /or nursing.

A very closely related and recurring theme with the service providers was that of wait lists. As mentioned above, there are very limited avenues to receive a diagnosis of ASD, resulting in lengthy wait times for children waiting to get a diagnosis. All service providers, both in healthcare, as well as within the community, acknowledged that every single service that families and children are trying to access have an associated waitlist. In order to see a pediatrician, it is "taking upwards of 4 to 6 weeks." For occupational therapy within the hospital, the waitlist is approximately 18 months. Speech language pathologists reference having a 5 to 6-week waitlist minimum at the hospital, and this is only for the initial assessment not treatment. If the child is determined by the speech language pathologist to require direct home services there is a 12-14 month waitlist. For community services such as the specialized daycare for children/ youth with special needs there are "extremely big waitlists." The admissions for this particular daycare only happens twice a year. If any applications come in throughout the year, they get "sifted onto a waitlist to be considered for possible acceptance into the program."

Most of the service providers interviewed were workers within the publicly funded healthcare system. Each of these service providers, however, had worked at one point in a private setting, offering children and youth a service with an associated fee. This idea of private therapy was a common theme discussed between the service providers. Several of the service providers agreed that private providers had decreased waitlists, however, the expense associated with trying to access private therapy made it very difficult for parents to afford, keep up with and commit to the process of the therapy. One of the service providers quoted "We always say that having a child with special needs is the fastest way to go broke." For some programs and services within the province they reserve places for children who in fact do not have a diagnosis of ASD. The justification behind this is that children with ASD are already availing of certain services, and therefore the spots should be reserved for children who do not have such services

available to them. Due to the application process for such funded programs and daycares within the province one service provider said "in a weird twisted messed up world it would make more sense to wait to get a diagnosis of ASD so that, if you wanted to avail of the centre, you could."

Other than the provincially funded ABA therapy, there are no additional therapies that are covered by the government. Several service providers noted this as being a barrier for children to whom the ABA therapy might not be suitable. The reason for this being that any additional therapies, outside of ABA must be paid for out of pocket, putting an additional strain on the parents and families.

Another significant barrier that kept arising was the idea of an information overload for the parents. One of the service providers explained "So there's this whole host of time where I think there's so much coming at parents where, they're really unable to even focus on what, what is required at this time." The pediatrician, the occupational therapist and the speech language pathologist made several references to the "large amount of information" being given to the parents, and also acknowledge the parents being "overwhelmed" but the diagnosis itself, in combination with the services they now need to try to get access, who to call, who to hire and how long these diagnostic procedures should take. Not only is the amount of information exceptionally large, but there is a gap acknowledged by the service providers that parents generally do not know where to look for support to help manage and support their child. This implies that there is support available to the parents, but parents are describing to the service providers that they do not know where to look for this support.

The service providers did however acknowledge that for the most part, the communication between them was "good". It was expressed that the communication between healthcare professionals was more fluid than between community service providers and the healthcare providers. Some disciplines expressed having better relationships in terms of

communication and collaboration than others. For example, the pediatrician expressed having "great communication with the speech language pathologist...", while the communication with the occupational therapist, physiotherapist and psychologist was not as good. Several service providers also indicated that the interdisciplinary communication between healthcare and schools often depended on the personality of the individuals, whether that be an individual therapist, a doctor or a principal.

Another facilitator that the service providers discussed frequently was the idea of advocacy. Providers often referenced the increased levels of success with treatment, reaching milestones and progressing when the parent was committed and advocating for their child. Not only was the idea of advocating discussed, but also the importance of providers encouraging the parents to advocate was emphasized. The child management specialist indicated the value and effectiveness that resulted from parent advocacy and discussed how one of the critical roles of a child management specialist is to inform the families, and empower them to be the most dedicated advocate for their child. The early childhood educator also agreed with this notion and discussed several examples of the positive impact that advocating for your child can have versus standing on the sidelines and waiting.

4.2.2.2. Accessing health care and community services.

Table 6. Most Prevalent Barriers and Facilitators to Accessing Health Care and Community Services

Barriers	Facilitators
lack of knowledge of service	more service providers being funded
not enough service providers	geographical location

daycare availability	quality of services
age restraints on accessing services	continuity of care/communication
geographical location	parent support
support for service providers	advocacy
continuity of care/ communication	
parent support	
finance (what does this mean?)	

This section describes to the barriers and facilitators associated with obtaining services from either a healthcare or community setting once the child has received a diagnosis of ASD from the developmental pediatrician.

Lack of knowledge of the different types of services was one very prominent recurring theme. Almost all of the service providers made some mention to parents/ guardians either not understanding what exactly the services were that their child required, did not know the purpose or role of the service, or did not know how to gain access to these services. The child management specialist for instance explained "people don't know about child management specialists, therefore parents end up looking for services in the wrong place, or not at all." The pediatrician expressed concern to the age restraints surrounding the therapies for each child. For example, a child can only access the publically funded speech language pathology until they are school aged. At this point, there is a speech pathologist in the school, and children must only avail of services from the school board speech language pathologist, unless they wish to pay for

private speech therapy. This posed as a barrier in terms of knowledge of the services because oftentimes parents are not aware of this age restraint. If they do not utilize the publically funded speech right from the beginning, they might spend months and months waiting to gain access to the speech language pathologist within the schools because there are so many students availing of this one provider. The occupational therapist stated that parents have very little knowledge of what an occupational therapist does, and as such, are unaware of the significant impact this service can have on their child with ASD. The early childhood educator also expressed concern about the accessibility of information regarding the specialized day care. The concern existed around the idea that there was no promotion or formal resources explaining the services of this daycare because there wasn't enough space to house new students.

Next to the lack of knowledge, the most significant barrier in accessing services in both community and healthcare was the simple fact of there not being enough providers. All participants expressed exasperation because there just simply are not enough providers in any of the roles; speech, occupational therapy, doctors, teachers, support workers, and psychologists. Based on the number of children that are looking to avail of services for all special needs, but especially for ASD, there are not enough providers in the school or healthcare systems to support the need. Although there has been some progress in some areas (speech language pathology) in terms of increased providers being funded specifically to help with coordination of care and addressing the population of children with ASD, this lack of providers is still the root of waitlists, decreased quality of service and sometimes even the absence of services. This barrier is even more prevalent in rural areas. IRTs expressed feeling understaffed based on the need that is in the classrooms, specifically in rural locations. IRTs are provided to each individual class based on an application process outlining the need of each classroom. Ideally there would be enough providers to address these needs, but that does not appear to be the case. The occupational

therapist described the physiotherapists, social workers and psychologists in the local children's hospital as being "overran" and "overworked", resulting in a breakdown in the collaboration with other providers, and a decrease in access to their service. In Newfoundland there is one specialized daycare that offers specific services and funding for children with special needs. This clearly outlines the significant lack of service and providers in this area. The early childhood educator made reference to this gap, and the speech language pathologist confirmed the gap, and this significant need.

On top of the overall lack of service providers, there is also a lack of support being offered to these service providers. As just mentioned, there are not enough of them to feel supported. But in addition, the mental and physical health needs of the workers who are working "nonstop" and "overtime" trying to offer a quality service to the children, are not being accommodated. It was described that there are no professional development opportunities being offered in the schools or daycare to offer teachers or assistants new methods to offer support to these children with ASD. There is no support being offered to the workers who have to manage with the emotional and psychological struggle the parents bring to the table as they battle with the challenges of having a child with ASD.

An additional barrier worth mentioning in this part of the journey was the lack of parent support, which has a similar mindset as parent advocacy for the child. The service providers all agreed that the more onboard the parents were with the diagnosis, as well as the treatment plan, the more likely the child was to have progress with different skills and reaching milestones. The parents play "a key role in delivering the outcomes" of the therapy. For most therapies, the providers will only do services up until a certain point, then it is up to the parents to continue the practice and carry out the objectives. When "parents are all in, you see significant gains and successes for the child." When this type of parental support is lacking, providers see significant

declines in the success of the child, sometimes even resulting in the parent losing the access to the child.

Finally, the idea of finance was an important theme. As discussed in the diagnosis section, accessing services in the healthcare and community sector can be extremely expensive. When trying to access private services, there are associated fees. However, even some funded therapies have additional mandatory costs such as childcare expenses. To avoid such expenses providers sometimes see an impact on the parents' involvement in the work labour force. Parents sometimes quit their job or take a leave of absence to be able to be home for the therapy of the child, and to remove the additional costs of childcare during therapy.

In regard to some more specific facilitators, the quality of the service that is being offered is being described as "exceptional" and "stellar" by the providers. Services such as occupational therapy have been created and implemented into treatment programs for ASD as a means to "support their learning." This therapy includes theories that are "evidence based, they're tried, true and tested…" meaning that there is supporting evidence behind the success and gains of the services that these providers are offering. Specialists in the area quoted that once the child, especially at preschool age, has received a diagnosis of ASD, the quality of services that they are receiving is "excellent."

4.2.2.3. Applied behavioral analysis therapy.

Table 7. Most Prevalent Barriers and Facilitators Regarding Applied Behavioral Analysis Therapy

Barriers	Facilitators
home therapists retention/ recruitment	parent support

concepts of which therapy is created from	effective therapy
parent support	
finance	
generalizability of skills	
lack of interdisciplinary service providers	
only funded therapy	
size of program	

As mentioned in Table 3 above, there are several key barriers and facilitators to accessing the ABA therapy being offered within NL. Interestingly enough, ABA therapy was the topic that appeared to have the most paradoxical themes between the service providers. Half of the service providers believed that ABA therapy was extremely effective and beneficial to the children that were availing of it and it appeared to be "doing a lot to unlock some of these children with ASD". Contrary to this theme, there were also several service providers that felt ABA therapy was too "black and white" and that "generalization of the skill was a big challenge." What was meant by this was that the discrete tasks that were testing in ABA were not easily applied to real life settings, and as such professionals struggled with the benefits of learning a skill than can not be generalized into a real life practice. Professionals in the occupational and speech language pathology fields felt that the concepts and grounds from which the ABA program was built off of was not effective. They believed that learning these skills needed to involve "way more than just failing and succeeding of certain discrete tasks." It appeared through the interviews that several

of the service providers in occupational therapy and speech language pathology were trying to connect and collaborate with the persons responsible for creating and implementing the ABA program. However, due to reasons such as personality conflicts and lack of wanting to collaborate, this coordination has yet to occur. One service provider stated: "I just feel that ABA is a wonderful thing, but when they can't put what they're learning into context of being around another group of children then it's not really valuable." This quote very clearly outlines the idealistic side of ABA but challenges the realistic side of it.

One of the barriers for ABA to consider based on the interviews with service providers is the lack of collaboration between interdisciplinary providers, as briefly mentioned above. ABA Therapy does not avail of outside any speech pathologists, any occupational therapists, and only one psychologist. The one psychologist is also a part of the diagnostic process, and as such is not available to offer services to children or their parents to talk about, discuss or manage their stress, worries and realizations of receiving a diagnosis of ASD. One of the participants stated that the ABA program has gotten "so big" with the number of senior therapists and home therapists in the program that many service providers feel the quality and effectiveness of the program has diminished and the collaboration is limited: "because there's so many of them now there's a lot of new people coming out and they're being trained and they're just not as accepting."

One consistent barrier across the board for all service providers was the idea of retention and recruitment of home therapists within the ABA program. Due to various reasons such as lack of financial stability, education opportunities and career opportunities, there tends to be a lot of turnover with the therapists. This poses a significant barrier as one of the principles of ABA therapy is consistency. Because the program has become so large, there is a large demand to be constantly training therapists that do not have great experience and do not have an open

mind. "Its gotten too huge I think. It's gotten too huge. And they're training all there new people and so, there's a lot of them being monitored all the time, by mentors and, I think they're scared to actually go outside of what they're supposed to do because they may not pass."

Finally, the last barrier that was discussed within the service providers was the idea that ABA was the only funded therapy. The reality of ASD is that every child with ASD sits somewhere on the spectrum, making every single diagnosis, ever treatment plan, every success and every failure very specific and unique to each child. The providers raised an interesting point that if this is how we treat this neuro-typical disorder, then why have we boxed the children and youth into availing of only one type of therapy.

4.2.2.4. The education system.

Table 8. Most Prevalent Barriers and Facilitators Regarding the Education System

Barriers	Facilitators
lack of education for providers	ISSP
lack of service providers	collaboration
inclusion	inclusion

As has been mentioned many times throughout the results section of this thesis, a large barrier in the education system is similar to other aspects of care and services in that there are not enough service providers. Participants expressed significant stress and burnout based on the number of children with ASD that they are responsible for within the classroom. In addition to a lack of IRTs, student assistants and support workers, all participants interviewed expressed concern about the lack of knowledge and education as well as the lack of training being offered

and provided to the individuals who are working with children with ASD. ASD is a highly variant diagnosis and can impact children with different levels of severity. There is significant education existing around managing and supporting children with ASD, and workers within the school system are not being provided with the opportunity or the resources to obtain any of this knowledge. Children are going from receiving a myriad of services from speech language pathology, occupational therapy, and full time ABA therapy and then once they become school age the majority of these services are either reduced significantly or eliminated all together, leaving children and teachers in a very difficult situation.

Items and protocols have been put into place such as Individual Student Service Plans (ISSPs), but often times these ISSPs are not reviewed, kept up to date or are not analyzed enough by the providers offering support to these students. Teachers within the school tend to work with other student assistants and IRTs, but there still appears to be a gap in the support for the child, as well as for the providers.

As a recurring theme, there is a lack of collaboration between professionals when it comes to implementing strategies for students with ASD in the school system. As it stands there is only one speech language pathologist assigned to several schools in the school system, making it near impossible to gain access to his/ her services. Newfoundland is also currently the only province in Canada that does not have occupational therapists in within the school system, and does not accommodate for professional input. "We've been battling this for about 15 years as occupational therapists, and our provincial association and all that have gone to government and said you know, we are the only province without OT's in the school system and everyone else can't be doing it wrong…". In additional, occupational therapists feel as though they are facing an ethical dilemma, "I just feel it's a big ethical issues for me personally because, as an OT I am

trained to treat a child and child's function in every environment but what I've been told is I can't do that anymore. So ethically, in my professional opinion, it's wrong."

One of the more interesting themes that arose from the service providers, which will be reviewed in the following section covering barriers and facilitators as expressed by the parents is the idea of inclusion. Many of the participants expressed varying opinions on the idea of inclusion, its benefits and its downfalls. One participant said "because as much as inclusion is a great thing in theory, it isn't- it doesn't make sense, like it really doesn't make sense." Another participant stated that inclusion is not always beneficial for every child. For example, with some serious behavior concerns, you have to pay an IRT and a student assistant for a situation that is just going to result in the child being removed from the classroom anyway One of the physicians also made an interesting point that as a result of the idea of inclusion, and children being forced into an environment where they are struggling, more parents are looking to medicate their child to hopefully be able to keep them in the school environment. But because the school system is so rigid there is a conflict, "because I don't want to sedate them but the school system says there's nowhere else for him to go. Unless we get his behavior under control and he's no longer violent, he's not allowed back in our classroom." Many service providers described this situation as "really frustrating" because inclusion is just not always the answer. It's also not always the case of trying to keep the children up with other's their own age, but the situation also arises that children with ASD have abilities that they try to express, for example they might be academically ahead, and as such they are getting bored in their classroom because they are not being allowed to do content beyond their grade level resulting in further disruption.

The teachers and IRTs in the school often describe a similar pattern. Inclusion is case by case dependent, and completely depends on the situation. Inclusion is not a one size fits all that can be applied to all kids. Funding has been decreased (lessening the number of support workers

being offered to work with these children) to help promote inclusion, but this isn't always helping. Participants explained that "kids need to learn from others as well as model behavior. If they are in an inclusive environment then they're not learning, or they're just debilitating other people's learning, and in this situation inclusion is counterproductive."

4.3. Chapter Summary

The main findings of this thesis stem from the discoveries found from the thematic analysis. The thematic analysis points to various barriers and facilitators to different aspects care. For the parents and the service providers, the main barriers were in receiving/providing a diagnosis, accessing services for health and community services (waitlists), ABA therapy and the education system. The examples supporting these barriers however varied significantly based on the participant sharing their experience. Often times there were parents that shared similar experiences with other parents, and the same between service providers. Such as reporting a high quality of service for the children, the significant impact of family support, the importance and effectiveness of advocacy, and the importance, yet lack of communication between providers.

The following Discussion chapter presents a fuller interpretation of these findings in relation to the ways in which they are the same and/or different from those presented in the pertinent literature. I also offer an explanation as to why and how parents and service providers agree on the fundamental barriers of the youth ASC system and what this could mean for recommended policy and practice change.

Chapter 5: Discussion and Recommendations

This chapter provides an interpretation of the findings in context with the literature. It is important to note that the majority of findings discovered in this current research were unique findings. A review of the literature revealed there was limited published work relating to or supporting the main themes developed in this thesis. Following this, recommendations are provided. Then the strengths and limitations of the study are discussed. This chapter positions the findings against the themes existing in the literature review, how they are similar, how they are different and what gaps remain. Finally, directions for future research are provided.

5.1. Interpretation of Barriers and Facilitators

There were several items that appeared to be consistent between what already existed in the literature and what was extracted during the thematic analysis. The main focus of this section will emphasize on findings that supported the main research question: *What are the main barriers and facilitators encountered by families and services providers when accessing services for ASD in Newfoundland?* Some of the lived experiences identified barriers and facilitators which supported themes such as challenges accessing diagnoses, as well as health and community services. Additional themes raised included the overall experience of ABA, as well as, the role of the education system. This current research also varies from the existing literature on specific barriers and facilitators within each of these overlying themes, and sometimes with some contradictory evidence forming a paradox with what already exists in the literature, or between the two different groups studied in this research. This is further indication that individual experiences with ASD diagnosis, treatment and support have a tendency to follow an individualized path.

The interpretation of these findings was guided by the Complex Cultural Nesting theory outlined in chapter 1. This is critical in the dissemination of my results as it sheds light on how

both persons and the people closest to them are inseparable from historical and current social systems (Tilleczek, 2014). In this research the child/youth, their parents, their family members and the service providers they interact with all contribute to the understanding of the social relations and experience that is expressed. The microsystem is outlined by the parents who express their own journey as well as their child through the system. The mesosystem addresses the interactions of the parents with service providers in health care, education, and other family members highlighting its own series of barriers and facilitators.

Both parents and service providers identified several facilitators and barriers to accessing care. Some of the trends could be clearly identified a barrier or a facilitator, but some could not be placed in a specific category as it was context dependent. As mentioned above, there were four main themes described: The Diagnostic Process, Accessing Services in Health Care and Within the Community, ABA Therapy and the Education System. Generally speaking, approximately half of what was voiced as barriers and facilitators had been previously mentioned in research pertaining to ASD. However, there still was still some subthemes, such as parent advocacy, inclusion, role of daycares, role of public health nurses and ABA therapy, as well as further evidence supporting pre-existing themes that arose in this current research. The discussion will begin by discussing what the service providers and the parents shared in common as their expressed barriers to accessing care, and will then continue to outline their differences. The same will be done for facilitators.

5.1.1. Barriers.

5.1.1.1. Barriers Surrounding the Diagnostic Process.

5.1.1.1.1. Perspectives Shared by the Service Provider and the Parents.

Both parents and service providers shared experiences that demonstrated barriers described as "information overload" upon receiving a diagnosis of ASD for the child. The

service providers spoke about individual events whereby they felt parents were "overwhelmed" by the "large amounts of information" being given to them addressing items such as services, therapy options, and therapy requirements. During this period of information overload, the service providers expressed there being an absence of support for the parents who are frantically looking for services and therapy options for their child.

Parents described this same barrier, but through their own lens. Parents felt they had so many questions about the journey they were travelling through, and that there was no one (that they were aware of) available to help them.

In both groups, the concept of wait times and a delay in diagnosis was shared. Each service provider explained the reality of there being a lengthy wait time to access services from all providers involved in providing a diagnosis. Parents expressed the exact same concern, and in most cases felt that the length of these wait times often resulted in a delayed diagnosis of ASD and as such a delay in the access to many services that could be beneficial to the child's progress. These findings were similar to the ones found by Sansosti, Lavik and Sansosti (2012) who conducted a mixed methods study to assess the family experience through the ASD diagnostic process by collecting and assessing qualitative and quantitative data. Results of the study showed that families reported a 2-year lag between first noticing delays in their children's behavior to the point of receiving a diagnosis (Sansosti et al., 2012). Families who received a diagnosis a later time expressed less satisfaction with the diagnostic process (Sansosti et al., 2012). In the current research *Patricia* stated that diagnosis took a year and a half which was "way too long". As a result in the delay of diagnosis for her child, she felt her child was put at a severe disadvantage because he was so delayed in gaining access to therapies.

5.1.1.1.2 Perspectives of the Parents.

The most prevalent barrier expressed by the parents in the current research in regards to the diagnostic process was the missed signs by the primary healthcare team. Approximately half of the parents in the current study believed there was a breakdown when it came to the early detection by primary healthcare providers. They felt that signs should have been picked up earlier by a public health nurse or family physician following the child. Unfortunately, in some of the cases ASD was not identified which led to a delay in the diagnosis. For example, *Maureen* felt dismissed by the public health nurse responded to her concerns with "give it a break, come back in a few weeks." *Maureen* also had similar experiences with her family doctor and the pediatrician. She describes that it was "only by fluke that *Lucy* got an ear infection and was seen by a different pediatrician in the Janeway that the behaviors of *Lucy* were noted as being abnormal."

Patricia had a similar experience in that her family doctor told her "boys don't develop as fast as girls", and as such *Patricia* shouldn't be alarmed by the delay in development with her son, *Luke*. *Patricia* brought *Luke* to a pediatrician who she also describes as having "missed the signs". *Patricia* shared "we were in the system with the pediatrician and then the developmental pediatrician, voicing our concerns, but the weren't being addressed or investigated in any way."

These findings were consistent with that of Sansosti et al (2012) who's participants identified the physicians and schools to be uninformed about ASD. The parent's described the medical and educational professionals to be "out of touch" with contemporary research and understanding of ASD (Sansosti et al., 2012). The study found that parents indicated pediatricians and other early child care providers told families that their child would eventually "grow out of it" or that it was "too early to look at autism" (Sansosti et al., 2012).

A meta-synthesis of parent's perspectives indicated the significant impact that was made by having a positive experience with primary healthcare providers (Boshoff, Gibbs, Phillips, Wiles & Porter, 2018). This supports the idea that if parents had a better interaction with these front line medical workers, it would lay the groundwork for future relationship with these service providers, as well as others (Boshoff et al., 2018). By parents indicating that they did not have a good interaction with these providers, as mentioned above, it can lead one to believe that they, for example *Patricia,* may have felt isolated and dismissed by the professionals and therefore was reserved in looking for support and guidance in the future.

Being a member of the labour force while trying to receive a diagnosis of ASD, as well as follow therapy plans for children with ASD proved to be a significant barrier for many of the parents interviewed in the study. Parents reported either having to request leaves of absence, reduce their working hours, or quit work all together so that they could be home to attend the appointments, diagnostic sessions and therapy sessions with their child. *Jill* described that she was currently on a leave of absence from work, but because she worked for a big company, the application process for time off was more readily available and easier to apply for. *Jill* reflected that she would never been able to adjust to a child with ASD, nor would she have wanted to pay someone to be home with her child during therapy. With both of these things in mind *Jill* expressed being grateful for her work allowing her to take the time. However, *Jill* did mention that not all parents have the luxury of surviving with only one parent working, which was a shared opinion of *Patricia* as well.

This was consistent with the findings of Cidav, Marcus & Mandell (2012) who through quantitative means established that of the individuals who completed their survey, parents of children with emotional and behavioral disorders lack appropriate services and resources which are needed to support work and family obligations. As such, the parents and families face

difficulties balancing children's care needs with that of the demands of their job (Ciday et al., 2012). Similar to *Maureen, Jill* and *Patricia* the parents in this study found it difficult to find childcare that was accessible, affordable and of high quality for their child with special needs (Ciday et al., 2012).

In further support of the thesis findings, it was founded that it was the mother's labor market outcomes who were more substantially affected by having a child with autism due to reasons such as being the child primary caregiver and decision maker as it relates to health services (Ciday et al., 2012).

5.1.1.1.3. Perspectives of the Service Providers.

There were also several barriers that arose in each individual group that the parent group did not discuss. For example, service providers addressed the number of available professionals that had the ability to diagnose children with ASD. *Nicole* the child management specialist said "there are only so many providers, and we just don't have the manpower to be taking on the demands that is associated with some of the children's cases." In this current research this represented a barrier because the number of providers able to make this diagnosis was not sufficient enough to support the number of cases of ASD that have been, or need to be, diagnosed in the province of NL. *Michael*, the pediatrician interviewed described that when he first started practicing in rural Newfoundland, he was not allowed to diagnose ASD. As such, people in his area were waiting for years to get to an urban centre to see a developmental pediatrician and get a diagnosis. In more recent years this is not as much of a concern as he is able to take part in the diagnostic process, and get the children who are suspected of having ASD into the system to allow them to start availing of services. In addition, *Michael* outlined the barrier of a lack of family doctors in the area. Without a family doctor *Michael* expressed "how does a child get a referral if they don't have a family doctor?" The interviews revealed that

service providers said that there were not enough developmental pediatricians and that their geographical location was restricted to urban centres.

Another barrier as discussed by the service providers during the diagnostic process was parental support. Providers in this research spoke about the obstacles that were faced when parents were in denial about the possibility of their child having ASD. A review of the literature did not show any articles making reference to this barrier as was expressed by the service providers. Although it did not show up in the review, it was a distinct barrier in the current research as every one of the providers referenced the struggle that is associated with implementing therapy options if the parents are not on board. The providers emphasized the effects of this barrier by providing examples as to how parents who support the diagnosis and are involved in the therapy tend to have significantly more success with their child achieving their milestones and individual goals, whereas when the parents are not committed nor involved, these achievements are less frequent. It is important to acknowledge that although a parent may be fully committed to the diagnosis and treatment goals of the child, based on the child's individual severity of the condition, milestones and goals can still be difficult to attain, regardless of the commitment level made by the parent.

The final barrier within this theme as expressed by the service providers was the cost associated with diagnosing a child with ASD. What the providers meant by this was that first, it takes a lot of time to provide a diagnosis of ASD. Whether it is in a publicly funded healthcare setting, or if it is in a private setting, requiring an out of pocket payment or private insurance coverage, the process requires significant resources. The process is comprised of a series of specialized tests and hours of observation. In a private clinic, if a child has been brought in by the parent suspecting ASD, there are several situations that could occur. Sometimes the provider feels competent and capable to make a diagnosis. Sometimes, the primary provider does not have

the training and ability necessary to offer a diagnosis. In this case the clinic could lose money because they had to send their patients somewhere else, or, could have to spend money because they needed to hire someone able to help with the diagnosis.

In 2007 a quantitative study was conducted to get a comprehensive look at the health care costs associated with children and adolescents with ASD. The findings were that expenditures associated with ASD with high relative to other mental health conditions, and were increased steadily over time (Leslie & Martin, 2007).

5.1.1.1.4. Reconciliation with the Literature.

Audas et al. describes services such as the Direct Home Services Program and Community Behavioral Services Program as being available to families/ caregivers caring for a child with ASD (2015). Although these services are available in Newfoundland, only one of the participants in the study made any mention to them. All of the other parents described looking for a service that would fill the role of the programs described, but for some reason the majority of parents interviewed were not being informed of these available services.

Mackintosh et al., (2012) also addresses the daunting reality parents face when having to sort through the enormous amounts of treatment options that come with a diagnosis of ASD. The literature does clearly articulate the amount of information that is given to the parents upon diagnosis and how it poses a negative impact, but there was no literature that addressed how it serves as a barrier for the families. In the current research the service providers outlined the overabundance of information as a problem, and the parents used examples as to how it was a barrier. Some parents felt that there was 'information overload', and the lack of support is what resulted in them not knowing where to look for funded services available for their child, and as such, they ended up using more expensive private therapy.

The findings related to wait times were discussed in the literature. The fact that primary care physicians are often lacking the clinical experience and training to assess and treat ASD was identified and as such, the individuals who are able to offer these services often have lengthy wait times (Zablotsky et al., 2014).

In the literature, researchers discussed the impact of persons receiving formal training in the diagnostic tools, and how it was more likely to result in effective use of these diagnostic tools for their clients, resulting in a higher rate of success when trying to diagnose children with ASD (Hathorn et al., 2014). This demonstrated the idea that there is an importance in having a sufficient number of providers that are capable of providing this diagnosis.

One article looked at the amount of increased time required by a family physician to be able to diagnose a child with ASD (Barton et al., 2012). The results of that study recommended that doctor's offices have designated individuals to assist in the screening, however shortages in staff and consistency of the screening procedure becomes an issue when it is divided among several individuals (Barton et al., 2012). This relates to the current research in regards to the disjointedness of the diagnosis process.

The first point of contact for parents seeking answers to mental health or behavioral changes is often community-based primary healthcare professionals such as public health nurses and family physicians (Lee et al., 2015). Family physicians are key in a timely diagnosis, and play an important role in the management and follow up of these children (Lee et al., 2015). Often the primary care physician does not have enough information regarding the availability of validated diagnostic tools, or they feel it is not their role to detect ASD but rather there are sufficient surveillance practices in place to detect ASD, family doctors are not often diagnosing children with ASD (Barton et al., 2011).

Another barrier expressed by the parents was the impact family had on the diagnostic process, as well as the impact that the diagnosis had on the family. Ekas et al., used an online study to assess hope, loneliness, perceived social support from friends and family, as well as, depressive symptoms in mothers whose child was going through a diagnosis of ASD (2016). The study showed that those who had family support expressed having less loneliness and fewer depressive symptoms (Ekas et al., 2016). This coincides with what was expressed by the parents in the current research. The parents interviewed for this thesis described comfort and gratitude when spouses, siblings and parents were supportive during the diagnostic phase. However, when spouses were not supportive, or other family members lacked support for the parents, the parent expressed significantly more stress, doubt and negative experiences with their child's diagnosis of ASD.

Families with children who have special needs have been found to reduce their working hours, or completely stop their paid employment as a result of different factors relating to the child's care needs (Zablotsky et al., 2014). This barrier held true in several of the interviews conducted for this current thesis.

5.1.1.2. Barriers Surrounding Accessing Health Care and Community Services.

5.1.1.2.1. Shared Perspectives of the Service Providers and the Parents.

Once the child has received a diagnosis they look to access therapeutic services for their child. Both parents and service providers alike indicated a barrier when it came to parents having sufficient information and knowledge pertaining to what services are available, and what services would be best for their child. In many of the interviews, parents expressed not knowing why the child needed to access occupational therapy, or what the purpose of occupational therapy was, for example. Both *Madeleine* and *Jill* expressed being embarrassed because originally they did not know what occupational therapy was for. Service providers also identified

this barrier by saying that parents often did not know what therapy was necessary, or what different types of therapy were available, and as such, they were not getting their child access to the therapy. To date, there has been no research published in this area, addressing simply the barrier of parents not knowing what therapy can best suit their child, and no research pertaining to strategies helping and assisting to overcome this barrier.

Geographical location was another barrier shared by the providers and the parents. The parents referenced that the closer they were to an urban centre, the more easily accessible the therapies were. In urban centres there was more opportunity for art therapy, Special Olympics programs, and music therapy lessons. Furthermore, for specific health related therapies such as occupational therapy, speech therapy and psychology, the urban centres were better equipped to provide support for children with ASD. The service providers also addressed how difficult it was for persons in more rural settings to either travel into the city for an assessment, an appointment or a follow up appointment, in comparison to the individuals who only need to drive 15-20 minutes to make the same appointments. It was noted by the service providers and the parents that the smaller the town or the city, the fewer service providers there were, yet again outlining a very clear barrier to the access to any service. It was also mentioned by several service providers how distance can be an issue when it comes to follow up. A number of providers will do home visits and offer follow up in the community or in the patient's homes. However, when families are so far out of town, this service may not be available. Providers also mentioned that it is very difficult to ask parents to commit to several follow up appointments, as every time they commit to a session they are also committing to significant travel time. Both parents and providers also referenced that smaller towns are just not equipped to have the same opportunities as larger centers. As such, children in rural areas have fewer healthcare and community services available to them.

The cost of services is a barrier that was mentioned by both providers and parents. The providers acknowledged the barrier of finance by saying that parents sometimes cannot wait to access publically funded services, and as such, branch out to use private services. These private services can be extremely expensive, especially when there is more than one service being accessed, and as the frequency of visits to these services increases. Parents share the exact same mindset. They have a sense of "hopelessness" as they are waiting to avail of services, and try to do whatever they can by trying to access private therapies, often putting themselves into debt to pay for these services.

Coordination and continuity of care is another barrier that was consistently described in both groups. Service providers interviewed for this project expressed the dire need for more collaboration between professional groups. The pediatrician described great communication between themselves and the speech language pathologist. However, she also mentioned that there was very little communication between herself and the physiotherapist, the occupational therapist, and the psychologist. The occupational therapist spent significant time addressing the difference in her background in comparison to the background of the other health and community providers. The IRTs described a lack of communication between the health and the education sectors, but felt as though the communication between education providers was proficient. Many of the healthcare providers expressed concern regarding the lack of communication and collaboration that existed between themselves (OT, SLP, pediatricians) and the ABA therapists. The majority of the healthcare professionals actually suggested there was active resistance from the ABA program when it came to collaboration.

5.1.1.2.2. Perspectives of the Parents.

The most prevalent barrier as expressed by the parents appears in almost every theme in this research work- wait times. Parents describe extremely lengthy wait times to obtaining

services, even after the child has been diagnosed with ASD, varying in length from 6-24 months depending on the service. *Maureen* described there being "wait lists for everything and anything people though might be helpful." *Patricia* shared a similar experience but only in the lead up to a diagnosis. As mentioned in a previous section, *Patricia* identified the wait time for a diagnosis to be far too long. However, she did feel that once a diagnosis was made, the wait times for the other services were not as bad in comparison. *Jill* outlined she experienced wait times for every step along the way: diagnosis, OT, SLP and ABA.

The findings of wait times being a significant barrier were unique in the sense that there appeared to be a significant gap in the literature when it came to addressing the realities, causes and recommendations to help minimize wait times. This research outlined that parents felt there were not enough service providers available to offer services to children within a reasonable amount of time. This amount of time increased based on the location of which the family lived in, as discussed above. There was a perception among parents that advocating for their child could reduce wait times considerably. This idea of advocacy will be further developed in a future section.

Several parents spoke of the struggles that they had when it came to support from their family. In some instances, it was the other spouse that either did not agree with the diagnosis of ASD, or did not feel committed to what was required of them in terms of being part of the therapy process. In other instances, parents referenced sisters, brothers, moms and dads, and how they played a role in supporting the family through gaining access to services. For example, a working parent might have found it difficult to take the child to and from different appointments and sessions, but if they had support from family members to help commute and participate in the sessions, the child was more likely to make it to the session, but also to succeed when implementing the strategies in other places outside of the therapy session.

Finally, the last barrier as described by the parents in reference to accessing services was the impact it had on employment. Some parents described how hours had to be reduced, time had to be taken off, and some parents even had to leave the paid work force entirely. This can have a number of impacts on the parents and families.

Parents in the current research described ASD as being a financial struggle. With a reduced income and pressure to access private services, there is financial strain placed on their family. Second, some parents addressed how it made them feel in terms of their own self worth. When they reflect on what they have done professionally, they sometimes find it a struggle as their work has had to come second to the disability that their child is facing. No parents interviewed regretted this choice, but they did express that it was not an easy aspect of the journey.

5.1.1.2.3. Perspectives of the Service Providers.

Similar to the diagnostic process, providers expressed the overall need for an increase in providers. Many of the providers feel extremely overworked, and bogged down, with very little support for themselves as providers. At times this support meant a need for more providers, and sometime this support was referred to as psychological and mental support for the stressful jobs that these providers are performing. *Lisa,* the early childhood educator, spoke about "burnout being common in their field." With the demanding nature of her job, *Lisa* expressed being "disadvantaged and under valued" because her mental health was never supported.

The service providers also discussed the barrier of daycares. Many daycares in Newfoundland do not allow flexibility in scheduling, making services such as part-time daycare, difficult to access. Children either attend the daycare full time, or not at all. Although the service of part-time daycare is available, operators of these daycares tend to prefer full-time students to fill their spaces. The service providers noted this as a barrier as a lot of parents want their child to

be utilize the maximum amount of funded ABA therapy, but also want their child to be have socialization opportunities. Unfortunately, there are very few places where both of these options can be accommodated. The early childhood educator mentioned one specialized daycare that at one point was a school predominantly for children with ASD. This school used to serve as an environment for collaborating with outside professionals to improve and implement services being offered within the facility, specifically for children with ASD. In more recent years the school has actually become less ASD oriented, as the government now feels that children with ASD are already able to access available services, and as such, reserve the spaces at the specialized daycare for children with other developmental and behavioral needs.

The age constraints on accessing certain services within healthcare and the community is also an identified barrier by the service providers. Service providers are locked into an age constraint when referring children for services, or accepting them into their clinic for services. For example, *Michael* can refer a preschool aged child to any number of publicly funded SLPs or OTs. However, as soon as this child turns school age, the publicly funded SLPs will no longer service these children, as there are SLPs that exist within the school system. The problem identified by the SLP, *Lynn Ann*, that was interviewed is that the schools are responsible for such an enormous number of students, and their purpose is to have input into the student's individual educational plan, limiting their ability to spend extended periods doing one on one work with the child. The providers feel that this often results in a disadvantage to the child, as the child often still requires extensive one on one services. This is another common place whereby parents look outside the public system for private therapy.

The final barrier as expressed by the service providers is the general support of the parents. Similar to what is discussed above in the diagnostic process, service providers emphasized the significant rise is success with different therapy plans when the parents are fully

invested. The majority of the providers described success in achieving milestones, breaking down barriers and making significant gains when the parents attended the sessions, believed in the process, implemented the strategies at home and then followed up with service providers.

5.1.1.2.4. Reconciliation with the Literature.

Children are not able to access government funded services until the child has a formal diagnosis of ASD (Barton, Dumont- Mathieu & Fein, 2012). In Newfoundland families are spread out across a vast landmass which only has resources and personnel to provide a diagnosis of ASD in the main urban centres. This idea of geography posing such an impact on access is not uncommon in other locations, but is especially prevalent on an island as large and dispersed as Newfoundland. To date, although this is a common barrier faced by individuals everyday on the island, there has been no published research addressing its impact or ways to help alleviate its impact. Parents describe the travel time to and from appointments as something that contributed to the length of time it took to receive a diagnosis for their child. As stated above, children are not able to avail of the government funded services until a formal diagnosis has been met, meaning children having to travel long distances on numerous occasions to receive a diagnosis of ASD have their access to these services prolonged even more.

Mackintosh et al., (2012) analyzed six themes that emerged from their research pertaining to the satisfaction level of the services being accessed by parents of children with ASD. One of these six key themes being the costs associated with having to access services. This research however does not expand on the burden that is placed on the parents for having to fund private therapy while waiting for the publically funded therapy to have space available.

Limited research has been conducted pertaining to inter professional collaboration. In 2014, Hebert et al, conducted novel research pertaining to the collaboration between speech language pathologists and occupational therapists; just two of the key members who play a role

in supporting children with ASD. There were four key ingredients required to have successful inter professional collaboration identified in this research: shared objectives, shared strategies, joint treatments and on-going collaboration (Hebert et al, 2014). Although this was only making reference to two members of the collaborative team, the literature supported the findings of my current research which found that parents noted that collaboration between professionals such as the speech language pathologists as well as occupational therapists either was supportive to their child, or in its absence they expressed "it would have been easier if one specialist knew what the other specialist had planned". As was outlined by Herbert et al., if inter professional collaboration is to exist, the providers need to share objectives and strategies which appeared to be missing in professional relationship between the ABA therapists and the healthcare providers.

The literature review revealed limited research pertaining to the overwhelming need for more service providers for these children. The only relevant article pertaining to the lack of service providers was in addressing the lack of primary care physicians that had sufficient information on diagnostic tools, and were proficient in the utilization of these tools (Barton et al., 2011).

The literature briefly outlined the age limitations on ABA therapy (Corsello, 2005) which will be discussed in more depth in the following section specifically identifying the barriers associated with the implementation and follow up of ABA therapy.

In New Zealand a group of researchers looked at the accessibility of an early intervention program and one of the factors affecting accessibility of the program was the support by the parents (Birkin et al., 2008). A similar idea can be inferred from what the service providers were saying in the current research.

Other research found that families of children who have special health care needs often need to reduce their working hours, or completely stop paid employment in order to help support and manage their child's healthcare needs (Zablotsky et al., 2015).

5.1.1.3. Barriers Pertaining to Applied Behavioral Analysis Therapy.

5.1.1.3.1. Shared Perspectives of the Service Providers and the Parents.

In Newfoundland and Labrador, ABA is the only therapy which is funded by the government and as such is one of the main reasons why it was the main therapy discussed in the interviews. The most significant barrier as described by both groups was the recruitment and retention of home therapists. Parents and providers both emphasized how difficult it was to not only find a suitable home therapist to work with the child, but in addition, the struggle that is associated in keeping a therapist. Due to a number of reasons ranging from insufficient pay, incompatible personalities, other career opportunities and future education endeavors, home therapists have a reputation of having an incredibly high turn over rate. This has a serious negative impact on the progress of the child for a number of reasons. Firstly, a significant portion of the ABA program is geared around consistency. Without consistency, the program struggles to deliver gains to the child. In addition, there is a struggle associated with frequently inviting new workers into the family home, having the child adjust to a new individual and get into a new routine. The idea of developing and/or maintaining a team is a barrier that has been addressed in previous research (Johnson & Hastings, 2002). Johnson & Hastings (2002) identified problems with recruiting and training staff, general shortage in staff and lack of appropriate training for the staff implementing the intervention.

Although ABA is a government funded therapy in Newfoundland, there is a significant financial impact on the parents as there is a childcare provider required to be in the house at all time when ABA therapy is occurring. So although the government will fund the salary of the

home therapist, they do not offer funding for an additional childcare provider, nor do they offer a stipend for a parent to take the time off work and stay home with the child during therapy. This financial barrier was identified by service providers and parents in this study.

Closely related to this barrier is the idea of ABA being the sole therapy funded by the province. With ASD being described as a spectrum disorder, the name itself implies that there are many varieties, forms, and varying degrees of ASD. As such, the parents and service providers expressed concern that multiple forms of therapy are not supported or covered by the government. The question arises, "What happens when this therapy no longer works for the child?" "What happens if this type of therapy never works for my child?" "What happens to my child when they reach grade 3, and no longer are age eligible to avail of any government funded services?"

Providers and parents also brought to light the reality of the difficulty of generalizability of the skills being learned throughout the process of ABA therapy. The therapy involves the learning of several abilities and concepts based on the failing and succeeding of discrete tasks. Although this can be very effective in some instances, one of the main barriers arising with ABA is the generalizability of the tasks being learned. These children are learning skills in a very controlled environment, but are unaware of how to apply these skills into a real life setting. The approach of ABA therapy is not conducive to real life experiences, as the therapist and child are tied to being in one location usually with few distractions.

5.1.1.3.2. Perspectives of the Parents.

On several occasions the senior therapist was reported as being a barrier. This was related to the idea of parent- senior therapist connection, and essentially the senior therapist just not being a good fit for the family. This is a significant barrier as the senior therapist is the individual responsible for assessing the child, and creating a program for the home therapist to

implement. If the parents feel that the senior therapist does not have a good connection with the child or family, then it will be difficult to create an effective plan for the child, and the parents might be less likely to embrace the program if they feel that it is not best suited to their child.

A consistent barrier throughout all of the themes listed in this thesis is the lack of information for the parents. The parents reported entrance into the ABA program as no exception. For a lot of parents, hiring a home therapist was the first time they ever had to go through the process of recruiting and hiring an employee. For individuals that lack experience in this area, this process can be stressful. In addition, some parents report a lack of guidance from the senior therapist, and the ABA program. Parents had no idea where to look for home therapists, nor how to go about this process. The longer the parents are without this information, the longer the child goes without implementing their program. The longer they go without using their hours, is less overall time they will get to use therapy, as the hours missed do not rollover as the child gets older.

Another barrier reported by the parents regarding ABA was the invasiveness they felt with people coming into their home. ABA therapy occurs in the home, and as such, every time a new senior therapist is introduced, or a new home therapist comes to work with the child, the family and parents have to be comfortable with these individuals being in their home. Although this is a manageable barrier for the parents, it was reported as also causing significant stress to the families and parents of the children receiving therapy. This was supported in the literature by Johnson & Hastings (2002) who found that there was a negative impact on family life and and invasion of the home when implanting home based interventions.

5.1.1.3.3. Perspectives of the Service Providers.

This research brought to light several concerns from the service providers that the ABA program itself has just gotten too large. It was suggested that at this point the program is so

focused on pumping out "certified individuals" that they aren't investing time in training competent therapists, instead they are just trying to get as many certified as possible. The obvious problem with this, as expressed by both providers and parents is that many of the home therapists in the industry are not competent and are not effective in implementing the therapy. Unfortunately, there are not many ways to determine this without hiring the individual, trying it out, and then finding out whether or not it will be a success or failure.

As briefly mentioned above, service providers described the severe lack of inter professional collaboration in the creation of the ABA program. Within the program in Newfoundland and Labrador there is one SLP and one psychologist that participate in the creation of program goals. Service providers identified two significant limitations of the ABA program: First, there is nowhere near enough support staff for a program of this size. Second, the program was felt to not look for any outside input, guidance or recommendations when creating and building their program. Service providers not involved within the specific ABA therapy find this extremely difficult as they feel that there should be more collaboration between the services, so that the best and most efficient plan can be made for the child.

5.1.1.3.4. Reconciliation with the Literature.

ABA based programs are endorsed as being the gold standard for treatment of children with ASD in North America (Mcphilemy & Dillenburger, 2013). Research shows that ABA not only has a positive impact on the child's communication, behaviors and independence but it has also been shown to positively impact the family as a whole in reference to quality of life (Mcphilemy & Dillenburger, 2013). In the current research *Jill* indicated similar feelings to this research, however, the majority of the parents expressed having more barriers than facilitators associated with ABA therapy.

5.1.1.4. Barriers Pertaining to the Education System.

5.1.1.4.1. Shared Perspectives of the Service Providers and the Parents.

The most significant barrier in the education system, as indicated by the service providers as well as the parents, was the lack of education and training of the individuals working with the children with ASD.

Inclusion was brought up by both parents and service providers and was seen both as a barrier and a facilitator. This findings pertaining to inclusion were also unique to this study, with no evidence of this being a concern being found in the literature. In the past there has been a lot of conversation around the importance of inclusion and the goal of including children with different special needs and behaviors, such as ASD, into the regular classroom setting. However, both groups brought to the surface a reality that said the exact opposite. Service providers expressed that some parents are so concerned with having their child "fit in" and be included that they are either medicating them to a point that is not beneficial to the child, just in order to manage and control the behaviors, or the child is being forced into a classroom where they are acting out, and then forcibly getting removed from school. Providers also commented that children with ASD are academically behind children of their own age in some cases, but in other instances well above. They are however expected to sit side by side with these children and learn at the same rate.

The majority of parents interviewed also viewed inclusion in a similar light. They expressed that the idea of inclusion was of course the ideal, but the reality of their children is that being a part of the regular classroom might not offer the child the best opportunity for success in their learning. In this situation, the parents are completely supportive of the child not being in an inclusive environment.

5.1.1.4.2. Perspectives of the Parents.

In combination with the lack of education for the individual, there is also simply just not enough funding being provided to hire a sufficient number of support staff within the schools. Parents expressed it is stressful at the beginning of every year to find out whether or not their child would be approved to receive support in the classroom.

Another barrier observed by several of the parents was the designation of student assistants. Several parents reported requesting a student assistant. If they were successful in receiving support for their child, it wasn't always necessarily true that their child would end up getting the support. One parent reported the administration applying for support for her child with ASD because of specific safety concerns, and then it was revealed to the parent that the school felt they could manage their child fine, and they actually assigned the support for other students in the class that did not qualify for support. This caused the parents to be outraged as they felt there was a "scarlet letter" being placed on their own child for the benefit of something/ someone completely unrelated.

5.1.1.4.3. Perspectives of the Service Providers.

Instructional Resource Teachers (IRTs) interviewed for the current research explained that a student assistant who is assigned to a student in the schools could be anybody- no specific education or experience is required. In an instance such as this, how can one expect the individual to be experienced and proficient in managing children with ASD when they have no training in the area? Even IRT's who are qualified with special education degrees often do not have specific training in working with children with ASD. This research brought to light the lack of education and support of the service providers in the schools who are supposed to be working with the children.

5.1.1.4.4. Reconciliation with the Literature.

Literature exists pertaining to parents having reported the support workers as having low levels of perceived disability- specific knowledge regarding ASD (Tucker & Schwartz, 2013). A similar theme was raised in White (2014), whereby concern was expressed about the training and qualifications of teachers, paraprofessionals and the school staff addressing/ serving students with ASD. White (2014) notes that although there are often general in-services and training offered within the schools, these sessions are often not documented or monitored making it difficult to identify their effectiveness or determine who has attended them.

5.1.2. Facilitators.

5.1.2.1. Facilitators Surrounding the Diagnostic Process.

5.1.2.1.1. Perspectives Shared by the Service Provider and the Parents.

The significant facilitator shared by the parents and the service providers in the diagnostic process was the idea of advocacy. Both providers and parents agreed that if the parent was not going to advocate for the child, the child was unlikely to get a diagnosis, or some of services they deserve. In multiple interviews parents provided examples of sitting on doctor's doorsteps, seeking second, third and fourth opinions, continuously making follow up appointments with their doctor. Some reported triggering behavioral outbursts from their child while in a doctor's office, just to get the doctor to see what they as parents were seeing at home. Many of the service providers interviewed acknowledged the need for a parent to advocate for their child. In fact, most of them acknowledged that one of their key roles as providers was to empower and encourage the parents to advocate for their child. At a time where money is being budgeted and monitored so closely, health, community services and education budgets are stretched, providers are barely able to provide the services they feel are absolutely necessary. In this case, the parents are the ones that need to own the responsibility, embrace being the expert in

their child, and advocate for the services that the child requires. However, this is not a simple responsibility to own as some parents will be more confident and more successful with it than others, creating yet another inequity.

5.1.2.1.2. Perspectives of the Parents.

Several of the parents recalled past experience as being a facilitator to receiving a diagnosis. What they meant by this was if they had a child who had previously been diagnosed with ASD, or if they had a close friend or family member who had been through the process, this helped facilitate what the parents next move would be. With taking past experience into consideration, the parents knew the best ways to receive a diagnosis, where to look for therapies, and what to look for in terms of services and getting on wait lists. Individuals who had no experience with the diagnostic process faced a significant barrier of not having enough information to be making the best and most effective decision for their child's care.

As was similarly described in the section on service providers, family involvement is key in success. The parents described the weight that was lifted off their shoulders when they had support from their partners and families. The parents who struggled with convincing their families of their realities, were the parents who reported experiencing a lot more stress during the diagnostic process.

5.1.2.1.3. Perspectives of the Service Provider.

One of the main struggles as mentioned by several service providers was communication between the providers. Often times there is not sufficient follow up occurring between physicians and support workers and because of this there is a lot of information that is not being shared that could improve outcomes. Community service providers expressed barriers in communication due to certain professionals being restricted from providing input, or posing inquires to other professionals. For example, a child management specialist is not allowed to go into the schools

and make recommendations or inquiries based on activities/ therapies that are happening within the schools. Speech language pathologists experience a similar barrier. Only speech language pathologists working in the school board can make recommendations to the school.

It was mentioned that in rural settings, communication was actually easier. The reason for this being that a lot of "informal" communication occurs. Some therapists may run into an IRT or a teacher in the supermarket and might end up having a conversation about a student or a client. They might discuss different experiences or stories that leave an impact on the provider, which in turn takes it into practice within their facility.

The pediatrician also expressed a lack of communication, especially between psychology, occupational therapy, and themselves. All providers expressed having very busy schedules and as such it is difficult to make time to schedule meetings with other providers, attend school meetings and discuss in a collaborative setting the care of every single child that each professional treats.

As mentioned in the previous section, lack of parental support can pose a significant barrier in the diagnostic process. However, if the parents are on board, and support the physician in the diagnostic process the significant gains that can be made by the child has been proven.

5.1.2.1.4. Reconciliation with the Literature.

Advocacy as it pertains to children with ASD has been described by parents of these children as a key coping strategy which enables them to move forward by redirecting their emotion and making them into action (Boshoff et al., 2018).

Another study showed the effects of training parents of youth with autism spectrum disorder on how to advocate for their adult disability service (Taylor, Hodapp, Burke, Waitz-Kudla & Rabideau, 2017). Although this study focused on accessing adult services, the findings that parents felt more comfortable advocating for services for their child with ASD and felt more

empowered is applicable to this study in that a program that teaches a parent to advocate for their child may support them in accessing more services.

An article pertaining to family support and how it dissipates hopelessness and loneliness in mothers who have a child being diagnosed with ASD was discovered (Ekas et al., 2016). In this article the researchers identified that hope was directly associated with the amount of family support being offered by the family (Ekas et al., 2016).

5.1.2.2. Facilitators Surrounding Accessing Healthcare and Community Services.

5.1.2.2.1. Perspectives Shared by the Service Provider and the Parents.

Interestingly, this section regarding shared perspectives on the facilitators to accessing healthcare and community services actually yielded only one sub-theme that was shared by the two groups.

From all of the providers and parents interviewed, one very consistent facilitator regarding the access to healthcare and community services was the quality of services being offered by professionals. All participants spoke very highly of their co-workers, other workers in the field, and their providers. Not one participant offered any examples to one area of service that lacked quality, and as such, there were no particular services, or service providers to avoid. This acted as a facilitator to accessing care, as families did not need to be looking to avoid certain services or providers.

5.1.2.2.2. Perspectives of the Parents.

From the perspective of the parents, they felt as though communication among the service providers was acceptable. As such, it was acknowledged that they were pleased with coordination of care, and that continuity did not serve as a barrier to accessing services.

Parents spoke frequently of the importance of family involvement. They discussed it as barrier in some cases, as discussed above, but they also described the facilitating role that it played when extended family supported the parents and the family through accessing services.

Parents identified the number of services available for their child to be plentiful, and as such acted as facilitator to accessing services. As mentioned, persons interviewed in the urban centre reported having more service options to choose from, whether it be healthcare or community based.

The majority of parents also spoke highly of the parent support groups that they joined. Several of the groups were composed of other mothers and fathers. Sometimes these groups included parents of children who were diagnosed recently, and some who had received a diagnosis for their child five years prior. The value of these support groups as stated by the parents was that they provided the parents the opportunity to hear stories from other people going through similar experiences as them, good and bad. Although parents often felt at a loss when it came to managing the large amount of information directed at them, they found support within these groups, as they were able to talk it through with other people just like themselves. For the parents that still participated in these groups years after their child had been diagnosed, they felt as though they were doing a return of service. Many of them expressed feeling satisfaction and gratitude for being able to offer advice and hope, as now they were already five years into their journey with ASD.

5.1.2.2.3. Perspectives of the Service Provider.

When service providers outlined what Newfoundland and Labrador was doing well in reference to providing and assisting in access to healthcare and community services they offered several examples of items which can be presented in paradox to some of the barriers that were listed. For example, geographic location can be a significant barrier for families from rural and

remote communities. Location is a definite barrier, posing problems for initial assessments, access to therapy options as well as follow up appointments. However, families living in urban centres, have ample opportunities to access community services as well as healthcare services. Wait times are still an issue in urban centres, however, as proximity is so close, appointments can be made on much shorter notice, and with a lot more flexibility, and as such, location was often referenced as a facilitator for service providers in urban centres.

Another sub-theme that came up in paradox by the service providers was the idea of parental support. Respondents reported a number of situations where not having the parents on side is posing a barrier to receiving a diagnosis, and accessing services. What is meant by this is the parents are not wanting a diagnosis of ASD for their child, and as such are looking for other explanations or options for their child, further delaying the diagnosis and access to therapy However, it is also equally likely that the parents are supportive of the doctor's diagnosis and recommendations, which results in the support from the parents being an important facilitator when moving forward and trying to access services.

The final example of paradox in this section was the theme of coordination of care and communication with service providers. Many of the hospital based healthcare professionals reported having good coordination of care, and good communication between other healthcare staff. The providers from the hospital did acknowledge that being in the same space supported this coordination, as collaboration only required walking down the hallway to get a second opinion or recommendation. However, private and public service providers from outside the main tertiary hospitals indicated that communication was less open and much more difficult.

Service providers in this current research have said that the government is starting to appreciate the need for more service availability in rural areas, and slowly they are allocating further funding to allow this to be implemented. For example, several occupational therapists

have just been funded to service areas 45- 90 minutes outside of the main urban centre, hoping that it will reduce some of the travel time and wait times for families coming from rural areas.

5.1.2.2.4. Reconciliation with the Literature.

Other than what has been discussed previously, there was limited research supporting these facilitators, resulting in the majority of these findings being unique to this study. However, there was one article found that contradicted some of findings of this thesis relating to the satisfaction levels for the services they were receiving. Macintosh (2012), reported that the majority of participants "disliked" the services they were receiving (Macintosh et al., 2012). Although there were no universally liked or dislike services in particular, as a whole they had expressed displeasure with their experience. In this current research, this was not the case. Although addressing many barriers to accessing care, once utilizing the service, all the participants in this study expressed satisfaction with the services.

5.1.2.3. Facilitators Surrounding Applied Behavioral Analysis.

5.1.2.3.1. Perspectives Shared by the Service Provider and the Parents.

As mentioned several times throughout this thesis, parent and family support was an agreed upon facilitator when implementing ABA therapy for a child. The more supportive and dedicated the family was the more success was achieved in therapy. This was a common standpoint of both provider and parent.

The effectiveness of the ABA Therapy was agreed upon by the majority of parents, and approximately half of the service providers. Some of the providers agreed with the parents in saying that ABA is indeed effective and can help "unlock" the children using this therapy. The other half of the service providers did not necessarily say the therapy was ineffective, but they had expressed areas of concern in different aspects of the program, whether it be the teaching method or the end result of being able to generalize the skills learned. Although discussing

aspects of the program that they did not like, no providers interviewed described the program as ineffective.

5.1.2.3.2. *Perspectives of the Parents.*

The parents agreed that one significant facilitator pertaining to the ABA therapy is that it is funded by the government. Although parents were still required to pay for childcare, as well as any additional tools or props needed for the ABA, the services of the home therapist as well as the senior therapist were funded, and this served as a significant facilitator for parents. Parents also outlined yet again that family support acted as facilitator for ABA therapy.

5.1.2.3.3. *Perspectives of the Service Provider.*

There were no unique findings from the service providers when discussing facilitators to the ABA program.

5.1.2.3.4. *Reconciliation with the Literature.*

Through a review of the literature, there was very limited research pertaining to the facilitators associated with ABA therapy and as such, the findings of this thesis are unique.

5.1.2.4. Facilitators Surrounding the Education System.

5.1.2.4.1. *Perspectives Shared by the Service Provider and the Parents.*

There was only one sub-theme that was shared by both groups as being a facilitator within accessing care in the education system: inclusion. As mentioned in the previous section, inclusion is one of the sub-themes that is perceived as both a barrier and facilitator. Inclusion serves as a facilitator when it works for the child. Both parent and provider shared the view that if the child was able to be challenged and succeed in a positive way while participating in the regular classroom, then without any hesitation inclusion is a facilitator for the child.

5.1.2.4.2. Perspectives of the Parents.

Parents mentioned that although the first point of contact made with teacher always had to be initiated by the parent themselves, once the lines of communication were established, they were effective. This idea of open lines of communication served as a facilitator because any time a situation arose that needed to be managed, if a recommendation or an inquiry had to be made, there was a process set up to be able to address it.

5.1.2.4.3. Perspectives of the Service Provider.

One of the significant facilitators as expressed by the service providers is the implementation of Individual Support Services Plans (ISSP), and the Individualized Education Plan (IEP). Between these two programs the abilities, goals, plans, services and implementation strategies are outlines for the individual with any special needs, but in the case of this research, ASD. Professionals within the school, and sometimes within the community and or healthcare services come in to the school to discuss the creation or updates for a child's individual plan. The reason that the ISSP and the IEP is such a facilitator is because it keeps all of the information regarding the child in one centralized location. These documents are made readily available to any person within the school system that will be working with the child. When the files are regularly reviewed and kept up to date, they can serve as an effective method of facilitating care for the child while they are at school.

Within the school system, the participants in this current research reported having good collaboration between principals, teachers and support workers. Although it was acknowledged that this is not always the case because depending on the size of the school, the willingness of the administration to support their staff as well as the families, and the dedication of the support workers a very different outcome can be yielded. However, in the interviews conducted for this

research, providers reported that communication and collaboration was a facilitator to administering competent and effective care to the children with ASD.

   5.1.2.4.4. Reconciliation with the Literature.

   There is literature pertaining to the value of inclusion for children with ASD, and how the school was considered to be key in creating an environment to enable inclusion (Falkmer et al., 2015).

   The literature outlines both parents and school professionals to be critical stakeholders in the creation and implementation of the ISSP and IEP (Tucker & Schwartz, 2016). This article outlines the benefits of being able to set, manage and obtain goals if these plans are organized and kept up to date (Tucker & Schwartz, 2016).

   It was determined that one of the most critical interactions between teachers and parents is being able to successfully communicate and problem solve. In most cases, this ability to communicate is actually more important than any direct intervention (Azad et al., 2016). Communication has been recognized as a facilitator of collaboration (Azad et al., 2016). When parents were unable to participate and offer input to the child's ISSP or IEP, there was indicative of a break-down in home- school communication and therefore there was a lot of associated displeasure (White, 2014).

5.2 Recommendations

   Although there were differences in the recommendations made by the service providers and the parents, based on what they felt to be the most significant barriers in their journey, there were several suggestions from both groups.

   Both providers and parents suggested the creation of an agency to manage and support ABA therapy services in the province of Newfoundland and Labrador. As was covered in depth in the above discussion of the barriers of ABA therapy, one of the most prominent barriers was

the idea of retention and recruitment of home therapists, and this was expressed by both groups. By establishing an agency, individuals could be trained using a common curriculum thus minimizing therapists not receiving proper training. This would create a reservoir of therapists, all located in one area, making the task of finding a home therapist easier. This way parents would have one place to look for therapists, and would know that they are getting fully certified and well trained individuals as a possible candidate to work with their child. One parent even recommended the local colleges combining ABA training with early childhood education. It could be advertised that there is dire need for service in this area, enticing individuals to look for education/ work in this field. By modifying the early childhood education programs local colleges could offer opportunities for people to become certified and involved with this very prevalent and employable field.

Another common recommendation of service provider and parent was to emphasize and focus on the crucial role a public health nurse could play in the identification and diagnosing of ASD in young children. If public health nurses had more specific training in ASD they would be more competent at identifying signs and symptoms at an earlier age, thus getting the child underway to receiving a diagnosis earlier, resulting in earlier access to ASD services. Although public health nurses do have the authority to refer children to a developmental pediatrician, the majority lack the training to recognize the early signs of ASD. Ideally there should be further training offered to improve these skills, resulting in improvement in early identification and early intervention.

Both groups also wholeheartedly agreed on the necessity of having an increase in the number of service providers available to these children, regardless of age. Whether it be more occupational therapists, speech language pathologists, psychologists, social workers or developmental pediatricians. As it stands, there are significant wait times in all aspects of the

journey (diagnosis, treatment and follow up). If there was in increase in the number of service providers available, the wait times would naturally decrease and more individuals would get the care and treatment they require.

Another recommendation shared by both parents and service providers is the idea of increased support groups for parents. Several of the interviews indicated the power and positive impact that support groups had on the some of the parent's experience of navigating the system. However, it was also clear that many people did not have access to such groups, or were unaware of the groups that existed. There needs to be an increased number of groups as well as clearer, better organized information being offered to parents about these support groups. As it stands when a child receives a diagnosis, the parent is typically overwhelmed and uncertain about what they should do next or what the standard practices are. A clinic or information centre would be a useful resource for parents to seek information about ASD, and would create a natural location for exchange of information between families and service providers. An information centre would play a key role in housing information pertaining to possible services, impacts of services, reasons for certain therapies, ways to find therapists and other important information. In Newfoundland there is a non for profit organization, the Autism Society of Newfoundland and Labrador (ASNL). However, through the course of these interviews, the ASNL was not discussed as a resource by any of the parents interviewed. Another recommendation is to improve the awareness and accessibility to this society, as the ASNL could be a key player in terms of advocacy, providing services and training other professionals around ASD.

Finally, the last recommendation that was shared by both groups was the idea of eliminating the concept of there being only one funded behavioral therapy for these children. In Newfoundland and Labrador, the government supports and funds the ABA program for children diagnosed with ASD. However, as has been very clearly outlined, ASD is a very individual

neuro-developmental disorder. No two children present identical symptoms or behaviors, yet it is expected that every child be treated with the same therapy and benefit and improve with the same therapy. Both parents and providers have recommended that the government should instead offer funding to families for a therapy of choice for their child with ASD. For some families ABA might work well. For other families, ABA might not work at all. And for some families, ABA might start out as being an excellent experience for their child, but as their child changes, advances or develops, ABA may no longer be beneficial to them. This does not mean that the child is no longer in need of support or therapy of some kind, it just means they are no longer benefit from ABA. The problem currently is that if and when this happens, the child and family are without any other funded options. They are left to their own resources to pay for any further or different therapy they prefer, leading to significant financial strain.

Service providers voiced several recommendations of their own. Many of them recommended more inter professional collaboration. Each discipline has an area they are most proficient in, for example, occupational therapists have a focus in activities of daily living, while speech pathologists are focused on speech, eating and swallowing, However, if there was an opportunity to collaborate as professionals, discuss possible treatment options and then share input and recommendations to the daycares and schools that these children are attending, there could be significant gains in the progress of the child. As it currently exists, care is often disrupted and disjointed. Also with improved collaboration and communication between service providers, other primary health care providers, like public health nurses and family physicians, would become aware of the signs that occupational therapists, speech language pathologist and developmental pediatricians are looking for in terms of diagnosis or progress in treatment.

5.3. Strengths and Limitations

By exploring the strengths and limitations of the current study, insight into future directions of this research are possible. Perhaps by outlining some of the strengths and limitations, other researchers may be compelled to addresses the limitations and further explore ASD services in Newfoundland and Labrador.

5.3.1. Strengths.

One of the strengths of this study is the use of multiple perspectives. It allows for an examination of the differences in how parents and service providers perceive access to care in Newfoundland. Another strength in this research was that to date, there is limited qualitative research pertaining to or exploring the barriers and facilitators to access to care for children and youth who have been diagnosed with ASD. Through the literature review it was revealed that some research pertaining to certain aspects of ASD had been explored in other parts of the world, however, there was still a significant gap existing from the perspective of the parent and the service provider and their accessibility to ASD services in Newfoundland.

Another strength of this research work is its place within the larger research project, ACCESS-MH (Tilleczek et al., 2014). Being a part of the larger team provided opportunity for proper training in qualitative techniques and opened doors to recruitment opportunities that might not have been accessible otherwise. The protocol and documents used to carry out the interviews were created within this larger project and as such were created by qualitative experts and were done with a high level of rigour (Tilleczek et al., 2014).

A major strength of this study is that one individual researcher was used to establish relationships, make connections, recruit individuals, conduct the interviews, analyze the data and disseminate the results. It allowed the research process to be consistent between all participants being interviewed for this study.

5.3.2. Limitations.

One of the more significant limitations that can be addressed regarding this study is generalizability. This research was only conducted in one province in Canada. Depending on where else this type of research is conducted and whom the research is conducted with, there could be significantly different findings. However, this idea does relate back to the initial disclosure that ASD is a very individualized neuro-developmental disorder. As such, most parents and service providers will have a very unique experience of what serves as barriers and facilitators in their journey. However, it would be very interesting to be able to compare themes that would arise between parents and service providers from other provinces.

Another limitation was that there were only a small group of providers included in this study. Expanding the perspectives of the different service providers involved in the care of a child with ASD would be valuable.

The method of convenience sampling can also pose as a limitation. Purposive sampling can sometimes be viewed as biased as the individuals who volunteered to participate in the study may not be a full representation of the population from which the sample came from (Burns & Grove, 1977)

Another useful extension would be to have experiences for the participants across the life course. In this study the data were obtained from the individuals at one instance in time. Their perspective's may differ based on where they are in their journey such as pre- diagnosis, during diagnosis, post diagnosis, and several years after reflecting back. Or for the service providers, when they first enter the field, when they are extremely busy in their work, or in retirement, looking back on what they had seen or experienced in their time. It is the intention of the larger ACCESS_MH project to conduct longitudinal analysis with willing participants to see how their journeys have shifted, morphed or evolved after several years.

5.4. Concluding Remarks

There are many factors which can impact and influence access to care for ASD. Although the primary focus of this thesis were barriers and facilitators to this access, an important finding to note is that the barriers and facilitators changed based on what portion of the journey the child/ family was travelling through at that time. For example, the barrier of wait times in accessing a diagnosis could be different or similar to a barrier of wait time in accessing speech language pathology or occupational therapy once the child has been diagnosed. A clear picture now exists in this small group of providers and parents who have experienced providing or accessing care. For both the service providers and the parents, the main barriers and facilitators were expressed in the diagnostic process, in accessing individual community and healthcare services, ABA therapy as well as the education system.

The most significant recommendations were focused around better organization of the ABA therapists, improving the knowledge and emphasizing the critical role a public health nurse could be playing in identifying early signs and symptoms of ASD, increasing funding to employ more service providers to help reduce wait times, creation and advertising of more support groups for the parents who are at a loss when it comes to the overabundance of information being given to them upon their child receiving a diagnosis of ASD and an improvement in inter-professional collaboration. In addition, a consistent and significant finding was the idea of increasing the flexibility in how funding is allocated and being used for therapies within the island. As expressed, ABA may not be effective for all individuals with ASD nor will one specific therapy necessarily suit one child through their life journey with ASD.

These findings have provided some insight into the provincial health system in Newfoundland and Labrador and have outlined where some improvements can be made in order to address some of the barriers to care. This research has also highlighted stories from the parents

and the service providers: their struggles, frustrations, saving graces, success and failures in dealing with the healthcare, education and community services in the province of Newfoundland and Labrador. It has also presented the perspective the service providers. By collecting stories from two perspectives the research offers invaluable stories and insights into how the systems are working, and how they are failing from a multifaceted approach, providing the opportunity to share feedback for health researchers and policy makers.

These journeys are unique and offer a snapshot of what is happening with parents trying to access neuro-developmental support for their child. This study is a small piece of a larger project which is exploring access and care in the child and youth mental health system across all four Atlantic Provinces in Canada. This type of research in Newfoundland is novel, and as such, leaving plenty of avenues for further research within this field. The findings of this research may provide guidance and insight for the Provincial Government, Autism Research Exchange groups or for the Autism Society of Newfoundland and Labrador to build upon. With this being said, it is critical for the existing programs, services and groups to be continuously re-assessed to help ensure best practices are in place for these populations, in accordance with both population needs as well as newly developed literature.

In conclusion, through recommendations made by the participants of this study, coupled with future research in the area, it is hoped that future research will reveal an improvement in the accessibility and deliverability of these neuro-developmental and mental health services.

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Health **R**esearch
Ethics **A**uthority

Appendix A— Parent Consent to Take Part in Research

TITLE: Barriers and Facilitators in Access to child/Youth Mental Health Services

Project Website: http://access-mentalhealth.ca/

INVESTIGATOR(S):

Principal Investigator – Memorial University
Dr. Rick Audas

Principal Investigators
Dr. Kate Tilleczek, University of Prince Edward Island
Dr. Scott Ronis, University of New Brunswick
Dr. Michael Zhang, Saint Mary's University

Post-Doctoral Fellow
Dr. Brandi Bell, University of Prince Edward Island

SPONSOR: The funder of this research is the Canadian Institutes of Health Research (CIHR).

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you do take part, you are free to leave at any time. If any questions make you feel uncomfortable, you are free not to answer them.

Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:
* discuss the study with you
* answer your questions
* keep confidential any information which could identify you personally
* be available during the study to deal with problems and answer questions

1. **Introduction/Background:**
   Child and youth mental health is a growing concern in Canada. The Canadian Mental Health Association now estimates that 10-20% of Canadian youth are affected by a mental illness. This

research is of interest in Atlantic Canada because of the reported rate of these disorders in the region. For instance, 30-35% of young (grades 7-12) women and 15-20% of young (grades 7-12) men in the Atlantic provinces show higher signs of depressive symptoms and close to 30% of Canadian high school girls engage in weight loss behaviours although many of them are not overweight. Focusing on Atlantic Canada presents both opportunities and challenges. The relatively small population and similar health care approaches provides an opportunity to make a difference in the region.

2. **Purpose of study:**

The key research objectives of the study are to: (1) document service delivery and care in the four provinces through analysis of large datasets and personal patient journeys, and (2) use this information and operations research to recommend more effective approaches to service delivery for mental health conditions.

3. **Description of the study procedures:**

We will record and analyze how treatment is received across government and non-government areas including Health, Education, Social Development, Public Safety, and Youth and Family Services. We will collect a variety of information from 240 individuals (80 children/youth, 80 parents, and 80 service providers) from across the Atlantic Canadian provinces (PE, NB, NS, NL). To do so, we are using interviews along with a picture/photo process. Information collected will be shared and compared across provinces.

4. **Length of time:**

If you choose to participate in this research project it will take 90-120 minutes of your time. You will be asked to participate in an interview of 60-90 minutes to talk about your child's journey with mental health. Prior to the interview, you will be asked to find 3-5 visual images that you feel represent your child's journey in some way and to bring these to the interview (this is not required, but can be a helpful way to think and talk about your/your child's experiences). At the beginning of the interview, you will be asked to fill out a socio-demographic survey which will take about 15 minutes. The interview will be audio-recorded. During the interview you will be asked to create a 'journey map.' This will involve placing items representing people, places, and things on a blank board to help show what your child's journey with mental health has been like.

This project will continue for four years and some participants will be asked to participate in a follow-up interview similar to the first (approximately 60-90 minutes). You can indicate whether you can be contacted for this purpose on the attached Consent Form.

5. **Possible risks and discomforts:**

We know of no harm that taking part in this study could cause. Researchers have been trained regarding the mental health conditions they are studying as well as techniques to encourage participation while limiting the risk of an emotional exit from interviews. Counseling services will be made available to participants who require them.

6. **Benefits:**

You may not benefit directly from this study. There is no guarantee that your participation will directly lead to changes in mental health services or changes in your or your child's experiences in the mental health care system.

A summary of the results will be available for participants. If you are interested in receiving the summary, please provide your contact information on the attached Consent Form. We will also ask you about the best ways to provide the study results to you. We are committed to sharing our research findings with our participants and those who are in a position to make positive changes for young people.

7. **Liability statement:**

    Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. **What about my privacy and confidentiality?**

    Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However, it cannot be guaranteed. For example, we may be required by law to allow access to research records.

    When you sign this consent form you give us permission to
    *   Collect information from you
    *   Share information with the people conducting the study
    *   Share information with the people responsible for protecting your safety

    <u>Access to records</u>
    The members of the research team will see study records that identify you only by a number or a code name in the final transcript.

    Other people may need to <u>look</u> at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by a member of the research team.

    <u>Use of your study information</u>
    The research team will collect and use only the information they need for this research study.

    Your name and contact information will be kept secure by the research team. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

    Information collected for this study will be kept for 15 years.

    If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study.

Information collected and used by the research team will be stored in a locked cabinet at the University of Prince Edward Island. Dr. Kate Tilleczek is the person responsible for keeping it secure.

<u>**Your access to records**</u>
You may ask the researcher to see the information that has been collected about you.

<u>**Exceptions to Confidentiality**</u>
Due to legal and ethical requirements, the research team must break confidentiality if:
1) The interviewer becomes aware of child abuse or neglect of someone who is under the age of 19 in NB/NL, 18 in PEI, 16 in NS or;
2) The interviewer becomes aware of sexual abuse perpetrated by a health care professional toward an identified adult or child; or
3) The interviewer becomes aware that the participant is threatening harm to oneself or another identified person.

9. **Questions or problems:**

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is: Dr. Rick Audas.
Principal Investigator's Name and Phone Number
Dr. Rick Audas
709-777-8867

The Research Ethics Boards of UPEI, UNB, SMU, and MUN have approved this research project. If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, or the ethical conduct of this study, you may contact the relevant Research Ethics Board (REB) associated with the province you are located. Contact information is noted below:

Province	University REB	Contact Information
PEI	UPEI	(902) 620-5104, reb@upei.ca
NB	UNB	(506) 453-5189, ethics@unb.ca
NS	SMU	(902) 420-5728, ethics@smu.ca
NL	Health Research Ethics Board (NL)	(709) 777-6974, info@hrea.ca

10. **Declaration of financial interest:**
The members of the research team have no conflicts of interest to declare.

After signing this consent you will be given a copy.

Signature Page

Study title: Barriers and Facilitators in Access to child/Youth Mental Health Services

Name of principal investigator: Dr. Rick Audas

By signing this form, I agree that:
1) *I have read and understood this consent form.*
2) *The study has been explained to me. All my questions were answered.*
3) *The possible harms and discomforts of this study have been explained to me.*
4) *I understand that I have the right to refuse to take part in this study. I also have the right to withdraw from this study at any time. e.g., before or even after the recordings are made.*
5) *I can ask any questions about the study at any time now and in the future.*
6) *I have been told that all research information will be kept confidential, except where required by law (e.g. suspected child abuse, court subpoena).*
7) *I understand that no information that would identify me will be released or printed.*
8) *I understand that no information about me (including recordings) will be given to anyone or be published without first asking my permission.*
9) *I understand that I can keep a copy of the signed and dated Consent Form.*

To be filled out and signed by the participant:

	YES	NO
I agree, or give consent, to participate in an interview		
I agree, or give consent, to be contacted to participate in a second interview in about 2 years' time If yes, please provide contact details (email or phone):		
I agree, or give consent, to being audio-recorded as part of this study		
I agree, or give consent, to have my selected images photographed as part of this study		
I agree, or give consent, to have my 'journey map' photographed as part of this study		
In addition, I give permission for the photographs and interview data to be used on the project website, http://access-mentalhealth.ca/ (understanding that I will not be identified in any way)		
In addition, I give permission for the photographs and audio recordings to be used for additional research projects on the same topic		
I agree, or give consent, for data collected from this study to be used in future publications such as dissertations, journal articles, and books		
I agree, or give consent, to allow the use of anonymous quotations from my interview in research reports (understanding that I will not be identified in any way)		

_____   _____   _____ _
Signature of participant   Name printed   Year Month Day

To be signed by the investigator or person obtaining consent

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

_____ - _____
Signature of investigator   Name printed   Year Month Day

Telephone number: _____

I understand that a short summary of the research results will be available to participants at some point in the future.

I would like to receive this summary: ___ Yes ___ No

Please indicate how you would like to receive the summary:

Mail to home _____   Email to you _____
Other _____

Please provide a mailing or email address:

Name: _____
Organization (if applicable): _____
Street Address: _____
City: _____ Province: _____ Postal Code: _____
Email: _____

HealthResearch EthicsAuthority

Appendix B— Service Provider Consent to Take Part in Research

TITLE: Barriers and Facilitators in Access to child/Youth Mental Health Services

Project Website: http://access-mentalhealth.ca/

INVESTIGATOR(S):

Principal Investigator – Memorial University
Dr. Rick Audas

Principal Investigators
Dr. Kate Tilleczek, University of Prince Edward Island
Dr. Scott Ronis, University of New Brunswick
Dr. Michael Zhang, Saint Mary's University

Post-Doctoral Fellow
Dr. Brandi Bell, University of Prince Edward Island

SPONSOR: The funder of this research is the Canadian Institutes of Health Research (CIHR).

Your have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you do take part, you are free to leave at any time. If any questions make you feel uncomfortable, you are free not to answer them.

Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:
• discuss the study with you
• answer your questions
• keep confidential any information which could identify you personally
• be available during the study to deal with problems and answer questions

1. **Introduction/Background:**
   Child and youth mental health is a growing concern in Canada.The Canadian Mental Health Association now estimates that 10-20% of Canadian youth are affected by a mental illness. This

research is of interest in Atlantic Canada because of the reported rate of these disorders in the region. For instance, 30-35% of young (grades 7-12) women and 15-20% of young (grades 7-12) men in the Atlantic provinces show higher signs of depressive symptoms and close to 30% of Canadian high school girls engage in weight loss behaviours although many of them are not overweight. Focusing on Atlantic Canada presents both opportunities and challenges. The relatively small population and similar health care approaches provides an opportunity to make a difference in the region.

2. **Purpose of study:**

The key research objectives of the study are to: (1) document service delivery and care in the four provinces through analysis of large datasets and personal patient journeys, and (2) use this information and operations research to recommend more effective approaches to service delivery for mental health conditions.

3. **Description of the study procedures:**

We will record and analyze how treatment is received across government and non-government areas including Health, Education, Social Development, Public Safety, and Youth and Family Services. We will collect a variety of information from 240 individuals (80 children/youth, 80 parents, and 80 service providers) from across the Atlantic Canadian provinces (PE, NB, NS, NL). To do so, we are using interviews along with a picture/photo process. Information collected will be shared and compared across provinces.

4. **Length of time:**

If you choose to participate in this research project it will take 90-120 minutes of your time. You will be asked to participate in an interview of 60-90 minutes to talk about your experience assisting youth and families dealing with mental health challenges in your province. Prior to the interview, you will be asked to find 3-5 visual images that you feel represent the current mental health system in your province and to bring these to the interview (this is not required, but can be a helpful way to think and talk about your experiences). At the beginning of the interview, you will be asked to fill out a socio-demographic survey which will take about 15 minutes. The interview will be audio-recorded. During the interview you will be asked to create a 'journey map.' This will involve placing items representing people, places, and things on a blank board to help show what you perceive a typical child's journey with mental health is like in your province.

This project will continue for four years and some participants will be asked to participate in a follow-up interview similar to the first (approximately 60-90 minutes). You can indicate whether you can be contacted for this purpose on the attached Consent Form.

5. **Possible risks and discomforts:**

We know of no harm that taking part in this study could cause.

6. **Benefits:**

You may not benefit directly from this study. There is no guarantee that your participation will directly lead to changes in mental health services.

A summary of the results will be available for participants. If you are interested in receiving the summary, please provide your contact information on the attached Consent Form. We will also ask you about the best ways to provide the study results to you. We are committed to sharing our research findings with our participants and those who are in a position to make positive changes for young people.

7. **Liability statement:**

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. **What about my privacy and confidentiality?**

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However, it cannot be guaranteed. For example, we may be required by law to allow access to research records.

When you sign this consent form you give us permission to
- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

<u>Access to records</u>
The members of the research team will see study records that identify you only by a number or a code name in the final transcript.

Other people may need to <u>look</u> at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by a member of the research team.

<u>Use of your study information</u>
The research team will collect and use only the information they need for this research study.

Your name and contact information will be kept secure by the research team. It will not be shared with others without your permission. In addition, neither you nor your agency will be directly or indirectly identified in any publications, and any information you provide will be aggregated with data we collect from other participants.

Information collected for this study will be kept for 15 years.

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study.

Information collected and used by the research team will be stored in a locked cabinet at the University of Prince Edward Island. Dr. Kate Tilleczek is the person responsible for keeping it

secure.

Your access to records
You may ask the researcher to see the information that has been collected about you.

Exceptions to Confidentiality
Due to legal and ethical requirements, the research team must break confidentiality if:
1) The interviewer becomes aware of child abuse or neglect of someone who is under the age of 19 in NL/NB, 18 in PEI, or 16 in NS;
2) The interviewer becomes aware of sexual abuse perpetrated by a health care professional toward an identified adult or child; or
3) The interviewer becomes aware that the participant is threatening harm to oneself or another identified person.

9. **Questions or problems:**

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is: Dr. Rick Audas.
Principal Investigator's Name and Phone Number
Dr. Rick Audas
709-777-8867

The Research Ethics Boards of UPEI, UNB, SMU, and MUN have approved this research project. If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, or the ethical conduct of this study, you may contact the relevant Research Ethics Board (REB) associated with the province you are located. Contact information is noted below:

Province	University REB	Contact Information
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10. **Declaration of financial interest:**
The members of the research team have no conflicts of interest to declare.

After signing this consent you will be given a copy.

Signature Page

Study title: Barriers and Facilitators in Access to child/Youth Mental Health Services

Name of principal investigator: Dr. Rick Audas

By signing this form, I agree that:
1) *I have read and understood this consent form.*
2) *The study has been explained to me. All my questions were answered.*
3) *The possible harms and discomforts of this study have been explained to me.*
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To be filled out and signed by the participant:

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I agree, or give consent, to participate in an interview		
I agree, or give consent, to be contacted to participate in a second interview in about 2 years' time If yes, please provide contact details (email or phone):		
I agree, or give consent, to being audio-recorded as part of this study		
I agree, or give consent, to have my selected images photographed as part of this study		
I agree, or give consent, to have my 'journey map' photographed as part of this study		
In addition, I give permission for the photographs and interview data to be used on the project website, http://access-mentalhealth.ca/ understanding that I will not be identified in any way)		
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I agree, or give consent, for data collected from this study to be used in future publications such as dissertations, journal articles, and books		
I agree, or give consent, to allow the use of anonymous quotations from my interview in research reports (understanding that I will not be identified in any way)		

_____   _____   _____

Signature of participant   Name printed   Year Month Day

To be signed by the investigator or person obtaining consent

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

_____   - _____

Signature of investigator   Name printed   Year Month Day

Telephone number: _____

I understand that a short summary of the research results will be available to participants at some point in the future.

I would like to receive this summary: ___ Yes ___ No

Please indicate how you would like to receive the summary:

Mail to home ____   Email to you ____
Other _____

Please provide a mailing or email address:

Name: _____
Organization (if applicable): _____
Street Address: _____
City: _____ Province: _____ Postal Code: _____
Email: _____

Appendix C— Parent Patient Journeys Interview – Time I

Note: Use developmentally appropriate language and a conversational approach; focus on narrative.

Questions and Probes:

A) **Early signs (retrospective)**
   ➤ Could you describe what was happening in your child's life when you first felt they would need support for their mental health? (family, school, friends, community, spiritual, other)
   ➤ What happened next? (probe with each of family, school, friends, community, spiritual, etc.)
   ➤ Were you pleased about this action or response? Why/why not?
   ➤ Start a journey map, what would be main elements of life journey at this time?
   ➤ What worked/did not work well for your child? (at all levels- ACCESS and CARE)
   ➤ What would you have liked to have seen happen? (at all levels)
      o What kind of support do you wish had been available in the beginning? (e.g., more information on support services or wait times, financial support, people to talk to, etc.)
      o What would you do differently?

B) **Entering the system (or not)**
   ➤ After this initial phase, what happened when you and your child were looking for support for their mental health? (family, school, friends, community, spiritual, other)
   ➤ What happened next? How long did you wait? What did you do?
   ➤ Were you pleased about this action or response? Why/why not?
   ➤ Return to the journey map, what would be the main elements of your life journey now?
   ➤ What worked/did not work well for you? (All levels, ACCESS and CARE)
   ➤ What would you have liked to have seen happen?
   ➤ What part did school, teachers, mental health, allied professionals, community supports, others play in this journey? How and what happened?
   ➤ What care services were available to you? How were those services coordinated? Was there any repetition in what was offered (redundancy)? How do you think services could be improved?
      o Did you pay for any services? Are you willing to pay for a better or faster service? How much?

C) **Exits and Returns**
   ➤ Were there any times in which your child left the system? Why? What happened?
   ➤ Did your child return? Why, how, what happened?

D) Recommendations and Directions (prospective)

- ➤ If you could speak to family doctors (therapists, teachers, other parents, kids, others) what would you like them to know about your child's journey?
- ➤ If you could make three recommendations for fixing the youth mental health system, what would they be?
  - ○ What services should be provided? Which services should be redesigned to work better for you?
- ➤ If you had a chance to map a system of youth mental health care in your province, what would it look like? Where would the young people and families begin and end in a perfect journey? Where are they mainly beginning and ending at present? (ACCESS and CARE)

Appendix D — Service Provider Patient Journeys Interview – Time I

Note: Use developmentally appropriate language and a conversational approach; focus on narrative.

Questions and Probes:

A) **Early signs (Access and issues)**
  ➢ What is generally happening in a child's life when they first need support for their mental health? (family, school, friends, community, other)
  ➢ Your intake process and data - evidence
  ➢ What happens next?
  ➢ Are you pleased about this? Why/why not?
  ➢ Start a journey map, what would be main elements of this time of a child's life?
  ➢ What works/does not work well for these children? (at all levels)
  ➢ What would you like to see happen? (at all levels)
      o What kind of support do you wish was available for these children?
      o What resources do you wish you had? What resources do you wish they had?
      o What would you do differently?

B) **Entering the system (or not)**
  ➢ What works/does not work well for the youth and families that you work with?
  ➢ What would you most like to see happen in an optimal journey?
  ➢ Do you (does your agency) use an ecological approach? Explain and state reasons.
  ➢ How do you collect and use evidence in your work?
  ➢ Coordination with others – is this necessary? If so, is it sufficient? What, how, what works, does not work in coordination at present?
  ➢ What issues do you see with continuity of care?
  ➢ What are common barriers and facilitators (personal, system and environment)?
  ➢ Primary, secondary and tertiary interventions – what do you use, why and what works/does not work - what has been tried and what should be tried? – WHY?
  ➢ Do the children you work with have to wait for services? How long? What causes these wait times? In what way could your services be improved?
  ➢ What supports are available to service providers to help them provide effective care/interventions?
  ➢ Cost benefit analysis of these interventions – have you had chance to do them? What would you like to say about this?

C) **Exits and Returns**
  ➢ What are the most common barriers to getting the help needed for mental health conditions?
  ➢ What are the most common facilitators for getting help?

D) Recommendations and Directions (prospective)

➢ If you could speak to family doctors (therapists, teachers, parents, kids, others) what would you like them to know about youth mental health journeys?

➢ If you could make three recommendations for fixing the mental health system, what would they be?

➢ If you had a chance to map a system of youth mental health care in your province, what would it look like? Where would the young people and families begin and end in a perfect journey? Where are they mainly beginning and ending at present?

Appendix E— Recruitment Support Letter

Title of Research Project:
Barriers and Facilitators in Access to Child/Youth Mental Health Services

Project Website: http://access-mentalhealth.ca/

Principal Investigator – UPEI
Dr. Kate Tilleczek   (902) 620-5127

Principal Investigators
Dr. Rick Audas, Memorial University of Newfoundland
Dr. Scott Ronis, University of New Brunswick
Dr. Michael Zhang, Saint Mary's University

Post-Doctoral Fellow
Dr. Brandi Bell, University of Prince Edward Island

Dear _____,

We are conducting research designed to develop a better understanding of the impact that mental health conditions have on children/youth, caregivers, service providers (e.g., health, education, social development), and society. We also aim to identify barriers to access and promising practices across the four Atlantic Canadian provinces (New Brunswick, Prince Edward Island, Nova Scotia, and Newfoundland and Labrador). An Atlantic Advisory Board with members from each province is helping to guide the project. We will be speaking with children/youth, parents, and service providers in each province.

The goal of this project is to take a diverse and innovative approach to studying how services are provided to children and youth identified with any of the following five mental health conditions: anxiety, depression, autism spectrum disorders, conduct disorder, and eating disorders. We intend to document and analyze how treatment is received across government and non-government sectors including Health, Education, Social Development, Public Safety, and Youth and Family Services. We will collect a variety of information from 240 individuals (80 children/youth, 80 parents, and 80 service providers). To do so, we are using interviews augmented with a visual mapping process (i.e., participants will have an opportunity to create a 'picture' of a journey through mental health using materials provided). Information collected will be shared and compared across provinces.

We are asking your assistance in recruiting participants into this project. If you are interested in helping us with recruitment, please contact Cathy Peyton at cpeyton@mun.ca or 709-777-8868, to discuss the demographic we are looking for.

We will be sharing the results of this project with participants in short summaries over the course of the project. If you are interested in receiving these summaries and/or the final report of the study, we will be happy to share them with you. The sponsor/funder of this research is the Canadian Institutes of Health Research (CIHR).

Thank you for considering our request.

Sincerely,

Dr. Rick Audas

The Research Ethics Boards of UPEI, UNB, SMU, and MUN have approved this research project. If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, or the ethical conduct of this study, you may contact the relevant Research Ethics Board (REB) associated with the province you are located. Contact information is noted below:

Province	University REB	Contact Information
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NS	SMU	(902) 420-5728, ethics@smu.ca
NL	Health Research Ethics Authority (MUN)	(709) 777-6974, info@hrea.ca

ACCESS-MH: Resources in Newfoundland **Please call 911 in the case of an emergency.** **Kids Help Phone:** 1-800-668-6868 Website: kidshelpphone.ca Find More: www.kidshelpphone.ca/ResourcesAroundMe/ **Canadian Mental Health Association - NL** Phone: (709)753-8550 Toll Free: 1-877-753-8550 Website: cmhanl.ca/ **Central Intake for Children and Youth** Phone: (709) 777-2200 **Outreach, Promotion and Prevention Services** Phone: (709) 777-5074	**ACCESS-MH: Resources in Newfoundland** **Please call 911 in the case of an emergency.** **Kids Help Phone:** 1-800-668-6868 Website: kidshelpphone.ca Find More: www.kidshelpphone.ca/ResourcesAroundMe/ **Canadian Mental Health Association - NL** Phone: (709)753-8550 Toll Free: 1-877-753-8550 Website: cmhanl.ca/ **Central Intake for Children and Youth** Phone: (709) 777-2200 **Outreach, Promotion and Prevention Services** Phone: (709) 777-5074
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Appendix G— Stakeholder Email Invite

Dear _____,

We are conducting research designed to develop a better understanding of the impact that mental health conditions have on children/youth, caregivers, service providers (e.g., health, education, social development), and society. We also aim to identify barriers to access and promising practices across the four Atlantic Canadian provinces (New Brunswick, Prince Edward Island, Nova Scotia, and Newfoundland and Labrador). An Atlantic Advisory Board with members from each province is helping to guide the project. We will be speaking with children/youth, parents, and service providers in each province.

The goal of this project is to take a diverse and innovative approach to studying how services are provided to children and youth identified with any of the following five mental health conditions: anxiety, depression, autism spectrum disorders, conduct disorder, and eating disorders. We intend to document and analyze how treatment is received across government and non-government sectors including Health, Education, Social Development, Public Safety, and Youth and Family Services. We will collect a variety of information from 240 individuals (80 children/youth, 80 parents, and 80 service providers). To do so, we are using interviews augmented with a visual mapping process (i.e., participants will have an opportunity to create a 'picture' of a journey through mental health using materials provided). Information collected will be shared and compared across provinces.

As a service provider who works with children/youth with mental health conditions, we would like to invite you to participate in this project. Please see the attached Information Letter. If you are interested, please contact Cathy Peyton at cpeyton@mun.ca or 709-777-8868, to schedule an interview.

The sponsor/funder of this research is the Canadian Institutes of Health Research (CIHR).

Thank you for considering our request.

Sincerely,

Dr. Rick Audas

The Research Ethics Boards of UPEI, UNB, SMU, and MUN have approved this research project. If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, or the ethical conduct of this study, you may contact the

relevant Research Ethics Board (REB) associated with the province you are located.
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NS	SMU	(902) 420-5728, ethics@smu.ca
NL	Health Research Ethics Authority (MUN)	(709) 777-6974, info@hrea.ca

Name: _____   Date: _____

Thank you for your volunteer participation in our research project *Barriers and Facilitators in Access to Child/Youth Mental Health Services*. Volunteers are the backbone of social science research; without you, we could not do our work.

We are sincerely grateful for the time you have dedicated to our project. You have willingly shared your experiences with us and helped us to ask informed questions of other young people in Atlantic Canada. We hope that the opportunity has been as valuable to you as it was to our research team.

You have been part of an important and ground-breaking research project. The information you have shared has provided valuable insight regarding the impact that mental health conditions have on children, caregivers, service providers (e.g., health, education, social development), and society. This information will help educators, government, and communities develop programs and policies to enhance the life experiences of young people.

Thank you again for your time and expertise. We trust that your future employers and educators will also see the value in your volunteer work with us. We will keep you informed about the work we are doing and invite you to visit our website to learn more at http://access-mentalhealth.ca/.

Sincerely,

Kate Tilleczek, PhD
katetilleczek.ca
Professor and Canada Research Chair
Director, Young Lives Research – UPEI
Research Scientist (Adjunct)
Hospital for Sick Children, Toronto, Canada

Appendix I— ACCESS-MH Patient Journeys - Interview Debriefing Script

That is all the questions that I have for you. Do you have anything else you like to add or any questions for me?

Thank you very much for sharing your journey with me. It is very important to us that we hear from children, youth, parents and service providers to learn more about what it is like for children and youth to experience mental health challenges and the mental health system.

[consult completed consent form]

Before you leave, I am going to take photographs of the images you brought and of your journey map (according to consent). [take photos]. Would you like to take your images with you or should I keep them?

We know that talking about these things can be difficult. Here is a list of resources in case you'd like to talk to someone. [provide laminated card with list of resources tailored to province, including local CMHA information]

Thanks again for your time. Here is a Certificate of Volunteer Participation (for child/youth and parent participants) and some compensation for your time/funds to cover your costs. [provide certificate; have participant sign receipt and then provide cash]

We will send you information about the study at a later time according to what you put on your consent form. In the meantime, if you (or your parents) ever have any questions about the research, feel free to contact us using the information on the copy of the consent forms that you (and your parents) have.

Appendix J— Interview Checklist

Prior to the interview

 Digital recorder (in full working order) [take 2 if available]

 Digital camera (in full working order)

 Extra batteries

 Receipt book

 Honoraria, child care & travel costs (if applicable and prearranged)

 Participant ID code (put on Face Sheet and say into recorder at beginning of interview) [get this from Brandi]

 Consent/Assent forms (x2 – one copy for us, one for participant)

 Face Sheets (x2 – one copy for participant to follow if needed, one to be filled in; both to be returned)

 Interview protocol

 Journey Mapping Kit

 Certificate of Volunteer Participation (if applicable – for child/youth & parent/guardian participants)

 List of Services (if applicable – for child/youth & parent/guardian participants)

After the interview

 According to the participant's consent form, take photographs of their images and journey map.

 For child/youth and parent/guardian participants: Enter the participant's name on the Certificate of Volunteer Participation and give document to participant.

 For child/youth and parent/guardian participants: Provide them with the List of Services.

 For child/youth participant: Provide honorarium and applicable travel or child care costs and have them sign the receipt book.

 For parent/guardian participant: Provide any applicable travel or child care costs and have them sign the receipt book.

Return to local field coordinator

 Digital recorder(s)

 Digital camera

 Journey Mapping Kit

 Signed consent form

 Extra consent forms

 Completed Face Sheet

 Extra Face Sheets

 Receipts for honoraria, child care, and/or travel payment

Appendix K- Chronological Coding Document

4_2_013_1: Maureen (Children: Lucy and Paul)

EARLY SIGNS
- Couldn't eat
- Other quirky habits that people thought were funny- didn't put it together (age 1)
- Took a year and a half to get diagnosed
- Paul walked late
- Paul at 18 months started demonstrating classic signs of ASD- this time, Maureen knew exactly what it was

SERVICE PROVIDERS
Public health nurse- give it a break, come back in a few weeks
Family Doc- same as nurse
- Kept going back to GP just to be told same thing over and over- it'll all work out, be patient
Pediatrician -
- All wanted us to hold off,
- Lucy got an ear infection so they went to Janeway, and Ped (different than before) started seeing behaviors and recommended getting tested for autism
Developmental pediatrician:
- Didn't like first one, so asked for another
- Loved the second- "some of the fog was starting to clear"
  - Once in with the develop ped, have never had issues availing of her service- very accommodating and accessible to the patient/ families (FACILITATOR)
  - Skips regular hospital protocol to accommodate for patients
  - Trusts her thoughts and recommendations 100%
  - "I trust her implicitly"
  -
Psychiatrist:
- Lucy still wasn't talking- this doctor put her on a drug, and two weeks to the day she woke up and started talking

Senior therapists- had multiple before they connected with one that they liked and could work with

DIAGNOSIS
- Process of getting diagnosed, and time of diagnosis cause ups and downs in life – "hilly"
- "All your dreams, and all your hopes and all what you envisioned in life was kicked out of you, right here."

EMOTIONAL REACTIONS
- Mental breakdown when husband said couldn't take child to the vet
- Once diagnosed "we kinda blindly went through it all"

- "bawlin and cryin and phoning everyone"- when Lucy ate solid food for the first time (cheese)
- second child diagnosed- wasn't "upset" per say, parents just went into game mode, because they knew what was required of them this time around
- wasn't all rosey- but was going to get the child from A-Z- this is what kept Maureen going
- "I felt like someone at an accident scene that's invisible, that people were supposed, big cities it happens to someone stabs people on the side walk and everyone's just walkin by no one's helpin. That's how I felt."
- **Stupidity-**
- **Hopelessness**
- **Suicidal**
- **Longing**- to win the lottery
- **Anger-**
  - o angry at church- why god?
- **Excitement**-when they succeed at something (accomplishments)
- sometimes she feels trapped and destroyed, other times she is elated and happy and dancing
- rollercoaster of emotions-

ABA
- Second or third therapist (in less than 2 years)
- "No ABA is better than bad ABA"
- availed of ABA as soon as, and for as long as possible
- lack of resource for therapists- no pool
- just went 7 months w/o ABA because couldn't find anyone to even apply, net alone hire for the job
- so much involved in this program, and so many individuals who are "certified" and have no clue what they are doing
- requires someone in addition to the therapist at home for therapy (childcare costs)
- decreases in hours as child gets older (BARRIER)- "Apparently Autism disappears and you get no ABA therapy funded by the government after grade 3"
- "ABA therapy is a Band-Aid solution"

EMBARRASMENT
- Kept her behind a year in school, didn't know how to send her to school with baby food
- When children have meltdowns

FAMILY
- Mentioned husband- saying no to the vet idea
- Dad
- Husband- very independent (half stubborn)- denied some services offered to him at first, but came to realize they were of huge advantage
- Dad comes in for camps
- Dad is Maureen's hero
  - o Also gets along well with husband

- Lack of connection with her own mother
  - But she still helps around the house and with the kids- makes things easier for sure
- Husband- partner in everything- sees eye to eye and is a great support through this journey
  - ASD has had no impact on their marriage

WAITLISTS
- Waitlisted for everything and anything people thought might be helpful
- Second time parents knew to waitlist for everything.. if he possible didn't need it- but at least they had him ready if he did
- Average waitlist ~18 months- but its not. More like 24 months- this family could afford private.. but not all families can
- Waitlist for develop ped second time around was zero- just took Paul with Lucy to next appointment
- Waittimes make it long and hard
  - ○

LACK OF RESOURCE
- Found true for Maureen over the last ten years of trying to navigate the system
- No good resource (in reference to ABA) to dip into

LACK OF INFO
- Didn't try other services because wasn't aware of what was out there
- So many questions- what why, whats going, whats wrong
- Had no idea her chances were increased to have another child with ASD ater she had one

KNOWLEDGE
- None in the beginning
- But as you go through the process you learn
- Once the second child was diagnosed with ASD, they had their own wealth of knowledge to draw on, so it was easier

RECOMMENDATIONS
- Offer offer ABA training in colleges in combination with early childhood education- promote the practically 100% job hirability
- Create a sound "bank" of individuals that families can go to to find qualified individuals to offer ABA
- Qualified bank of people, training and provision of ABA therapists (example to old age services/agencies)
- Colleges are "sitting on a goldmine here"- make money of off tuition by guaranteeing practically 100% employability – SUPPLY AND DEMAND
- **"To the money people"**- putting all this money into drug rehab for people that choose to do it to themselves, and have no plan on stopping it anytime soon
  - "my kids did nothing wrong. I did everything right when I was pregnant"- still do not get the same financial support or services as drug addict cousin

- o   need more money- for OTS, speech, everything
- **CONA people**- wake up and tap your industry
    - o   Modify the ECE program and offer opportunities for people to get certified and involved with the social science paramedical field- and include further training for ABA within it
- **Government people**- create a provisional governing body for these certified individuals
    - o   Make health care and education your two primary focusses to put your money into
- More public health nurses and GPS to be more aware and educated in ASD- this disorder is not typical, and these are the professionals who are encountering these children at the early ages
    - o   They don't necessarily need to diagnose but maybe they can help point in the right direction
- Create a clinic for people to go to to get more information, get answers, and maybe even a diagnosis- but at the very least, information for the parents PRIOR to the diagnosis so they can get informed and prepared
- Perhaps if the government offered more than just one option for therapy, it would speed up some waitlists because people would have more choice
    - o   Allow for their to be a combination of therapies- every child different, they all need different things
- Need to stop ending the support at grade 3- children are still needing it in certain forms after this point
- Don't need financial aid in the form of actual cash handout- they just need more services from the government

OTHER THERAPIES
- Art, music aquatic, equestrian, social thinking- all provided through a centre in town
    - o   Flexibility within these services when it comes to addressing specific need of child
    - o   Most were not funded and all had to be paid for in addition to other costs

TECHNOLOGY
- APPLE PRODUCTS- "Steve Jobs as patron saint of Autism."
    - o   Apps and ipads were so helpful with verbal, relaxation
- Paul would be on his ipad all day every day if he could

FINANCIAL (Barrier)
- $25000 a year for childcare- which is required for ABA
- - money for other therapies
- cost of private speech/ OT/massage
- a lot of frustration associated with the idea of lack of financial support
- they can't access certain services because on paper they make too much money- but then its putting them in debt, because they have to pay for all the services they are accessing
- "Parents are physically, mentally and financially drained"
- "average family is in debt 25-100 K in debt because of Autism"
- needed to refinance house

- don't go on vacation- can't afford to- "paying off Autism"
- they are working class, making money- on paper look like they have an income of over 100,000 dollars BUT they are paying off student loans, paying for services and paying to put food in their parents fridge
- ABA is "free" but associated costs (child care, therapies, additional hours) all are expense out of your own pocket

SCHOOL SYSTEM
- no poor dealings
- daily contact with the teachers
- accommodating
- transportation to and from school
- student assistants
- accommodating for Paul-making school work for his specific needs, helping him improve
- provided Paul the opportunity to gain huge strides (words, socialization etc)
- uses take home notebooks to help ensure good communication with parents

WORK
- very accommodating with schedule

COMORBIDITITIES
Anxiety- comes on with change in routine for Paul
- also anxiety with Lucy

COPING
- store the horrid stuff- survival tactic
- try to remain hopeful
- surround yourselves with others in a similar situation to you
    o go to understanding environments (pirate camp)
- child is still going to get from A-Z-
    o "There's nothing bad that's going to happen. Over my dead bdoy. We're all going to get to Z. We just don't know how."
- Still have plans and goals for her kids
    o Kids have fears, and barriers, but they will get to the end!
    o Wants them to go to university- aspirations for them

SUPPORT
- find out very quickly who your real friends are
- camps for children with ASD
    o they all understand the situation: wandering, exercises, etc
    o it creates a sense of familiarity, a send of understanding and a sense of family for persons who understand what we do and see every day
- trying to care for children with special needs, and parents who need support
    o need financial help

4_2_015_1 : Patricia (Child: Luke)

SERVICE PROVIDERS
GP- same old story, "boys don't develop as fast as girls"
    - GP never got on board- so they bypassed her
didn't get the help they needed
Pediatrician- also missed the signs
**"we were in the system with the pediatrician and then developmental pediatrician. Voicing our concerns but they weren't being addressed or investigated in any way."
Develop Ped- not seen until after the second child was born and after they started OT and speech
    - put on a wait and see process- stayed here from when Luke was 18 months until he was 3.
    - used personal connection to get in to see develop ped- sat outside her office
"And that's when we got into the developmental paediatrician. It wasn't through referral. It was because you know, out of desperation"

    -still sees develop ped once a year
Senior Therapist- amazing relationship
-believe sthe success of Luke was because of the senior therapist- owes her everything
Psychologist- working with Patricia and Luke now in going through the process of telling Luke he has ASD
Daycare Workers- before diagnosis, never ever contacted the parents. Once diagnosed, they would call for everything

Home therapist- when they finally got the right fit- she was basically family. She went on family vacations with them. Cared for the sister AND Luke.

EARLY SIGNS
- wasn't hitting milestones
- issues with texture of food
- no gestural communication
- participated in lots of extracurriculars- as they noticed gaps in his development, they availed of more community services to try to help build upon gaps or delays

SERVICES
-started private OT and speech
- had speech and OT come to house, which is even more expensive, but less wait time again
- started at daycare- but ended up getting pulled- didn't like the focus that was put on his ASD- wanted Luke to be treated more "normal"
- saw a psychologist for child and for parent

WAIT TIMES
- first in waiting for private- not that long
    - could speed it up even more by paying for them to come into the home
- once diagnosed, VERY LITTLE wait times - was supposed to be 18 months, they got in after 6 weeks

- lost 1.5 years worth of ABA waiting to get a diagnosis

  - WL to see psychologist is 2.5 years !!! Need to go private- anxiety attacks need to be addressed
  - An OBVIOUS barrier- all throughout the beginning.
    - Delayed diagnosis, therapy, support etc

ADVOCATING
- was about to get pushed out the door again, and Patricia triggered a meltdown in Luke
"And we were getting ready to be pushed out the door again to be honest and, I knew a lot of his anxiety triggers , so I kind of, provoked him, He had a complete meltdown at the developmental pediatricians' office, to which time she felt that that time it was a good time to have him assessed."
- type of parents that when he couldn't speak, we spoke of him.
- paperwork struggle to get a therapist started working with Luke- Patricia threatened to sit and call the news in order to share her story and advocate for her child to get what was needed done
      "I would never consider myself a confrontational person, or, a bully to get my way. But you gotta be those things to get the job done."

-"Sitting on the sidelines, you're not getting anywhere. Right?!"

COMORBIDITIES
Anxiety
- Luke has anxiety triggers- led to the initial assessment for diagnosis of ASD
- biggest issues to overcome pertained to Luke's anxiety
- child's anxiety manifested in a physical form- was aggressive to mom- stress caused early delivery on second child
- Luke can now talk through his anxiety
- Patricia attended conferences to learn about understanding and dealing with Luke's anxiety.
-the only thing he still struggles with is anxiety
-when he gets sick, he gets more anxious, and can't handle it as well
-bullying in school brings out anxiety also
-most anxiety attacks are in private of own home

Hearing loss
- 30% loss- no wonder he was anxious

EMOTIONS
- **Relieved** - but angry about diagnosis (took too long)
-**stressful**- setting up ABA
- **overwhelmed** form constant visitors into your home (Senior therapist, home therapist, speech, OT, psychologist)
- **desperation** - to get a diagnosis
- **sad (crying)**- when talking about Luke being physical
-**guilt**- carried huge guilt- questioned her actions during pregnancy etc
      - very sick during second childs pregnancy, so Nicholas was in a playpen a lot (crying here

again)
    - guilt didn't exist just for the child with ASD- because so much focus on the child with ASD, the other sibling learning disability was missed
    - "there's a guilt component to that. Because you're so consumed by the needs of the special needs child. That sometimes the typical child can get lost."
    - feel like a neglectful mom

-**frustration**- "losing marbles" with the lack of coordination of information
    - also frustrated over the fact they lost 1.5 years of therapy while waiting to get in to get a diagnosis

    - also get frustrated with the people that say he was misdiagnosed- he wasn't misdiagnosed, he worked hard to get where he is with his therapy

DIAGNOSIS
- took a year and a half- way too long
- delayed diagnosis meant paying for own services out of pocket
- told family right away
    - was harder to tell friends
        - Patricia wanted Luke to be treated as Luke, not as a child with ASD- so they decided against (still to this day,) not telling some friends

SUPPORT
- disorganization upon onset of diagnosis
- no support for the HUGE amount of information being thrown at them
- lack of coordination of information between the health care and community service providers
- once diagnosed, parent support group became a good place for learning of opportunities and idea

ABA
- stressful- hiring your own therapist
- first therapist didn't fit
    - caused a lot of anxiety- hiring, firing
- generally difficult to keep home therapists
- program worked really well for Luke- started school less than two years later as a "typical little boy"
- didn't use basic ABA program- senior therapist adopted one form the states (unbeknownced to the health authorities)
    - child flourished in this program
- key in the success of this program was consistency from EVERYONE involved
-once Luke turned 6, he ha the opportunity to avail of ABA until he was 8, but parents declined because Luke was doing so well
- first therapist was hired within a month of diagnosis (not too bad of a wait time)
- but took 4 months to find a therapist that actually fit with child and family (BARRIER)
    - All as a result of "redtape"
-basic ABA would not have worked for her child

- need the more detail oriented break down from the States
     - this wasn't offered by the provincial healthcare- but the senior therapist went above and beyond and made it happen
- highly recommend ABA- but it's not for everyone
- negative aspects of ABA- used to a 1 on 1 setting- can't really apply their skills in "real life" environment or with other people around
     - struggle when they have to be in a classroom with others to learn and apply skills
-ABA is NOT for everyone

FINANCIAL
- had to shell out money for private because couldn't get a diagnosis
- the double the salary of the ABA therapist to help try to find a good reliable one
- tough- trying to get the best services with the means they had
- being able to afford to attend the Geneva conference
-really feel for the families that can't afford the countless associated costs

FAMILY
- takes toll on family (immediate and extended)
- family wasn't supportive originally. Thought that Patricia had issues (not sure i this was because of being ashamed, or just doubting the idea)
     - caused more stress- and Patricia had to start seeing a psychologist
- at one point her husband wasn't supportive- and for the sake of Luke, and his need for support and consistency, Patricia told her husband he could go
     - eventually came around, but still some programs he did not want any part in
- aggressive behaviours from Luke were also very hard on family
- no support on husbands side
- her parents worked- little support

- Sister of the child with ASD played a significant role in the therapy of the child with ASD. Helped Luke learn to take turns, share, listen etc- just as a buddy in general
- Sister was social butterfly which helped him interact socially
- Sister is amazing at re-direction (without even knowing it)- helps navigate anxiety
     o Effects on the sister- "left out child"- and missed out on a lot of opportunities she would have probably normally had if they hadn't needed to be so dedicated and sensitive to the child with ASD

EDUCATION
- Patricia had an undergrad in Kines- helped her notice early signs
     - also helped her to know that the basic ABA was not going to work for her child- worked with senior therapist to accommodate the ABA program to be more suited to her child
- reached out to a past educator as one of her first branches of support when Luke was diagnosed
- went to the Geneva conference- to educate herself on opportunities and possibilities for children with ASD

TYPICAL/ NORMAL
- wanted her son to be treated normal
-" I don't want him to be special. I want him to be just like everybody else"- in reference to his daycare experience
- placed Luke in as many "typical programs" as possible (swimming, music etc)
    "Our goal was we wanted him to role model typical children."
- once Luke was doing so well (Age 6) they stopped ABA so that he didn't have to miss out on some of the typical social things occurring after schools when he would normally be doing ABA
- Attended the Y program- home therapist would go with him… but they did the program created by the Y
-"Learning to take turns…and be a kid"
-wanted him treated typically in schools- didn't want student assistants unless it was ctually necessary
-never wanted luke's diagnosis to be a crutch
- social experiences aided by attending different events: golf camps with typical kids

COPING
- parent support groups- extremely helpful
- had facilitators for the support meetings
availed of library and social story boards from the community society for autism
-at the age the child is currently at, he is able to find the positive in situations- helps everyone with coping

SCHOOL SYSTEM
- Wanted to hold him back a year- but mom was encouraged to let him attend with his peers
- He struggled forming social bonds, but academically thrived
    o Especially with boys- easier with girls
        ▪ Because of hearing loss- couldn't play contact sports
- Small class sizes helped
- Good communication through the schools and with the teachers – but always introduces herself to the teacher at the beginning of each year
- Thrives academically
- One year they tried to give him a SA and it was revealed later that it wasn't for Luke, but rather it was because there were a lot of kids with behavioral issues in the class
    o Patricia denied this, not only because it was wrong, but because it placed a scarlet letter on her child for no reason
- BULLYING- is a huge issue in school- which evokes anxiety
- Felt schools have victimized her son because of his diagnosis
- Some teachers were great, some were awful- reality of school system
- Doesn't specifically gravitate towards kids with ASD- doesn't hang out with cool kids, or the ones that nobody likes- he's in the middle

WORK
- Had to quit her job to be home for therapy
  - o HARD- causes one to reflect on self worth and success- NO REGRETS

RECOMMENDATIONS
- **Moms**- trust your gut
  - o Advocate!!!!- believe that YOU are the expert in your child
  - o Take into consideration the advise of experts, but trust your own expertise more
    - ▪ "Believe what you want to believe. Try what, Try whatever you can try"
- **Educators/ Service Providers**- LISTEN MORE
  - o "I think there's a real lack of listening component. There's definitely a lack of compassion."
- **Inclusion**- not ALWAYS a good thing. – every child is different, and it depends what is best for each specific child.
  - o "Like fi you want to meet his needs, is that the right environment for him to be in? Like I said, I'm all for inclusion, but I think there are exceptions

TECHNOLOGY
- Luke is obsessed with technology, and would live on it if he could

4_2_020_1 (Parent: Jill and Son: Markus)

EARLY SIGNS
- Fussy baby right from beginning-
- Limited speech
- Although service providers didn't think in the beginning- mother knew child had ASD
- A family member had mentioned ASD being in the family- and that's what planted the seed when she started noticing abnormal behavior
- Didn't seem to be exhibiting " typical" behaviors- but this can sometimes be chalked up to age (they're just young) AND he's a little boy so he "develops slower"

SERVICE PROVIDERS
- Pediatrician- was being followed for something completely unrelated
    - Mother inquired to the ped at this point RE: ASD, but pediatrician did not think that that was the case
    - Was initially "relieved" by the doc not thinking so- but this was temporary as Jill was confident that Markus had ASD
    - Had him waitlisted for speech by the time Jill returned, and agreed to waitlist him for the remainder of the ASD services
- Two years between getting ped on board, and seeing develop ped
- Developmental pediatrician- once Jill finally got in with Markus to see them, they completely agreed with ASD, and didn't even go through the ASD testing
- Senior Therapist- good relationship

DIAGNOSIS
- Doc did not think at first that it was ASD- delay in diagnosis
- Then had to wait on waitlist to see developmental ped to get a diagnosis
    - Took a year to get the diagnosis
- Was diagnosed at age 3 years, 4 months

EMOTIONS
Frustration- with pediatrician who didn't think it was ASD
Grateful- about the impact the specialized Day Care has had on both Jill and Markus
Worry- about sending him to a regular school
- Worried about the support he will receive
- How much training do these support workers have in schools?
Guilt- why does my child have ASD? What could I have done differently- but can't focus on this every day

WAIT TIMES
- Waitlist for speech
    - Did private speech in the meantime
    - Was in in less than a year
- Waitlist for developmental pediatrician-
    - Waited a year for diagnosis !
- Waitlist for OT

SERVICES/ THERAPIES
- Speech
  - o Services at the hospital have been really good for this
- OT
- Tried music therapy- but wasn't a good fit for Markus
- Markus is very active so needs to be in active activities
- Gymnastics- class for children with ASD
- Day Care (specific for children with special needs or special circumstance
- ABA
- Swimming through the local Autism Society
- Availed of direct home services PRIOR to the diagnosis
- Inquired to develop ped about alternative services- she offered nothing
  - o Even though family was willing to travel etc

ABA
- Has been a definite barrier/ challenge
- Is currently on 4th therapist in a year
  - o Some go back to school
  - o Some just don't work
- Really hard to hire all these therapists while dealing and coping with the reality of the diagnosis
- Don't mind people coming into their home- which is a huge bonus with this therapy- as this could be extremely stressful to people who don't like people in their space
- Direct home services therapist turned into their ABA senior therapist (very lucky)
- Hiring the therapists, and the ABA process is where Jill feels there has been a lack of support, and a gap
- Sometimes you doubt the process of ABA- but then you see its gains in certain activities and successes the child has
  - o Progress for Markus was slow at first, but he is now getting more gains, and as such, Jill feels better about the ABA program
- If a parent can't afford to give up work, or afford to pay for childcare-the child misses out on the opportunity to avail of ABA- really sad and "wrong"

FACILITATORS
- Good speech services at the hospital
- Developmental pediatrician was very good and supportive
- Day Care had incredible support for Markus, and for Jill
- Appears to be good coordination of care between medical service providers
- Hospital team: speech and OT- offer fantastic services
  - o Offered so much support and advice for in home care, not just at his appointments
    - ▪ Offer the tools needed to apply it at home and in real life
- Public is becoming more aware of Autism

FAMILY
- Didn't lean on family right away- more conservative

- o But when opening up to family, they were all supportive
- Told her partner, but he didn't believe that Markus was autistic
  - o But eventually was supportive
- Markus ahs a younger sister- who enjoys him, but he isn't really into her
  - o But having a sister is good for him- invades his space a little
- Got pregnant with second child before a formal diagnosis was received- won't have any more children now

SUPPORT
- Didn't avail of anything through the local societies
- Felt very supported by the Day Care that Markus attended
  - o Started a support group there for parents
  - o Even after child is no longer at day care, parents can attend and avail of the support groups
- Feels lucky to have a lot of support through her own journey
- When Markus was diagnosed by the develop ped, Jill was provided an "Autism Services List" by a social worker who helps walk you through some of your options

DAY CARE (EDUCATION)
- Originally had placed Markus in a "regular" daycare- where it became so evident to them that he was autistic
  - o Original day care referred him to "Specialized day care"
    - ▪ Had to undergo an application/interview and home visit process- but luckily, they were chosen
- Incredibly amount of support through this specialized day care
- Once accepted into the specialized day care, there was no process of applying for other support- it's already there for your child
- Kids accepted into the specialized day care at age 2 and can avail of the services until they are school aged.
- Markus is about to start regular school in Sept – nervous about the support he will receive
  - o Slightly concerned to the qualifications of the support workers within the school
    - ▪ Do they know about ASD?
- Guidance counsellor of school is accessible- they're not going to go looking to talk to you, but will talk if the parent seeks it out
- No OT's within the school- but recommendations can be made through the parent, and the parent can communicate it to the schools
- "I feel like I'm gonna face the biggest challenge now, with the school system. I feel like it's gonna be a huge challenge."
  - o Worried about decreased support, and not having as good of a team as what they currently have

BARRIER
- Length of time it took to get a diagnosis
- Limited space in specialized day care

- In the regular day care- child had to be assessed and see what types of support were needed- then they would need to apply for them- no guarantee they would receive the support
- concerned to the qualifications of the support workers within the school
  - o Do they know much about ASD?
- ABA
  - o Hiring the therapists, and the ABA process is where Jill feels there has been a lack of support, and a gap
    - ▪ Believes this process could be made easier on parents
- Biggest barrier: ASD itself
  - o Trying to make your child happy and comfortable
- Sometimes feeling like you need to justify behavior of the child to other people

RECOMMENDATIONS
- Government- pay the ABA therapists more- entice and motivate therapists to stay longer
- Family- support each other
  - o talk more about the home life, and personally what it's like to have a child with ASD- which nobody else understands
    - ▪ "I had to bring him to the grocery store and he melted down and then I melted down"
      - • people don't get this- so it's important to talk about it amongst your family to provide yourself some support
- Wait times- the time waiting for a diagnosis needs to be reduced or eliminated
  - o Once a parent suspects it, there NEEDS to be immediate services

WORK
- Jill is currently on a leave of absence from work because of the demands of having a child with ASD
  - o Doesn't mind it- prefers to be home with her child than to pay someone else to be home with him
- Works for a big company- so longer stints in terms of absence is easier to apply for

FINANCIAL
- Having a child with ASD is financially draining.
  - o The private services if necessary
  - o Leaving work
  - o Reducing hours at work
  - o Paying for babysitters
- Financial difficulties often lead to relationship difficulties

4_2_050_1 : Madeleine (Grandon: Theo)

EARLY SIGNS
- Lack of social cues
- Seemed different than other children

DIAGNOSIS
- Went to several doctors and never got the answer she was looking for
- Had to get referred to an Urban centre
- After seeing several doctors in the urban center, he was diagnosed to b eon the spectrum
- Took a couple of years to get the diagnosis

RURAL SETTING
- Not many services available to Sean
- Tried participating in programs for kids with special needs, but due to the small population and limited opportunity, the only program available consisted of mostly children who were much more severe then Sean- so he stopped going (BARRIER)
- No community supports or services offered in small area

ADVOCACY
- Mother wouldn't sit around and wait- she would insist until everything is in order

EMOTIONS
- **Relief**- diagnosis offered relief
    - " when you have a diagnosis, then you know, what the challenges are gonna be, and you know, then you can start to begin reading up on it and you know what to expect and you can work on it"
- **Pity**- once diagnosed, because you feel so bad for the child
- **Sad** – when the child with ASD gets used by other children

SERVICE PROVIDERS
Doctors- diagnosed him
Psychologist- for private counselling

SCHOOL
- was offered some support in primary school, but not elementary , junior high or high school
- not enough counsellors in school (BARRIER TO ACCESSING CARE)
- the little support provided in the schools can be viewed two ways:
    - 1) positively- forced him to cope on his own
    - 2) negatively- probably could have been been provided some support and guidance in navigating and fitting into social situations
- good teachers helped with socially immersing him
    - also helped with the transition between schools
- struggle with principal
    - wasn't accepting of the diagnosis of ASD in some of his students

- Goes to school regularly in the morning- but then leaves in the afternoon for tutoring
- Teachers do not have enough training in ASD (BARRIER)
  - And not just the teachers who are teaching these kids, but the assistants, other teachers in the school- anyone who might be interacting with these kids should be comfortable and educated on being able to handle different situations

FAMILY
- good family support when Sean was diagnosed
- no denial- just understanding and support of the diagnosis
- Sean's sister was never really directly impacted at school because there was a big enough age difference that their schooling never really overlapped- made it easier for the sister
- Dedicated, educated and loving parental support is key in the success of a child with ASD
  - So much of the success is attributed to this

SERVICES
- Never availed of ABA or speech
- Not a lot of support in the medical field
- Availing of private counselling
- Tried participating in programs for kids with special needs, but due to the small population and limited opportunity, the only program available consisted of mostly children who were much more severe then Sean- so he stopped going (BARRIER)

FUTURE
- Will be able to get a job as a result of family connections (small town)

CO MORBIDITY
- Street and Anxiety- socially – trying to fit in

RECOMMENDATIONS
- Needs to be more support for the parents
  - SO much info, and nowhere to go to help get guidance of help
- **Government**-
  - Put money into research
  - Put money into having more people on the floor (school wise)
- Help needs to be offered in the beginning- at an earlier age
- More support for the family (not just parents) but support for the siblings who have to adjust and go through the process
- "we have to have more training for everyone, the whole society needs… to be educated."

FINANCE
- Tutor is out of pocket- very expensive: Family can afford it, but most families couldn't

4_3_014_1: Jan (Occupational Therapist)

EARLY SIGNS
- Someone in their every day life has recognized lags in their development

ACCESS
- There used to be a service that you could gain access to the OT's without having to be referred through the hospital- that has sense been removed
  - This is tough because sometimes there is a refusal of service or people just don't feel its necessary (accessing less people)
    - Refusal to the service often comes from the parents *denial* or *lack of education/ experience* (maybe it's their first child and they have no idea what to look for)
      - "I guess denial or lack of belief that there is an actual issue."
- **Priority Sequence**
  1) Failure to thrive for a feeding concern AND
     Children at risk to themselves or others (kicked out of school etc)
  2) Everyone else

These priority sequence exist because its what has been deemed the most ethical approach at this time

INTAKE PROCESS

Current Process
- Very new process
- Fill out a parent questionnaire provided by a **nursing coordinator**
- **Nurse coordinator**- will then determine what services that patient requires (she is the referral into OT)
  - Referrals once they get to OTs are usually accurate and suiting
- Assessment (1-1.5 hours long)-

Old Process
- More team based- worked well

RURAL
Facilitator
- There are new jobs just opened up and hired for speech, and OTs in **rural areas**
  - just recently granted by the government after an acknowledgement of those areas being seriously underserviced

Barrier
- rural youth- do not get the same access to re-checks, follow ups or acces in general because of proximity to services
  - unless these kids are taking the trips into town, they are just not getting the services
- there are very little visits to schools or day cares in the area to help provide education, because those priorities are barely even accomplished in urban centers.

WAIT TIMES
- Currently around 18 months
  - Children usually get referred between 1 and 3- so 18 months from that time is when they will get access to services
- But these wait times have improved- they used to be longer

<u>Recommendations</u>
- Early intervention, would help decrease wait times!

SERVICE PROVIDERS
- Nurse coordinator- parent questionnaires
- Occupational therapist
- Speech therapist
- Pediatricians
- Psychologist
- Physiotherapy
- Social worker

<u>Recommendations</u>
- Link of with **public health nurses** and **community health nurses** to discuss developing milestones
  - These are the healthcare professionals interacting with these kids at an early age
  - The more educated they are on what an OT might be looking for, the earlier identification and earlier interventions can occur
    - "but it's like if we could work together we could have a stellar service, you know what I mean?"

SERVICES
- Jan wishes there was a way to provide access and services to children within the perinatal program, who currently do not show any obvious signs of needed service, but often come up down the road
- Kids need to be accessing services as soon as they require them
  - "If a child is referred at 12 months we should be seeing them at 12 months."
- Role of OT is functional goal based
- OT's are trying to make service more inclusive while decreasing **wait times**
- Sensory rooms for OTs to do tasks and analysis in
- When working with kids who have been diagnosed with ASD, OT will set up a community visit
- Liase between some community agencies but not often to private therapies UNLESS they child cannot gain access or is not granted therapy within the hospital

Facilitator
- "occupational therapy is there to support their learning"
- "the things that we are doing are evidence based, they're tried, true and tested."
- Within child development division
    - There are new jobs just opened up and hired for speech, and OTs in **rural areas**
        - just recently granted by the government after an acknowledgement of those areas being seriously underserviced

Barrier
- once diagnosed from the hospital, they have nowhere to go to be followed or access service
    - government feels OT is not an essential enough service to take away teaching units
- OT's "trying to be client centered but also very aware that, sometimes there's a lack of education in knowing what OT is what what we can do "
- PT and social worker that the OT's can access are COMPLETELY overran

Recommendation
- move to an early intervention program
- discharge at 5 (like SLP- but SLPs have someone to follow them in schools)
- need more social workers, more psychologists, more physio, more speech
- take kids from perinatal program- these kids are not currently getting serviced but once they are identified, have often times missed the early intervention stage- if they get them earlier they can help avoid this

Private OT
Pros
- The individuals that seek out private care are usually the "go-getters" the ones that want to make progress, and the ones that actually follow through with the therapy
- Tend to see more bang for your buck

Cons
- Expensive
- Follow up is left to the family
- Treatment is so expensive that it is often times hard to convince parents to "follow up" or come back in for reassessments because they've already paid so much for it at this point

Public OT
Pros
- More time with the patients
- Easier to make a follow up appointment (because they don't have to pay for it!)
    - This is the critical appointment as its where they start to understand and try out some interventions and then come back and ask questions about what they found for their child

ABA
- if child is availing of ABA, it is easier for OT to go into home and meet with home therapist and do a visit
  - here they can see what programs are being completed and make any necessary recommendations
- Senior therapists and Ot's have very different background and training, so their assessments are usually quite different

Facilitator
- When there is a collaboration between ABA therapists and OT- you see significant success sin the child's progress

Barrier
- sometimes there is a difference between what the senior therapist and the OT think are age appropriate tasks and programs
  - but there is an effort to work with the programs and mesh together
- relationships with the senior therapists vary
  - some are great
  - some really don't see where the OT is coming from in terms of "normal development"
- OT's believe the programming in ABA is too black and white
  - There is a bigger issue than failing or succeeding at discrete tasks
- Size of the ABA program
  - "growing so quickly because they can't have a waitlist, that there's no way to tack that issue because every time you turn around there are more therapists and they're just going through the motions of this black and white assessment"
- programming itself OTs don't agree with- the discrete trial, fail or succeed method
- kids who have been diagnosed with ASD and are receiving ABA services are NOT allowed to avail of the hospital psychologist because they have two psychologists within their program available to them
  - problem is- these psychologists do not do individual therapy, they are a part of the assessment process
  - so these children are just unable to access any sort of funded psychologist

COORDINATION OF CARE
- OT's don't always get along with the senior therapists
- There are a lot of speech pathologists within hospital, and they all work together to collaborate on newest research and successful programming
- If goals cannot be met with OT, they will liaison between pediatrician or developmental pediatrician for the child

Barrier
- There is no collaboration between mental health division and child development division at the hospital
  - They do not pass cases back and forth, they are treated as two completely separate entities

FAMILY
- parents need to be more educated on what OT's can help with, what their role is
- family goals and expectations are an important part of the OT process
- "for 90% of our population, or 95% of our population, once the parents follow through on a program it works out well."

EDUCATION

Barrier
- only province that does not have OT's in school system
- "we've been battling this for about 15 years as occupational therapists, and our provincial association and all that have gone to government and said you know, we are the only province without OT's in the school system and everyone else can't be doing it wrong…"
- could be providing a better service in the hospitals if the schools could offer complementary therapy at school age
- in reference to the role that they can have within schools
  - "I just fig it's a big ethical issue for me personally because, as an OT I am trained to treat a child, child's function in every environment but what I've been told is I can't do that anymore. SO ethically, in my professional opinion, it's wrong"

Facilitator
- Some daycares had an inclusion program- was fantastic

Recommendations
- Bring OT's into schools

EXITS AND RETURNS
- in trying to manage the waitlist they discharge children once their needs have been addressed
  - this doesn't mean that their issues are no longer there, it just means the OT has provided them the tools and goals to work towards
  - once the OT has provided the family/ child with the education and tools necessary- the goal on their end has been met- it's up to the parents to help achieve the individuals tasks
- child is able to re-enter the system with a NEW functional goal within a one year period.
  - After this the child must go back on the waitlist (with a new referral)

4_3_016_1: Lynn Ann (Speech Pathologist)

EARLY SIGNS
- Child isn't talking
- Behavior issues
- Parents are frustrated- wanting the child to tell them what's wrong, but obviously the child is unable at this time
- For ASD specifically- inability to initiate communication

ACCESS
- Referrals are necessary
  - Can self refer
  - Doctor / nurse can refer
- Then goes through intake process
- Once child is discharged, they are able to come back as a follow up- common right before starting school (they don't have to go on WL)

Intake Process
- Referrals (no priority sequence based on who it comes from)
- Intake secretary
- Parent questionnaires (once these are filled out and returned- this determines the "intake date"
  - Sometimes make it difficult to determine severity
- Initial assessments occur 4 times a year (hence why there is about a 5-6 month waitlist)

Current way:
- The intake team no longer meet as a team- if it goes through speech, than just the head SLP will go through referral and might send out as necessary
- Provide a home program after initial assessment including 1-3 goals to work on @ home while waiting to avail of services
- Kids are being seen earlier (between ages 2-3)
- SLP now go to NICU discharge planning rounds and identify children at this time and place them on waitlists
- Kids are seen in follow ups as they progress through their goals

Old Way:
- Reviewed all referrals as a team
- More collaborative
- Could be waiting up to 18 months before getting any information or feedback
- Originally children were on waitlists for so long they weren't even getting seen until they were 3.5-5 years of age

EXITS AND RETURNS
- Only discharge patients if not showing up for sessions
  - This became necessary due to the WL- needed to implement a stricter attendance policy

EARLY INTERVENTION
- Preventative
- Programs:
  o Beginning to communicate- facilitates language at a young age
    ▪ Toys you should play with
    ▪ How to play with children

WAITLISTS
- From their intake date, it is about 5-6 months before initial assessment
- 12-14 months for direct home services
- There is a priority sequence in availing of services:
  o 1) feeding and swallowing
  o 2) voice disorders: fluency/ stuttering
  o severe motor speech

SERVICES
- If child doesn't need services after initial assessment, they are referred on for a parent workshop (less **wait time**)
  o These workshops are geared around educating parents and providing them with info to help children while waiting for direct home therapy
- Might get passed along to direct home services
- Two new positions just added for speech language pathologists SPECIFICALLY focussed on children with ASD- hoping that this will improve the coordination of care between professionals
- SLP focus more on eye contact, watching other children and joint attention as this is what children with ASD commonly lack- without these skills they cannot develop their speech and communicative skills
- Children going into school get prioritized into **social groups**
- SLP's- offer treatment in office
  o Assessments
  o Daycare visits
  o Home visits
    ▪ *those who avail of home services do not get in office treatment and vice versa*
      • "We gotta have equality somewhere"
- <u>Social Groups</u>- being offered bye SLPs to 5 children at a time for 5 sessions
- Development of knew <u>language programs</u> which are being implemented by SLP
- "We do what's best for the child. Whatever works for the child at that particular point and time."
- Services in the hospital sometimes are better than the private clinics because the SLPs in hospital don't filter patients through as fast. Spend more time working with each individual, because they don't have to worry about money coming in
  o In hospitals there is time allocated to talking and communicating with parents/families

- o More freedom for SLPs to say that they need to because they don't have the "power of money" hovering over them. Able to have more frank conversations
    - ▪ In private this is more sensitive because without the patient, there is no money
- Haven't heard of people leaving province to gain "better" speech services

Barrier (to providing services)
- SPACE
    - o There are 10 SLP and only 3 available treatment rooms
    - o Room space- don't have space to run the sessions continuously because they are sharing physical space with OT (in running social groups)
    - o
- TIME
    - o Scheduling and timing in general is required to effectively treat a child with ASD is so demanding
- Lack of psychology- only one psychologist available within the hospital- she's on overdrive
- Specialized Daycares- only have limited space. SO the supports that can be offered by these places are often not tapped into because so many people are turned away
- No connection or communication between local community support groups or services and the SLPs in the hospital
- Being housed in a hospital- children are terrified of a "hospital"

Recommendations:
- Would like to see early play groups
- Need more space
    - o "You know so it's, it's like I said, if we had better space I think we could offer different types of programming. More innovative programming. We're limited a lot by our space."
- Need to be community based (versus stuck in a hospital)
    - o "The kids who come to see us, they're not sick. They don't need to be in a hospital to come to see us."
        - ▪ If they weren't in hospital they could avoid parking issues, fear of hospitals etc

SUPPORTS
- Parent workshops avail for parents

FAMILY
- Hard to make parents see the root of an issue, and see the bigger picture
    - o SLP focus more on eye contact, taking turns and watching other people
- If family is all in, you will see obvious gains and successes in child

ABA
- SLP'S try to input programs into ABA
    - o Hard- because they don't always mesh with what they're doing

- ST is more real life settings versus the structured ABA
  - o Try to get the parents to focus more on the generalization of skills versus the discrete trials
- Concern with ABA- **IF** its not working, parents and children are in trouble because it's the only thing funded by the government
- Easier to speech with children not doing ABA
- Lynn Ann belief to the effectiveness of ABA: "I don't think there's any one miracle treatment"

Barrier
- inability to leave the home
  - o Can't undergo *generalization* to real life because it is against the rules to leave the home (unless supervised by childcare- single parents can't often do this
- "The problem now is that the ABA program has gotten so structured that it's difficult for us, a lot of them are very resistant to inputting a lot of our stud into the programs. So we're struggling a little bit with that right now."
- Expensive- hard to quit job to do own daycare, but so expensive to pay for daycare
- Program is SO large now
  - o "because there's so many of them now there's a lot of new people coming out and they're being trained and they're just not, as accepting"
  - o "it's gotten too huge I think. It's gotten too huge. And they're training all these new people and so, they're a lot of them are being, monitored all the time, by mentors and, I think they're scared to actually go outside of what they're supposed to do because they may not pass."
- Managers of SLP have TRIED to meet with ABA- but there is always resistance
- No SLP within ABA at all

Recommendations:
- "But I think parents should have the option to choose what they want to do"
  - o **need government funding once they choose**
- not one treatment better than the other
- Needs to be Open for parents to choose what's best for their own child
  - o This may change over time. One therapy might not be appropriate for the child's entire life
- Need to be more acceptance of SLP with ABA program so that frustrations can decrease "You know, they don't take us as being a specialty area and that we have a knowledge. I mean, we did our whole degree in this. And that we have a special knowledge. And so, we're not feeling, that, we're welcomed into the program.

CONTINUITY/ COORDINATION OF CARE
- Collaboration and continuity of care between speech and ABA is a struggle
  - o Have put in efforts to collaborate with ABA- by spending a couple of hours in the home for home visits with therapists- not working as great now
- Communication amongst team is being worked on (home therapist, OT, SLP, Psychology, day care workers)
  - o Really focussing on getting into day cares, and getting them involved (difficult because children are spread out EVERYWHERE)

- o SLP's are trying to see what's happening within the daycares to see if they can help facilitate any of the goals being set out

Barrier:
- Not all healthcare team members are situated in the same space which makes basic and simple questions for simple communication much harder
- ABA did not want speech housed in their space

EDUCATION

Facilitator:
- SLPs are present in schools
    - o The ones in schools are presented with a list of any child who may have availed of speech therapy while at the hospital
    - o "We actually are lucky that we can discharge them and they have someone else responsible for that. OT's have to follow them right through. Which has huge impacts."
- SLPs from the hospital sometimes offer one day education session to make it more available and accessible to teachers

Barrier:
- lack of education for teachers within the education system

Recommendation:
- implement more education surrounding speech therapy into early childhood education college programs
- implementation of the Hanen Program
    - o "Learning Language and Loving It"- "I think it's really necessary. I think they need it"
    - o one semester course- could collaborate with college semesters
- teaching the early childhood educators more so they know what to be working towards

3_3_017_1- Nicole (Child Management Specialist)

SERVICES
- **Direct home services** – early intervention for any child birth- school aged child
  - o Province wide
- Diagnostic teams (3 separate teams) spread across the province (**barrier**)
  - o Usually the ones to refer to the child management specialist
  - o Sometimes a pediatrician who is confident can also refer
- As a **child management specialist**- you do not necessarily have training to be a senior therapist and provide direct services to children with ASD
- As a **senior therapist**- you are certified to apply direct home services to child

EARLY SIGNS
- When a CMS sees them the child may or may not already be accessing services from direct home services
- Sometimes they only come to them once they have received a diagnosis
- Child is not talking like they should
  - o Get a lot of referrals from speech
- Child is experiencing certain challenges

DIAGNOSIS
- Info overload for parents
  - o "SO there's this whole host of time where I think there's so much coming at parents where, they're really unable to even focus on what, what is required at this time. And then I feel it's very very lengthy time."

ACCESS
Barrier
- Profession is not well known, so people often look for services in the wrong people first (adds time to when they are starting therapy)
- **Rural**- small community and as such Nicole was the only service provider in the area- she ends up having a dual caseload
- **# of service providers **- there are only so many service providers, and they just don't have the manpower to be taking on the demands that is associated with some of these children's cases

Intake Processes
Direct Home Services
(Urban Centre)
- 30 day MAX allowed from the point of referral to the determination of eligibility
- intake coordinator
  - o creates file
  - o child goes on WL
    - ▪ this file gets sent to the next available child management specialist on the list
    - ▪ from here the eligibility of the child to receive service is determined

- eligibility determined from a screening test (Brigance System)
  - if child qualifies for service they have to go back on **WAIT LIST**

ASD Services
- technically there can be no wait list fir autism services- its mandatory accessibility- but WL seem to creep in while waiting for a senior therapist
- intake occurs through program manager
- URBAN: first step is to a **social worker**- and they make contact within 24-48 hours from receipted referral
  - They help deal with the mass amount of information, and the emotional rollercoaster that these families are going through upon diagnosis
  - There are TWO social workers avail within the urban local health authorities- and they are extremely skilled-
    - Makes the job easier for the child management specialist as the **social worker** has already determined they are ready to start therapy
- **Psychologist** –on staff to help support grieving families/ parents
  - **BARRIER**- there is only one on staff
- in **RURAL**- this support from the social worker may not be available- so the child management specialist might have to provide service AND make the first point of contact
  - **BARRIER- (RURAL)**
    - This is a huge difference between urban and rural and "I think one of the biggest challenges for rural"
      - Contact is made with family just receiving diagnosis
      - Probably already know them (small place)
      - Huge grieving/ adjustment period of diagnosis
        - This requires a very special skills et which is not taught in the child management specialist training- people acquire it, but it's not taught- its learned "virtually, being the only service provider"
        - "Beyond our capacity"
    - CMS is doing everything – "it was just too much"
    - No extra services for children with ASD (extra curricular etc)

FAMILY
- Challenges are welcomes when there is good support from the family
- Importance of consistency, as well as dedication and work behind the scenes to help carry out the therapy
  - It is possible that if family is not committed to applying therapy and attending sessions that they may no longer be able to avail of services *(direct home services)*
    - **Barrier AND Facilitator**
      - Necessary rule as there are so many people that need to access care
      - BUT its hard because sometimes it's not the fault of the child, and they may lose access to services as a result of lack of dedication or commitment from family

- o For Autism services its not as straight forward to remove services as there are SO MANY **service providers** involved (employee, home therapist)- but the support of the **social worker** in the urban areas helps here (barrier for **rural**)
- **always the opportunity to re-refer within the age appropriate window
  - o but families must be able to indicate what has changed since the last time they tried therapy (role of **social worker** in urban centres vs **rural**)
- **parent**- often necessary in helping with deliverables and goal reaching of the ISSP
- parents are encouraged to be advocates for their child
- service providers to try to engage and reiterate the importance of family involvement and advocacy all through the child's life
- once they "graduate" ABA- the goal is that they will have ben provided all the necessary info to gain support if necessary
  - o provide info on activities for their child
  - o give info on service providers
- If family turns down service for whatever reason, they are not flagged for future access once they want to return
- huge focus of service providers to help empower families

CONTINUITY OF CARE
- Gaps are inevitable between service providers (people leave, move, retire, have children)
- When children come and go form the system, sometimes they can end up with the same service providers

Facilitator
- "there is very much a model of, it doesn't matter where you are you can move within the province and you just carry your programming with you and it should be effortless and seamless. And that, for the most part, has been my experience."
- In **rural** areas it's easy to follow up on progress as you tend to see the child and parent every where.
- In creation of ABA programs- there is a collaboration between all service providers who are working with the child
  - o Other professionals might request the opportunity to check in and re-evaluate the child's progress at a ceratin time

ABA
- main idea is that it is **task analysis** of a skill
- up to 30 hours before Kindergarten
- kindergarten= 15 hours per week
- grade 1-3 = 10 hours per week
- all these # of hours are determined by the **child management specialists** assessment
  - o "just because you can avail of 30 doesn't mean that it's required or necessary or even recommended"
    - ▪ parents COULD push for max hours and often times CMS will defer to parents
- "the expectation is that the school system will modify the support that they get in the schools (**EDUCATION**)

- - The idea is that between what the school is offering full time in combination with the limited ABA, the hope is that the intervention is being provided
    - And there is a collaboration between CMS and schools (**education**)
- Early detection has become more common
- caregiver in home is required, but not provided and covered by local health authorities
  - recommended that it is the personal caregiver of the child that is there during therapy as they can help apply it to real and everyday life (**generalization**- of learned behaviors).
  - This will also help reduce the cost to the family
- **Senior therapist**- responsible for teaching the home therapists and modifying the plans as the behaviors change
- **Home therapist**- delivers and accepts data based on the objectives
  - A lot of creativity is expected of them- in order to effectively deliver different programs
  - Collaboration between **home and senior therapist**- they meet with every week for first 6 months
- **Brigance screen**- is used to assess where the child is with their progress and to help adjust programming as necessary
- **ABA** is play based
- Ideally there is a separate room for therapy, so child can associate time spent in this room as therapy time
- Family's decision to hire/ fire therapist

Barrier
- **late diagnosis**- if they get diagnosed late, they don't get to "make up" their hours- there is a direct impact on the amount of intervention they are able to receive
- only 10 hours of therapy is not ideal
- **RETENTION AND RECRUITMENT**
  - Six months in, there is often a new home therapist
    - As such, constantly starting over with the home therapists and as such the child's progress
  - Why are there retention issues?
    - Not enough money (people need to make a living)
    - Scheduling is difficult
    - Hard to schedule meetings with CMS and senior therapists- they're not allowed to extend their office hours outside a regular work day
    - Home therapists leave for better, higher paying jobs
    - Leave for university
    - Leave for another career
    - Working in homes is not ideal- personal and intrusive- also hard to work for the parent of the child doing therapy

- Skill level of home therapists

- o "Ideally you'd have a home therapist that's very skilled. That doesn't happen regularly. So that's a huge barrier to service for actually."
- No ABA delivered in schools- programming can be discussed if requested, but it' not required.
- Parents wanting to do part daycare (for socialization purposes) and part ABA
  - o A lot of daycares won't allow this- so they either avail of one or the other
  - o "If you modify your hours here at our daycare in any way then we can't hold space for you."
- Barrier of ABA is the inability to leave the home
  - o Can't undergo *generalization* to real life because it is against the rules to leave the home (unless supervised by childcare- single parents can't often do this)
- The inflexibility of being able to bring therapy outside the home puts a serious limitation on the programs being delivered
  - o Whether it be because parent is unable to leave another child home
  - o Lack of transportation
- Home therapist is not allowed to transport the child because there is no business insurance with ABA
  - o *family can opt into it- but an extra expense !
- ABA has no additional money to offer (no respite to offer)
- Family hiring the "wrong" therapist- sets them behind

Facilitator
- Even when therapists change- programs remains the same for consistency
- Province has gold standard for ABA
  - o Very limited WL for obtaining autism services
  - o Program is court mandated
  - o Program is not income tested
  - o Our government funds ABA
  - o Persons often can't afford services elsewhere

RECOMMENDATIONS
- Creation of an agency to manage ASD/ABA services
  - o Families often don't even know what ABA is- net alone what is required in getting it up and running
  - o An agency would ensure people are certified and competent in the delivery programs
-

EDUCATION
**huge piece of the puzzle
- "the expectation is that the school system will modify the support that they get in the schools (**EDUCATION**)
  - ▪ The idea is that between what the school is offering full time in combination with the limited ABA, the hope is that the intervention is being provided

- And there is a collaboration between CMS and schools (**education**)
- **RURAL**- very easy to be up to date with different parts of therapy and team because everybody knows everybody
  - You might personally know the principal or the guidance counsellor, and therefore makes it easy to follow up with patients in an informal way/ setting at times
- **URBAN**- feels more like constant catch up
  - BUT- there is the individualized student service plan (ISSP)- which is a provincial wide standard which is in place to help promote collaboration and consistency between service providers working with the child (health and education)
- ISSP
  - Goal is to develop the strengths and the needs of the child
  - Once needs are determined, goals are established
  - People necessary to work on these goals are determined
  - Determine where and when the goals are to be worked on
  - Includes any services/ therapies that the child is availing of
  - Individuals on team depends on the age of a child
    - Under school aged: child management specialist preschool teacher, day care representative, parents, OT, speech, pediatricians
  - Organized and called upon by the CMS
  - ISSP's are collected and all kept in same file and the plans are adjusted and accommodated based on the change in services and service providers
  - Once child starts school and **Individualized Education Plan** is created which represents the accommodations that the child receives, or alternate curriculum or courses that the child accesses.
- Services available within schools for children with ASD:
  - Student assistants
  - special transportation
  - safety plans
- once child goes to school it is not required that the CMS knows everything happening within school.
- CMS is NOT able to walk in and offer therapy recommendations, can only contribute if it is requested by the school.
- **Barrier of ISSP:**
  - Training for the ISSP has decreased, so new people coming into the system are not as educated on how exactly it should be put together or monitored, and what it should consist of
    - **this results in the ISSP losing its actual intention
- **Facilitator of ISSP**
  - When working and being monitored properly- it a huge facilitator for coordination of care and success in the child's program

Barrier
- "not as collaborative maybe as it could be or should be"
  - outside therapies and services cannot go into schools, only parents

- If you modify your hours here at our daycare in any way then we can't hold space for you."
    o In reference to inquiring to availing of daycare and ABA

SUPPORT FOR SERVICE PROVIDER
Facilitators
- rely on teams for support and guidance
- shared folder for resources
- resource rooms
- trainer mentors for becoming certified
- manager
- access to outside professionals

Barriers:
- **unfortunately none of these resources exist in **RURAL**
- In becoming certified (mentors) are limited in **rural** areas

FINANCIAL BARRIER
- Childcare can be a huge financial barrier for families
- Parents quit job so they can fill the childcare role
    o Good because now they don't have to pay for it
    o Bad because they aren't making any money
- Family can opt into business insurance- but no coverage from the government
- Costs money to be able to provide supplies for therapy
- ASD is not considered a cognitive disorder, so families are unable to access "special child welfare allowance"
- "First of all it's really hard to get, not everyone is willing to give a score. And Autism Spectrum Disorder alone, some children are quite bright! So there's no funding"

4_3_019_1 – Lisa (Special Needs Early Childhood Educator)

BACKGROUND
- Originally started as an Autism Centre
- But really more of an early intervention centre
- Four programs within the agency- one is child/ youth based, the remainder focus on services and support for families/parents

EARLY SIGNS/ ACCESS AND ISSUES
- Must be 24 months to start at the centre and can avail of services until they enter into school (between ages 5 and 6)
- Usually no diagnosis in the child when they first come to day care centre
  - Might be on <u>wait lists</u> for seeing develop ped, but often time no diagnosis when they start
- This day care centre does a lot of referrals to the hospital
- This day care centre offers support to the families in accessing services
- There is a small class size (restricted space)
- Ratios are determined based on the demand of children at that given year
- Currently trying to get children at an early age (**EARLY INTERVENTION**)- so they can apply services, and get them out earlier
  - Appears to be a more effective concept for both the children and the parents accessing services- the earlier they can avail, the more benefit they have from it

Barriers:
- Class size
- sometimes classes are filled based on dynamics- not always because of the highest need for the child
  - if they need a model student, they'll take a higher functioning child versus the child that might require more support and services
- Ineffective intake process
- If a child has been diagnosed with ASD, or is availing of any therapies for potential ASD, they are getting denied acceptance to the centre because admissions feels they already have services available to them
  - Obvious decrease in number of acceptances of children who have ASD
- Big waitlists **
  - Admissions only happen twice a year- if application comes in outside of those time slots, they get sifted onto a waitlist
- Transportation-
  - Bus will only go so far to pick up (**RURAL BARRIER**)
    - if sessions are missed due to geographical barriers, they are provided the opportunity to make a change, but if they can't, they are asked to leave
  - Needs to be very concrete reasons as to what you require assistance in transportation

Facilitators:
- There is a bus service offered to individuals (children and parents) who do not have the means to go back and forth to services
- Even if they aren't accepted into full time day care- children still have community groups or certain parent programming that they can avail of- so it's not that there is NO service provided to these individuals
- Home visits are avail for families- so educator might go into their home once a week to see how the programming is being applied and worked on in their home environment
- Childcare service available for parents when they are attending programming-
- Service providers from the day care often help with the transition into schools- speaking with guidance counsellors/ teachers etc
- Provide opportunity for other service providers (speech, OT, ABA therapist) to come in and observe the programming happening within the centre

Recommendations:
- More holistic approach to acceptances
- Understanding that even child may be availing of some services, they may still require this service also (service overlap at times might be necessary)
- GOVERNMENT- Require more staff funding – then they could take more kids
  - Can't apply for private funding because its publically funded

ENTERING THE SYSTEM
- Acceptance through an admissions committee
  - Committee is well represented by a well rounded staff (supervisors, executive director, social worker and heads of four programs offered)
  - Acceptances are done "based on the family, based on how much they need us, and also based on who we've already accepted."
  - Classes are built for modelling behavior too- so not always taking the individuals that need it most
- Referral is necessary
  - Could be from a service provider, or from themselves
- Committee will review paperwork first to determine reason for needing to access their service,
- Then home visits occur before any decisions are made
-
- There needs to be a reason for the child to attend this centre
  - Either the child requires special support, or the parents do
  - And there needs to be involvement and commitment from parents and child
- Families get reassessed throughout the year to determine whether or not they will continue on within the program (**POSSIBLE EXITS FROM THE SYSTEM**)
- Centre is accessible to all types of children and families depending on their situation

EXITS AND RETURNS TO THE SYSTEM
- Participation is a key part of availing services- if there is no participation, a child or parent can no longer avail of the service
- Admission sets realistic goals with parents in terms of commitment and participation-

       o So each family has their own specific expectation and requirement
          ▪ If this is not achieved, they are removed from programming
- However, if goals are not reached

COMMUNICATION
- There is some line of communication between admission staff and educators in the classroom
- Provide opportunity for other service providers (speech, OT, ABA therapist) to come in and observe the programming happening within the centre
- Good partnership and communication with the hospital
  - A develop ped saves one spot a month for someone from this day care to help with severe cases avoiding some *waitlists*

ABA
Barrier:
- "I just feel that ABA is a wonderful thing, but when they can't put what they're learning into context of being around another group of children then it's not really valuable"
- ASD is so individuals, ABA can't work for everyone
- Once diagnosed- families need to wait for services (**wait times**) but they have no idea what to be seeking out, or doing in between
- Financial barrier- someone needs to be home- so either need to pay for child care, or stay home
- Kids often times don't avail of ABA service, because it's just too expensive – even though its "funded"

FINANCE
- Tend to service lower income families
- Center is WAY cheaper than child care
  - Food included
  - Fully funded
- Parents often times cannot go back to work
  - "we always say that having a child with special needs is the fastest way to go broke"
    - ▪ either need to be extremely wealthy, or on social assistance, where everything is paid for

GENERAL BARRIERS
- People not know about the service
  - Or they find out about it too late- so they can't avail of the service for as long , or at all
  - If people don't already know how to avail of the correct services, they would never find out about this centre- not openly accessible.
- If you're deemed "not a fit" but admissions- you don't get waitlisted- you just don't avail of services
- No support to the service providers at all (for their own mental health)
  - Burnout is common in their field

- o Mental fatigue
- o Emotional exhaustion
- o And STILL nothing has bene put in place to help ease or support them through this
- Persons in charge at the higher up admin level "See" things differently than the staff who are in the classroom doing the work
  - o They don't see certain concerns as valid arguments- so they get dismissed
- The empathy, sincerity and concerns being brought forth by the working staff is often seen as a weakness
  - o "Do they really think that's necessary or are you just being a whiner"
- less funding- less support staff in classrooms-
  - o "But how much you can input depends on how much time you have when you're not just putting out fires. You can't actually do the work"
- reiteration of the change in thought process of not providing children who already have access to services, this day care service (children with ASD)
  - o "So like in a weird twisted messed up world it would make sense to wait to get diagnosed with autism so that- if you wanted to avail of the centre"
- decreased involvement of parental expertise on the child- admin thinks they "know better"
- class size
- no personal development offered by the center for their staff to help increase their skillset of working with children with different types of special needs
- government decreased funding to promote inclusion
  - o "because as much as inclusion is a great thing in theory, it isn't- it doesn't make sense, like, it really doesn't always make sense"
    - ▪ kids need to learn and model- but if they're in an inclusion environment and they're not learning, or they're just debilitating other peoples learning- then inclusion is counterproductive
- having a child with special needs is extremely trying on a relationship

WAITTIMES
- Usually always need to wait to access this service
- There are fairly strict guidelines that persons need to follow in order to avail of services- otherwise they are removed so that waitlists can be accommodated for

RURAL
- Needs to be supports like this center across the province- not just in urban centers
-

GENERAL FACILITATORS
- The centre offers a continuity of care by ensuring smooth transitions into other centres
- The day care center has good documentation of goals, progress and programs
- Centre offers families and parents access to a lot of supports- and helps ensure they can gain access
- Parent/ peer groups created for support for children/ youth with ASD
- Center acts as a bridge for families to local autism society

RECOMENNDATIONS AND DIRECTIONS
- PD days for service providers
  - o "mental health first aid"- but apparently its too expensive (**Finance**)
- more funding- so that this type of support can be offered to the staff
- supports and amount of funding need to be higher
  - o "because as much as inclusion is a great thing in theory, it isn't- it doesn't make sense, like, it really doesn't always make sense"
    - ▪ kids need to learn and model- but if they're in an inclusion environment and they're not learning, or they're just debilitating other peoples learning- then inclusion is counterproductive
  - o more funding would = more support= progress= more inclusion
- more holistic approach
  - o need to consider the families expertise on the child as well as other professional opinions
- provide services earlier to potentially help decrease the need of services later
- **more mental health and emotional support needs to be offered to the families during the diagnosis process**
- try to get/teach the parents to be a solid advocate for their child
  - o the child needs this from their family

FAMILY
- Four programs within the agency- one is child/ youth based, the remainder focus on services and support for families/parents
- This day care centre offers support to the families in accessing services
- Home visits are avail for families- so educator might go into their home once a week to see how the programming is being applied and worked on in their home environment
- Families get reassessed throughout the year to determine whether or not they will continue on within the program (**POSSIBLE EXITS FROM THE SYSTEM**)
- Centre is accessible to all types of children and families depending on their situation
- Centre offers families and parents access to a lot of supports- and helps ensure they can gain access
- Depending on **FAMILY** – "there's some families who want, like, they're like really great advocates for their child"
- Offering support and services to parents pertaining to how it effects your relationships and self esteem as a parent
  - o Parents often isolate themselves and remove themselves from any sort of support.

4_3_048_1 and 4_3_049_1

BARRIERS
- When work with children with ASD- you can always anticipate a problem when there is a change in routine/schedule-
- Parental resistance to diagnosis sometimes delays the "official" diagnosis
- Resistance from families
    - Sometimes parents don't want children to become dependent on support being offered by IRT's
- IRT's not required to do follow up plan- but they are the people working with these kids- so would be so helpful if they would
- Documentation left by IRTs doesn't always get reviewed
- When IRT is working with more than one kid that is extremely demanding- you can only do what you can- lack of support can be extremely frustrating and not helpful to the children
    - 1 IRT had 5 children with ASD
- You MAY get an IRT even without a diagnosis based on the obvious developmental delays the child might have.. but this support is lost as of grade 4
- Not all children with ASD get an IRT- academically may excel, but socially they struggle- but they don't get support for this
- Parent's not wanting certain interventions
    - Depending on the situation, sometimes parent's don't "believe" its ASD- not just uneducated families feel this way. Sometimes educated informed families struggle with the diagnosis
        - But then these children could be missing out on intervention and support opportunity
- Student assistants could be ANY ONE- could be a bus driver one day, and in the classroom assisting the next- no education or training
- If there is no space for the child to safely go- they aren't allowed to go to school
- **Rural location**-not as much support avail - Specifically in private schools- HUGE lack of support
- Comprehensive assessment- uses diagnosis from doctor, then IRT and ed psych take documentation from schools, do some observing and complete a comprehensive file review to see if they have an exceptionality
    - Even when a child has a clear diagnosis, and evidently needs support, a file still needs to be constructed- it is A LOT of work and time consuming, for an answer they already have
- There isn't great communication between healthcare providers and education service providers
- Too many kids requiring assistance
- Parents are in denial
    - In order to provide any sort of outside therapy or assistance out of the classroom, support of parent is critical (requires consent- they sign of on IEP)
        - Parent only gets overruled if the child is aggressive and posing a threat
            - If an agreement can't be made between child and parent- child is sent home

- **Resistance from parents again ****
- **Rural location**- there is only one behavioral management specialist- when she went on maternity leave, they were unable to fill her position- so it was just vacant-
  o Reality of living in a smaller more rural area where there is not as many people to fill these types of roles
  o Gap in the services result in a lack of consistency which is very detrimental to children with exceptionalities (especially children with ASD)

FACILITATORS
- Collaboration between speech language pathologist and classroom teacher when making programs
- Programming transition plans in place and files done up to organize and summarize child's progress
  o Accessible via a school drive- anyone who needs access can gain access via this forum
- Ironically- the fact that all jobs are not permanent forces IRT to have things well documented in case their job changes
- When there is enough will power and support, teachers can help offer early intervention
- IRTs get paid more money, and have more education- encourages people to want to do this job
- One day of the cycle they have a meeting scheduled to discus special education
  o Included ed psych, autism consultant etc- collaborative approach
- Special services team meetings help keep staff on track- helps with clear communication
  o Allows people to be to the point and offer experience with the child, as well as share strategies with the different children
  o Also helps to pass along any communication that might be happening with the parents to one member of the team so that everyone is on same page
- **Rural location**- because of small rural location, there seeps to be good collaboration between ABA therapists and IRTs
- IRTS and classroom teachers do feel good support in this rural area from their principal and guidance counsellor
  o "we work collaboratively together and you do get the support from the administration, guidance, IRTs, classroom teachers…all been nothing but supportive"

ANXIETY
- Change in schedule causes anxiety
- Common comorbidity for children with ASD is anxiety
- It's a reality for these children- anxiety will not go away- they just need to learn to cope and manage
  o Requires a lot of hard work and consistency- but progress can be made

FAMILY
- Sometimes there is resistance (denial, worry, embarrassment)
  o Even after a diagnosis, family may request a re-assessment

- But once family is on board with diagnosis and therapies- it becomes easier to implement consistent behaviors
- Parent's not wanting certain interventions
    - Depending on the situation, sometimes parent's don't "believe" its ASD- not just uneducated families feel this way. Sometimes educated informed families struggle with the diagnosis
        - But then these children could be missing out on intervention and support opportunity

SERVICES
- IRT's help implement small structured changes into the child's schedule
- Also responsible for creating transition plans for students to help them as they move from grade to grade.
- Create visual schedules and quiet rooms to help with consistency and predictability of day for these children
- Teach them coping/calming mechanisms to apply to when something triggers them
- Each program and plan is built around the individual child- ASD is so individualized that no one plans can be applied to two children.
- IRT's are applied for on an individual basis- certain criteria required for the school board to provide support within a classroom
    - Often use documentation of incidents to help plead the case for support
- Comprehensive assessment- uses diagnosis from doctor, then IRT and ed psych take documentation from schools, do some observing and complete a comprehensive file review to see if they have an exceptionality
    - Conducted to keep everyone accountable and consistent

COMMUNICATION
- **Rural Location**- they know the parents- are able to easily communicate with them
- if there is no communication from the old school to the new school, it is likely child will not be able to avail of services until a plan is set up for the child (takes a long time)
- ABA therapist get to attend ISSP meetings to keep informed

GENERAL EXPERIENCE
- Children are usually diagnosed by the time they are getting to school
- Such a variety of personalities and characteristics when it comes to children with ASD
    - Girls with ASD – usually different than working with boys (easier)
- "the medical professional has input, they- we value their opinion but it doesn't mean that we have to follow their dictates"
- **inclusion** is case and situation dependent- not for all kids

RECOMMENDATIONS
- Encourage IRT's to read through past files and programs of their students
- Also encourage them to follow up with past teachers and assistants so that they can obtain as much information as possible about the children they are working with
    - "so you have to know the kid, every one of them is different"
        - when talking about the success of the child

- most valuable advice in being an IRT- flexibility and experience
    - "which is more important, is having experience and having a willingness to be flexible"
        - deal with all kind of impossible and disgusting situations- need to have the personality to brush it off, and deal with the task at hand which is usually never what you planned
- would be great to have the opportunity to meet directly with healthcare professionals who are diagnosing, interacting and working with the children so that all the information can be delivered first hand
- put 2 IRTs in every classroom- not just required for the children with exceptionalities- they would offer invaluable support
- benefit to having a social worker within the school
    - "social worker is very involved in the environment and in the home environment and the afterschool programs and the parents and like their struggles, because of academic- a lot of financial difficulties and things around that area so it makes a difference because then you're aware"
- parents need to be offered more education on the reality of having a child with an exceptionality,

4_3_069_1 –Michael- Pediatrician

EARLY SIGNS
- Behavior issues present themselves
  o Not performing to parents/ schools expectations
- If its before age 5- these behaviors are usually noted at home
- But if the child is functioning enough to make it to 5- behaviors usually present themselves once the child is presented in a structured environment with a lot of external stimuli

<u>Intake Process</u>
- Referral from NP or GP is necessary to see pediatrician
  o Typical referral: "three and a half year old with behavior disorder, parents are concerned about development, prior assessment"
- **Wait time**- once referral received- usually about 1 month- 6 weeks
- Michael might say he is diagnosing child with ASD based on strong indicators- and might suggest to family to start availing of ABA services right away- instead of waiting for formal diagnosis from the develop ped

Barrier
- Originally ped in rural area NOT allowed to diagnose- so **wait time**s were super long to get in to see the developmental pediatrician to receive a formal diagnosis
- Most people in **rural** area do not have a family doctor- how is it possible to access services without a GP?
- Only NPs and GPs can refer- barrier to those who cannot access either of these resources
  o Public health nurses- should be able to refer- they check in on the progress of the child and see first hand development – but they still cannot refer

Facilitator
- Michael approached childhood development program and pleaded the case that for children who are showing blatant obvious signs of ASD, he be able to diagnose them so they could start availing of ABA services as soon as possible- this was granted permission which helped with **wait time**s

<u>Intake Process Cont'd…</u>
- If it's a preschool age child Michael is confident has ASD- he refers to ABA to start services
- If it's a preschool age child Michael is not confident with- he refers to speech, audiology, developmental psychology and the 8-hours program, as well as OT and PT
- School aged children is harder
  o **Barrier-**
    ▪ can't access speech therapist through the local health authority- once you turn school age- must use the SLP within the school
      • Results in much longer **wait time**s

Barrier- preschool age child needs psych assessment, audiology assessment and a speech therapy assessment BEFORE the 8 hours team will accept referral

- o looking more like 2 academic years before child is getting diagnosed with ASD-which means 2 years before the qualify for any help within the schools

Facilitator
- quality of service once child is diagnosed is excellent (specifically for preschool age)
  - o harder for school aged because there are fewer resources within the school
- preschool age children- **FACILITATOR**- have more access to more services, more therapy hours etc
  - o so even if child cannot be 100% diagnosed, ped can still refer to so many services
    - ▪ main resource is *direct home services*
      - • this service sends a behavioral management specialist into the home to help the parents with the most concerning behavior
      - • "direct home services and behavioral management especially really target the autistic behavior"
- it works best when Michael (Pediatrican) can diagnose with ASD

Barrier
- school aged- only get access to school psychologist, which may only occur once
- if Michael can not diagnose with ASD- waiting for the diagnosis in a school aged child
  - o huge barrier because can't avail of other services without huge **wait times**
- biggest struggle with school aged children with ASD is the sensory processing disorder
  - o this is frustrating as a service provider because there is a child not achieving because we don't have the access to services that this child requires
- psych ed profiles take FOREVER-
  - o mainly because there is a lack of school psychologists (only 1 psychologist for every 10 schools)
- only thing that Michael can offer school aged children is OT and ABA (until the end of grade 2)
  - o SO if it's a grade 3 child:
    - ▪ No ABA
    - ▪ No speech referral (only access within schools- huge wait times)
    - ▪ No spontaneous psych ed profile to get on list for 8 hour team
    - ▪ All they can do is **WAIT**

Recommendation
- Have a process in place that allows the professional to recommend to the school that this child is demonstrating signs of ASD and to get the psych-ed profile done asap so that they are no waiting 2 academic years to offer the child support

COORDINATION OF CARE
- Between health professionals (pediatrician- speech) communication is great (quarterly updates)
- Not as much communication between pediatricians and OT and PT
- **Large gap** in the communication between psychology and pediatrician
- 8 hour team is good with communication of results and feedback (2-3 weeks)
- communication and coordination of care between pediatrician and **education system** depends on the specific school, and more specifically, the principal

- o some schools offer lots of detail information
- o other schools Michael hardly hears from at all
  - believes this has to do with the size of the school, the number of demanding kids within the school and how accommodating and attentive a school can be
- **Barrier**- often times pediatrician is invited to attend the individualized student support plan meeting- but it is impossible for one pediatrician to attend all these meetings. Over 60% of Michael's practice is ADHD/ ASD children who require these plans- just not enough time.
- **Facilitator**
  - o Michael has taken the time to go into schools and educate , inform and provide useful information to schools/teachers/ principals
  - o Autism Itinerant- like an occupational therapist for ASD- they go into the classrooms and schools and identify barriers and triggers for these children and possible modifications for these things

WAIT TIMES
- Why is it happening?
  - o Large number of referrals
    - Easily 30 referrals a month- and with the current # of service providers, only 60 can be completed A YEAR
  - o Not enough service providers
    - If one gets sick, or gets pregnant- there is no one to fill in for them, and therefore 8 hour assessments are either being minimized or paused- so nobody is getting a diagnosis at this time

SUPPORT FOR THE SERVICE PROVIDER
- Because Michael is a private pediatrician, any additional services he wants to include in his clinic, he needs to provide payment and support billing
  - o Which results in him not having access to many of his own services, but instead relies on the network of professionals in the area-
    - This is not exclusive to him, which poses issues with wait times etc

EXITING AND RE-ENTERING THE SYSTEM
- Not common
  - o Sometimes happens when parents are not ready to accept diagnosis
- "I see most parents and families really do appreciate the services that's available and how it's available and they do tend to stick with it. In the autism piece, not so much in the anxiety and depression piece, but in the autism for sure they tend to stick with it."
- Sometimes high functioning children with ASD get lost in the system because they were starting to improve so parents back off of therapy, but then something happens to trigger them again, and they're back looking to avail of services

SERVICES
- Speech pathology
- Occupational therapy

- Psychology
- Audiology
- 8 hour team
    - team of 4-5 individuals coming together to give the most accurate diagnosis of a child
    - team consists of pediatrician, OT, SLP, child psych and maybe PT
    - BIG **wait time** for this process
- ABA
    - Is working- lots of kids going in non-verbal and coming out talking
    - Incredibly effective
    - Commonly a lot of resistance from parents at first (strangers being in house etc)- but within 6-8 months parents are coming back raving about results
    - "I find that it does unlock a lot of these kids"
- **Facilitator**
    - Once kids are getting diagnosed, and getting services, they are doing well
- **Barrier**
    - Finding ABA therapist
        - Geographically- **rural** poses barrier for this

RECOMMENDATIONS
- More 8- hour teams
- More members in the teams
- Would like to suggest that there is more than one kid assessed at a time
    - There are several professionals evaluating the child at once, why can't we split up the professionals and have more than one child be assessed at a time, and just filter them through the different professionals on the team
    - Could decrease **wait time** by half!
- Remove psych ed profiles from children whose pediatricians have expressed real concern about ASD- is this step actually necessary, or is it just prolonging their access to support and care (specifically delaying access to the 8 hour team diagnosis)
    - Doesn't need to be removed completely- maybe just occur after the diagnosis
    - In regards to why they require the psych ed profile: " my personal belief is they put that in because the waitlist is so long"
        - Provides the kids something to do in the meantime, and helps with the big influx all at once- makes it seem like more is being done
- Would like to see ABA therapist, child psychologist, speech therapist etc work with the school to facilitate transition from one provider to the next

BARRIER
- Rules and regulations of school board present barriers for kids
    - Idea of **inclusion** does not always act as beneficial for every child
        - With serious behavior concerns you have to pay an IRT and a SA for a situation that just results in the child being removed anyways
        - Children are getting requested to be medicated which is not always necessary- they're just being forced into an environment that they don't belong in

- "cos' I don't wanna sedate them but the school system says there's nowhere else for him to go. Unless we get his behavior under control and he's no longer violent, he's not allowed back in our classroom
  - REALLY FRUSTRATING as a professional- **Inclusion**- not always the answer
- Schools won't let kids be advanced either
  - If a child with ASD is academically ahead, they are getting bored in their classrooms because they are not allowed to do content beyond their grade level, so now they are getting disruptive
- Michael compared ASD to cancer- a life threatening disease- but instead there is nothing to give these children except a **wait time**. ASD is a ticking time bomb for parents- and the idea of losing valuable time is horrifying.
  - Every day that passes, their kid is getting further behind
  - As a parent, Michael feels NO WAIT TIME is acceptable.

FINANCIAL
- Private psych ed profiles can be conducted- to help decrease **wait time**s- but insanely expensive (**barrier**)