

A Comparative Analysis of Community-Based Service Providers for “Extreme” Case ASD:
Exploring Activity Program Options

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ABSTRACT

The purpose of my research was to examine how community-based organizations in the Niagara region provide programs for children with Autism Spectrum Disorder (ASD), who are considered to represent “extreme” or “severe” cases. A qualitative, comparative case study was conducted that focused on three organizations who provide summer recreation and activity programs, in order to examine the issues these organizations face when determining program structure and staff training; and to understand what the threshold for physical activity is in this type of setting, and how the unique needs surrounding these “severe” cases are met while attending the program. Purposeful sampling was employed to select a supervisor and senior staff member from each organization to discuss the training process, program development and implementation, and the resources and strategies used within their organization’s community-based program. A confirming comparative analysis was comparative analysis of a parents survey with six mothers whose children are considered “severe” indicated that camp staffs’ expectations are unrealistic where as the parents and supervisors have more realistic expectations within the “real world” of camp. There is no definition of “severe” or “extreme” and therefore severity is dependent upon the context.

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Chapter I- INTRODUCTION

Background

“If you’ve met one person with Autism, you’ve met one person with Autism.” –unknown author

Individuals with Autism Spectrum Disorder (ASD) are all unique, as there is an infinitely variant continuum of features of low to high level of intellectual functioning; no two individuals with ASD are identical. Each disorder on the spectrum has both unique and shared attributes that change frequently with development, and differ in children of the same chronological age but different development age (Reid & Collier, 2002). ASD is one of the most prevalent developmental disabilities in North America as it is estimated that the prevalence of Autism Spectrum Disorders in the United States is 1 per 88 children (Baio, 2008) and 1 per 94 children in Canada (NEDSAC, 2010). There is no reference to severity within the diagnostic criteria.

Diagnosing an individual with ASD can be difficult as there is no medical test, (i.e., blood test), to diagnose the disorder (Lord et al., 2006). The diagnostic criteria for ASD according to the DSM-IV-TR (APA, 2000) share three common areas of impairment: qualitative impairment in social skills; qualitative impairments in verbal and nonverbal communication; and restricted and repetitive interests or behaviours (APA 2000, Baranek, 2002; Connolly, 2008; Lord et al., 2006; Reid & Collier, 2002). The Autism Spectrum continuum of developmental severity has Autistic Disorder, at the more severe end of the spectrum, individuals with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) are on the middle of the spectrum as they vary with their functional level and development, and individuals with Asperger’s Disorder tend to have average to above average intellectual functioning (APA 2000; Lord et al., 2006). Within the diagnostic criteria there is not a set definition of what impairments or combinations of impairments are considered “severe” or “extreme.” These impairments have

the potential to have a significant impact on the person with ASD and their families' quality of life, by limiting the person's opportunities to participate in social and community activities (Horner et al. 2002; Matson, LoVullo, Boisjloi & Gonzalez, 2008).

To address these impairments there are a variety of approaches that target specific areas of ASD (communication, social and behaviour) as there is no "cure" for Autism. Parents and guardians of children with ASD are inundated with a variety of treatments, interventions and programs that claim to "cure" or "fix" their child's Autism. Many of these treatments or programs are not evidence-based practices that have been established through research as being effective and efficacious. Educational best practices and comprehensive treatment models, for example Treatment and Education of Autistic and other related Communication handicapped Children (TEACCH), Applied Behaviour Analysis (ABA), and Intensive Behaviour Intervention (IBI), are all considered to be evidence-based practices that are effective and efficacious. Perry et al. (2008) discuss how efficacy is if a treatment or intervention can be shown to work under "ideal" clinical conditions where "good" candidates (with no co-morbidities) are selected and trained therapists are administering the treatment according to the manual and are well supervised. In the "real-world" this is considered a clinical setting where every component is controlled and tracked. Effectiveness, according to Perry et al. (2008) is when the intervention or treatment actually works in "real life" situations, where there is less control, where clients are more severe or complex and staff are likely to be less trained and supervised and the treatment is diluted and the manual is not followed as closely. It is important to note that there are no documented effective or efficacious treatments or interventions for children with ASD participating in a community-based, recreational program or camp. All interventions discussed in Perry et al. (2008), were based in a clinical setting or an educational setting that is a controlled

environment overseen by experts. Often times in a “real world” setting, bits and pieces from different approaches are applied to create programs that will meet the child’s needs. “It is also increasingly evident that there is no single best suited and universally effective method for all children and youth with ASD” (Simpson, 2005, p.145). The best programs appear to be those that incorporate a variety of objectively verified practices and that are designed to address and support the needs of individual students and the professionals and families with whom they are linked (National Research Council, 2001; Olley, 1999; Simpson 2005). In order to be effective these interventions and treatments need to align with the needs of the individual, as well as the program planners and implementers and how they are used by appropriately trained, knowledgeable personnel. One size does not fit all.

Rationale

This study is a qualitative, comparative case study that aims to address the issues faced by community organizations that include children and youth with “extreme” Autism in their summer recreation and activity programs. While there is an abundance of literature on Autism, adapted activity for persons with Autism and other forms of instructional programs for persons with Autism, there is very little research on activity programming and “extreme” Autism, and almost no research on community-based programming and “extreme” Autism. This study will make an effort to explore and examine this under-explored topic of “extreme” Autism and community-based programming.

I will use a qualitative comparative case study design involving three organizations. I have been fortunate to have been an “insider” in all of these organizations previous to this research and am familiar with the contexts, the children, and the parents. This offers me a unique opportunity of established rapport and trust. I was able to conduct interviews with several levels

of program design and delivery personnel at all the organizations and a meaningful post-analysis parent survey to further elaborate on my findings.

I locate myself within a critical disability studies framework, which also acknowledges the necessity of a theory of complex embodiment (Siebers, 2010). Critical disability studies addresses the realities of socio-political and cultural contexts for persons with disabilities, and how these intersect with power differentials, power dynamics and power distribution. This means that disability does not exist in a vacuum, but is influenced by forces grounded in ablest ideology and values. Complex embodiment compels an honest and realistic acknowledgement of the body that actually exists and will continue to exist, regardless of changes and improvements in access, funding, supports and attitudes. Placed in this present study, this means that children and youth with “severe” Autism are influenced by medical, socio-economic, and cultural forces (to name a few) and will manifest on the severe end of the spectrum even in the best of conditions. Regarding the language of severity, this does not reflect the individual but it is relational to the context and that is evident within my study. The use of the term “severe” or “extreme” is used as an adjective or in conversation with participants, and it is not assuming inherency within the people. The project is presented using the vernacular of the cohorts and I recognize that people are not inherently severe in and of themselves, they are people. They are manifesting particular body expressions which in particular contexts will be perceived in a certain way.

The complex body remains complex. This does not mean that we ought not to address the conditions which can and should be improved.

Significance of Research & Context

Within the Niagara region, there are three organizations that provide community-based, recreational camps and programs to individuals on the severe end of the Autism Spectrum. There is a fourth organization that provides programs, camps and respite services but any individuals requiring one-to-one support the family must supply and pay for the support worker (which can range from \$15-20 per hour), as well as the fees associated with the program. The chart below provides an overview of the three organizations I will be examining.

Table 1

Overview of Organizations

Organization A	Organization B	Organization C
Population Served		
Ages 4-28+ Individuals with Autism Spectrum Disorder and other co-morbid disabilities	Ages 5-20 Individuals with Autism Spectrum Disorder and other co-morbid disabilities	Ages 3-15 Individuals with a variety of disabilities
Staff Ratios		
Ratios are based on the needs of participants and numbers of student volunteers. 1:1 support for participants with high needs 2:1, 3:1, 4:1 based on participants needs	1:1 support for participants with high needs 3:1 support for high functioning participants	A limited number of spaces and weeks are available for children who require a helping hand in a smaller ratio to have a successful camp experience. 1:1, 2:1 or 3:1 support available
Spaces Available per Week		
Spaces are based upon the number of student volunteers that are committed to working at camp. Approximately 40-60 spaces per week. 25-35 spaces reserved for participants requiring 1:1 support	25 spaces per week 10 spaces reserved for participants requiring 1:1 support 15 spaces reserved for participants requiring 3:1 support	5-15 spaces depending on campers needs, location and staffing St.Catharines up to 6/week Niagara Falls up to 4/week Welland up to 3/week

15-25 spaces available for participants requiring 2:1,3:1 or 4:1 support		
Length of Camp		
7 hours/day 8:30-3:30pm 2 weeks during August	6.5 hours/day 9:00-3:30pm First 6 weeks of summer holidays Early drop-off (8:30am) and late pick-up (4:30pm) provided for \$5.00.	8 hours/day 8:30-4:30pm 9 weeks of summer Extended Care Morning – 7:30am to 8:00am, \$15/week Afternoon – 5:00 to 6:00pm, \$20/week
Registration Process		
E-mail containing camp profile is sent out to returning participants Spaces are filled on a first come, first serve basis based on profile submission. Profile is completed by parent/guardian	Register online, profile sent via e-mail by program assistant. Spaces are filled on a first come, first serve basis for up to 2 weeks of camp/participant based on profile submission and payment. Further weeks may be offered depending upon registration numbers and staffing.	Completed at one of the organizations locations branches and cannot be completed online. Parent must be in contact with senior staff prior to registration. First come, first serve basis with up to 4 weeks of camp available per participant. Parent must meet with senior staff to complete profile.
Cost Per Week		
\$125/week	\$250/week for members \$300/week for non-members	\$250/week
Staff Hierarchy		
Supervisor Coordinators Senior staff/mentors Student Volunteers (support staff)	Program Manager Program Assistant Senior Staff Support Staff Volunteers	Camp Director Regional Supervisor Senior Staff Head Counselor Counselor/Support Staff
Training		
1 day trainings offered 2-3 months prior to camp. Weekend before camp, 2 day training lead by the supervisor with support from coordinators and senior staff/mentors	Non-violent crisis intervention certification course 4 days of training led by Program Assistant and senior staff.	Non-violent crisis intervention certification course 2 day Camp conference with all camp staff 2 day Program Support specific training 1 day onsite training

Reading material provided 2-3 months prior to camp training		
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All three of these organizations do not operate under any clinical guidelines according to Perry et. al's (2008) description of effective as they are "real world" situations. Each of these organizations face challenges in providing services to children with "severe" manifestations of ASD in the Niagara region. Due to limitations in funding and staffing these organizations are only able to provide services to participants for a limited number of weeks, not the entire summer (i.e. Organization A: camp is only 2 weeks; Organization B: 2 weeks with the possibility of more being available; Organization C: up to 4 weeks). Due to these limitations all of these camps are only able to offer a certain number of spaces and it is often on a first come, first serve basis. There is no guarantee that if you are a returning camper that you will secure a space as often times you must complete each camp's profile and provide full-payment to secure a space. For parents whose children are newly diagnosed, they are often not aware of these camps, the registration process and the limitations involved. Parents must coordinate and manage the services they access for their child, and this often occurs months in advance as many will want to have their child in care for a majority of the summer. Some parents have waited a year and a half to three years for overnight respite care from a local agency. There is a fee associated with this service that they may receive once or twice in the summer months. Below is an example of the summer schedule of parents with children who are "severe" cases and the cost of attending these organizations camps.

Table 2

Approximate Cost for Summer Recreation Programs

	Program/Camp Attending	Cost per Week
Week 1	Overnight respite from a local agency	\$200
Week 2	Organization C Camp	\$250
Week 3	Organization B Camp	\$250
Week 4	Organization B Camp	\$250
Week 5	Overnight respite from a local agency	\$200
Week 6	Organization C Camp	\$250
Week 7	Organization C Camp	\$250
Week 8	Organization A Camp	\$125
Week 9	Organization A Camp	\$125
	APPROXIMATE TOTAL COST:	\$1,900

This schedule is an example of how parents who have children with high needs will attempt to create some type of structure and routine within their child's day during the summer. Many of the parents will try to register their child for consecutive weeks at the same camp so that their child becomes accustomed to the camp schedule, routine, and staff. All of the organizations will attempt to match each camper with a staff member who will be able to meet their needs. Many of the parents hope that they will have the same staff for all the weeks they attend camp. Unfortunately this is not always possible as the supervisory staff must consider the following factors: number of campers attending camp each week, level of severity and needs of each camper; number of staff available; the skills of each staff and who works well with the campers attending, and staff time-off requests. All of these factors impact the camp's ability to provide a program that will meet needs of these "severe" campers. Each of these organizations has a similar approach to programming for these campers with high needs but it is their training, execution, and delivery of the program that differs. Organizations A and B would be considered segregated camps for children on the Autism Spectrum that provide ASD specific programming whereas Organization C attempts to include a variety of children-both with and without

disabilities- into more typical camps. This is the main challenge that these organizations face is ensuring that they are providing a safe environment for both the staff and campers and a program that is meeting the unique and diverse needs of these campers who are considered “severe” cases.

Researcher’s Background

Since the age of thirteen when I obtained my first job as a March Break Counsellor at a municipal camp, I have been involved in recreation programs and camps. Throughout my post-secondary career, I continued to instruct recreation programs and work at the municipality’s summer camps. Within these programs I came across very few participants with disabilities but any children with disabilities that did participate in our camps and programs required simple accommodations and modifications. I became involved in camps and programs at Brock University as an instructor and coordinator with the PALS Program and Sports School within the Recreation and Athletic departments. Autism was not on my radar until the spring of my third year, when I signed up to participate in the Brock ASD Movement Camp and to become a Coordinator of the Special Needs Activity Program (S.N.A.P). These two programs challenged me in a way that I had never experienced. I was intrigued and excited to be working with children and adults with ASD because every day was a new experience with a new challenge.

After being accepted into my Masters, I was able to work for a local agency, as a frontline staff member at a group home for teens with severe ASD, who were too violent, aggressive, and destructive to live at home. Working for this local agency allowed me to work within the Children’s Autism Program (CAP), a Section 23 class for children with ASD ages 6-12 years of age. The CAP class runs a TEACCH program by providing movement programming as a treatment for children who school boards cannot integrate or include because they are too aggressive, violent, destructive or disruptive. I worked as part of a team that consisted of a

Movement Specialist and certified teacher. Using the TEACCH program within the CAP and seeing the benefits of using a TEACCH program, motivated me to go to the University of North Carolina and become trained in the TEACCH program.

I have been employed by all three of the organizations I am examining in this study. For Organization A, I have been a student volunteer (support staff), senior staff, and coordinator. For Organization B, I have been a support staff, senior staff, program assistant, and program consultant. For Organization C, I was the senior staff. Each of these experiences has provided me with a wealth of insider insights and information. I witnessed these programs and camps struggling to provide programming to participants with ASD that are “severe”. While working for one of the organizations I had to work with young, inexperienced camp staff to transition a child in camp from full one-to-one support to no support over an eight week period as a result of funding being cut and the camp not being able to provide support to this child. This situation was the tipping point for me to focus my research on community-based organizations, as parents depend on the organization’s programs and camp as a form of child-care or respite and these programs are assets within the Niagara ASD community.

There is limited literature focusing on community-based programs for individuals with “severe” ASD as the literature focuses on evidence-based behaviour programs within a clinical or educational setting. My hope is that insight derived from this in depth comparative case study may disclose processes that could contribute to more meaningful, relevant, and dignified programming and program support within community-based programs as these children with “severe” ASD are becoming adults that require day-programs within the community.

Research Goals and Questions

Based upon my past experiences and review of the literature, the purpose of this comparative analysis is to examine how community-based organizations provide programs for children who are “extreme” cases. This study will focus on three community-based service providers, who deliver programs which they designate as inclusive, (i.e., which includes programming for children with disabilities who attend). Through the support staff and supervisor’s perspectives, I will explore programming, training and structure of the programs being provided by these community-based organizations; issues relating to identifying the movement and communication needs of “extreme” cases; as well as developing programs and training to meet their unique needs.

The following research questions will be examined:

1. What are the thresholds for physical activity within a community-based organization that provides programs for children with ASD?
2. How do programs committed to participants with ASD identify the physical and communication needs of “extreme” cases?
3. How are communication and physical needs addressed within community-based organization that provides programs for children with ASD (through training, programming and program’s structure)?
4. What issues/barriers are associated with using TEACCH strategies to provide physical activity opportunities within these programs?
5. What is needed for these programs to provide physical activity to “extreme” cases?

The current literature review will outline Autism Spectrum Disorder, “extreme” or “severe” cases, the importance of physical activity and the Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) method. An explanation of the rationale, research questions, purpose, and methodological considerations of the study will follow. Within the “methods” section, the research design, participant recruitment and selection, ethical considerations, and analysis process will be discussed.

Chapter Overview

The following four chapters will provide a more detailed description of the study and research process. Chapter two provides a literature review on several relevant areas applicable to this research: Autism Spectrum Disorder and “Extreme” Cases, an overview of effective practices focusing on comprehensive treatment models and educational best practices, and the benefits of physical activity. Chapter three contains the methodological considerations for this study: the research design, participant recruitment and selection, ethical considerations and analysis. Chapter four details the major findings of the analysis, while chapter five discusses the meaning and implications of the findings as well as the study limitations and future directions.

Chapter II- REVIEW OF LITERATURE

Autism Spectrum Disorder and “Extreme” Cases

Autism Spectrum Disorder (ASD) is the most prevalent of communicative and sensory disorders in the child population and is a general category of complex developmental disorders, which are characterized by severe and pervasive impairment in several areas of development. ASD is a continuum that includes: Autistic Disorder (AD), Asperger's Syndrome (AS), Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Rett's Disorder and Childhood Disintegrative Disorder (DSM-IV-TR; APA, 2000). Individuals with ASD have delays or impairments in the following areas: communication and language skills, reciprocal social interactions, lack of symbolic or imaginative play, presence of unusual sensory experiences, restricted repetitive and stereotyped patterns of behaviour, interests, and activities (APA, 2000; Baranek, 2002; Connolly, 2008; Reid & Collier, 2002). According to the DSM-IV-TR (APA, 2000) the disorders share three common areas of impairment: qualitative impairment in social skills; qualitative impairments in verbal and nonverbal communication; and restricted and repetitive interest or behaviours (APA 2000, Lord et al., 2006). The term “spectrum” is used commonly to refer to a continuum of developmental severity, with Autistic Disorder, at the more severe end of the spectrum were as individuals with Asperger's Syndrome tend to have average to above average intellectual functioning (APA 2000; Lord et al., 2006). There is no reference to severity within the diagnostic criteria. Diagnosing an individual with ASD can be difficult as there is no medical test, such as a blood test, to diagnose the disorder (Lord et al., 2006). In 2013, the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) will be released by the American Psychiatric Association containing the new diagnostic criteria for Autism. The DSM-5 is creating controversy within the Autism world as it is to include a new category called

Autism Spectrum Disorder which would incorporate several previously separate diagnoses, including Autistic Disorder, Asperger's Syndrome, Childhood Disintegrative Disorder and Pervasive Developmental Disorder Not Otherwise Specified (APA, 2012). In changing the criteria, one of the goals is for physicians to recognize that each person will display differences in relevant symptoms and behaviours rather than labelling a person categorically. According to the APA (2012), the change will help clinicians accurately diagnose people, rather than providing general labels that may not be consistent across clinics and centres. "Symptoms of these four disorders represent a continuum from mild to severe, rather than a simple yes or no diagnosis to a specific disorder. The proposed diagnostic criteria for Autism Spectrum Disorder specify a range of severity as well as describe the individual's overall developmental status--in social communication and other relevant cognitive and motor behaviors (APA, 2012)."

Currently, the DSM-5 is not published and therefore, the new diagnostic criteria and the continuum of mild to severe symptoms cannot be used as a point of reference for this study. The term "spectrum disorder" is derived from the infinitely variant continuum of features, of low to high level of intellectual functioning. Each disorder within the spectrum has both unique and shared attributes that change frequently with development and differ in children of the same chronological age but different development age (Reid & Collier, 2002). This study will focus on children who are considered to be "severe" cases (on the low functioning end of the Autism Spectrum). The DSM-IV-TR does not define or refer to "severe" Autism, rather, this is an idiom/common term that is used within the Autism community to describe an individual on the lower end of the spectrum. To ensure that the participants and I had a point of reference and understanding of "extreme" case I had to create a definition of "extreme" case based upon the current literature.

“Extreme” cases are the manifestation of the most intense features of the disability; this includes challenging and disruptive behaviours, limited communication skills, poor social development and ongoing presence of a caregiver for support of basic needs. Challenging and disruptive behaviours, according to Didden et al. (1997), can be divided into three classes (a) external destructive (e.g., aggression, property destruction), (b) internal maladaptive (e.g., self-injury, stereotypic movements, pica), and (c) socially disruptive (disruption, inappropriate verbalizations, noncompliance) or combinations of the above.

Individuals who could be considered these “extreme” cases consistently exhibit these manifestations and this can have a significant impact on the person’s quality of life, can threaten personal safety and the safety of others, and can drastically limit the person’s inclusion in educational settings, social relationships, typical home environments and community activities (Horner et al. 2002; Matson, LoVullo, Boisjoli & Gonzalez, 2008). While I presented the participants with the term “extreme” case, ironically “severe” is the language used most frequently. I will be using the term “extreme” in my research and interview questions and if used by participants in their responses but will use the vernacular of the cohort which is “severe” throughout the rest of the study.

Effective Practices

Within the field of Autism there is no “treatment” that would represent a “cure” for this developmental disorder. The approaches discussed in this section consist of interventions intended to address specific areas of ASD (communication, social and behaviour) by drawing from specific components from educational best practices and comprehensive treatment models (TEACCH, ABA and IBI). All of these interventions are considered to be evidence-based

practices that are effective and efficacious. Perry et al. (2008) highlights an important distinction between efficacy and effectiveness:

“Efficacy refers to whether a treatment or intervention can be shown to work under “ideal” conditions. Clients are selected to be “good candidates” with no co-morbidities; therapists are well trained (often graduate students) and well supervised; and treatment is carefully planned and implemented faithfully according to a manual. Effectiveness, on the other hand, involves whether the intervention actually works when applied in “real life” situations, where there is typically less control over relevant variables. Clients are likely to be more severe, complex, and/or heterogeneous; staff are likely to be less well trained and supervised; and treatment is likely to become diluted and to “drift” from the manual” (p. 623).

Efficacy and effectiveness will be further discussed in Chapter four and Chapter five. Each child with ASD has unique needs. According to Simpson (2005), successful outcomes require not only an effective model be chosen but also that it be properly matched with the needs of a particular student and the planning team (professionals, parents and families). “It is also increasingly evident that there is no single best suited and universally effective method for all children and youth with ASD,” (Simpson, 2005, p. 145). The best programs appear to be those that incorporate a variety of objectively verified practices and that are designed to address and support the needs of individual students and the professionals and families with whom they are linked (National Research Council, 2001; Olley, 1999; Simpson 2005). In order to be effective these interventions and treatments need to align with the needs of the individual, as well as the

program planners and implementers and how they are used by appropriately trained, knowledgeable personnel. Simpson (2005) supports the notion that one size does not fit all:

“It is highly likely that time will confirm that there are no universally effective strategies and methodologies and that individual students will respond differently to different strategies... if basic elements of effective programming are not incorporated into interventions and treatments and programs are not based on objectively verifiable effective methods, children and youth with ASD will fail to achieve outcomes that fully reflect their capabilities,” (p.147).

It is important to note that there are no effective or efficacious treatments or interventions in the literature for children with ASD participating in a community-based, recreational program or camp. All interventions discussed were based in a clinical setting or an educational setting that is a controlled environment overseen by experts.

Comprehensive Treatment Models

A combination of the effective approaches and strategies are used in comprehensive, intensive, ASD-specific intervention programs. According to Perry & Condillac (2008), comprehensive programs typically include an educational or skills development orientation together with some therapeutic intervention(s) for problem behaviour, often using a multidisciplinary team (including the parents), and the program takes place in various settings (home, school, agency). These programs focus on the child's needs by ensuring the curriculum or program is well suited to the child's particular strengths and deficits. The New York Guidelines (NYSDH, 1999) and National Research Council Report on Educating Children with

Autism (NRC, 2001) provide recommendations to parents and professionals regarding selecting an appropriate comprehensive program:

Table 3

Guidelines for Selecting an Appropriate Comprehensive Program

New York Guidelines for Sound Comprehensive Programs Curriculum (NYSDH, 1999)	National Research Council (NRC, 2001)
<ul style="list-style-type: none"> - Specifically designed for Autism, extra focus on attending to environment, imitation, social and play skills, language and communication - Individualized for child's strengths and needs <p>Settings/environment:</p> <ul style="list-style-type: none"> - Highly structured and supportive - High degree of routine, predictability - Families highly involved in intervention planning, delivery sometimes - Progression from 1:1 to group settings - Progression from more restricted to more natural settings - Long-term planning for as great a degree of independence as possible <p>Skill building:</p> <ul style="list-style-type: none"> - Includes strategies to assist in transitions (short- and long-term) - Includes strategies for generalization to more natural settings <p>Reduction of problem behaviour:</p> <ul style="list-style-type: none"> - Functional approach (understanding function of behaviour), changing antecedents to prevent, teaching replacement skills 	<p>They recommended that all children with an ASD diagnosis should receive education/intervention which:</p> <ul style="list-style-type: none"> - begins as early as possible (i.e., pre-school); - is intensive in nature (25 hours/week 12 months/year); - is individualized and systematically planned to address specific measurable objectives; - uses a curriculum focusing on communication, engagement, social, play, cognitive, self-help, behaviour, and motor goals; - uses data-based decision-making processes; - provides sufficient individualized 1:1 attention; - uses only empirically-supported approaches to problem behaviour - includes planning for generalization and transition planning to next settings; - has families actively involved; and - teaches specific goals in settings with typical peers (see Peer-Mediated Instruction section) whenever possible

I will describe Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH), Applied Behaviour Analysis (ABA) and Intensive Behavioural Intervention (IBI) because they exemplify many of the processes listed above. I will be

discussing the effectiveness of each of these interventions within a practical recreation program or camp within chapters four and five.

Treatment and Education of Autistic and related Communication Handicapped (TEACCH)

TEACCH is a structured teaching system that was specifically designed for individuals with ASD. It was developed at the University of North Carolina and is currently a statewide program that provides a comprehensive spectrum of services to children, youth, and adults with ASD, their families, and communities (Marcus, Schopler, & Lord, 2001). TEACCH has an empirical orientation, and many TEACCH professionals have created assessments and intervention approaches, been actively involved in journals, edited books, resources and manuals that have had a significant impact within the field. The TEACCH system advocates for creating teaching and independence to the individual, and for services to include the perspectives and experiences of families as they should be considered “co-therapists” (Schopler, 1994). The guiding-concepts of the TEACCH system have been summarized as: improved adaptation, parents’ collaboration, assessment for individualized treatment, structured teaching, skills enhancement, cognitive and behavioral therapy, generalist training (Panaeri et al., 2009). The underlying premise for structured teaching is to modify the environment in order to meet the needs of individuals with ASD. Four main components are related to this process: (a) physical organization that refers to the layout or setup of the teaching area for both academic and functional teaching; (b) visual schedules that show students what activities they will do and when; (c) work systems that inform students about what and how many activities have to be done; (d) task organization that informs students on within-task actions (Schopler et al. 1995). Behaviour problems are addressed according to a functional approach with an emphasis on prevention and use of cognitive and behavioural strategies. TEACCH does extensive teacher

training locally, and has provided many training workshops for broader audiences as well as parent specific “Make and Take” workshops. A number of "day treatment" classrooms in Ontario operated by children's mental health centres, operate rather similarly to a TEACCH program (Perry & Condillac, 2003). Many studies have shown the effectiveness of the TEACCH program, which have been implemented in many different countries and adapted to different situations (home-based, mainstream schools, special schools, residential centers, etc.) for a period from 4 to 12 months (Probst and Leppert 2008; Hume and Odom 2007; Tsang et al. 2007; Siaperas and Beadle-Brown 2006; Norgate 1998; Ozonoff and Cathcart 1998; Panerai et al. 1997, 1998, 2002). TEACCH is program that can be applied to all natural environments and is not meant to be used solely within a clinical setting. The program focuses on the unique needs of the child and designing a program which will increase independence and quality of life.

Applied Behaviour Analysis (ABA)

Often ABA and IBI are used synonymously but this is not an accurate understanding of the two different programs. Applied Behaviour Analysis (ABA) is traditionally defined as "... the science in which procedures derived from the principles of behaviour are systematically applied to improve socially significant behaviour to a meaningful degree and to demonstrate empirically the procedures employed were responsible for the improvement in behaviour" (Baer, Wolf, & Risley, 1968; Cooper, Heron & Heward, 2006). ABA is an approach that is not restricted to Autism or young children and is not necessarily intensive nor always involves one-to-one instruction. Behaviour analysis for Autism uses procedures that have been demonstrated (through applied research) to work in helping individuals to learn new skills in an enjoyable way. As well, problem behaviours are assessed and systematically remediated through effective intervention plans, which look at the function(s) of the target behaviour, (Perry & Condillac,

2003; Reichow et al. 2011). Within Ontario there are regional ABA-based services and programs that are for all children with Autism. According to the Ministry of Children and Youth Services (2013), ABA-based services do not address all the needs that children with Autism may have nor are the services offered in an intensive way over a long period of time. ABA-based services target a child's highest priority skill area(s) and are approximately provided for two to six months, typically two to four hours per week.

Intensive Behaviour Intervention (IBI)

Intensive Behavioral Intervention (IBI), is a treatment approach that is based on the principles of Applied Behavior Analysis (ABA), and has a strong body of empirical support demonstrating efficacy for improving the functioning of children diagnosed with ASD (Leaf et al. 2011; Leaf, McEachin, & Taubman 2008; New York State Department of Health, 1999; Perry & Condillac, 2003; Simpson, 2005). IBI is an intensive application of ABA where a child usually works with a therapist for 20 to 40 hours a week. IBI is an approach delivered to children with Autism in order to decrease challenging behaviours, increase appropriate behaviours and promote development. In Ontario, according to Perry & Condillac (2003), trained instructor therapists are supervised by senior therapists, under the clinical supervision of registered psychologists. IBI may initially include a one-to-one discrete trial approach (often useful initially), as well as more naturalistic approaches which may take place in home-based programs, specialized small group settings, or integrated settings (Perry & Condillac, 2003; Reichow et al., 2011).

Both ABA and IBI use behavioural teaching methods that have effectively demonstrated the increase of communication skills, social skills, activities or daily living and academic skills in community settings (Perry & Condillac, 2003; Repp, Favell, & Munk, 1996). A wide range of

techniques based on learning theories are used within behavioural teaching in order to focus on discernible environmental events that prompt, increase, and maintain behaviours. ABA applies behavioural teaching to develop specific skills to individuals of differing ages and varying levels of ability, while IBI is specific to individuals diagnosed with ASD, is more intensive, and for young children. The quality of life of individuals with ASD can be positively impacted by skill development (Horner et al., 2002). Several key components of behavioural teaching can be used to increase skill development regardless of the individuals' cognitive level. First, key behaviours to teach are identified, second, task analysis is used to break down the behaviours being taught into manageable steps, and third, appropriate technical strategies need to be applied to the teaching of the new skill (e.g., modelling, prompting, reinforcement, and error correction), (Perry & Condillac, 2003). In order to maintain the new skills, Martin & Pear (1999), recommend that maintenance strategies need to be implemented to enhance generalization and build life-long skills.

Environmental & Visual Supports and Structure

TEACCH, ABA and IBI all identify that a key component in ensuring new skills are maintained is environmental supports and structure. Environmental support can play an important role in the lives of individuals with ASD as many of them depend upon routine for day-to-day functioning. Often times these routines are not functional and changes to these routines can cause a great deal of distress to the individual and family. Children with ASD who are considered “severe” may have skill deficits that pose a significant challenge during unstructured time and without proper supports there is potential for increased problem behaviours to occur. Dalrymple (1995) reviewed environmental supports for individuals with ASD and suggests four types of environmental supports:

- temporal supports to sequence events over time;
- procedural supports to outline steps of an activity or the relationship of items to events or people;
- spatial supports to provide information about environmental organization; and
- assertion supports to help initiate interactions or assert control over the environment

Any of these environmental supports can be enhanced through the use of visual cues (Quill, 1997; 2000). An environment structured specifically for individuals with ASD has visual cues in different forms (e.g., picture schedules or written lists) depending upon the individuals functioning level. Picture activity schedules are used to help increase independence and decrease adult assistance when completing a task or following routines. When schedules are used over time, adult prompts are faded and levels of independence increase. These schedules can be used in written or picture form and can be used in a variety of different environments (e.g., home, school, or community). Research has also confirmed that these schedules can generalize across people and settings (MacDuff, Krantz, & McClann, 1993; Perry & Condillac, 2003). For example, within a camp setting the environment can be structured using visual supports to allow a child with ASD to dress independently. Visual supports can be used in conjunction with all four types of Dalrymple's (1995) environmental supports:

- Temporal supports → daily picture schedule outlining the order of the day's activities
 - E.g. Lunch, Bus, Change for swim, Swimming, Change for swim, Bus, Snack, Home time
- Spatial Supports
 - Change for swim picture may be a picture of the Men's washroom sign
 - Child's locker may be labelled with his name

- Procedural supports → using task analysis to break down the steps needed to undress for swimming
 - Could be referred to as a mini-schedule or work system
 - Examples of Pictures Used:
 - Take out swimming bag (contains extra blue plastic bag, towel, crocs and bathing suit)
 - Take off Shoes
 - Take off Socks
 - Take of Shirt
 - Take of Shorts
 - Take off Underwear
 - Put bathing suit on
 - Put crocs on
 - Put clothes and shoes into blue plastic bag
 - All Done
- Assertion Supports → creating a choice board for the child to select which activity they would like to do in during swimming
 - E.g. waterslide, noodles, ball

By using both visual supports and structuring the environment based on the child's needs, over time we would be able to fade out the adult prompts as the child's independence increased. The end goal of putting these supports in place is have the child be able to undress for swim using the environmental and visual supports independently with little or no adult assistance. This skill can potentially be generalized across environments (e.g. undressing at home) and people (e.g. with

parent). All three comprehensive models use a form of these visual and environmental supports and strategies based upon the individualized needs and skills of the child with ASD.

Similarities between Comprehensive Treatment Models

All three of these comprehensive models share several common strategies and activities. As I previously stated the best programs appear to be those that incorporate a variety of objectively verified practices and that are designed to address and support the needs of individual students and the professionals and families with whom they are linked (National Research Council, 2001; Olley, 1999; Simpson 2005). Due to its specific criteria for age of participant, amount of hours needed for the intervention, and trained therapists, IBI is not applicable or generalizable in a practical setting but it does apply the principles of ABA. Callahan, Shukla-Mehta, Magee, & Wie (2010) compared ABA and TEACCH and found that both models shared 37 intervention components. The full list of 37 intervention components can be found in Appendix A. In examining the strategies used within the ABA and TEACCH models, there was a variety of recommended activities including general best practices (e.g., creating an individualized program based on the needs of the child) as well as very specific materials, strategies/techniques and curriculum, (Callahan et al. 2010). Below are 11 of the 37 shared intervention components that can be applied in a practical setting such as camp or a recreational program:

- Teachers and service providers who are knowledgeable, experienced, and qualified in autism, including how to correctly apply and evaluate behavioral management, communication, social interaction, independent living, cognitive and academic skill instructional interventions, and related strategies and curricula
- An individualized program developed and implemented to provide meaningful educational benefits (including measurable and adequate gains in the classroom)

- Assessment of all relevant domains (including social competence, communication, environmental influences, physical functioning/motor skills, academic/vocational skills), using a variety of methods, in order to develop individualized goals and objectives
- Relevant, individualized staff training, including ongoing in-service training opportunities
- The measurement, documentation, and reporting to parents of student progress toward annual goals and objectives
- Individualized programming which addresses non-academic content areas (including attending to elements of the environment, imitating others, language comprehension, use of language, playing appropriately with toys, interacting socially with others, recognizing emotions, and self-help skills)
- Direct involvement of parents and family members in their own child's school program
- Development of life skills, and vocational/employment/occupational skills through school-based and community/work-based learning experiences)
- Training parents to be significant providers of services and interventions in order to achieve more extensive generalization and better maintenance of treatment effects
- The use of specialized curricula and strategies to teach communication skills (including script fading, written social phrases, functional communication training, and teaching spontaneous self-initiated responses/verbal imitations)
- Transition programming implemented at all ages and levels, using proactive positive behavioral supports

When combining these items with specific components of TEACCH or ABA, it would result in effective and individualized programming that would increase independence and skill development. Callahan et al. (2010), focused on using ABA and TEACCH within a school based environment as a majority of school boards within the United States and Canada apply several ABA and TEACCH strategies within the classroom. As of May 17, 2007 within Ontario, the Ministry of Education created Policy/Program Memorandum 140 that focuses on incorporating methods of Applied Behaviour Analysis into programs for students with ASD. The Ministry of Education identified ABA as an effective instructional approach as “this memorandum is intended to strengthen collaborative working relationships between parents, schools, and the community. This collaboration is *essential* for supporting positive learning for students with ASD,” (Ministry of Education, 2007). The next section will further explore educational practices that are effective with students with ASD.

Effective Educational Practices

With the prevalence of ASD increasing in North America, there is no shortage of research on the best-practices for educating a child with ASD. To address the unique needs of a student with ASD and the challenges a teacher may face with them in their classroom, the Ontario Ministry of Education created “Effective Educational Practices for Students with Autism Spectrum Disorders,” a resource guide, in 2007. This guide was meant to further support school boards in the education of students with ASD in elementary and secondary schools. This resource refers to the United States National Research Council’s (2001) resource guide, *Educating Children with Autism*, which provides programming recommendations for educators. Both of these resource guides support the similar characteristics of the comprehensive treatment

models as identified in the previous section. Within each section of the Effective Educational Practices guide there are “Tips for Teachers” which are charts that provide quick reference on strategies that have been found to be effective; “Tools & Techniques” from Ontario school boards and regional autism service provider agencies; “Insight” for deepening your understanding of ASD; “Key Facts” for consideration in planning programs for students with ASD; and “Resources” for additional information and further study, (Ministry of Education, 2007 , p. 5).

One area that both education resource guides avoid discussing is inclusion, integration and segregation. The Ministry of Education (2007) resource guide asserts that educators need to ensure that they provide students with opportunities for “real learning experiences, flexibility and options should be built into the planning of teaching strategies, materials, and student activities,” (Ministry of Education, 2007, p. 34). The Ministry of Education (2007) resource guide does discuss the ability of students with ASD and how their learning experience may be affected by limitations in communication and social skills. The resource guides discuss that one-to-one, individual instruction when initially learning a skill is beneficial and once the skill is mastered then it can be generalized to a group setting. In order to facilitate learning and create a positive educational environment, it would be beneficial for teachers to have an understanding of autism and the characteristics of children with autism (Mesibov & Shea, 1996; NRC, 2001; Ministry of Education, 2007). Due to deficits in communication, children with ASD have trouble understanding what to do and when to do it which then causes anxiety and confusion. As a result, this causes withdrawal and disruptive and self-stimulatory behaviors (APA, 2000; Collier & Reid, 2003; Jones & Block, 2006; Mesibov & Shea, 1996). By creating a structured learning environment that is predictable we would be able to decrease these disruptive behaviours. Students with ASD require a structured learning environment in order to understand what is

expected of them in specific situations, to assist them in anticipating what comes next, and to learn and generalize, (Iovannone et al., 2003; Ministry of Education, 2007; NRC, 2001).

Within Ontario, the Catholic and public boards' approach to special education differs, in that the Catholic board focuses on inclusion where as the public board focuses on integration. The Niagara Catholic District School Board (NCDSB) adopts the "Inclusive Model of Special Education" where they are "committed to the inclusion of students with special education needs within their home schools and in their age-appropriate classes. Inclusion is the students feeling of belonging, in a community of learning that honours equality, student diversity and spiritual respect. As a result of this philosophy, the model of program delivery is rooted in a seamless approach to serving students with special education needs from Early Years to graduation. The Niagara Catholic District School Board is also committed to the philosophy that all students within its jurisdiction are provided with the opportunity to access programs, services and supports that will maximize their potential and receive an education commensurate with their identified needs," (NCDSB, 2013). Table 4 below outlines the seven beliefs of the NCDSB inclusive model of special education, whereas the following table (Table 5) lists the guiding principles of special education which are followed in the DSNB:

Table 4

7 Beliefs of the Inclusive Model of Special Education (NCDSB, 2013)

Belief 1:	All students can succeed
Belief 2:	Universal design and differentiated instruction are effective and interconnected means of meeting the learning or productivity needs of any group of students.
Belief 3:	Successful instructional practices are founded on evidence-based research, tempered by experience

- Belief 4:** Classroom teachers are key educators for student’s literacy and numeracy development
- Belief 5:** Every child has his or her own unique patterns of learning.
- Belief 6:** The classroom teacher needs the support of the larger community to create a learning environment that supports students with special education needs.
- Belief 7:** Fairness is not sameness

Table 5

Guiding Principles of Special Education (DSBN, 2013)

1. All students can learn and should experience learning success.
2. All students with special learning needs will receive special education services to help meet those needs.
3. Parents/guardians are an important part of a student’s success.
4. Students have a right to learn in the classroom setting that best meets their needs.
5. School communities recognize the value and contribution of every student.
6. Efforts to build or adapt educational services to accommodate students with disabilities in a way that promotes their inclusion and full participation are considered first. (*Ontario Human Rights Council*)

The report also discusses the framework for the provision of special education services, which is described as “as a collaborative process that encompasses the supports, services and strategies that provide the opportunities for each student to reach his/her potential,” (DSBN, 2013, p.1).

The chart below outlines premises of the DSBN’s general philosophy and service delivery model of special education:

Table 6

Premises of the DSBN General Philosophy and Services Delivery Model of Special Education

Parents/guardians are an important part of a student's success and are therefore invited and encouraged to be involved in their child's education through ongoing communication between the family and school personnel.

An In-School Team is expected to facilitate the collaborative problem solving, decision making and planning for students who are experiencing difficulty in their learning environment.

An Individual Education Plan (IEP) is established for every student identified as "Exceptional" and any other student requiring an IEP as determined by the In-School Team.

All students identified by an Identification, Placement and Review Committee (IPRC) as Exceptional, as defined by the Ministry of Education, are served in the most enabling environment available.

A range of placements is available across the District School Board of Niagara.

Age appropriate opportunities for integration are planned, consistent with the learning needs of the student as part of the Individual Education Plan for each student.

Within the world of special education there is a divide in the research regarding integration, inclusion and segregation. This divide is magnified when focusing on educating a child with ASD due to their unique needs and characteristics of the disorder. Students with ASD are heterogeneous in their presentation of behaviors and in their unique preferences, interests, and learning styles requiring individualized instructional support needs (Dunlap & Robbins, 1991; Iovannone et al., 2003); Ministry of Education, 2007; NRC, 2001. According to Closing the Gaps (2009), a document focusing on supporting students with special education needs and the Ministry of education's commitment to meeting the needs of a wide range of learners and closing the achievement gap for all students in Ontario, students who have special education needs are placed in regular classrooms where they receive programs and services and this is considered integration/inclusion. As of 2009, "approximately 79% of all students (82% secondary) receiving special education are placed in regular classrooms for more than half of the

instructional day,” (Closing the Gaps, 2009, pp.17). There are several differences between the special education policies and practices of both the Catholic and public school boards, however the common focus is that each child learns differently and this must be considered when providing an individualized program to meet the child’s needs. Including or integrating a child with ASD into a physical activity environment such as physical education poses several challenges for teachers due to the variety of deficits associated with ASD.

Providing Physical Activity to Individuals with ASD

Participating in physical activity can be a challenge for children with ASD due to social, behavioural, and motor deficits associated with the disorder (Pan, 2008; Pan & Frey, 2006; Reid & Collier, 2002; Sherrill, 1998). Children with ASD experience delays or deficits in motor skill acquisition, low motivation (Reid, O’Connor & Lloyd, 2003), lack of self-monitoring skills (Hughes, Russel & Robbins, 1994) and an inability to generalize learned behaviours across varied environments (Todd & Reid, 2006) resulting in physical activity being an undesired activity. Difficulties communicating with others, understanding social cues, engaging in stereotypic movements (Levinson & Reid, 1993, Prupas & Reid, 2001) and challenging behaviours inhibit the child’s ability to interact and perform appropriately within the environment (Baranek, 2002, Connolly 2008, Reid et al., 1991, Sherrill, 1998). Participation in physical activity has been shown to decrease stereotypic, self-stimulatory and challenging behaviours while concurrently increasing on-task behaviour and appropriate responding (Baranek, 2002; Connolly 2008; Levinson & Reid, 1993; Reid & Collier, 2002). Physical activity is essential for the overall well-being of a child with ASD, considering the physical, social and behavioural benefits of participation. According to Pan and Frey (2006), children with ASD often have few opportunities for extra-curricular physical activity involvement

because of the competitive and segregated nature of community-based recreation programs. Children with ASD are often unable to participate in adapted physical activity programs such as the Special Olympics as they cannot be categorized due to the characteristic continuum of ASD. The unique behaviours of these children tend to challenge those involved in creating and implementing physical activity programs, (Horvart et al. 2011).

In their review of eighteen studies that involved physical exercise and individuals with ASD, Lang, Koegel Kern, Ashbaugh, Regester, Ence, Smith & Smith (2010) evaluated (a) participant characteristics, (b) type of exercise, (c) procedures used to increase exercise, (d) outcomes, and (e) research methodology. A variety of exercise activities (e.g., jogging, weight training, bike riding) were offered to the 64 participants that ranged in age from 3-41 years of age. Following the exercise interventions decreases in stereotypy, aggression, off-task behavior and elopement were reported but fatigue was not likely the cause of decreases in maladaptive behavior because on-task behavior, academic responding, and appropriate motor behavior (e.g., playing catch) increased following physical exercise. Results suggest that programs for individuals with ASD may benefit from including components designed to incorporate regular and specific types of physical activity. One of the main goals of the review was to inform and guide practitioners as they develop school and residential programs for individuals with ASD. According to four studies (Celiberti et al., 1997; Elliot et al., 1994; Kern et al., 1984; Levinson & Reid, 1993) vigorous exercise has a more pronounced effect than milder less strenuous exercise. Prupas & Reid (2001) found that in some cases multiple exercise sessions per day may be preferred than one, longer session (between 4-90 minutes) per day. In this review of studies, the authors also highlighted their findings that there was limited information provided regarding the teaching procedures use to teach exercises to individuals with ASD. However, several common

procedures and strategies emerged from the studies. According to Lang, Koegel Kern, Ashbaugh, Regester, Ence, Smith & Smith (2010), embedding exercise into age appropriate activities and games may increase motivation to engage in exercise. If exercise becomes a preferable or reinforcing activity, then procedures used to increase exercise may be simplified requiring less prompting and programmed reinforcement (Best & Jones, 1974; Prupas & Reid, 2001). In most studies, prompting hierarchies were used with physical prompts that are gradually faded being the most common approach. The researchers identified that there were several gaps in the current research but focused on the procedures used to teach or maintain exercise, the effects of exercise across the whole spectrum as none of the studies had participants with Asperger's and research aimed at determining the mechanism by which exercise positively influences behaviors is needed. The authors felt that understanding this mechanism would likely lead to improvements in the use of exercise to treat various behaviors (e.g., stereotypy) and could further assist practitioners in the development of more efficient and effective programs for individuals with ASD.

It is apparent from the literature that various treatment approaches are utilized within a clinical and educational setting to intervene in the social and behavioural deficits of individuals with ASD. Very few studies have been conducted to explore the application of physical activity within a community-based setting for individuals with ASD. Currently, individuals living in Ontario with mental health and other disabilities are entitled to certain rights, protections and accommodations under the Ontario Human Rights Code (1990) and the Accessibility for Ontarians with Disabilities Act (2005). According to the Ontario Human Rights Code (1990), individuals with mental health and other disabilities are entitled to equal rights, opportunities and freedom from discrimination. Employers, landlords, service providers and others are legally

obligated to provide accommodation for people with disabilities to the point of alleviating or avoiding “undue hardship” in relation to costs, health or safety issues. By 2025, the Accessibility for Ontarians with Disabilities Act’s (AODA) goal is to make Ontario accessible and barrier free for people with disabilities. Barriers can include physical, organizational, technological, communications and/or attitudinal barriers (AODA, 2005). Standards to address these barriers are being developed for information, communication, customer service, employment, transportation and the built environment. These two laws are enabling individuals with ASD to access recreational programs and services, though organizations providing these programs and services need to build their capacity to break down the above mentioned barriers that are preventing severe individuals within the community from accessing these recreation programs and services.

Chapter III- METHODOLOGY

Research Orientation

Community-based organizations provide an excellent opportunity to explore a variety of topics and perspectives to that could better demonstrate how these organizations are meeting the needs of children with ASD, and where to focus future research. Research within community-based organizations and their programs is limited to a more quantitatively oriented perspective where the focus is on community-based IBI or ABA programs. Expanding the research to include community-based organizations such as camp and recreational programs based upon the support staff, and supervisor and parent viewpoint, can provide a fresh outlook on the quality of services provided and will expand the literature regarding the application of best-practices such as TEACCH strategies and physical activity within community-based organizations and programs.

Through qualitative methods, there is a wealth of in-depth and detailed information that allows for a more holistic perspective on the complex phenomenon being investigated as it was an intricate system that is more than the sum of its parts and has complex interdependencies and system dynamics (Patton, 2002). Currently, within the Niagara Region there is a growing number of children with ASD, many of these are “severe” cases. These children are members of the community and they should have the opportunity to participate in community-based organizations that provide programs that will meet all of their unique needs. Seeking input from staff, supervisors and parents can inform service agencies of the type of programs the “severe” cases require, and provide an opportunity to develop training and recommendations to the community-based organizations that could shape more meaningful, relevant, and dignified programming and program support.

Design

The design of this research project is a comparative, descriptive case study. I will conduct an in depth exploration of three separate cases with comparisons built into the description and analysis. A case study is "an examination of a specific phenomenon such as a program, an event, a person, a process, an institution, or a social group," (Willis, 2007, p. 238). I am specifically focusing on exploring an issue through one or more cases within a bound system. Creswell (2007) discusses that researchers will explore a specific 'bound case' within a designated period of time, and will use several different sources of information (i.e., observations, interviews, and document analysis) to develop a description of a case (an individual, group of individuals, activity, event or program) which illustrates their research problem. The most appropriate methodological choice for this research was a case study design as it provides several advantages which are useful to critical research (Willis, 2007):

1. It allows the researcher to gather rich, descriptive data in an authentic setting;
2. It is holistic and thus supports the idea that much of what we can know about human behaviour is best understood as lived experience in the social context;
3. Unlike experimental research, it can be done without predetermined hypotheses and goals.

My project is an example of an occurrence of a particular research problem within a group, setting, culture or other context which would be considered a representative example of case study (Willis, 2007). To better understand and gain insight into the lived experience of the participants I conducted interviews with each of the participants. Through the development of

open-ended interview questions I was able to receive rich descriptions and insight within this setting and was able to organize patterns and important themes that I discovered from the multi-layered data analysis. I have had several experiences within this specific environment where organizations were struggling to provide programs for children with complex and unique needs, hence, I cannot avoid bringing my own experiential history to this research project. Fortunately qualitative designs encourage this acknowledgement.

Participant Recruitment

I recruited a sample of three supervisors and three support staff from three different community-based organizations for the current study. I recruited all participants by word-of-mouth and personal contact through the management of the community-based organizations. Potential participants contacted me by phone and e-mail to express their interest and for me to explain the details of the study and confirm the participant's interest and availability. As a researcher, I was acquainted with all of my participants as I had previously been an employee at each of the organizations and have worked within each of the community-based organizations. The nature of these relationships was strictly professional and contact between myself and the participants was re-established specifically for the purpose of recruiting these participants.

Sample

I employed purposeful sampling to select the participants for the study; three supervisors and three senior staff, one of each from the organization. I selected a supervisor and senior staff from each organization as they were in a position to discuss the training process, program development and implementation, and the resources and strategies used within their community-based organization focusing on the programs they provide to individuals with ASD.

Each organization is considered a “Case” and within each case there is a data set of a senior staff interview and supervisor interview. It may be worth noting that that all participants but Senior Staff A and Supervisor C, were female, and these two male participants did have different views of “severe” cases that will be further discussed in Chapter five.

Data Collection

Each of the participants and I set an agreed upon date and environment where the participant would feel most comfortable to complete the interview. Participants received the letter of invitation (see Appendix B) and signed the consent form (see Appendix C) and were advised to feel free to ask any questions they might have. I reminded the participants that if they were uncomfortable with any part of the study they could leave then, or at any point during the study, with no repercussions. I retained a copy of the informed consent for my records and the other was provided to the participant. None of the participants had any questions during the informed consent process. Before beginning the interview, I answered any questions the participant had. I also reminded the participant that they may refuse to participate at any time without any form of penalty and should a participant decide to withdraw from the study, all data to that point would be destroyed and the participant’s data would not be included in the analysis. I gave participants a chance to ask any additional questions and then reminded them that the tape recorder would be turned on (as long as they were comfortable with this). I reiterated that no one other than the researcher and supervisor would have access to the recordings. Once the recording devices were activated, I proceeded to ask the questions outlined in the Interview Script of either the supervisor or support staff, occasionally probing for more information, repeating questions, or rewording the question for the participants to understand. Each participant engaged in a 30-60 minute interview. The purpose of the interview with the supervisors from community-based

organizations was to facilitate a more in depth analysis of the participants' experiences with "severe" cases, how their program includes these children and their decisions into the program provisions. The purpose of the interview with the senior staff was to facilitate an in-depth analysis of the participants' experience of having to work with "severe" case children enrolled in community-based programs and the training they received. A copy of the senior staff and supervisor interview questions can be found in Appendices D and E respectively.

Research Question Development

To examine community-based organizations and their ability to serve "severe" cases from a qualitative perspective, I developed a variety of research questions designed to describe the training process, program development and implementation, and the resources and strategies used. The questions were developed according to Patton's (2002) six basic types of questions: experiences and behaviour questions, opinion and value questions, feeling questions, knowledge questions, sensory questions, and background/demographic questions. Time frame questions (past, present and future) were also asked to help develop a more in depth description and understanding of the community-based organizations. In order to deepen the response to a question, and therefore increase the richness of the data, I prepared probes and follow-up questions in advance and used them as necessary. I used open-ended questions for all the participants in an attempt to gain a better understanding of "severe" cases within community-based organizations and future directions and recommendations for providing more meaningful, relevant and dignified programming for "severe" cases.

Transcribing

Following each interview, I transcribed each session verbatim into Microsoft Word® documents using Sony Digital Voice 3® software.

Ethical Considerations

Ethical approval for conducting this research has been secured from Brock University Research Ethics Board (File # 10-152); see Appendix F for Certificate of Ethics Clearance.

All of the participants are active members within their professional communities, and among their colleagues and families with children with ASD. It was important to offer them the option of anonymity and confidentiality with regards to their participation in this study. To remain consistent and preserve the privacy and integrity of all participants, I assigned each supervisor and senior staff a letter: A, B, or C, based on their organization and referred to each as such consistently throughout all remaining activities in this study, including reporting and discussing the findings in this paper.

Data Storage

There was one master copy of research data that included all participants' names, initials, gender, and organization. Personal identifiers were collected during the course of the research to allow for people to withdraw. I did not use any information from the data that would allow children, parents, or participants to be identified in the findings. I transferred all written data to a memory stick which will be wiped upon completion of the project. I retained this master copy in a separate folder, in a locked cabinet in a controlled access room. All data gathered was kept completely confidential. I replaced names of the participants with letters corresponding to the organization they worked for (e.g. Organization A, Supervisor A, Support Staff A) so I could compare within and between cases during my analysis. I maintained participant confidentiality and released only coded data. Only researchers working on this project had access to this data.

Participants will not be identified in any way should findings be published. Participants were given the opportunity to receive their transcripts following the completion of the study.

Data Analysis

In an attempt to understand how community-based organizations provide programs for “severe” cases and how it may be improved, I reviewed the data from all levels of investigation multiple times. I analyzed data in three levels according to Patton (2002), with level one being a within-case content analysis. I used a read-and-jot technique with open coding method to code by categories people, places, objects and happenings, as well as identify key words and revelatory phrases within each case. Level two was a cross-case analysis by topic cluster, using constant comparative methods. Level three of the analysis focused on the sensitizing concepts from the literature to draw further comparisons and identify patterns. For an abbreviated overview of the layered analysis process refer to Appendix Q.

I consolidated using the findings from Level one and two of the analysis to connect the emerging thematic patterns to the proposed research questions. To increase the construct validity of the study results, I utilized methods such as interviewing, reflective journaling and ongoing re-reading emerging ideas and interpretations. As a reflective, retrospective journal keeper, I had a unique history by being an employee at each of these community-based organizations and working within the specific programs. I used my own field notes in a flashback strategy to supplement the interview transcripts (Patton, 2002).

Level 1: Within-case Analysis

To organize and manage the data sets, I printed each original transcript (see Appendix G). This enabled me to examine the data of each individual case. Recursive engagement with the transcripts enabled me to highlight and identify: a) important and/or repeated incidents of people,

places, objects and happenings (see Appendices H & I) and b) key words/revelatory phrases. I charted summaries of revelatory phrases for both supervisors and senior staff (see Appendices J & K respectively). Key words for “extreme” cases for both supervisors and senior staff are summarized in Appendices L and M respectively. Throughout the entire level one process I maintained a constant comparison by reading and recording written notes. I repeated this process within all 6 interview transcripts.

Level 2: Cross case Analysis

The interview script for the supervisors contained 49 questions and the interview script for the senior staff contained 48 questions. As a reflexive exercise, I learned quickly that this is a difficult number of questions to manage in a question-by-question analysis and would take into consideration the intended analytical process and study design when creating interview templates in future studies. I clustered the questions under the following topics:

- Describing an “Severe” Case: Questions 1, 2, 3
- Organization: Questions 4, 5, 6, 7
- Interviewees Role
 - Senior Staff: Questions 9, 10, 11, 13
 - Supervisor: Questions 9, 10, 11, 12, 13, 14
- Expectations and Relationships
 - Staff: Questions 12, 14
 - Supervisor: Question 41
- Meeting the Needs of the Child: Questions 15,16,17
- Programming: Questions 15,16,17,18
- Challenges/Barriers: Questions 19, 25

- Physical activity: Questions 20, 21, 22, 23, 24
- Integration: Questions 18, 25
- Accommodations and Strategies: Questions 26, 27, 28, 29
 - Throughout entire interview
- Behaviour Management: Questions 30, 31, 32, 33
- TEACCH: Questions 34, 35, 36, 37, 38, 39, 40
- Training
 - Senior Staff: Questions 41, 42, 43, 44, 45, 46
 - Supervisors: Questions 42, 43, 44, 45, 46, 47
- Additional Questions
 - Senior Staff: Questions 47, 48
 - Supervisors: Questions 48, 49

There were a total of 14 question topic clusters that I managed in two separate charts: one containing the supervisor's clustered questions and the other containing the senior staff's clustered questions (see Appendix N for Supervisor Chart and Appendix O for Senior Staff chart). I re-read the interviews of the supervisors and then senior staff using the above question topic clusters which I then used across the three supervisor interviews and then the three senior staff interviews again using constant comparison notes, while seeking patterns. I distilled patterns from a further comparison of supervisors and senior staff.

Level 3: Sensitizing Concepts

Level 3 is a deductively oriented level of analysis whereas levels one and two were more inductively orientated. The focus of the third level of analysis used salient sensitizing research concepts from the literature to interrogate, clarify and confirm or disconfirm the patterns that

were found in Level one and two. Sensitizing concepts can "... provide some initial direction to a study as a fieldworker inquires how the concept is given meaning in a particular place or set of circumstances being studied" (Patton, 2002 p. 278).

The sensitizing concepts from the analysis were: TEACCH, "Severe" Cases, and Approach to Behaviour Management and Programming. These concepts from the literature also arose from patterns found in Level one and two. I used the sensitizing concepts in Chapter five for recommendations and future research directions. For an abbreviated overview of the layers of analysis please refer to Appendix Q.

Confirming Comparative Analysis

Within my ethics approval I did receive permission to interview parents and with their permission view their child's file from each organization. Prior to beginning this study I did not consider parents to be a part of the organizations. It was not until I finished the first two levels of analysis when I saw the thematic patterns and felt that the parent's perception would provide an opportunity to further triangulate my findings. I also had come to the realization that parents are a vital and integral part of all of these organizations.

Following my three levels of analysis, I created questionnaires that contained 22 questions derived from the patterns and themes from levels one and two of my analysis. I administered these questions through an anonymous online survey approach which allowed parents of designated "severe" case children who had previously accessed the services of organizations A, B, and C to provide feedback without being identified.

I used the parent responses to confirm or disconfirm the patterns and themes from levels one and two of analysis and the deductive analysis from the sensitizing concepts as well as this created triangulation and provided an additional way to internally validate my results.

Chapter IV- FINDINGS

Levels of Data Analysis

This chapter was organized according to the three-level process that I used to analyze the data. I reviewed the data from all levels of investigation multiple times. I analyzed data in three levels according to Patton (2002), with level one being a within-case content analysis. I used a read-and-jot technique with open coding method to code by categories people, places, objects and happenings, as well as identify key words and revelatory phrases within each case. Level two was a cross-case analysis by topic cluster, using constant comparative methods. Level three of the analysis focused on the sensitizing concepts from the literature to draw further comparisons and identify patterns. For an abbreviated overview of the layered analysis process refer to Appendix Q.

I consolidated using the findings from Level one and two of the analysis to connect the emerging thematic patterns to the proposed research questions. To increase the construct validity of the study results, I utilized methods such as interviewing, reflective journaling and ongoing re-reading emerging ideas and interpretations. As a reflective, retrospective journal keeper, I had a unique history by being an employee at each of these community-based organizations and working within the specific programs. I used my own field notes in a flashback strategy to supplement the interview transcripts (Patton, 2002).

Upon completing my analysis, I created questionnaires that contained 22 questions derived from of my patterns and themes from levels one and two to confirm or disconfirm the patterns and themes from levels one and two of analysis, as well as this created triangulation and provided an additional way to internally validate my results. Six mothers with children who are

considered to be “severe” cases were asked to participate in an anonymous survey. The survey contained 22 questions and was completed online. Findings were determined using inductive and deductive methods guided by the research questions:

1. What are the thresholds for physical activity within a community-based organization that provides programs for children with ASD?
2. How do programs committed to participants with ASD identify the physical and communication needs of “extreme” cases?
3. How are communication and physical needs addressed within community-based organization that provides programs for children with ASD (through training, programming and program’s structure)?
4. What issues/barriers are associated with using TEACCH strategies to provide physical activity opportunities within these programs?
5. What is needed for these programs to provide physical activity to “extreme” cases?

Level 1: Within-case Analysis

The first level of analysis is a within-case analysis where I read each interview and focused on important and/or repeated incidents of people, places, objects and happenings as well as key words and revelatory phrases. While reading the interviews I maintained a constant comparison of read and jot notes.

People, Places, Objects and Happenings (PPOH)

People

Within all of the supervisor's interviews, five main types of people emerged: 1) parents, 2) children with various needs, 3) a continuum of staff, 4) associated professionals from their community and 5) typical, able-bodied, same-aged peers.

In all of the supervisor interviews parents were a topic of discussion in the following areas:

- Staff preparedness and program planning for their camper directly linked to the amount of information the parent provided in the profile
- The willingness of the parent to provide honest, detailed information about their child directly connects with the supervisor's and senior staff's ability to provide a child centred approach as opposed to the staff trying out different activities or strategies to see which ones will be successful
- Quality of information over quantity
- Supervisor's relationship with parent also connected to organization's ability to meet child's needs and provide child with a positive, successful camp experience

Senior staff discussed parents and their role in completing the profile but did not emphasize the importance of having a relationship with parents.

Two out of the three supervisors referred to the level of functioning of a child who would be a "extreme" case. All of the supervisors provided examples of children they considered to be "extreme" and how their staff adapted and modified activities to have the child attend camp. The supervisors consistently referred to the definition of an "extreme" case that was provided and they were able to pull out components of the definition that were present in children they have in their camps. Two out of three senior staff felt that "extreme" case children could be both low and high functioning on the Autism Spectrum.

The continuum of staff was consistently referred to throughout the interview. All three of the supervisors discussed that they have a hierarchy of more experienced staff, who are in a leadership or mentorship type role due to their level of experience and confidence in working with children with various needs. The lack of skills and experience from new and/or less experienced staff or volunteers was a main focus in the interviews as they impacted the type of children the supervisors could accept as well as the level of programming they could provide. Senior staff focused on the inexperienced staff and also the hierarchy of supervisors, senior staff, and support staff.

Professionals from other community agencies and organizations were brought in by the supervisors as a component of their trainings. The supervisors indicated that all of the staff were unable to transfer the knowledge they learned from the professional and apply it in a practical setting (when working with a child). It does not appear that community agencies work together to ensure that training or the topics of training are consistent across the region. All mentioned that they would like to work with other professionals and benefit from their knowledge but it only occurs if the supervisor requests another professional come into present.

Senior staff discussed that they appreciated when professionals from other agencies would come in to present but only if it was a topic they were not familiar with. They also discussed how they wished there could be more professionals coming in to present or consult with difficult behaviours during camp.

There was a notable omission of the discussion about typical, able-bodied, same aged peers as a variable. They were occasionally referred to as “other campers” but there was no discussion about them. Two organizations did mention that it would be a goal for some of their

campers to be able to have social interactions with peers but they did not discuss typical, able-bodied same aged peers. Senior staff completely disregarded typical, able-bodied, same aged peers.

Places

The main focus of places within the interviews were sites/locations where camp activities took place, communities (i.e. location of programs) and means of transportation (i.e. bus ride).

All three supervisors discussed the gym as a space that was a highly used space during a camp day. Two out of three supervisors discussed the pool as a place that their campers enjoyed and that they would ensure their campers had regular access (daily) to the pool. All of the camps had different sites/locations for specific activities at camp which seemed to serve as a way for the supervisors to control the activities the staff were doing, and the children needed different spaces for specific activities. To me this suggests a form of behaviour management/programming as Senior Staff A indicated "...if you can control the environment you can control the behaviour of the child." This idea will be discussed further in the chapter as well as in Chapter five as there is a connection to other patterns and sensitizing concepts.

All of the supervisors mentioned the specific communities where their camps took place throughout the Niagara region.

Two out of three of the supervisors discussed the means of transportation and gave me the impression that the success of bus rides was dependent upon a) the time of day (going to an activity or coming home), and b) how well the staff prepared the child for the transition.

Senior staff mainly focused on the specific activities that took place during the camp day. They did not focus on the community as a whole but were more site/location specific versus big picture. All staff discussed the gym, pool and bus.

Objects/Strategies

I chose to include strategies as a part of objects as these strategies are the main tools used in developing programs for the children and ensuring a successful camp experience. Within all of the supervisors' interviews five main objects/strategies were discussed: 1) profiles and the registration process, 2) physical activity, 3) preventing and minimizing behaviours, 4) effective supports and strategies, and 5) staff training.

As previously discussed in the "people" section, parents play a vital role in the staff's ability to prepare an appropriate individualized program for the child based on how much information the parent provides in the profile. The profile appeared to be a significant component in the registration process but all supervisors discussed how their relationships with parents were equally as important in ensuring their staff was equipped with as much knowledge as possible prior to camp. Supervisor A had a second profile that was completed by her staff after they had worked with the child at camp. It is a nice tool that can be compared to the parents profile and used as an ongoing record to see how the profile changes overtime.

Senior staff discussed that the profile could be beneficial if the parents filled them out with enough detail. It did seem that the senior staff would have liked more time to program plan and train but seemed to disregard the profile as soon as they were in a practical setting.

Physical activity was viewed as an important activity at each camp. While they all recognized the benefits of physical activity they all had different viewpoints of what they considered to be physical activity.

All three organizations used low ratio support (1:1 support) and visual supports when working with an extreme case child. All of the strategies/tools or accommodations they used are in Appendices H and I within the “Accommodations & Strategies” section. They did all discuss how they provide their staff with these tools but whether or not the staff uses them correctly is a whole different matter. Senior staff tended to focus on individual locations of the activities and the visual support whereas supervisors focused on the whole of the camp and ensuring everyone was equipped with the strategies and supports they required.

Happenings

Supervisor A’s two major happenings were “Meltdown Mondays” and the student volunteers’ lack of experience. “Meltdown Mondays” is a happening that Supervisor A wishes could occur at training as “Meltdown Mondays” bring her students into reality and show them what skills/strategies they need and how prepared they need to be.

“Meltdown Mondays” and the students’ lack of experience can both be connected to the embedded curriculum, station based pedagogy and simple strategies. All of these complex concepts are presented as simple ideas and in an approachable manner. The student volunteers essentially take for granted the embedded curriculum, station based pedagogy and strategies and diminish them; “...they seem to think that they’ll just be able to do it so they minimize the difficulty of how simple... it’s simple but it’s not easy”. As a result of this way of thinking, they do not plan and this, combined with a lack of experience causes “Meltdown Mondays”.

“The inconsistency is the biggy, and untrained undergraduate students who really don’t understand Autism and don’t understand the significance of particular kinds of strategies and how it would really help them as the teacher as well as the child. And those insights begin to happen mid-way through camp but I would really like them in place on the first day of camp.”

Supervisor B happenings were ensuring that programs were individually driven and that debrief sessions occur after camp and programs.

“Our programs are individually driven so it depends on the criteria of the program. There are some that require children to have some certain abilities and if they are unable to meet those because our inability to provide the right amount of care for them then they would be excluded for those situations. But most are quite open, its only if for some reason we’re not able to meet that need that we would have to look at alternatives, but we get really creative at adding an additional support, having the parents bring additional support, we get tons of additional information beforehand to find out what are the areas that might be of issue”.

Supervisor B highlighted that fact that after each session the staff meet and have a discussion and debrief about the session. This provides them with an opportunity to break down a situation if needed and adjust for next session. She connects this back to parents not providing all the information even though they ask for it.

Supervisor C happenings were creating a program to suit the child’s needs, and the impact of funding cuts on providing camps/programs. A common happening for Supervisor C would be selecting an appropriate program to meet the needs of the child even if it was not the

child or parent's preference. This supervisor was focused on ensuring the child had a positive camp experience and the child was set-up to be successful. He provided examples of where they would modify and adapt a child's schedule to suit their needs. He provided an excellent example of allowing a child to swim twice a day so she was engaged, active and enjoying herself. Another happening that Supervisor C discussed was the gradual yearly decrease of funding provided by the region and the impact that has had on programs and camps. "Every year when I started we were able to offer 6 weeks of camp to a family at no additional cost, like they would just pay regular camp price and then it was 4 weeks and then our current program". Currently in their programs they are unable to offer any kind of direct support to children with special needs as they do not have the funding to hire support workers for programs.

Senior staff A discussed the bus ride home and "...at the end of the day the bus ride home from wherever we are, on the bus ride back to the school it is 10 times quieter and relaxed than it is going to be out there because it's the end of the day and they have just been worked to the bone all day...". He linked this result to the fact that the children are attending a camp that's main focus is physical activity. Similar to his supervisor, Senior staff A discussed "Meltdown Mondays" and felt that these could be avoided by "...revamping training to make it more effective so volunteers are more prepared to work with the kids and we don't have a lot of time we lost that first day at camp cause it's so chaotic and people are panicking so we are trying to revamp training to better prepare people so we cannot have as many problems".

Senior staff B felt that her supervisor wanted to fill spots in camp but isn't there to help staff when the child is an "severe" case. "...earlier provision of information would've been nice... if you're having a really severe child, I think that maybe before camp to have a talk with the parents and like I mean throwing a kid in that's never been to camp and is extremely low you're

just asking for trouble. Which we had but she wasn't there to help right so?" Senior staff B also discussed how profiles need to be filled out more in-depth by parents "...there just needs to be more information like the profiles that we're given are definitely in depth but at the same time they're not necessarily filled out in depth". This combined with staff's inexperience and lack of preparation impacts how the camp is able to meet the needs of the child. She discussed how staff "...needed more time to go over profiles, more time to prep for camp, call families, talk to other staff who know the kids." She felt that the level of experience the staff had directly impacts how the staff can meet the needs of the campers. She felt strongly that Organization B should be "...hiring staff who are experienced and qualified... [as there are] ...huge gaps in the knowledge that the staff team has." Senior staff C had the same happening as her supervisor as this past summer the Region of Niagara cut their funding by 40%, which decreased the number of spots they could have available for children with special needs as staffing was cut by 50% as a result of the funding cuts. In previous years she has been able to offer additional weeks (campers are able to receive 4 weeks of camp); however this summer she was unable to offer these additional weeks which put a strain on single parents trying to find care for their child. She also provided an excellent example of how she was able to keep an extreme case child from being kicked out of their weekend program. This required her to be his 1:1 support as well as supervising the other staff and children but she "just made it work."

Revelatory Phrases and Keywords

Revelatory phrases and keywords were pulled from the interview transcripts throughout my analysis. Some revelatory phrases were recorded in my initial read-and-jot where as others became more impactful as I worked through the different levels of my analysis. Revelatory phrases are organized by Supervisors (Appendix J) and Senior Staff (Appendix K). Bold quotes

are ones that stood out to me as revelatory and I kept the dialogue between myself and the participant in the chart to provide a context for the revelatory phrase. Keywords were pulled from my PPOH analysis and out into chart form for Supervisors (Appendix L) and Senior Staff (Appendix M) and were repeated several times to be considered a keyword. These keywords and revelatory phrases revealed more than the informant may realize. This will be expanded upon further in Chapter five.

Revelatory Phrases regarding Extreme Case Campers

Supervisor A related a quote from Martha Graham, who is one of the foremost movement educators and dancers of the 20th century to her student's lack of ability to observe and see what the child's body is presenting them. "Movement never lies. It is a barometer. Telling the state of the soul's weather for all who can see it". Supervisor A wants her students to be aware of other ways the child is communicating with their body and for her students to pick up on the tension, distress, postural or gestural cues their bodies are showing. She does not want her students assuming that because a child cannot speak they cannot communicate; she wants her students to observe and see. But this skill cannot be taught, it is learned, so that if you can see you can see it, you can tell what's going on with that child.

She puts into perspective the skills that are not commonly considered or valued when working with children with high needs but they are vital skills to have success when working with this population.

"Staff must learn to be better lookers, seers, watchers. They have to practice attentiveness in ways they are not used to...they have to develop that skill with the non-verbal kids.

They need to develop a comfort with mess, drool, spit, vomit, snot, shit, pee, mushy food.

Most of them aren't prepared for the intimacy of this facilitation. Feeding, cleaning, dressing, undressing, bathing, toileting. They're very squeamish about touching other peoples' bodies...they need to understand that Autism manifests in an embodied way, the disabilities that they're working with manifest themselves in embodied ways and they can't make it into a cognitive exercise or a verbal exercise, it is an embodied exercise.

Until they actually encounter the child... so those are skills that they need over and above their ability to be attentive and engaged and interested in the child for 8 hours. On for 8 hours. ON for 8 hours, ON! Not texting, not thinking about their friends not worrying about their friends not thinking about anything but these kids. FOR 8 HOURS... that kind of attentiveness and disciplined focus is what this calls for... So at the end of the day they should be freaking exhausted and most of them are...not to mention the planning".

Supervisor A said what everyone was thinking but did not want to say. She was very honest about the skills and level of comfort it requires to work with these children. She also was the only participant to openly discuss how you really cannot integrate these children

"But I think it's a myth you can integrate a severe case, I think they can be in the same room with able-bodied peers umm but I think the idea that they're going to on their own function safely, and with dignity, with a group of same aged peers without some sort of additional facilitation I think that's absurd. It's an absurd expectation. I think, unrealistic in terms of how these kids are in the world, can I help the other kids appreciate what it's like for this kid to be in the world this way, perhaps, but they didn't come to camp to learn about autism".

When asked the question “What should I have asked you that I didn’t think to ask?”

Supervisor B focused on the information provided in the profiles and the issue that it may impact the staff’s view and ability to effectively meet the needs of the child and create assumptions and fear about working with these children.

“One thing I am surprised that you didn’t ask about actually is if we get all this information about kids beforehand does that set like a judgement or you know what I mean? *Do we make predetermined beliefs about a child before they even walk in the door and therefore potentially hinder their involvement or change it in a way more than what we even needed to do based on what they say on paper*”.

“I find that that happens sometimes, *that parents state the worst*, which rightfully so, we’ve got some kids who have some significant needs and really have caused a lot of difficulty for families but when you put it down on paper it sometimes comes across in a very negative way. *I think that this kind of really interferes with sometimes how we set up our programs, and I really wish there was a way to get around that*. I don’t know what the best way to do that, sometimes it might just be the wording of our questions; we’re always trying to adjust to change. *It would be nice if there was always a way to meet the kids beforehand*”.

Supervisor C comes from the largest non-profit organization of all the participants. He openly discussed that serving children with high needs is not at the fore front of the organization’s focus of their programs. “*They’re trying to serve the most amount of people possible so they’re really not focusing on the most extreme cases cause it’s the minority of*

people that come to the program so they will do their best to try to accommodate but they can't and they won't. They won't stretch beyond their means". This was one of the reasons why Supervisor C left the organization: "...we could have done so much more but didn't...I wanted to see that kind of stuff (children with special needs participating in programs) but I know that it wasn't going to happen, not now anyways. *The focus just wasn't there; the people on top didn't have that interest or focus*".

None of the senior staff participants had any revelatory phrases that seemed salient enough to be impactful in summarizing some key findings. Their revelatory phrases focused on their individual experiences, specific programming, activities and other staff's abilities. Senior staff A feels that his supervisor has expectations that are "a bit more than your ordinary senior staff" as he has more experience, is male, and the history of their relationship.

"So her expectations of me are a little bit higher it might be cause I'm not going to say that I'm not better at it than everyone else, but I have more experience and I'm a male and as much as I don't like that to be something that sticks over my head it is so she depends on me for certain situations that she can't with a female...just because being a big tall male has more of an impact sometimes than being small, short female"

Senior staff A commented that he doesn't like that being "a male sticks over his head but his supervisor depends on him for certain situations where she can't with a female". He gave me the impression he does not want to be valued by a supervisor solely because he is a male but his responses indicated otherwise " ... I guess my picture of an "severe" case might be a little different than anyone else's being a big, tall male I feel like unmanageable behaviour doesn't really exist for me".

When asked about meeting the needs of the child Senior staff B commented:

“...well basically the parents are telling you what they want. What their expectations are, what their goals are I mean...it’s different in all the programs. Like camp there’s no real set goal because it’s supposed to be more of a social, fun, thing but in the programming for like u know, the social skills and the I guesslife skills...which I don’t really agree with but... basically the parents are telling us what they are wanting us to work on”.

She also felt that meeting the needs of the child “depends on how the staff is.” “...they have intentions of meeting their needs but I think it depends on the level of staff you’re hiring” and again linked staff experience and education in the level of programming as in programs she saw an increase in behaviours because the group was not doing physical activity and the “staff was uneducated and didn’t know why the behaviours were happening”. She went on discuss how once a staff who was experienced and educated in physical activity was put in charge of the group there was a drop in behaviours because there was physical activity and structure in place.

Senior staff C was one of the only participants who openly discussed how she goes against her organization’s behaviour management system to meet the needs of the child

“I believe that redirection is a good thing but I feel like there are times when you need to just remove the child from the situation like they need to be removed and redirection is not going to work and they need time to cool off and you need to remove them from the situation bottom line. And I do kind of go against the redirection policy because I feel like it’s important. *And no one has ever said anything to me so I keep doing what I do*”.

Keywords regarding “Severe” Case campers

The chart below describes how each participant referred to or described an “severe” case camper.

Table 7

Keywords regarding “Severe” Case campers

Supervisor A
<p>“Extreme” cases are “kids that nobody wants” and they typically manifest simultaneity, there’s this plus this plus this....”.</p> <ul style="list-style-type: none"> • Non verbal • Maybe self-injurious • Maybe anger management issues • High anxiety • Compulsive • Tube fed • Doesn’t toilet <p>“...the disability and the sort of cascade of things that often accompany the disability”.</p> <p>“Severe or extreme probably can manifest in many ways like they can be manically severe like fragile or sick or they can be behaviourally severe as in like the Tasmania devil (makes his noise)”.</p> <p>“There is more going on than a single dimension disability. It’s complicated.”</p> <p>Severe case at her camp she gets more internal maladaptive and socially disruptive, finds A and C go together “the internal maladaptive kids are the ones who are hurting themselves and stimming and so forth and destroying property, aren’t being compliant they’re just sort of involved in their own stuff...outcome is non-compliance but that is not their intention”.</p>
Supervisor B
<p>“Extreme” cases can manifest themselves in 2 different ways:</p> <ul style="list-style-type: none"> • “The severity level of their diagnosis in that way they are extremely impaired in all

areas”.

- “The impact that those areas of impairment are happening on their family. With a whole lot of cases that would be crisis or high needs but they don’t necessarily have a severely impaired child”.
- “severely impaired”

Definition of “extreme” case

“How it is not necessarily based on the severity level but how much it’s interfering with functionality. Because you can have someone who’s quite gifted in their verbal abilities but become extremely aggressive and not be able to be in the school environment and take advantage of that”.

“..indicated that it can be based on functioning level without stating that but also with severity level without stating that... encompass more people this way in a more positive way”.

Supervisor C

An “extreme” case is someone who requires a great deal of support.

- Someone who is 1:1 if not more
- More challenging behaviours
- Struggles with transition
- Flight risk
- Limited communication

“...something that requires additional support that’s what I would say is an “extreme” case”.

Senior Staff A

“Extreme” child is unmanageable with extreme difficulties that equal extreme:

- Behaviours
- Sensory issues
- Overly aggressive and a lack of ability to do normal things (daily living skills and social skills) and have a normal life.
- Non-compliance
- Easily distracted
- Difficulty to redirect when they get focused on something
- Inability to do complicated movements
- Non-verbal – so you don't know what they want, what they're trying to tell you
- Very stimulated
- Need to get rid of distractions to get them engaged
- "Just difficult to work with them"

Comments on "extreme" case definition provided:

Felt that you could get specific and technical with the definition but it was a good broad definition that was extreme

Provided specific examples of "severe" cases

Senior Staff B

"Extreme" child is:

- Lower functioning
- Non-verbal
- Fairly aggressive
- At the end of the spectrum.

Focused on low functioning

Felt they had three "extreme" cases at camp based on definition

"...the lower functioning kids, there's always communication problems". .

"...you can tell people about transitional things, all those objects, having schedules and stuff like that but when you're having an extreme case like that, that's not necessarily going to be enough".

"managing it".

Senior Staff C

An “extreme” child displays:

- SIB’s
- Has severe meltdowns at times
- Aggressive tendencies may not be able to function within a group of other children
- Needs support to be integrated.

Mentioned self-injury twice

Discussed a high functioning “severe” case as an example

“Severe” case within Organization C- “Right now our kids aren’t very severe they are pretty high functioning so it’s not that big of a deal but if we were to have those more severe cases there would be, we would need to you know train our staff a little bit more”.

No participant used the term “extreme” case, I feel that it is not the correct term to identify these children as I do not use that term in my professional conduct. All of the supervisors did use the definition that I provided them with but the senior staff did not apply it at all. No person described an “extreme” case the same; there were some similar references based on needs, level of support and behaviours but every participant had a different definition of what they considered to be “extreme” or “severe” This will be further discussed in Chapter five. Both participants from organization C did not seem to have as much experience or exposure to “severe” cases as the other participants. I believe this is because they are the only organization that integrates children with special needs whereas the other two organizations have segregated camps and programs. This also brings attention to the idea that there is in fact a spectrum of “severe.”

It was also interesting to note that none of the participants discussed the strengths or positive skills these children possessed and I believe this links into the stigma and assumptions

and fears that Supervisors A and B referred to as well as this links to how the DSM refers to an individual.

Level 2: Cross case Analysis

Level two of analysis was a cross case analysis by topic cluster using constant comparative methods. The interview script for the Supervisors contained 49 questions and the interview script for the Senior Staff contained 48 questions. Due to the large number of questions I clustered the questions under the following topics:

- Describing an “Severe” Case: Questions 1, 2, 3
- Organization: Questions 4, 5, 6, 7
- Interviewees Role
 - Senior Staff: Questions 9, 10, 11, 13
 - Supervisor: Questions 9, 10, 11, 12, 13, 14
- Expectations and Relationships
 - Staff: Questions 12, 14
 - Supervisor: Question 41
- Meeting the Needs of the Child: Questions 15,16,17
- Programming: Questions 15,16,17,18
- Challenges/Barriers: Questions 19, 25
- Physical activity: Questions 20, 21, 22, 23, 24
- Integration: Questions 18, 25
- Accommodations and Strategies: Questions 26, 27, 28, 29
 - Throughout entire interview

- Behaviour Management: Questions 30, 31, 32, 33
- TEACCH: Questions 34, 35, 36, 37, 38, 39, 40
- Training
 - Senior Staff: Questions 41, 42, 43, 44, 45, 46
 - Supervisors: Questions 42, 43, 44, 45, 46, 47
- Additional Questions
 - Senior Staff: Questions 47, 48
 - Supervisors: Questions 48, 49

There were a total of 14 question topic clusters that I managed in two separate charts: one containing the supervisor's clustered questions and the other containing the senior staff's clustered questions (see Appendix N for Supervisor Chart and Appendix O for Senior Staff chart). I reviewed all interviews using the above question topic cluster and documented any patterns or comparisons. I distilled patterns from a further comparison of supervisors and senior staff. The reduced patterns from the cross-case analysis are: knowledge and use of TEACCH concepts, improvement of training, describing "severe" case campers, concerns with staff, effectiveness and use of profiles, approach to behaviour management, narrow definition of physical activity, accommodations and strategies, integration, and programming.

Knowledge and use of TEACCH concepts

Both participants from Organization C did not have a previous knowledge of TEACCH program or its concepts. They did acknowledge that they used visuals. Supervisor B has received the three day TEACCH training and feels that within her organization TEACCH concepts are not fully understood by the staff in the life skills program and therefore it fails miserably. She does feel that it provides a solid base to start from when kids are struggling and they are able to build

little pieces of what it is when they feel it fits. It is interesting to note that the Senior staff B does not have the correct understanding of TEACCH and she is leading trainings and teaching the staff these concepts. Through her research, Supervisor A has a well-rounded understanding of TEACCH and its benefits and she recognizes that it is tailored to the child and works with strength based reasoning. Supervisor A discussed that a downside to TEACCH is that it is an expensive training as you have to travel to receive the training and it is more of a behaviour program. Senior staff A is the only participant who has worked in an Autism classroom that runs a full TEACCH program. He however has not received any form of training but feels confident that he could implement TEACCH concepts.

Overall, all of the camps were implementing some TEACCH concepts: e.g. visual schedule, task analysis, but they do not have the resources or the training to run a full TEACCH model. While they all believe it is a very beneficial program they do not feel they have the ability to use all of the TEACCH concepts.

Improvement of Training

- Needs improving
- More *practical* than policy

Every participant felt that their training could improve in many areas. Senior staff A and B felt that their trainings needed to be more interactive and practical rather than sitting and listening to a presenter overwhelm them with information. Both participants from Organization C felt that their special needs specific training is very beneficial but the rest of their integrated camp training is not relevant or practical for the staff. Supervisor B brought up an excellent point

that the training is solely dependent upon the staff that is providing the training and their knowledge and experience. She felt that training gets cut short because more time is spent on policies than focusing on the children participating in the program. Both participants from Organization C also felt that the quality of their training depended on the individuals running the training which had pro's and con's. Supervisor A and B both discussed wanting to have their staff better able to observe their children and read their cues to intervene and avoid situations if possible. Supervisor A felt that her training is practical but it is not as effective as she would like it to be as she has "Meltdown Monday's" where students fail to plan and follow the embedded curriculum and use the strategies. She wishes that there was a way she could not lose a day of camp and have the "ahh haa" moments following "Meltdown Mondays" occur before camp.

Describing "Severe" Case campers

- "Severe" Cases
 - Moving target
 - Language: impaired/severe/lower functioning/"non-compliant"
 - Idiosyncratic understanding
 - Supervisors like definition and referred to it

No two people described an "severe" or "extreme" case the same. This again highlighted the gap in definition for agencies and professionals to refer to. A common reference in the two segregated camps was that they take the kids no one wants. All of the participants did refer to an "severe" case seeming to have multiple issues that build upon each other...similar to a co-morbid diagnosis but all of their features manifest under the Autism Spectrum. It was also interesting to

note that “extreme” is not a commonly used word among the field; “severe,” lower functioning, non-compliant, amount of support, and impairments were all terms used to refer to a child with “complex” needs. The supervisors were the only participants to comment on the definition and refer back to it as they described a child in an example. Whereas the senior staff read over the definition and made a comment and did not refer to it again. Senior staff A did comment that “...it was nice that you could get specific and technical with the definition but it was a good broad definition of what was extreme”.

There were two male participants in the study, Senior staff A and Supervisor C. Senior staff A openly stated “ ... I guess my picture of an “severe” case might be a little different than anyone else’s being a big, tall male I feel like unmanageable behaviour doesn’t really exist for me.” Supervisor C leaned towards this feeling as well but did not openly state it. Senior staff C felt that she encountered very few “severe” cases at her camp and within her definition she focused upon self-injurious behaviours. Supervisor B had a very unique outlook on “severe” as she felt that it was the severity level of their diagnosis in how they are extremely impaired in all areas as well as the impact that impairment has on their families. She also seemed to indicate that there could be quite a few families whose children are not severely impaired, but she felt that if the family is in crisis or had high needs that impact could be considered “severe.” Supervisors A and B were the only two supervisors who acknowledged that “severe” can occur on both ends of the spectrum.

Concerns with staff

- Better staff are needed
 - Volunteers → Good, but so what?

All of the participants would have liked to have better quality staff but the senior staff participants were very honest in the reality that the wage these organizations are paying their staff are attracting a first time employee who is looking to gain experience and they have very few experienced, well trained, returning staff. The senior staff also indicated that there was a high turnover in staff and the organization's ability to meet the needs of the children solely depends on the quality of staff. Clearly there are limits of how the organizations can recruit quality staff and hold on to them.

It should be noted that only Organization A does not have paid staff as they have undergraduate students who are earning credits but a very interesting note is that the mentors who are the more experienced professionals return on as volunteers as they have established a close relationship with Supervisor A and are very connected to the camp and the families/children attending the camp.

Effectiveness and use of profiles

- Profiles
 - Common practice in training to review but tend to depart from in application
 - Dependent on how much information the parents provide

Profiles were a commonly used tool across all organizations. Each organization uses a different profile and there are not set questions or continuity between the organizations on the type of questions or profile being used. Profiles were all used as a tool in training; they were reviewed so a staff could gain a better understanding of the child they were going to be working

with and therefore be able to create a program plan that meets the child's needs. However it did appear that once in a camp setting or an applicable setting the profile is departed from and not referred back to. This could be linked to the fact that all of the participants except Senior staff A discussed that they are dependent upon the amount of information the parent provides. There did seem to be a link between the relationship the senior staff or supervisor had with parent and the amount of information the parent provides. I feel that in the moment or in-action the profile is disregarded and the staff working with the child or the senior staff coaching/mentoring others do not refer to the profile rather they go on instinct, their previous experience with the child, or what strategies may work with a child in general. This will be further discussed in Chapter five.

Approach to behaviour management

- Proactive rather than reactive

All organizations had a “proactive rather than reactive” approach but they all seem to rely heavily on the experience of their staff coaching/mentoring, and how developed the coach/mentors' skills are. All of the senior staff interviewed are in a mentoring/coaching role within their organization but all referred to their role differently. Senior staff A would like to be more supportive and coach and “empower the volunteers” but within his camp, he is considered the “fixer” or the “finisher” (he is the main person or last resort who comes in and addresses a behaviour). He does not like to think this has to do with the fact he is a 6'7 male. Whereas Senior staff B described her role “...as someone who is able to provide strategies” but never described her role as supporting rather she would have to step in, take over and solve the problem and provide significant follow through...she linked this with the fact the organization does not

employ staff who are trained to deal with kids at a certain behaviour level. Whereas Senior staff C described her role as being a resource for her staff and there to oversee them and help deal with behaviours, and she acknowledged her role as coach as she does not have as experienced staff. She also did indicate that if needed she would step in but would like to be a resource first. The senior staff did feel that more training from a trained behaviour specialist or consultant was needed as the staff need to understand the functions of a behaviour versus trying to avoid a behaviour. Senior staff C openly stated that she goes against her organizations policy of redirection because there are some children that need to be removed from the situation in order to calm down. Supervisor A was the only participant to touch on maintaining the child's dignity and keeping them and the other participants safe. All three supervisors touched on being aware of the safety of the child and then the safety of the other participants.

Narrow definition of physical activity

Senior staff A openly admitted that physical activity is his supervisor's specialty and he does have a limited knowledge but is constantly learning more. Organization A is the only program that has a camp wide embedded curriculum and uses a station based pedagogy. It is interesting to note that participants from both Organization B and C had attended workshops on the importance of ASD and movement presented by Supervisor A. But Organization B and C had different ideas of what effective physical activity is for extreme cases. Organization B is starting to employ more of the volunteers from Organization A therefore they are having more knowledgeable staff in the area of physical activity. Whereas the participants from Organization C felt that physical activity was "playing tag", and other camp games and they considered those activities to be adequate amounts of physical activity for "severe" cases. All participants had

been exposed to the Special Needs Activity Program within their area that Supervisor A oversees.

Accommodations and Strategies

- Similar across all organizations

To avoid repetition, accommodations and strategies were put into a chart under key words (See Appendices H and I). All organizations used similar accommodations and strategies when working with any child with ASD. Senior staff C did comment on how everyone can benefit from a visual schedule not just a child with special needs. All of these accommodations and strategies come from the best practices that will be discussed in section 3. It should be noted that the concepts from the best practices do overlap and each best practice pulls from another. For example both ABA and TEACCH use visuals or task analysis to teach new skills.

Integration

- Varied responses/attempts made
- Buy in from all staff or no go

Supervisor A was the only person from the segregated camps to acknowledge she was segregated and felt there were many benefits to this model. Whereas participants from Organization B which is also segregated did not comment on the fact that they did not integrate children with ASD with typical peers. It was unclear if they view integration as while at camp they are integrating high functioning and low functioning children together...when they just have

them in the same building. This is different from their programs where high functioning and low functioning programs are run on two separate nights. Organization C is the only camp that integrates and Senior staff C did discuss how she does not want to be able to pick her campers out of a crowd: “I don’t want them sitting off to the side, I don’t want to walk into the camp and say oh those are my campers sitting by the tree”. Supervisor C was the only participant to discuss social inclusion versus physical inclusion and felt that the success of having his camper with special needs included was having buy-in from all of the camp staff and trying to have all staff aware of how to adapt and modify activities. This was also the only person to say that the organization was not as effective as it could be.....felt that Organization C in general “...shies away from it”.

Programming

- Attempts to individualize
- Some systematic programming
- Staff somewhat rigid → protocol focus more so than child

Organization A has an over-arching program that is more structured in helping to guide students as to what activities they should be doing with their child. At each station they are able to choose and plan what activities they would like to do and at what level, therefore catering to create an individualized program based on the needs of the child. This planning is a very important piece and is an issue when volunteers are not coming prepared with a plan in place. Organization B and C both try to have their staff create individualized program plans to meet the needs of the child. Organization B does have specific spaces for specific activities but Supervisor

B did note that the staff are often rigid towards the program description and do not consider the child's needs and abilities. Whereas organization C allows for the staff to create their own schedule for the child. All 3 organizations fall short on having their staff be effective program planners as they all feel their staff could be better trained and more experienced.

Level 3: Sensitizing Concepts from the literature

The focus of the third level is to use salient research literature concepts to interrogate and clarify the patterns described in levels one and two. These sensitizing concepts are: effective practices, "severe" cases, approach to behaviour management, and programming. These topics are the most salient within my review of the literature and they are also the most prominent within my analysis. I will also discuss these sensitizing concepts further in Chapter five.

Overall effective practices according to Perry et al., (2008), "...are interventions that actually work when applied in "real life" situations, where there is typically less control over relevant variables. Clients are likely to be more severe, complex, and/or heterogeneous; staff are likely to be less well trained and supervised; and treatment is likely to become diluted and to "drift" from the manual," (p. 263). It is important to note that there are no effective or efficacious treatments or interventions for children with ASD participating in a community-based, recreational programs or camps. All interventions discussed were based in a clinical setting or an educational setting that is a controlled environment overseen by experts. Based upon the comprehensive treatment models (ABA and TEACCH) and the resource guides on effective educational practices (National Research Council- Educating Children with Autism, 2001; Ontario Ministry of Education- Effective Educational Practices for Students with Autism

Spectrum Disorder, 2007) I will explore specific components of these effective practices, and behaviour management and programming strategies in further detail below in dialogue with my cross case patterns and salient revelatory phrases with attention to how these practices are applied within a community-based camp or program setting.

Knowledgeable, Experienced and Qualified Personnel

Within the literature there is constant reference to having teachers and service providers who are knowledgeable, experienced, and qualified in autism. Callahan et al., (2010) state that this should include how to correctly apply and evaluate behavioral management, communication, social interaction, independent living, cognitive and academic skill instructional interventions, and related strategies and curricula. In the research literature there was not a standard definition of what characterized an individual as knowledgeable, experienced (no indication of amount of years needed) or qualified (no list or outline of courses or programs). Both TEACCH and ABA are associated with programs that can train and qualify you to be certified in either area. Callahan et al., (2010) discuss how both comprehensive models have robust national training networks (ABA is associated with national certification programs at the bachelor's and master's degree levels), and you are able to become trained and certified to implement and run a TEACCH program.

Within the community-based camps and programs, supervisors were knowledgeable based upon their experience, but only Supervisor B had taken a 3 day TEACCH training in Toronto . None of the participants had taken Autism related degrees or programs in their post-secondary education. Rather, they attended workshops or presentations about ASD or ASD-related topics that had increased their knowledge of ASD. It is interesting to note that the senior staff

interviewed were very critical of their support staff not being trained and experienced enough and how this does affect their ability to meet the needs of the “severe” cases. However none of the senior staff had taken additional programs or courses in TEACCH or ABA. Only Senior staff B was taking her Masters of Applied Disability Studies where there is an ABA stream. The issue to be discussed in Chapter five is: does “experienced” equal “qualified” when there is little knowledge and assessment behind that experience? Also, how does this translate to staff training; does qualified staff equal effective staff?

Assessment

Within all of the literature review for comprehensive models and educational practices the need for constant assessment and review of programming was present across all areas. This assessment is vital for providing an effective program to meet the needs of the child with ASD (Ministry of Education, 2007; NRC 2001; Perry & Condillac, 2003; Simpson, 2005). The only tool of assessment within the community-based programs are profiles completed by the parents prior to their child attending the camp or program. Supervisor A does have her support staff/volunteers complete a profile after they have worked with a child so when the child attends another one of her camps or programs they have the strategies that were successful and activities that they prefer. The profiles are a tool that is completed prior to camp by the parents, used within training to prepare the staff for the child they are working with, but then in the field are seldom used or referred to. Each organization uses a different profile, varying in length, questions asked and how they are completed. An informal assessment of the child is done in the moment or in-action but how is this “assessment” applied in re-evaluating and adjusting the child’s program at camp? Effective practices in education and comprehensive teaching models, emphasize the need for individualized programming based upon the child’s unique strengths and

needs (Ministry of Education, 2007; NRC, 2001; Perry & Condillac, 2003, Simpson, 2005).

Again the issue comes back to the qualifications, knowledge and experience of the support staff, supervisors and senior staff as it is not a realistic expectation to be assessing a child within a camp or program when a majority of the personnel are not experienced in administering assessments, and the assessments are designed for a clinical or education setting.. It is also not a realistic expectation for the camp staff to create an individualized program based off of the profile completed by the parents and the staff's previous experience or knowledge of the child.

Can these community-based camps provide effective programs that are individualized and adaptable when the personnel have limited knowledge and abilities? Can effective individualized programs be developed in a camp setting that is not organized around clinical standards? Are clinical standards realistic for camp contexts? Are there other ways for camps to be effective?

One-to-One, Individual Instruction

Both the comprehensive models and the effective educational practices recommended that there is sufficient one-to-one individualized attention or instruction given to children with ASD (Ministry of Education, 2007; NRC 2001; Perry & Condillac, 2003). This was especially needed when a child with ASD was learning a new skill or transitioning to a new environment. The research did not discuss the amount of time required for a child who had complex or high needs such as behaviour outbursts, aggression, self-injurious behaviour or those who do not have self-help skills or independence. There is a high demand for one-to-one support within these community-based camps but the camps struggle to meet this demand due to the cost to provide one-to-one staff or as Supervisor A experiences, volunteers committing to her programs and then attending on a consistent basis. The research literature does infer that the environment should be highly structured and the more consistent and predictable the environment, the more independent

a child with ASD can be, therefore less staffing and one-to-one instruction should be needed. Is there a naïve reliance on the “structured environment” as a transition tool in and of itself?

Environmental & Visual Supports and Structure

The research literature on comprehensive models and educational practices identifies that a key component to any program is providing an environment with visual supports and structure that meet the needs of the child with ASD. All of the community-based programs try to structure the environment and use one or more of Dalrymple’s (1995) four types of environmental supports:

- temporal supports to sequence events over time;
- procedural supports to outline steps of an activity or the relationship of items to events or people;
- spatial supports to provide information about environmental organization; and
- assertion supports to help initiate interactions or assert control over the environment

Any of these environmental supports can be enhanced through the use of visual cues (Quill, 1997; 2000). An ASD structured environment has visual cues in different forms (i.e., picture schedules or written lists) depending upon the individual’s functioning level. None of the programs structure their environment to the extent that TEACCH does as a result of the camps/programs not having a space that is exclusively used by them, or is a permanent space. All three of the camps do provide their support staff with picture schedules, but the support staff either do not see the value or importance of these visuals, or they have not been properly trained on how to effectively use them. Due to deficits in communication, children with ASD have

trouble understanding what to do and when to do it which then elicits anxiety and confusion.

This then causes withdrawal and disruptive and self-stimulatory behaviors (APA 2000; Collier & Reid, 2003; Jones & Block, 2006; Mesibov & Shea, 1996). By creating a structured learning environment that is predictable we “should” be able to decrease behaviours. Students with ASD require a structured learning environment to know what is expected of them in specific situations, to assist them in anticipating what comes next and to learn and generalize (Iovannone et al., 2003; Ministry of Education 2007; NRC 2001). The reality is, that the camp environment itself is not a controlled, predictable environment due to the chaotic arrival and departures and multiple transitions that occur within the day. When discussing controlling or structuring the environment as an approach to behaviour management, the following are statements made by the participants:

- Senior staff A “...if you control the environment, you control the behaviour”.
- Senior staff B “You just kind of set-up the environment and hope that there are no behaviours and if there is its just redirection and just trying to calm them down and get them back to a place where they are happy”.
- Supervisor B states “...our overall approach would be to provide a strong enough structure that the children aren’t going to need any behaviour management to start with. There’s going to be enough everyday tools, transitional tools, structural tools, visual tools and support tools throughout every part of their experience that they will be our behaviour management”.

These are examples of the naive reliance upon structuring the environment to manage the behaviours. It is clear that these participants “hope” that if they structure the environment enough there will be minimal behaviours but this is not the reality of camp due to the unpredictable

environment and staffing issues. The concept of being proactive rather than reactive was also an additional approach to behaviour management; the following statements were made by the participants:

- Senior staff A: "...always doing the same things every day, speaking to them in the same way, getting them into a routine and not breaking that routine unless absolutely necessary...prevention instead of reaction".
- Senior staff B: "I'd say that they try to be proactive but it is more reactive".
- Supervisor A: "In a nut shell it is prevention rather than fix. So we try to anticipate and prevent rather than intervene after the fact".

Senior staff A is under this impression that by controlling the environment he can rely upon structure and consistency to control the behaviour. Despite the fact that he goes on to provide examples of how the camp and staff attempt to control the child's behaviour through the environment and ultimately the child overcomes the environment despite all of the staff's efforts to be "proactive, rather than reactive." Senior staff B is very direct in her comment of the camp attempting to be proactive but in reality it is more reactive. Again the effective practices are in fact not effective within the real world of camp chaos. However Supervisor A does bring up an interesting point within her comment of "...prevention rather than fix". She is referring to the traditional rehab model and its focus of "fixing" the individual and placing them back into the "real world." The question becomes what is the real world? These findings have clearly indicated that these effective practices will not work within the "real world" of camp.

Severe Cases

Within the literature there is no specific description of what qualifies a case to be “severe.” There are several references to severe but there is no definition given to define the characteristics of a “severe” case. Each of the participants used the term “severe” but did not use term “extreme.” Based upon each of their exposure and experiences to “severe” children they all defined “severe” differently. If each of these participants coming from three different organizations defines “severe” differently, then how are they providing programming to meet the areas of need of the child that they consider to be “severe”? It seems that there is no consistency in programming across the region. Based upon the literature, I created a definition of “extreme” case for my participants to refer to:

“Extreme” cases are the manifestation of the most intense features of the disability; this includes challenging and disruptive behaviours, limited communication skills, poor social development and ongoing presence of a caregiver for support of basic needs. Challenging and disruptive behaviours, according to Didden et al. (1997), can be divided into three classes (a) external destructive (e.g., aggression, property destruction), (b) internal maladaptive (e.g., self-injury, stereotypic movements, pica), and (c) socially disruptive (disruption, inappropriate verbalizations, noncompliance) or combinations of the above. These “severe” cases consistently exhibit these manifestations and this can have a significant impact on the person’s quality of life, can threaten personal safety and the safety of others, and can drastically limit the person’s inclusion in educational settings, social relationships, typical home environments and community activities (Horner et al., 2002; Matson, LoVullo, Boisjoli & Gonzalez, 2008).

Only the supervisors referred back to the definition above when describing children that they considered to be “severe” (see Appendix L for Keywords on “Severe” Cases: Supervisors, and Appendix M for Keywords on “Severe” Cases: Senior Staff). The supervisors also expanded

on key areas of the definition. Supervisor B's role is focused on supporting families within her organization so she commented on two main areas: "...the severity level of their diagnosis in that way they are extremely impaired in all areas...the impact that those areas of impairment are having on their family...with a whole lot of cases that would be crisis or high needs but they don't necessarily have a severely impaired child". Within my definition I do refer to the "ongoing presence of a caregiver for support of basic needs" and she was the only participant to expand upon this point and the affect this has on the family as a whole. Supervisor B also commented that she appreciated that the definition was

"...not necessarily based on the severity level but how much it's interfering with functionality. Because you can have someone who's quite gifted in their verbal abilities but become extremely aggressive and not be able to be in the school environment and take advantage of that... it can be based on functioning level without stating that but also with severity level without stating that...encompass more people this way in a more positive way".

Supervisor A also did not have a very narrow definition as she referred to extreme cases as "kids nobody wants" and those that typically "...manifest simultaneity, there's this plus this plus this." She feels that: "severe or extreme probably can manifest in many ways like they can be medically severe like fragile or sick, or they can be behaviourally severe as in like the Tasmania devil(makes his noise)...there is more going on than a single dimension disability; it's complicated ". While the DSM-IV-TR-APA, (2001) does consider impairments in communication, social interactions and restricted and stereotyped patterns of behaviour, they do not consider the child's level of independence or ability to complete basic living skills. Both participants from Organization C referred to two different children that were "higher

functioning” but they considered them to be severe based upon their inability to self-regulate and control their reactions. Are “severe” participants from an “integrated” camp considered to be “severe” in segregated camps such as Organization A and B? This again comes back to each organization using different profiles and essentially having a different definition of what they considered to be “severe”. Also, is a child accepted into the camps based upon the supervisor’s and staff experience/exposure to “severe” cases and the level of “severe” that they can handle? What is each camp’s threshold for “severe”?

Confirming Comparative Analysis: Parents’ Survey

Within my ethics approval I received permission to interview parents of “severe” case children, and with their permission, view their child’s file from each organization. Prior to beginning this study I did not consider parents to be a part of the organizations. It was not until I finished the first two levels of analysis, when I saw the thematic patterns and felt that the parent’s perception would provide an opportunity to further triangulate my findings. I also had come to the realization that parents are a vital and integral part of all of these organizations.

Following my three levels of analysis, I created questionnaires that contained 22 questions derived from my patterns and themes from levels one and two. I administered these questions through an anonymous online survey approach which allowed parents of designated “severe” case children who had previously accessed the services of organizations A, B, and C to provide feedback without being identified.

I used the parent responses to confirm or disconfirm the patterns and themes from levels one and two of analysis and the deductive analysis from the sensitizing concepts. This created triangulation and provided an additional way to internally validate my results.

The questions were grouped in topics: information about their child (Question 1-4), profiles (Questions 5-11), programming (Questions 12-15), staff (Questions 9, 16-18), and Niagara region camps (Questions 19-21). The Parents' survey questions and responses can be found in Appendix P.

Information about their child

When asked to describe their child, the mothers all discussed their child's behaviours, communication skills, the amount of support their child requires and the need for routine. Three of the children display internal maladaptive self-injurious behaviours and all six display some form of challenging or disruptive behaviours. I would consider all six of these children to be extreme cases based on my definition. Two of the children are diagnosed with severe Autism, three are diagnosed with Autism and are developmentally delayed, and one child is diagnosed with Autism, pancreatic insufficiency and cystic fibrosis. The entire group stated their child required 1:1 support at camp and four commented on their child needing to be supervised at all times due to safety concerns. Five out of six of the mothers discussed their child's need for routine:

- Mother A: "Lives by routine, but has gotten much better at sudden changes."
- Mother C: "He likes to know what his day entails, especially if it is something new."
- Mother D: "...hates change, wants to control everything, needs routine."
- Mother E: "Home life fairly routine. Certain activities have to happen on certain days."

- Mother F: "...needs structure and routine at all times."

It is interesting to see that when describing their child, the mothers describe their child's need for control, routine or structure and how this need for control and structure translates into all areas of their children's lives. Each of the mothers described their child's communication skills, but only five stated the visual support their child also requires. It should be noted that when the mothers were describing their child's communication skills, they followed this description with the type of visual support that their child uses. When asked what strategies or accommodations needed to be in place for their child to have success at camp the mothers agreed with the options I provided (sensory room, visual schedule, pictures, and first/then board) but three mothers provided additional information that was more detailed. This confirms my findings and what the literature states that having a structured environment with the right visual supports in place "should" help to better support a "severe" case, but again, in the "real world" is this possible? This concept of control and routine within the "real world" will be further discussed in Chapter five.

Profiles

Within my findings, profiles were discussed by both the senior staff and supervisors and were present across all levels of my findings. When asked if the camp profiles provide a well-rounded view of their children, only Mother C disagreed. This may be due to her child's other medical needs as she stated that "it would be more effective to have the questionnaire coupled with a phone conversation." She discussed her dislike regarding communication questions: "...makes it seem like he can understand so much because he can read and type or I make it seem like he isn't capable of much because he can't answer basic questions and only uses 3-4 word combinations to speak." This is an important point when discussing "severe" cases who

can verbally communicate, write, tell time etc. and yet they have challenging and disruptive behaviours. Can parents be expected to accurately portray their child when they are writing down their answers so that the camp can meet their child's needs? Mother F stated she dislikes answering repetitive questions and she does feel the questions asked are appropriate but: "it gets tiring always being asked the same questions and filling out forms." Mother E wished they were asked what their expectations are from camp and Mother C wished she was asked what are some goals (in specific areas) and then provided some examples so she can pick a goal based on what the camp is able to teach. I did not think to ask what the parent's expectations are of the camp but I did ask what expectations they have of the camp staff working with their child.

Organization B does ask what goals the parents have at camp but parents often answer either very general (e.g. "to have fun") or a goal that is too specific and unattainable (e.g., become toilet trained). What is the expectation of camp from the staff's point of view and the parents' point of view? Are their expectations the same or do they differ? Are the expectations too high or low? What is a reasonable expectation to have of camp? This will be discussed more in Chapter five.

In her interview, Supervisor A commented: "lots of my parents lie because they're afraid I won't take their kid," and I probed further about parents being forth coming with information. She discussed how "the kids who have been coming, their parents will be honest...because the parents trust [her] and she is able to tell the students working with them what this child needs and what he is good at". Supervisor A feels the toughest children are the new ones because

"Sometimes the parents are disingenuous and helpful....sometimes they give you more information than they know they do. They say "oh the child will be no trouble at all and then they list his meds...I've been working with this population long enough to know

what the medications mean, what it indicates, so the parents may not give me verbal descriptions, but the meds give me insight into some of the stuff that's going on".

Working within all of these organizations has given me the opportunity to engage with parents who are very forth coming with information about their child and parents who are not as forth coming with information. I wanted to get the mothers' point of view on this topic and their responses were as follows: Do you feel some parents with children similar to yours are hesitant to be honest when filling out profiles? Why do you think they are hesitant? Mother's E and F accept that if they want their child's needs to be met at camp then they need to provide as much information as possible. Mother E confirms Supervisor A's feeling of parents worrying that their child will not be accepted:

"Some parents may be hesitant because they fear their child might not be accepted into the program because their needs are too high. Some parents may have camp as their only form of child care during the summer or other holidays so their child needs to go to camp, and they can't risk their child not being accepted. Some parents may be hesitant to put a label on their child because special needs camps tend to cost more. *The level of autism my child has cannot be hidden so it's obvious she's not a typical 10 year old.*"

These mothers cannot hide or mask their child's Autism and the level of support that is required. They have limited choices of which camps their children can attend as they know which camps will accept their child and which camps will turn them away. Mother E's point of camp being a parent's only form of childcare especially for "severe" cases is very evident within the Niagara region. These mothers are planning their summer based upon the weeks they are accepted into Organization A, B, and C's camps as well as respite because they only have these four options for care depending on their child's age and needs.

Mother C feels that "...it is also very difficult, though necessary, to talk about your child's interfering behaviours. It can get depressing listing it all out. On paper you make them look so bad. You feel awful as a parent hashing up all of this negative info when all you want to do is brag about your child and point out all of their good qualities." If these mothers are not brutally honest when completing the profile about their child's needs and behaviours then they will not receive the support that is needed. Supervisor B discussed this concept as well:

"...if we get all this information about kids beforehand does that set like a judgement...or do we make predetermined beliefs about a child before they even walk in the door and therefore potentially hinder their involvement or change it in a way more than what we even needed to do based on what they say on paper. I find that that happens sometimes, that parents state the worst, which rightfully so, we've got some kids who have some significant needs and really have caused a lot of difficulty for families but when you put it down on paper it sometimes comes across in a very negative way. I think that that kind of information requirement really interferes sometimes with how we set up our programs, and I really wish there was a way to get around that. I don't know what is the best way to do that, sometimes it might just be the wording of our questions; we're always trying to adjust to change. It would be nice if there was always a way to meet the kids beforehand".

Mother C confirms Supervisor B's thoughts:

"I feel like my son has no privacy. There have been so many people who have worked with him over the years, so many people sitting around and discussing his interfering behaviours (especially his screaming) and I hate adding to that list of people who have to know about my son's most vulnerable and difficult moments. A lot of people who come

in contact with my son don't understand and take seriously the dignity and respect of the child they are serving. They talk about their interfering behaviours like it's a big joke, 'Oh that's the kid who...'. Of course I worry about intentionally throwing my son under the bus and scaring people off'."

Is there a way for the organizations to receive this information about the child's needs and behaviours so that parents do not feel they are being negative and scaring staff away? Is there a way that this information can be presented to staff in a way that we respect the child's privacy and dignity and not scare the staff but still have them prepared for the reality of working with this child?

The profiles are used by the camp staff to gain a better understanding of the child and how to meet their needs but all participants felt that their ability to plan and prepare depends upon how detailed the parent completes the profile. The mothers were asked: "To provide the camp with a well-rounded view of your child and their needs would you prefer to: fill out a detailed profile, speak to the staff working with your child or bring your child to the camp facility?" All of the mothers stated they would want to speak to the staff working with their child on top of completing a profile. This shows that if provided the option to speak to a staff to ensure their child's needs are met, the parent wants to do so. Four of the mothers also stated that if it was a new camp they would want to go to the camp facility to expose their child to the new space to better prepare their child and the camp staff. Only organization C's Senior Staff sits down with a parent to complete the profile. One would assume that this increases the staff's ability to better prepare and plan a program to meet the child's needs. Mother C discusses that this is not the case "Not at Organization C. The coordinator was extremely knowledgeable, but the information did not trickle down to the support staff at all. They acknowledged that, though,

and apologised. Everything they said they would do, they didn't... They weren't able to support him." The mothers were asked if they felt the camp staff read the profile and used the information when planning for their child as the profile seemed to be used in training but then never used in-action or in the moment at camp. Mother C's point of the senior staff not passing the information on to the support staff and properly preparing them was reiterated by Mother E as she felt: "Sometimes camp staff are not given a schedule themselves on what the activities for that day will be before my child arrives so they aren't prepared by their senior staff." This confirms that support staff directly working 1:1 with these children are not adequately prepared and trained by their senior staff. Are the senior staff too overwhelmed with the amount of support staff and campers they are overseeing or are the senior staff not being trained on how to mentor and coach their support staff effectively? Also is it reasonable for the senior staff to sit down with each parent to discuss the profile? What is the best way to ensure all of the information required to meet the child's needs is a) documented by the senior staff and parents, and b) utilized effectively outside of training and in-action? Mother F suggested that "the camps should keep copies of profiles of our children from the previous year, have the parents read the profile from the prior year and make changes and additions as needed." Ideally this "should" be easily implemented but this requires the senior staff to be organized and file all the profiles away, but due to the high staff turnover this may not be possible. It would be interesting to check in with Supervisor A and see if the second profile she has her students complete is stored and given to the student's working with the child the next year. Again in the "real camp world" what is the best way to collect the profile information from the parents and have staff utilize it outside of training? Is there an opportunity to list the strengths as well as the deficits and not have the profile focus on the negatives?

Camp Staff

In their interviews the staff participants expressed concern about the experience of staff that were hired and they felt that the staff needed to be better trained. I asked the mothers two questions: What qualities or characteristics do you want the camp staff working with your child to possess (patience, comfortable with self-care activities, willing to learn etc.), and what expectations do you have of the camp staff working with your child? I have put their responses into a side by side chart below:

Table 8

Camp Staff

	Qualities & Characteristics of Staff	Expectations of Staff
A	All of the above. (patience, comfortable with self-care activities, willing to learn)	Patience, tolerance, compassion, fun loving, knowledge in the disability of my child
B	Happy, outgoing attitude with some sort of background with autism/special needs.	To have patience. Also giving my child time to respond to questions/requests.
C	Patient, comfortable with self care, not shocked easily by things, Humble, vigilant at watching, responsible, kind, energetic	To keep my child safe and engaged in the activities as much as possible. To teach and encourage them.
D	Understanding of Autism , Lots of patience, lots of energy, to get it	To keep them safe, ensure they have lots of fun, to understand Autism and to enjoy what they are doing!!
E	Camp staff ideally have to have lots of patience, energy, and enthusiasm. They need	My expectations are the above. I am organized when it comes to sending my child

	to be comfortable with self- care activities if accidents happen, and willing to find a balance between doing too much for my child vs. too little to help. They need to be willing to learn and not roll their eyes when I am explaining to them some of the things my child needs. If they are dedicated to trying to provide a safe and fun environment then the camp will be a success.	anywhere for the day. Notes are written on snacks, extra clothes are provided, and I try any make it convenient for the staff that work with my daughter to find what they need when she is asking for it. I don't expect perfection. I just expect my daughter to be kept safe and to have fun. I would like it if she is kept busy, and active too. I'm not expecting her to do what everyone else is doing. I just want her to have an enjoyable day.
F	Eagerness to Learn, comfortable with self-care activities, confidence, lots of patience, is able to ask questions if not sure of what to do with the child.	Make sure child is safe, accurately communicate what happens throughout the day with our child whether it be good or bad. To help child achieve goals throughout the camp.

Characteristics/Qualities of Staff

Only two of the mothers wanted the staff to have an understanding or knowledge of ASD. Experience was clearly not a key characteristic or quality they look for in the staff working with their child, (although I would have loved for Mother D to expand upon her comment of “to get it”, as I have heard many of these mothers comment on how certain camps and individuals “get it”, they “get” their kids). This response was the exact opposite of the staff participants as

they all wanted their support staff to have more experience. Patience and positive/happy/enthusiastic energy were the two main characteristics that five out of six of the mothers wanted the staff to possess. These two characteristics were not mentioned by either the supervisors or the support staff. Being comfortable with self-care was an area that four of the mothers wanted the staff to possess as Mother E stated: “they need to be comfortable with self-care activities if accidents happen, and be willing to find a balance between doing too much for my child versus too little to help.” She touched on an area of self-care that is seldom discussed as often it is that balance of knowing the level of the child’s self-care skills and the staff supporting the child when they actually require support. Three of the mothers wanted the staff to have a willingness to learn as Mother F stated the staff “...is able to ask questions if not sure of what to do with the child” and I again enjoyed Mother F’s honesty when she stated “they need to be willing to learn and not roll their eyes when I am explaining to them some of the things my child needs.” The “willingness to learn” is a key characteristic that contributes to successful and meaningful programming for “severe” case children.

Expectations of Staff

This was one of the questions I was most excited about viewing the mother’s responses to, as I saw the high expectations the supervisors and staff have of the support staff/volunteers and wondered if the mothers have similarly high expectations. Mother E had an excellent description of her expectations in the “real world” of camp:

“I am organized when it comes to sending my child anywhere for the day. Notes are written on snacks, extra clothes are provided, and I try and make it convenient for the staff that work with my daughter to find what they need when she is asking for it. *I don't*

expect perfection. I just expect my daughter to be kept safe and to have fun. I would like it if she is kept busy and active too. I'm not expecting her to do what everyone else is doing. I just want her to have an enjoyable day.”

This mother’s statement summarizes the key points that all the mothers expected in their staff: for their child to be kept safe, keep their child busy and active, and having fun and an enjoyable day. I appreciated her honesty in stating how hard she works prior to her child arriving at camp to be organized so it is easier on the staff. Is she aware of the reality of camp and the chaos? I also was impressed by her statement of “I don’t expect perfection.” Is this because she accepts and acknowledges her child is going to give the staff “a run for their money” and exhaust them? I also appreciate that she accepts her child for who she is: “I’m not expecting her to do what everyone else is doing. I just want her to have an enjoyable day.” This acceptance of her child within the “real world” of camp is a refreshing viewpoint. Mother F also is clearly aware of the reality of her son at camp as she wants the staff to “accurately communicate what happens throughout the day with our child whether it be good or bad.” Due to her son’s high level of need and self-injurious behaviour she needs to know the good, the bad and the ugly so she can prepare for how he his evening can go. Do the supervisors and senior staff have unrealistic expectations of their support staff? Or again is it this idea of what is the “real world” of camp?

Programming

Based upon the expectations that the supervisors and staff have a diverse understanding of the types of activities that are important for these children, especially in the area of physical activity, I wanted to discover what activities the mothers believed should be a part of their child’s day. When asked to rank specific camp activities (See Appendix P, Question 12) the

mothers had mixed results on how valuable fine motor activities (e.g. colouring, crafts, puzzles, and reading) were to their child's day. The sensory break was the only activity the mothers ranked as very important. Swimming every day, community outings and gymnastics had five of the mothers valuing it as very important and one valuing it as important. These mothers clearly identify that their child being active and having access to sensory breaks is a priority. When asked to identify their top five "must have" activities, swimming was the only activity that all six mothers included. Each mother did have physical activity listed but they all defined it differently: movement (physical activities), gymnastics or some type of gross movement activities, gym activities (trampoline, ropes, mats, balls), lots of movement time, gym activities and gymnastic activities. These mothers clearly understand that physical activity is a vital activity in their child's day but, like the other participants in the study, do they understand why it is important and what types of activities are more important than others? This confirms that more educational opportunities need to be provided to both parents and staff about the benefits of physical activity and how to implement it into a child's day. This will be discussed further in Chapter five.

Niagara Region camps

As previously stated, there is a lack of programming in the Niagara Region for "severe" cases. The mothers confirmed this point. In the additional comments section three of the mothers commented on the lack of programming available for their children. Mother C stated: "there aren't many that provide service to children with high needs such as mine. I feel a great amount of desperation every summer because I just hope and pray he can get into the only two camps he has succeeded at." This comment is an excellent example of the desperation that parents with these "severe" case children feel each summer as they attempt to fill up 10 weeks of summer

with camps that offer limited enrollment; as Mother E stated: “More camp spots are needed for campers that have higher needs. Typical kids can go to any camp depending on their interests. I pick camps depending on their level of support and if there is 1:1 support available for my daughter.” All of the organizations I have examined are full each summer because there is high demand for camps that offer 1:1 support. Mother E has to evaluate which camps are appropriate for her daughter and which camps will attempt to meet her needs. Mother F’s son is 20, he is the only adult in the group and she feels a higher level of desperation as he finishes school in the middle of June and has between 12-14 weeks of summer to fill. Mother F stated: “There are no camps or activities for adults that need one to one supervision after they turn 21.” Each year Organization A and B raise the maximum age for adults who require 1:1 support but there are no camps dedicated to adults in the Niagara region. This is an issue that will be discussed in Chapter five.

All of the mothers would recommend Organization A and B to another parent. Mother A would recommend Organization C to another parent but Mother E stated that she would only recommend Organization C to a parent depending on the child’s level of need. Clearly these mothers do not have a large selection of camps where they are able to send their child. Once their child is over age 12 they only have Organization A and B as options. This is an issue that will be further discussed in Chapter five.

I am very thankful for the parent’s participation in this questionnaire and the further analysis it provided.

Research Questions

I will briefly revisit my research questions and relate them to the findings. They will be further discussed in Chapter five.

1. What are the thresholds for physical activity within a community-based organization that provides programs for children with ASD?
2. How do programs committed to participants with ASD identify the physical and communication needs of “extreme” cases?
3. How are communication and physical needs addressed within community-based organization that provides programs for children with ASD (through training, programming and program’s structure)?
4. What issues/barriers are associated with using TEACCH strategies to provide physical activity opportunities within these programs?
5. What is needed for these programs to provide physical activity to “extreme” cases?

Thresholds for Physical Activity

One of the main thresholds for physical activity is the participants’ knowledge and understanding of physical activity. Due to limited experience and training, the support staff struggles to implement a physical activity program. This also connects with some of the supervisors and senior staff having limited training and experience in the area of physical activity. Each organization defined physical activity differently and provided various activities they felt would be appropriate for “severe” cases. Due to her research focus and background on ASD and physical activity, only Supervisor A was able to provide meaningful and appropriate physical activity to her campers that were “severe” cases. While she is knowledgeable and able to create an environment specifically for physical activity, her volunteers are often new to

working with children with ASD and physical activity; making it difficult for them to plan and implement physical activity programs. Space and equipment are another threshold as only Organization A had a wide range of equipment available to them as they run their camp out of a post-secondary location which has a large gymnasium, gymnastics equipment, access to hiking trails, large shapes and other equipment. Organization B does have shapes and some sports equipment but because their camp moves every two weeks they are unable to have large pieces of gymnastic equipment. Organization C does not have a camp specifically for children with ASD as their program integrates children with ASD into other camps and therefore they do not have a space dedicated to physical activity.

Identifying Physical and Communication Needs

All three organizations identify the child's needs based upon four areas/factors: 1) profile, 2) staff's previous knowledge of child's needs, 3) interacting with the parents, and 4) camp staff's knowledge and experience of ASD in general. While the profiles are completed by parents, the findings indicated that often they are not completed with enough detail, which requires the staff to rely on their previous knowledge of the campers to meet the physical and communication needs of the child. I also identified that even if the profiles are completed with a large amount of detail they are referred to during training but are then mostly disregarded in-action at camp. The profile is not the tool referred to. Rather, the staff use their previous knowledge of the child and knowledge and experience of ASD to meet the needs of the child. This caused me to question why we have the profile and ask the parents to complete it if the staff do not utilize it. How might ongoing use of the profiles be built into camp?

Addressing the Physical and Communication Needs

The physical and communication needs are addressed in training and then in-action at camp. Each organization has a training that provides strategies to the staff as to how to program for the physical needs and what strategies are effective in meeting the child's communication needs. It was indicated by all participants that these trainings are not as effective as they would like and require improvement. While all the organizations have the best intentions to prepare their camp staff during training they do rely on senior staff members to coach and support the staff working with the child. Supervisor A wished that she could use the first day of camp as training day because it is only when the volunteers are with the kids and experiencing how challenging it is to address their physical and communication needs that they realize what strategies they need to be using and that they need to program plan. To meet the physical needs of the child, both Organization A and B create stations for the camp staff to visit to eliminate the staff having to create activities. Both organizations struggle with the staff not having the physical activity knowledge and experience so even though they provide these physical activity stations, the staff still struggle to have their child participate.

All of the camps provide visuals for their staff to use to meet the communication needs of the child. Often the staff members do not see the value and importance of using these visuals and/or they do not know how to use them correctly. Meeting the physical and communication needs seem to develop over the course of the week at camp as once the staff have seen, in-action, how to use the visuals and understand how to perform activities at the station, then they value and understand why these activities and supports are in place.

TEACCH Issues/Barriers

The main issue of using TEACCH strategies within a community-based setting is that supervisors and staff are not trained in the TEACCH system. The TEACCH system is too complex of a system to implement within a community-based camp. Organizations are able to use specific strategies such as a visual schedule and using visuals at activities to better support the campers. This is limited again by the knowledge and experience of the supervisors and staff and their ability to train and coach/mentor the support staff. In a clinical or controlled school setting, TEACCH is an effective system but in the “real camp world” it is not effective.

Providing Physical Activity

This particular question will be better address in the recommendations sections in Chapter five.

Chapter V- DISCUSSION

“Effectiveness”

A common theme that occurred repeatedly throughout Chapter 4 was the idea of effectiveness and each organization’s ability to utilize effective strategies from the comprehensive treatment models and educational practices discussed in the review of literature.

Perry et al. (2008) discussed that effectiveness involves:

“...whether the intervention actually works when applied in “real life” situations, where there is typically less control over relevant variables. Clients are likely to be more severe, complex, and/or heterogeneous; staff are likely to be less well trained and supervised; and treatment is likely to become diluted and to “drift” from the manual” (p.623).

Using Perry et al.’s, (2008) description of effectiveness, the organizations struggled in the following areas:

“...whether the intervention actually works when applied in “real life” situations, where there is typically less control over relevant variables;”

All of the camps were unable to ensure the proper use of the environmental structures and strategies such as visual schedules. There also was a naïve reliance on the structure of the environment to provide effective programming and aid in behaviour management.

“Clients are likely to be more severe, complex and/or heterogeneous;” Based on the complex embodiment model, disability is social constructed rather than biologically driven and due to the perceived complex and high level of needs of the “severe” cases, the organizations were unable to view the impairments as differences rather than deficits and struggled to create

and maintain individualized programs and appropriately match staff to meet the needs of the severe campers.

“Staff are likely to be less well trained and supervised;” Personnel employed by the organizations had limited knowledge and abilities which directly affects the quality of the training of staff and therefore the delivery of the camp program. Only Supervisor B had formal TEACCH training, but she was the only participant who had formal training with any of the comprehensive models.

“...and treatment is likely to become diluted and to “drift” from the manual.” Organizations are not able to follow specific programs or treatment models so therefore they do not have a clinical standard to maintain or a manual to follow.

Based upon the findings in Chapter four it is evident that the clinical standards of having effective interventions in “real life” situations are very general, and these organizations were only able to apply specific components, strategies, and environmental structures that fit within “real world” camp situations. The comprehensive treatment models and educational practices are not effective in a “real world” camp as the clinical standards cannot be adhered to.

Many “Real Worlds”

Through the findings of Chapter 4, I was able to explore: “What is the real world?” and three “worlds” emerged: the clinical world, the camp world and the parent world. The clinical world, based on Perry et al. (2008), describes efficacious as:

“Efficacy refers to whether a treatment or intervention can be shown to work under

“ideal” conditions. Clients are selected to be “good candidates” with no co-morbidities;

therapists are well trained (often graduate students) and well supervised; and treatment is carefully planned and implemented faithfully according to a manual”(p.623).

The clinical world is the “ideal” world where every aspect is regulated and controlled and everything is perfect. The clinical world selects the participant that will have success, make the most progress and produce results that will enable clinicians to write glowing reports to receive more funding. If you do not “fit” the ideal participant criteria you are not accepted. Participants that are severe or have a co-morbid diagnosis are not the ideal candidates in the clinical world. The skills, strategies learned and programs/interventions used in the clinical world cannot be maintained by parents and other personnel. The parents and other personnel attempt to apply components of the clinical world in ways that are practical in their own world.

The camp world often aspires to implement the programs and interventions from the clinical world, but does not have the capacity to meet the clinical standards. While the senior staff have the intention to implement components of the clinical world, the lack of training, experience, qualifications and consistency of the all camp staff do not allow for clinical programs to be fully implemented. I do not view this as a negative as camp is a unique environment that is constantly changing and adapting. The supervisors and parents accept camp for what it is: a chaotic and FUN world, where the participants can be themselves and enjoy experiencing new activities that the clinical world cannot provide. The benefit of the camp world is that the staff can use the visual structures and strategies to enable these “severe” cases to be in the community and participating in almost any activity and environment. I do not mean to be providing a false reality of the “real” world of camp that is filled with fun, new experiences and “smells like roses” so-to-

speak. “Severe” cases, like a majority of individuals on the spectrum, do not like change or a disruption in routine so when these camps pack 60 of them on to a bus or try to put on bowling shoes there are undoubtedly meltdowns and behaviours. Organizations A and B go on community outings such as Marineland, Zooz, going to a community park, go-karting and mini-putting that clinical programs would never consider attempting as a result of the unknown variables. It is the unknown that makes camp real and similar to the real everyday lives of the parents and families of the “severe” case children.

“People think because they have worked with him at camp or at a program they understand how hard my life is and what I go through on a daily basis. Put yourself in my situation. When you’re with him at camp, you have the ability to ask for help from another staff when you’ve had enough. You have someone to watch him while you eat lunch, change, or go to the bathroom. You have back-up. You only have him for 8 hours of your day and then you can go home, rest and get ready for tomorrow.

When I go home it’s me, I don’t have the back-up of extra staff to watch him while I make dinner, do the laundry or go to the washroom. So I hold it for eight hours. If he is up all night, I’m up all night. I still have to get up in the morning, keep the routine going and be on schedule. I can’t take a day off.” ~ A mother of a child with severe Autism

It is the honesty of this mother that caused me to realize the reality of her world and no matter how efficacious or effective an intervention or program is, it will not fully function within her world. She may use specific components and bits and pieces of interventions but at the end of the day she will do whatever it takes to get through her day. She may put some of the environmental

structures and strategies in place within her home but only what is practical and will make her child happy. She will use visuals and other strategies when necessary but she and her family are not able to run a full TEACCH or PECS program. At the end of the day, each of these “severe” cases belong to a family who are each other’s back-up and support and view the “severe” case as a son, daughter, brother or sister who is a part of their family.

Realistic Expectations?

A topic that emerged from the findings discussed in Chapter four, was the expectations placed on the support staff by the supervisors and senior staff, and whether or not these are realistic expectations to have within a camp setting. To explore this idea of what is a “realistic expectation,” I asked the parents what their expectations were of camp and the camp staff to see if their expectations differed from the supervisors and senior staff.

The Supervisors and senior staff had very high expectations of their support staff that quite frankly were unrealistic. All participants acknowledged that their training needs improvement yet they do not seem to take the quality and lack of training into consideration when discussing their expectations of their under trained, under qualified and under experienced support staff! All of the senior staff interviewed acknowledged that part of their role is to train, coach and mentor the support staff but they all are very critical of the support staff’s inability to program plan and use the environmental structures and strategies. The mothers were far less critical of the camp personnel. Only two of the mothers wanted the staff to have an understanding or knowledge of ASD. Experience was clearly not a key characteristic or quality they look for in the staff working with their child, whereas all of the senior staff wanted all of the support staff to be experienced, knowledgeable and have received additional training on ASD.

Patience and positive/happy/enthusiastic energy were the two main characteristics that five out of six of the mothers wanted the staff to possess. These two characteristics were not mentioned by either the supervisors or the senior staff. Being comfortable with self-care was an area that four of the mothers wanted the staff to possess, for example Mother E stated: “they need to be comfortable with self-care activities if accidents happen, and willing to find a balance between doing too much for my child versus doing too little to help.” She touched on an area of self-care that is seldom discussed as often it is that balance of knowing the level of the child’s self-care skills and the staff assisting the child when they actually require support.

The findings in Chapter four indicate that clinical standards, and therefore comprehensive treatment models and educational practices, cannot be consistently or accurately implemented in a recreation setting. It is admirable that the senior staff have high expectations of what can be accomplished by the support staff but the reality is that they themselves and the organization do not have the capacity, training, experience and time to meet and implement such clinical standards. What is fascinating is the parents seem to accept the real world of camp and do not compare it to any of the comprehensive treatment models or educational practices. Mother E had an excellent description of her expectations in the “real world” of camp in stating that

“I am organized when it comes to sending my child anywhere for the day. Notes are written on snacks, extra clothes are provided, and I try and make it convenient for the staff that work with my daughter to find what they need when she is asking for it; I don't expect perfection. I just expect my daughter to be kept safe and to have fun. I would like it if she is kept busy and active too. I'm not expecting her to do what everyone else is doing. I just want her to have an enjoyable day.”

This mother's statement summarizes the key points that all the mothers expected in their staff: their child to be kept safe, keep their child busy and active, and having fun and an enjoyable day. All of the mothers do not expect perfection as they know how demanding their child can be. Supervisor A discusses the expectations she has of her student volunteers when working with extreme cases

"...over and above their ability to be attentive and engaged and interested in the child for 8 hours. On for 8 hours. ON for 8 hours, ON! Not texting, not thinking about their friends not worrying about their friends not thinking but anything but this kids. FOR EIGHT HOURS... that kind of attentiveness and disciplined focus is what this calls for... So at the end of the day they should be freaking exhausted and most of them are...not to mention the planning".

This attentiveness and being "ON" is a realistic expectation as it relates to the staff ensuring the safety of the camper they are working with. The senior staff appear to not be accepting the "real" world of camp as their expectations are based on what camp "should" be, what training "should" consist of and how experienced and knowledgeable the support staff "should" be whereas the supervisors and parents appear to have more realistic expectations within the "real" world of camp.

Contexts and Severity

Within the findings of Chapter four, no participant described an "severe" case the same; there were some similar references based on needs, level of support and behaviours but every participant had a different definition of what they considered to be "severe". Within the three organizations there clearly are varying levels of what each organization considers "severe". Each organization will accept "severe" participants based on their previous knowledge of the

participant and how comfortable and familiar the supervisor and senior staff are in handling the participants behaviours. The “severe” participants from an integrated camp such as Organization C are not considered to be “severe” cases at Organization A and B. Yet there is a threshold of severe for each organization, as Supervisor C comes from the largest non-profit organization of all the participants. He openly discussed that serving children with high needs is not at the forefront of the organization’s focus of their programs. “They’re trying to serve the most amount of people possible so they’re really not focusing on the most severe cases cause it’s the minority of people that come to the program so they will do their best to try to accommodate but they can’t and they won’t. They won’t stretch beyond their means”. Supervisor C was focused on “...ensuring the child had a positive camp experience and the child was set-up to be successful...”

He provided examples of where they would modify and adapt a child’s schedule to suit their needs. He provided an excellent example of allowing an “severe” case child to swim twice a day so she was engaged, active and enjoying herself. This child was 7 years old and their behaviours were manageable when the Supervisor was able to modify the program to a location where he was able to better control the environment and schedule. Another example of Organization C’s threshold for severe is one of the mothers whose child attended Organization C’s camp was given a refund for her remaining weeks at camp as the staff could not handle her child. The camp staff of Organization C had reached their threshold of severe and was unable to manage the child at camp as the Mother was receiving multiple calls from the staff on a daily basis to pick up her child due to her child’s behaviours. This child had been attending Organization C’s camp since the age of 5 and the child is now 11. At Organization A and B camps the child still exhibited the same behaviours but the camp staff’s threshold of severe is much higher than Organization C and the mother did not receive a single call home from either of these camps. Organization A and B

do have to ensure that any camper who they consider to be severe be paired with a very strong and experienced staff member, preferably one who has previously worked with the camper. The senior staff will also ensure that the staff receives additional information and strategies about the camper, the staff may have a walkie-talkie for extra support as well as a separate, quiet area for the camper. While these may seem like additional supports they are provided to almost all of the “severe” campers attending Organization A and B. All of the mothers who completed the parent survey have children who are considered to be severe but their level of severity is fully dependent upon who they are paired with, what environment they are in and how their day has gone. An example of how the level of severity depends on the context is when the mothers have their respite workers take their child out into the community. The respite worker is selected by the family in most cases because the worker is familiar with the child and has connected with both the family and the child. When out with the respite worker, and participating in preferred activities, the child who is considered “severe” is happy, content and very compliant. This is just one example of how the context impacts the perceived level of severity. Staff A discussed how he perceives level of severity “... I guess my picture of an severe case might be a little different than anyone else’s being a big, tall male I feel like unmanageable behaviour doesn’t really exist for me”. Supervisor C leaned towards this feeling as well but did not openly state it. Severity is in the eye of the beholder and is define by the individuals threshold of what they consider to be severe.

Recommendations and Future Directions

Real World of Camp Training & the Structured Environment

All of the participants interviewed discussed the need to improve their camp training as it was not adequately preparing the support staff. Policies and procedures must be included in an

organization's training for liability and safety purposes, but the organizations should consider having additional time dedicated to the "real" world of camp. The literature states the importance of having a structured environment with the right visual supports in place to better support an extreme case, but in the real world of camp this is not always possible. My findings indicated that clinical standards cannot be transferred to a recreational setting as the programs are often not supervised by a clinical psychologist, camp personnel are not trained to follow specific clinical protocols and they have limited to no experience in gathering data, performing assessments and--based on the assessment--adjusting the program. A majority of camp personnel are under the illusion that camp should be a structured, controlled environment similar to the clinical world. There a naïve reliance on the "structured environment" as a transition tool in and of itself. The reality of the camp world is that it is a chaotic environment where staff attempt to plan and implement visual supports and a structured environment but the day usually never goes as planned due to the unpredictability of the "severe" cases and the camp environment constantly changing. As a result of these two factors the camp staff are constantly having the react which does not create a structured and controlled environment. It may be beneficial to have a portion of training dedicated to better understanding of the camper, observation skills, and how to effectively use the visual supports and strategies in all different environments rather than rely on the structure of an environment. The supervisors of the organizations focused on camp as a whole and had realistic expectations of camp and of their staff. It would be beneficial for the senior staff to be mentored and coach by their supervisors or a specific training where the focus is on their expectations of camp as a whole, camp staff and their mentoring and coaching skills.

Profiles

The profile is a tool that varies across all organizations and is not utilized by staff outside of training. Hence it is not an effective tool. Profiles are meant to provide camp personnel with a background and overview of the camper they will be working with. The parents accept that in order to have their child's needs met they must complete the profile in a way that provides the camp staff with a realistic view of their child, while not being overly negative and scaring the camp staff. The parents who participated in the parent survey were more than willing to complete a detailed profile, meet with the staff working with their child prior to camp, and if necessary, bring their child to camp to meet the staff and have their child become comfortable with the space. Each summer the mothers will take the time to complete a new profile for each organization even though their children have been attending camp from 4-15 years. A more effective way of completing or updating profiles should be considered by all organizations to ensure that they are receiving relevant information that will assist the staff working with the "severe" cases. The information gathered in the profile should be presented to staff in a way so they respect the child's privacy and dignity and not scare the staff, but still have them prepared for the reality of working with the "severe" case.

Returning camp staff rarely refer to, or review the profile as they assume that their prior experiences with the child prepare them to work effectively with the child. Returning staff also feel the need to provide the new camp staff with how *they* feel the new staff should be working with the camper and what works. Once in the real world of camp and in the moment or in-action, the profile is disregarded. Rather, they go on instinct, their previous experience with the child, or what strategies may work with a child with ASD in general. Camp staff do not have open access

to the profiles as they contain personal information and are normally kept in an office or binder only accessed by the senior staff and supervisors. The use of the profile should be integrated into the daily notes or communication-log so that parents and staff use it as point of reference on a daily basis.

What is needed for these programs to provide physical activity to “extreme cases?”

In order for physical activity to be a permanent part of any of these recreation programs, the organizations need to receive funding from either the government (through a program grant) or a private funder. For either of these two options to occur, further research is necessary to reinforce the importance of physical activity in a recreation setting for “severe” cases. Furthermore, future research on the benefits of physical activity for “severe” cases in other settings such as clinical and educational environments would assist in other sectors being open to the idea of physical activity programs.

All of these “severe” cases are going to become adults and there is a lack of publicly and privately funded day programming or long term care programs in general for “severe” cases that require 24/7 1:1 care and support. As Mother E stated her son is 21, he only has two programs to attend and she is concerned about his programming options in the not-so-distant future. Future studies focusing on physical activity within an adult day program would provide these organizations with a plausible model of how to incorporate physical activity into their own programs. In order for these day programs to provide physical activity there needs to be an increase in the training opportunities that focus on physical activity as well as the appropriate space and equipment required.

Considering there is no training course or certificate for professionals on how to facilitate movement and carry out appropriate movement activities, an option could be creating a camp and program specific training for the staff of these organizations that could be run at minimal cost with minimal equipment over a half or full day training period.

Future Directions

Utilizing the parents as resources in future studies would be beneficial as the mothers who participated in the parent survey are more than willing to participate in any study that could help their child obtain quality of life both in the community and at home. A pilot study using the parents as consultants to help guide the use of profiles as well as staff training may assist organizations in providing more practical training and programs that meet the needs of the staff and camper. Another study focusing on the effectiveness of camp would also be beneficial as camps struggle to receive funding as they do not have the capacity to collect data on how effective camp is to the families and the community. To these families camp is not a leisurely, recreation activity to keep their kids busy; it is an integral part of supporting these families. Camp is a part of a continuum of services and the Niagara Region as a whole needs to recognize the value of camp.

Upon the completion of this study, it is clear that this is just the beginning as there is a need for future research to be done on understanding “severe” individuals with ASD and how organizations can provide programs to meet their needs over the course of their lives. It is the parents and mothers of these children who will continue to support each other and advocate on behalf of their child to the organizations, researchers and other service providers within the Niagara region to create programs and training for individuals with “severe” ASD.

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Appendix A

37 Shared Intervention Components (Callahan, Shukla-Mehta, Magee, & Wie, p. 78-81, 2010)

1. Teachers and service providers who are knowledgeable, experienced, and qualified in autism, including how to correctly apply and evaluate behavioral management, communication, social interaction, independent living, cognitive and academic skill instructional interventions, and related strategies and curricula
2. An individualized program developed and implemented to provide meaningful educational benefits (including measurable and adequate gains in the classroom)
3. Assessment of all relevant domains (including social competence, communication, environmental influences, physical functioning/motor skills, academic/vocational skills), using a variety of methods, in order to develop individualized goals and objectives
4. Relevant, individualized staff training, including ongoing in-service training opportunities
5. The measurement, documentation, and reporting to parents of student progress toward annual goals and objectives
6. Ongoing monitoring and evaluation of the effectiveness of the teaching interventions being used
7. Modifying the intensity, methods, and/or curriculum of a student's program if there is a documented lack of progress over an extended period of time
8. The use of specialized curricula/strategies to teach social skills
9. Instructional programming that targets all affected areas of development in order to meet the unique characteristics and individualized needs of each child
10. Establishing secure, caring teacher–student relationships, and engaging children in active, positive interactions with adults
11. Individualized programming which addresses developmental content areas (including communication, social development, adaptive behavior, cognitive development, and adaptive physical education)
12. Ongoing monitoring and evaluation of the program's overall effectiveness
13. Providing instructional interventions and related services that promote or support intensive and/or extended academic, social, and behavioral engagement (including extended-day and extended-year programming)
14. Individualized programming which addresses non-academic content areas (including attending to elements of the environment, imitating others, language comprehension, use of language, playing appropriately with toys, interacting socially with others, recognizing emotions, and self-help skills)
15. Direct involvement of parents and family members in their own child's school program
16. Development of life skills, and vocational/employment/occupational skills through school-based and community/work-based learning experiences)
17. Training parents to be significant providers of services and interventions in order to achieve more extensive generalization and better maintenance of treatment effects
18. The use of specialized curricula and strategies to teach communication skills (including script fading, written social phrases, functional communication training, and teaching spontaneous self-initiated responses/verbal imitations)

19. Active engagement of children throughout the day in intensive instructional programming, with repeated planned teaching opportunities and frequent opportunities to practice new skills
20. Transition programming implemented at all ages and levels, using proactive positive behavioral supports
21. Intensive generalization programming (the use of materials, interventions, and environments designed to teach skills that are necessary for successful transitions and functioning in new environments)
22. The use of specific motivational procedures (preferred items and natural reinforcers) in order to increase responsiveness to social and environmental stimuli
23. The effective use of reinforcement, including the use of natural and direct reinforcing consequences
24. The use of detailed task analysis (breaking complex behaviors into smaller parts) in order to systematically teach new skills and sequences of behavior
25. The use of incidental teaching and/or naturalistic teaching (arranging the teaching environment to increase motivation and students' opportunities to respond to a variety of stimuli in the child's natural environment)
26. Peer-mediated interventions, including the involvement of typically developing peers in collaborative activities, including social skill training groups and play groups
27. The use of task variation (using a variety of tasks and/or the interspersal of tasks the child has already mastered when teaching new skills) in order to improve motivation and responding
28. Use of materials, interventions, and environments that are conducive to broadly generalized intervention effects
29. Providing an intensive treatment program in the classroom, resulting in active engagement of each student for a minimum of 25 h per week
30. The use of internal and external consistency in the school environment (internal in the use of instructional strategies and external across teachers and settings)
31. Use of curriculum-based assessment (repeated measurements of academic target behaviors, using direct observation and recording of a student's performance of the curriculum as a basis for making instructional decisions)
32. The use of pivotal response training (teaching skills and behaviors that are central to wide area of functioning and produce generalized improvements)
33. The use of desks, furniture, and other materials in the classroom designed, arranged, and/or adapted to meet individualized student needs and increase appropriate responding
34. Individualized programming which addresses traditional academic content areas (including math, reading, and writing)
35. Incorporating students' preferences and/or interests into the instructional program or curriculum in order to teach new skills and/or modify instructional tasks
36. The use of technology, including computers, handheld electronic devices, and other augmentative communication devices
37. The use of self-management strategies (including self-evaluation, self-monitoring, and goal setting) to teach new skills and/or support newly learned skills

Total number of "BOTH" components: 37

Appendix B

Letter of Invitation

April 2012

Title of Study: A Comparative Analysis of Community-Based Service Providers for “Extreme Case” ASD: Exploring Activity Program Options

Principal Student Investigator: Laurie-Beth Brown, Masters Student, Centre for Applied Disability Studies, Brock University

Faculty Supervisor: Dr. Maureen Connolly, Faculty, Department of Kinesiology, Brock University

I, Laurie-Beth Brown, Masters Student, Department of Applied Disability Studies, Brock University, invite you to participate in a research project entitled “A Comparative Analysis of Community-Based Service Providers for “Extreme Case” ASD: Exploring Activity Program Options.”

This study will focus on how community-based organizations who provide programs for children with ASD who are “extreme cases.” This study aims to focus on the programming, training and structure of community-based programs through the support staff’s and supervisor’s perspectives and exploring issues relating to identifying the movement and communication needs of “extreme cases” and developing programs and training for these community-based programs.

The expected duration of your participation includes your participation in an interview lasting 30-60 minutes.

This study will provide insight into the unique needs of children with ASD within the Niagara Region that are participating in these community-based programs. This research may assist in more programs being offered within the Niagara Region who are “extreme cases.” This study provides an opportunity to provide training and recommendations to the community-based organizations that could contribute to more meaningful, relevant, and dignified programming and program support.

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca)

If you have any questions, please feel free to contact me.

Thank you

Laurie-Beth Brown
Principal Student Investigator
Masters Student
(905)359-7323
lb05rg@brocku.ca

This study has been reviewed and received ethics clearance through Brock University’s Research Ethics Board (file # 10-152)

Dr. Maureen Connolly
Faculty Supervisor
Professor
905-688-5550 ext. 3381
mconnolly@brocku.ca

Appendix C

Letter of Consent

April, 2012

Title of Study: A Comparative Analysis of Community-Based Service Providers for “Extreme Case” ASD: Exploring Activity Program Options

Principal Student Investigator:

Laurie-Beth Brown
Masters Student
Centre for Applied Disability Studies
Brock University
(905)359-7323
lb05rg@brocku.ca

Faculty Supervisor:

Dr. Maureen Connolly
Professor
Department of Kinesiology
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INVITATION

You are invited to participate in a study that involves research. This study will focus on how community-based programs provide programs for children with ASD who are “extreme cases.” This study aims to focus on the programming, training and structure of community-based programs through the support staff’s and supervisor’s perspectives and exploring issues relating to identifying the movement and communication needs of “extreme cases” and developing programs and training for these community-based programs.

WHAT’S INVOLVED

As a participant, you will be asked to participate in a standardized, open-ended interview with the principal student investigator that will be audio-taped. Participation will take approximately 30-60 minutes of your time. Approximately 2 weeks after your interview, once the transcription of your interview has been completed, the principal student investigator will be contacting you by e-mail to participate in the member checking process. The member checking process allows for you to view your transcript interview and gives you the opportunity to elaborate or comment on any portion of your transcript. Participation in the member checking process will take approximately 30-60 minutes of your time.

POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include gaining valuable insight into the unique needs of children with ASD within the Niagara Region that are participating in these community-based programs. This research may assist in more programs being offered within the Niagara Region who are “extreme cases.” This study provides an opportunity to provide training and recommendations to the community-based organizations that could contribute to more meaningful, relevant, and dignified programming and program support. This also will add to the sparse body of literature on the children who are “extreme cases” participating in community-based programs. **Possible risks include participants becoming upset or sad, in which case participants are encouraged to seek further counselling available to them through community support organizations. These community support organization are able to**

provide therapeutic follow up as necessary. Decisions about research participation will not be related in any way to program delivery. Data collected from informants will not be used for secondary data. Only the principal investigator and student investigator will view the data. The written analysis of the data will not give information that will be related back to informants. Otherwise, there are no anticipated risks associated with participation in this study.

CONFIDENTIALITY

All information you provide is considered confidential; your name will not be included or, in any other way, associated with the data collected in the study. Furthermore, you will not be identified individually in any way in written reports of this research.

There will be one master copy of the interview transcript that includes all participants' demographic information: names, initials, gender, and organization. This information will not be included under the data that needs to be analyzed. Personal identifiers will be collected during the course of the research to allow for people to withdraw. I will not be using any information from the master copy of the interview transcript that will allow children, parents, or consultants to be identified in the findings. This master copy of the interview transcript will be retained in a separate folder and kept locked in a controlled access room. The participants then will be coded with unique numbers and their data will be analyzed with these unique codes.

Data collected during this study will be stored in a locked cabinet to keep secure in a controlled-access room. All written data will be transferred to a data stick which will be wiped upon completion of the project. This will ensure the data is secured. Only researchers working on this project will have access to this data. Participants will not be identified in any way should findings be published. Participants will be given the opportunity to receive their transcripts following the completion of the study. Data will be kept for the duration of the study after which time all data will be wiped from data stick and any paper copies will be shredded. Access to this data will be restricted to Laurie-Beth Brown and Maureen Connolly.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. **Furthermore, the data is not anonymous, you may decide to withdraw from this study up to the point when the interview is completed and may do so without any penalty.**

PUBLICATION OF RESULTS

Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available (include information about whom to contact, how to contact them and when feedback will be available).

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact the Principal Investigator or the Faculty Supervisor (where applicable) using the contact information provided above. This study has been reviewed and received ethics clearance through

the Research Ethics Board at Brock University (#10-152). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

CONSENT FORM

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____

Signature: _____ Date: _____

Appendix D
Senior Staff Interview

Describing an “Extreme Case”

What do you think of when you hear the term “extreme case” child?

What is your definition of a child with ASD who is an “extreme case?”

What changes or additions would you make to this definition of “extreme case?”

Organization

Describe for me the types of children your organization provides programs to?

What is your organization’s overall goal/mission for your programs?

What is your organization’s policy for accepting children who are “extreme cases?”

What characteristics or qualities set your program above other programs in the area?

How effective do you feel your organization is at integrating extreme cases into your programs?

Interviewee’s Role

Describe for me your role within this organization?

What education (program, level, etc.) have you received?

What experience do you have working with children with ASD?

What expectations do you feel your supervisor has of you as a support staff?

What is your role with working with children who are “extreme cases”?

Meeting the Needs of the Child

How do you determine the needs of a child participating in your program?

Describe for me the process of how you would meet the needs of an “extreme case” child within your program?

- i.e. Meet with parents to create a profile, previous case notes etc.

In your opinion, how effective is your program at meeting the child’s needs?

Describe for me the process of how you would create and structure a program for a child who is participating in your program?

What are some of the challenges/barriers you experience when creating this program?

What is your opinion on incorporating physical activity into the program?

In your opinion, what are some of the advantages of incorporating physical activity into the program?

In your opinion, what are some of the disadvantages of incorporating physical activity into the program?

What are some physical activities that you would add into the program?

What are the challenges you experience when trying to integrate a child into the program?

Describe for me how your program would accommodate a child who....Based on previous examples discussed in interview

Describe for me the tools/resources (pictures, schedules) your program uses to meet the needs of the child?

Describe for me the strategies you would use when a child:Based on previous examples discussed

What changes do you feel the program could make to better accommodate the child's needs?

How does your organization determine when a child is not a good fit for your program?

- Describe the process that your program goes through, when determining if a child is not having success in your program? - what factors/risks are you looking for?

Training

Describe for me how your organization trains your staff who works with children with special needs?

- What types of presenters or topics are covered at training?
- How does the training vary when support staff are working with a child who has "extreme" needs?

How effective/practical do you feel the training you receive is?

What training topics do you feel you benefit from the most?

What training topics do you feel are not as beneficial?

What areas/topics do you feel you could be better trained in?

What additional training do you feel you would benefit from?

Describe for me how you feel your supervisor supports you within your role?

Concluding Questions

Please tell me a question you wished you would have been asked?

Is there any other information you would like to add?

Appendix E
Supervisor Interview

Describing an “Extreme Case”

What do you think of when you hear the term “extreme case” child?

What is your definition of a child with ASD who is an “extreme case?”

What changes or additions would you make to this definition of “extreme case?”

Organization

Describe for me the types of children your organization provides programs to?

What is your organization’s overall goal/mission for your programs?

What is your organization’s policy for accepting children who are “extreme cases?”

What characteristics or qualities set your program above other programs in the area?

How effective do you feel your organization is at integrating extreme cases into your programs?

Interviewee’s Role

Describe for me your role within this organization?

What training do you receive that better prepares you for helping your staff as they work with this population?

What additional training do you feel would benefit you in your current role?

What is your role with working with children who are “extreme cases”?

Meeting the Needs of the Child

How do you determine the needs of a child participating in your program?

Describe for me the process of meeting the needs of an “extreme case” child within your program?

- i.e. Meet with parents to create a profile, previous case notes etc.

In your opinion, how effective is your program at meeting the child’s needs?

Describe for me the process of how a program is created and structured for a child who is participating in your program?

What are some of the challenges/barriers you experience when creating this program?

What is your opinion on programming physical activity into the program?

In your opinion, what are some of the advantages of incorporating physical activity into the program?

In your opinion, what are some of the disadvantages of incorporating physical activity into the program?

What are some physical activities that you would add into the program?

What are the challenges your staff experiences when trying to integrate a child into your program?

Describe for me how your program would accommodate a child who....Based on previous examples discussed in interview

Describe for me the tools/resources (pictures, schedules) your program uses to meet the needs of the child?

Describe for me the strategies your staff uses when a child is... (refusing to leave, needing a break etc.) Based on previous examples discussed in interview

What changes do you feel the program could make to better accommodate the child's needs?

How does your organization determine when a child is not a good fit for your program?

- Describe the process that your program goes through, when determining if a child is not having success in your program? - What factors/risks are you looking for?

Staff

What expectations do you have of your staff when working with a child that is "extreme case?"

Describe for me how your organization trains your staff who works with children with special needs?

- What types or presenters or topics are covered at training?
- How does the training vary when support staff are working with a child who has "extreme" needs?

How effective/practical do you feel is the training your staff receives?

What training topics do you feel your staff benefits from the most?

What training topics do you feel are not as beneficial for your staff?

What areas/topics do you feel your staff could be better trained in?

What additional training do you feel your staff would benefit from?

Concluding Questions

Please tell me a question you wished you would have been asked?

Is there any other information you would like to add?

Appendix F



Brock University
Research Ethics Office
Tel: 905-688-5550 ext. 3035
Email: reb@brocku.ca

Social Science Research Ethics Board

Certificate of Ethics Clearance for Human Participant Research

DATE: 11/2/2011
PRINCIPAL INVESTIGATOR: CONNOLLY, Maureen - Kinesiology
FILE: 10-152 - CONNOLLY
TYPE: Masters Thesis/Project STUDENT: Laurie-Beth Brown
SUPERVISOR: Maureen Connolly
TITLE: A Comparative Analysis of Wrap Around Service Provision for "Extreme Case" ASD: Exploring Activity Program Options

ETHICS CLEARANCE GRANTED

Type of Clearance: NEW

Expiry Date: 11/30/2012

The Brock University Social Sciences Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from 11/2/2011 to 11/30/2012.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 11/30/2012. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at <http://www.brocku.ca/research/policies-and-forms/research-forms>.

In addition, throughout your research, you must report promptly to the REB:

- a) Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
- c) New information that may adversely affect the safety of the participants or the conduct of the study;
- d) Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved:

Jan Frijters, Chair
Social Sciences Research Ethics Board

Note: Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.

Appendix G

Sample of Original Interview Transcript: Supervisor B

How effective or practical do you feel the training is?

Depends on how much time we get to spend on that case or at least behaviour specific portion is. Um, depending on whose lucky enough to be able to provide the training. Uh, if there if its someone who feels um that we can get through the policies and meet all the requirements of the organization and still have enough time or the staff that are willing to put in the time to really learn about the folks who are going to be involved in the program, um those are the most effective trainings. Um, if it ends up being a training where we have to cut it short or the policy portion takes longer then uh that's where I find the staff sometimes if there not as well versed coming into the program have a little bit more difficulty with those types of kids. Um in mostly, like I said before, it's their confidence level. I don't think they feel prepared when that kind of thing happens when we haven't prepared them for that. I would like to see that be a standard part of our training and be an extensive part, not just an afterthought but you know you have to follow the legalities of organization and make sure you cover all that other stuff too.

What training topics do you feel that the staff benefits the most from?

Again it depends on the type of staffing, if its new staffing, this is another thing that I think we could change with our staff training, is new staffing verses staffing that have been around for a while. The new staff they need some basics, they need to be brought up to speed and we lose the older staff when that is happening cause they've been around already they don't need to hear the same spiel on ASD again so it's better if we I think if we could focus our training needs. But I think that the pieces that are going to be most effective are the looking at the what if's do you know to manage those extreme issues that pop up for the kids that aren't necessarily extreme cases but have extreme moments and for those folks who we already know are to coming in who potentially have extreme case or are extreme cases that are going to be issues all the way through and how we manage those. I think that's going to be the most effective training. But people who are brand new are not going to be open to that, that's just going to scare them away so I think we have to be a little bit careful on how we present that kind of information.

And you talked about that sometimes the policies take away from the training, are there any other topics that you feel aren't as beneficial for the staff?

Ya, most staff could care less about our organizational structure, I know it is an important piece and I value you it, I work here, I am a permanent staff here, it's different for staff that are just coming in and working a three hour shift for a twelve week period. They don't care. They need to know that we are an organization and what we do but they really just don't need to, I don't

believe that we need to spend as much time as we do on the hierarchy of our organization and the history. That's great information but maybe we just give that out as a handout. I think that would give us more time to focus on the point of why those staff are here which is to work directly with the kids and giving them the focus they need.

Are there any areas or topics that you feel the staff could be better trained?

Ya they need to be better trained in behaviour management strategies and basic skills that will prevent behavioural issues, um, I you know I think that there's very few times where there ever should be a child unable to control themselves in the situation around them if the staff are trained well enough to read the cues and use their observational techniques and intervene before we get to that point. We can become very well versed in what their cues are by getting that information through parents if they are willing to share it will us beforehand obviously and know what is going to trigger things and have responses to have that prior to that, but if they don't have that time to really observe and practice they're not going to necessarily going to see it as quickly as they need to and we end up with a potentially dangerous situation.

What additional training do you think your staff would benefit from, so whether they would go away to a different organization or?

It's kinda of difficult with our staff because they are very very temporary. A few hours so investing in them to go to training opportunities is difficult for a non-profit organization um, things we do do are offer them free opportunities to attend the trainings that we do bring to the area. It would be great if they did chose to attend all of those trainings and learn from the professionals we bring in and because its not a requirement or something that they are needing to do they don't always do that but um, you know being familiar with the sensory issues of our kids, the anxiety levels of our kids, behavioural techniques, the movement needs, uh, it would be so many areas if they just had more familiarity with that I think that that would be able to uh culminate together to make a nice package of a solid worker who could be able to seal that before it hits something.

Okay so these are just a few concluding questions, what should I have asked you that I didn't think to ask?

..pause... huh, hmm that's a good question let me think about that one.

Is there any other information that you would like to add?

That's not any better of a question. Laughing... what other question could you have asked me. Hmmm. Knowing what I know what I know what you're trying to study. I don't think so.

There's no pressure.

Well..pause... one thing I am surprised that you didn't ask about actually is it kinda of like if we get all this information about kids beforehand does that set like a judgement or you know what I mean like uh, do we make predetermined beliefs about a child before they even walk in the door and therefore potentially hinder their involvement or change it in a way more than what we even needed to do based on what they say on paper. Cause I find that that happens sometimes, that parents state the worst um, which rightfully so, we've got some kids who have some significant needs and really have caused a lot of difficulty for families but when you put it down on paper it sometimes comes across in a very negative way. I think that the kind of really interfere with sometimes how we set up our programs, and I really wish there was a way to get around that. I don't know what the best way to do that, sometimes it might just be the wording of our questions, we're always trying to adjust to change. It would be nice if there was always a way to meet the kids beforehand.

I guess going off on that topic, do you feel that the staff um, makes a lot of assumptions about extreme cases or has fears?

Yes, ya

And do you feel then that are they well coached on how to handle this or is that when the confidence and experience piece?

I think that's the experience piece and self confidence in their abilities. The longer, not that most first staff have been around very long, most staff are young, the more they do it, the more they realize that it's okay to have a thought but it's an opinion that makes a difference. If you are setting yourself up to already have a predetermined opinion about a child before they walk in the door, it really changes their approach, you can have some thoughts on what they might be like and being open to that being changed drastically in the first five seconds and I don't know if every staff gets that concept because they're given the information on a piece of paper that says that this kids probably going walk in and smack me in the face before the end of the night and it's hard not to be weary of what that might look like.

Do you think that the staff feels supported when working with an extreme case, like that there behaviour lead or supervisor supports them or do you feel like the kinda of again unsure?

I think it depends on the staff, and it depends on the staff and it depends on the person that their working with. I think that if they have set It up so that they are in a very supportive role and uh are there involved and the staff feel that then I think they do. Um, has there been times in the past where that hasn't been the case, absolutely. Has it been exacerbated because the staff don't have the self-confidence, absolutely. I think it's a mix of a lot of different pieces, um but ya, I wish that there was a, some I almost wish we could do video tapes of kids before I guess part of the application process for some of these things, so that they can see the happy smiling kid as well as the melt down kid, before the kid ever walks in the door.

**Do you feel then that the application process could be better and have more improvements?
Just from your experience from working with the parents and seeing that side of things?**

I think it's always, everything's always open to improvements you learn from our mistakes and our professor always said if we don't look back at things ten years ago and cringe then we haven't gone anywhere in life and I think that totally implies, we can stuck in a rut sometimes and we don't open up to change but I think every single time we have to look at the last it and just tweak it and see what we can do better this time. If we had all the time and money in the world, I think there is so many things we can do better but I think with the means that we have we're doing the best we can! And I think its meeting most people's needs.

That's great is there anything else that you wanted to add?

I am done

Appendix H
 People, Places, Objects & Happenings Senior Staff

People		
Senior Staff A	Senior Staff B	Senior Staff C
“Severe”Cases <ul style="list-style-type: none"> • High Functioning • Low Functioning • Youth/Teenagers Supervisor Volunteers Senior Staff Parents	“Severe”cases <ul style="list-style-type: none"> • High functioning • Low functioning Parents Family Support Coordinator NVCi consultant Staff Senior Staff Supervisor B Supervisor A	Staff <ul style="list-style-type: none"> • 1:1 staff • Senior Staff • Regional supervisor • Camp Director Agency Consultants Supervisor A Campers
Places		
Senior Staff A	Senior Staff B	Senior Staff C
<ul style="list-style-type: none"> • Camp • School • Gym • Community • NTEC • SNAP • CAP Class • School board • Classroom • Pool • Bowling • Beach • Outside • Sensory Room • MacBain Centre • Fine Motor Room • Bus • Training 	<ul style="list-style-type: none"> • Programs • Camps • Brock Movement Camp • City • Open area • School board • Bathroom • TEACCH activity • Bethesda • Pathstone • Red Roof • Social Skills program • Life Skills program • Gym • Smaller room • Outside • Home 	<ul style="list-style-type: none"> • Camp • Programs • Niagara Falls • School board • SNAP • Forest • Gym • Kids First program • Structured environment • Agencies • Niagara region • Burgoyne woods • Fort Erie • Community Living • Bus • Active games • Computer

<ul style="list-style-type: none"> workshops 	<ul style="list-style-type: none"> Pool Bus Outdoor games Craft Water play Movement station Fine motor Training workshops 	<ul style="list-style-type: none"> Gross motor Structured free time Hiking Training <ul style="list-style-type: none"> Conference city
Objects & Strategies/Tools		
Senior Staff A	Senior Staff B	Senior Staff C
Physical activity <ul style="list-style-type: none"> Springboards Benches Games Parachutes Equipment Big shapes Mats Scooters Balls Ropes Climber Strategies/Tools <ul style="list-style-type: none"> Same schedule of activities Strict and firm Basic verbal communications First, Then Very simple Specific instructions Pictures Visuals Breaks to calm down Leave early Countdowns Constant reminders Transitions Funding Profiles	<ul style="list-style-type: none"> Information Policies Protocols NVCI Money supplies Incident forms Profiles Debrief Curriculum Superflex Social Times Education Physical Activity <ul style="list-style-type: none"> Medicine ball Trampoline Stations Strategies/Tools <ul style="list-style-type: none"> Break Stations Rewards Token system Talker Visuals Social stories Transition warnings Library of resources Daily schedule Choices Sensory toys 	Physical Activity <ul style="list-style-type: none"> gross motor balance beams vaults trampolines mats balls Policies OCA Standards Case scenarios Missing camper drills Sign language Education Profile Funding Strategies/Tools <ul style="list-style-type: none"> Token boards PECS Transitions 1:1 support Program plan Resource binder Social story Schedule Sensory toys

Policies resources		<ul style="list-style-type: none"> • Behaviour management • Adapting • Changing activity • Countdowns • Visuals • Redirection • First, Then
Happenings		
Senior Staff A	Senior Staff B	Senior Staff C
<p>Bus ride home “...at the end of the day the bus ride home from wherever we are, on the bus ride back to the school it is 10 times quitter and relaxed then it is going to be out there because it’s the end of the day and they have just been worked to the bone all day...”</p> <p>Chaotic First Day “Revamping training to make it more effective so volunteers are more prepared to work with the kids and we don’t have a lot of times we lost that first day at camp cause it’s so chaotic and people are panicking so we are trying to revamp training to better prepare people so we cannot have as many problems.”</p> <p>Control the environment you can control the behaviour “...if you control the environment you can control the behaviour a lot more so we tried to control the environment a lot more.”</p> <p>“Uhh take’em for a break if they are having trouble with a</p>	<p>Supervisor wants to fill spots but isn’t there to help staff “..earlier provision of information would’ve been nice... if you’re having an a really “severe” case I think that maybe before camp to have a talk with the parents and like I mean throwing a kid in that’s never been to camp and is extremely low you’re just asking for trouble. Which we had but she wasn’t there to help right so?”</p> <p>Profiles need to be filled out more in-depth “I mean especially if the parents have a language barrier I think there just needs to be more umm information like the profiles that we’re given are definitely in depth but at the same time they’re not necessarily filled out in depth.”</p> <p>Staff Preparation and experience Staff not prepared for child who was “severe” case, had behaviours and has language barrier</p> <p>Needs more time to go over</p>	<p>Funding cut by 40% ”I would say the region cutting our funding is a big deal for me...By 40% so I feel like we had to turn so many kids away this summer and staff away this summer because of this funding cut and our numbers are drastically lower compared to last summer. So staff this summer I had 4 compared to 6 I had last summer. St.Catharines now has 6, compared to the 12 staff last summer. Cut by half pretty much.”</p> <p>“Ya because we can’t accept as many kids as we did last year because we don’t have the staff to support them so kids that I like for example 2 campers I had last summer who because we guarantee them the 4 weeks, yet the 4 weeks and then if you want extra we put you on a waiting list and then if staff is available then you get those additional weeks. In previous years we have been able to give these additional weeks to these 3 specific families who need them because their parents are working or single</p>

<p>specific activity at a specific time you would take'em for a break get them to calm down."</p> <p>"...a situation of a high stim say you use the rope example we took the ropes away from them like we eliminate the behaviour."</p> <p>"So if the kids was losing his mind in the fine motor room when there was 15 other kids in there you take him up 5 min early so you can get his fine motor in and then allow him to stay in the room for 5 min once the 15 kids show up so he kinda gets to used to it and then u leave and go do something else so for a gross motor activity."</p> <p>"...if they're having a struggle with the shapes at the moment you take'em and run'em around the somatic square and go back to the shapes. You start small and work big so stuff like that."</p>	<p>profiles, time to prep for camp, call families, talk to other staff who know kids</p> <p>Meeting the needs of the camps depends on how the staff is (their level of experience).</p> <p>Hiring staff who are experienced and qualified, understand functions of behaviour etc."</p> <p>"huge gap in the knowledge"</p>	<p>parents but this year because of all this funding cut I can't even do it. So now the parents are mad at me say "What am I supposed to be doing with my kid for the month of August because I work full time, I am a single parent what am I supposed to do. And I'm like..."</p> <p>Keeping an "Severe" Case in a program</p> <p>"I had him all of this year in my kids first program that I ran and honestly he is extreme case like he is very challenging and like it was me who kept him in the program because I knew mom needed a break and its good for him and its good for him to be here but like there are so many times that I was questioned by my supervisors if he was benefitting from the program? Are you sure you want to keep him in the program? Then I have mom telling me that he was kicked out of an organization, kicked out of all these programs mom's like this is the only place that hasn't kicked him out. So I worked with mom and we worked together and kept him in the program...I was like you know what mom's stressed I just want to work with mom and work with him to make him successful because like I have hard time and feel bad for these parents who their kids have been kicked out of these</p>
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		<p>programs and they need a break.”</p> <p>“So that required me to step in too and I’m supervisor I’m overseeing but with him I almost had to step in and be a 1:1 support. So it was kind of like me ok I have to step in as a 1:1 support even though I’m supposed to be overseeing and we will just make it work.”</p>
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Appendix I
People, Places, Objects & Happenings Supervisors

People		
Supervisor A	Supervisor B	Supervisor C
<p>“Severe” Cases</p> <ul style="list-style-type: none"> • Lower functioning • High functioning <p>Undergraduate students</p> <ul style="list-style-type: none"> • More qualified • Lack of applied learning • Program planning • Lesson planning • Accommodation • Needs assessment • Observation • Analysis skills <p>Grad students</p> <p>Senior Staff/Mentors</p> <p>Support workers</p> <p>Parents</p> <p>Professionals</p> <p>Interpreters</p> <p>Camp photographer</p>	<p>“Severe” cases</p> <ul style="list-style-type: none"> • Level of functioning <p>Parents</p> <p>Families</p> <p>Siblings</p> <p>Typical peers</p> <p>Volunteers</p> <p>Professionals</p> <p>Staff (new and old)</p> <ul style="list-style-type: none"> • Patience • Exhausting working with “severe” case • Prepared • Confidence level • Better trained in behaviour management strategies • Observe • Practice • Read the cues • Experience • Self-confidence in abilities 	<p>“Severe” cases</p> <p>Staff</p> <ul style="list-style-type: none"> • Program support • Senior Staff • Camp director • Program Coordinator • Male staff • Camp staff <p>Families</p> <p>Parents</p> <p>Teens</p> <p>Staff</p> <ul style="list-style-type: none"> • Exhausted • preparing for next outburst or running away
Places		
Supervisor A	Supervisor B	Supervisor C
<ul style="list-style-type: none"> • University • Gym • Camp • Campus recreation 	<ul style="list-style-type: none"> • Agencies • Programs • Organization • School environment 	<ul style="list-style-type: none"> • Programs • Community organization • camp

<ul style="list-style-type: none"> • In the field • Beach bowling • Bus go-carting • Swimming • Pool • Ropes course (challenge by choice) • Mini putt • Amusement park • Marineland • Program • Physical environment • Sensory room • Training • workshops <p>Stations</p> <ul style="list-style-type: none"> • Educational gymnastics • Fitness stations • Height and flight station • Outdoor activity station • Game skills station • Fine motor station 	<ul style="list-style-type: none"> • Classroom • Niagara • Park • Conference • Local agencies • Government/provincial • Facility • Training • Conference • Craft • debrief 	<ul style="list-style-type: none"> • Welland • St.Catharines • Pre-school program • School-aged program • Teen program • Kids first and kaleidoscope program • Conference • Training • Workshops • School • Outdoor camp • Camp on island • Child care • March break camp • Indoor camp • Science camp • Gym • Weight room • Playground • Autism Ontario camps • McMaster • Bus • swimming
Objects & Strategies/Tools		
Supervisor A	Supervisor B	Supervisor C
<ul style="list-style-type: none"> • Courses • Registration form/profile • 1:1 support • Research • Course assignments • Safety • Sign language • NVCi • Buddy pedagogy (co-active work) <p>Strategies/Tools</p> <ul style="list-style-type: none"> • Same sequence everyday • Group divisions by age 	<ul style="list-style-type: none"> • Social skill program • Life skills program • Siblings programs • Money • Profile • Incident forms <p>Strategies/Tools</p> <ul style="list-style-type: none"> • 1:1 support • Routine • Breaks • Reinforcement tools • Transitional items • Communication tools • Visuals • Pictures 	<ul style="list-style-type: none"> • Profile • Funding • Money • Physical barriers • Service dogs • CPI Training <p>Strategies/Tools</p> <ul style="list-style-type: none"> • Alternative drop-off/pick-up time • Curriculum • Program planning • Pictures • Visual schedule • Cell phone for pictures/music

<ul style="list-style-type: none"> • Station based pedagogy • Embedded curriculum • Movement education profile • Laban movement theory <p>Stations</p> <ul style="list-style-type: none"> • sub-divided spaces • big space into small spaces • discrete separated spaces • specific purpose <p>Educational Gymnastics station</p> <ul style="list-style-type: none"> • climbing • gripping • hanging • swinging • stacking • big gross motor activity • weight bearing • different levels • prepositional relationships <p>Movement concepts/Themes</p> <ul style="list-style-type: none"> • body • space • relationships • effort (quality of movement) <p>Tools/Strategies</p> <ul style="list-style-type: none"> • countdowns • warnings • re-directions • stim toys • stim activities • visual schedule • picture exchange • planned transition • tell don't ask • First, Then 	<ul style="list-style-type: none"> • Structured to meet needs • Accommodate • Alter • Social curriculum • Structure • Everyday tools • Structural tools • Visual tools • Support tools • Behaviour management strategies • Reinforcement • Triggers • How to prevent issues • Sensory • Sib's • visual schedule • Wii • X-box • rotation • structured routines • activities well laid out • TEACCH • Structured teaching <p>Physical Activity</p> <ul style="list-style-type: none"> • Motor activities • Walking • Running • Climbing • Mats • Gymnastics type equipment • Rolling • Upper body muscles • Wall to climb on • Floor type activities • Ball throwing • Basketball 	<ul style="list-style-type: none"> • Microsoft or clip art • Modify • Proactive • Write out program plans • Resources • Time away from group to calm down • Redirecting • Proactive • Focus on positives • Praise <p>Physical Activity</p> <ul style="list-style-type: none"> • Soccer • Tag type games • Relay races • Camp activities • Run around gym • Bosu ball • Scooter boards • Balance • Exercise balls • Gym mats • Decrease behaviours
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<ul style="list-style-type: none"> • Simple singular tasks • Avoid questions that can be answered yes or no • Social stories • Warnings • Prompts • Rewards • Have a plan • Modify on the fly • Task analysis • Reading postural and gestural cues • Anticipate and prevent rather than restrain • Prompts with visuals • TEACCH <p>Money</p> <p>Ratios</p>		
Happenings		
Supervisor A	Supervisor B	Supervisor C
<p>Meltdown Mondays</p> <p>“...they meet with their mentor/senior staff at the end of the first day and the senior staff/mentor say “Well how did that thing works that you thought was gonna work. And they go it didn’t work at all it was awful and so then you have a place to start. I wished there was a way to get them to that point in training so that we could have better first days.”</p> <p>“The Meltdown Mondays ya. I think that’s the biggest problem they seem to think</p>	<p>Programs need to individually driven based on participant</p> <p>“Our programs are <i>individually driven</i> so it depends on the criteria of the program. There are some that require <i>children to have some certain abilities and if they are unable to meet those because our inability to provide the right amount of care for them then they would be excluded for those situations.</i> But most are quite open, its only if for some reason we’re not able to meet that need that we would have to look at alternatives,</p>	<p>Meeting Needs of Child but may not be parent or child’s preference</p> <p>“...so we would pick the camp based on that even though it <i>might not the child’s preference but we want to set the child up for success</i> we would also kind of look at the staff we had available sometimes we would maybe move staff because the Organization C services all different areas... if there’s a staff in St.Catharines that we think might be really strong, like a male staff for example, because in Welland we don’t</p>

<p>that the embedded curriculum is obvious and it is obvious you know in its obviousness they diminish it. They seem to think simple singular instruction, obviously I can do that umm one instruction at a time, consistently give, without yes or no built into it, telling don't asking they seem to think that they'll just be able to do it so they minimize the difficulty of how simple like its simple but it's not easy do u know what I mean."</p> <p>Student's Lack of experience and commitment Like so much of what we present is simple. Almost obvious but it's not easy. It just simple and embedded curriculum is a simple idea, station based pedagogy is a simple idea, breaking stuff into pieces and then putting them back to together as teaching phrase sis a simple idea but it's not easy. It takes a lot of planning and thinking and they have not had the experience of having to plan and think so because it simple they believe it's easy and then they are horrified."</p> <p>"The biggy, inconsistency is the biggy, and untrained undergraduate students who really don't understand Autism and don't understand the significance of particular kinds of strategies and how it would really help them as the teacher as well as the child. And those insight begin to</p>	<p>but we get really creative at adding an additional support, having the parents bring additional support, we get tons of additional information beforehand to find out what are the areas that might be of issue. We're prepared for running behaviours or um, aggressive behaviours."</p> <p>"...we're not able to manage some of the destructive behaviours get a little bit tricky because we don't have padded walls, so that's a really a strong behaviour we'd have to look at if it's a program within inside and if we can't avoid that we might have to worry about that. But if it's an exterior program like within in the park we wouldn't have to worry about those issues and we could include them in the program. <i>It would be based on the individual program but our goal would never be to exclusive and always to try to figure out a way to get every child involved.</i>"</p> <p>Debrief "...that's our opportunity to really break down if a situation did occur and what needs to be done with potential training or information sharing has to happen in order to adjust for the next time. So uh, I think we try to build it all the way through because we're not always fully aware before they enter the program. <i>Parents don't always provide all the</i></p>	<p>have any male staff, we might move some over so we try and set some things up for success."</p> <p><i>-Interaction with parent is key</i></p> <p>Adapted program to suite her needs (swimming) "That was something she really enjoyed umm and it was kid of her movement,. She wouldn't, she would go into gym, but she wouldn't engage in the games. She didn't understand instructions and seemly an interest in being involved. So water was kind of her hook, if it involved water, we could get her engaged. And the playground, she liked to run around the playground sometimes with kids out there sometimes with none at all."</p> <p>Funding Cuts We don t have additional staff and that's a <i>funding issue</i> we can't afford to put support in place for that so depending on the child we would have some kids who would come to camp and receive support but would attend programs and not receive support in programs because programs are shorter just an hour in duration so sometimes they don't need support. And child care we don't know what it is now... we used to have support in child care. But again we had support for that but it got cut and cut and cut."</p> <p><i>"Every year when I started we</i></p>
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happen mid way through camp but I would really like them in place on the first day of camp. Umm my under grad students who.. do not...ummm have a mature understanding of planning and what it means to have a plan umm and ummm modify a plan on the fly if necessary and that the modifications are part of an anticipator set that comes with the plan I think that's a... a constraint."	<i>information even though we ask it."</i>	<i>were able to offer 6 weeks of camp to a family at no additional cost, like they would just pay regular camp price and then it was 4 weeks and then current program."</i>
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Appendix J
Revelatory Phrases Chart: Supervisors

Supervisor A
<p>Martha Graham who is one of the foremost movement educators and dancers of the 20th century, she says movement never lies. That's what she says "movement never lies. It is a barometer. Telling the state of the souls weather for all who can see it."</p> <p>And that's what I think the students need to do. They need to be able to look, and see what are these kids bodies presenting them. You know</p> <p>Not just," oh they can't speak" or they can point or they can direct me somewhere they need to look at the body and read tension or read distress or read happiness, or read the gestural postural cues that these kids are giving us ALL THE TIME.</p> <p>They haven't been taught to see. That's what Martha Graham it tells the state of the souls weather for all who can see it. That means if you're able to see it you can tell what's going on.</p> <p>Question topic: Integration "Well it's not an integrated program. Right? So my program is not integrated in the true sense so I don't have umm a mass off...non-disabled kids at camp and I'm inserting a severely umm autistic person in there. My camp is segregated everyone at the camp is autistic... somewhere on the spectrum and the ratios are reasonably low so umm I don't think I am integrating them"</p> <p><i>"But I think it's a myth you can integrate a "severe" case, I think they can be in the same room with abled bodied peers umm but I think the idea that they're going to on their own function, safely, and with dignity, with a group of same aged peers without some sort of additional facilitation I think that's absurd. It's an absurd expectation. Umm and I think umm...unrealistic in terms of how these kids are in the world, can I help the other kids appreciate what it's like for this kid to be in the world this way, perhaps, ummm but umm but they didn't come to camp to learn about autism."</i></p> <p>"... staff must learn to be better lookers, seers, watchers. They have to practice attentiveness in ways they are not used to...they have to develop that skill with the non-verbal kids. They need to develop a comfort with mess, drool, spit, vomit, snot, shit, pee, mushy food. Most of them aren't prepared for the intimacy of this facilitation. Feeding, cleaning, dressing, undressing, bathing, toileting. They're very squeamish about touching other peoples' bodies...they need to understand that Autism manifests in an embodied way, the disabilities that they're working with manifest themselves in embodied ways and they can't make it into a cognitive exercise or a verbal exercise, it is an embodied exercise."</p> <p><i>"Until they actually encounter the child... so those are skills that they need over and above their ability to be attentive and engaged and interested in the child for 8 hours."</i></p>

“On for 8 hours. ON for 8 hours, ON! Not texting, not thinking about their friends not worrying about their friends not thinking but anything but this kid. FOR EIGHT HOURS umm that kind of attentiveness and disciplined focus that what this calls for you know. So at the end of the day they should be freaking exhausted and most of them are.. umm not to mention the planning.”

Do you think that it's out of fear or the unknown

“ Yes it's fear, its classic stigma. I mean the dimensions of stigma are organized around affect, cognitive, and behavioural. You know and the dimension fear is the affective component of stigma. Stereotyping is the cognitive component of stigma, and social control is the behavioural control of stigma so wanting to control something gets at the behavioural dimension, wanting to stereotype them is the cognitive dimension and being terrified of them is the cognitive dimension but it's all stigma. These kids are stigmatized and largely because their invisible. And we don't have them out in the public eye and they're not seen as priorities in how we prepare our practitioners and their umm part of it is integration but integration has to be meaningful I mean these kids aren't learning French so if they're in a French school there has got to be a good dignified reason why they are there. They need to get something out of it and so do the other kids and that kind of exposure just isn't happening in meaningful ways and that's why people are afraid. I think.”

Supervisor B

Question- Extreme Case

Well I think it can be taken *two different ways*, I'd say the most obvious way to take that would be in regards to *the severity level of their diagnosis*. Um in that they are extremely impaired in you know all areas. Or I would say that it's more the *impact that those areas of impairment are happening on their family*. I think there's a whole lot of cases that I would think that would be crisis or high needs but they don't necessarily have a severely impaired child. Do you know what I mean.

How it's not necessarily based on the severity level but how much it's interfering with functionality. Because you can have someone who's quite gifted in their verbal abilities but become extremely verbally aggressive and not be able to be in the school environment and take advantage of that.

Tools and curriculum

Probably pull the most information out of structured teaching and TEACCH strategies to use for extreme cases. Not that they all need all of elements of that but the portions of the extreme nature of that program that allow them to function in a way that lowers their anxiety is probably why we would target that type of programming the most. But I wouldn't say that there is any one curriculum that would fit any one specific extreme case, they would all be so different, it's going to be just what we are going to need for that child. I wouldn't want to pin point it to a certain curriculum.

What should I have asked?

One thing I am surprised that you didn't ask about actually is it kinda of like if we get all this information about kids beforehand does that set like a judgement or you know what I mean like

uh, do we make predetermined beliefs about a child before they even walk in the door and therefore potentially hinder their involvement or change it in a way more than what we even needed to do based on what they say on paper.

Cause I find that that happens sometimes, *that parents state the worst* um, which rightfully so, we've got some kids who have some significant needs and really have caused a lot of difficulty for families but when you put it down on paper it sometimes comes across in a very negative way. *I think that the kind of really interfere with sometimes how we set up our programs, and I really wish there was a way to get around that.* I don't know what the best way to do that, sometimes it might just be the wording of our questions, we're always trying to adjust to change. *It would be nice if there was always a way to meet the kids beforehand.*

Additional Question

Do you feel then that the application process could be better and have more improvements? Just from your experience from working with the parents and seeing that side of things?

I think it's always, everything's always open to improvements you learn from our mistakes and our *professor always said if we don't look back at things ten years ago and cringe then we haven't gone anywhere in life and I think that totally implies, we can stuck in a rut sometimes and we don't open up to change but I think every single time we have to look at the last it and just tweak it and see what we can do better this time.* If we had all the time and money in the world, I think there is so many things we can do better but I think with the means that we have we're doing the best we can! And I think its meeting most people's needs.

Supervisor C

You mentioned personally you feel you could do a good job... but what about the organization as a whole?

I think there is still room to grow. It's not right at the fore font of what they are trying to do with their programs. *They're trying to serve the most amount of people possible so they're really not focusing on the most extreme cases cause it's the minority of people that come to the program so they will do their best to try to accommodate but they can't and they won't. They won't stretch beyond their means.*

It was hard to separate myself, that was one of my biggest issues with Organization C was that we could have done so much more but didn't and that was part of the reason why I was kinda ready to get out of there was that I wanted to see that kind of stuff happen but I knew that it wasn't going to happen, not now anyways.

Did it not happen because of funding and money and that need to give programs to the many and not the few...?

The focus just wasn't there, the people kinda on top didn't have that interest or focus.

How does your org determine if child is a good fit for camp?

Typically umm if they are danger to themselves or other would be the biggest one. So we had, we have had campers who are constantly acting out at the other kids in camp or the counsellors

exhibiting SIB that we weren't really able to prevent umm then that would usually be the deciding factor as a safety thing. *We can't, we don't want to put other kids at risk in order for 1 child to be in camp*, and then ..uhh.. I would say that would be the biggest one.

So did u ever have to send a child home because they were being physically aggressive like a child could be an Extreme Case?

Mmhmm...we have. Ummm we have sent kids home before who aren't extreme cases. *Ya we have like, personally, umm I would exhaust any sort of avenue i had to try and make that child successful in camp before I get to that point.*

Appendix K
Revelatory Phrases Chart: Senior Staff

Senior Staff A
<p><i>Control the environment you can control the behaviour</i></p> <p>“Uhh take’em for a break if they are having trouble with a specific activity at a specific time you would tak’em for a break get them to calm down.”</p> <p>“...a situation of a high stim say you use the rope example we took the ropes away from the like we eliminate, <i>if you control the environment you can control the behaviour a lot more so we tried to control the environment a lot more.</i>”</p> <p>“...so if the kids was losing his mind in the fine motor room when there was 15 other kids in there you take him up 5 min early so you can get his fine motor in and then allow him to stay in the room for 5 min once the 15 kids show up so he kinda gets to used to it and then you leave and go do something else so for a gross motor activity.”</p> <p>“...if they’re having a struggle with the shapes at the moment you take’em and run’em around the somatic square and go back to the shapes. You start small and work big so stuff like that.”</p> <p>Question: Policies about accepting extreme cases</p> <p>“... I guess my picture of an extreme case might be a little different than anyone else’s being a big, tall male I feel like unmanageable behaviour doesn’t really exist for me.”</p> <p>Supervisor’s expectations of staff</p> <p>“So her expectations of me are a little bit higher it might be cause I’m not going to say that I’m not better at it than everyone else, but I have more experience and I’m a male and as much as I don’t like that to be something that sticks over my head it is so she depends on me for certain situations that she can’t with a female. Ummmm just because being a big tall male has more of an impact sometimes than being small, short female.”</p> <p>Describe process of how you create a program for extreme case</p> <p>“We don’t treat them different differently because they are severe which I think kinda helps...”</p> <p>Disadvantages of TEACCH concepts with Extreme cases</p> <p>“...no disadvantages as long as it’s done right”</p>
Senior Staff B
<p>Determine needs of child in program</p> <p>“...well basically the parents are telling you what they want. Their expectations are, what their goals are I mean ...its different in all the programs. Like camp there’s no real set goals because it’s supposed to be more of a social, fun, thing but in the programming for like you know, the social skills and the I guess....life skills...which I don’t really agree with but...umm basically the parents are telling us what they are wanting us to work on.”</p>

How effective program is at meeting child's needs

"...depends on how the staff is." "...they have intentions of uhh meeting their needs but I think it depends on the level of staff you're hiring."

Using physical activity in programs

Saw an increase in behaviours because the group was not doing physical activity...once movement was incorporated behaviours decreased.

"Staff was uneducated and didn't know WHY behaviours were happening"

Reward system used, reinforcing proper behaviours there was an extreme drop in behaviours.

Staff C Revelatory Phrases

How effective are you at meeting the needs of children

"...uhh we want to be adapting activities so they can participate in these activities, we don't want to be adapting it so we are changing the activity completely we want to adapt so they can participate in some sort of way right because I don't want them sitting off to the side like my thing is I don't really want to my goal, I don't want to walk into the camp and say oh those are my campers sitting by the tree. So that's what it's all about."

Advantages or disadvantages to behaviour management

"I believe that redirection is a good thing but I feel like there are times when you need to just remove the child from the situation like they need to be removed and redirection is not going to work and they need time to cool off and you need to remove them from the situation bottom line. And I do kind of go against the redirection policy because I feel like it's important. *And no one has ever said anything to me so I keep doing what I do.*"

Appendix L

Keywords “Severe” Cases: Supervisors

Supervisor A
<p>Extreme Cases are “kids that nobody wants” and they typically manifest simultaneity, there’s this plus this plus this....”</p> <ul style="list-style-type: none"> • Non verbal • Maybe self-injurious • Maybe anger management issues • High anxiety • Compulsive • Tube fed • Doesn’t toilet <p>“...the disability and the sort of cascade of things that often accompany the disability”</p> <p>“Severe or extreme probably can manifest in many ways like they can manically severe like fragile or sick or they can be behaviourally severe as in like the Tasmania devil (makes his noise)”</p> <p>“There is more going on than a single dimension disability. It’s complicated.”</p> <p>“Severe” case at her camp she gets more internal maladaptive and socially disruptive, finds A and C go together “the internal maladaptive kids are the ones who are hurting themselves and stimming and so forth and destroying property, aren’t being compliant they’re just sort of involved in their own stuff...outcome is non-compliance but that is not their intention.”</p>
Supervisor B
<p>Extreme cases can manifest themselves in 2 different ways:</p> <ul style="list-style-type: none"> • “The severity level of their diagnosis in that way they are extremely impaired in all areas.” • “The impact that those areas of impairment are happening on their family. With a whole lot of cases that would be crisis or high needs but they don’t necessarily have a severely impaired child.” <p>“severely impaired”</p> <p>Definition of extreme case:</p> <p>“How it is not necessarily based on the severity level but how much it’s interfering with functionality. Because you can have someone who’s quite gifted in their verbal abilities but become extremely aggressive and not be able to be in the school environment and take advantage of that.”</p> <p>“..indicated that it can be based on functioning level without stating that but also with severity</p>

level without stating that... encompass more people this way in a more positive way.”
Supervisor C
<p>An extreme case is someone who requires a great deal of support.</p> <ul style="list-style-type: none">• Someone who is 1:1 if not more• More challenging behaviours• Struggles with transition• Flight risk• Limited communication <p>“something that requires additional support that’s what I would say is an extreme case.”</p>

Appendix M
Keywords on “Extreme” Cases: Senior Staff

Senior Staff A
<p>Extreme child is unmanageable with extreme difficulties that equal extreme:</p> <ul style="list-style-type: none"> • Behaviours • Sensory issues • Overly aggressive and a lack of ability to do normal things (daily living skills and social skills) and have a normal life. • Non-compliance • Easily distracted • Difficulty to redirect when they get focused on something • Inability to do complicated movements • Non-verbal – so you don’t know what they want, what they’re trying to tell you • Very stimulated • Need to get rid of distractions to get them engaged • “Just difficult to work with them” <p>Comments on extreme case definition provided: Felt that you could get specific and technical with the definition but it was a good broad definition that was extreme.</p> <p>Provided specific examples of extreme cases</p>
Senior Staff B
<p>Extreme child is:</p> <ul style="list-style-type: none"> • Lower functioning • Non-verbal • Fairly aggressive • At the end of the spectrum. <p>Focused on low functioning</p> <p>Felt they had 3 extreme cases at camp based on definition “...the lower functioning kids, there’s always communication problems” “...you can tell people about transitional things, all those objects, having schedules and stuff like that but when you’re having an extreme case like that, that’s not necessarily going to be enough.” “managing it”</p>
Senior Staff C
<p>An extreme child displays:</p> <ul style="list-style-type: none"> • SIB’s

- Has severe meltdowns at times
- Aggressive tendencies may not be able to function within a group of other children
- Needs support to be integrated.

Mentioned self-injury twice

Discussed a high functioning extreme case as an example

Extreme case within Organization C:

“Right now our kids aren’t very severe they are pretty high functioning so it’s not that big of a deal but if we were to have those more extreme cases there would be, we would need to you know train our staff a little bit more.”

Appendix N

Level 2- Cross Case Analysis Supervisors

Questions were clustered based on topics

Describing an “Severe” Case
<p>Supervisor A</p> <p>Extreme Cases are “kids that nobody wants” and they typically manifest simultaneity, there’s this plus this plus this....”</p> <ul style="list-style-type: none"> • Non verbal • Maybe self-injurious • Maybe anger management issues • High anxiety • Compulsive • Tube fed • Doesn’t toilet <p>“...the disability and the sort of cascade of things that often accompany the disability.”</p> <p>“Severe or extreme probably can manifest in many ways like they can manically severe like fragile or sick or they can be behaviourally severe as in like the Tasmania devil (makes his noise).”</p> <p>“There is more going on than a single dimension disability. It’s complicated.”</p> <p>Severe case at her camp she gets more internal maladaptive and socially disruptive, finds A and C go together “the internal maladaptive kids are the ones who are hurting themselves and stimming and so forth and destroying property, aren’t being compliant they’re just sort of involved in their own stuff...outcome is non-compliance but that is not their intention.”</p>
<p>Supervisor B</p> <p>Extreme cases can manifest themselves in 2 different ways:</p> <ul style="list-style-type: none"> • “The severity level of their diagnosis in that way they are extremely impaired in all areas.” • “The impact that those areas of impairment are happening on their family. With a whole lot of cases that would be crisis or high needs but they don’t necessarily have a severely impaired child.” <p>“severely impaired”</p> <p>Definition of extreme case:</p>

“How it is not necessarily based on the severity level but how much it’s interfering with functionality. Because you can have someone who’s quite gifted in their verbal abilities but become extremely aggressive and not be able to be in the school environment and take advantage of that.”

“...indicated that it can be based on functioning level without stating that but also with severity level without stating that... encompass more people this way in a more positive way”

Supervisor C

An extreme case is someone who requires a great deal of support.

- Someone who is 1:1 if not more
- More challenging behaviours
- Struggles with transition
- Flight risk
- Limited communication

“...something that requires additional support that’s what I would say is an extreme case.”

Organization

Supervisor A

Could walk into her camp and see a full spectrum of children with different manifestations of ASD.

Her goal is to provide “meaningful, developmentally appropriate physical activity for kids on the Autism spectrum.” Her phenomenological and semiotic research on Autism is what distinguishes her program from others as her program is “organized around what it means to be embodied in the world.” She feels that is the centre of her organization whereas other programs are “organized around rehabilitation have rehab at the centre and the lived experience of the person on the periphery where as I revere that, their lived experience is the centre of my organization and the rehab pieces are out on the periphery.”...“organized around the bodies they have as opposed to organized around the bodies we’d like them to have.”

Organization A wants the children to develop play based skills so they can have friends, so they can participate in a physical activity repertoire that is meaningful to them, so they can grow up and fall safely, dress themselves, have functional physical activity, flexibility, strength and activities of daily living so our more severe cases” “meaningful embodied engagement with the world.”

Her untrained personnel of undergraduate students are volunteers where half are highly motivated to work in the field and the other half are motivated to get what they perceive as an easy credit and how hard can it be to hang out with a kid for a week or two weeks. As a result of having undergraduate students as staff she is able to offer camp to more children (60 per week) where as if she had paid personnel she would only be able to offer 20 spaces per week. She also has senior staff/mentors who have vast experience and are able to act as mentors for the young undergrad students.

Provides a 2 week camp and then a special needs activity program and Saturday SNAP during

the school year.

Photographer who provides actual images of activity they are going to be doing for visual schedule

Supervisor B

- Provides programs for all ages right through to adulthood
- Recreational based activities with a social component (special events)
- Run by volunteers and staff
- School aged programs that run 2 sessions per year → social skills or life skills based

Goal/Mission "...we would provide each individual living with ASD with higher quality of living and feeling like a respected and dignified individual in the community."

Policy for Extreme Cases:

No official policy as programs are individually driven so it depends on the criteria of the program. "There are some that require children to have some certain abilities and if they are unable to meet those because of our inability to provide the right amount of care for them then they would be excluded for those situations. But most are quite open, it's only if for some reason we're not able to meet that need that we would have to look at alternatives, but we get really creative at adding an additional support, having the parents bring additional support, we get tons of additional information beforehand to find out what are the areas that might be of issue."

May not be able to manage the more difficult cases where there are destructive behaviours due to their facilities but would look at options as to how to accommodate.

"...our goal would never be to exclude and always try to figure out a way to get every child involved."

Sets program apart:

"...In Niagara there are very few ASD specific programs that provide programming year round. Do a fairly good job of retaining and continuing our staff and volunteer through the programs. So they are continuing to get better and better at providing service to the families so it's not that each time families become involved it's a new group, you know totally new experience because there's a lot of consistency in the programming and how it is provided because there is a lot of carryover of people who are involved."

Separate program is government funded program that provides free social learning opportunities for the whole family to eventually be able to go into the public and try the activity on their own.

- Family focused programs
- Sibling specific program

Supervisor C

- Provides programs for infants right up to adulthood
- Drop-in programs
- Day camps
- Child care
- Swimming lessons

- People can in and use facilities
- Programs are typically age appropriate: pre-school, school aged, teens

“...all types of children, inclusion is one of the main guides, we try to have programs for anyone that we can. That didn’t always work. Sometimes kids would come in and we wouldn’t know that they needed maybe some additional support so they would always be too successful while they were in programs but open to all.”

“We never turn anyone away”

“I would never turn anyone away I would try to put different things in place and try it out and then if it was at the point where we couldn’t, that child couldn’t be successful in our program with the supports put in place, our program wouldn’t be the best fit for them.”

(“I don’t know if the organization feels the same way, I don’t know that they do, but so we would see that some of our programs we didn’t have a budget in place to provide supports so it would be more challenging, so we would put them in a smaller group, we would put them in a smaller group, accommodations like that.”

Sets program apart from other programs in Niagara:

Smaller community and easier to develop relationships with families and staff carry-over was high so staff knew kids attending camp or programs

Interviewee’s Role

Supervisor A

For the past 20 years she has been a professor at a local post-secondary education facility but was initially hired as an advanced gymnastic professionalist but does not have any formal qualifications for disability. Her training in phenomenology and physical education has allowed her to work and research within the field of disability, adaptive physical education and disability studies specially autism. Has her masters in administration and is an award winning teacher.

Additional training: TEACCH, sign language, sensory integration curriculum

Will work directly with a the students who are working with the extreme cases as they “tend to be a little unnerved initially” so she will do quite a bit of co-active work or buddy pedagogy (that she has developed). “I often get called in to work with the socially disruptive kid, mostly because I think they’re all afraid of me for some strange reason.” She comments on how she chooses her battles well and doesn’t sweat the small stuff. “If someone is physically aggressive or violent I’m not going near’em until they calm down.”

“...but I know how to spot something before it escalates. I’m a good observer so I don’t ever see anything happening out of nowhere because I don’t think that things happen out of nowhere I just think we need to be better observer, and I’m, a good observer so I can tell when a kid is getting agitated or getting u know on the edge of his threshold and that’ll be the time I go over to someone and say” I think u could bring him into the sensory room for a bit or I think he’s had enough of this space or I think he could use a little break here.”

So you’re actively able to engage on the floor with your staff, you’re not in an office or..?

Oh no no NONONO I'm on the floor on in the gym or in the field or in the pool or wherever. I'm watching like a hawk most of the time. Ya I'm very present. Maybe too present. I don't know...maybe they feel too surveyed. Ya I think I'm present."

Supervisor B

Has worked for Organization B for the past 7 years as a family support coordinator and event coordinator. Has her undergraduate degree in child and youth studies with a so-major in sociology. She completed her masters in child and youth studies and focused on human rights issues for individuals with developmental disabilities.

Will consult and train the program staff but deals directly with parents and supporting them.

Involvement with Extreme Cases:

- If there was an severe case in participating in programs she gets called in to help problem solve and adapt the environment/program to suit their needs.

"I think it's probably because I can tap in to all of the little bits that I know to try to be able to pull together a plan and get more information and come up with a plan that might work for that kid. Most of the folks that we have working with us are really knowledgeable about the basics, that's why they are working with us. It's when it's the extreme cases that are different from the norm, of ASD um that it gets a little bit challenging for people who aren't really sure where to go. Um and I'm not very hesitant to leap in and try and figure it out so that's usually where I get pulled in."

Supervisor C

Started off at a 1:1 Support staff at camp and worked his way up to program coordinator and integration supervisor.

- Senior staff role: talking to families, placing kids in camp, hiring the staff, placing kids with staff, developing strategies to put in place at camp
- Program Coordinator: running all programs run out of specific location

Has received his Bachelors in inclusive and therapeutic recreation and has worked in a variety of clinical, residential and recreational settings.

Role with Extreme Case:

"I would work with the staff working with the kids. If the kids were more severe, with this definition I might be there to support even more or umm maybe that wasn't the best fit and we were seeing more behaviours so we put another staff in I tried to find a good match for that or have the child like I would move the child into a different camp if need change the environment and try to limit some of the behaviours that we were seeing."

Expectations & Relationships

Supervisor A

*see Challenges/barriers

"Until they actually encounter the child. You know so those are skills that they need over and above their ability to be attentive and engaged and interested in the child for 8 hours. On for 8

hours. ON for 8 hours, ON! Not texting, not thinking about their friends not worrying about their friends not thinking but anything but this kid. FOR EIGHT HOURS that kind of attentiveness and disciplined focus that what this calls for you know. So at the end of the day they should be freaking exhausted. And most of them are...not to mention the planning.”

Feels she has unrealistic expectations:

- Read and prepare
- Plan

“And at some level I supposed even though I think it’s probably the most primitive form of learning in the early going I just expect them to obey, fake it until you make it. Do what I tell you, until you understand why I’m telling you. I wish they would do that more.”

Different expectations for someone working with extreme cases?

Expects them to adapt on the fly, plan, be flexible, patient, level of your own awareness of level of energy around kids, sensitivity to child, better observation skills, comfort with more intimate bodily based engagement with more severe kids.

Supervisor B

Staff working with extreme cases:

- chose staff with a bit more experience from other situation outside of working with us
- make sure they are well versed in the skills that the child has as well as their own skills and how they are able to work together with that individual
- strong communication skills → parents and staff who are working to build program

“They have to make sure there not only understanding what is coming into them and processing that and being able to apply it with that kid but being able to give information back and feedback to be able to change or alter the program as necessary.”

- Obviously they’re going to have to have all of their training in regards to non violent or any other supports that they may need to support that individual in a safe manner.
- Report writing is going to be a pretty significant piece. Whether its formal reporting if an incident does/were to happen or informal reporting just on how things are going just on how we are tracking the individuals progress throughout the program.

“I would say a whole lot of patience. Cause it can be exhausting working with someone who is in that kind of extreme case model and um, it takes a special type of person.”

Supervisor C

- Safety
- social inclusion is a part of how are we going to meet some little milestone to try to get this child included into camp
- expect 1:1 staff be supported by other camp staff and feel comfortable to ask for help

Meeting the Needs of the Child

Supervisor A

Ask certain questions on registration form to indicate needs: will a worker be accompanying them- gives her a little more insight so if someone’s accompanying them maybe they need a little

more support, are there issues that your child really needs to work on, are there things we need to be aware of- where she gets more indications of where the child is on the spectrum “lots of my parents lie because they’re afraid I won’t take their kid.”

Discusses how 75% of her campers are returnees (one has been coming since he was 4- now 19) because the parents trust her and she is able to tell the students working with them what this child needs and what he is good at. The toughest children are the new ones because “sometimes the parents are disillusioned and helpful...sometimes they give you more information than they know they do. They say “oh the child will be no trouble at all and then they list his meds and I can look at the meds and go “ahhha ok well.. “ umm we’ve got this and this this and this and this so clearly they’re-there’s going to be trouble ok. So I’ve been working with population long enough to know what the, medication mean, what it indicates, so the parents may not give me verbal descriptions, but the meds give me insight into some of the stuff that’s going on.”

Changes her profile every year- this year asking the parents to designate whether they think if their child is 1:1. (p.7) This is one of my grad students idea as part of their course assignment lets have the students fill out the profile on the kid so you who have worked with the kid now fill out the profile so we can compare to the parents profile. So I like that.

Parents being forth coming with information

“The kids who have been coming the parents will be honest. The new kids, I think they will not want their child to be un-safe, like I’ve had parents of new kids say” so and so is a flight risk...watch him” right? Well thank-you for saying that! I would rather know that your kid runs away then u say ”oh he’s just wondering compliant child” u know umm so the parents seem to be forthcoming like in that regard. Sometime I think bc they’re around the child so much they notice things, the autism so much they...under estimate how good the kid can actually be. They may think their kid is a 1:1 But he’s not.”

“...they are genuinely physically tired, they get an enormous amount of gross motor activity which I think this population of child is lacking and bc the kids with the severe manifestation, the violent kids, the destructive kids, they tend to sit out so much or they’re sort of out of the activity loops soo much they they’re getting heavy and they’re getting bored and they’re getting more and more behind their same age peers in terms on their physical repertoire so their looking weirder and weird and the chances of them developing any kind of engagement with any kind of same age peers are getting slimmer and slimmer and so the physical piece is very helpful.”

Supervisor B

Profile that gathers “ behavioural information, social information, communication, sensory, safety related issues any of the kinds of the things that may impact the child’s ability to participate if we are not prepared for them. We do have a stock pile of different types of I guess I would say screening that we do for kids to make sure, not that they necessarily fit but we are prepared to meet their needs when coming into a program.”

“...if there was anyone that showed some alarming or red flag type issues that we would fit into our typical structure we would probably have some kind of discussion with all of the program folks involved to determine what it was that is outside of that norm.”

- If it was a safety related issue, often we're looking at what can we do to get around that, what kind of extra precautions do we need. Those are usually fairly easy to get around.
- IF it's again if its just a matter of behavioural issue or social issue where we need some extra support again typically we can get around that. It's going to be if its something that is very unique.
- Some of the kids have, some of the more odd behaviours like some of the strange pica issues or um self-injurious behaviours that's kinda hard to figure out what the trigger is or what it is that we need to do to prevent it. Those are the only where we really sit down for a while and try to come up with the plan.

"A key person is that is always going to be the parent and getting their information of what may work. In the past we have even gather information through the parent, through the schools or other agencies that they have already taken part in programs that are similar to areas so see what was successful and what hasn't been just to get that idea of maybe there thinking of something or maybe they've experienced something that went wrong and maybe we can get an idea of how to do it right. But ya typically it's just a discussionary process and then a planning piece."

Ways to better accommodate child's needs

More money to have more staff (and all the best staff) so they could have plans and be overly organized

Supervisor C

Profile "...which is more or less and assessment prior to camp months before camp would even start either myself or one of the other supervisors would contact the parents and go through the child's strength, the child's need, where are they going to need some extra support, if they were to exhibit some behaviours, what would those look like. What strategies work with those different behaviours...just getting to know a little bit more about the child."

"Sometimes we would contact the school umm it would depend on the child and if we had a previous relationship with the child if they were in some of our other programs so we could get some more information. But mostly it was just talking with the parents."

Extreme case needs: Determine what camp was the best fit ... want to set child up for success and look at what staff would be a good fit. Set the child up for success

Felt that camp did a great job meeting needs because of the strong staff and strong relationships with the kids there weren't too many surprises. New kids bring the surprises.

Feels that within programs there is still room to grow as Organization C does not offer 1:1 support during programs "It's not right at the fore front of what they are trying to do with their programs. They're trying to serve the most amount of people possible so they're really not focusing on the most extreme cases cause it's the minority of people that come to the program so they will do their best to try to accommodate but they can't and they won't. They won't stretch beyond their means."

Programming

Supervisor A

“We work off the profile, we do age group division, lose age group divisions, we work off of standards, motor development , developmental milestones for want of a better word although certainly I’m not a slavish advocate of stage theory” the children will do this at this age”

Using as a guideline they’re psycho-motor affective and cognitive interactions around what they would expect to see for particular age based activities.

“...we’re primarily interested in the psycho motor and so that really determines the program, the program is also of course organized around autism so its heavily structured the same sequence happens every day for the same amount of time and then you move to the next thing and its always in that same sequence there are no more than 8-12 kids in the space at a time. Although as our numbers get biggest there are more and more kids in a space at a time.”

Program Spaces:

- Sub-divided because my spaces on campus are relatively small
- Structured so that one type of activity is not connected to another type of activity so in this space we do this in this space do this and this space we do this
- Taking up the principles of managing the environment
- Discrete separated space, big space are made into small space
- Every space has a specific purpose and that’s what u do in it
- We try to prevent bleed over like contamination from other spaces most of that problem is my students not the kids.
- Very tailored to the disability if we have kids who are stimming excessively we try to do our best to redirect them away from their stim toys or we try to engage their stim toys and stim activities as redirects or as prompts or as rewards.
- We’re sensitive to their autism we keep the stim, auditory, and visual stimulation as low as possible

Camp Schedule of Morning Stations and Community Activities:

- Educational gymnastics
- Fitness
- Game skills
- Outdoor activities
- Height and flight
- Fine motor
- Afternoon go swimming and then on an outing (beach/bowling, go karts/miniputt, Marineland/Zooz, ropes course, splash pad/playground)

Supervisor B

*see “Meeting Child’s Needs”

Supervisor C

Use profile and previous knowledge of child, would talk to parents prior to starting to camp to see how things were going

Always willing to adapt:

“The nice thing about the program that we had, was that the last couple years the parents were paying for the program support program they weren’t paying for the specific camp, so we had options, and they had 1:1 staff, so we had a lot of flexibility in moving them around because we didn’t have to worrying about ration and numbers and things like that cause they had their own staff, whereas in the past we weren’t able to do that.”

Provided examples of adapting to meet campers needs

Push for programming before camp → active and passive games

Challenges/Barrier

Supervisor A

“The irony for me is that many of the people who, the students, who participate as facilitators, leaders umm ought to be more qualified than they are in terms of where I find them in their degree programs. But they have had such an alarming lack of applied umm learning this often their first encounter with actually applying their knowledge of program planning, lesson planning, accommodation, needs assessment, um... observation analysis their skills are quite impoverished actually, on the one hand it’s a great opportunity for them to develop those skills on the other hands the kids are the causalities in some ways because they are not getting trained personnel.”

“The biggy, inconsistency is the biggy, and untrained undergraduate students who really don’t understand Autism and don’t understand the significance of particular kinds of strategies and how it would really help them as the teacher as well as the child. And those insight begin to happen mid way through camp but I would really like them in place on the first day of camp”

“Students do not have a mature understanding of planning and what it means to have a plan, to modify a plan on the fly if necessary and that the modifications are part of an anticipator set that comes with the plan.”

“The barrier’s always money, how much money to pay for buses and swimming.”

Barrier- “...student committing to the camp and then backing out do that we don’t have the ratios- a consistent problem”

“My do not know how to give instruction in simple singular phrases. They talk too much. They don’t plan enough.” “I don’t think they take it seriously until they actually get there after the first day...”

“The Meltdown Mondays. I think that’s the biggest problem they seem to think that the embedded curriculum is obvious and it is obvious you know in its obviousness they diminish it. They seem to think simple singular instruction, obviously I can do that one instruction at a time, consistently give, without yes or no built into it, telling don’t asking they seem to think that

they'll just be able to do it so they minimize the difficulty of how simple but it's not easy. So much of what we present is simple. Almost obvious but it's not easy. It just simple and embedded curriculum is a simple idea, station based pedagogy is a simple idea, breaking stuff into pieces and then putting them back to together as teaching phrases is a simple idea but it's not easy. It takes a lot of planning and thinking and they have not had the experience of having to plan and think so because it simple they believe it's easy and then they are horrified."

Students reaction to embedded curriculum and campers "Horried...ohh this is really hard. It is, you know. Um why won't he do this- because he's autistic...ohh..."

Struggle with using University space- The university would rather rent out the space she uses than let her use it for 50 or 60 people. They would like to make money.

Program longevity – if she is not at the university it will not run. Program depends upon her

"Students lacking the observation skills to be better lookers, seers, watchers, they have to practice attentiveness in ways they are not used to. They have to be comfortable with mess, drool, spit, vomit, snot, shit, pee, food, mushy horrible looking food. Need to develop a comfort level with that level of assistance. Aren't prepared for the intimacy of this facilitation. Feeding, dressing, cleaning, dressing, undressing, bathing, toileting. They need to understand that Autism manifests in an embodied way the disabilities their working with manifests themselves in embodied ways and they can't make it into a cognitive exercise or verbal exercise it's an embodied exercise."

Supervisor B

"I'd say the biggest challenge I get is inflexibility of the people we provide the program to. It's not always the people who come up with the program who are providing the program."

Program staff: "...the program is presented in a way and they feel that that's a program. And so many kids need flexibility and how that program is offered and that staff may not have that skill base on how to flex it. It sometimes takes that staff plus the supervisory staff plus the whole programming team to figure out how to change that and that can't necessarily happen instantaneously. So you have a time factor there where the child may be missing out on program or not be able to be included in the same way that they would hope to be included right from the beginning if we can't find a simple way to flex something."

Money- "It would be great to just hire everybody and be able to offer as many program spaces as we needed but that's not always something we have the flexibility to do."

Supervisor C

Funding:

"We don't have additional staff and that's a funding issue we can't afford to put support in place for that so depending on the child we would have some kids who would come to camp and receive support but would attend programs and not receive support in programs because programs are shorter just an hour in duration so sometimes they don't need support. And child care we I don't know what it is now... we used to have support in child care. But again we had

support for that but it got cut and cut and cut.

“Every year when I started we were able to offer 6 weeks of camp to a family at no additional cost, like they would just pay regular camp price and then it was 4 weeks and then specialized program—cost has increased as well.”

“I’d love to offer support to any kid who need support coming to program but I don’t have the 6-700 dollars of funding I’d receive for camp. It’s a high amount and we don’t have that and I can’t throw another staff in there.”

Challenge→ people on top of Organization C did not see the need to provide 1:1 support during programs...want to serve the masses not the minority

“It’s just the hire ups that don’t see the need. I kinda get it because there is other, there is Autism Ontario camp and other programs that these kids can go to. Are we the best place for them to go to? Maybe not in some ways? But I think we are one of the most accessible and conformable places and we are always going..., social skills programs come and go but kids drop in programs run all the time and all year. Maybe one day they will come around.”

“That one be one of my personal beliefs and what I wanted to see in terms of inclusions and support in programs didn’t quite line up with what the overall sort of mission of Organization C sort of is, and I wasn’t in a position where I could facilitate any sort of change, like I was able to a bit like with the camp and my branch whereas some other branches may not so I think that was a challenge, and funding.”

“And I’d really stretch my volunteers to support kids at camp, at March Break camp I would have some of my teens and leaders in training to support kids in camp because we would only have 1 support staff. Some kids don’t need as much support they just need someone to be a bit more aware of their needs.”

Integration

Supervisor A

Her program is not integrated as all children have ASD. “But I think it’s a myth you can integrate a severe case, I think they can be in the same room with abled bodied peers but I think the idea that they’re going to on their own function, safely, and with dignity, with a group of same aged peers without some sort of additional facilitation I think that’s absurd. It’s an absurd expectation. I think it’s unrealistic in terms of how these kids are in the world, can I help the other kids appreciate what it’s like for this kid to be in the world this way, perhaps but they didn’t come to camp to learn about autism.”

Supervisor B

In past 7 years “ think I can only think of maybe two or three times that we’ve had to and I wouldn’t even say exclude a child but get really creative on how to provide them some type of service. Um, it may not be that exact program, we may have to provide it in a different way, we may have to look at a different option but it’s been very few and uh on average it all of our programs together we’re are well over 1000 program spaces in a year. That’s pretty good for

being inclusive”)

Staff's Abilities

“The inability to be flexible from that program without feeling like they’re not doing the right thing...confidence level.”

“They don’t think that they can do it. When they see a kid who is extreme, um, they automatically are like woah. I can’t do that!”

“And it kinda takes a special breed of people who of course are the ones we try to get but they aren’t always like that who have that natural ability to understand that it’s something you can do we just have to be creative on how to accomplish that. And the other I think is that’s I guess it’s partly the same.”

“It’s inexperience, it’s not common that we have extreme cases in every group so they don’t have the opportunity to practice I guess working with those kids because they aren’t the common kid.”

Supervisor C

“Honestly, I don’t think very effective, I think I really tried, I tried really hard and my staff, Organization C in general I don’t think does it very well. They kinda shy away a little bit cause there’s not that many people are familiar with ASD or other disabilities. You can kinda get a bit like stand offish about it, and not know what how to go about doing in. So I really tried to in Welland, all the staff around me and all my staff, it’s really not that bad you have to be a little bit aware. The organization in general shies away from it.”

“...social inclusion vs physical inclusion... someone just being there opposed to being involved in the program.”

Challenges his staff faced → resistance from other camp staff..” you can only do so much as one staff you need to have the buy-in of all the other staff.”

Issues of hiring staff as support staff but then they are needed elsewhere and then throwing someone else in and then they have no idea how to integrate the child because they didn’t have the tools to do so.

Accommodations & Strategies

Supervisor A

Accommodations/Strategies built into the program:

- Lots of countdowns and warning countdowns so that transitions are managed well-planned transition
- Visual schedules(large and individual)
- Picture exchange
- Social stories
- Tell don’t ask

- First this then this

**see programming section for more detail on program components

- Large spaces into smaller ones
- Station based

Supervisor B

“Where do you want me to start? That list is endless. I think we’re pretty much willing to do almost anything”

- Visuals
- Reinforcement tools
- Transitional items
- Communication tools
- Change the structure of their program the actually scheduling to accommodate their needs
- Staffing changes “we will we find some kids do better with some certain staff then they do with others and we have no problems switching things up”
- Changing arrival and departure times
- Change rooms
- Change materials

“...we’re pretty much are open to adjusting wherever it’s necessary.”

“So we don’t look at it as the child whose having a problem. It’s something that we’re doing that isn’t quite fitting so we adjust that and use whatever strategies necessary to try and make it the best fit possible.”

Resources that benefit Extreme Cases:

“I would say we would probably pull the most information out of structured teaching and TEACCH strategies to use for extreme cases. Not that they all need all of elements of that but the portions of the extreme nature of that program that allow them to function in a way that lowers their anxiety is probably why we would target that type of programming the most. But I wouldn’t say that there is any one curriculum that would fit any one specific extreme case, they would all be so different, it’s going to be just what we are going to need for that child. I wouldn’t want to pin point it to a certain curriculum”

Supervisor C

Accommodations/strategies:

- Willing to work with service dogs
- Picture schedule
- Visuals
- Cell phone to play music or movie to redirect
- Adapt activities
- Adapt environment
- Adapt schedule
- Re-direction
- Breaks

- Would do anything to ensure child was successful at camp

Better accommodate- Better understand child's needs and how to accommodate and modify as need to help those kids be included in camp.

Behaviour Management

Supervisor A

"In a nut shell is prevention rather than fix. So we try to anticipate and prevent rather than intervene after the fact. We do not non-violent so we don't do restraints none of my students are trained in restrains so they can't do it. They are told if there's an episode they need to remove the other kids keep the kid contained, keep themselves safe, contact someone if there's a safety issue. They would contact me or their angel. Then depending on what's going on umm some of use with more skill in de-escalation would attempt to de-escalate."

"Prevention is our biggy and if they're in an episode, safety and dignity of the person, safety and getting the other kids out of the area."

Supervisor B

"...NVCi trained so they are managing the behaviour in trying to de-escalate it and avoid any kind of confrontational situation."

"Approach, our overall approach would be to provide a strong enough structure that the children aren't going to need any behaviour management to start with. There's going to be enough everyday tools, transitional tools, structural tools, visual tools and support tools throughout every part of their experience that they will be our behaviour management. If we need additional tools, uh, then that's where we're going to look at each individual child."

"But if we need to think outside the box then we're going to go back to what are we going to need to do to deescalate. The safety of the other children is most important and then safety of our staff is next most important. But hopefully what we have set up in the first place and planning would be enough."

Supervisor C

Behaviour Management strategies:

- NVCi all support staff
- Organization has child guidance policy as behaviour management "to ensure the child is successful and be proactive to the behaviour rather than reactive to the behaviour
- Ignoring the behaviour if possible
- Setting the child up for success so that the behaviour may not present itself
- Not punishing the behaviour but re-directing
- Taking a break to calm down

Advantages:

Being proactive will help you see less behaviours especially if all staff are on board and staff are able to predict behaviours as much as possible and focusing on the positives rather than negatives.

- Help to reinforce good behaviours

Disadvantages:

“Extreme Case is a bit more challenging to find those positives sometimes because the kids are always exhibiting these (gestured towards definition) challenging behaviours.

“It’s really hard to praise them for positives. I think staff would get lost in that sometimes. Like even if they sat down for 2 minutes, it’s like great job sitting for 2 minutes that would get lost sometimes because they are caught up dealing with these other more extreme behaviours you are exhausted almost it’s really hard to you’re just unfortunately preparing for the next outburst or running away or whatever comes up.”

“So I think the behaviour management approach is really good but I think for extreme case it kind of falls to the way side because it’s harder to do that, I think the principles are still good but it needs to be kind of shifted a little bit so that strategies are in place so it’s more specific to that individuals and their needs...”

Extreme cases not a good fit within program:

“Typically if they are danger to themselves or other would be the biggest one. We have had campers who are constantly acting out at the other kids in camp or the counsellors exhibiting SIB’s that we weren’t really able to prevent then that would usually be the deciding factor as a safety thing. We can’t, we don’t want to put other kids at risk in order for 1 child to be in camp.”

TEACCH

Supervisor A

“...my experience with the TEACCH program I know the TEACH program because I’ve researched it and I’m familiar with the premises. Unless you actually embedded yourself in it and take it you’re only going to get the most general info about it. In many ways our camp enacts an incredible amount of the premises and strategies involved in the TEACCH program.”

TEACCH program components:

- I do understand it tailors to the child.
- It works with strength based reasoning, it works through redirection it engages the full taxonomy- physical, psychomotor, physical affective cognitive it has much more of a behavioural component than I deploy and it is more deliberately behavioural in terms of directing behaviours in certain fashions and removing behaviours in certain fashions so we don’t enact that but I’d say on a lot of the premises of the TEACCH program we are fairly in line. Aside from the explicit formal behaviour management goals of TEACCH.

No formal training in TEACCH

Advantages:

Feels it would definitely benefit extreme cases.”

Disadvantages:

- Specialized nature of the training to say it is a “TEACCH program”
- Expensive as you have to travel to do it
- It’s a behaviour program so if it was more context sensitive to physical environments that

would be the only downside because it doesn't have that context sensitive to physical and psychomotor environment.

Supervisor B

She is formally TEACCH trained but has not experienced their full 5 day classroom training only a 3 day training in Toronto.

Learn and understand all of the components of TEACCH and how to apply them → uses that knowledge and provides information to families/programs.

“Strongly structured model that outlines way in which children can best function and learn...number of different elements...main function is to make sure kids know what to do, where to start, what to do, what to do next, and what to do when they're done.”

“So making sure that they understand you know the structure within what they're trying to learn and how to actually accomplish that while still being reinforced and feeling they know what they are getting out of it. Basically creating value in learning.”

“Uses visual supports, creating structure and scheduling. Providing reinforcement at the end.”

TEACCH in Life skills program:

“In the chapters longer programs especially in the life skills programs which is the program for kids that are more impaired, they tend to run all of their activities around the TEACCH structure and a movement structure. So they rotate through a number of activities that are well laid out and providing them with a structured routine that the kids can rotate through each week and provide them with the same activities. We tend to use modified, minor pieces of it if it fits unless it actually fits with the whole model into a longer program.”

Opinion of TEACCH:

“Solid base to start from when kids are struggling able to build little pieces of what it is when they feel it fits. It's definitely a nice base for um, whatever type of program as long as we kinda of that in the back of our mind for everything that we're structuring it gives us a nice kind of solid base to start from.”

TEACCH for Extreme Cases:

“Anxiety reduction is the number one result that they see in kids...it shocks me sometimes how they so quickly settle into a structured routine when it's so clearly laid out for them. When you know the week before they had no clue what they were doing. They were running around like chickens with their heads cut off. So like ya, they're very easy to adapt to the TEACCH model, it's not offensive to any kid at any level, as long as you target their knowledge range when you're building it, it's very flexible in that way. And they respond to it so well.”

Disadvantages:

- “...if it's done wrong...I've seen a whole lot of not doing it very well that fails miserably”
- “...especially in our life skills program, we have some staff that don't quite get the concept of TEACCH and they haven't been trained so I get it but it's probably one of the

explanation pieces that we need to work on in our training to make sure they understand these concepts better.”

- “But there’s a portion of TEACCH that really tries to build some independence in the skills that they’re trying to accomplish... because our life skills is a 1-1 on base program, some of our staff don’t get that. And so instead of building in the independence piece during those tasks, they are still so on top of individual which if they use the TEACCH model in their school environment or in another portion of their life, it’s actually quite offensive to them and that is their time and that can create some tense moments between staff and the individual who is actually taking part in the program.”
- “That’s a simple one that I have seen on many occasions and I think that is just guidance of the staff that needs a bit more information there.”
- “I have also seen a lot of visuals used improperly. The biggest one we tend to under estimated kids abilities and we force pictures on them when they really don’t need them when words are fine or vice versa and I think that they if they’re knowledgeable they become quite offended by that and that tends to turn them off of that type of structure but in actuality that type of structure is really good for them if we were providing it in the right way.”

Supervisor C

- A little familiar with TEACCH
- No formal training
- Would use visuals and schedule but not purposefully

Training

Supervisor A

“...the training and attentiveness of my undergraduate students contributes to some of that being less consistently implemented then I would like.”

“2 days of training where she gives them a background on ASD, the embedded curriculum and how to plan for this population.”

“...very practical but not as effective as she’d like it to be. Wishes first day could be training as year after year she sees “Melt down Mondays” and the students finally clue in to what it is actually going to be like working with this child.”

Training topics:

- Background on ASD
- Typical expectations
- Profiles
- Worst/best case scenarios → problem solve
- Back ground on embedded curriculum
- Set up space so they know how everything is set-up, should be used and understand them
- Go over schedule and how to use a visual schedule

“Their issues are they don’t know the schedule, they don’t know the spaces, they don’t know

how to transition, they don't know how to use the visual schedule, they don't know how to phrase tasks, they have a plan that is too vague for the needs that they meet. And so in that effect even though they are exposed to all that when they get in the moment they do not enact it so I would have to say it's ineffective."

"Or they're more responsive in the moment or more capable in the moment."

Beneficial training topics:

- Background on ASD
- What to do at each station
- Realistic expectations
- Scenarios and problem solving

Not as Beneficial Topics:

- Phrasing
- Planning
- How to maximize the environment
- Don't retain the way you should work with kids with ASD, they revert back to old habits

Additional training:

- Course on ASD that is a prerequisite to camp that covers program planning, station creation, observation and analysis.
- 1:1 work with a child prior to camp

Supervisor B

Training overview :

- Have to participate in a certain number of training hours
- NVC
- Policies and procedures

"I would say the best training we do is when we actually talk about the needs of our kids and the unique nature of what they need to be supported in these types of programs. Every program we do is slightly different and we try to target the training to the staff so that it meets the needs of the kids in that program."

"...Sometimes I don't think we don't spend enough time on that because we have to spend so much time on the policies and the legal part of that so we have to simplify or shorten the time we actually spend on the kids in the program."

"... most meaningful education for the staff is getting to know who's actually there."

Debriefing after programs are done, a briefing will occur prior to programs if needed:

"... that's our opportunity to really break down if a situation did occur and what needs to be done with potential training or information sharing has to happen in order to adjust for the next time. So uh, I think we try to build it all the way through because we're not always fully aware before they enter the program."

"Parents don't always provide all the information even though we ask it."

Issues that affect training

- Depends on who provides training
- Training get cut short because more time is spent on the policies than focusing on the children who are participating in the program

“... like I said before, it’s their confidence level. I don’t think they feel prepared when that kind of thing happens when we haven’t prepared them for that. I would like to see that be a standard part of our training and be a extensive part, not just an afterthought but you know you have to follow the legalities of organization and make sure you cover all that other stuff too.”

Practical vs. policies:

- Depends on if they are a new or returning staff
- Training should be different for returning versus new as returning staff don’t need to hear the same ASD spiel

“I think that the pieces that are going to be most effective are the looking at the what if’s do you know to manage those extreme issues that pop up for the kids that aren’t necessarily extreme cases but have extreme moments and for those folks who we already know are to coming in who potentially have extreme case or are extreme cases that are going to be issues all the way through and how we manage those.”

“...providing organizational hierarchy in a handout and “. I think that would give us more time to focus on the point of why those staff are here which is to work directly with the kids and giving them the focus they need.”

Better trained:

- Behavioural management strategies and basic skills to prevent behavioural issues
- Staff to read cues better and use their observational techniques and intervene before a certain point

“We can become very well versed in what their cues are by getting that information through parents if they are willing to share it will us before hand obviously and know what is going to trigger things and have responses to have that prior to that, but if they don’t have that time to really observe and practice they’re not going to necessarily going to see it as quickly as they need to and we end up with a potentially dangerous situation.”

Additional training topics:

- Sensory
- Anxiety
- Behavioural
- Physical activity/movement needs

Supervisor C

Overview of Training:

“...camp conference where all staff come together where there are specific sessions they have to attend and they also have some options depending on their position.”

- Camp structured as a hierarchy so each level received a different training

- 3 or 4 days of support staff specific training while other staff were at their specific camp sites
- Special needs, how to accommodate and adapt programs, manage behaviours

Is training effective?

“...you can do lots of different training but its different when u actually get to camp. Umm it would’ve been great to have some more hands on, like if we had a chance to meet some of the kids...kind of like a meet and greet with some of the kids coming in so we can get a chance to see not just a piece of paper.”

- Did feel that the support staff training is effective and staff are prepared and have an understanding when going into camp

“I think it needs to be everybody though, I don’t think u can train a handful of people and expect the whole camp to be a fully inclusive environment when not everyone has that same training.”

Beneficial Topics:

- NVCi as it gives them tools they need to deal with extreme behaviours that might present themselves
- How to modify and adapt activities → see how they can change the environment if possible or switch up some rules as they don’t directly do the programming

Not Beneficial

- Some of the camp conference sessions
- Also very repetitive so staff are just sitting and not absorbing any of the information

Better trained:

- Have outside organizations come in and speak like Autism Ontario would be beneficial, having parents come in and talking about the importance of camp → training is dependent upon the experience of the senior staff running it

“...so if you don’t have strong staff running the training the staff that are getting trained aren’t going to get as high calibre of training because the senior staff aren’t as strong.”

Physical Activity

Supervisor A

What physical activity looks like at your program:

- a standard movement education curriculum, movement education is organized around conceptual engagement with movement
- It’s organized into 4 large experiential thematic, of body, space, quality of movement and relation.
- Generate those thematics through different stations the station based pedagogy
- Educational gym which is a station that has a lot of climbing, gripping, hanging, swinging, stacking, big gross motor activity, that involved both limb girdles, shoulders and hips , through a large range of motion, weight bearing, and different levels of and so prepositional relationships with apparatus, near, far over, under beside beneath around, a lot of work bodily work in weight transfers and weight management, controlled falling changes of level etc.

- So it's an integration of the body, space and relations with a very heavy focus on the quality of movement.

Have a number of stations that allow them to experience different forms of body, space and relationship:

- Education gymnastics stations that very gross motor, organized around body management
- Fitness stations that organize around cardio respiratory stress, flexibility strength development, symmetrical, strength development cause a lot of our kids are strong in some areas but are very weak in other areas.
- They've got splinter skills that are very cool to have u know but don't translate into play with peers.
- Trying to expand their physical repertoire and many of them are unfit. It's one of the reason their game play skills are so poorly developed is because they are not fit.
- The game based skills allow them to participate in games that have a high likelihood for them to actually engage in.
- Tend to avoid territory type games like soccer, basketball, hockey football, cause there's too much cooperation built into the game and anticipation of what someone else will do, processing of a lot of interpersonal variables that take these kids a little more time doesn't mean that we don't teach them the skills that will help them in those games but those games are just too frustrating
- Most of the game based skills we teach are games that translate into targeting type of game or partner based games so targeting games like bowling, golf, curling, bocce, darts, shuffle board
- Then variations on those game and then games that involve taking those kills into implementable situations like keeping something going for a period of time a badminton type of game or a tennis type of game or a batting striking type of game
- Kids learn sending, striking skills → A lot of these kids have really interesting catching or receiving skills but they don't track well into two hand catching. They can catch two objects in two hands but they don't necessarily track down to using the two hands together to catch one object.
- So maximizing their sending and striking and targeting skills in a way that allows them to participate in those times of games and then eventually buddying up into modified games so we have game skills station.
- A fine motor station which allows them to do more low key type of activity colouring, art work, puzzles
- We have umm a height and flight station where we're working on high apparatus and bouncy apparatus.
- We have outdoor activity station (ODA) where their actually in the outdoors, a non-built environment, their hiking, they're working with nature, their doing scavenger hunts, we do work with side walk chalk, bubble things that help them interact with the outdoors in ways that aren't competitive or I suppose stress producing. They don't have to acquire things or are not on the clock unless they want to be on the clock u know
- A lot of challenge by choice in the ODA setting and our kids love the outdoors they like the hike, they like being on a long a hike, they like being in the woods, they like noticing thing, they like talking about things they notice so we have a lot of parallel curricular,

cognitive affective engagement in our ODA station.

Camp Activities -Community Outings:

- Out trip we take them on a bus somewhere every day.
- Day 1 we try to keep it low key just the splash pad and then swimming,
- Day 2 we do a challenge by choice ropes course which some kids really like and some kids really hate
- We do Marineland we go to an amusement park for a day that's usually a hit.
- We do go carts which is always a hit, go karts and mini put. They love it. I would say 95% of our kids love the go karts.
- We have bowling, and beach. We go bowling and go to the beach. Most of our kids like that. Umm and then we have little side bars like when we're at the beach we do tattooing and face painting, they kind of get off on that. We bring beach games and so forth,
- We try to transfer if we know we are bowling our skills based stuff from the morning is geared towards bowling if we know we're go karting of skills based stuff is getting in and out of small spaces, you know so we try to tailor the mornings curriculum to the things we are doing.

Swimming:

- We swim 3-4 days a week. They love the swimming; they're just honestly they are just water dogs. Honestly our kids love to swim. Aquatics is a great part of our program they really come alive in the aquatic environment. They don't have to worry about falling, they don't have to worry about running, the aquatic environment is very liberating for our kids.
- We need a pool that has got a warmer temperature and lots of stuff besides water so slides, varying degrees of depth, toys the one we go to has a ramp it has bubbles, it has spray, it has sort of splash pad stuff built into the pool its self. Umm which they seem to like a great deal.

Opinion on Physical Activity:

- "I think it's probably the best vehicle to use for kids who are trying to learn other things. I'm frankly horrified that it's the thing that seen as the thing that is the most expendable of most programs. To me it is what I organize around. I will forgo other aspects of the program but the physical is huge. It's huge. I know autism is classified as a communicative disorder and in some ways a cognitively disruptive disorder in many ways, processing and so forth but I really see it as an embodiment issue and that if we ignore the embodied aspects I think we ignore them I don't mean embodied as let's fix them I mean embodied as lets understand how they are in the world, in this body that they inhabit. So I'm frankly horrified that more of that is not being done. But it's not."

Disadvantages:

- Keep kids hydrated due to the amount of medication they are consuming and if they are dehydrated their medications will become more concentrated.
- Higher likelihood of injury: they have an increased likelihood to fall expectantly and their behaviours around unexpected events can be so extreme

- Roughness: kids get escalated as a result of physical activity

“...for kids who you’re worried about their physical strength getting even better and hurting u more they get stronger. They will get stronger and fitter they will. I mean that’s a downside for some.... But I think the risks outweigh- the benefits outweigh the risks in that regard.”

“downside is big kids frighten small teachers but they are big anyway.”

Advantages to physical activity:

- Sleeping
- Metabolic rate- activity helps their sluggish metabolism
- Helps them get hungry so they can be less picky eaters
- Expands their social repertoire
- Allows them to perform their activities of daily living, showering, dressing, climbing stairs→ range of motion, flexibility, strength, cardio
- Weight management due to meds but also will teach them how to fall safely and not hurt themselves

Physical activities to add→ drama and juggling/circus type activities

Supervisor B

Physical activity at program/camp:

“We often try to build in active pieces even in to our least active types of programs. Something as simple as building in a movement break within the timing of a craft activity”

“...and it’s not always something overly active but something of a cleaning up activity in the middle where the kids are going to have to get up and move and we conveniently leave the garbage can on the other side of room. We try to be creative on those kinds of things so it’s not just a very stationary.”

Opinion on physical activity:

“I think it’s a must! I don’t think that kids with ASD do well when they are 100% stationary. The older they get sometimes that’s all they want to do, but they don’t seem to be a productive socially or behaviourally or intellectually.”

“...using videos games such as Xbox kinetic or Wii to get the teens up and moving and engaged.”

Physical activity for extreme cases:

“Yes often some of the more severe cases have transitioning issues, so we’ll work in motor activities right at the beginning of the event or activity. This would be more of if there was an ongoing program where we had the luxury of several weeks to figure out a plan that worked really well for them but we would just incorporate whether it’s you know actual gross motor activities of walking, running, climbing, we’ll use mats, we have a lot of different gymnastic type mats, we can look at rolling and different things as well.”

“We’ll often build those things at the beginning just to bring down the anxiety and work them into the environment and then if again needed in that period of time revisit those types of

activities.”

“We do lots of fine motor activities throughout as well although those aren’t as relaxing for most of the kids who have extreme cases its more the larger gross motor activities that we really have to think about what’s the best way to work that in.”

“I find that a lot of those kids are deep pressure seekers, um or at least physical attention type seekers where they are really looking for physical interaction with another individual so that’s often a time where we have a 1:1 pairing at least for that period of time so that instead of that being uh a targeted behaviour towards an individual the individuals are being involved and participating with that child with those motor skills.”

Physical activity additions to program/camp:

- Wishes there could be a gym type space in the facility as she would like to see more upper body climbing activities

“...we can’t really target those upper body climbing muscles very well because we don’t a wall to climb. But we do, but not that they can do in an appropriate way. I think that would be a huge benefit for those kids that need the upper body motion. We do try to get it with some floor type activities but it’s not the same, the climbing piece would be nice.”

“Same with the ball throwing and that type of thing we don’t have the facility here to do that.”

“It would be nice to have an outdoor, fenced in space, as well maybe with some basketball again something that’s very appropriate if people were watching what’s going on.”

“So kids can feel like they’re fitting in a bit socially and maybe even work in some typical peers in there but you know not necessarily in an unsafe way making sure it’s secure for them.”

Supervisor C

Physical activity at camp/program:

- All programs have physical activity...big component of the organization that health is one of their main values so all programs have some active component
- Soccer, tag, canoeing, relay races, octopus, scooter boards, exercise balls
- Because of his position he would be able to take kids up to the workout area and use the Bosu balls

“ I think it’s really important I think in my experience you see a decrease in behaviours regardless of what needs they have...umm it’s just good to balance their day.”

Advantages of physical activity:

- Only other time other than school where these kids will be exposed to physical activity

Disadvantages:

- Some of the activities like tag where the physical barrier is difficult for some kids to play
- Feels the benefits outweigh the negatives

- Did mention physical barriers → would adapt as much as possible

Provided a great example of how they saw that a girl who was an extreme case. She loved swimming and it calmed her so they were able to adapt her day so she could swim twice a day.

Improvements:

- Staff to have a more purposeful understanding of the why some activities are better than others

Additional Information

Supervisor A

“Martha Graham who is one of the foremost movement educators and dancers of the 20th century, she says movement never lies. That’s what she says “movement never lies. It is a barometer. Telling the state of the soul’s weather for all who can see it. And that’s what I think the students need to do. They need to be able to look, and see what are these kid’s bodies presenting them. You know Not just,” oh they can’t speak” or they can point or they can direct me somewhere they need to look at the body and read tension or read distress or read happiness, or read the gestural postural cues that these kids are giving us ALL THE TIME. They haven’t been taught to see. Right? That’s what Martha Graham it tells the state of the soul’s weather for all who can see it. That means if you’re able to see it you can tell what’s going on.”

Stigma: “One thing I could say is typical responses to severe kids or extreme case is not good... Yes it’s fear, its classic stigma. I mean the dimensions of stigma are organized around affect, cognitive, and behavioural. You know and the dimension fear is the affective component of stigma. Stereotyping is the cognitive component of stigma, and social control is the behavioural control of stigma so wanting to control something gets at the behavioural dimension, wanting to stereotype them is the cognitive dimension and being terrified of them is the cognitive dimension but it’s all stigma. These kids are stigmatized and largely because they’re invisible. And we don’t have them out in the public eye and they’re not seen as priorities in how we prepare our practitioners and their umm part of it is integration but integration has to be meaningful I mean these kids aren’t learning French so if they’re in a French school there has got to be a good dignified reason why they are there. They need to get something out of it and so do the other kids and that kind of exposure just isn’t happening in meaningful ways and that’s why people are afraid. I think.”

Supervisor B

Families with extreme kids hesitant to attend events or programs:

“We typically are getting kids who aren’t extreme because those are the families who are able and willing to try something new and the folks who have the extreme cases are hesitant to come out to these types of programs because they have had some failure in the past and they are not really sure if they want to try again.”

“Typically there are the ones who try the longer programs. They’re looking for anything it’s because the parents are looking for some respite which I totally understand. Our ongoing programs are typically staffed so that parents don’t have to be there and involved. And so it’s an opportunity for them to drop their kid off and have an hour off. So I think that those are the ones

that tend to lean towards.”

“We do have a number of kids that will come out to the special event type activities um but I find that some of the parents find it more exhausting cause it’s just one more thing that they’ve added to the agenda and it’s a change to the routine which throws things off and typically its more getting involved in an ongoing program that they I would say they lean towards.”

Questions I should have asked:

“...if we get all this information about kids beforehand does that set like a judgement...or do we make predetermined beliefs about a child before they even walk in the door and therefore potentially hinder their involvement or change it in a way more than what we even needed to do based on what they say on paper. Cause I find that that happens sometimes, that parents state the worst um, which rightfully so, we’ve got some kids who have some significant needs and really have caused a lot of difficulty for families but when you put it down on paper it sometimes comes across in a very negative way. I think that the kind of really interfere with sometimes how we set up our programs, and I really wish there was a way to get around that. I don’t know what the best way to do that, sometimes it might just be the wording of our questions; we’re always trying to adjust to change. It would be nice if there was always a way to meet the kids beforehand.”

I guess going off on that topic, do you feel that the staff um, makes a lot of assumptions about extreme cases or has fears?

“Yes, ya.”

And do you feel then that are they well coached on how to handle this or is that when the confidence and experience piece?

“I think that’s the experience piece and self confidence in their abilities. The longer, not that most first staff have been around very long, most staff are young, the more they do it, the more they realize that it’s okay to have a thought but it’s an opinion that makes a difference. If you are setting yourself up to already have a predetermined opinion about a child before they walk in the door, it really changes their approach, you can have some thoughts on what they might be like and being open to that being changed drastically in the first five seconds and I don’t know if every staff gets that concept because they’re given the information on a piece of paper that says that this kids probably going walk in and smack me in the face before the end of the night and it’s hard not to be weary of what that might look like.”

Supervisor C

“It was hard to separate myself, that was one of my biggest issues with the organization was that we could have done so much more but didn’t and that was part of the reason why I was kinda ready to get out of there was that I wanted to see that kind of stuff happen but I knew that it wasn’t going to happen, not now anyways.”

Did it not happen because of funding and money and that need to give programs to the many and not the few...?

“The focus just wasn’t there; the people kinda on top didn’t have that interest or focus.”

Did you feel there was a need for that?

“I think, I look at two of our programs... at least we used to have that...I don’t know what it’s like now but we used to have a huge interest for it. And I look at the amount of kids we service in the summer, which is huge and then during the year we got nothing, like we don’t do anything for them really other than camp. Like we have programs but if they need any other type of extra support then they aren’t going to do well in programs like they aren’t going to...”

“I think specific to the Organization C, we didn’t always know the extreme cases. It kind of came as a surprise. Sometimes we did we tried to prepare as much as possible sometimes we would get kids from FACs that would get sent over they wouldn’t fit all of this description (definition) definitely some of it umm they wouldn’t have support in place, we wouldn’t know much about them and then we would have to try and figure it out so that came up sometimes..I can think of maybe a handful of kids that fit this definition.”

“...so a lot of times it’s so dependent on what the family tells. If they decide to not tell us anything because they don’t want to pay the extra we don’t know until they kinda get there... and it’s a surprise or they go online and they don’t have to fill this out and then surprise! That’s been my most challenging campers I can think of were the ones we didn’t know and we didn’t have support for. The ones we had support for we were ready for the parents were more forthcoming of information.”

When he first started as a support staff he worked with an extreme case.

Appendix O
Level 2- Cross Case Analysis Senior Staff

Describing an “Severe” Case	
Senior Staff A	<p>Extreme child is unmanageable with extreme difficulties that equal extreme: behaviours, sensory issues, overly aggressive and a lack of ability to do normal things (daily living skills and social skills) and have a normal life.</p> <p>Felt that you could get specific and technical with the definition but it was a good broad definition that was extreme.</p> <p>Provided specific example of severe case</p>
Senior Staff B	<p>Extreme child is lower functioning, non-verbal, fairly aggressive and at the end of the spectrum. Focused on low functioning</p>
Senior Staff C	<p>An extreme child displays SIB's, has severe meltdowns at times, aggressive tendencies may not be able to function within a group of other children and needs support to be integrated.</p> <p>Mentioned self-injury twice</p>
Organization	
Senior Staff A	<p>Organization A provides a 2 week camp to children to adults who are on the Autism Spectrum with a goal to provide physical activity and movement to promote social inclusion, cooperation among peers and help them develop as individuals.</p> <p>Organization A does not have a policy on who they will or will not accept, they are accepting of all individuals with ASD.</p> <p>They are the only program in the Niagara Region who focuses on movement and are housed in an post-secondary recreation facility that has a variety of gymnastics and athletic equipment.</p>
Senior Staff B	<p>Organization B provides programs and camps the children and youth on the Autism Spectrum. The organization also provides support to parents through workshops and providing these</p>

programs as a form of respite to the parents.

Staff B stated that there is quite a bit of discussion around accepting extreme cases campers into the programs as the staff wants to ensure they can manage their behaviours in the program environment but there is no policy on accepting extreme case.

Staff B felt that their program accepts many of the children that other programs in the city will not accept as Organization B has: higher paid, better trained and more experienced staff; more funding and support; are able to deal with the behaviours.

Senior Staff C

Within their camp program, Organization C provides 1:1 support for children with a variety of disabilities that can range from Autism, Down syndrome, cerebral palsy and they may have behavioural needs.

The organization's overall goal is to have children be successful in their camp programs and get as much out of camp as they possibly can just like every other child we want them to have fun, an opportunity to build social relationships with other children and learn how to socialize with other children.

To Staff C's knowledge they don't turn any child away and are accepting of every child and want to work with the child and parents to ensure success. "Accepting to all people no matter their ability."

Interviewee's Role

Senior Staff A

Staff A has 6 years of experience working with a variety of individuals on the spectrum in a local agency that provides respite, Autism class and group home services. Staff A is in the process of completing his undergraduate degree in Child and Youth studies as he previously had a diploma in Police Foundations.

Staff A is a senior staff/mentor who oversees a group of undergraduate volunteers that are working with the individuals with ASD. When working with the volunteers the role of the senior staff/mentor includes "mentoring, guiding, directing, assisting when needed and intervening when necessary."

Staff A is also working with the supervisor to "revamp the training to make it more effective so the volunteers are more prepared to work with the kids."

In previous years, when working with extreme cases he has taken on the role of intervening and leading by example when a volunteer is unable to handle an extreme case's behaviours. (p.4, Q13) This year, he would like to "empower the volunteers" to mentor them by offering advice on how they can better handle a situation.

Senior Staff B

Staff B has completed an undergraduate degree in Speech and Language and is in the process of completing her Masters of Applied Disability Studies. Staff B has worked as an educational assistant in the NCDSB, a horseback riding instructor at a local agency, a respite home, and

currently is working as an instructor therapist in a provincial IBI program.

Within the organizations camps and programs, Staff B is a senior who provides strategies to staff as to how they should “cope with and prevent” behaviours. She would step in and redirect the child when a behaviour was occurring and figure out “what was happening and try to solve the problem.”

When working with extreme cases, Staff B would “provide the follow through for a lot of the behaviour strategies that we were trying to implement because the organization does employ a lot of people that aren’t as trained in dealing with kids at that level so if there was a behaviour happening I would basically have to step in and take over.”

Senior Staff C

Staff C has completed an undergraduate degree in Child and Youth Studies and is continuing her education by attending teacher’s college. This is her second year as senior staff at organization C. She has volunteered at the SNAP program at Brock University and worked for special needs camp and programs as well as a Greater Toronto Area city camp.

Staff C is a senior staff within the organization’s special needs camp and program. She oversees the integration of campers with special needs into various camps. Prior to camp Staff C along with another senior staff complete camper profiles and develop training. During camp, Staff C oversees her staff and is “there to deal with any issues that may arise, help deal with behaviours that may arise, be there to coach my staff in different situations, cause some of them are only familiar working with certain disabilities, so I’m there a resource for them and then I’m there to step in if need be so..”

Expectations & Relationships

Senior Staff A

Staff A feels that his supervisor has expectations that are “a bit more than your ordinary senior staff” as he has more experience, is male and the history of their relationship. The supervisor consulted to the group home where Staff A was the full-time staff of an individual with ASD and OCD.

Staff A did comment that he doesn’t like that being “a male sticks over his head but his supervisor depends on him for certain situation where she can’t with a female.” Gave interviewer the impression he does not want to be valued by supervisor solely because he is a male.

Staff A feels that his supervisor is “always there for him” and is “incredibly supportive” of him and his role at camp. He appreciates that his supervisor is open minded to suggestions and never disregards his advice or suggestions.

Senior Staff B

Staff B discussed that her supervisor expected her to “run camp and make sure that I communicated with the parents what was happening, that I was in constant communication with her with what was happening” and complete daily paperwork and reporting tasks.

Staff B felt that her supervisor did support her last year in bringing in their NVCI trainer to consult on a new extreme case child but felt that “...they want to fill up spots, they want camp to

be full so we'd have situation where there was a kid with a language barrier and we weren't familiar with them and he was extremely aggressive and I felt there could have been more support there instead of them calling up in the morning saying you have a new kid."

Staff B felt that her supervisor supported her in helping go through camper profiles, providing lots of time to prepare for camp but would have liked an earlier provision of information on the extreme case child stated above as Staff B felt that "throwing a kid in that's never been to camp, has a language barrier and is extremely low, you're asking for trouble. Which we had but she(supervisor) wasn't there to help right"

Senior Staff C

This past summer Staff C did not have a direct supervisor so if any issues arouse she would consult the Camp Director or Regional Supervisor. "We are both returning senior staff so we know what we are doing and they just trust us to do it. It is frustrating though."

Supervisor's expectations:

Felt her supervisor expected her to support her staff"... as it can be a very challenging, tiring and stressful job, a resource that is approachable and available to her staff, visit each site every day, to check in on staff provide them with breaks, answer and questions and step in and deal with different issues and different behaviours."

Felt her supervisor was very approachable and knowledgeable as Staff C "is no expert I just try my best" but felt very supported by her supervisor knowing that "she was there to back me up and support me when I need support too is helpful."

Meeting the Needs of the Child

Senior Staff A

Staff A discussed that his supervisor is the main individual who determines the needs of a child by dividing them into groups and assigning volunteers based on needs and he "never has a say in that." Severe cases needs are met by assigning them a 1:1 volunteer so "they would have all the attention on them" and reviewing the profile completed by the parents.

Felt that the severe case's needs were met by giving them a 1:1 staff and "they are dealt with the same way the staff deals with everyone else." Staff A does not appear to feel as though he has any control in meeting the needs of an severe case

Staff A created his own 1-10 ranking scale for how effective camp is at meeting the child's needs. "1 being really really terrible at meeting the needs and 10 being really really good at meeting the needs, he felt camp was a 8.5-9.5. He focused on the purpose of camp of having the kids participate in physical activity and not going outside the walls of camp as they are not a treatment program or behavioural institute. Staff A gave the camp a 10 for meeting the physical activity needs of an extreme case child.

Senior Staff B

"Depends on how the staff is" Staff B felt that meeting the needs of the child was dependent on the level of the staff and their intentions in meeting the child's needs.

The camp staff would develop a daily schedule that would help with behaviours this included

gross motor activities because she felt it would tire them out a bit. She also discussed blocking the child's day so that they would be doing reinforcing activities (she used water play as that was an camper's favourite activity) as a larger component versus craft which was a non-preferred activity.

Staff B felt that reviewing the profile was helpful but if there was returning staff it was very beneficial as they would be more familiar with the camp schedule and how to "maximize what was reinforcing and minimizing what he didn't like or taking it away."

Senior Staff C

To meet the needs of the child, Staff C will call or meet with the parent's to complete the camp profile, which is a series of questions about their child. "I find that a lot of our parents are really open and willing to share information with you not really trying to hide anything....I am very lose with all our parents they'll call me whenever they need to I'll call them when I need to. It's a pretty open relationship."

Staff C felt that they are pretty effective in meeting the needs of severe cases as she will look at the needs of the child and based on those needs she will determine how they need to adapt activities so they child can participate. "... because I don't want them sitting off to the side like my thing is I don't really want to my goal, I don't want to walk into the camp and say oh those are my campers sitting by the tree. So that's what it's all about."

"...last year umm one of our campers had a visuals schedule and instead of just excluding them with just their own visual we had a whole visual schedule for the whole group. We posted it on the wall for the whole group to see so it wasn't just this one camper having their own separate thing it was the whole group. Everyone likes to know what is coming next it's not just our kids. I like to know what I'm doing next so why wouldn't they."

"We're here for these campers so if you're not going to meet the needs to meet the needs of the campers then I'm sorry but it's not a place for you."

Programming

Senior Staff A

Discussed how everyone has a general schedule and everyone does the same activities but they are tailored to what the child is capable of, based on their level of functioning.

"We don't treat them different differently because they are extreme which I think kinda helps so say if you try and integrate the same schedule kinda keeps things simple and keeps things consistent because you can't have 25 different schedules running throughout the day."

He refers again to "same way we structure for every other kids" Same reference to treating extreme cases same as everyone else.

Senior Staff B

See above section "Meeting the Needs of the Child"

Senior Staff C

See above section "Meeting the Needs of the Child"

Challenges/Barriers

Senior Staff A

Barriers discussed were the volunteer's lack of experience, understanding the proper way to work with these kids and motivation to be at camp are consistently a barrier. He's hoping these barriers can be overcome by revamping their training. Another barrier is the ratio of volunteers to kids and there always are fewer volunteers. This impacts the amount of support the senior staff/mentors can provide as they are often "running around with their heads cut off trying to help everyone who needs help."

Senior Staff B

Money

Staffing was discussed as a barrier/challenge if children at a certain level (referred to definition again) if "you're hiring people that might have an education or any education or been in a placement that doesn't mean they're necessarily qualified but it's hard you know because the staff doesn't get paid a lot of either so it's hard to recruit umm people that are going to be consistently coming back for \$10.00-\$10.25/hr that are willing to work that hard so I mean it's a double edge sword that way."

Felt that staff education is a barrier as staff may not be familiar or experienced in dealing with self-injurious behaviour or knowing the functions of a behaviour and that is a "huge gap in knowledge"

Senior Staff C

Lack of communication during registration process as she starts 1 month after another senior staff. Parents will call her upset because they have been waiting 3 weeks for a phone call but a message was never passed on to her that she was supposed to contact them.

Staff knowledge and training

"Probably shouldn't be saying this...non-profit, pays less than other organizations so they get quite a few people who are looking for that first time/part time job who really have not had that type of experience in dealing with kids."

"A lot of these people think you know-oh ya I can working with kids with special needs it's no problem, it's not challenging and then they come into it and are like wow I didn't expect this."

Funding cut by 40%.

Physical Activity

Senior Staff A

As a result of physical activity being the main focus at this camp, physical activity is embedded into every activity the children participate in by having them move in ways they may not be used to:

- Swimming everyday: doing aqua athletics in the pool
- Gross motor activities: shapes, climber, ropes, trampoline to have the children use their own body weight
- Being pulled on scooters
- Outdoor activities: hiking and walks
- Games for high functioning kids: soccer, baseball

- Community outings: bowling, beach

Staff A's opinion on physical activity was that the results are eye opening and impressive as it decreases child's anxiety, sensory issues and behaviours. He describes parent's smiling as they tell him their child slept through the night because their child was exhausted and how that impacts all areas of their lives.

Staff A did not feel that there were any disadvantages to physical activity and did not feel that he was knowledgeable enough to discuss any physical activities he would like to add.

He did feel that extreme cases are non-compliant when presented with physical activity because "A-they don't want to do it, B-they don't know how to do it, C-are afraid to do it so non-compliance is definitely the biggest challenge and then but once you get them doing or find a way to get them to do it it's like a whole new ball game."

Senior Staff B

Felt that as a result of Dr. Maureen Connolly coming in to the organization to do a presentation on the importance of movement and physical activity for children with ASD her supervisor is promoting it more to her staff and in programs which in turn is helping the children participating.

Felt that her supervisor is now seeing that physical activity is more than just running around for 20 minutes but that you should "have them use medicine balls and creating movement stations. Activities:

- Trampolines
- Playing with balls

Advantages:

Provided an excellent example of how a staff who was very knowledgeable in the importance of movement and physical activity was able to come into a social group of high functioning young, energetic boys with HFA/Asperger's. The group was initially showing quite a few behaviours when a staff member who was uneducated about the importance of physical activity and movement was leading the group. Staff B had the staff who was familiar with physical activity be in charge of the group and they implemented movement/activity stations, token/reward system to reinforce proper behaviour and there was an extreme drop in behaviours across the whole group.

Felt that there are no disadvantages to physical activity but the issue is "getting everyone on the same page and getting people to buy into it." She discussed her experience in schools and that "...it's not the emphasis, the emphasis is trying to target the goal and table time is more important than taking them to the gym." She felt that "providing the education might be costly depending on the cost of running the workshops that might be the only disadvantage to a program happening or having everyone taking a day off to do an in-service but other than that I don't see any disadvantages."

Senior Staff C

Felt that camp in general is pretty physical but there is time for structure free time of camp wide games (manhunt in forest- hide and seek running game) and swimming.

Advantages:

Feels physical activity is important as children are getting lazier as a result of being in front of the t.v. and computer. Felt it is very important for kids to come to camp and “be physical” and play physically active games- running around, skipping, and jumping.

Need to alternate between active and passive games.

Kids don’t have the opportunity to be physically active at home so they need to get that at camp

Disadvantages

Felt no disadvantages but felt if a child is in a wheelchair this would be a disadvantage of how to adapt games.

Additional activities:

Would like to add mats, balance beams, vaults and trampolines similar to SNAP program but that all costs money.

Integration

Senior Staff A

“Any extreme case that I’ve seen come in to camp has been included in everything that we do whether it juts sometimes it just takes a little bit more time and a little bit more effort to get them involved.”

“We are effective because we have good people in positions to help these kids as much as we are able to with what we are allowed to do. We always win, at camp we always win if the kid is going to sit there and struggle and be noncompliant with their worker then the worker is going to get someone else and if I can’t do it then I’m going to get someone else so if it takes 4 people to move that god damn kid that kid gonna be doing something one way or the other.”

“Non-compliance they just don’t A-they don’t want to do it, B-they don’t know how to do it, C-are afraid to do it so non-compliance is definitely the biggest challenge and then but once you get them doing or find a way to get them to do it it’s like a whole new ball game.”

Senior Staff B

Discussed communication issues with lower functioning extreme case’s and staff not knowing how to use PECS schedule or sign language and therefore they are unable to support that form of communication.

Did feel that integrating a higher functioning extreme case who is aggressive or “socially destructive” is difficult as they will alienate themselves socially from the group “after they’ve seen what one of the destructive behaviours, they don’t want to be around the kids.”

“If you don’t have staff that can support it then you have a whole other problem.”

Senior Staff C

“Alright” but feels staff could be better trained. “Probably shouldn’t be saying this...non-profit, pays less than other organizations so they get quite a few people who are looking for that first time/part time job who really have not had that type of experience in dealing with kids.”

Accommodations & Strategies

Senior Staff A

Felt it was completely dependent on the child but would use the following strategies

- Visuals
- Basic verbal communication paired with visual
- Go to an activity 5 min early, alternate activities to introduce them to child
- Countdowns
- Visual schedules
- Reminders for transitions
-

Additional question about eating:

“...pick your battles we’re not going to teach the kid to eat in 2 weeks. Help the kid eat so they can do whatever else after.

Additional question about aggression:

“...take them for a break or the sensory room then go right back to the activity they were doing.”

“...if you control the environment you can control the behaviour a lot more...”

Senior Staff B

Accommodations/Strategies:

- Pair child who uses alternate form of communication with a staff who is familiar with it
- Visuals
- Choices
- Get the child to express what they want by pointing
- Sensory items
- Visual schedules
- Constant transition warnings
- Social stories
- Transitional objects
- Alternative plans(Plan A or Plan B)
- First then
- Superflex(social curriculum)

“The staff don’t get a lunch so they sit with the kids at lunch, if they need to be fed then that’s the staff’s responsibility.”

“...things are changed and modified based on their functioning level what you know they are capable of doing.”(1 craft for high functioning campers and 1 craft for lower functioning campers)

NVCI training for staff to be prepared for aggressive children

“... we’re providing activities that like you know are higher preference that they, using things that are reinforcing to try and break the matter and focus for a short period of time.”

Senior Staff C

Accommodations/strategies:

- Token boards using PECS

- Visual schedules
- Arriving or leaving an activity 5 min early to avoid chaos
- Countdowns
- Transition warnings
- Extra time to complete activities
- Visual schedules
- All about me profile→ focuses on interests versus skills
- Fidget bags→ squishy balls, puzzles, crayons, colouring books and other sensory type toys
- Resource binder→ disabilities, characteristics, strategies for dealing with behaviours

Behaviour Management

Senior Staff A

The mentors/senior staff or volunteers are not able to physically intervene if a child is having a behaviour but they focus on early intervention to avoid “massive blowouts or meltdowns.”

Staff A uses the following strategies to manage behaviour:

- Taking a child for a break(walk, hike, gross motor or sensory room) to de-escalate and then returning to the activity once the child is calm
- Modifying an activity to have the same focus, and being consistent to avoid behaviours

Importance of consistency “always doing the same things every day, speaking to them in the same way, getting them into a routine and not breaking that routine unless absolutely necessary...prevention instead of reaction.”

Advantages:

- “...prevention, being proactive as opposed to reactive.”

Disadvantages:

Felt there very few disadvantages to being positive and proactive however this is solely dependent upon the volunteers motivation for being at camp and how that can affect the child’s behaviour.

Senior Staff B

“I’d say that they try to be proactive but it is more reactive.”

“I think there a lot of things that are changed about how to deal with the behaviours, there’s not enough, I mean they don’t really know, the parents don’t even know what’s causing the behaviour and I think that that’s there’s a lot of assumptions about why behaviours are occurring and there’s a lot of, I think that it’s hard for some of the people that have seen behaviours, oh that’s just child X or whatever, or I mean like they don’t really look at changing it as much.”

Felt that the short time frame of training and length of programs is not enough time for the staff to be informed as much as they should be about behaviours and in dealing with those behaviours.

“The purpose is for them to have fun. You just kind of set up the environment and hope that there are no behaviours and if there is its just redirection and just trying to calm them down and

get them back to a place where they are happy, it's not really a therapy camp so..."

Advantages:

Felt that organization is willing to take risks and incur losses by supporting a variety of children especially those who other organizations would not take.

Disadvantages:

Felt that a weekend of NVCI training is not enough because staff are then dealing with and being reactive to the behavior versus learning to avoid the behaviour.

Senior Staff C

Redirection

Commented that Organization C is not big on timeouts they want them to redirect

"I believe that redirection is a good thing but I feel like there are times when you need to just remove the child from the situation like they need to be removed and redirection is not going to work and they need time to cool off and you need to remove them from the situation bottom line. And I do kind of go against the redirection policy because I feel like it's important. And no one has ever said anything to me so I keep doing what I do."

TEACCH

Senior Staff A

"Exposed" to different aspects of TEACCH for past 6 years.

4 years has worked in a children's autism program class where TEACCH is used throughout the entire classroom.

TEACH at camp

Use visual schedules at camp with a big generic schedule board that doesn't move or get modified.

Have individual schedules for campers that volunteers can take-off and move pictures and set-up the child's schedule.

Don't do a "ripping and matching" system

No formal TEACCH training.

"My understanding of TEACCH is using visuals to help...using a visual program to help kids function in their day, function more effectively throughout the day, helping kids have a better understanding of their day of life of how to do things of how to behave I guess so you can work that through social stories of what their expectations are. TEACCH helps with all aspects of life depending on the kid...modify TEACCH to meet the needs of each individual kid."

Advantages:

"It's fantastic! Cause a lot of these kids don't know how to communicate especially the lower functioning kids and even the higher functioning kids need to know what's going on. From my experience if a high functioning kid presents as "normal" he still can't process their still not processing things like we think they are so even that's what the more generic schedule board is

for. So a kid can look at his day and see what's going on. I think it's fantastic there's not a lot of more beneficial ways of communicating with these kids than through concepts developed through TEACCH."

Advantages for extreme cases:

"Extreme cases generally have a terrible time communicating a lot of behaviours can develop through lack of communication and lack of understanding. So extreme cases it's beneficial because it lets them A- it lets them have a voice B- it lets us communicate with them better, whether it be a thousand different things like letting them know that everything is alright or how to behave properly or what their day is going to look like it's like you have an extreme case and you have one example with no visuals what so ever and verbally talking to them all day long every day and you have a same case using your visual and your TEACCH concepts you're going to have drastic behaviours with the non visual schedule compared to the visual schedule so it's just a way of keeping them calm letting them know what's going on, letting them have an understanding of their day in terms of camp that's as far as it goes. Like we don't do social stories or anything like that it more like letting them know what's expected of them."

Disadvantages:

"I want to say no right off the hop but I meanI say no but like you want to make sure depending on the kid what concepts you are using and what you aren't using, so for example you have kid who is extreme OCD you are not going to show him a 15 PECS schedule because he will just obsesses over certain things all day. So there is no disadvantage as long as it's done right."

Senior Staff B

Used at camp and Life skills(lower functioning) program

No formal TEACCH training

"...they've always had it at programs, but I really know not much at all about TEACCH."

"...we didn't even talk about it last year at training because I didn't know what I was talking about so I wasn't going to tell them, I know the order the bins go and that's it."

"It's basically just green, yellow, red bin with a fine motor activities in it, that we set up a TEACCH station and like there might be like four different stations. And they would have the kids you know go through the activities and complete them."

"I'm sure that TEACCH is an effective program. But I don't know or that anyone knows how to properly implement, no one has been through training I don't think. Even when I started here, we like talked about, what was expected of it, like what do you want the kids to do, but like they I don't think anyone really knew what they were talking about."

Advantages/Disadvantages:

- Structured
- Beginning and end
- Work on fine motor
- Individualized

Senior Staff C

Has heard about it from school but doesn't know exactly of what it is.
Training
<p>Senior Staff A</p> <p>Felt that training was an “exhausting” experience as you “just kind of sit there and listen for the entire day about everything camp is about and what’s going on in camp.</p> <p>Training needs to be re-vamped as it is not very effective or practical as they are sitting and listening to someone speak for the entire day.</p> <p>Would like to see a cohesive team at camp as it could impact the success of camp if everyone is working together.</p> <p>“...volunteers more engaged and interactive during training.”</p> <p>Training length: One day is listening and another is go over more details and then setting up camp.</p> <p>The volunteers working with the extreme cases do not receive different training but it is up to their group’s senior staff/mentor to prepare the volunteers working with extreme cases.</p> <p>Beneficial Topics: preparing volunteers how to manage difficult behaviours</p>
<p>Senior Staff B</p> <p>Discussed going up to Autism Support Services and having a three hour course is not enough to know why things are happening in regards to a behaviour and would rather see a behaviourist or Behaviour Analyst come in to discuss behaviour and why it is happening.</p> <p>Program training is 3 hours with an overview of expectations, program goals, ABC’s behaviour, incident reports, overview of organization, and case scenarios.</p> <p>Camp training is more intense over the course of four days.</p> <p>Felt that training was not effective as you sit for four hour hours and listen to someone talk about the functions of behaviour and it is a lot of information to take in.</p> <p>Beneficial to have group discussion and discuss case scenarios and to learn about the whole spectrum because at camp the staff could be working with both high and low functioning kids so they need to be prepared for any situation.</p> <p>Felt self-care is overlooked in training</p> <p>Beneficial topics: Alternative communication as quite a few kids are non-verbal</p> <p>Not a beneficial topics: Doing ice breakers all day</p>
<p>Senior Staff C</p> <p>“...for the past year and this summer, a lot of our staff are very new and they do need a lot of coaching and training and I feel like that is something we need to improve on in future years because I feel like right now our kids aren’t very severe they are pretty high functioning so it’s</p>

not that big of a deal but if we were to have those more extreme cases there would be, we would need to u know train our staff a little bit more.”

“A lot of these people think you know “oh ya I can working with kids with special needs it’s no problem, it’s not challenging and then they come into it and are like wow I didn’t expect this.”

City specific training topics:

1 day go over site specific details and policy and procedure, day to day camp operations

1 day program specific training:

- Behaviour management
- Adapting activities
- Scenarios
- Strategies
- Resources
- Overview of profile
- Overview of program

2 days of camp conference:

Staff get to sign up for different sessions run by senior staff(camp games, adapting activities for children with special needs, camp songs, transitions, and missing camp drill)

Feels that training is repetitive and would like to see community agencies brought in to speak from their standpoint about their experiences and ideas.

“...cause like I said we’re not experts we’re still young too and we haven’t experienced all there is to experience so maybe bring in people from Autism Ontario to talk to the staff about different ideas and different things they can do I think would be beneficial so if I go back next year, I would look around and see who can we have in to speak to them so it’s not just us lecturing them.”

Additional Information

Senior Staff A

Senior Staff B

“..the profiles that we’re given are definitely in depth but at the same time they’re not necessarily filled out in depth.”

Senior Staff C

Funding cut

“By 40% so I feel like we had to turn so many kids away this summer and staff away this summer because of this funding cut and our numbers are drastically lower compared to last summer. So staff this summer I had 4 compared to 6 I had last summer. St.Catharines now has 6 compared to the 12 last summer. Cut by half pretty much.”

“...ya because we can’t accept as many kids as we did last year because we don’t have the staff to support them so kids that I like...for example 2 campers I had last summer who because with our program we guarantee them the 4 weeks, yet the 4 weeks and then if you want extra we put

you on a waiting list and then if staff is available then you get those additional weeks. In previous years we have been able to give these additional weeks to these 3 specific families who need them because their parents are working or single parents but this year because of all this funding cut I can't even do it. So now the parents are mad at me say- what am I supposed to be doing with my kid for the month of August because I work full time I am a single parent what am I supposed to do. And I'm like..?"

Appendix P

Parent Survey Questions & Responses

How would you describe your child?

Parent A

Amazing!!

Lives by routines, but has gotten much better at sudden changes...her behaviours are few and far between, but when she does have a meltdown there is a lot of screaming and some self-injury (head banging)

She does have verbal communication, but usually only speaks when it suits her or is offered a great reinforcement...she also uses echolalia. She uses picture schedules and when and then boards.

She is an amazing girl, full of love and laughter...she has a great sense of humour and enlightens us every day, even if it doesn't always run smoothly.

Parent B

Happy and cuddly boy who loves music, fairly easy to transition, limited expressive language; 5 word sentences, not having conversations yet, excellent receptive language, a mover and a seeker.

Can have head hitting behaviours, usually short and usually when he has pain from getting his adult teeth.

Fairly good life skills but still needs help in many areas. No safety awareness yet.

Parent C

My son requires 1:1 support. He doesn't know stranger danger or understand privacy in a washroom. He doesn't understand street safety. He can speak words to let you know his requests, but has very limited capabilities to answer questions. He likes to know what his day entails, especially if it something new. If it is an un-preferred activity to him, the task must be broken down into small learnable components, many reinforcements such as praise, gross motor movements, tickles, edibles given to keep him wanting to do the task. He works well with a visual or written schedule and a timer to see how long activities last. He often lets out a high pitched scream when he's frustrated or anxious which is very startling. He has OCD which interferes greatly at times. He may jump, stomp, bolt or even bite occasionally. You have to

know him well to notice his anxiety levels, when to offer breaks and when to change activities. He loves music, computers, birthday parties, swimming, horseback riding, gymnastics, baking, trampoline, swings, bike riding, and being around other kids.
Parent D Loves movement, hates change , wants to control everything, needs routine, verbal and uses a daily schedule
Parent E Needs to be kept busy. Needs supervision during waking hours, especially in unfamiliar surroundings. Needs to have an area to take a break when overwhelmed. Needs schedules, and reminders for ADL. Home life is fairly routine. Certain activities have to happen on certain days. Scripts quite often, and requests situations that require imagination. Behaviours have increased since she has gotten older. A lot of her behaviours are escape, or work avoidance. At school she runs from the gym or screams when she can't have computer time. Difficulty with noise, mostly someone yelling, or raising their voice. She seems to be able to tell the difference when someone is cheering and getting upset. She communicates mostly verbally, but it isn't always functional. Has a lot to say, but it isn't always functional. Enjoys going to camp most of the time. Enjoys being around other kids, but seems more comfortable around adults. Affectionate, enjoys hugs (deep pressure squeezes).
Parent F Very high needs, non verbal, self-injurious, uses Picture Communication System to communicate, needs structure and routine at all times, and has to be cared for at all times because of safety.
What is your child's diagnosis?
Parent A Severe Autism/PDD
Parent B Severe autism
Parent C Autism and Pancreatic Insufficiency
Parent D Autism and development delay
Parent E Autism and development delay, Autism (classified moderately severe) diagnosed at 20 months
Parent F Autism/Developmentally Delayed
Does your child require 1:1 support when attending camp?
Parent A Yes

Parent B Yes
Parent C Yes
Parent D Yes
Parent E Yes
Parent F Yes
What strategies or accommodations need to be in place for your child to have success at camp? (visual schedule, pictures, first then board, sensory room etc.)
Parent A All of the above
Parent B All of the above would help!
Parent C I listed most in the first box.
Parent D First then, schedule, lots of movement!! Sensory room would be a bonus
Parent E visual schedule or written schedule first/then board sensory room is ideal but even a space when she can run, jump (a gym), or get a break from noise transitional warnings some degree of choice on what activities she can do during recreation time 1:1 support
Parent F Visual Schedule, pictures, sensory room, one on one supports at all times, needs help with self-help skills, dressing, washing, toileting, as well as safety issues, needs to be cared for at all times
The questions on the camp profiles allow you to provide a well-rounded view of your child and their needs.
Parent A agree
Parent B Agree
Parent C Disagree
Parent D Agree
Parent E Agree
Parent F

agree
What types of questions do you dislike answering on the profile?
Parent A No answer
Parent B Haven't come across any yet.
Parent C I dislike trying to answer his communication questions. I ether make it seem like he can understand so much because he can read and type or I make it seem like he isn't capable of much because he can't answer basic questions and only uses 3-4 words combinations to speak. It's soooo hard to describe the behaviour challenges he has and the triggers in a small space. For my son, they are constantly changing. I also take it for granted how much I change the environment or situation proactively without even realising. It would be more effective to have the questionnaire coupled with a phone conversation.
Parent D None they need to know my child
Parent E I haven't come across any so far.
Parent F Repetitive questions
What questions do you wish were asked?
Parent A
Parent B Haven't thought of any yet. The few that I have filled out pretty much cover it.
Parent C What are some goals (in specific areas)? Include examples so parents can pick from some that you are able to teach.
Parent D Not sure
Parent E What are your expectations from camp? Most of the profiles I have answered have been thorough and what works well is if I also get to talk to someone that will be working with my child to further clarify what she needs.
Parent F The questions we are asked are appropriate but it gets tiring always being asked the same questions and filling out forms
Do you feel some parents with children similar to yours are hesitant to be honest when filling out profiles? Why do you think they are hesitant?
Parent A
Parent B Not sure.
Parent C Yes. For many of us parents we are used to our situations, so we see our kids through a mother's

eye. It is also very difficult, though necessary, to talk about your interfering behaviours. It can get depressing listing it all out. On paper you make them look so bad. You feel awful as a parent hashing up all of this negative info when all you want to do is brag about your child and point out all of their good qualities. I feel like my son has no privacy. There have been so many people who have worked with him over the years, so many people sitting around and discussing his interfering behaviours (especially his screaming) and I hate adding to that list of people who have to know about my sons most vulnerable and difficult moments. A lot of people who come in contact with my son don't understand and take seriously the dignity and respect of the child they are serving. They talk about their interfering behaviours like it's a big joke, "Oh that's the kid who....." Of course I worry about intentionally throwing my son under the bus and scaring people off.

Parent D

Yes! Maybe they are uncomfortable with some of their child's behaviors

Parent E

Some parents may be hesitant because they fear their child might not be accepted into the program because their needs are too high. Some parents may have camp as their only form of child care during the summer or other holidays so their child needs to go to camp, and they can't risk their child not being accepted. Some parents may be hesitant to put a label on their child because special needs camp tend to cost more.

The level of autism my child has cannot be hidden so it's obvious she's not a typical 10 year old. It's not something I would personally do because I would want her to be well taken care of and not left to anyone that is not clear on what her needs are.

Parent F

I don't think they are hesitant, you have to be as honest as possible for the camps to fulfill your child's wants and needs.

Do you feel that the camp staff read the profile and use that information when planning for your child?

Parent A

I would like to think so...for the most part we have been very fortunate, we are trusting that the camp is doing their part / responsibility

Parent B

Yes.

Parent C

Not at the YMCA Helping Hands Program. The coordinator was extremely knowledgeable, but the info did not trickle down to the support staff at all. They acknowledged that though and apologised. Everything they said they said they would do, they didn't.....They weren't able to support him.

I feel the SNAP and Movement camps are excellently run. I feel like the programs really meet the needs of children with ASD. The support staff come prepared and they try to pair your child up with a good match. It is well organized and well supervised.

The AO camps are fabulous. I can tell they read the profiles and are well supported. They try to incorporate the things you write down on the profiles.

Parent D

Yes! AO camp and Brock camp
Parent E Over the years the use of the information in her profile has gotten better. Every camp is a little different, but I find that if I am clear on the two or three points that she really needs like a visual schedule people have been more accommodating. Sometimes camp staff are not given a schedule themselves on what the activities for that day will be before my child arrives so they aren't prepared by their senior staff.
Parent F Not all the time, but I would hope that for the most part that they do, would like staff to ask parents questions if they are not sure of themselves.
To provide the camp with a well-rounded view of your child and their needs would you prefer to: (fill out a detailed profile, speak to the staff working with your child, bring your child to camp facility..., other____)
Parent A It depends on the camp...it was a first time camp, definitely would want to meet with the camp leaders and check out the facility
Parent B Speak to the staff working with your child.
Parent C I think it is different for each case. Some kids could just do a profile. For me, I would like to fill out a profile and speak to the staff. If it's a new camp, I would like to bring him in prior to expose him to the facility and staff.
Parent D Speak to the staff working with your child.
Parent E All of the above
Parent F All of the above
Additional Comments about Profiles
Parent A No answer
Parent B No answer
Parent C It may be nice to include an "all about me" section where it talks about pets and their names, siblings and their names, favourite foods favourite tv shows, favourite vacation
Parent D No answer
Parent E The first two for sure. The first two are a MUST. The third point is great for a newbie staff, or a child who is going to camp for the first time. It's great to make that option available. My child is fine if I get a picture, or the person's name so I can start to talk to her about working with LB at camp on Monday. If it's a familiar camp then she isn't as anxious about the staff that will be with her. She knows AO camp, camp at MacBain, respite camp and Brock camp. Those references

are familiar to her. A name and picture is a bonus.
Parent F I think the camps should keep copies of profiles of our children from the previous year, have parents read the profile from the prior year and make changes and additions as needed.
Please list your top 5 "must have" activities at camp
Parent A Movement (physical activities) Storybooks, puzzles, colouring/painting Sensory room Swimming Some sort of community outing for socialization
Parent B Swimming Outings Sensory Breaks Gymnastics or some type of gross movement activities Group Activities
Parent C Gym activities (trampoline, ropes, mats, balls) Swimming Game skills Group activities Community outings
Parent D Swimming Gym time Lots of movement time Fun social outings Learning activities
Parent E Daily swim or water play, outings, gym activities, sensory breaks, simple crafts A lot of the activities are "somewhat important" because their importance changes depending on how much my child likes the activity. That seems to change so it's hard for me to grade them. It's not listed but I need a camp that is not solely an outdoor, or solely an indoor camp. It's got to have a mix of both.
Parent F Hiking, swimming, gymnastic activities, life skills activities, social activities
What camp(s) in the Niagara region do you feel provide the most activities to meet your child's needs?
Parent A Snap YMCA (helping hands camp)

Parent B S.N.A.P. He hasn't been to very many camps yet.
Parent C Brock movement and AO
Parent D Autism Ontario Brock Movement Camp
Parent E Brock Movement Camp AO camp Y camp - gymnastics camp
Parent F Brock University Movement Camp Autism Ontario Niagara Chapter Camp
What camp(s) in the Niagara region do you feel meet the physical (movement) needs of your child?
Parent A Snap YMCA (helping hands camp)
Parent B S.N.A.P.
Parent C Brock Movement
Parent D Brock
Parent E Brock Movement Camp AO camp Y camp - gymnastics camp
Parent F Brock University Movement Camp Autism Ontario Niagara Chapter Camp
Additional Programming Comments
Parent C Don't force a child to do something or you may create a real aversion. You have to know what you are doing and build up a rapport.
Parent F Not enough programming or activities for the high needs children especially after age 21.
What qualities or characteristics do you want the camp staff working with your child to possess? (patience, comfortable with self-care activities(toileting, dressing), willing to learn etc.)
Parent A All of the above.

Parent B Happy, outgoing attitude with some sort of background with autism/special needs.
Parent C Patient, comfortable with self care, not shocked easily by things, Humble, vigilant at watching, responsible, kind, energetic
Parent D Understanding of Autism , Lots of patience, lots of energy, to get it
Parent E Camp staff ideally have to have lots of patience, energy, and enthusiasm. They need to be comfortable with self- care activities if accidents happen, and willing to find a balance between doing too much for my child vs. too little to help. They need to be willing to learn and not roll their eyes when I am explaining to them some of the things my child needs. If they are dedicated to trying to provide a safe and fun environment then the camp will be a success.
Parent F Eagerness to Learn, comfortable with self-care activities, confidence, lots of patience, is able to ask questions if not sure of what to do with the child.
What expectations do you have of camp staff working with your child?
Parent A Patience, tolerance, compassion, fun loving, knowledge in the disability of my child
Parent B To have patience. Also giving my child time to respond to questions/requests.
Parent C To keep my child safe and engaged in the activities as much as possible. To teach and encourage them.
Parent D To keep them safe, ensure they have lots of fun, to understand Autism and to enjoy what they are doing!!
Parent E My expectations are the above. I am organized when it comes to sending my child anywhere for the day. Notes are written on snacks, extra clothes are provided, and I try and make it convenient for the staff that work with my daughter to find what they need when she is asking for it. I don't expect perfection. I just expect my daughter to be kept safe and to have fun. I would like it if she is kept busy, and active too. I'm not expecting her to do what everyone else is doing. I just want her to have an enjoyable day.
Parent F Make sure child is safe, accurately communicate what happens throughout the day with our child whether it be good or bad. To help child achieve goals throughout the camp.
Additional Comments on Camp Staff
Parent C I don't like when they report negative things in earshot of everyone. Privacy and respect please
Parent D Make sure they are well trained and know about Autism
Parent E I've been lucky that most of the people I've met that have worked with my daughter have been

dedicated, responsible and conscientious workers.
What camp would you recommend to another parent?
Parent A Snap YMCA (helping hands camp) Bethesda NTEC respite
Parent B S.N.A.P. and Autism Ontario's Life Skills
Parent C Movement and AO
Parent D Autism Ontario Brock movement camp
Parent E AO camp or Brock camp Y camp depending on the child's level of need My child is able to go for overnight respite camp, but she hasn't tried it yet so I can't recommend it at this time.
Parent F Brock University Movement Camp
What sets the camp you would recommend apart from other camps?
Parent A Best interest of the child...fun, safe, energetic, great staff, and that my child enjoyed it...I would not force her to partake in something that just wasn't working
Parent B They get "it" (autism).
Parent C The supervision, the organization, the knowledge of autism, the proactive approach, the sheer amount of activities, the quality is amazing
Parent D Understanding and lots of fun!!
Parent E AO camp you get a longer day and the option of extended care. Also it is offered in NF, St. Catharines and Welland. I have the least worry with this camp. A close second is Brock camp because it is more economical for everyone and they have more day trips planned. Their drop off can be a little overwhelming for both child and parent.
Parent F Specifically geared towards children with Autism, activities that are geared towards our child's ability level.
Additional Comments/thoughts on camps in the Niagara Region

Parent C There aren't many that service children with high needs such as mine. I feel a great amount of desperation every summer because I just hope and pray he can get into the only two camps he has succeeded at.			
Parent D We went to the y and it wasn't a good experience! Not enough training for staff, no clue about Autism			
Parent E More camp spots are needed for campers that have higher needs. Typical kids can go to any camp depending on their interests. I pick camps depending on their level of support and if there is a 1:1 support staff available for my daughter.			
Parent F There are no camps or activities for adults that need one on one supervision after they turn 21.			
Please select what activities you believe are important activities that should be a part of your child's day.			
Not at all Important	Somewhat Important	Important	Very Important
	Crafts		Reading
Parent A	Somewhat Important	Parent A	Important
Parent B	Somewhat Important	Parent B	Somewhat Important
Parent C	Somewhat Important	Parent C	Somewhat Important
Parent D	Important	Parent D	Important
Parent E	Somewhat Important	Parent E	Somewhat Important
Parent F	Not at all important	Parent F	Important
	Puzzles		Colouring
Parent A	Important	Parent A	Important
Parent B	Somewhat Important	Parent B	Somewhat Important
Parent C	Not at all important	Parent C	Not at all important
Parent D	Important	Parent D	Important
Parent E	Somewhat Important	Parent E	Not at all important
Parent F	Important	Parent F	Not at all important
	Swimming Everyday		Group Activities
Parent A	Very Important	Parent A	Very Important
Parent B	Important	Parent B	Very Important
Parent C	Very Important	Parent C	Very Important
Parent D	Very Important	Parent D	Very Important
Parent E	Very Important	Parent E	Somewhat Important
Parent F	Very Important	Parent F	Very Important
	Tags Games		Hikes/Walks
Parent A	Somewhat Important	Parent A	Important
Parent B	Important	Parent B	Important
Parent C	Somewhat Important	Parent C	Very Important
Parent D	Important	Parent D	Very Important
Parent E	Somewhat Important	Parent E	Somewhat Important
Parent F	Somewhat Important	Parent F	Very Important

	Community Outings park, bowling, beach etc.		Game Skills throwing, catching, hitting, etc.
Parent A	Very Important	Parent A	Important
Parent B	Very Important	Parent B	Important
Parent C	Very Important	Parent C	Very Important
Parent D	Very Important	Parent D	Important
Parent E	Important	Parent E	Somewhat Important
Parent F	Very Important	Parent F	Very Important
	Gymnastics		Seated activities
Parent A	Important	Parent A	Important
Parent B	Very Important	Parent B	Somewhat Important
Parent C	Very Important	Parent C	Important
Parent D	Very Important	Parent D	Important
Parent E	Very Important	Parent E	Somewhat Important
Parent F	Very Important	Parent F	Important
	Sensory Breaks		
Parent A	Very Important		
Parent B	Very Important		
Parent C	Very Important		
Parent D	Very Important		
Parent E	Very Important		
Parent F	Very Important		

Appendix Q
Thesis Defense PowerPoint Presentation



Design

Critical Disability Studies framework

- Theory of complex embodiment

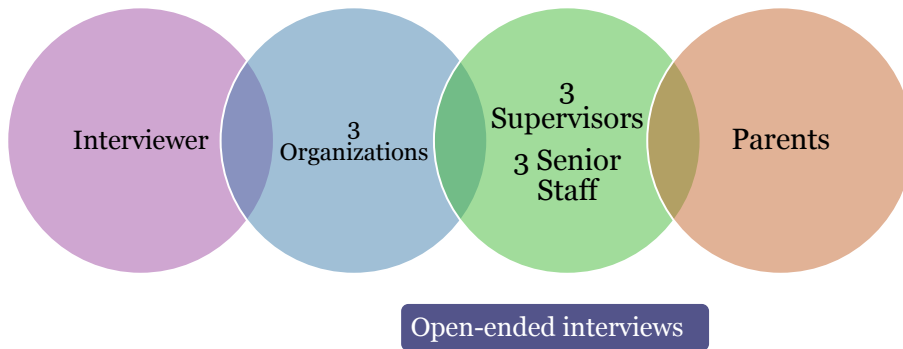
Qualitative, comparative case study

- Community-based recreation programs complex phenomenon
- In depth exploration of three cases
 - Explored via 2 distinct cohorts within each case
 - Comparisons built into the description and analysis.

Insider perspective

- Experiential history

Methods



Data Analysis

Level 1 Within-In Case (each interview)

- Important and/or repeated incidents of people, places, objects and happenings
- Key words/revelatory phrases

Level 2 Cross Case/Cross Cohort by Topic (Supervisors; Senior Staff)

- Clustered questions by topic (patterns)

Level 3 Sensitizing Concepts

- TEACCH, Extreme Cases, Approach to Behaviour Management and Programming.

Level 4 Member Check- Parent Survey

FINDINGS- Level 1 & 2

Level 1: Within-Case (each interview)

- Happenings- most prominent pattern
 - “Meltdown Mondays” (Org. A)
 - Programming impacted by funding (Org. C)

Level 2: Cross-Case/Cross Cohort by Topic (Supervisors; Senior Staff)

- Concerns with staff
 - Experienced, top quality staff wanted!
- Approach to behaviour management
 - Proactive rather than reactive

FINDINGS- Level 3 & 4

Level 3 Sensitizing Concepts

Environmental & Visual Supports and Structure

- Senior Staff A “...if you control the environment, you control the behaviour.” (p.8)

Level 4 Parents’ Survey

“it is also very difficult, though necessary, to talk about your interfering behaviours. It can get depressing listing it all out. On paper you make them look so bad. You feel awful as a parent hashing up all of this negative info when all you want to do is brag about your child and point out all of their good qualities.” –Mother C

