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An Exploration of Parental Experiences with Interventions for Children and Adolescents with Autism Spectrum Disorder

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AN EXPLORATION OF PARENTAL EXPERIENCES WITH INTERVENTIONS FOR
CHILDREN AND ADOLESCENTS WITH AUTISM SPECTRUM DISORDER

(Thesis format: Integrated Article)

by

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Graduate Program in Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment
of the requirements for the degree of
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Abstract

Autism Spectrum Disorder (ASD) is defined as a group of pervasive developmental disorders that cause clinically significant impairments in social, occupational and overall functioning. The current body of research highlights the importance of community based interventions, programs and services for this population across their lifespan. This dissertation explores parental experiences with interventions, programs and services for their children and adolescents with ASD.

This dissertation contains three manuscripts in addition to the introductory and concluding chapters. The first manuscript explores the current literature on occupational therapy based interventions for school aged children with ASD. Manuscript two presents the findings of an interpretive narrative exploration regarding parental perspectives on interventions for their children with ASD. This manuscript is analyzed using a Critical Social Theory (CST) lens and explores the themes as shared within the stories of the participants. The third manuscript explores current service delivery models for adolescents with ASD throughout their transition to adulthood. A CST lens has been used to critique the structures, environments and institutions in which adolescents and young adults with ASD operate throughout their transition to adulthood.

This thesis contributes new knowledge to the growing body of information regarding parental perspectives on interventions for their children with ASD. It presents both confirmatory findings surrounding the importance of interventions for children and adolescents with ASD and identifies current service gaps for this population. It has provided insight into parental perspectives on interventions, programs and services for their children and has added their stories to the current literature. Additionally, the use of a CST lens

provides an opportunity to explore current social structures that impact service delivery for this population.

Key Words: Autism Spectrum Disorder, Autism, interventions, parental perspectives, children, adolescents, narratives, critical social theory

Co-Authorship Statement

I, Kaitlyn <u>Gain,</u> acknowledge that the three integrated manuscripts included within this thesis all resulted from collaboration with co-authors. In all three manuscripts, the primary intellectual contributions were made by the first author, who: researched and designed the methodologies, conducted literature reviews, sought appropriate ethical approval, recruited all participants, collected and transcribed all data, led the analysis of all data, and led in the construction and writing of all manuscripts.

The contribution of co-author Dr. Angela Mandich was primarily through her research supervision of the primary author, theoretical guidance, and support in the intellectual and editorial process of creating the work and preparing it for publication.

The contribution of co-author Dr. Lilian Magalhães was primarily through theoretical and methodological guidance to the primary author and support in the intellectual and editorial process of creating the work and preparing it for publication.

The contribution of co-author Dr. Janice Polgar was primarily through her theoretical and methodological guidance of the primary author and support in the intellectual and editorial process of creating the work and preparing it for publication.

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Chapter 1

1   Introduction

This dissertation presents a qualitative exploration of parents' personal stories

surrounding the selection and implementation of programs, services and interventions for

their adolescents with Autism Spectrum Disorder (ASD). To begin, I will present a brief

introduction of ASD, followed by a synopsis of the literature on interventions, programs

and services currently available for this population. The importance of the transition from

adolescence to adulthood for this group will be highlighted. Next, the research design

will be discussed, identifying the location of myself as the researcher, the ontological and

epistemological position and the theoretical frameworks used within the scope of the

included studies. Finally, I will outline the plan of presentation of this dissertation.

1.1   Autism Spectrum Disorders

Autism Spectrum Disorder (ASD) is defined as a group of pervasive

developmental disorders characterized by severe impairments in communication and

social interaction across multiple contexts and an increased prevalence of repetitive and

stereotypical behaviours (American Psychiatric Association, 2013). According to the

DSM-V, these symptoms cause clinically significant impairments in social, occupational

and overall functioning (American Psychiatric Association, 2013). Autism Spectrum

Disorder has been regarded as the most severe psychiatric disorder in childhood

(American Psychiatric Association, 2013; Shyu, Tsai & Tsai, 2010) and as recent

prevalence rates demonstrate, ASD is one of the most common developmental disabilities

(Centers for Disease Control and Prevention, 2014). Autism Spectrum Disorder impacts 1

in 68 children in North America (Centers for Disease Control and Prevention, 2014) and in the province of Ontario, there are an estimated 70,000 individuals living with ASD (Autism Ontario, 2014). There is no cure for the disorder at this time (Autism Ontario, 2014; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010). Individuals with ASD typically have difficulties in social interactions, verbal and non-verbal communication, play, and leisure activities (American Psychiatric Association, 2013; Case-Smith & Arbersman, 2008; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010). Individuals with ASD may exhibit repeated body movements such as hand flapping or rocking and demonstrate resistance to changes in routine. They may also experience sensitivities in sight, hearing, touch, smell and taste and in some cases display aggressive or self-injurious behaviours (American Psychiatric Association, 2013; Case-Smith & Arbersman, 2008; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010).

1.1.1   Interventions, Programs and Services Across the Lifespan

As children and adolescents with ASD experience significant difficulties in daily functioning, they are frequently referred for various therapies at home, in treatment facilities and within the school setting (Case-Smith & Arbersman, 2008; Fombonne, 2003; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010). Due to the spectrum nature of ASD and the unique presentation of the symptoms, it has been highlighted that no one approach is effective in alleviating symptoms in all cases (American Psychiatric Association, 2013; Case-Smith & Arbersman, 2008; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010). Currently,

various types of interventions are available for children with ASD. These include but are not limited to: behavioural approaches such as applied behavioural analysis (ABA) and intensive behavioural interventions (IBI); cognitive interventions; psychosocial interventions; communication based interventions; sensory based and sensory motor therapies; emotional interventions; neuropsychological treatments; medical interventions; and alternative approaches such as dietary interventions and animal assisted therapies (American Psychiatric Association, 2013; Autism Ontario, 2014; Case-Smith & Arbersman, 2008; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010). Research indicates that a wide variety of healthcare professionals work to implement these interventions. These include: physicians; psychiatrists; psychologists; speech and language pathologists; occupational therapists; applied behavioural analysis therapists; physical therapists; social workers; social skills training therapists; and music therapists (Autism Ontario, 2014; Case-Smith & Arbersman, 2008; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010).

Within the literature, a number of studies suggest that the effectiveness of interventions for this population is challenged by the diverse manifestation of the symptoms (Frances, 2005; Howlin, 2005; Kasari, 2002; Lord, Rutter & Le Couteur, 1994; Rogers & Vismara, 2008; Schall & Martin, 2005; Volkmar, Lord, Bailey, Schultz, & Klin, 2004). In the absence of consistent empirical evidence regarding the effectiveness of treatments and interventions, parents are continuously struggling to decide whether or not a particular treatment has been or would be effective for their own child (Goin-Kochel, Makintosh & Myers, 2009; Levy & Hyman, 2003, 2005; Levy,

Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003; Hebert, Sharp & Gaudiano, 2003).

Parents of children with ASD have the greatest responsibility for making decisions about

their children's medications, diet and educational and therapeutic programming (Goin-

Kochel, MacKintosh & Meyers, 2009; Green et al., 2006) and are centrally involved in

choosing their children's treatments. Within the literature is has been suggested that this

search for intervention and treatment is often further complicated by consistently new

interventions that have not been evaluated objectively (Goin-Kochel, Mackintosh &

Myers, 2009; Green et al., 2006).

In a number of studies, parents reported that their children were enrolled in an

average of five to seven different treatments (Goin-Kochel, Mackintosh & Myers, 2006;

Green et al., 2006) with one child accessing 47 interventions at one specific time. The

large number of intervention options for this population, combined with the lack of

empirical evidence for most interventions can leave parents and families feeling confused

and frustrated as they attempt to navigate the current medical system and determine the

best intervention option(s) for their children (Goin-Kochel, Mackintosh & Myers, 2006;

Green et. al, 2006).

1.1.2   The Transition to Adulthood

The transition from adolescence to adulthood is considered to be one of the most

important developmental processes in the life course of an individual (Hendricks &

Wehman, 2009; Osgood, Foster & Courtney, 2010; Stewart, Law, Rosenbaum & Willms,

2001). How an adolescent fares in this transition is said to have a long-term impact on

their future, occupational participation and overall quality of life (Hendricks & Wehman,

2009; Osgood, Foster & Courtney, 2010). Within North America, moving into adulthood

involves a difficult and long transition for typically developing adolescents (Osgood,

Foster & Courtney, 2010; Settersten & Ray, 2010). This transition from school and

community based services to adulthood can be a particularly challenging time for

adolescents with disabilities (deFur & Patton, 1999; Hendricks & Wehman, 2009; Schall

& Wehman, 2008; Sitlington & Clark, 2006). This is thought to be especially true for

adolescents with ASD, as they attempt to negotiate their way into college, work,

community participation and independent living (deFur & Patton, 1999; Hendricks &

Wehman, 2009; Schall & Wehman, 2008; Sitlington & Clark, 2006).

Recent literature highlights the importance of programs, services and

interventions focused on transition planning for this population (Hendricks & Wehman,

2009; Wehman, 2006; Wehman, Smith & Schall, 2009). For adolescents and young

adults with ASD, transitions at this stage typically include completing school, gaining

meaningful employment, participating in postsecondary education, contributing to a

household, increasing independence in activities of daily living, engaging in meaningful

community activities and experiencing satisfactory personal and social relationships

(Osgood, Foster & Courtney, 2010; Stewart, Law, Rosenbaum & Willms, 2001;

Wehman, 2006).

Despite the vast array of services, programs and interventions available for school

aged children with ASD, opportunities for adolescents and young adults are lacking

(Gray, 2002; Hendricks & Wehman, 2009; O-Brien & Daggett, 2006; Schall, Cortijo-

Doval, Targett & Wehman, 2006). The services provided to this oppressed population as

children (Freire, 1993) often come to an end during the transition to adulthood, despite

the identified need for significant continued support during this difficult time (Gray,

2002; Hendricks & Wehman, 2009; O-Brien & Daggett, 2006; Osgood, Foster & Courtney, 2010; Schall, Cortijo-Doval, Targett & Wehman, 2006). The impact of this lack of support and accessibility to services on families and young adults has yet to be discussed in the literature and is explored in this dissertation.

1.2   Methodological Choices

This dissertation draws on qualitative research methods that allow for in-depth exploration into parents perspectives on interventions, programs and services for their children with ASD (Campbell-Breen & Polland, 2006, Riessman, 2008; Wells, 2011). Using a narrative methodology based within storytelling allows the voices of the participants to be heard (Campbell-Breen & Polland, 2006, Riessman, 2008; Wells, 2011), and provides an opportunity for parents to tell their stories of their experiences and challenges associated with intervention selection and implementation for their children (Campbell-Breen & Polland, 2006, Riessman, 2008; Wells, 2011). For some, the act of narrating a life event can facilitate positive change (Chase, 2005; 2008) at personal and/or societal levels. The use of storytelling as a qualitative methodology has allowed for a better understanding of the critical issues faced by the participants within the presented studies.

1.2.1   Theoretical Framework

This dissertation is situated within an interpretive paradigm, which seeks to understand and reconstruct knowledge (Finlay, 2010; Guba & Lincoln, 1994). Ontologically, interpretivism is characterized by 'relativisim', which recognizes the existence of multiple meanings and subjective contrasted realities (Finlay, 2010; Guba &

Lincoln, 1994). Within these manuscripts, it is understood that all participants will be

sharing stories of their constructed realities. Each of these stories related to intervention

selection and implementation for children with ASD will be unique interpretations of the

meanings that they, the participants, have attached to these experiences. Thus, these

stories will not be taken at face value as a single reality, but rather analyzed and

interpreted as participants' multiple realities (Finlay, 2010; Guba & Lincoln, 1994).

Epistemologically, research findings in the interpretivist paradigm are understood

to be transactional and subjectivist (Finlay, 2010; Guba & Lincoln, 1994). It is

recognized that both the researcher and participant influence the research process, and

that presented findings are co-constructed by both parties (Finlay, 2010; Guba & Lincoln;

1994). Thus, throughout the course of this dissertation, I have not attempted to bracket

myself from the research, but rather, have acknowledged that I am part of the world I am

studying. In doing so, I have engaged in an iterative process of reflection throughout the

research process (Finlay, 2010; Guba & Lincoln; 1994).

1.2.2 Critical Social Theory

Throughout this dissertation, Critical Social Theory (CST) (Agger, 2013; Freire,

1993; Riessman, 2008) is applied as a lens to explore the narrative data. Critical Social

Theory offers researchers a way to explore and question the power imbalances within

social relationships (Canella & Lincoln; 2009; Friere, 1993; Sumner & Danielson, 2007).

It provides an opportunity to probe for systematic oppression and to investigate the

underlying power structures that impact the health delivery system for adolescents and

young adults with ASD (Agger, 2013; Canella & Lincoln; 2009; Friere, 1993; Sumner &

Danielson, 2007). More specifically, CST focuses on critically assessing power relations

at the sociocultural, economic and political levels and exploring how these imbalances inform knowledge and shape societal structures (Browne, 2000; Jennings, Parra-Medina, Hilfinger Messias & McLoughlin, 2006). Critical Social Theory seeks to put criticism at the forefront of knowledge production. It critiques ideology and relations of dependence, revealing hidden relations of domination and power inherent in societies' fundamental structures and ideologies (Browne, 2000).

When addressing the issue of oppressed populations, Freire (1993) highlights "a culture of silence", where the people lack a voice, and are often unaware they are entitled to one. Cultural and societal structures, in addition to family values and experiences, influence one's belief about the causes and course of ASD in their children (Daley, 2004; Goin-Kochel & Myers, 2005; Mandell & Novak, 2005). Furthermore, these underlying structures play a role in families' therapeutic decisions at micro, macro and meso levels (Cannella & Lincoln, 2009; Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Goin-Kochel & Myers, 2005; Mandell & Novak, 2005) by limiting what programs are available for specific groups and how these groups are able to access these services.

In the decision making process of program, intervention and service implementation for their children with ASD, families must explore the options available to them, evaluate their participation in occupations that bring meaning to their lives, and access services that will aid them across their childhood and into the transition to adulthood (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Goin-Kochel & Myers, 2005; Mandell & Novak, 2005). This population however, operates in a society with power structures that may impede their ability to successfully meet these needs and voice their concerns (Agger, 2013; Freire, 1993; Riessman, 2008).

This dissertation presents three integrated manuscripts that focus on parents' experiences with interventions, programs and services for their children with ASD. A brief overview of these papers will be presented here.

1.2.3   Scoping Review

Recently, scoping reviews have began to be used within the health and rehabilitation sciences field as a means of using a single review to examine a range of literature on a broad topic (Arksey & O'Malley, 2005). Although definitions of scoping reviews vary within the literature, Mays, Roberts and Popay (2001; p. 194) suggest that scoping reviews share a similar aim: "To map rapidly the key concepts underpinning an area of research and the main sources and types of evidence available…"

Arksey and O'Malley (2005) have expanded upon this broad definition and have outlined four common types of scoping reviews. Perhaps the most comprehensive type of review focuses not only on summarizing and disseminating the research in a particular area, but also on seeking to identify gaps within the existing literature. According to Arksey and O'Malley (2005), this type of scoping review takes the process of dissemination one step further by drawing conclusions based upon the literature, discussing the relevance of the findings, and identifying any gaps, discrepancies and areas for future research. These types of scoping reviews in particular, have the potential to not only be a valuable source of information, but also to inform policy makers, health care practitioners and consumers who might otherwise lack the time and resources to review the available literature in such depth (Arksey & O'Malley, 2005).

Scoping reviews differ from other types of reviews in that their method is guided by a requirement to identify all relevant literature in the area, regardless of study design.

The process of a scoping review is not considered to be linear, but instead is an iterative process requiring the researchers to engage in a number of stages in a reflexive and comprehensive manner (Arksey & O'Mally, 2005). These authors describe five stages involved in conducting a scoping review: identifying the research question; identifying the relevant studies; study selection; charting the data and; collating, summarizing and reporting the results. These five stages were the foundation for chapter two of this dissertation.

1.2.4   Narrative Methodology

Chapter three presents an interpretive narrative design that was used to explore the stories of parents' personal experiences with selection and implementation of interventions, programs and services for their children with ASD. The participants were asked to tell their stories throughout this process. Using a narrative methodology gives participants the opportunity to present their stories as they experienced them, and allows them to provide unique insights into their contexts and experiences (Campbell-Breen & Polland, 2006; Riessman, 1993; 2008; Wells, 2011). Furthermore, it allows the researcher and the broader audience to understand what components of their experiences the participants deem as relevant in their process of choosing their child's interventions (Chase, 2005, 2008; Lieblich, Tuval-Mashiach & Zilber, 1998; Molineux & Rickard, 2003; Riessman, 1993, 2008; Wells, 2011). Using this methodology, allows for participants' stories to extend beyond what researchers, academic institutions and funding sources have already deemed relevant within this context (Chase, 2005, 2008; Lieblich, Tuval-Mashiach & Zilber, 1998; Molineux & Rickard, 2003; Riessman, 1993, 2008; Wells, 2011). Within the healthcare field, understanding the narrative experiences of

parents' intervention selection allows researchers and clinicians to gain insight into this process and may influence their therapeutic decision making (Goin-Kochel & Myers, 2005; Mandell & Novak, 2005).

The interpretive narrative methodology used in this study is situated within a CST (Cannella & Lincoln, 2009; Chase, 2008; Freire, 1993; Riessman, 2008; Wells, 2011) lens. According to Chase (2005; 2008), the process of narrating a significant life event or group of events has the ability to facilitate positive social change, and narrative research seeks to 'give voice' to marginalized individuals or groups (Chase, 2005; 2008; McLaughlin & Tierney, 1993; Riessman, 2008). Similarly, using a CST perspective to explore emerging themes within the stories of the participants offers a means to question the power within social relationships and an opportunity to probe for systematic oppression (Cannella & Lincoln, 2009; Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Friere, 1993; Goin-Kochel & Myers, 2005; Mandell & Novak, 2005; Sumner & Danielson, 2007). It also provides an opportunity for exploring the underlying power structures, which shape the current healthcare delivery system (Canella & Lincoln, 2009; Friere, 1993; Sumner & Danielson, 2007).

This interpretive narrative study explores the stories of parents' experiences with intervention selection and implementation for their children with ASD. Although this has been identified as an area of importance in both academic and clinical settings, this has yet to be explored with the literature (Hendricks & Wehman, 2009; O-Brien & Daggett, 2006; Schall, Cortijo-Doval, Targett & Wehman, 2006). There are a number of benefits to studying these stories within a CST lens (Chase, 2008; Freire, 1993; Riessman, 2008; Wells, 2011). Firstly, it provides insight into the intervention selection and

implementation process of the participants and adds a new perspective to the literature.

Secondly, it allows for the exploration of cultural and societal structures that influence

therapeutic decision making for families. Specific information on the methods used for

the narrative study will be discussed in chapter three.

1.2.5   A Critical Paper on Current Service Delivery Models

Chapter three presents an interpretive narrative study that explores the stories of

parents' experiences with intervention selection and implementation for their children

with ASD. This study highlights a number of themes, which emerged from the stories of

the participants and are discussed within this chapter of this dissertation. Throughout the

course of the data analysis process, the theme of *accessibility of services during the*

transition to adulthood emerged. This theme incorporates a large number of smaller

subthemes and is intertwined as a central concept throughout the personal narratives of

all participants. This theme is explored in depth in chapter four.

As previously discussed, academic and clinical literature highlights the challenges

associated with the transition to adulthood for adolescents with ASD (Hendricks &

Wehman, 2009; Wehman, 2006; Wehman, Smith & Schall, 2009). Furthermore, the

importance of having accessible programs, services and interventions focused on

transition planning and increasing independence during this stage is identified within the

literature (Hendricks & Wehman, 2009; Wehman, 2006; Wehman, Smith & Schall,

2009). In order to convey the breadth, depth and significance of the parental discourse

within this context, the theme of *accessibility of services during the transition to*

adulthood will be explored through the application of CST in chapter four. Within this

paper, CST has been used as a theoretical lens to critique the structures, environments

and institutions in which adolescents and young adults with ASD operate throughout their transition to adulthood. Furthermore, the discrepancies between currently policy and legislation within the province of Ontario and the voices of the participants within this dissertation will be discussed.

1.3   Location of the Researcher

As previously stated, research findings within an interpretivist paradigm are understood to be transactional and subjectivist (Finlay, 2010; Guba & Lincoln, 1994). Within this paradigm it is recognized that both the researcher and participant influence the research processes, and that presented findings are co-constructed by both parties (Finlay, 2010; Guba & Lincoln; 1994). As such, I feel that it is important to share my personal and professional interests and background in this topic so that readers may better understand the views and theoretical assumptions with which I entered this research project.

I am a female in my mid-twenties studying as a PhD student in the Health and Rehabilitation Sciences Program (Child and Youth Health field) at a Canadian University. My passion for research in the area of ASD, stems from my extensive experience working with this population over the past decade. As a high school student, my summer jobs involved working and volunteering in the local community as a camp counselor, integrating children with ASD into a summer camp program. This experience fueled my passion in this area and since this time, I have worked with families in a variety of capacities including a Personal/Family Support Worker, Program Volunteer Coordinator and Activities Coordinator through the local chapter of Autism Ontario.

I am a recent graduate of the Masters of Occupational Therapy (MSc. OT) program, and have been working as an occupational therapist in the area of School Health Services since September 2012. In this role, I support a variety of clients within the school setting, including those with ASD. As most of my previous experience relates to school aged children, I entered my doctoral program believing that my research was going to be focused on this specific group. I began to complete a scoping review in an attempt to better understanding the current literature on occupational therapy interventions, which are available for school aged children with ASD (see Chapter 2). Throughout this process, I came to recognize that a wide variety of interventions are available for school aged children. Many of these programs are publicly funded and offer parents choice and flexibility surrounding the interventions that work best for their children. I felt quite optimistic regarding the literature presented within this scoping review, however when I began discussing my findings with families who have adolescents and young adults with a diagnosis of ASD, my optimism waned.

I shifted my focus to the academic literature on programs, interventions and services that are available for adolescents and young adults with ASD. I quickly became aware of the service limitations that exist within the current healthcare system for adolescents and young adults with this diagnosis. I have come to recognize that families are often faced with a number of difficult decisions and challenges when deciding on the implementation of specific interventions, programs and services for their children, and began my doctoral work to further explore this topic across the lifespan.

I am aware of my current beliefs on interventions for this population, and have been engaging in a constant process of reflection throughout the course of my time as a

doctoral student. I have made a conscious effort to recognize my theoretical assumptions and hence, focus on my own biases surrounding interventions for children and adolescents with ASD. Throughout this process I have participated in ongoing journaling and reflection activities.

1.4   Plan of Presentation

This dissertation is presented in an integrated article thesis format, with each chapter presented as an independent, publishable manuscript. As such, it is important to note that there will be some level of repetition throughout each of the chapters. This is intentional, and serves the larger purpose of each manuscript being able to stand alone beyond this compiled dissertation.

The introductory chapter (Chapter 1) of this dissertation was developed to set the stage for this research. This chapter has briefly explained current literature on ASD and the scope of interventions, programs and services available for this population. Additionally, the significant transition to adulthood for this group was discussed. This chapter has also provided the reader with the research designs and the theoretical frameworks used within this study.

Chapter two presents a scoping literature review of academic research on interventions used within occupational therapy practice for children aged 3-13 with ASD. This chapter identifies current occupational therapy interventions being used as treatment for children with ASD, examines the breadth of these interventions and discusses current gaps in the academic literature. This scoping review sets the stage for the original

research presented in chapters three and four, as it highlights the wealth of interventions available for this population.

In Chapter three, the first of two studies conducted for this dissertation is presented. It explores the narratives provided by eight participants surrounding their stories of interventions, programs and services for their children with ASD. The methods used to collect and analyze these narratives are presented in more depth in this chapter. This chapter presents the global impressions and themes (Lieblich, Tuval-Mashiach & Zilber, 1998; Molineux & Rickard, 2003; Riessman, 1993, 2008; Wells, 2011) that run through each of the individual stories, as well as the common themes across participants' narratives. The contributions and implications of these findings and the directions for future research are presented here.

Chapter four is a manuscript presenting the theme of *accessibility of services during the transition to adulthood*. This theme emerged from the interpretive narrative study discussed in chapter three. This theme incorporated a large number of smaller subthemes and was intertwined as a central concept throughout the personal narratives of all participants. The significance of this theme in each of the participant's stories, in addition to the importance of this transition time highlighted within the literature (Hendricks & Wehman, 2009; Wehman, 2006; Wehman, Smith & Schall, 2009), necessitated that this theme be explored in a separate manuscript. Within this paper, the theme of *accessibility of services during the transition to adulthood* is discussed within and across the stories of the participants. Additionally, a CST lens has been used to critique the structures, environments and institutions in which adolescents and young

adults with ASD operate throughout their transition to adulthood. Implications of this study and directions for future research are highlighted.

Chapter five presents the final considerations of this dissertation. This chapter discusses concluding messages, study limitations and methodological strengths and constraints. The measures used to maintain the quality of this research throughout are also presented. I conclude with my final reflections on this process.

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Chapter 2

2   Occupational Therapy Interventions for School-Aged Children with Autism Spectrum Disorder: A Scoping Review

Autism Spectrum Disorder (ASD) is defined as a group of pervasive developmental disorders characterized by severe impairments in communication and social interaction across multiple contexts as well as an increased prevalence of repetitive and stereotypical behaviours (American Psychiatric Association, 2013). According to the DSM-V, these symptoms cause clinically significant impairment in social, occupational or overall functioning (American Psychiatric Association, 2013). Autism Spectrum Disorder has been regarded as the most severe psychiatric disorder of childhood (American Psychiatric Association, 2013; Shyu, Tsai & Tsai, 2010) and is one of the most common developmental disabilities (Centers for Disease Control and Prevention, 2014). Although prevalence rates vary within the literature, recent studies report that ASD affects 1 in 68 children in North America (Autism Ontario, 2014; Centers for Disease Control and Prevention, 2014). The cause of ASD is not generally agreed upon within the literature and no cure for the disorder is available at this time (American Psychiatric Association, 2013; Centers for Disease Control and Prevention, 2014; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010).

Autism Spectrum Disorder impacts the development of the brain, primarily in the areas of social interaction and communication (American Psychiatric Association, 2013). Individuals with ASD typically have difficulties with social interactions, verbal and non-verbal communication and play and leisure activities. These individuals find it difficult to

communicate with others and often have difficulty relating to the outside world

(American Psychiatric Association, 2013; Case-Smith & Arbersman, 2008; Keenan,

Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai &

Tsai, 2010). Children with ASD may exhibit repetitive body movements such as hand

flapping or rocking and may demonstrate resistance to changes in routine. Children may

also experience sensitivities in sight, hearing, touch, smell and taste and in some cases

may display aggressive or self-injurious behavior (American Psychiatric Association,

2013; Case-Smith & Arbersman, 2008; Keenan, Dillenburger, Doherty, Byrne &

Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010)

As children with ASD experience significant difficulties in daily functioning, they

are frequently referred for various therapies at home, in treatment facilities and within the

school setting (Case-Smith & Arbersman, 2008; Fombonne, 2003; Huebner, 1992).

Research demonstrates that early diagnosis and intervention results in dramatically

increased positive outcomes for children with ASD (American Psychiatric Association,

2013; Case-Smith & Arbersman, 2008; Howlin, 2008; Keenan, Dillenburger, Doherty,

Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010). Currently,

various types of interventions are available and occupational therapists are among the

large group of healthcare professionals that provide services to this population and their

families (American Psychiatric Association, 2013; Case-Smith & Arbersman, 2008).

2.1   Occupational Therapy and ASD

Children with ASD often present with a wide range of occupational performance

issues that interfere with their daily functioning and full participation in self-care,

productivity and leisure domains (American Psychiatric Association, 2013; Case-Smith

& Arbersman, 2008). Predominant characteristics of ASD that affect a child's occupational performance include: limited communication skills, including delayed or deficient language; impaired social interactions; limited participation in developmentally appropriate play; sensory processing difficulties; and behavioural challenges (American Psychiatric Association, 2013; Case-Smith & Arbersman, 2008; Fombonne, 2003).

Young children with ASD often develop language at a slow rate, or not at all (American Psychiatric Association, 2013; Barry & Burlew, 2004; Case-Smith & Arbersman, 2008). They often do not use gestures to communicate or relate to others with eye contact or verbalizations (American Psychiatric Association, 2013; Case-Smith & Arbersman, 2008). As they develop, children with ASD may begin to use limited language, but often without communicative intent (Case-Smith & Arbersman, 2008). Children with ASD often prefer to spend time alone and may show decreased interest in making friends and engaging with their peers and others (American Psychiatric Association, 2013; Barry & Burlew, 2004; Case-Smith & Arbersman, 2008). They often present with deficits in social-emotional functioning and are less responsive to social cues such as eye contact, reading facial expressions and understanding gestures and nonverbal communication (Case-Smith & Arbersman, 2008; Rodger & Brandenburg, 2009). The social play of children with ASD is also significantly limited. These children often lack the ability to engage in spontaneous, imaginative or pretend play with their peers, may not engage in the imitation of others and lack joint attention skills (American Psychiatric Association, 2013; Case-Smith & Arbersman, 2008; Rodger & Brandenburg, 2009).

In addition to deficits in communication, social interaction and play skills, there is significant evidence that children with ASD process sensory information differently from

typically developing children (American Psychiatric Association, 2013; National Institute of Child Health and Development, 2005). Many children with ASD have aversions to olfactory and gustatory sensations (American Psychiatric Association, 2013; Baranek, 2002; Case-Smith & Arbersman, 2008) and demonstrate unusual aversions to touch and auditory stimulations (American Psychiatric Association, 2013; Baranek, 2002). Evidence suggests that these underlying sensory impairments often create barriers to a child's ability to function in a day to day environment in both home and school settings (Case-Smith & Arbersman, 2008), and often have a significant impact on a child's behaviour (Baranek, 2002).

Challenging behaviours, such as aggression, non-compliance, self-injury and stereotypy are common to school age children with ASD (American Psychiatric Association, 2013; Machalicek, O'Reilly, Beretvas, Sigafoos, & Lancioni, 2007). Children with ASD may be overactive or very passive, throw tantrums for no apparent reason and may show an obsessive interest in a single item, idea, activity or person (Baranek, 2002; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010; Machalicek, O'Reilly, Beretvas, Sigafoos, & Lancioni, 2007; Myers & Johnson, 2007). Some children display aggression towards themselves and/or others and many demonstrate significant difficulty with changes in routine.

Given the breadth and depth of occupational performance limitations that children with ASD experience, a wide range of interventions are often required to ensure the best possible outcome for the child (Case-Smith & Arbersman, 2008; Fombonne, 2003; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010). Evidence suggests that service providers must consider the unique pattern of strengths and difficulties of the

individual child when developing an intervention plan (American Psychiatric

Association, 2013; Case-Smith & Arbersman, 2008; Keenan, Dillenburger, Doherty,

Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010) and

occupational therapists are well equipped to play a role in this process. According to the

Canadian Association of Occupational Therapists (CAOT) Position Statement on

Occupational Therapy and ASD (2012):

> Occupational therapy services are client-centered and focus on the individual's
>
> and family's needs, goals, values and priorities. When working with children with
>
> ASD, occupational therapists look at the interaction of the child/youth within their
>
> environment, which includes the family, school system, community programs and
>
> other health professionals. Due to the complexity and range of difficulties in areas
>
> of function, an individualized evaluation and intervention program is required
>
> which promotes collaboration among all professionals involved. (p. 17).

The role of occupational therapists working with children with ASD is to promote

their full participation in the occupations of everyday living (Case-Smith & Arbersman,

2008; Polatajko & Cantin, 2010). In most settings occupational therapists are members of

an interdisciplinary team of healthcare professionals who evaluate, plan and implement a

child's individualized treatment program (Case-Smith & Arbersman, 2008; Keenan,

Dillenburger, Doherty, Byrne & Gallagher, 2010; Polatajko & Cantin, 2010). As part of

an interdisciplinary team, occupational therapists are able to offer a unique perspective

that focuses on the child, their occupations, and their interactions with the environment.

The focus of occupational therapy intervention is to enable occupational performance and

participation in activities of daily living (Case-Smith & Arbersman, 2008; Polatajko & Cantin, 2010).

Although intervention programs are developed on an individual basis to meet the needs of each child, occupational therapists working with school aged children often focus on a number of domains. These include: enhancing the child's sensory processing; sensory-motor performance; social-behavioural performance; self-care; and participation in play (CAOT Position Statement, 2010; Case-Smith & Arbersman, 2008; Polatajko & Cantin, 2010). For example, occupational therapy may focus on issues such as feeding, bathing, hygiene and sleep, which are significant issues for children with ASD, through adapting the tasks and environment as well as teaching new skills and strategies (CAOT Position Statement, 2012). In the school setting, occupational therapy focuses on improving school performance by addressing the underlying deficits impacting the child's occupational performance (CAOT Position Statement, 2012). Occupational therapists may adapt classroom tasks and the school environment to promote a child's success. Using a variety of service models, ranging from consultation with educators and families to direct service delivery, occupational therapists are able to make a difference in a child and family's daily functioning (CAOT Position Statement, 2012; Polatajko & Cantin, 2010) and promote independence in a child's day to day life.

This scoping review of the literature considers the breadth and depth of occupational performance issues exhibited by school aged children with ASD and the range of intervention approaches that are used by occupational therapy practitioners working with this population. It is organized by theoretical approach and includes: sensory integration and sensory based approaches; cognitive based approaches; social

skills based programs; parent directed/mediated approaches; behavioural approaches; and alternative approaches, such as animal assisted therapy (CAOT Position Statement, 2012; Case-Smith & Arbersman, 2008).

2.2   Methods

In recent years, scoping reviews have emerged within the health and rehabilitation sciences field as a means of using a single review to examine a range of literature on a broad topic (Arksey & O'Malley, 2005). Although definitions of scoping reviews vary within the literature, Mays, Roberts and Popay (2001; p. 194) suggest that at a general level, scoping reviews share a similar aim: "To map rapidly the key concepts underpinning an area of research and the main sources and types of evidence available…".

Arksey and O'Malley (2005) have expanded upon this broad definition and have outlined four common types of scoping reviews. Perhaps the most comprehensive type of review focuses not only on summarizing and disseminating the research in a particular area, but also on seeking to identify gaps within the existing literature. According to Arksey and O'Malley (2005), this type of scoping review takes the process of dissemination one step further. These types of reviews draw conclusions based upon the literature, discuss the relevance of the findings and identify any gaps, discrepancies and areas for future research (Arksey & O'Malley, 2005). These types of scoping reviews in particular have the potential to be a valuable source of information and inform policy makers, health care practitioners and consumers who might otherwise lack the time and resources to review the available literature in such depth (Arksey & O'Malley, 2005).

Scoping reviews differ from other types of reviews in that the method is guided by a requirement to identify all relevant literature in the area, regardless of study design (Arksey & O'Malley, 2005). The process of a scoping review is not considered to be linear, but instead is an iterative process requiring the researchers to engage in a number of stages in a reflexive and comprehensive manner (Arksey & O'Mally, 2005). These authors describe five stages involved in conducting a scoping review: identifying the research question; identifying the relevant studies; study selection; charting the data and; collating, summarizing and reporting the results (Arksey & O'Malley, 2005). These five stages were the foundation of this study.

2.2.1   Research Question

The aim of this scoping review is 1) to identify occupational therapy interventions that are currently being used as treatment for children with ASD; 2) to examine the breadth of these interventions through a holistic process; and 3) to identify and discuss any gaps in the literature that may be addressed through future evaluations. The following question guided the literature search and selection of research articles for use in the present study: What are the current trends related to occupational therapy based interventions for children ages 3-13 with Autism Spectrum Disorder?

2.2.2   Identification of Relevant Studies

In the present review, a broad search of eight electronic databases was conducted. These databases included: CINAHL, Medline, EMBASE, PubMed, SCOPUS, PsycINFO, ERIC, and the Cochrane Library. These databases were specifically chosen because they contain literature that is relevant to occupational therapy practice.

Other search strategies that were employed throughout the scoping review process included hand searching relevant articles found in the reference list of selected articles, and searching online grey literature. This review includes both quantitative and qualitative peer reviewed articles published between 2002 and 2013 in the English language.

The following search terms were used in the present study: Autism; Autism Spectrum Disorder; ASD; Autistic Disorder; Aspergers, Aspergers Syndrome; Occupational Therapy; Occupational Therapies; Occupational Therapy Treatment(s); School Based Intervention(s) and; Occupational Therapy Intervention(s). Individual terms were searched in each database and similar terms were grouped together using "OR". The culmination of similar terms were then grouped together using "AND". For example, the term 'Autism Spectrum Disorder' was combined with 'Autism' using "OR", and the resultant articles were then grouped with 'Occupational Therapy Interventions' using "AND".

2.2.3 Study Selection

Due to the overwhelming results on the search engines, inclusion criteria were devised to ensure the studies were relevant, accessible and manageable. The inclusion criteria required that the studies:

(i) Involved elementary school-aged children (ages 3-13 years) with a diagnosis of ASD;

(ii) Focused on an intervention that is based upon one of the following theoretical approaches which were most prevalent within the literature and commonly used within occupational therapy practice:

     a. Alternative Approaches

     b. Behavioural Approaches

     c. Cognitive Based Programs

     d. Parent Directed/Mediated Approaches

     e. Sensory Integration and Sensory Based Interventions

     f. Social Skills Based Programs;

(ii) Reported on occupational outcomes including function in productivity, self-care, leisure, quality of life, or self-efficacy in performing education directives and/or daily tasks;

(iii) Included interventions that are within the scope of the occupational therapy profession;

(iv) Were published in a peer-reviewed journal, available in full-text online, and available in the English language and;

(v) Were published between 2002 and 2013

The process of the present scoping review was documented in an audit trail to optimize the quality of the review (Arksey & O'Malley, 2005). Studies were first sorted through an initial screening of titles and abstracts eliminating 1246 items. The remaining articles were then read in full, and either discarded based on the inclusion criteria (143), or their information was charted (61). The content of these 61 articles will be elaborated on in the proceeding section.

2.2.4   Charting the Data

"Charting" is described by Arksey and O'Malley (2005) as a "technique for synthesizing and interpreting data by sifting, charting and sorting material according to

key issues and themes" (p. 26). All of the studies that met the requirements of the inclusion criteria were read in full and summarized using an excel spreadsheet. The original categories included: author(s); year of study; title of study; name of journal; database of origin; research aim/purpose; study design; population; setting; interventions; results; summary of findings; study limitations and additional notes. These categories were created to organize the data in a way that would make trends easily identifiable within the literature and highlight the important pieces of information that were derived from each study. Through the combination of the 14 original categories, the themes were derived.

A summary table was subsequently created to ensure consistency and organization in this process, as well as to allow for a more clear and comprehensive display of the findings. The information presented in the summary table (see Table 1, Appendix A) includes: author; year; treatment category; and the main findings of the studies included within the review. The results are organized by the theoretical approach represented in the literature (see Table 2). Synthesizing the data in this manner helped to display a clear and focused view of what interventions are currently being utilized and their main implications for school aged children with ASD. As the majority of the studies were quantitative in nature, and included main findings relevant to the effect of the interventions, the authors within this study determined the effect of each theoretical approach. Based on this, each study was identified in one of the theoretical approaches and placed in a category of 'effective', 'ineffective' or 'inconclusive/no results' (Peat, Entwistle, Hall, Birks & Golder, 2010; Reeves et al., 2011).

Table 2. Research design of selected articles

	Qualitative	Quantitative	Review	Total
Animal Assisted Therapy	1	3	0	4
Behavioural Approach	1	19	1	21
Cognitive Based Programs	0	5	0	5
Parent Directed/Mediated Approaches	0	2	0	2
Sensory Based Interventions	0	12	0	12
Social Skills Based Programs	0	17	0	17

2.2.5 Collating, Summarizing and Reporting the Results

The final sample of articles can be placed into three main categories of research designs: quantitative, qualitative and review articles (see Table 2). There were a large number of studies with a quantitative design (n=58), while a smaller number of articles utilized qualitative (n=2) (Conroy, Asmus, Seller & Ladwig, 2005; Solomon, 2010) or review methodologies (n=1) (Reynhout & Carter, 2008). Among the quantitative research articles, a small number of studies were randomized controlled trials (n=8), while the majority of studies were quasi-experimental in nature, or case-study designs containing quantitative methodologies (n=50). The reviewed qualitative articles contained both a two-subject case study design (n=1), which was based on parental journaling and qualitative feedback and a study exploring teacher's perspectives on the use of social stories as an intervention for children with ASD. Finally, one review article met the inclusion criteria for the present study and was included.

2.2.6   Study Participants

Many of the studies reviewed provided little description of the study participants. In most cases, this description contained only their age, diagnosis, and identified occupational performance issues. Although the age and number of participants varied within the selected studies, all participants were between the ages of 3 and 13 years and had a diagnosis of ASD (American Psychiatric Association, 2013).

Most of the participants included within the articles were part of a convenience sample selected from children receiving public or private services by healthcare professionals. Inclusion criteria for selection in all of the studies was a formal diagnosis of an ASD made by a physician or a psychiatrist using the diagnostic criteria defined in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2010). The total number of participants included within the selected articles in the present review is 857.

2.3   Main Findings

The results of the present study are organized by the theoretical approach to intervention represented within the literature, and can be classified into six broad categories (see Table 1, Appendix A).

The first theoretical intervention category, Animal Assisted Therapy, is viewed as a relatively new intervention technique within the field of ASD (Bass, Duchowny & Llabre, 2009; Martin & Farnum, 2002; Sams, Fortney, & Willenbring, 2006). This intervention approach is beginning to be used by occupational therapists and other healthcare professionals working with children with ASD (Bass, Duchowny & Llabre,

2009; Martin & Farnum, 2002; Sams, Fortney, & Willenbring, 2006). Four of the articles included in the present review focused on this intervention approach. All four articles suggested that animal assisted therapy such as therapeutic horseback riding and the use of service dogs provide school aged children with a diagnosis of ASD with support across a number of domains, including social interactions and communication (Bass, Duchowny & Llabre, 2009; Martin & Farnum, 2002; Sams, Fortney, & Willenbring, 2006; Solomon, 2010). These results highlight the potential benefit of including animal assisted therapy in the treatment of children with ASD, and the justification for further research in this area.

The second category includes 21 articles that examined the efficacy of behavioural interventions for school-aged children with ASD. These behavioural approaches included a variety of specific interventions including intensive behavioural interventions (Eikeseth, Smith, Jahr & Eldevick, 2002; Eikeseth, Smith, Jahar & Eldevik, 2007), interventions which utilized applied behavioural analysis principles (Ciceroa & Pfadtb, 2002; Conroy, Asmus, Seller & Ladwig, 2005), and the use of social stories (Adams, Gouvousis, VanLue, Waldron, 2004; Barry & Burlew, 2004; Crozier & Tincani, 2002) within the school environment. Although the majority of these studies yielded positive results (n=16), one study found that the use of social stories in the classroom was not effective in increasing time spent looking at a book during group reading time for three children with ASD (Sansosti, Powell-Smith, & Kincaid, 2004). Similarly, four articles presented inconclusive findings on the effectiveness of behavioural interventions with this population when applied within the school environment.

Five articles using a cognitive approach to treatment demonstrated promising results. All five of the included articles focused on applying the Cognitive Orientation to

Daily Occupational Performance (CO-OP) approach to specific child and parent selected

goals related to the development of life skills (Phelan, Steinke & Mandich, 2009). Each

of these five studies suggested that the CO-OP approach has the potential to benefit

school aged children with ASD when used as an intervention within the occupational

therapy process (Phelan, Steinke & Mandich, 2009; Rodger & Brandenburg, 2009;

Roger, Ireland & Vun, 2008; Rodger, Pham & Mitchell, 2009; Rodger, Springfield &

Polatakjo, 2007). The authors suggested a need for future research exploring this specific

intervention approach with this population.

The next category of interventions that displayed support within the literature is

parent mediated/directed approaches *(n=2)* (Boyd, McDonough, Rupp, Khan & Modfish,

2010; Sofronoff, Leslie & Brown, 2004). Although numerous occupational therapy

interventions contain a parent-mediated or directed component, these interventions focus

solely on parent instruction and implementation of specific interventions (Boyd,

McDonough, Rupp, Khan & Modfish, 2010; Sofronoff, Leslie & Brown, 2004). Despite

the vast amount of research available in this area, a limited number of articles that fell

within this domain failed to meet the inclusion criteria for the present review. Both

articles that were included showed positive results for the use of parent directed

intervention approaches within occupational therapy practice.

Arguably one of the most inconsistent intervention approaches reviewed in the

present article focused on a variety of sensory based interventions (Devlin, Healy &

Hughes, 2011). A total of 12 articles met the inclusion criteria and were included in this

study which focused on a variety of sensory based interventions and strategies including

brushing, seating, structured sensory integration protocol and the use of a weighted vest.

Of those 12 articles, three displayed effective results (Schilling & Schwartz, 2004; Pfeiffer, Koenig, Kinnealey, Sheppard & Henderson, 2011; Schadd, Benevides, Kelly, Maillouz-Maggio, 2012) while six interventions were found to be ineffective (Davis, Durand & Chan, 2011; Umeda & Deitz, 2010 Watling & Dietz, 2007) and three called for further research in the area (Bagatell, Mirigliani, Patterson, Reyes & Test, 2010; Van Rie & Heflin, 2009). Sensory based approaches are often used by occupational therapists working in the area of pediatrics, necessitating further research into the efficacy of specific sensory approaches and how to best integrate them into the school environment (Bagatell, Mirigliani, Patterson, Reyes & Test, 2010; Van Rie & Heflin, 2009).

Finally, 17 articles investigating the use of social skills based programs were included in the present study and included studies that explored the use of such programs within the classroom environment (Beaumont & Sofronoff, 2008; Cragat & Horvath, 2003; Crooke, Hendrix & Rachman, 2007). Similar to the articles focused on sensory based approaches, the main findings presented within these studies were variable. Ten of the reviewed articles found various social skills programs to be an effective occupational therapy intervention for children with ASD, while two articles found the intervention to be ineffective. Five articles expressed the need for future research in this area to determine more conclusive results.

2.3.1   Intervention Effects

Based on the review of the included articles, the study results can be discussed in three stands: effective, ineffective, and inconclusive/no results (see Table 3) (Peat, Entwistle, Hall, Birks & Golder, 2010; Reeves et al., 2011). Although the majority of the studies included in the present review yielded positive results (n=40), nine studies

indicate that the intervention was ineffective as the results were not statistically

significant, or no change was observed in the outcome variables of interest. One of the

articles with negative results used a behavioural intervention, while six articles indicated

that sensory based interventions were ineffective within the study. Two articles

examining social skills based interventions expressed ineffective results. In addition,

twelve articles either yielded inconclusive results (n=11) or no results (n=1) because this

article was a survey format and did not yield conclusive outcomes.

Table 3. Theoretical approaches and main findings in selected articles.

	Effective	Ineffective	Inconclusive/ No Results	Total
Animal Assisted Therapy	4	0	0	4
Behavioural Approach	16	1	4	21
Cognitive Based Programs	5	0	0	5
Parent Directed/Mediated Approaches	2	0	0	2
Sensory Based Interventions	3	6	3	12
Social Skills Based Programs	10	2	5	17

2.3.2   Outcome Evaluation

The effect of the interventions was based on measurements of the following

dependent variables. These dependent variables were selected as outcome measures for

this review as they are common functional variables used within the occupational therapy

field when working with this population:

1. On-task behaviour/sustained attention – attention to task (reading, table top

    activities) (productivity)

2. Social skills - play with peers, empathy, ability to play with others, sharing ideas with others etc. (productivity/leisure)

3. Academic success/school functioning – improved participation in structured class time, improved school marks (productivity)

4. Behaviour - decreased disruption of class, following classroom routine, decreased screaming (productivity)

5. Cognition – improved scores on standardized tests, ability to complete novel activities thus improving independence in ADLs (productivity/self-care/leisure)

6. Emotional functioning – crying, screaming, increased independence, emotional regulation, improved participation (productivity/self-care/leisure)

7. Family functioning – parental reports of overall family functioning (productivity)

8. Sensory processing – stereotyped behaviours, emotional regulation (productivity/self-care/leisure)

2.4   Discussion

2.4.1   Themes

The present scoping review identified four major themes and provides information that can be used by occupational therapists as a guide for selecting, planning and integrating interventions for children with ASD. Although the studies were based on a variety of theoretical frames of reference, several themes of importance to occupational therapy emerged. This discussion focuses on the themes that are relevant to occupational therapy practitioners working with this population.

1. *The majority of the literature focused on occupational therapy based interventions for school aged children with ASD is quantitative in nature and does not take into account the perspectives of parents, teachers and healthcare providers working with this population.*

Based on the included 61 articles, only two articles (Conroy, Asmus, Seller & Ladwig, 2005; Solomon, 2010) incorporated qualitative research methodologies exploring parents' and teachers perspectives on the provided intervention. With a large number of occupational therapy based interventions to choose from and the unique presentation of ASD symptoms in this population (American Psychiatric Association, 2013; Case-Smith & Arbersman, 2008; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010), clinicians and researchers must ensure that parental perspectives on interventions are taken into account throughout the therapeutic process. Future research should further explore the experiences of parents, teachers and healthcare providers throughout this process.

2. *A wide range of non-pharmacological occupational therapy interventions were found useful in promoting successful performance of specific occupations in school aged children with ASD within the home and school settings.*

Based upon the 61 articles included within this scoping review, a vast array of interventions were found to be successful in improving the daily functioning of school aged children with ASD. The present review proposes that behavioural interventions are the most common and most researched type of interventions used by clinicians working with children with ASD. These types of interventions are typically used to manage

disruptive and self-injurious behaviours, to increase on-task behaviours at home or school and to encourage the development of new skills through reinforcement schedules. A large number of specific strategies have been identified and were used within the studies in the present review. These include applied behavioural analysis principles (including the more specific intensive behavioural intervention therapy), the use of social stories, token economies, time-outs, and individual behaviour programs. The outcomes of these interventions varied within the literature, although overall behavioural interventions yielded positive results when used with school aged children.

Additionally, four studies included in this review have demonstrated that the use of animals with children with ASD has lead to significant improvements in daily functioning. Throughout the included articles, the definition of 'animal assisted therapy' varied from the use of therapy dogs in therapy sessions, to therapeutic horseback riding interventions, to the use of service dogs both in the home and school environments. Regardless of the specific intervention, the use of animals was deemed effective in increasing the use of non-verbal communication, language and social interaction with this population (Bass, Duchowney, & Llabre, 2009; Martin, & Farnum, 2002; Sams, Fortney, & Willenbring, 2006; Solomon, 2010).

All of the five articles, which investigated the efficacy of a cognitive approach for children with ASD, focused on the use of the Cognitive Orientation to Occupational Performance (CO-OP) approach. Each article found that the CO-OP approach was successful in increasing the social skills, organizational skills and overall occupational performance when used by school aged children with ASD (Phelan, Steinke & Mandich,

2009; Rodger & Brandenburg, 2009; Roger, Ireland & Vun, 2008; Rodger, Pham & Mitchell, 2009; Rodger, Springfield & Polatakjo, 2007).

Although a large number of articles focusing on investigating the efficacy of parent mediated/directed approaches were initially reviewed, only two met the inclusion criteria of the present review (Boyd, McDonough, Rupp, Khan & Modfish, 2010; Sofronoff, Leslie & Brown, 2004). Both articles focused on an individualized program developed to include the parents in the intervention process and yielded positive results. Both articles found that parent mediated interventions were effective in decreasing repetitive/stereotypical behaviours in children with ASD and in increasing their overall occupational functioning. These articles highlighted the importance of parental involvement in the therapeutic process (Boyd, McDonough, Rupp, Khan & Modfish, 2010; Sofronoff, Leslie & Brown, 2004).

Finally, 12 articles focusing on sensory based interventions, and 17 articles examining the efficacy of social skills programs were included in the present review. Although the studies were based on different theoretical frames of reference, the overall outcomes were similar. Both the articles focused on sensory based interventions and those examining the efficacy of social skills programs yielded varying results. Of the sensory based intervention articles, three found this intervention to be successful in improving the daily functioning for children with ASD. Similarly, 10 of the 17 articles that examined social skills based programs found the intervention to be successful.

Overall, the present review identified a number of non-pharmacological interventions for children with ASD that yielded positive results, and would be beneficial for use by occupational therapists working with this population.

3. Research related to the effectiveness of occupational therapy interventions for children with ASD is challenged by the heterogeneous nature and complexity of the spectrum disorder.

Despite the positive outcomes described in many of the included studies, it quickly became evident that ASD is a complex disorder and presents differently in each child. Due to the diverse manifestation of the symptoms, it is important to acknowledge that although many of these interventions were deemed successful with the study participants, they may not meet the needs of other children with an ASD. A number of studies highlighted the difficulty with conducting research in this field, as the presentation of the disorder is so variable, and must be taken into account when interpreting the results (Case-Smith & Arbesman, 2008; Eikeseth, Smith, Jahr, & Eldevik, 2002).

4. While many single treatment approaches have been shown to be effective throughout this review, many of these interventions targeted very specific domains. A comprehensive, multi-disciplinary treatment approach is needed to address global behavioural, developmental and sensory needs of the child.

Although a vast number of studies included within the present review yielded positive results, many of these studies focused solely on a single intervention and very specific outcome measures. Given the breadth and depth of the occupational performance

limitations often experienced by children with ASD, a wide range of interventions are often required to ensure the best possible outcome for the child (Case-Smith & Amersman, 2008). Based on the data that emerged from the present review, it is important that service providers recognize the unique pattern of strengths and difficulties of the individual when developing an intervention plan. Autism Ontario (2014), further recognizes the necessity for unique treatment plans, and highlights the importance of comprehensive approaches to intervention, which often include a combination of techniques.

Although research related to the effectiveness of interventions for children with ASD is challenged by the complexity and variability of the disorder, the evidence gathered in this review suggests that therapies utilizing these theoretical frames of reference can improve occupational outcomes in children with ASD. Occupational therapists working within an evidence based practice model can utilize the information provided within the present review and use this information to help shape their practice and intervention implementation for children with ASD.

2.4.2   Strengths and Limitations

Several limitations of the present scoping review must be considered when interpreting results and designing future studies. The primary limitation of the present review relates to the search strategy and the exclusion criteria used. Although key electronic databases including CINAHL, EMBASE, PubMed, SCOPUS, and PsychINFO were used to gather all potential articles, the use of additional databases may have yielded more results. Additionally, due to the strict inclusion criteria, surrounding the participants, a large number of articles were excluded.

In addition to the identified limitations, there are a number of strengths associated with the present review. Firstly, the use of the methodology outlined by Arskey and O'Malley (2005) for use with scoping reviews, ensures rigor within the study. As outlined within this methodology, saturation was reached prior to the end of the literature search, ensuring the breadth of the present study. Finally, this review has the potential to greatly contribute to the literature as it explores a large number of interventions for children with ASD across a wide variety of theoretical frameworks.

2.4.3   Gaps in the Literature and Implications for Future Research

Despite the breadth of the present scoping review, many questions are left unanswered and additional information is required. Given the overall positive outcomes associated with the articles reviewed in the present study, additional research should be conducted in this area. As previously discussed, many of the included studies focused primarily on a single intervention and very specific outcome measures. Future research should further explore the use of eclectic (combined) intervention approaches with school aged children with ASD, to more comprehensively address more global symptoms and increase overall functioning.

Additionally, the National Institute of Child Health and Development (2005), suggests that the generalization and maintenance of skills are important instructional outcomes for students with ASD. As many children with ASD have difficulty transferring skills learned in one setting or situation to untrained settings or situations and/or have difficulty maintaining skills over time, research should begin to focus on this area. Few of the included studies investigated the generalizability of the intervention effects over time or across situations.

Finally, future literature should focus on the stories of parents and families throughout the intervention process to gain a better understanding of their perspectives and experiences through a qualitative methodology. Future research in this area will help guide occupational therapists and other healthcare professionals working with school aged children with ASD. Specifically, further research into the efficacy of combined/eclectic intervention approaches, as well as a cost-benefit analysis of such approaches would be of great benefit to healthcare professionals in this field.

2.5   Conclusion

The present scoping review outlined the relevance of occupational therapy to ASD intervention, and provided a brief overview of the literature base in this area. The study methods and procedures were presented followed by the results and discussion, highlighting themes, gaps in the literature and implications for future research. The present study holds the potential to add a new perspective to the literature in this area. Through summarization of the current literature and discussion of the emergent themes, this review may inform not only occupational therapists working with children with ASD, but also policy makers, other healthcare practitioners, consumers and researchers.

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Chapter 3

3 A Narrative Exploration of Parents' Experiences with Intervention for Children with Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is defined as a group of pervasive

developmental disorders characterized by severe impairments in communication and

social interaction across multiple contexts and an increased prevalence of repetitive and

stereotypical behaviours (American Psychiatric Association, 2013). According to the

DSM-V, these symptoms cause clinically significant impairments in social, occupational

and overall functioning (American Psychiatric Association, 2013). Autism Spectrum

Disorder has been regarded as the most severe psychiatric disorder in childhood

(American Psychiatric Association, 2013; Shyu, Tsai & Tsai, 2010) and as recent

prevalence rates demonstrate, ASD is one of the most common developmental disabilities

(Centers for Disease Control and Prevention, 2014). Autism Spectrum Disorder impacts 1

in 68 children in North America (Centers for Disease Control and Prevention, 2014) and

within the province of Ontario, there are an estimated 70,000 individuals living with

ASD. There is no cure for the disorder at this time (Autism Ontario, 2014; Keenan,

Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai &

Tsai, 2010).

Individuals with ASD typically display difficulties in social interactions, verbal

and non-verbal communication, play, and leisure activities (American Psychiatric

Association, 2013; Case-Smith & Arbersman, 2008; Keenan, Dillenburger, Doherty,

Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010). Individuals

with ASD may exhibit repeated body movements such as hand flapping or rocking and

have resistance to changes in routine. They may also experience sensitivities in sight, hearing, touch, smell and taste and in some cases display aggressive or self-injurious behaviours (American Psychiatric Association, 2013; Case-Smith & Arbersman, 2008; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010).

As children and adolescents with ASD experience significant difficulties in daily functioning, they are frequently referred for various therapies at home, in treatment facilities and within the school setting (Case-Smith & Arbersman, 2008; Fombonne, 2003; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010). Due to the spectrum nature of ASD and the unique presentations of the symptoms, it has been highlighted that no one approach is effective in alleviating symptoms in all cases (American Psychiatric Association, 2013; Case-Smith & Arbersman, 2008; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010). Currently, various types of interventions are available for children and adolescents with ASD. These include, but are not limited to: behavioural approaches such as applied behavioural analysis and intensive behavioural interventions; cognitive interventions; psychosocial interventions; sensory based and sensory motor therapies; emotional interventions; neuropsychological treatments; medical interventions; and alternative approaches such as dietary interventions and animal assisted therapies (American Psychiatric Association, 2013; Autism Ontario, 2014; Case-Smith & Arbersman, 2008; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010).

Research indicates that a wide variety of healthcare professionals work to implement these interventions and include: physicians; psychiatrists; psychologists;

speech and language pathologists; occupational therapists; intensive behaviour intervention therapists; physical therapists; social workers; social skills training therapists; and music therapists (Autism Ontario, 2014; Case-Smith & Arbersman, 2008; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010).

Based on the breadth of interventions available for children and adolescents with ASD, a scoping review of the literature surrounding occupational therapy based interventions for school aged children with ASD was conducted (Arksey & O'Malley, 2005) (See Chapter 2). This scoping review identified the interventions that are currently being used as a treatment for children with ASD and examined the breath of these interventions. It consisted of 61 studies seeking to explore intervention approaches within the school setting. The review suggests that research related to the effectiveness of occupational therapy interventions for children with ASD is challenged by the heterogeneous nature and complexity of the spectrum disorder and that many occupational therapy interventions which are successful with some participants, do not meet the needs of all children with ASD.

Within the broader literature a number of studies suggest that the effectiveness of interventions expanding beyond occupational therapy practice are also challenged by the diverse manifestation of symptoms in this population (Frances, 2005; Howlin, 2005; Kasari, 2002; Lord, Rutter & Le Couter, 1994; Ospina et al., 2008; Rogers & Vismara, 2008; Schall & Martin, 2005; Volkmar, Lord, Bailey, Schultz, & Klin, 2004). In the absence of consistent empirical evidence regarding the effectiveness of treatments and interventions overall, parents are continuously trying to decide whether or not a particular

treatment has been or would be effective for their own child (Goin-Kochel, Makintosh & Myers, 2009; Herbert, Sharp & Gaudiano, 2003; Levy & Hyman, 2003, 2005; Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003). Parents of children with ASD are centrally involved in choosing their children's treatments and have the greatest responsibility for making thoughtful decisions about their children's medications, diet and educational and therapeutic programming (Goin-Kochel, MacKintosh & Meyers, 2009; Green et al., 2006). This search for treatment is further complicated by outpourings of new treatments, many of which have only anecdotal support from studies with one or a few participants and have not been evaluated objectively (Goin-Kochel, Mackintosh & Myers, 2009; Green et al., 2006).

In two separate studies, parents reported that their children were currently enrolled in an average of five to seven interventions (Goin- Kochel, Mackintosh & Myers, 2006; Green et al., 2006) with one child accessing 47 tretments at one given time. The lack of empirical evidence for most interventions combined with the large number of intervention options for this population, often leave parents and families feeling confused and frustrated as they attempt to navigate the medical system and determine what is the best treatment option(s) for their children (Goin-Kochel, Mackintosh & Myers, 2006; Goin-Kochel, Mackintosh & Myers, 2009; Green et. al, 2006). The findings of the present study incorporate parents' stories and experiences of this search, providing a new perspective that expands upon the quantitative research literature concerning parental selection and implementation of interventions for their children with ASD.

This interpretive narrative study was designed to explore the stories of parents' personal experiences with selection and implementation of interventions, programs and

services for their children with ASD. The participants were asked to tell their stories throughout this process. Using a narrative methodology gives participants the opportunity to present their stories as they experienced them, and allows them an opportunity to provide unique insights into their contexts and experiences (Campbell-Breen & Polland, 2006; Riessman, 1993; 2008; Wells, 2011). Further more, it allows the researcher and the broader audience to understand what components of their experiences participants recognize as relevant events in their process of choosing their child's interventions (Chase, 2005, 2008; Lieblich, Tuval-Mashiach & Zilber, 1998; Molineux & Rickard, 2003; Riessman, 1993, 2008; Wells, 2011). Using this methodology, allows for participants' stories to extend beyond what researchers, academic institutions and funding sources have already deemed relevant within this context (Chase, 2005, 2008; Lieblich, Tuval-Mashiach & Zilber, 1998; Molineux & Rickard, 2003; Riessman, 1993, 2008; Wells, 2011) and seeks to provide a new perspective to the current literature in this area. Within the healthcare field, understanding the narrative experiences of parents' intervention selection, allows researchers and clinicians to gain insight into this process and may influence their therapeutic decision making process (Goin-Kochel & Myers, 2005; Mandell & Novak, 2005).

Within the present study, the interpretive narrative methodology was situated within a Critical Social Theory (CST) perspective (Cannella & Lincoln, 2009; Chase, 2008; Freire, 1993; Riessman, 2008; Wells, 2011). Cultural and societal structures, as well as family values and experiences, influence one's beliefs about the causes and course of ASD in their child (Daley, 2004; Goin-Kochel & Myers, 2005; Mandell & Nocak, 2005). Furthermore, these underlying structures play a role in their therapeutic

decision making at micro, macro and meso levels (Cannella & Lincoln, 2009; Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Goin-Kochel & Myers, 2005; Mandell & Novak, 2005). According to Chase (2005; 2008), the process of narrating a significant life event or group of events has the ability to facilitate positive social change, and narrative research seeks to 'give voice' to oppressed individuals or groups (Chase, 2005; 2008; Friere,1993; McLaughlin & Tierney, 1993; Riessman, 2008). Similarly, using CST to explore emerging themes within the stories of the participants offers a means to question the power within social relationships and an opportunity to probe for systematic oppression (Cannella & Lincoln, 2009; Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Friere, 1993; Goin-Kochel & Myers, 2005; Mandell & Novak, 2005; Sumner & Danielson, 2007). It also provides an opportunity for exploring the underlying power structures, which shape the current healthcare delivery system (Canella & Lincoln, 2009; Friere, 1993; Sumner & Danielson, 2007).

This interpretive narrative study explores the stories of parents' experiences with intervention selection and implementation for their children with ASD. This has yet to be explored within the literature. There are a number of benefits to studying these stories within a CST lens (Chase, 2008; Freire, 1993; Riessman, 2008; Wells, 2011). Firstly, through exploring the stories of parents, this study offers insight into the intervention selection and implementation process of the participants and adds a new perspective to the literature. Secondly, this study further explores cultural and societal structures that influence therapeutic decision making for families.

3.1   Methods

The present study was conducted as part of a larger project exploring the transition to adulthood for adolescents with ASD and parents' experiences with interventions over their child's life. This project was conducted for the purposes of the primary author's doctoral degree requirements. This article is written in the first person from the perspective of the primary author, and the primary author conducted all components of this study. Consultation with the other authors was provided at all stages of this research project to facilitate reflection and ensure a high quality of research throughout this process.

For this study, I utilized an interpretive narrative methodology that is situated within CST (Freire, 1993; Kincheloe, McLaren & Steinberg, 2011; Riessman, 2008; Wells, 2011). Narrative research was selected as it seeks to prioritize the accounts of the participants, focusing on the stories and experiences of the individuals (Campbell-Breen & Polland, 2006, Riessman, 2008; Wells, 2011). For some, the act of narrating a life event can facilitate positive change (Chase, 2005; 2008) at personal and/or societal levels. By presenting participants' stories as they experience them, I am not seeking to understand the historical and temporal accuracy of the experiences (Riessman, 2008), but rather the experiences as they impacted their treatment and intervention choices and their perspective on what services, programs and interventions are available for their children.

3.1.1   Participants

Informed verbal and written consent was obtained from all participants prior to their participation in this study. The inclusion criteria for participants as follows:

1) participants must live in an urban center in Ontario;

2) participants must be over the age of 18;

3) participants must be the parent of a child between the ages of 15 and 21 with ASD;

4) participants must speak English proficiently to conduct the interview; and

5) participants must be willing to discuss their stories of intervention selection and implementation for their children

Ethics approval was obtained from the University Non-Medical Ethics Review Board and recruitment information was provided to a Chapter of Autism Ontario within the urban center where the study was completed. Participants were recruited via email and word of mouth through this local non-profit organization. Fitting with qualitative research, this interpretive narrative study was conducted with a small group of eight participants to allow for rich and insightful data to be gathered (Chase, 2005; Denzin & Lincoln, 2005; Wells, 2011).

The eight participants within this study had children between the ages of 15 and 21 with a diagnosis of ASD. Participants with children within this age range were recruited as these parents have had experience with interventions, programs and service selection across their childhood. I omitted all potentially identifying information of the participants to maintain anonymity, and all participants have been given pseudonyms which are used throughout this study. Participant's demographic information is presented in Table 4.

Table 4. **Demographic information of participants.**

Participant	Gender	Age of Child
Sarah	Female	15
John	Male	21
Grace	Female	15
Natalie	Female	17
Trish	Female	17
Jessica	Female	16
Linda	Female	15
Martha	Female	18

3.1.2 Collecting the Narrative Data

Informed verbal and written consent were obtained prior to the interview. The

stories of the eight participants were gathered through individual face-to-face interviews

with the researcher. These interviews allowed for the participants to share their stories

and experiences, highlighting what they felt to be the most significant components

(Chase, 2005; Lieblich, Tuval-Mashiach & Zilber, 1998; Wells, 2011). Within narrative

methodology, no two interviews are alike (Lieblich, Tuval-Mashiach & Zilber, 1998;

Wells, 2011) and the narratives are influenced by a variety of factors, including the

interaction between the researcher and the participants (Lieblich, Tuval-Mashiach &

Zilber, 1998; Wells, 2011).

Based on the course, breadth and depth of the participant's story, the initial

narrative interview session ranged from 45 to 120 minutes. The initial interview

contained one overarching question: "*Tell me your story of your experiences with*

interventions, programs and services for your child over the course of his life." This

question was constructed to be broad and open-ended, so participants could elaborate on

their experiences the way that they had experienced them (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 1993; Wells, 2011). In doing so, the participants had control over how their story was told and were not constricted by considerations such as chronology and specific questions (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 1993; Wells, 2011).

Throughout the narrative process, my primary role was that of an active listener (Lieblich, Tuval-Mashiach & Zilber, 1998; Wells, 2011). I spoke only to respond to the questions of the participants as they shared their stories and to ask for elaboration or clarification of something they had shared. Follow-up interviews were then completed with participants where the global impressions and general themes within their individual stories were discussed (Lieblich, Tuval-Mashiach & Zilber, 1998; Wells, 2011). At this time, all participants had the opportunity to add to their stories of intervention, selection and implementation for their children and discuss the themes within their stories.

3.1.3   Analysis of the Written Narratives

Holistic Content Analysis for narrative research was used as the data analysis (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008; Wells, 2011) framework in this study. Riessman (2008) highlights the importance of prior theory serving as a resource for the interpretation and analysis of written narratives. In this study, the themes that emerged were identified in light of the research purpose, participants' data, available literature and a CST lens. Analysis of narrative research is described as a co-constructed and iterative process (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008). The stages outlined below were applied at various points within the process as themes began to emerge (Lieblich, Tuval-Mashiach & Zilber, 1998).

Transcription of the interviews is an interpretive practice, where the researcher chooses how to present the messaging and stories of the participants (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 1993, 2008; Wells, 2011). For this study, I began this process by transcribing all interviews verbatim. This is the initial step in laying out the foundation and themes of the narratives for analysis (Lieblich, Tuval-Mashiach & Zilber, 1998; Wells, 2011). I subsequently immersed myself deeply within the data by reviewing, multiple times, the participant transcripts, audio recordings, field and memo notes and researcher journal entries to ensure a clear understanding of any nuanced meanings and subtleties of my interactions with the participants (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008; Wells, 2011). This continued until foci or patterns within each story began to emerge. I then recorded my initial and global impressions of the material (Lieblich, Tuval-Mashiach & Zilber, 1998). According to Lieblich, Tuval-Mashiach & Zilber (1998), obtaining a global impression of each participants' story is a central component within this process. This global impression serves as the main theme or feeling of the story that captures both the content and the emotion and guides the analysis processes (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008; Wells, 2011). The global impression within each story often evolves throughout the data analysis process (Lieblich, Tuval-Mashiach & Zilber, 1998).

Following the development of my global impressions (Lieblich, Tuval-Mashiach & Zilber, 1998), I assessed each narrative for its themes by reading the participants' stories multiple times (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008). In doing so, I kept an open mind and I allowed the stories to speak for themselves (Riessman, 2008). Although this process is not clearly outlined within Holistic Content

Analysis due to the emergent and iterative process, Lieblich, Tuval-Mashiach and Zilber (1998) explain that if you believe in your ability to detect the meanings within the text, it will "speak" to you. To identify themes, the researcher must determine the content or main foci that they will follow through the evolving story (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008). Special focus should be given to elements that strayed from the rest of the story's message, or to those elements which the participant has repeated at different points in the story (Lieblich, Tuval-Mashiach & Zilber, 1998).

Coding software (NVivo) was used at this point as an organizational tool to assist in the thematic analysis process (Denzin & Lincholn, 2000; Scott & Garner, 2003; Kendall & Murray, 2005; Tesch, 2013). Within each story, content related to emergent themes was placed into boxes within the NVivo program. This was done to help organize and highlight the main foci within the stories of the participants (Lieblich, Tuval-Mashiach & Zilber, 1998). Story analysis across narratives was then explored. Theorizing across a number of stories by identifying common thematic elements across research participants is an established tradition within narrative research (Reissman, 2008). According to Riessman (2008), each theme should be explored within the context of the narrative from which it came, and not as a discrete unit of data. In this study, once themes had emerged from each story, the similarities and differences were compared to one another through a CST lens. The following Findings section presents the global impressions and themes derived from the Holistic Content Analysis process (Lieblich, Tuval-Mashiach & Zilber, 1998).

3.2   Findings

To effectively present narrative research, I will allow the narratives to "speak for themselves" (Riessman, 1993; Wells, 2011) by first presenting a representation of the participants' stories to the audience. I will then provide the global impressions and themes derived from each story, followed by the common themes that emerged from across the narratives (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 1993; Wells, 2011). The components of the stories which are italicized highlight the use of the participants' own words.

3.2.1   Sarah

Sarah's story spoke of the conflict surrounding her role of parenting an adolescent with ASD and the lack of supports available to her and her son within the community. Sarah told of the *fighting and clawing* which was required to obtain both a *diagnosis* of ASD and community based supports. Sarah highlighted her *frustration* with the programs she was involved in while her son was growing up and her feelings that *they lied to her* surrounding components of the intervention that they were involved in as a family. She described the transition to adulthood as *a difficult process for anyone, but throw in the diagnosis and stuff and it's even harder.* Sarah highlighted her son's current difficulties with his morning routine and daily transitions, and explained that the supports they have received *have helped for a little bit,* but overall fail to provide adequate *long term support.*

3.2.2   John

John's story highlighted the challenges associated with the spectrum nature of the ASD diagnosis. John described waiting for *the diagnosis* and the importance of the *explanation* that came along with it. He described his son as *deceptive* because of his diagnosis of *ASD with language* as he has a *sophisticated language ability*. John spoke of the spectrum nature of the diagnosis and highlighted the fact that *there is no one thing that will work for an ASD kid*. John further spoke about the impact that spectrum has on the appropriateness of the community based interventions, programs and services. He described public services as *overworked and underfunded* and highlighted the negative impact of *bureaucracy* and *agency red tape* on service delivery within the community. John described himself as an *advocate* for his son and shared stories of how this was necessary over the course of his life to ensure he was receiving adequate support within the school and community settings.

3.2.3   Grace

Grace's global impression was stigma and dissatisfaction with the Canadian medical system. Grace and her family *moved to Canada* when her son was an adolescent and highlighted the *disappointment* she felt with the services here. Grace explained the struggle she had because the doctors in Canada *did not accept the diagnosis* and said that her son did not have ASD. Grace explained the *lack of support* she had as newcomer to this country and how her ability to access services was limited, as she often *had to pay out of pocket for support*. Grace highlighted the *disconnect* she felt between services and explained because of this *disconnect* she *didn't know where to turn*. Grace told of the difficulty she had within her family unit throughout her son's *adolescence* and how she

had to *turn to the police* because of her sons *needs and disability.* Grace highlighted the impact of this on her family, as she often felt the neighbors were *judging* her and saying *"hey, this house always has the police at it."*

3.2.4   Natalie

Natalie's story spoke of her search for support, resources and answers. Natalie began her story by sharing an experience where her son had threatened to *kill himself* as he felt he had *no friends at school.* Natalie explained that the doctor's response to this was to *take this medicine… and this one*, which she did not agree with. Natalie spoke of the *social isolation* that her son felt at school, and how she felt that teachers set him up for *failure within the social setting.* Natalie shared her challenges of obtaining a *diagnosis*, and having to pay *out of pocket,* as *important services were not available without this diagnosis.* She shared that based on their location within the city, a number of important programs were not accessible to her and her son. Throughout her story, Natalie highlighted the significance of *answers and parental support,* sharing that the local non-profit organization she is involved with *are all so friendly and welcoming, it's like a family.*

3.2.5   Trish

The global impression of Trish's story is a lack of fit – searching for the own in the ASD community. Throughout Trish's story, she highlighted the process she went through to obtain a diagnosis for her son. Trish explained that a number of clinicians failed to appropriately identify her child as having ASD, as he is *higher functioning* on the spectrum. Trish told of her *negative experiences* with a number of healthcare professionals who continuously gave prescriptions of multiple medications without

spending *any time* with her son. Trish shared how she had to *fire the medication pushers* to provide the best care for her child. Trish highlighted her son's negative experiences within the school system and how he felt he had *nowhere to turn* when he needed support at school. She shared that she was *frustrated* with the connection between services in the community, and how *everything she knows was learned on her own*.

3.2.6   Jessica

Jessica's story spoke of a lack of community acceptance and supports in adolescence and adulthood. Jessica highlighted her struggle of finding *new healthcare professionals*, as her current services providers would no longer support her son after the age of 16. Jessica shared that the skills her son has learned throughout the programs they have been involved in have been helpful within the intervention context, but they haven't successfully *transferred to actually provide support in the community.* Jessica explained her feelings surrounding the medical system and being part of *guinea pig trials*. She shared her *frustration* with the focus placed on medications as opposed to interventions. Jessica highlighted her *frustration with wait lists and poorly handled* organizations in the community.

3.2.7   Linda

Linda's story focused on the tension between the diagnosis of ASD and adolescence. Linda shared that her son is *not aware of his diagnosis of ASD*. Linda highlighted the importance of the diagnosis, and how she had to *pull strings* to obtain it. She explained that her son was involved in intensive therapies when he was younger however he is not currently involved in any sort of *outside intervention.* Linda explained that she continues to work with her son in a number of areas, and views these

interventions as *inside interventions.* Linda told of the *difficult transition to high school* and adolescence and highlighted her perception that her son was *lacking a sense of purpose* within the school setting. Linda emphasized her son's involvement with formal and informal sports, and shared her perspective of this being an important tool for him to *learn skills, build relationships and engage with his peers.*

3.2.8   Martha

Martha's global impression focused on a fear of engagement, labeling and the transition to adulthood. Martha began her story by highlighting her *frustration with services ending when her son turns 18 years old.* She highlighted her *fear* of being a *single parent and having nowhere to turn* for support during this time of transition. Martha's son was diagnosed with ASD a year and a half ago, and Martha shared that she felt *alone* in the process. Martha shared that *community agencies failed to provide her with the information she needed* surrounding this diagnosis. As Martha's son was only recently diagnosed, he has had limited access to community programs, interventions and services over the course of his life thus far. Martha feels her son would have greatly benefited from some of the programs, but *was unable to attend as he didn't have a diagnosis.*

3.3   Global Impressions and Themes

Lieblich, Tuval-Mashiach and Zilber (1998) highlight the importance of obtaining a global impression of each narrative. The global impression seeks to present the resounding theme or feeling of each story and conveys the narrative's mood and message

(Lieblich, Tuval-Mashiach & Zilber, 1998). The global impressions of each narrative are

presented in Table five.

Table 5. Global impression of each participants' narrative

Participant	Global Impressions of Each Narrative
Sarah	Conflict: Community support and the role of parenting
John	Challenges associated with the spectrum of ASD
Grace	Stigma and dissatisfaction with the Canadian medical model
Natalie	The search for support, resources and answers
Trish	Lack of 'fit': Searching of the 'own' in the ASD community
Jessica	Lack of community acceptance and supports in adulthood
Linda	Tension between the diagnosis and adolescence
Martha	Fear of engagement, labeling and the transition to adulthood

Table five seeks to provide the reader with the overall feeling of the participants'

experiences with interventions, programs and services for their children with ASD. These

global impressions will also set the stage for the themes within each narrative as seen in

Table six.

Table 6. Themes of each participants' narrative

Participant	Main Themes Within the Narrative
Sarah	Interventions failing to provide long-term support
	Difficulty with daily transitions
	Conflicting role as a parent
	Lack of client-centered interventions
	Fight for services and support
	Transition to adulthood
	Fight for the diagnosis
	Without a voice
	Medication pushing
	Alternative medicine
John	Waiting for the diagnosis
	Services failing to provide support
	Parent as the expert
	Difficult decisions surrounding transition to adulthood
	Spectrum nature of the diagnosis
	Inappropriate interventions
	Frustration with public services
	Clinicians not understanding

Grace   Lack of available support, treatment and interventions
               Dissatisfaction with doctors and services
               Transfer of the diagnosis to Canada
               Fight against the medical model
               Nowhere to turn with an adolescent
               Impact on the family unit
               Lack of resources and needs of child not being met
               Disconnect between agencies

Natalie   Medications as a cure
               Failing to reach potential
               Lack of inclusion and school as a negative experience
               Need for parental advocacy
               Diagnosis needed to access services
               Paying out of pocket to access community supports
               Importance of parental support
               Nowhere to turn in a crisis
               Difficulties in the transition from school to adulthood

Trish   Lack of professionalism with service providers
               Pressure for medicating
               Blaming the parents
               Need and fight for a diagnosis
               Labeling and compartmentalizing the child
               Fighting the school system and lack of appropriate support
               Reliance on family for support
               Disconnect between services
               Disappearing services in the transition to adulthood
               Importance of occupation

Jessica   Waiting for programs
               The search for services
               Support through non-profit organizations
               Lack of skill transfer following interventions
               Medication pushing and lack of satisfaction with doctors
               Waiting for the diagnosis
               Dissatisfaction with public services
               Disappearing supports in transition to adulthood
               Fight against the school system

Linda   Stigma surrounding diagnosis
               Lack of community based services in adolescence
               Fight to obtain a diagnosis
               Difficulty with transition to high school
               Dissatisfaction with supports within the school system

           Need for a sense of purpose
           Engagement through occupation

Martha   Frustration with disappearing services in adolescence
           Fear and challenges in transition to adulthood
           Diagnosis as an importance piece of the puzzle
           Significance of being a single parent
           Nowhere to turn and need for support
           Impact of disengagement and lack of meaningful occupations
           Labeling and stigma
           Diagnosis to access services

3.4   Themes Across Narratives

Following the analysis of each individual narrative, four major themes emerged across the stories of the participants (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008). These themes are *the impact of the diagnosis*, *medical model failing to provide answers*, *the journey through services*, and *accessibility of services during the transition to adulthood.* The first three themes will be presented as they emerged from the data and will be further explored in the discussion component of this paper. The theme of *accessibility of services during the transition to adulthood* will be discussed in chapter four. This theme was expansive as it incorporated a large number of small subthemes and a large amount of data from within the personal narratives of all participants. In order to convey the breadth and depth of the discourse within this context, it will be explored through a CST lens in the proceeding chapter.

3.4.1   Impact of the Diagnosis

Receiving a diagnosis of ASD can be a traumatic experience for parents and families as they begin to understand and plan for their child's future care (Howlin & Moore, 1997; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Stuart &

McGrew, 2009). All parents identified the "*piece of paper*" providing their child with a diagnosis of ASD as an important component to their personal narrative. All parents began their stories discussing the diagnosis of ASD, or highlighted the diagnosis as a central part within their personal narrative. John began his narrative by sharing *"Probably the biggest thing, was that it took a while to get a diagnosis about what exactly was going on… right?"*. Jessica echoed this, beginning her story with *"Well, initially, this was before we even had a diagnosis of ASD…"*. To these individuals, the diagnosis was an important piece of their journey through services and one worth fighting for.

Linda shared her story of the fight for her child's diagnosis. *"… he [the doctor] didn't even want to diagnosis him…. So my husband pulled some strings and we got in to see [another doctor] and she diagnosed him at 22 months…"* Natalie highlighted her fight. *"…We had to seek private. A private psychologist because there is no government… we went to [a government agency] and they said 'Oh! He's fine! He's just a teenager'…. So then we had to seek other help. It cost us almost $3000 to get the diagnosis…."*. Martha shared her story for the fight for a diagnosis, which lasted almost 15 years. *"It's only been a year and a half since we've had the diagnosis… we got the diagnosis on the end of, 2011. And it was hell."*

Along with the fight against the healthcare professionals and the current medical system that was highlighted by a number of parents, the contradictions of this process were exemplified. Trish outlined the tension she felt while fighting for a diagnosis, but at the same time, she was hesitant to be given a label for her child*: "So I got emotional. It's hard to want to have your child finally be diagnosed with something."* Sarah shared what

the diagnosis meant to her: *"To me personally, it's a piece of paper [the diagnosis]. But what it meant was that my son is going to get the services that he needs in the school."* Jessica echoed the concept that receiving the diagnosis was central to accessing community services, programs, interventions and supports. *"So, I just needed that piece of paper to give to the school and say…, 'He needs more, than what's available….' And if I didn't have the diagnosis, then he wouldn't get more… and that's the part that sucks."* When asked to tell her story of her experiences with interventions for her child when he was growing up, Natalie replied *"We had none. No diagnosis, no entrance…."*

These components of the participants' personal narratives echo a number of studies, suggesting that receiving a diagnosis of ASD is a challenging and unclear process which can take a long time and is often difficult to understand for parents and families (Howlin & Moore, 1997; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Stuart & McGrew, 2009). Although a difficult process, to these families, the diagnosis meant much more than "*the piece of paper"*, in that it provided them with answers and allowed them accessibility to programs and services within the community.

3.4.2   Medical Model Failing to Provide Answers

For many families, a diagnosis of ASD is followed by a variety of questions and concerns regarding the present and future care of their child (Howlin & Moore, 1997; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Stuart & McGrew, 2009). Turning to a trusted professional within the local community, can be an important strategy in understanding this process and in providing valuable services for their child. This was exemplified by Martha who shared *"As soon as I got the diagnosis, I called*

[local organization] initially, because when we got the diagnosis, you get like 2, 3, pages of like here. And that's it. And for me, I was like, 'are you kidding?'"

Despite contacting local organizations in an attempt to access community based services, many participants highlighted the disempowerment they felt with the current medical model, and their dissatisfaction with the standard of care they received from healthcare professionals within their community. Sarah shared *"And literally, every psychologist we were at, patted [child] on the head. If we were at the psychiatrist appointment for an hour, it was because we were in the waiting room. I mean, they saw us for 15 minutes max."* John echoed this concern *"Some [the doctors] didn't even talk to him [child]!"*. Trish further explained her feelings surrounding her experiences within the healthcare system. *"And so it would be like this – 'How are you doing? How's your pills working? See ya.' Okay, but who's helping him? And that's what floored us. Because we went into this system believing that because he was being recognized [with the diagnosis], that someone was going to help us. And you know, we waited… and that never happened. So we are still waiting."*

Other families shared their stories focusing on the pushing of medication and lack of client centered services. Grace said *"And I think the thing that really punched us in the face, was when they told us to start seeing a psychiatrist, and we were like 'Yeah! [child] is going to get help, counseling and care! And all they are is dope pushers."* Other participants echoed this perception. Sarah shared *"…One doctor we previously had at [local organization], talked to me for an hour while [child] played in the corner, non-creatively. And then handed me a prescription for liquid Prozac. [Child] was 4 years old."* She further shared her perceptions of another healthcare professional they were

involved with: *"...Like I have no respect for the man... I don't know if he is practicing anymore or what... but we used to call him 'Prozac Doctor'"*.

Throughout the narratives, the power differentiations felt by participants between the healthcare professionals and themselves were highlighted, in addition to the limitations and restrictions felt within the current medical system. Research continues to highlight the importance of early intervention and services for this population (Case-Smith & Arbersman, 2008; Howlin & Moore, 1997; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Stuart & McGrew, 2009), however the lack of client centered care was identified throughout each personal narrative. Participants shared that they felt alone on this journey and shared the difficulties they had while trying to navigate the medical system. Participants also shared feelings of confusion and frustration with the lack of support they were provided by healthcare professionals.

3.4.3   The Journey Through Services

In addition to the dissatisfaction with the current medical system and focus on the "*pushing*" of pharmacological interventions, a number of participants described their "*journey through services*" as a complicated, unique path, which differed from those of others. As ASD is a complex diagnosis, which impacts functioning across a variety of areas (DSM-IV: American Psychiatric Association, 2013), the strengths and areas for support required for each individual differ. The complicated journey through services identified by parents' mirrors the complexity and spectrum nature of the diagnosis. John who shared his story, exemplified this: *"The problem is... there is no... there is no... one style of anything that will work for an ASD kid... You need to have 25 different things sitting on a shelf that you can pull off at any one time..."*

Sarah shared her experiences with formal interventions through varying government organizations. *"So, we actually, we've been involved with the behavioural people, on and off at [local organization] from when he was kind of young…"* Trish and Natalie described their involvement with these organizations and traditional therapies: *"He was in play therapy at [local organization] when he was young…"* and *"He's been in speech therapy when he was really young, because of the way he would come up with words like… metamorphosis at age three…"* Concerns surrounding the efficacy and client centered nature of some of these interventions were brought to the forefront by Sarah: *"I was disappointed… I mean, [child] seemed to like it, he enjoyed going to it, but I knew nothing… I was like totally out of the loop and that frustrated me greatly."*

Although a number of participants highlighted the use of traditional services and therapies throughout their journey, some families shared their experiences with other types of interventions and services that were an important component to their personal narratives. This was exemplified by Sarah who shared: *"…so then we tried homeopathy… we paid out of pocket for a variety of supplements to integrate into [child's] diet."* Trish shared *"we tried removing gluten and casein from [child's] diet. It seemed to be beneficial…"* Not all participants identified these types of services as being a part of their journey. Linda shared *"…and some families try supplements and stuff… it's not something we ever did."*

In addition to traditional and alternative intervention approaches, a number of families identified recreation and leisure activities as being an important component in their child's journey. Linda exemplified this: *"Special Olympics and [local organization] hockey have been great for him! That was a real turning point for him."* Natalie echoed

the importance of participation in such activities *"...[child] participates in Tae Kwon Do, which we have to pay for, but he really enjoys it, and I feel it has really helped him."*

This component of the participants' personal narratives echoes the findings of other studies which suggest that parents of children with ASD try many varied interventions and therapies for their children (Goin-Kochiel, Mackintosh & Meyers, 2009). These interventions and services may vary among families, however, despite the unique journey through services and interventions shared by participants, one common theme emerged: as their child aged, the availability of programs, interventions and services began to disappear. This theme will be further discussed in detail in chapter four.

3.5   Discussion

The themes presented throughout this study resound with the current discourse regarding parents' experiences with interventions, programs and services for their children with ASD. Additionally, these themes add a new dimension and information to the literature, through the inclusion of a CST lens. Throughout their stories, all participants identified the process of receiving a diagnosis as being both an important and difficult component in their journey as a family. Fitting with current research (Howlin & Moore, 1997; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Stuart & McGrew, 2009) many participants shared the tension and disempowerment they felt throughout this difficult time. Tension surrounding the process of receiving a diagnosis, labeling their child, and the questions and fears about how to best move forward in their lives following a diagnosis of ASD were highlighted within the stories of the participants.

Similar to a study completed by Midence and O'Neill (1999), receiving a diagnosis of ASD was initially thought by families to be beneficial in providing both answers surrounding their child's care and in increasing their "*accessibilit*y" to community based interventions and supports (Howlin & Moore, 1997; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Stuart & McGrew, 2009). Some parents expressed feelings of hope surrounding the diagnosis, as they believed they would finally be able to access community based services and receive the help and support that was needed for both their child and their family.

Following the diagnosis, many participants shared that they first turned to trusted health care healthcare professionals (doctors, psychologists and psychiatrists) within their local community for the support and answers they were seeking. Keenan and colleagues (2010) and Midence and O'Neill (1999) identify this time following the diagnosis as being a challenging and confusing time for families. It is suggested that local community based services can often provide support at this critical time (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Midence & O'Neill, 1999). Participants within the present study shared beliefs that they would be able to obtain necessary services and support, however the disempowerment and frustration they felt and their dissatisfaction with the current service delivery models within the local community were highlighted throughout their stories. Liptak and colleagues (2006) suggest that families of children with developmental disabilities demonstrate dissatisfaction with several aspects of the health care healthcare system and interventions provided by these providers. They further suggest that families with children with ASD articulate the most dissatisfaction. Similarly, participants within the present study expressed concern surrounding the lack of

time health care healthcare providers spent with them and their child, the supports and interventions provided by these professionals, the over-prescription of medications and the amount of unmet needs. Their overall feelings of disempowerment and dissatisfaction with the current medical system were highlighted throughout their stories.

Each participant described their journey through the diagnosis of ASD and available services as a unique entity, which differed from the journey of their peers. It became clear, that the spectrum nature of ASD and the complexity of the diagnosis influence the programs, services and interventions selected by each family. Similar to other studies exploring this area, accessibility to services, availability of services, feelings of trust and support and personal beliefs were cited as playing a significant role in the decisions of each family's journey (Thomas, Ellis, McLaurin, Daniels & Morrissey, 2007). Many participants identified both conventional and alternative interventions as being part of their journey and although not always satisfied with the quality of care provided to them and their families, many described a variety of services, which were available for their school aged children.

As their children began to transition into adolescence and adulthood, many participants shared their growing concern surrounding the disappearance of services and lack of availability of programs and interventions for their children at this important stage. The transition from school services to adulthood has been identified within the literature as being difficult for adolescents with ASD as they begin to transition into college, work, community participation and independent living (deFur & Patton, 1999; Schall & Wehman, 2008; Hendricks & Weham, 2009). Parents shared that throughout this time, their decision making surrounding appropriate interventions, programs and

services was restricted due to the lack of available support for this population. These stories highlighted the need for additional programs for this population during this critical time. This area will be further explored in chapter four.

3.6   Study Limitations

The present paper has outlined the analysis of the stories provided by eight parents surrounding their experiences with interventions, programs and services for their children with ASD. The use of narrative methodology was carefully selected as a way to explore these experiences from the perspective of the participants (Lieblich, Tuval-Mashiach, & Zilber, 1998; Riessman, 1993, 2008; Wells, 2011), however the use of narrative methodology includes some considerations for the future applicability of the research. According to Molineux and Rickard (2003), relying on personal stories for accuracy is unwise, but wholly appropriate if the research is exploring how individuals understand events in the context of their own lives. As this was the purpose of the present study, a narrative methodology was able to highlight the participants' subjective accounts of the events that affected their lives and their search for treatment (Lieblich, Tuval-Mashiach, & Zilber, 1998; Riessman, 1993, 2008; Wells, 2011).

Another consideration surrounds the participants within the present study, as they were recruited from one geographical area within the province of Ontario. Similarly, all participants were recruited from the same non-profit organization. Individuals and families, who are involved with this organization, may have similar ideas surrounding intervention selection and community based service delivery, as they may have received services within the same time frame and under the same government policies. Future research should explore the stories of families outside of this geographical location.

3.7   Directions for Future Research

This study explores parents' experiences with intervention, program and service selection and implementation over the course of their child's life using an interpretive narrative research design. There are many areas of overlap between the information provided by the participants in this study and the findings in the literature, however the findings of his study add a new perspective and depth to the literature in this area, particularly through the use of CST as a theoretical lens.

This study has the potential to inform other parents and service providers of a child with ASD, and may provide insight into the experiences of the participants and allow the sharing of their stories with others (Lieblich, Tuval-Mashiach, & Zilber, 1998; Riessman, 1993, 2008; Wells, 2011). The themes generated from this study also have the potential to provide health professionals with information regarding the factors that impact a parents' experience with intervention, and to help guide service implementation (Chase, 1994; Lieblich, Tuval-Mashiach, & Zilber, 1998; Wells, 2011). Additionally, this study may inform program development, funding decisions and health professional education. Through the sharing of stories of the participants' experiences, changes across a variety of areas may be implemented to allow parents and service providers of children with ASD to be better empowered to access and navigate the system (Chase, 1994; Cannella & Lincholn, 2009).

Future research must consider the voices of parents across geographical locations to explore their stories on service delivery and intervention selection and implementation. Continuing research should also incorporate the voices of the adolescents and young adults, in addition to healthcare professionals providing service to this population. Doing

so, would allow for a more comprehensive understanding of the stories of all individuals involved in this process. Finally, more exploratory research into the types of programs, supports and services parents would find helpful over the course of their child's life would add a new perspective to the current literature in this area.

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Chapter 4

4   Nowhere to Run: A Critical Paper on the Current Service Delivery Models for Adolescents and Young Adults with Autism Spectrum Disorder

4.1   Setting the Context

Chapter three presented an interpretive narrative study that explored the stories of parents' experiences with intervention selection and implementation for their children with Autism Spectrum Disorder (ASD). This study highlighted a number of themes that emerged from the stories of the participants and were discussed within the previous chapter of this dissertation.

Throughout the course of the data analysis process, the theme of *accessibility of services during the transition to adulthood* emerged. This theme incorporated a large number of smaller subthemes and was intertwined as a central concept throughout the personal narratives of all participants. Previous literature highlights the challenges associated with the transition to adulthood for adolescents with ASD (Hendricks & Wehman, 2009; Wehman, 2006; Wehman, Smith & Schall, 2009). Furthermore, the importance of having accessible programs, services and interventions focused on transition planning and increasing independence during this stage is identified within the literature (Hendricks & Wehman, 2009; Wehman, 2006; Wehman, Smith & Schall, 2009). In order to convey the breadth, depth and significance of the parental discourse within this context, this theme will be explored through a Critical Social Theory (CST) lens in this chapter. Within this paper, CST has been used to critique the societal

structures, environments and institutions in which adolescents and young adults with ASD operate throughout their transition to adulthood.

This paper will provide a brief overview of ASD and present the current literature on the transition to adulthood for this population. Critical Social Theory and its application within the present paper will then be discussed. The methods used within the present study will be outlined and the theme of *accessibility of services during the transition to adulthood* will be presented. Finally, the discrepancies between current policy and legislation within the province of Ontario and the voices of the participants within this study will be discussed along with the study limitations and directions for future research.

4.2   Introduction

Autism Spectrum Disorder is defined as a group of pervasive developmental disorders characterized by severe impairments in communication and social interaction across multiple contexts and an increased prevalence of repetitive and stereotypical behaviours (American Psychiatric Association, 2013). According to the DSM-V, these symptoms cause clinically significant impairments in social, occupational and overall functioning (American Psychiatric Association, 2013). ASD impacts 1 in 68 children in North America (Centers for Disease Control and Prevention, 2014) and within the province of Ontario, there are an estimated 70,000 individuals living with ASD. There is no cure for the disorder at this time (Autism Ontario, 2014; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010). As individuals with ASD experience significant difficulties across their lifespan (American Psychiatric Association, 2013; Case-Smith & Arbersman, 2008; Keenan,

Dillenburger, Doherty, Byrne & Gallagher, 2010; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010), they are frequently referred for a variety of community based interventions, programs and services (Green, Pituch, Itchon, Choi, O'Reilly & Sigafoos, 2006; Goin-Kochel & Myers, 2005). Recent literature highlights the importance of programs focused on transition planning and increasing independence in activities of daily living (ADLs) for this population as they enter adulthood (Hendricks & Wehman, 2009; O-Brien & Daggett, 2006; Smith & Schall, 2009).

4.2.1   The Transition to Adulthood

The transition from adolescence to adulthood is considered to be one of the most important developmental processes in the life course of an individual (Hendricks & Wehman, 2009; Osgood, Foster & Courtney, 2010; Stewart, Law, Rosenbaum & Willms, 2001). How an adolescent fairs in this transition has a long-term effect on their future, occupational participation and overall quality of life (Hendricks & Wehman, 2009; Osgood, Foster & Courtney, 2010). Within North America, moving into adulthood involves a long and often difficult transition for typically developing adolescents (Osgood, Foster & Courtney, 2010; Settersten & Ray, 2005). This transition from school and community based services to adulthood can be a particularly challenging time for adolescents with disabilities (deFur & Patton, 1999; Hendricks & Wehman, 2009; Schall & Wehman, 2008; Sitlington & Clark, 2006). This is thought to be especially true for adolescents with ASD, as they attempt to negotiate their way into college, work, community participation and independent living (deFur & Patton, 1999; Hendricks & Wehman, 2009; Schall & Wehman, 2008; Sitlington & Clark, 2006).

Recent literature highlights the importance of programs, services and interventions focused on transition planning for this population (Hendricks & Wehman, 2009; Wehman, 2006; Wehman, Smith & Schall, 2009). For adolescents and young adults with ASD, transitions at this stage typically include completing school, gaining meaningful employment, participating in post secondary education, contributing to a household, increasing independence in ADLs engaging in meaningful community activities and experiencing satisfactory personal and social relationships (Osgood, Foster & Courtney, 2010; Stewart, Law, Rosenbaum & Willms, 2001; Wehman, 2006).

Despite the vast array of services, programs and interventions available for school aged children with ASD, opportunities for adolescents and young adults are limited within both North America (Gray, 2002; Hendricks & Wehman, 2009; O-Brien & Daggett, 2006; Schall, Cortijo-Doval, Targett & Wehman, 2006) and the local community (Ontario Partnership for Adults with Aspergers and Autism, 2008). The services provided to this oppressed population as children (Friere, 1993) often come to an end during the transition to adulthood, despite the identified need for continued support during this difficult time (Gray, 2002; Hendricks & Wehman, 2009; O-Brien & Daggett, 2006; Ontario Partnership for Adults with Aspergers and Autism, 2008; Osgood, Foster & Courtney, 2010; Schall, Cortijo-Doval, Targett & Wehman, 2006). Programs, services and interventions focused on the continued development of life skills, ADLs, independent living, meaningful community participation and social interaction are among the recommended services for this group (Gray, 2002; Hendricks & Wehman, 2009; O-Brien & Daggett, 2006; Ontario Partnership for Adults with Aspergers and Autism, 2008; Osgood, Foster & Courtney, 2010; Schall, Cortijo-Doval, Targett & Wehman, 2006).

Despite the recognized need for these services, the impact of the lack of programming on families and young adults throughout this time of transition has yet to be explored within the literature. The voices of this population will be presented within this paper through a CST lens.

4.2.2   Critical Social Theory

Critical Social Theory (Agger, 2013; Freire, 1993; Leonardo, 2004; Riessman, 2008) is a multidisciplinary knowledge base which offers researchers a lens to explore and question the power imbalances within social relationships (Agger, 2013; Canella & Lincoln; 2009; Friere, 1993; Leonardo, 2004; Sumner & Danielson, 2007). It provides an opportunity to probe for systematic oppression and to explore the underlying power structures that impact the health delivery system for adolescents and young adults with ASD (Agger, 2013; Canella & Lincoln; 2009; Friere, 1993; Leonardo, 2004; Sumner & Danielson, 2007). More specifically, CST focuses on critically assessing power relations at the sociocultural, economic and political levels and explores how these imbalances inform knowledge and shape societal structures (Browne, 2000; Jennings, Parra-Medina, Hilfinger Messias & McLoughlin, 2006; Leonardo, 2004). Critical Social Theory seeks to put criticism at the forefront of knowledge production (Leonardo, 2004). It critiques ideology and relations of dependence revealing hidden relations of domination and power inherent in societies' fundamental structures (Browne, 2000).

Cultural and societal structures, in addition to family values and experiences, influence one's belief about the causes and course of ASD in their child (Daley, 2004; Goin-Kochel & Myers, 2005; Mandell & Nocak, 2005). Furthermore, these underlying structures play a role in families' therapeutic decisions at micro, macro and meso levels

(Cannella & Lincoln, 2009; Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Goin-Kochel & Myers, 2005; Mandell & Novak, 2005) by identifying and limiting which programs are available for specific groups and how these groups are able to access these services. Within this paper, a CST lens has been used to critique the structures, environments and institutions in which adolescents and young adults with ASD operate throughout their transition to adulthood. It is anticipated that this paper will provide insights that can guide health care practitioners and inform policy, thus improving services for adolescences and young adults with ASD.

4.3   Methods

Consistent with an interpretive narrative methodology (Chase, 2005, 2008; Lieblich, Tuval-Mashiach & Zilber, 1998; Molineux & Rickard, 2003; Riessman, 1993, 2008; Wells, 2011) this article is written in the first person from the perspective of the primary author. A summary of the interpretive narrative methodology and CST perspective as it was applied in this context will be discussed in this section (Freire, 1993; Kincheloe, McLaren, & Steinberg, 2011; Riessman, 2008; Wells, 2011).

A narrative methodology was used in this study as a way to provide participants the opportunity to share their stories as they experienced them to provide unique insights into their contexts and experiences (Campbell-Breen & Polland, 2006; Riessman, 1993; 2008; Wells, 2011). Using this methodology allows for participants' stories to extend beyond what researchers, academic institutions and funding sources have already deemed relevant within this context (Chase, 2005, 2008; Lieblich, Tuval-Mashiach & Zilber, 1998; Molineux & Rickard, 2003; Riessman, 1993, 2008; Wells, 2011). Within the healthcare field, understanding the stories of parents' experiences throughout their child's

transition to adulthood allows researchers, policy makers and clinicians to gain insight into this process (Goin-Kochel & Myers, 2005; Mandell & Novak, 2005), and has the potential to shape policy and legislation at a macro level. Cultural and societal structures often play a role in families' therapeutic decision make processes (Cannella & Lincoln, 2009; Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Goin-Kochel & Myers, 2005; Mandell & Novak, 2005), and mandate what programs and services are available to particular groups at particular points in time.

According to Chase (2005; 2008), the process of narrating a significant life event or group of events has the ability to facilitate positive social change, and narrative research seeks to 'give voice' to oppressed individuals or groups (Chase, 2005; 2008; Freire, 1993; McLaughlin & Tierney, 1993; Riessman, 2008). Similarly, using a CST perspective to explore emerging themes within the stories of the participants offers a means for the researcher to question the power within social relationships and an opportunity to probe for systematic oppression (Cannella & Lincoln, 2009; Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Freire, 1993; Goin-Kochel & Myers, 2005; Mandell & Novak, 2005; Sumner & Danielson, 2007). It also provides an opportunity for exploring the underlying power structures, which shape the healthcare delivery system (Canella & Lincoln, 2009; Freire, 1993; Sumner & Danielson, 2007).

4.3.1 Participants

Eight participants were involved within this study, and all are parents of adolescents or young adults between the ages of 15 and 21 with a diagnosis of ASD. Participants' demographic information is presented in Table 7. The names of the participants have been changed to protect their identity.

Table 7. Demographic information of participants

Participant	Gender	Age of Child
Sarah	F	15
John	M	21
Grace	F	15
Natalie	F	17
Trish	F	17
Jessica	F	16
Linda	F	15
Martha	F	18

4.3.2 Collecting the Narrative Data

Informed verbal and written consent was obtained from all participants prior to their participation in this study, and all participants met the inclusion criteria outlined in chapter three. Ethics approval was obtained from the University Non-Medical Ethics Review Board and recruitment information was provided to a Chapter of Autism Ontario. Participants were recruited via email and word of mouth through this organization.

The stories of the eight participants were gathered through individual face-to-face interviews with the first author (Chase, 2005; Lieblich, Tuval-Mashiach & Zilber, 1998; Wells, 2011). Based on the course, breadth and depth of the participant's story, the initial narrative interview session ranged from 45 to 120 minutes. The initial interview contained one overarching question: "*Tell me your story of your experiences with interventions, programs and services for your child over the course of his life.*" This question was constructed to be broad and open-ended to allow participants to elaborate on their experiences the way that they had experienced them (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 1993; Wells, 2011). Follow-up interviews were then completed with participants where the general themes within and between their stories

where highlighted (Lieblich, Tuval-Mashiach & Zilber, 1998; Wells, 2011). All participants participated in a follow-up interview where they had the opportunity to add to their stories of intervention, selection and implementation for their children and discuss the themes which emerged from within their stories (Lieblich, Tuval-Mashiach & Zilber, 1998; Wells, 2011).

4.3.3   Analysis of the Written Narratives

Holistic Content Analysis for narrative research was used as the data analysis (Lieblich, Tuval-Mashiach & Zilber, 1998; Wells, 2011; Riessman, 2008; Wells, 2011) framework in this study. I began this process by transcribing all interviews verbatim. This is the initial step in laying out the plot and themes of the narratives for analysis (Lieblich, Tuval-Mashiach & Zilber, 1998; Wells, 2011). I then focused on reviewing the participant transcripts, audio recordings, field and memo notes and researcher journals. By immersing myself within the data I was able to gain a deeper understanding of the nuanced meanings and subtleties of my interactions with the participants (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008; Wells, 2011). This was done until foci or patterns within each story began to emerge. I then recorded my initial and global impressions of the material (Lieblich, Tuval-Mashiach & Zilber, 1998). The global impression serves as the main theme or feeling of the story that captures both the content and the emotion.

Following the development of my global impressions (Lieblich, Tuval-Mashiach & Zilber, 1998), I assessed each narrative for its themes (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008; Wells, 2011). Coding software (NVivo) was used at this point as an organizational tool to assist with the thematic analysis process (Denzin &

Lincholn, 2000; Kendall & Murray, 2005; Tesch, 2013). Within each story, content related to emergent themes was placed into boxes to highlight the main foci within the stories of the participants (Lieblich, Tuval-Mashiach & Zilber, 1998). Story analysis across narratives was then conducted. In this study, once themes had emerged from each story, the similarities and differences were compared to one another through a CST lens. The following Findings section presents the global impressions and themes derived from the Holistic Content Analysis process.

4.4   Findings

4.4.1   Global Impressions and Themes Within the Narratives

The global impression seeks to present the resounding theme or feeling of each story and conveys the narrative's mood and message (Lieblich, Tuval-Mashiach & Zilber, 1998). It also provides the reader with the overall feeling of the participants' stories within this context. The global impressions of each narrative are presented in Table 8.

Table 8. Global impression of each participants' narrative

Participant	Global Impressions of Each Narrative
Sarah	Conflict: Community support and the role of parenting
John	Challenges associated with the spectrum of ASD
Grace	Stigma and dissatisfaction with the Canadian medical model
Natalie	The search for support, resources and answers
Trish	Lack of 'fit': Searching for the 'own' in the ASD community
Jessica	Lack of community acceptance and supports in adulthood
Linda	Tension between the diagnosis and adolescence
Martha	Fear of engagement, labeling and the transition to adulthood

Following the development of the global impressions of each narrative, themes from within each participant's narrative were derived (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008; Wells, 2011). These themes are presented in Table 9.

Table 9. Themes within each participant's narrative

Participant	Main Themes of Participants Story
Sarah	Interventions failing to provide long-term support
	Difficulty with daily transitions
	Conflicting role as a parent
	Lack of client centered interventions
	Fight for services and support
	Transition to adulthood
	Fight for the diagnosis
	Without a voice
	Medication pushing
	Alternative medicine
John	Waiting for the diagnosis
	Services failing to provide support
	Parent as the expert
	Difficult decisions surrounding transition to adulthood
	Spectrum nature of the diagnosis
	Inappropriate interventions
	Frustration with public services
	Clinicians not understanding
Grace	Lack of available support, treatment and interventions
	Dissatisfaction with doctors and services
	Transfer of the diagnosis to Canada
	Fight against the medical model
	Nowhere to turn with an adolescent
	Impact on the family unit
	Lack of resources and needs of child not being met
	Disconnect between agencies
Natalie	Medications as a cure
	Failing to reach potential
	Lack of inclusion and school as a negative experience
	Need for parental advocacy
	Diagnosis needed to access services
	Paying out of pocket to access community supports
	Importance of parental support
	Nowhere to turn in a crisis
	Difficulties in the transition from school
Trish	Lack of professionalism with service providers
	Pressure for medicating
	Blaming the parents
	Need and fight for a diagnosis

Labeling and compartmentalizing child
Fighting the school system and lack of appropriate support
Reliance on family for support
Disconnect between services
Disappearing services in the transition to adulthood
Importance of occupation

Jessica   Waiting for programs
               The search for services
               Support through non-profit organizations
               Lack of skill transfer following interventions
               Medication pushing and lack of satisfaction with doctors
               Waiting for the diagnosis
               Dissatisfaction with public services
               Disappearing supports in transition to adulthood
               Fight against the school system

Linda   Stigma surrounding diagnosis
               Lack of community based services in adolescence
               Fight to obtain a diagnosis
               Difficulty with transition to high school
               Dissatisfaction with supports within the school system
               Need for a sense of purpose
               Engagement through occupation

Martha   Frustration with disappearing services in adolescence
               Fear and challenges in transition to adulthood
               Diagnosis as an importance piece of the puzzle
               Significance of being a single parent
               Nowhere to turn and need for support
               Impact of disengagement and lack of meaningful occupations
               Labeling and stigma
               Diagnosis to access services

4.4.2   Themes Across Narratives

Following the analysis of each individual narrative, four major themes emerged

across the stories of the participants (Lieblich, Tuval-Mashiach & Zilber, 1998;

Riessman, 2008; Wells, 2011). These themes are:

1. *Impact of the diagnosis*;

2. *Medical model failing to provide answers*;

3. *Journey through services*; and

4. *Accessibility of services during the transition to adulthood.*

The first three themes were presented as they emerged from the data within the previous paper (see Chapter 3). The theme of *accessibility of services during the transition to adulthood* will be discussed in this section. This theme was too large to explore as a small component of the previous paper, as it encompasses a variety of societal and structural implications and incorporates a number of subthemes. The sub-themes of the larger theme will be presented here. These include:

1. *The transition to adulthood;*

2. *Disappearing services;* and

3. *Nowhere to run*

4.4.2.1   The Transition to Adulthood

Throughout their personal narratives, all participants identified the needs of their children during their transition to adulthood as being different than the needs of their typically developing peers, and highlighted this time of transition as being a challenging one for them and their family. Sarah highlighted this by saying, *"I mean that's a hard transition for anybody [adolescence to adulthood], but with the diagnosis stuff… it's even harder"*. Martha shared her fears and concerns about this time of transition, and what it meant for her and her family, *"…and here I am, I have a son who is going to be you know, 17, 18, and very likely won't be ready to be as independent as other teenagers. So it's shocking, and it's scary and for me, it's absolutely terrifying, being a solo parent as well, I've got to like sail the ship."*

Many participants highlighted the specific needs and challenges they were facing throughout this time of transition. Sarah shared her thoughts by saying, *"Of course when*

he was little it was a little easier, because he didn't have to remember a key, he didn't have to remember a wallet…" Other parents highlighted their specific concerns with their child's ability to independently complete their daily activities, such as grocery shopping, money management and getting a part-time job. John exemplified that by stating, *"The grocery thing… would not happen. Right? He would be at a loss. Money handling… I was talking to him about money handling, because we're trying to figure out you know, can I get a job at the bowling alley, where he's handing out shoes? Because that he could do. Right? But could he handle money? I'm not 100% sure about that, right?"* Other participants highlighted their concerns about their child's ability to function independently. Grace shared, *"No! They are not ready at all! I don't even think that [child] has matured with his age at all… he's not… he looks like a very mature guy, but inside, I know he's not mature at all… he's not capable of doing anything… he can't live in the house without us being there for two days…"* This fear was echoed by Martha who also voiced her concern surrounding her child's ability to safely navigate social and sexual relationships: *"And relationships. I mean, here's the thing too… I think that relationships are… I mean sexuality is huge! I mean where do you learn the boundaries? And I think they are in a real kind of precarious place… and I mean, again, like [child] you know… I don't know… will he be able to live independently… possible… semi-supported… ya maybe… full supported, I don't know…"*

Despite the need for support identified by the participants within this study during the transition to adulthood, parents have shared that it is their perspective that programs and services are often disappearing and are not providing adequate support that meets the needs of their families. This leaves their adolescents and young adults with limited

opportunity within the local community, when there is a definite need identified for this particular group.

4.4.2.2 Disappearing Services

Within the present study, when asked what services and interventions she and her family were accessing now to support her child in his transition to adulthood, Linda responded, *"…in terms of programs and community services… I'm not aware of what you were thinking of… I didn't know there were any at this age…"*. Similarly, this lack of accessible support was echoed by Martha who shared, *"I was looking for summer programming… [for her 18 year old son] and couldn't find anything! I looked! I looked! I looked!"* Jessica also voiced her concern with the lack of available programming by stating, *"So I think, personally, my husband and I are both fairly knowledgeable about it, and I do think that there is a lack of programming… I mean, they hit that magic age of 18 and then there is nothing for them."* Similarly, Natalie highlighted the lack of opportunity for her child to learn new skills or engage in meaningful occupations within the local community:*"…but there's nothing for him to do, other than Tae Kwon Do, that we have to pay for. There's nothing that the government… like they have lots of things like drop-in programs for the little kids, but they have nothing for the teenagers… and that's why I think, you know, lots of teenagers have gone the wrong way…"*

Some parents highlighted single programs as being available for their child, although they all identified concerns surrounding the appropriateness of these programs. Jessica highlighted her dissatisfaction with the one program they were involved in: *"… the first thing we have kind of gotten into recently, is the [program] thing… first of all, they wouldn't take him in until he had turned 16… so I guess we had looked the year he*

was 15, because we were starting to think about part-time employment and that… we were want to get him moving along… we thought it was very slow, finally getting… it was actually a year, before someone finally called…" The concern surrounding the appropriateness of the available programming was highlighted by John, who shared, *"I finally called up his case worker, who's number 4 in like 2 years… and I just kinda said to him, like, what kind of training do they give you guys, what kind of background do you have… and I mean, I wasn't trying to be a jerk, it's just like, you put him in the dish room at a restaurant… it's fast pace, it's high pressure, that is not a good fit for him…"*

Over the course of their personal narratives, all participants highlighted the challenges associated with the transition to adulthood and the lack of available community based support and programming available for their children throughout this challenging time. Also highlighted within the stories of the participants were their feelings of "*frustration"* and their "*confusion"* surrounding where to turn next.

4.4.2.3   Nowhere to Run

Throughout their stories, participants have highlighted their need for community based assistance and support and their feelings of *"helplessness"* surrounding where to turn during this difficult time. When explaining potential programs that would support his son in engaging in meaningful occupations, John shared, *"And nobody is home with him during the day now, so he is on his own… my parents live just up the road, so he will disappear and go up and see grandma and grandpa a lot… That's our only support system right?"* Grace echoed this feeling of isolation and lack of community support: *"Everywhere is telling you "No!" and when you have so many struggles at home, itself, I don't know what else is left for you to give…"* Martha also highlighted her experiences,

and feelings surrounding being a single parent and uncertainty regarding where to turn for support: *"And then we called and I got an answering machine saying that it could be a 6-8 month waiting period and we will return your call. And I lost it…"*

In addition to voicing concerns surrounding a lack of community based family support, many participants highlighted their feelings of *"helplessness"* and *"hopelessness"* and having to turn to medical facilities and law enforcement as a *"last resort"*. Both Trish and Grace highlighted their experiences by sharing, *"So, two years passed, and it was really getting to the point that we didn't know what to do, so we went to the police department. And we said "We cannot control the situation at home" and "I had to take him to Emerg… because he was out of control."* Participants identified this as being a *"last resort",* and questioned whether the programming in these facilities was appropriate and able to meet the needs of their families.

Despite the lack of support expressed by a number of participants, Natalie highlighted the importance of non-profit organizations as being both advocates and supporters of their children throughout this time of transition when she shared: *"And then we started seeing [coordinator] at the [non-profit] Group… and she is fabulous…very welcoming… very welcoming… you know at first I was kind of like… "oh… I don't belong…" but they are all like "Oh! Come on in!!""*.

The voices of the participants in this section highlight the importance of providing accessible programs, interventions and services to this specific group. Although one family shared that they have found support in a local non-profit organization, a number of

other participants have voiced their feelings of *"aloneness", "helplessness" and "hopelessness".* They have voiced that they feel they have "*nowhere to run".*

4.5   Discussion

The theme of *accessibility of services during the transition to adulthood* was presented throughout this paper as three subthemes: *the transition to adulthood; disappearing services* and; *nowhere to run*. These themes add a new dimension to the current discourse within the literature when viewed through a CST lens (Chase, 2008; Freire, 1993; Riessman, 2008; Wells, 2011) and highlight the need for future exploration into parental perspectives on current service delivery models for their adolescents and young adults with ASD.

Throughout their stories, all participants identified the transition to adulthood as being a unique and challenging time and highlighted a variety of occupations that were associated with this transition, including budgeting, meal preparation, grocery shopping, obtaining employment and living independently. Recent literature also highlights the struggles associated with the transition from adolescence to adulthood for individuals with disabilities (deFur & Patton, 1999; Hendricks & Wehman, 2009; Schall & Wehman, 2008; Sitlington & Clark, 2006) and emphasizes the importance of addressing these occupational issues to ensure success and community participation in adulthood (deFur & Patton, 1999; Hendricks & Wehman, 2009; Schall & Wehman, 2008; Sitlington & Clark, 2006).

Despite the research indicating the importance of providing continued support to individuals throughout this transition (deFur & Patton, 1999; Hendricks & Wehman,

2009; Schall & Wehman, 2008; Sitlington & Clark, 2006), participants within the present study highlight their feelings of *"loss", "disempowerment"* and *"hopelessness"* throughout this time. Many families highlighted the need for programs to support their child's development, however all families expressed concern surrounding the disappearing of current services, programs and community based supports during this time. Current literature highlights the abundance of programs and services for school aged children with ASD and recognizes the lack of available programming during this stage of transition (Gray, 2002; Hendricks & Wehman, 2009; O-Brien & Daggett, 2006; Ontario Partnership for Adults with Aspergers and Autism, 2008; Schall, Cortijo-Doval, Targett & Wehman, 2006).

Recently, research has begun to employ CST to explore the relationship between health and the underlying structures in society that produce inequalities within this area (Agger, 2013; Canella & Lincoln; 2009; Friere, 1993; Leonardo, 2004; Sumner & Danielson, 2007). Participants within the present study shared their need for additional programs and services to assist their adolescents and young adults in the transition to adulthood. Many participants also shared frustration surrounding their lack of ability to obtain these needed supports. Critical Social Theory suggests that hierarchal structures within society inform the development of knowledge and determine whose voices are heard (Agger, 2013; Canella & Lincoln; 2009; Friere, 1993; Leonardo, 2004; Sumner & Danielson, 2007). These societal structures determine the types of programs, services and interventions that are available to families during this time of transition. Structures start at the macro level of policy makers and the government who decide what programs and services will be privately and publicly funded, which programs and services will be

available throughout the lifespan and who is eligible for such services (Agger, 2013; Canella & Lincoln; 2009; Friere, 1993; Leonardo, 2004; Sumner & Danielson, 2007). As heard through the voices of participants within the present study, these criteria and limitations influence the service delivery models within the local community and leave families with *"nowhere to run"*.

Current legislation within the province of Ontario highlights a number of discrepancies between policies outlined for adolescents and young adults with ASD and the experiences of families as heard within the present narratives. Since the mid-2000s, the provincial government has been working towards transforming the developmental services sector for adults with disabilities in Ontario (Select Committee on Developmental Services, 2014). The key goals of this legislation are highlighted within the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2008)* and include providing greater governmental support focusing on: social inclusion; respite for caregivers; residential partnerships with families; critical life transitions; people with specialized needs; and quality supports and services.

Despite the need for further addressing these issues, specifically respite for caregivers, supporting families in critical life transitions and providing quality support and services, there is a definite discrepancy between the focus on improving services in these areas and the stories shared by parents within the present study.

Firstly, a major funding source for children with ASD, which provides funding for family support and engagement in meaningful community based occupations, is

documented as supporting individuals until the age of 18 (Select Committee on Developmental Services, 2014). Although current legislation highlights a new program that some individuals may be eligible for following their 18th birthday, the eligibility for this program is limited and the program itself is not identified as a support used by participants within the present study. This program focuses primarily on individuals with physical disabilities, which often limits the availability of the program for this population (Autism Ontario, 2014; Ontario Partnership for Adults with Aspergers and Autism, 2008; Select Committee on Developmental Services, 2014).

These funding changes and eligibility criteria limit parental respite support and adolescent's access to meaningful engagement in community based occupations by denying them access to community participation with necessary support. These societal structures, government policies and funding limitations can be viewed as disturbing their ability to regularly partake in these activities (Laliberte Rudman, 2013) and necessitate a call for action through lobbying and additional advocacy for this population.

Secondly, in 2013, the Ministry of Youth and Child Services of Ontario introduced a policy framework entitled *Transition Planning for Young People with Developmental Disabilities* to improve the experience of youth who are transitioning to adulthood (Select Committee on Developmental Services, 2014). Despite the call for formalization of the responsibilities of the Ministries, service agencies and other community partners in the transition process, the stories of participants within the present study did not reflect that this is actually occurring. Research in this area continues to be limited, and the evidence base about services for adults with ASD is underdeveloped and uninformed (Autism Ontario, 2014; Ontario Partnership for Adults with Aspergers and

Autism, 2008; Shattuck, Narendorf, Cooper, Sterzing, Wagner & Taylor, 2012). Local non-profit organizations continue to share the perspective of the participants within this study. They are continuing to advocate for this population and highlight the scarcity of available services and supports for adolescents and young adults with ASD (Autism Ontario, 2014; Ontario Partnership for Adults with Aspergers and Autism, 2008).

Finally, current legislation impacts the quality of services and supports by limiting the potential for funding of public services for this population (Autism Ontario, 2014; Ontario Partnership for Adults with Aspergers and Autism, 2008; Select Committee on Developmental Services, 2014). Numerous service agencies describe what they consider to be systemic and continuous underfunding of the developmental services sector for adolescents and young adults as they transition to adulthood (Autism Ontario, 2014; Ontario Partnership for Adults with Aspergers and Autism, 2008; Select Committee on Developmental Services, 2014; Shattuck, Narendorf, Cooper, Sterzing, Wagner & Taylor, 2012). Participants within the present study echo this limitation, with one participant describing his experiences with services for his child by sharing, *"I don't know if they are under trained or under funded, but…"*

4.6   Study Limitations

This paper has outlined eight parents' stories surrounding their experiences with the transition to adulthood for their children with ASD. In addition, CST was applied to further explore the parental narratives and to critique the structures, environments and institutions in which adolescents and young adults with ASD operate throughout their transition to adulthood. This study has the potential to inform program development, and funding policy and legislation at micro, macro and meso levels within the province and

nationwide. In hearing the stories of the participants and their personal experiences and challenges with their child's transition to adulthood, personnel at service delivery and governmental levels can garner a greater insight into the needs of this particular group.

Despite the potential to inform program development, funding decisions and health professional education, some considerations must be addressed within the present study. All parents were recruited from a single geographic location in an urban center in Ontario. Throughout their personal narratives, common themes emerged, surrounding the availability of local programs, services and interventions throughout this time of transition. Individuals and families who are involved with this organization may have similar ideas surrounding intervention selection and community based service delivery. They may have received services within the same time frame and under the same government policies. Future research should explore parents' perspectives on the transition to adulthood across various urban and rural locations across the province and nationwide.

4.7   Areas for Future Research

This study explores parents' experiences with the transition to adulthood for their children with ASD using an interpretive narrative research design. There are many areas of overlap between the information provided by the participants in this study and the findings in the literature. These findings also add new perspective and depth to the literature in this area, particularly by the use of CST as a theoretical lens.

Future research must consider the voices of the parents, children and service providers across geographical locations to explore their stories on the transition to

adulthood. Gaining the continued perspectives of these groups can further support advocacy efforts for necessary services for this oppressed population (Freire, 1993). Continuing research should also explore the stories of non-profit advocacy organizations who are supporting this population during this critical time. In doing so, an understanding of the *"fight"* associated with this transition would be highlighted and this, in turn, may further support policy and legislation changes.

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Chapter 5

5 Final Considerations

Chapter five concludes this dissertation and will highlight the new contributions of this work to the current literature on parental experiences with interventions, programs and services for their children with Autism Spectrum Disorder (ASD) (see Chapter 3). It will also discuss current service delivery models for adolescents and young adults with ASD as explored through a critical social theory (CST) lens (see Chapter 4). The methodological contributions and constraints related to the use of an interpretive narrative methodology will be presented, followed by an explanation of the adopted criteria for evaluating trustworthiness within this dissertation. Finally, my final reflections on this process will be discussed.

5.1 Research Implications

5.1.1 Contributions to Understanding Parental Perspectives on Interventions for Children with Autism Spectrum Disorder

Chapter two of this dissertation provided insight into the current literature on occupational therapy based interventions for school aged children with ASD. The scoping review highlighted four main themes that identified knowledge gaps in the literature. These knowledge gaps included a lack of parental perspectives on the wide variety of available programs, services and interventions and assisted in structuring my methodology for chapter three of this dissertation.

Chapter three provided new insights and expanded on the current knowledge base surrounding how parents perceive and experience interventions for their children with

ASD. An interpretive narrative methodology (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008) situated within a CST lens (Cannella & Lincoln, 2009; Chase, 2008; Freire, 1993; Riessman, 2008; Wells, 2011) explored parents' experiences with intervention selection and implementation for their children. Chapter three highlighted three main themes that emerged from the stories of the participants that both resounded with current literature (Hendricks & Wehman, 2009; O-Brien & Daggett, 2006; Schall, Cortijo-Doval, Targett & Wehman, 2006) and added a new dimension within the academic discourse in this area.

Fitting with current research (Howlin, 2005; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Stuart & McGrew, 2009) all parents identified receiving a diagnosis of ASD as a difficult and challenging time. Questions and fears about how to best move forward in their lives following a diagnosis were highlighted within the stories of the participants. For many participants, receiving a diagnosis of ASD was initially thought to be beneficial in providing both answers surrounding their child's care and in increasing their *accessibility* to community based services, interventions and supports (Howlin, 2005; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Midence & O'Neill, 1999; Stuart & McGrew, 2009). Some parents expressed *feelings of hope* surrounding the diagnosis. They shared their belief that they would finally be able to access community based services and receive the help and support that was needed for both their child and their family.

Current research suggests that local community based services can provide support for families throughout this critical time (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Midence & O'Neill, 1999). However, participants within the present

study highlighted the *disempowerment* and *dissatisfaction* they felt with the current

service delivery models in the local community. Parents expressed their concern

surrounding the *lack of time health-care providers spent* with them and their child prior

to making recommendations, *the support* and *appropriateness of the interventions*

provided by these professionals and the *over-prescription of medications*. All parents

highlighted a variety of *unmet needs within the current healthcare system* and identified

challenges surrounding their journey through services for both themselves and their

children.

The use of a CST lens within an interpretive narrative methodology allowed for a

novel exploration into underlying societal structures that influence therapeutic decision

making for families at micro, macro and meso levels (Cannella & Lincoln, 2009; Dyches,

Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Goin-Kochel & Myers, 2005; Mandell

& Novak, 2005). This is a new contribution to the discourse in this area. Societal

structures start at the macro level of policy makers and the provincial and federal

governments who decide what programs and services will be privately and publicly

funded, what these programs and services will entail and who is eligible for such services

(Ontario Partnership for Adults with Aspergers and Autism, 2008; Select Committee on

Developmental Services, 2014). Within the present study, these criteria limitations, such

as requiring a *label or diagnosis* to receive support, were identified by parents as barriers

to service. Furthermore, parents highlighted their *frustration* and *dissatisfaction*

surrounding how much time healthcare professionals spent with their children, wait list

times and the overall quality of the provided interventions.

More micro structures identified as barriers to service within the present study highlighted the environment in which the parents and child live, specifically their *proximity to provided services* and the *lack of service providers or agencies that were accessible* to them. Finally, societal structures at the meso level, including the lack of *community and school based support, the attitudes* of healthcare providers and the newest *intervention trends,* and what is currently being funded, were also identified as impacting the stories of parents. Based on these findings, this research has added a new perspective to the literature in this area and has highlighted the societal structures which impact parental decision making surrounding interventions, programs and services for their children. This dissertation has identified discrepancies between parental perspectives on service delivery models and the current service delivery models currently available within the province. This research has the potential to inform and shape government policy and guide healthcare professionals in this field to ensure that the needs of clients and families in Ontario are better met.

5.1.2   Contributions to Understanding Current Service Delivery Models for Adolescents and Young Adults with Autism Spectrum Disorder

In addition to contributing to the current literature on parental perspectives on programs, interventions and services for their children, this dissertation both supported current research and added new contributions to understanding current service delivery models for adolescents and young adults with ASD in the local community (see Chapter 4).

Aligning with the current discourse on the *transition to adulthood,* all participants identified this life stage as being a unique and challenging time for both themselves and their children (deFur & Patton, 1999; Hendricks & Wehman, 2009; Schall & Wehman, 2008; Sitlington & Clark, 2006). A variety of activities of daily living (ADLs) were identified by parents as being associated with this transition, including budgeting, meal preparation, grocery shopping, obtaining employment and living independently. Recent literature highlights the struggles associated with the transition from adolescence to adulthood for individuals with disabilities (deFur & Patton, 1999; Hendricks & Wehman, 2009; Schall & Wehman, 2008; Sitlington & Clark, 2006) and emphasizes the importance of addressing these occupational issues to ensure success and community participation in adulthood (deFur & Patton, 1999; Hendricks & Wehman, 2009; Schall & Wehman, 2008; Sitlington & Clark, 2006).

Despite the research indicating the importance of providing continued support to individuals throughout this time (deFur & Patton, 1999; Hendricks & Wehman, 2009; Schall & Wehman, 2008; Sitlington & Clark, 2006), participants within the present study highlight their feelings of *loss, disempowerment* and *hopelessness*. Many families shared their need for programs to support their child's development and all families expressed concern surrounding the disappearing of current services, programs and community based supports during this time. Current literature highlights the abundance of programs and services for school aged children with ASD and recognizes the lack of available programming during this stage of transition (Gray, 2002; Hendricks & Wehman, 2009; O-Brien & Daggett, 2006; Ontario Partnership for Adults with Aspergers and Autism, 2008; Schall, Cortijo-Doval, Targett & Wehman, 2006).

Additionally, this thesis confirmed current research highlighting the importance of this transition time for young adults with ASD. Through identifying gaps in current service delivery models, this dissertation explored the current societal structures which influence this through a CST lens (Agger, 2013; Canella & Lincoln; 2009; Friere, 1993; Leonardo, 2004; Sumner & Danielson, 2007) and provided information regarding current legislation and policy documents which influence this decision making.

Within Ontario, current legislation follows an early intervention approach (Select Committee on Developmental Services, 2014) to service provision and identifies a wide variety of programs, interventions, services and supports available for children with ASD and their families (Select Committee on Developmental Services, 2014). This dissertation highlighted a number of discrepancies between policies outlined for adolescents and young adults with ASD and the experiences of families as heard within their personal narratives.

Since the mid-2000s, the provincial government has been working to transform the developmental services sector for adults with disabilities in Ontario (Select Committee on Developmental Services, 2014). The key goals of this legislation are highlighted within the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2008)* and include providing greater governmental support focused on: social inclusion; respite for caregivers; residential partnerships with families; critical life transitions; people with specialized needs; and quality supports and services.

Despite the need for further services addressing these issues, specifically surrounding respite for caregivers, working to support families in critical life transitions and providing quality support and services, there is a definite inconsistency between the focus on improving services in these areas and the stories shared by parents within the present study.

Firstly, a major funding source for children with ASD that provides funding for family support and engagement in meaningful community based occupations, is documented as supporting individuals until the age of 18 (Select Committee on Developmental Services, 2014). Current legislation highlights a new program for which some individuals may be eligible following their 18th birthday, however the eligibility of this program is limited and not identified as a support used by participants. This program focuses primarily on individuals with physical disabilities, which often limits the availability of the program for the population with ASD (Autism Ontario, 2014; Ontario Partnership for Adults with Aspergers and Autism, 2008; Select Committee on Developmental Services, 2014). These funding changes and eligibility criteria limit an adolescent's access to meaningful engagement in community based occupations by denying them access to community participation with necessary support. These societal structures, government policies and funding limitations can be viewed as disturbing this populations ability to partake regularly in these activities (Laliberte Rudman, 2013), and necessitate a call for action through lobbying and additional advocacy for this population.

Secondly, in 2013, the Ministry of Youth and Child Services of Ontario, introduced a policy framework entitled *Transition Planning for Young People with Developmental Disabilities* to improve the experience of youth who are transitioning to

adulthood (Select Committee on Developmental Services, 2014). Despite the call for

formalization of the responsibilities of the Ministries service agencies and other

community partners in the transition process through regional protocols, the stories of

participants within the present study did not reflect this. Research in this area continues to

be limited, and the evidence base about services for adolescents and adults with ASD is

underdeveloped and unformed (Autism Ontario, 2014; Ontario Partnership for Adults

with Aspergers and Autism, 2008; Shattuck, Narendorf, Cooper, Sterzing, Wagner &

Taylor, 2012). Local non-profit organizations continue to share the perspective of the

participants within this study and are continuing to highlight the scarcity of available

services and supports for adults with ASD and advocate for this population (Autism

Ontario, 2014; Ontario Partnership for Adults with Aspergers and Autism, 2008).

Finally, current legislation limits the quality of services and supports by

restricting the potential for funding of public services for this population (Autism

Ontario, 2014; Ontario Partnership for Adults with Aspergers and Autism, 2008; Select

Committee on Developmental Services, 2014). Numerous service agencies describe what

they consider to be systemic and continuous underfunding of the developmental services

sector for adolescents and young adults with ASD as they transition to adulthood (Autism

Ontario, 2014; Ontario Partnership for Adults with Aspergers and Autism, 2008; Select

Committee on Developmental Services, 2014; Shattuck, Narendorf, Cooper, Sterzing,

Wagner & Taylor, 2012).

These findings not only make a new contribution to the literature in this area, but

are also a call for action within the local community. Parents of adolescents with ASD

have identified gaps in programs, services and community based interventions and have

shared that they require *more community support.* Despite the identified focus of this

transition time within the policy literature, the needs of this oppressed population (Friere,

1993) are not being met. This dissertation is able to inform future government

programming in this area, provide current and relevant information to non-

profit/advocacy organizations working with this population and inform the current

practices of healthcare providers in this area.

5.1.3   Contributions to Methodology

This dissertation has contributed to the growing body of narrative research in the

area of Child and Youth Health (Chase, 2008; Lieblich, Tuval-Mashiach, & Zilber, 1998;

Wells, 2011). As highlighted in previous chapters, narrative research allows the voices of

the participants to be heard (Campbell-Breen & Polland, 2006, Riessman, 2008; Wells,

2011) and provides a space for parents to tell their stories of their experiences and

challenges associated with intervention selection and implementation for their children

(Campbell-Breen & Polland, 2006, Riessman, 2008; Wells, 2011). For some, the act of

narrating a life event can facilitate positive change (Chase, 2005; 2008) at personal and/or

societal levels. The use of storytelling as a qualitative methodology throughout this

dissertation has allowed for a better understanding of the critical issues faced by the

participants within the presented studies. Through the participants' stories, I was able to

gain insight into their perspectives and explore the discrepancies between these voices

and current service delivery models within the local community.

5.2 Quality Criteria for this Research

Over the course of this research process, I have engaged in a variety of practices to ensure the quality of my study. According to Morrow (2005, p.15), a study's quality and trustworthiness should be assessed "on the basis of the paradigmatic underpinnings of the research and standards of the discipline." Based on this, the criteria for evaluating my research differs from those criteria that would be used to evaluate research using different methods and methodologies and must account for the practice involved in an interpretive paradigm and narrative inquiry. In this section, I will outline the criteria I used throughout this research process to ensure the quality of my studies.

As proposed by Lincoln and Guba (1986), authenticity criteria can be used to ensure trustworthiness for constructivist and interpretivist research. Although these authenticity criteria can be used to ensure quality within this ontological perspective, Patton (2002) recently integrated constructivism and social constructivism, thereby identifying standards of quality that embrace subjectivity (Morrow, 2005). Patton's (2002) quality criteria of interpretivist research better fit with the location of this research and were used to ensure trustworthiness within this study. These quality criteria include: dependability; triangulation; particularity; researcher reflexivity; praxis; verstehen; and dialogue (Patton, 2002).

According to Patton (2002), *dependability,* as a quality criterion, demands that a systematic process be followed throughout the research process. Within this dissertation, I ensured this criterion was met through following a detailed data collection and analysis process. Throughout this research, I maintained an audit trail (Rogers, 2008) that included documentation that allowed me to track the process and changes common to the

iterative process of qualitative research. This audit trail allowed the research team to track and justify the decisions made regarding the study design and analysis. Documents related to this audit trail included study design proposals, which were reviewed by the University Ethics Board and the advisory committee of my doctoral work, memos regarding the data collection process and experience, field notes regarding the context and activities of data collection, and reflective journaling throughout the research process. Keeping a clear audit trail has been a beneficial practice throughout this journey.

Two additional criteria for trustworthiness outlined by Patton (2002) are *triangulation* and *particularity*. *Triangulation* is defined as "capturing and respecting multiple perspectives" (Patton, 2002, p. 546), while *particularity* focuses on doing justice to the integrity of unique cases. Throughout this research process, these criteria were met through a variety of ways. Firstly, Holistic Content Analysis for narrative research was utilized for data analysis (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008; Wells, 2011). This is a three-step process that ensures the voices of each participant are heard (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008; Wells, 2011). Throughout this process, I deeply immersed myself within the data by reviewing the participant transcripts, audio recordings, field and memo notes and researcher journal entries multiple times so I was able to better understand the nuanced meanings and subtleties of my interactions with the participants (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008; Wells, 2011). I then followed the three-stage analysis process, which involved the development of a global impression of each story (Lieblich, Tuval-Mashiach & Zilber, 1998), the development of themes within each narrative (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008; Wells, 2011), and the development of

themes across the stories of the participants (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008; Wells, 2011). Special focus was given to elements to which the participant had devoted a greater amount of time or repeated at different points in the story (Lieblich, Tuval-Mashiach & Zilber, 1998), as well as to those points that deviated from the rest of their story (Lieblich, Tuval-Mashiach & Zilber, 1998). This ensured that I was capturing and respecting multiple perspectives, while respecting the integrity of the unique components of their stories.

Secondly, participants engaged in multiple interviews, which allowed for an opportunity to employ the use of member-checking (Carlson, 2010) to ensure that the global impressions (Lieblich, Tuval-Mashiach & Zilber, 1998) and themes derived within the narratives (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 2008; Wells, 2011) truly captured the voices of the participants. The goal of member-checking was not only to seek accuracy in what the participants said, but also to ensure that I understood the meaning that they associated with their stories. Based on this, the participants were not asked to review their transcripts verbatim, but rather to review the global impressions and themes associated with their stories. Participants were free to revise their messages or themes at this time.

Researcher reflexivity has also been identified as an important component of the interpretive research quality criteria (Patton, 2002), and a central component to my research process. Throughout this time, I engaged in consistent reflective journaling and discussion with my advisory committee, which allowed me the opportunity to not only reflect upon my subjective responses, but also upon my method of research. In doing so, I was able to create an ongoing dialogue, which allowed me to reflect upon my own

experiences and understanding of the world, how these views may influence the research process and the points of weakness in my methods or data analysis process. Reflexivity has also proven to be an important tool in this research process.

Patton (2002) highlights the notion of *praxis,* which emphasizes the integration of theory and practice in interpretive research. Throughout this process, CST (Agger, 2013; Freire, 1993; Leonardo, 2004; Riessman, 2008) was used as a lens to critique the structures, environments and institutions in which individuals with ASD operate throughout their lifespan. Through consistent reflection and dialogue with my advisory committee, I ensured that my research was embedded within a strong theoretical base and that the location of this research was reflected within all areas of this dissertation.

Finally, *verstehen,* which implies the notion of ensuring an enhanced and deep understanding of the voices of the participants, is discussed. Through the in-depth data collection and analysis processes highlighted above I worked to ensure that this criterion was met throughout my study.

5.3   Methodological Constraints

Throughout my dissertation there are three methodological constraints that should be highlighted. These constraints are not necessarily limitations of the presented research, but, rather, can be viewed as related to the reality of conducting an in-depth qualitative study for the purposes of a doctoral thesis.

Firstly, all participants within the present study were recruited from a single geographic location in an urban center in Ontario. Throughout their personal narratives, common themes emerged surrounding the availability of local programs, services and

interventions throughout the lives of their children with ASD. Participant recruitment from one local organization has some limitations. Firstly, individuals and families who are involved with this local non-profit organization may have similar ideas surrounding intervention selection and community based service delivery. They may attend similar events and support groups, and have the opportunity to share their views in this area.

Secondly, all participants had children between the ages of 15 and 21. These families may have received services for their children within the same time frame and under the same government policies.

Finally, there are several considerations surrounding the data collection and analysis process that need to be addressed. For the purposes of my doctoral thesis I collected, transcribed and analyzed all of the data presented in this study. In doing so, I was able fully immerse myself in the data and ensure consistency throughout the analysis process (Chase, 1994; Lieblich, Tuval-Mashiach, & Zilber, 1998; Wells, 2011). Other researchers may have provided new or different interpretations of the data. Again, this is not a strength or constraint within the present study, but a reality within qualitative research.

5.4   Final Reflections

This concludes my dissertation, exploring parents' personal stories surrounding the selection and implementation of programs, services and interventions for their adolescents with ASD. I have been able to contribute new and meaningful information to the body of literature in this area by the addition of qualitative data based within CST. I have enabled researchers, policy makers and healthcare providers to consider the stories

of parents with children with ASD and to focus on the issues identified by this group. In doing so, I have given voice to this oppressed population (Friere, 1993) and provided the opportunity to focus on both the problems and solutions that are relevant and applicable to this group.

On a personal level, this research process has been a journey. It has required a great deal of personal reflection throughout. As a clinician working with this population and a researcher within the academic setting, I found I was able to offer a unique perspective of both families and service-delivery models for this group. I am honoured to have been able to address these topics and add the stories of these families to the greater body of research. Thank you to all of the participants who shared their stories and enabled me to give voice to this topic.

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Appendices

Appendix A

Table 1. Summary table of key features of the final literature sample.

Author (Year)	Theoretical Approach	Main Findings of the Study/Key Features
Bass, Duchowny, & Llabre (2009)	Alternative Approach - Animal Assisted Therapy	Participants exposed to therapeutic horseback riding exhibited greater sensory seeking, sensory sensitivity, social motivation, and less inattention, distractibility, and sedentary behaviors.
Martin, & Farnum (2002)	Alternative Approach -Animal Assisted Therapy	Participants exhibited a more playful mood, were more focused, and were more aware of their social environments when in the presence of a therapy dog.
Sams, Fortney, & Willenbring (2006)	Alternative Approach -Animal Assisted Therapy	Participants demonstrated significantly greater use of language and greater social interaction in sessions incorporating animals when compared to sessions using standard occupational therapy techniques.
Solomon (2010)	Alternative Approach -Animal Assisted Therapy	Participants socially benefited from interactions in which service and therapy dogs are included according to parental reports.
Ciceroa & Pfadtb (2002)	Behavioural Approach	All participants reduced toileting accidents to zero and learned to spontaneously request use of the bathroom within 7±11 days of training within a structured school setting. Gains were maintained over 6-month and 1-year follow-ups.
Conroy, Asmus, Seller & Ladwig (2005)	Behavioural Approach	Following implementation of the intervention, the student's stereotypic behavior decreased during the times indicated by the visual cue that it was unacceptable to engage in stereotypy according to qualitative parental reports.
Eikeseth, Smith & Eldevik (2002)	Behavioural Approach – Intensive Behavioural Intervention	Participants may make larger gains with intensive behavioural interventions when compared to a control group. This treatment can be successfully implemented in school setting.

Eikeseth, Smith, Jahr & Eldevik (2002)	Behavioural Approach – Intensive Behavioural Intervention	Behavioural treatment group showed larger increases in IQ and adaptive functioning; fewer aberrant behaviours and social problems at follow up.
Eikeseth, Smith, Jahar & Eldevik (2007)	Behavioural Approach – Intensive Behavioural Intervention	Behavioral treatment group showed larger increases in IQ and adaptive functioning and displayed fewer aberrant behaviors and social problems at follow-up.
Adams, Gouvousis, VanLue & Waldron (2004)	Behavioural Approach – Social Stories	Social story intervention is a beneficial tool in decreasing frustration behaviors exhibited during homework time.
Barry & Burlew (2004)	Behavioural Approach – Social Stories	The researchers found support for the use of social stories to teach choice making and play skills to children with an ASD.
Crozier & Tincani (2002)	Behavioural Approach – Social Stories	Social stories increased appropriate behavior and decreased inappropriate behavior for two of the three participants. The addition of verbal prompts was necessary to increase appropriate behavior for the third participant.
Delano & Snell (2006)	Behavioural Approach – Social Stories	The number of target social skills displayed increased after the intervention was introduced The duration of social engagement increased for all three students. Two students demonstrated generalization to a classroom setting, requests, and making contingent responses.
Ivey, Heflin & Alberto (2004)	Behavioural Approach – Social Stories	The use of Social Stories produced a 15% to 30% increase in participation during novel events for all three participants.
Lorimer, Simpson, Myles & Ganz (2002)	Behavioural Approach – Social Stories	There was a decrease in interrupting verbalizations and tantrums when the social stories were available to participants.
Ozdemir (2008)	Behavioural Approach – Social Stories	The use of properly constructed social stories without additional behavioral management interventions may be effective in decreasing the disruptive behaviors of children with an ASD.

Reynhout & Carter (2008)	Behavioural Approach – Social Stories	Social Stories were widely used by teachers to target a diversity of behaviors, with children of different ages who demonstrated varying degrees of autism, a range of cognitive ability and varying expressive and receptive language skills.
Reynhout & Carter (2009)	Behavioural Approach – Social Stories	The use of social stories did not increase time spent looking at a book during group reading time.
Sansosti, Powell-Smith & Kincaid (2004)	Behavioural Approach – Social Stories	The reviewed studies did show efficacy of Social Story interventions with a variety of children with ASD
Sansosti & Powell-Smith (2006)	Behavioural Approach – Social Stories	Increase in the social behavior of two of the three participants when the treatment was implemented, however the maintenance of target behaviours not observed.
Scattone, Tingstrom & Wilczynski (2006)	Behavioural Approach – Social Stories	An increase in appropriate social interactions occurred for two of the three participants after the intervention was implemented.
Toplis & Hadwin (2006)	Behavioural Approach – Social Stories	The results showed an increase in targeted life skills behaviours when social stories were used for three of the five children.
Phelan, Steinke & Mandich (2009)	Cognitive Approach – CO-OP	Following the intervention, improved ratings of performance and satisfaction were reported by participants on selected goals.
Rodger & Brandenburg (2009)	Cognitive Approach – CO-OP	Both participants we able to engage in CO-OP intervention to successfully improve their occupational performance.
Rodger, Ireland & Vun (2008)	Cognitive Approach – CO-OP	Both participants improved in social and organizational skills, and they generalized and transferred their learning to their home and school environments.
Rodger, Pham, Mitchell (2009)	Cognitive Approach – CO-OP	Both participants were able to utilize cognitive strategies

to effectively solve their motor performance problems.

Rodger, Springfield, & Polatajko (2007)	Cognitive Approach – CO-OP	The CO-OP approach was effective in teaching client-chosen motor based goals to a child with ASD.
Boyd, McDonough, Rupp, Khan, Bodfish (2010)	Parent Directed/ Mediated Approach	Significant reductions in repetitive behaviors were found for all participants and maintenance of treatment effects for four of the five participants.
Sofronoff, Leslie & Brown (2004)	Parent Directed/ Mediated Approach	Parent management training can be an effective intervention for parents of a child diagnosed with an ASD.
Devlin, Leader & Healy (2008)	Sensory Approach/ Behavioural Approach	Behavioural intervention was more effective in reducing self-injurious behaviour than the sensory integration approach.
Devlin, Healy, Leader, Hughes (2011)	Sensory Approach/ Behavioural Approach	Behavioural intervention was more effective than sensory integration therapy in the treatment of challenging behavior.
Davis, Durand & Chan (2011)	Sensory Based Approach - Brushing	Brushing had no marked affect on levels of stereotypy.
Bagatell, Mirigliani, Patterson, Reyes & Test (2010)	Sensory Based Approach - Seating	Each child demonstrated a unique response. The results illuminate the complex nature of children with ASD and the importance of using sound clinical reasoning skills when recommending sensory strategies for the classroom.
Schilling & Schwartz (2004)	Sensory Based Approach - Seating	Substantial improvements in engagement and in-seat behavior when participants were seated on therapy balls. Social validity findings indicated that the teachers preferred the therapy balls.
Umeda & Deitz (2011)	Sensory Based Approach - Seating	No clinically relevant changes in the in-seat or on-task behaviors of either participant were observed with cushion use.

Pfeiffer, Koenig, Kinnealey, Sheppard & Henderson (2011)	Sensory Based Approach – Sensory Integration	Significant positive changes in Goal Attainment Scaling scores for both groups; more significant changes occurred in the intervention group, and a significant decrease in autistic mannerisms occurred in the intervention group.
Schadd, Benevides, Kelly, Maillouz-Maggio (2012)	Sensory Based Approach – Sensory Integration	The intervention is safe and feasible to implement, acceptable to parents and therapist, and therapists were able to implement protocol with adequate fidelity.
Van Rie & Heflin (2009)	Sensory Based Approach – Sensory Integration	Sensory based interventions may have a positive effect for some, but not all students with ASD.
Watling & Dietz (2007)	Sensory Based Approach – Sensory Integration	No clear patterns of change in undesired behavior or task management emerged through objective measurement.
Marr, Mika, Miraglia, Roerig & Sinnott (2007)	Sensory Based Approach – Sensory Stories	Three children had a positive change in their behavior after reading a Sensory Story. The fourth child also showed a positive change in his behavior; however, behaviors were already improving during baseline, making interpretation difficult
Hodgetts, Magill-Evans, Misiaszek (2011)	Sensory Based Approach – Weighted Vest	The use of weighted vests to decrease stereotyped behaviors or arousal in children with ASD in the classroom was not supported.
Kane, Luiselli, Dearborn & Young (2004)	Sensory Based Approach – Weighted Vest	Wearing the weighted vest did not reduce stereotypy or increase attention to task. Three participants appeared to have a negative influence.
Quigley, Peterson, Frieder & Peterson (2011)	Sensory Based Approach – Weighted Vest	No functional relationship between weighted vests and participants' problem behaviors or increased independence in the classroom.
Barry et al. (2003)	Social Skills Based Program	Results indicate an improvement in greeting and play skills but less clear improvements in conversation. Parental reports of greeting, conversation and play skills outside of the clinic setting indicated significant improvements in greeting skills.

Beaumont & Sofronoff (2008)	Social Skills Based Program	The Junior Detective Training Program appeared to be effective in enhancing the social skills and emotional understanding of children with an ASD.
Cragar & Horvath (2003)	Social Skills Based Program	Although there were qualitative changes observed during the group and reported by the parents, the participant had not yet generalized his new skills significantly outside the group setting. Nine-month follow-up suggests that the participant has made significant improvement in social skills over time.
Crooke, Hendrix & Rachman (2007)	Social Skills Based Program	Significant changes on both verbal/nonverbal domains across participants following the intervention.
DeRosier, Swick, Davis, McMillen, Matthews (2010)	Social Skills Based Program	Children who participated in intervention group exhibited significantly greater mastery of social skill concepts compared to children in the control group.
Frankel et al. (2010)	Social Skills Based Program	Participants improved on parent measures of social skill and play date behavior and child measures of popularity and loneliness. 87% of children receiving the social skills intervention showed improvements.
Koenig et al. (2010)	Social Skills Based Programs	Participants in the treatment group were rated as improved on the primary outcome measure, (un-blinded parent report), but not on the secondary out-come measure, a parent questionnaire.
Krieger, Schultz & Newsom (2006)	Social Skills Based Program	Members of both groups increased pro-social behaviours. The direct teaching group make more gains in social skills
Legoff & Sherma (2006)	Social Skills Based Programs	Both groups showed significant improvement, Lego participants improved more than comparison subjects.
Lopata, Thomeet, Volker & Nida (2006)	Social Skills Based Program (Cognitive Behavioural	Significant improvement in social skills for the overall program based on parent and staff reports.

Approach)

Lopata, Thomeer, Volker, Nida & Lee (2007)	Social Skills Based Program	Significant improvements in social skills and problem behaviors for participants noted. However there was no significant differences for face emotion recognition for participants.
Lopata et al. (2010)	Social Skills Based Programs	Significant treatment effects were found for five of seven primary outcome measures.
Stichter, O'Connor, Herzog, Lierheimer, McGhee (2011)	Social Skills Based Program	Significant improvements on direct assessments measuring theory of mind and problem solving, and parent perceptions of overall social abilities and executive functioning for participants.

Appendix B: Ethics Approval

Western Research

Research Ethics

Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Angela Mandich
File Number:103594
Review Level: Delegated
Approved Local Adult Participants:10
Approved Local Minor Participants:10
Protocol Title: Transitioning to Adulthood: A Pilot Trail Teaching Life Skills to Young Adults Through a Summer Camp Program
Department & Institution: Health Sciences\Occupational Therapy,Western University
Sponsor:
Ethics Approval Date: May 07, 2013 **Expiry Date:**August 31, 2013
Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Revised Letter of Information & Consent	Here is a copy of the revised LOI. The two changes are highlighted in 'track changes'. 1. Days of camp changed from 'Monday to Friday' to 'Monday to Thursday' 2. UWO phone number and extension added. The voicemail messages will be left on a password protected account in a locked office.	2013/05/01

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Ethics Officer to Contact for Further Information

___ Erika Basile	✓ Grace Kelly	___ Shantel Walcott
(ebasile@uwo.ca)	(grace.kelly@uwo.ca)	(swalcot@uwo.ca)

This is an official document. Please retain the original in your files.

Western University, Research, Support Services Bldg., Rm. 5150
London, ON, Canada N6A 3K7 t. 519.661.3036 f. 519.850.2466 www.uwo.ca/research/services/ethics

Appendix C: Letter of Information

Project Title: Transitioning to Adulthood: A Pilot Trial Teaching Life Skills to Young Adults through a Summer Camp Program

Principal Investigator: Dr. Angie Mandich, School of Occupational Therapy, Western University

Letter of Information

1. **Invitation to Participate**
    You and/or your child are being invited to participate in this research study entitled 'Transitioning to Adulthood: A Pilot Trial Teaching Life Skills to Young Adults through a Summer Camp Program'. This information is being distributed by Autism Ontario London on behalf of the project researchers.

2. **Purpose of the Letter**
    The purpose of this letter is to provide you with information required for you and/or your child to make an informed decision regarding participation in this research project.

3. **Purpose of this Study**
    The purpose of this study is to provide Occupational Therapists with a new approach in the treatment of adolescents and young adults with Autism Spectrum Disorders (ASDs). This study seeks to provide a cognitive, community based, therapeutic summer camp run by an Occupational Therapist and Occupational Therapy students at Western University. This treatment program is focused on using the Cognitive Orientation to Occupational Performance (CO-OP) approach to improve daily living skills and ease the transition to adulthood for study participants. The CO-OP approach will be used throughout the course of the 3-week camp program as an intervention to work on specific daily living skills chosen by participants. The CO-OP approach will be integrated into the daily programing and focus on improving specific tasks related to activities of daily living required within the transition to adulthood. This program will incorporate community-based activities and the use of technology, specifically Ipads, to improve the overall functioning of adolescents and young adults with ASD.

4. **Inclusion Criteria**

   Individuals who are between the ages of 15 and 21 at time of intake and have a diagnosis of an ASD (Including Aspergers Syndrome) are eligible to participate in this study.

5. **Exclusion Criteria**

   Individuals who are currently receiving cognitive based therapy are not eligible to participate.

6. **Study Procedures**

   If you and/or your child agree to participate, you will be asked to attend an initial assessment session at Western University in London, Ontario, where you will be asked to participate in both narrative interviews surrounding your experiences with interventions for you and your child and two standardized assessments focused on selecting and understanding your goals throughout the camp program. The two standardized assessments include:
   - The Canadian Occupational Performance Measure (COPM) is an interview designed to help participants identify and set goals for the summer camp. Each participant and their parents will be asked to identify three activities of daily living tasks to be worked on during the summer camp program. Once goals are set, a behavioural rating scaled called the Performance Quality Rating Scale (PQRS) will be used to show the performance and quality changes of participant goals during the summer camp.
   - The Vineland Adaptive Behaviour Scales (VABS) will be completed. The VABS is an interview that will be completed with parents reporting on their child's skills across a number of areas including communication, socialization and daily living skills. All these assessments will be done at the beginning of the camp and the end of the camp. The PQRS will be used throughout the study to measure day to day changes

   It is expected that this initial assessment session will take approximately two hours. A three week camp block based out of Elborn College at Western University will be run from July 8th – 26th, 2013 from 9:00am-3:00pm Monday to Friday. A post-camp assessment session will follow the three-week camp, allowing for evaluation of change in performance goals. There will be a total of 10 adolescents and young adults participating.

7. **Possible Risks and Harms**

   There are no known or anticipated risks or discomforts associated with participating in this study.

8. **Possible Benefits**
   The possible benefits to participants may include improved independence in activities of daily living and specific goal attainment to ease the transition to adulthood.

9. **Compensation**
   The use of Ipad Mini technology will be used throughout the summer camp program. Following the completion of the three-week summer camp block, you and/or your child will be compensated for your participation in this study, and keep the Ipad and applicable applications used throughout the program.

10. **Voluntary Participation**
    Participation in this study is voluntary. You and/or your child may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no consequences.

11. **Confidentiality**
    All data collected will remain confidential and accessible only to the investigators of this study. If the results are published, you and/or your child's name will not be used. If you and/or your child choose to withdraw from this study, your data will be removed and destroyed from our database. While we will do our best to protect your information there is no guarantee that we will be able to do so. All data collected will remain confidential and accessible only by the investigators of this study. Your research records will be stored in the following manner: locked in a cabinet and/or on a password-protected computer in a secure office; and they will be destroyed after 5 years. If we find information we are required by law to disclose, we cannot guarantee confidentiality. Representatives of Western University Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

12. **Contact for Further Information**
    If you require any further information regarding this research project or your participation in the study you may contact

Dr. Angie Mandich   Kaity Gain, PhD Candidate, 2014
School of Occupational Therapy   School of Occupational Therapy
Western University   Western University

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics

13. Publication

If the results of the study are published, your name will not be used. If you would like to receive a copy of any potential study results, please provide your name and contact number on a piece of paper separate from the Consent Form.

This letter is yours to keep for future reference.

Appendix D: Consent Form

Consent Form

Project Title: Transitioning to Adulthood: A Pilot Trial Teaching Life Skills to Young
Adults through a Summer Camp Program

Study Investigator's Name: Dr. Angie Mandich, School of Occupational Therapy,
Western University

I have read the Letter of Information, have had the nature of the study explained to me
and I agree to participate. All questions have been answered to my satisfaction.

Child's Name (please print):

_____

Participant's Name (please print):

_____

Participant's Signature:

_____

Date:

_____

Parent/Legal Guardian (Print):

_____

Parent/Legal Guardian (Sign):

_____

Parent/Legal Guardian (Date):

_____

Person Obtaining Informed Consent (please print):

       _____

Signature:

       _____

Date:

       _____

Curriculum Vitae

Kaitlyn Gain, PhD Candidate, OT Reg. (Ont.)

Education

Western University, London, ON

PhD Candidate, Child and Youth Health, Faculty of Health and Rehabilitation Sciences	2011 – present
MSc. (OT), Masters of Occupational Therapy	2009 – 2011
B.A. Psychology, Honours Specialization	2004 – 2007

Scholarships and Academic Honours

Ontario Graduate Scholarship (OGS) Recipient ($15,000)	2012 – 2013
Ontario Graduate Scholarship (OGS) Recipient ($15,000)	2011 – 2012
CIHR Health Professional Student Research Award (HPSRA) ($3500)	2011 – 2012
Ontario Society of Occupational Therapists (OSOT) Student Award	2011
Ontario Graduate Scholarship (OGS) Recipient ($15,000)	2010 – 2011
The University of Western Ontario Graduate Club Student Bursary ($500)	2010 – 2011
Kings University College at the University of Western Ontario Humanitarian Award Recipient	2008

Related Experience

Western University, London, ON

Sessional Instructor, School of Occupational Therapy   Summer, 2012
Instructor for the OT9613 course, Consolidation of Occupational
Therapy Practice

Teaching Assistant, PT9524B   Spring, 2014
Working under the direction of Dr. Denise Connelly, School of Physiotherapy
Assisting with a number of duties including marking exams and papers
and guest lecturing

Graduate Research Assistant   2008 – present
Working under the direction of Dr. Angela Mandich, School of Occupational Therapy
Assisting with a number of research projects focused on understanding daily
activity and occupation for children with Autism Spectrum Disorders (ASD)

Guest Lecturer, School of Occupational Therapy
Gain, K. & Wilson, J. (March, 2014). Developmental Disorders and Adolescence:
        Occupational Implications. The School of Occupational Therapy, OT9562b,
        Western University, London, Ontario.

Wilson, J. & **Gain, K**. (November, 2013). Autism: Occupational Implications. The
        School of Occupational Therapy, OT9531a, Western University, London,
        Ontario.

Gain, K. & Wilson, J. (November, 2013). Autism: The Lived Experience. The School of
        Occupational Therapy, OT9531a, Western University, London, Ontario.

Pace Homecare, London, ON   2012 – present

School Health Support Services (SHSS) Occupational Therapist
Providing Occupational Therapy services to a caseload of 100 students
across schools in the Lambton Kent District School Board (LKDSB) and
the St. Clair Catholic District School Board (SCCDSB)

Thames Valley Children's Centre, London, ON   2011 – 2012

Private Intensive Behavioural Intervention (IBI) Therapist
Working 1:1 with a child with an ASD three times weekly, following a
program focused on improving early math and literacy skills, social skills,
emotional regulation, activities of daily living and overall global
functioning using behavioural principles

Victorian Order of Nurses (VON), London, ON   2005 – 2012

Personal Support Worker
Working 1:1 with nine children with developmental disabilities (ie. Individuals
with ASD, behavioural challenges, Down Syndrome, physical challenges and
hearing impairments) in a variety of community and recreational settings

The Boys and Girls Club of London, London ON   2003 – 2007

Inclusion Camp Councilor
Working as an Inclusion Camp Counsellor with children with developmental
disabilities to facilitate engagement and integration into daily summer camp
programming

Academic Service

Western University, London ON

Occupational Therapy Student Council President   2010 – 2011
Planning and coordinating biweekly student council meetings. Responsible
for leading twenty first and second year Occupational Therapy Student Council
members in a number of areas throughout the academic school year

Occupational Therapy Open House Coordinator   2010 – 2011
Leading a committee in the organization of the University of Western
Ontario School of Occupational Therapy Open House designed to
provide information to students interested in the Occupational Therapy
profession

Occupational Therapy Student Council Vice President Events   2009 – 2010
Involved in the planning and organization of social and Occupational
Therapy related events throughout the course of the school year

Related Community Service

Autism Ontario London Chapter, London ON   2007 – 2014

Coordinator of the Pin Pals Bowling Program
Providing one on one support to 25 children with ASD to allow them to engage
in a weekly bowling program. Program designed to work on bowling skills,
effective communication, appropriate social interactions and life skills

A League of Our Own Soccer Coach
Head coach for a soccer team of 15 children with ASD. Coordinating 15
Volunteers to help promote active participation for participants. Program
designed to work on task commitment, effective communication, appropriate
social interactions and increasing independence in activities of daily living

Children's Aid Society, London ON   2005 – present

Big Sister Volunteer
Big Sister program through Children's Aid Society – weekly visits with an
assigned little sister. Working to encourage participation in meaningful activities
and increase independence across all areas

Bann King Kaew Orphanage, Chang Mai, Thailand   January, 2008

Child Development Service Worker
Completed child development assessments and made recommendations to
support growth of developmental milestones for 25 children ages 0-6

The University of Western Ontario, London ON   2005 – 2008

King's Kids Club Vice President
Planning and organizing weekly recreational events and activities for large
groups of high needs children with volunteer support

Dominican Republic Education and Medical Support (DREAMS) Coordinator
Organized and traveled to the Dominican Republic on three occasions, working
to build homes, schools and medical centers in underprivileged communities

Research Contributions

Grants

Gain, K., Wilson, J. & Mandich, A. (2012). *Transitioning to Adulthood: A Pilot Trial
     Teaching Life Skills to Young Adults with ASD through a Summer Camp
     Program.* Funded by The C. Kingsley Allison Research Award at Western
     University in the amount of $9000.

Presentations

Oral Presentations
Wilson, J., **Gain, K.** & Mandich, A. (accepted, October, 2014). Concept mapping: A
     dynamic, individualized and qualitative method for uncovering occupational
     meaning. 2014 Joint International Conference, Globalization & Occupational
     Science: Partnerships, Methodologies & Research, Minneapolis, Minnesota,
     United States of America.

Gain, K. Wilson, J. & Mandich, A. (May, 2014). The transition to adulthood: Teaching
     life skills to young adults with Autism Spectrum Disorder through a community
     based occupational therapy summer program. Child Health Symposium 2014,
     Thames Valley Children's Centre, London, Ontario, Canada.

Gain, K., Wilson, J. & Mandich, A. (May, 2014). The use of iPad technology and concept mapping in facilitating independence in adolescents with Autism Spectrum Disorder. Child Health Symposium 2014, Thames Valley Children's Centre, London, Ontario, Canada.

Wilson, J., **Gain, K**. & Mandich, A. (May, 2014). Concept mapping and cognitive orientation to daily occupational performance. 2014 Canadian Association of Occupational Therapy (CAOT) Conference (2014), Fredericton, New Brunswick, Canada.

Gain, K., Wilson, J. & Mandich, A. (March, 2014). The use of Ipad applications to facilitate independence within the school setting with adolescents with Autism Spectrum Disorders. Technology in Education Symposium at Western (TIES), London, Ontario, Canada.

Gain, K., Wilson, J. & Mandich, A. (November, 2013). Transitioning to adulthood: A pilot trial teaching life skills to young adults through a summer camp program. 11th Scientific Association of Caribbean Occupational Therapists (ACOT) Conference, Grand Cayman, Cayman Islands.

Wilson, J., **Gain, K.** & Mandich, A. (November, 2013). Concept mapping and the CO-OP approach: Facilitating independence in adolescents with Autism Spectrum Disorders. 11th Scientific Association of Caribbean Occupational Therapists (ACOT) Conference, Grand Cayman, Cayman Islands.

Poster Presentations
Gain, K., Wilson, J. & Mandich, A. (accepted, October, 2014). Critical narratives: Parents stories of the culture of interventions for children with Autism Spectrum Disorders. 2014 Joint International Conference, Globalization & Occupational Science: Partnerships, Methodologies & Research, Minneapolis, Minnesota, United States of America.

Gain, K., Wilson, J. & Mandich, A. (May, 2014). Teaching life skills to young adults with Autism Spectrum Disorders. 2014 Canadian Association of Occupational Therapy (CAOT) Conference, Fredericton, New Brunswick, Canada.

Felix, K.M., **Gain, K.,** Paiva, E. & Whitney, K. (April, 2011). Upper extremity motor learning among individuals with parkinson's disease: A meta-analysis evaluating movement time in simple tasks. The School of Occupational Therapy Supervised Research in Occupation (SRO) Conference, London, Ontario.

Workshops

Gain, K., Wilson, J. & Mandich, A. (submitted, September, 2014). Transition to adulthood for adolescents with ASD: A summer camp program. Ontario Society of Occupational Therapists (OSOT) Conference (2014), Toronto, Ontario, Canada.

Publications

Book Chapters

Mandich, A., Wilson, J. & **Gain, K**. (in press). Cognitive Intervention for Children. IN Case-Smith, J. & O'Brien, J. (Eds.), Occupational Therapy for Children, 7th Ed. Location: Elsevier.

Peer-Reviewed Journal Articles

Wilson, J., Mandich, A., Magalhaes, L., Polgar, J. & **Gain, K.** (in press). Children's participation in the co-occupation of play: Concepts, meanings and relevance. *Journal of Occupational Science.*

Felix, K.M., **Gain, K.,** Lisson, S., Movsessian, Y. & Whitney, K. (2013). Celebrating student reflections on occupational transitions: A chilean journey. *WORK, 44,* 69-71.

Felix, K.M., **Gain, K.,** Paiva, E. & Whitney, K. (2013). Student reflections on unexpected work transitions due to natural disaster in Chile. *WORK, 44,* 81-84.

Felix, K., **Gain, K.,** Paiva, E., Whitney, K., Jenkins, M.E. & Spaulding, S.J. (2012). Upper extremity motor learning among individuals with parkinson's disease: A meta-analysis evaluating movement time in simple tasks. *Parkinson's Disease, 2012,* 1-7.