

Exploring the Experiences of Children with Autism Spectrum Disorder Participating in a  
Therapeutic Social Group

by

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Bachelor of Science, University of Victoria, 2007

A Thesis Submitted in Partial Fulfillment  
of the Requirements for the Degree of

MASTER OF ARTS

in the School of Child and Youth Care

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University of Victoria

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**Supervisory Committee**

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## Abstract

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The purpose of this research was to explore the experiences of children diagnosed with Autism Spectrum Disorder in a therapeutic social group. Using a social constructionist theoretical framework and drawing on disability theories, the study examined how participants' experiences were co-constructed through relationships, language and socio-political factors. A generic qualitative research paradigm was used with particular attention paid to social constructionist methodology. Video recordings and field notes were collected over three sessions during an established therapeutic social group at a community organization with five children ages 10-13, and two adult group facilitators. Verbatim transcripts were analyzed using an inductive process that took into account and acknowledged the co-construction of the information. Salient themes were identified based on multiple readings of the data, analyzing and re-analyzing how the experiences of children in the group are constructed. The research emphasizes the strengths and skills exhibited by the children, their strong friendships with one another and how they construct their identities. The study also examines how the highly structured learning environment produced an artificial quality to "real world" experiences and questions what "normal" social skills are. The research highlights how both children and facilitators assume deficits and explores the label of autism from a socio-political lens. The study contributes to the research on lived experiences of children with autism, including insights into how practitioners can work *with* children rather than providing services *to* them.

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## **Acknowledgements**

First and foremost, I would like to acknowledge the participants for sharing their experiences with me, and for continuing to inspire me in my practice. It is a privilege to be a part of your lives.

I would like to thank my supervisors Jennifer White and Daniel Scott for your ongoing dedication and support throughout this process. I appreciate your honest feedback and continuous guidance.

Finally, I would like to thank my family and specifically my husband, Craig for your unwavering support and love that carried me through to the end.

## **Chapter One: Introduction**

### **Research Inspiration**

For the past decade, I have had the privilege of working with children and youth diagnosed with an Autism Spectrum Disorder (ASD). I started my work as a Behavioural Interventionist, working with an interdisciplinary team of Behavioural Consultants, Occupational Therapists and Speech-Language Pathologists. Later, I worked more closely with Speech-Language Pathologists as a Speech-Language Pathology Assistant and social group facilitator. Many of the children I have worked with began intensive behavioural intervention in their preschool years, and have continued receiving therapeutic supports as they entered school. I have had the great honour of working with and learning from many of these children throughout their preschool, elementary school and now middle school years. In my work I have been involved in providing intervention services to children and youth with ASD based on many of the principles of evidence-based practice to change behaviour. I am faced with the tensions of being directed to provide services *to* children with ASD, while trying to work *with* this population and allow for their perspectives to be heard and understood. The relationships that I built with the children and families inspired me to look deeper at, and reflect on the ways in which I practice while allowing the children's voices and perspectives to be acknowledged.

### **Research Purpose**

The objective of this research is to better understand the experiences of children who have Autism Spectrum Disorder (ASD) and who have participated in a therapeutic social group. Using a social constructionist theoretical framework and drawing on disability theories, this

research aims to examine how participants' experiences are co-constructed through relationships, language and socio-political factors.

### **Research Questions**

The research questions are: What are the experiences of children in a therapeutic social group? How are children's experiences in a therapeutic social group constructed? Specifically, how are these experiences constructed through relationships, language and socio-political factors?

### **Framework**

The research study is presented in five chapters. Chapter One provides an introduction that includes the inspiration behind and purpose of the research, the research questions and a note about the language used throughout. Chapter Two provides a literature review describing the current literature on disability studies and constructions of disability as it relates to autism and autism therapies. Chapter Three describes the social constructionist methodology used. This includes a description of how a generic qualitative research paradigm was used, including the specific methods employed. Chapter Four presents the findings and discussion together and is broken into two main themes that were identified in the data, with relevant sub-themes. Chapter Five discusses the implications of the research for practice, education and future research possibilities, including limitations and concluding remarks.

### **A Note about Language**

Disability studies have varying points of view about how best to refer to "people with disabilities" or "disabled people". In this work, I have chosen to follow in the footsteps of Berger (2013) by not making a specific ideological choice but rather explaining both viewpoints. As Berger states, those who refer to "people with disabilities" or "individuals with autism" use

“person first” language to emphasize the person as an individual that is not defined by their disability. This language is what I was taught to use in my practice and is often taught in disability courses, including in the Child and Youth Care, Attending to Disability course. It is also common, however to refer to “disabled people” or “autistic people” as a way to highlight the disability as a positive aspect of the individual, something that is not to be ashamed of that cannot be separated from their identity. This practice is most often seen in self-advocate groups and to identify a common cause of a particular political constituency (Berger, 2013). In this thesis I have chosen to not privilege one type of language over another and use both “person first” and “disability identity” language throughout with the understanding that the use of this language will change based on the context.

## Chapter Two: Literature Review

The following chapter describes the current literature on disability studies and constructions of disability as it relates to autism and autism therapies. More specifically, the chapter outlines the literature on dominant theories in disability as they relate to autism including: the medical model, social model, critical disability studies and how multiple perspectives can be applied. The chapter includes literature on medical and scientific constructions of autism treatment as well as critical perspectives on intervention, disability identity and lived experiences.

### Disability Studies

Disability studies can have many different meanings to different people. Soder (2009) describes a narrow and wide definition of the field. Soder's narrow definition is tightly connected to the political activism of disabled persons, seeing disability as something that we construct through discourses, languages and norms. Soder's wide definition makes reference to research about disability in the social sciences and humanities without a connection to particular meta-theoretical assumptions or political activism. The following paragraphs highlight some of the dominant theoretical orientations in disability studies, which include both the narrow and wide definitions as described by Soder.

**Medical.** The medical model defines disability as an individual defect that must be cured or eliminated in order for the person to achieve full competence as a human being (Siebers, 2011). This dominant view of disability focuses on diagnosis, prevalence and treatment of disability as a pathology for which therapy should be sought (Krcek, 2013). In the context of autism and autism research the medical model ranges from seeking a genetic link to causes of

autism in an attempt to eliminate the disorder to therapeutic treatment methods that are based on behavioural and cognitive principles aimed at changing behaviour of the individual.

Silberman (2015) describes the work of Bernard Rimland, who sought to find a single metabolic pathway that could be averted by dietary intervention, much like the genetic condition phenylketonuria (PKU). In the 1960s, Rimland believed that autism might also be caused by a single genetic factor, much like PKU-induced intellectual disability, which has and continues to be the basis for interest in the biomedical dimensions of autism today (Silberman, 2015).

Biomedical interventions based on Rimland and Wakefield's since debunked theories that vaccines leave some children unable to adequately digest proteins found in gluten and casein are still popular among parents and practitioners of alternative medicine, advocating for a GFCF (gluten-free casein free) diet along with high doses of vitamins, minerals and enzymes all aimed at eliminating the theoretical biomedical causes of autism within the child (Silberman, 2015).

Unlike PKU, recent genetic testing into the cause of autism has shown that a common genetic factor among those with the diagnosis account for less than 1% of all cases, solidifying a common saying in the autism community that "if you meet one person with autism, you've met one person with autism" (Silberman, 2015, p. 14). The example of biomedical interventions for autism and the need to find a single genetic cause to eliminate the disorder speak to the extreme side of the medical model, which views autism as a pathology within the person that needs to be eliminated in order for the individual to become normalized.

The most popular treatment method and most widely accepted evidence-based method for the treatment of autism is applied behaviour analysis (ABA) (Krccek, 2013). ABA uses behavioural principles such as operant conditioning, reinforcement, and shaping aimed at reducing undesirable behaviours and increasing desirable behaviours (Milton, 2012). While

many of the mainstream treatment methods for autism do not expressly promote a cure or elimination of autism “within the child”, all promote change on the part of the individual towards more socially acceptable or normalized behaviour.

**Social model of disability.** The social model of disability is often seen as a direct challenge to the medical model, which views disability as a collection of symptoms that require treatment (Turner, 2011). As Turner states, the social model of disability takes into account the perspective of those with disabilities, and takes into account how politics and culture contribute to the concept of disability. As Morgan (2012) states:

Services that seek to ameliorate the disadvantages ‘suffered’ by disabled people are replaced by a more holistic evaluation of the extent to which societal structures, processes and cultures are disabling and the identification of strategies to remove these barriers and promote more inclusive environments and practices. (p. 218)

The social model of disability emphasizes that an individual is being disabled, not by their impairment, but by the failure of society to organize and take into account difference (Dowling & Dolan, 2010). “For example, being unable to walk does not, in itself, prevent an individual from going shopping, but public transport that is inaccessible to wheelchair users does” (Dowling & Dolan, 2010, p. 23). The social model has been extremely important in reframing disability both politically and individually. Politically, the social model has been central in advocating for political change including the removal of barriers and anti-discrimination legislation (Watson, 2012). Individually, the social model has allowed those with disabilities to reframe their impairments to understand that they are disabled, not by their own physical or mental impairments, but by society’s lack of accommodation (Watson, 2012).

Corker and French (1999) bring attention to the dualism that the social model of disability creates; distinguishing between disability, which in this model is viewed as socially constructed, and impairment, which is referred to as a physical attribute of the body. Corker and French recognize the positive attributes of the social model as a groundbreaking concept, which has provided much political stimulus for people with disabilities. However, the dichotomy between disability and impairment is seen as problematic as disability tends to be valorized while impairment tends to be marginalized or silenced. Shakespeare (2008) emphasizes how prevailing approaches to disability neglect the social and environmental contexts of disability, but also rejects the direct challenge to the medical model, stating that:

Despite the deficiencies of medical sociology and medical ethics, it would be foolish to ignore the many valuable contributions to understanding disability made from these perspectives. Moreover, it is not medicine, but inappropriate medicalization, which is the root of the problem. (p. 11)

As Shakespeare stresses, we cannot create a crude dualism between the medical model and social model of disability. Social constructionism has been welcomed as a tool for political change, but a realist and medically based approach to understanding impairment is also important to improving the quality of life of many individuals. Goodley (2013) speaks of the turn in disability studies to recognize the biological impairment and the idea that “impairment *is* a predicament and *can* be tragic” (p. 643). Although this is an important turning point away from the dualistic approach of the social model of disability, Goodley emphasizes the ambiguity of the disabled body as we move through different physical, social, political and historical spaces.

**Critical disability studies.** Goodley (2007) describes the politicization of disability. “While individual, medical and deficit models continue to dominate thinking *about* disabled

people, critical disability studies calls for counter-hegemony *with* disabled people” (Goodley, 2007, p. 319). In this perspective, Goodley describes disability as an expression of a wider socio-economic, political and cultural formation that specifically, although complexly excludes people with impairments. Goodley (2013) describes how bodies matter and can be conceptualized through post-structuralist views on intersecting material and symbolic forces such as sex, class, age and race. Critical disability studies focuses on intersectional analysis, shifting attention away from the problems of disablism to the problems of ableism, or normativity. Goodley describes crip theory, which draws largely from ideas on queer theory as an example of these intersecting ideas. “Disabled people occupy *cripping* positions of subversion, connection and reappraisal precisely because they embody Other positions to those demanded by ableist cultures” (Goodley, 2013, p. 638). In this perspective, the stereotypical disabled body is rejected and presented as a place of becoming, reflection and production. Goodley states that critical disability studies have been criticized for focusing too much on the theoretical, and losing the connection with the real material problems of disabled people’s lives. However, he purports that critical disability studies “might be viewed as the logical consequence of disabled people and their allies unpacking and illuminating the complex nature of disability” (Goodley, 2013, p. 641). Critical disability studies opens the space for understanding the way that multiple forms of oppression and discrimination intersect, and shifts attention away from the disabled onto exploring the ableist ideal.

**Applying multiple perspectives.** The variety of perspectives theorizing disability speaks to the complexity of the field and the many ways that disability can be constructed and understood. Goodley and Runswick-Cole (2014) provide an in-depth illustration of applying multiple theories to observational research using a poststructuralist disability studies approach. Goodley (2011) describes “The impaired body is an educated, parented, observed, tested,

measured, treated, psychologized entity with a long history of being materialized through a multitude of disciplinary practices and institutional discourses” (p.114). Goodley and Runswick-Cole use four disability perspectives to read the observations of an 11-year-old girl, Rosie, who is diagnosed with autism. The authors use the medical model and social model of disability, which have previously been described. In addition, the authors introduce the Nordic relational model of disability, which views disability as a mismatch between the person’s capabilities and the environment. In the Nordic model, disability is defined as a relationship between the person and their environment. This is in contrast to the medical model, which places the problems of disability within the person and the social model of disability, which places the problems of disability firmly in the environment. Lastly, Goodley and Runswick-Cole use a socio-cultural stance centered on the digital culture in the lives of young people to read their observations. The readings presented outline a fascinating account of how different theoretical models provide vastly different outcomes and interpretations of Rosie. Goodley and Runswick-Cole (2014):

struggle with the pathologising tendencies of the autism canon; feel unnerved by the structurally deterministic possibilities offered by the social model reading; wonder about the difficulties associated with normalization so adored by the Nordic relational model; and feel confused by the ‘disability-lite’ nature of the social-cultural narrative. (p. 63)

By presenting a multiplicity of readings, Goodley and Runswick-Cole seek to accept the uncertainty of theoretical models. The authors urge practitioners and researchers to unsettle dominant discourses and engage in more reflexive analyses and practices when working with children and young people. Goodley and Runswick-Cole plea:

...consider the ways in which the politics of disability and childhood are always being constructed and contested in a host of familial, professional, academic and cultural

contexts, and to find and address those moments when we feel unnerved and confused, in wonder or emboldened by stories of disability and childhood. (p. 64)

### **Scientific and Medical Construction of Autism Prevalence and Treatment**

The dominant, medical model of understanding disability focuses on diagnosis, prevalence and treatment of autism as a pathology for which a diagnosis and treatment should be sought (Krcek, 2013). The following section speaks to the scientific and medical constructions of autism and treatment methods.

The prevalence rate of ASD in Canada is impossible to pinpoint because there is no Federal monitoring system (Government of Canada, 2016). In the United States, the most recent statistics suggest that 1 in 68 children are diagnosed with an Autism Spectrum Disorder (Center for Disease Control and Prevention, 2014). Autism is not linked to ethnic or social backgrounds and affects children of all races and socioeconomic status (Autism Society of Canada, 2014). According to The Autism Society of Canada, autism is usually diagnosed within the first three years of life, and is four times more prevalent in boys than in girls. Although researchers are confident that genetics contribute significantly to a diagnosis of autism, autism is diagnosed using the *Diagnostics and Statistical Manual of Mental Disorders (DSM)*, meaning that ASD is diagnosed on the basis of behaviour-based criteria rather than biology-based medical testing (Krcek, 2013). ASD is diagnosed based on the following criteria summarized according to the *DSM-5* and presented by Nevid, Rathus and Greene (2014): persistent deficits in social communication and social interaction across multiple contexts: restricted, repetitive patterns of behaviour, interests or activities; symptoms are present in the early developmental period; symptoms cause clinically significant impairment in social, occupational or other important areas of functioning.

Therapeutic interventions for children with ASD are recommended and most children require special education support and intervention services (Humphrey & Parkinson, 2006). Interventions are usually individualized and based on goals created by parents and clinicians such as Speech-Language Pathologists, Occupational Therapist and Behavioural Consultants. Interventions continue when the children reach school age and often consist of a range of therapies and supports to target academic, social, communication, self-regulation, motor/sensory functioning and life skills, both within and outside of school hours; intervention goals are then carried out by a behavioural interventionist (outside of school) or an educational assistant (within the school). Various interventions for children with ASD are proven to be effective in creating changes in behaviour and addressing the core deficits of ASD (American Psychological Association, 2014). For example, intensive early intervention such as applied behaviour analysis therapy has claimed the most scientifically valid success in managing autistic behaviours (Kreck, 2013).

Children with ASD who have similar cognitive and language abilities to their peers often show a discrepancy between their average or high intelligence and ability to adapt to real-life social situations (Saulnier & Klin, 2007). Interventions aimed at increasing social skills and social cognition in children with ASD is supported by research that shows improvements in social skills following intervention. “Social *skills* training which involves the explicit teaching and reinforcement of desired discrete social skills, has been and continues to be a key feature of intervention for children with autism” (Crooke, Hendrix & Rachman, 2008, p. 581). Crooke et al, address the limitations on the ability to generalize the skills to other contexts. The use of cognitive-behavioural treatments (CBT) may address the underlying reasons for particular unwanted behaviours with the aim of reducing the behaviour long-term by improving social

cognition (Rotheram-Fuller & MacMullen, 2011). Teaching social cognition is more complex as it involves teaching the knowledge required to adapt to various social situations based on individual and environmental contexts including verbal and nonverbal social information (Crooke et al., 2008). Crooke et al. measured observed social behaviours of children ages 9-11 in an unstructured setting pre and post treatment to test the efficacy of their therapeutic social group. Treatment consisted of group sessions once a week for 8 weeks and followed a curriculum designed to target social cognitive deficits, focusing on teaching the ‘why’ behind social behaviour and understanding the thoughts and feelings of others. Generalization sessions also occurred weekly in the unstructured setting. Each lesson consisted of an initial gathering, a formal lesson, and then opportunities to practice the lesson. It is important to note that a similar curriculum to that used by Crooke et al. is used in the social groups for this research. The study found that children’s overall expected verbal and non-verbal behaviours increased and overall unexpected verbal and non-verbal behaviours decreased from pre to post training. It is also important to note that these pro-social behaviours increased in an environment that was different from the treatment environment. This shows that treatment in a clinical setting could create changes outside of the setting without explicitly having to teach across multiple areas.

Bauminger (2007) evaluated the effectiveness of using a cognitive-behavioural-ecological (CB-E) approach to enhance social skills in children ages 7-11 with High Functioning Autism Spectrum Disorders. The study focused on the effectiveness of using a group CB-E intervention to improve children’s social skills including both social behaviour and social cognitive capabilities. The curriculum included formal teaching and opportunities to practice the concept or skill. Comprehensive assessment took place immediately before and immediately after treatment and included overt cooperative skills within and outside the group as well as

direct and indirect treatment effects on social cognition. The study found that overall social and emotional understanding and problem solving increased on most assessment measures.

Laugeson, Gantman, Dillon, and Mogil (2012) examined the use of the PEERS intervention program to teach social skills to middle and high school youth ages 12-17 years with Autism Spectrum Disorder. Measures consisted of a variety of rating scales filled out by parents, youth and teachers pre-treatment, post-treatment and at 14 week follow up. In addition, an intelligence test and adaptive behaviour scale was completed. The PEERS program consisted of 14 small group sessions occurring weekly. Children and parents attended separate sessions concurrently. Children's sessions consisted of teaching aimed at helping make and keep friends and included role play opportunities to practice the skills being taught. Parent sessions reinforced the concepts children were learning and included weekly socialization homework assignments. Both youth and parent groups included psychoeducational and cognitive-behavioural treatment methods. The study found that overall, social skills improved significantly in the Treatment Group compared to those in the Delayed Treatment Control group. In addition, social skills knowledge and hosted get-togethers improved as a result of the intervention. Lastly, it is important to note that most of the skills continued at the 14-week follow-up, showing that the skills seem to have been maintained.

While the above examples of research on teaching social skills and social cognition to children with ASD show improvements in skills being taught, little is known about the experiences of children receiving these interventions. It is evident that these programs are aimed at changing the behaviour of individuals and is most often done *to* the children rather than *with* them.

### **Constructions of Disability and Critical Perspectives**

The following section will briefly describe the literature on critical perspectives on interventions, disability identity and the lived experiences of those involved in interventions.

**Critical perspectives on interventions.** Humphrey and Parkinson (2006) offer a critical perspective of research on interventions for children on the autism spectrum. They speak to the increasing emphasis in the field of education on implementing practices that are based on scientific evidence in order to prove effectiveness. However, external validity becomes a concern when experimental research designs are used; “the more scientifically and methodologically rigorous an experimental approach is...the more detached it becomes from the extremely complex context within which the intervention takes place” (Humphrey & Parkinson, 2006, p. 80). Social validity, the extent to which individuals other than the researchers value the research goals and procedures, also becomes a concern when researchers fail to include research users such as teachers, parents, children and young people in the research process. Humphrey and Parkinson describe a fundamental concern regarding research in this area: the focus on child variables and outcomes, indicating that the problem is “rooted firmly ‘within the child’ and underplays, or even ignores, the impact of environmental factors” (p. 81).

Meanwhile, Brownlow (2010) emphasizes the social model of disability and reframes autism as a rejection of the concept of disability as a problem within the individual, but rather as a social construction that puts the individual at a disadvantage because of the failure of society to accommodate the individual’s differences. Molloy and Vasil (2010) speak to the idea that once children are labeled with a diagnosis, they tend to be defined by their label, which often limits others’ expectations of them. Mahoney (2003) discusses the limitations that are often associated with rigid diagnostic labels, “it is common to assume that her score or diagnosis is a capsule summary of who she is or what she is capable of becoming” (p. 40). When a diagnosis is made

using the medical model, many of the individual's unique personality traits are viewed as symptoms of the disorder rather than expressions of his or her unique differences (Molloy & Vassil, 2010). Additionally, the medical model ascribes to the concept that the disability or disorder is firmly established within the individual, without recognizing the expectations of the social contexts in which the individual exists (Molloy & Vassil, 2010). Gergen (2009) further emphasizes this idea by stating that one is only disordered by virtue of social convention and that whether a behaviour constitutes a problem is determined by the structure of relationships. If disability is socially constructed, then the onus should not just be on the individual to change to fit into society, but for the person's wider social network, including family members and professionals to change to better support the individual (Brownlow, 2010). At present, societal conventions dictate what is considered 'normal' behaviour and these individuals are living in a world where their differences put them at a disadvantage in establishing relationships and gaining employment. For those with a formal diagnosis, the recognition of differences and strengths of the individual need to be emphasized over pathologizing and categorizing.

**Disability identity.** Bagatell (2007) examined identity and the power of discourse in individuals with disabilities. From a social constructionist view "individuals have multiple, changing identities that are expressed in specific, though fluid, social relationships" (Bagatell, 2007, p. 413). Bagatell used ethnography to work closely with a young man, Ben, with high functioning autism to understand and make meaning of his experiences. Ben described feelings of failure: failure to fit in, failure to conform and failure to act "normal". Bagatell (2007) describes Ben's sense of self as being constructed within a society that did not accept him, which eventually led him to attempt suicide. After attending a local autism conference, Ben became connected with the "Aspie" community and started to form an alternate identity, realizing that

his neurological make-up was a normal part of his experience, rather than something shameful or deviant (Bagatell, 2007). In this community, autism is seen as a neurological difference, not an illness or disability. “The ‘problem’ is not the person with autism, but the constraints of the social world” (Bagatell, 2007, p. 420). However, Ben also realized that although autism was one identity, he needed to construct multiple identities through experiences in multiple communities in order to fully engage in a variety of settings. Bagatell’s article highlights the importance of disability as a social construction, while also highlighting the importance for the individual to work through understanding this construction in order to develop multiple identities. Bagatell highlights the importance of shifting away from deficits to social participation to better engage the individual in the process of identity construction.

Baines (2012) examined how high school youth with autism construct identities through social interactions and how the participants were able to demonstrate nuanced efforts to distance themselves from the autism label. Baines used ethnography of multiple contexts to observe the interactions of participants and how they formulated identities within different social worlds. Baines identified that participants recognized the importance of their actions in various contexts, and attempts to compartmentalize their disability by attempting to act “normal”. Participants distanced themselves from prevailing storylines associated with autism in order to “have the right to be respected by others on their own terms” (Baines, 2012, p. 559).

**Lived experiences of intervention.** It is clear that the experiences of those receiving interventions need to be included when engaging in research. Research has begun to include the voices of parents and sometimes children. Research has explored parents’ experiences with therapeutic interventions. In Mackintosh, Goin-Kochel and Myer’s (2012) study, parents reported on the difficulties of managing children’s interventions and the impact on the family’s

quality of life. However, as Hill (2014) describes, the voices of parents, school staff and other professionals has been prioritized over the voices of young people. “Furthermore, studies that have included young people tend to have triangulated their voices with those of their parents and school staff, with published articles often giving precedence to the ideas of the adult contributors, with the voices of young people being markedly overshadowed or absent” (Hill, 2014, p. 80).

Although there is a paucity of research on the lived experiences of children and youth with ASD, some researchers have begun to see the value of representing these voices. Hill (2014) used photo elicitation to explore the experiences of secondary school education from the perspective of young people with ASD. Students were given opportunities to take photographs of meaningful places within the school environment, and these photographs were then used as the basis for informal discussion with the researcher about their school experiences (Hill, 2014). In Hill’s study, young people described their school supports such as teaching assistants as a source of guidance when difficulties were encountered while also recognizing that they did not need or want the teaching assistants’ support all the time. Hill described the youths’ strengths in recognizing their own learning needs: “Not only were the young people able to describe strategies that they employed, but they were also able to suggest future adaptations that could be made to help them further” (p. 86). Hill recognized that it is vital to hear the perspectives from individuals with ASD about their experiences with supports and to allow the youth to identify what supports are most useful or desired.

Humphrey and Lewis (2008) used semi-structured interviews, student diaries and drawings to explore the mainstream school experiences of youth on the autism spectrum. Humphrey and Lewis also addressed the role of teaching assistants in the student’s experiences. Although some students appreciated the additional support, especially in helping to reduce

anxieties, students also saw the visibility of support as emphasizing their ‘difference’ from other students. “Having a member of support staff ‘shadowing’ them in lessons immediately impeded pupils’ attempts to blend in with the rest of the class” (Humphrey & Lewis, 2008, p. 39); students often spoke about bullying and attributed the mistreatment to being different from the other students.

McLaughlin and Rafferty (2014) used semi-structured interviews to explore the experiences of diagnosis and secondary school experiences for students with Asperger’s Syndrome. McLaughlin and Rafferty found that students had similar experiences relating to the support services they received in school; students expressed that the teaching assistants often did things for them that they could do themselves, thus reducing their independence and agency. From the existing literature, it is clear that listening to the voices of youth with ASD is a powerful method of learning about their experiences.

The perspectives of individuals with ASD are starting to be recognized and heard. Publications such as *Autism’s Own*, a peer-reviewed journal authored and edited completely by people on the autism spectrum offers a first-hand account of the subjective experiences and thoughts of individuals on the spectrum. While these voices are clearly valuable in beginning to understand the perspectives of persons with ASD, they privilege the educated, adult voices of those on the spectrum and children’s voices are yet to be heard.

The current research is influenced by the literature described above, even as they intersect and challenge one another. “Disability is a highly complex variable, it is multi-dimensional and it cuts across the range of political, social and cultural experiences” (Watson, 2012, p. 194).

Siebers (2011) advocates for a nuanced and complicated approach to disability research:

If the field is to advance, disability studies needs to account for both the negative and positive valences of disability, to resist the negative by advocating the positive and to resist the positive by advocating the negative – while never forgetting that its reason for being is to speak about, for and with disabled people. (p. 5)

The current study attempts to juggle the nuanced perspectives that disability studies provide while opening up space for the voices and experiences of the young people participating in the research to be heard.

### **Chapter Three: Methodology**

The following chapter describes the methodology employed in the research. Specifically, it describes how my personal position influenced the research process, including my practice experience and academic affiliations in the School of Child and Youth Care. It incorporates a description of the social constructionist framework, which includes a description of how knowledge is constructed through language, relationships and socio-political factors. Finally, the chapter presents the methodological framework used, a generic qualitative research paradigm including a description of the theoretical positioning, congruency between methodology and methods, rigor and analytic lens.

For the purpose of this study I explored the experiences of children who have Autism Spectrum Disorder (ASD), and participated in a therapeutic social group. The research questions are: What are the experiences of children in a therapeutic social group? How are children's experiences in a therapeutic social group constructed through relationships, language and socio-political factors?

#### **Personal Position**

As Caelii, Ray and Mill (2003) state, "a researcher's motives for engaging with a particular study topic are never a naïve choice" (p. 5). My work in a variety of roles with children with ASD has greatly influenced my decision to embark on this research. In reflecting on my practice, I have been struck time and again by the experiences that each child brings to the therapeutic setting, and how much the children with whom I work have taught me. In my practice, the medical model as described in the literature review prevails and I am often tasked with providing therapeutic interventions and outcomes that can be observed and measured objectively, while trying to incorporate the desires, voices and needs of the children with whom I

work; attempting to teach children new skills to navigate their environments, while also recognizing their inherent strengths and abilities that do not require change. These two contradictory approaches create a discomfort in my practice, which has motivated me to embark on this research. Social constructionism and disability theories have challenged me to move past the notion of the “knowing teacher and ignorant student, of teaching as a cause of learning” (Gergen, 2009, p. 240). My hope for this research is to recognize and advocate for the important contributions that children make to their own growth, development and wellbeing and to better understand how their experiences are constructed.

It is also important to situate myself within my discipline and field of study. Caelii, Ray and Mill (2003) state, a further positioning occurs by the discipline in which the researcher is associated with, and disciplinary allegiances can often be taken for granted. White (2007) states:

Child and Youth Care is an active and diverse, relatively new field of professional practice that is broadly concerned with promoting and supporting the optimal development and well-being of infants, children, youth and families in specific contexts through approaches that focus on individuals *and* their social circumstances and environments. (p. 227)

As a child and youth care practitioner, there is an emphasis on praxis, the integration of multiple ways of knowing, doing and being, all of which contribute to a reflective, ethical and relational practice (White, 2007). Mattingly, Stuart, and Vandervan (2002) present the professional competencies and values that guide child and youth care work. These values center on five core competencies: professionalism, which includes flexibility and self-reflection; respect for cultural and human diversity; promotion of the optimal development of children, youth and their families; the development of genuine relationships based on collaboration and empathy; and the

use of developmental practice methods. As a practitioner and researcher in the child and youth care field, I am influenced and guided by these particular values. Bellefeuille and Ricks (2010) further this positioning and describe a child and youth care approach to research centered on relational inquiry where practice informs research and research informs practice. The lines between research and practice become blurred; a relational inquiry approach rejects the distinction between self and other and purposes that the self-other relationship, which is foundational in practice is also foundational to research design (Bellefeuille & Ricks, 2010).

The challenge is to know what we need to know, be willing to suspend knowing when faced with contradictory evidence, and then wonder what accounts for what is happening before our very eyes, while considering multiple options given the circumstances. It's paradoxical; it requires us to know and not know at the same time. (Bellefeuille & Ricks, 2010, p. 1237)

It is with these multiple understandings that I approached this research. I have “attempt[ed] to craft a process that opens up to multiplicity, to ongoing-developing-changing realities and relations, to other (ness) - including possible changes in self and in [my] positions on particular issues” (McNamee & Hosking, 2012, p. 47).

### **Social Constructionist Framework**

As Denzin and Lincoln (2003) state, qualitative research is a situated activity that locates the researcher in the world and consists of a set of interpretive practices that make the world visible. The present study works within a social constructionist framework that highlights that multiple realities exist and that there is no single or objective truth. Through our interactions and relationships, we are constantly changing and being influenced by our experiences. Gergen (2011) describes three domains of agreement that often describe social constructionist theory: the

social origins of knowledge, the centrality of language, and the politics of knowledge. First, Gergen describes how knowledge of the world and knowledge of the self are constructed through human relationships. An important aspect of social constructionism is the idea that knowledge is not discovered but rather constructed within a specific community, through agreement on specific rules and practices. In the context of my research project, the medical model and evidence-based practices such as applied behaviour analysis or cognitive behaviour therapy are seen as the right ways to change the behaviour of children with ASD, because the particular community has constructed a set of communal traditions and practices that place value in these methods and ways of seeing the world. The second domain Gergen highlights is the centrality of language, “in which meaning is understood as a derivative of language use within relationships” (p. 109). Language is used within specific domains to reinforce the ideas and values that have been agreed upon within a specific community. In the context of this research, specific language is used amongst the group members to describe social behaviours. For example, the facilitator and the group members talk about using a “Social Fake” to describe telling a white lie, or pretending to be interested in something another person is saying to make the other person feel good (Winner, 2014). This specific use of language can provide a shared understanding that allows the group members to use a concrete, common language within the group to help make sense of social complexities. Gergen describes the third domain of social constructionist theory by highlighting the political implications of how knowledge is created through relationships within a particular community and how this is interpreted. He writes, “One comes to understand that the realities, rationalities and values created within any social enclave have socio-political ramifications” (Gergen, 2011, p. 110). For example, the therapies that children receive are considered necessary because of their particular diagnosis; this results in heavily funded services

aimed at improving the lives of children with ASD, but not necessarily taking into account the ableist ideal that dominates this field. McNamee and Hosking (2012) conceptualize how in a social constructionist framework, one can bear witness to and be a part of the cultural, social and political research environment, rather than merely reporting on “subjects” under observation.

The children, facilitators, teaching environment and I are all active participants in constructing knowledge and reality related to children’s participation in a therapeutic social group. This research takes place within a specific historical, sociocultural and political context that shapes what is known, what can be said and how this knowledge may be interpreted. A social constructionist approach does not mean that we can create any reality that we choose; it is a distinctive and purposeful way of seeing and questioning the social world that takes into account the “practical workings of *what* is constructed and *how* the construction process unfolds” (Holstein & Gubrium, 2008, p. 5). It is also important to recognize that through this type of inquiry, the researcher is not simply making discoveries about the world, but that as the research questions are being asked, the very nature of what is being examined is changed through the inquiry (McNamee & Hosking, 2012). In this study, the experiences of youth with ASD are explored with the understanding that research is an interactive process that is shaped by both the researcher’s and participants’ personal histories, gender, social class, race and ethnicity (Denzin & Lincoln, 2003). As Denzin and Lincoln state, there is no clear window into the inner life of an individual. Any interpretation is filtered through the context of the individual, and observations are socially situated in-between the knowledge of the researcher and participants. As McNamee and Hosking (2012) state: “Inquiry can be thought of as being open and curious and taking a reflective orientation toward our own practices and judgments” (p. 100).

### **Methodological Framework**

Denzin and Lincoln (2003) recognize that “an embarrassment of choices now characterizes the field of qualitative research. There have never been so many paradigms, strategies of inquiry or methods of analysis for researchers to draw upon and utilize” (p. 29). The present study draws from a generic qualitative research paradigm. Caelli, Ray and Mill (2003) describe generic qualitative research as a methodology that is not explicitly defined by an explicit or established set of philosophical assumptions. Rather, the focus is on understanding a specific experience or event. In the context of the present research, using generic qualitative research allows me to better understand how the therapeutic group experiences of children with ASD are constructed without being guided explicitly by an established set of philosophic assumptions and specific qualitative methodologies (Caelli et al., 2003). This, however leaves the research methodology very open so when working within this paradigm it is important to consider what parameters need to be included in order to ensure the research is credible. Caelli and colleagues outline four key areas that must be addressed when aiming for credibility in generic qualitative research: theoretical positioning of the researcher, congruency between methodology and methods, strategies to establish rigor and the analytic lens through which data are examined.

**Theoretical positioning.** Theoretical positioning refers to the researcher’s motives and personal reasoning regarding the nature of the research, and how these inevitably shape the inquiry (Caelli et al., 2003). A further positioning occurs through the researcher’s association with a particular discipline. In the context of the current research, I have stated previously, in my personal position, both the reasons why I am embarking on this research and my disciplinary affiliations in practice and in Child and Youth Care.

**Congruency between methodology and methods.** Generic qualitative research also requires that methodology be clearly distinguished from methods. In the context of this research, a social constructionist framework is used to describe the beliefs about knowledge and how the research should proceed. For example, it is recognized that multiple realities exist and that there is no single or objective truth. Additionally, three key premises of social constructionist theory are used to guide the research: the social origins of knowledge, the centrality of language, and the politics of knowledge (Gergen, 2011). This methodology is distinguished from the methods employed: the tools, techniques and procedures that are used to gather data (Caelli et al., 2003). While there is a clear distinction between methods and methodology, in generic qualitative research, there needs to be congruency between the two. For example, the current research draws upon some of the observational techniques of ethnography using a social constructionist framework. While the technique of observation is based on ethnography “such methods may be imported into a generic approach without invoking the methodology of origin only as long as they are congruent with the research question and the purpose of the research” (Caelli et al., 2003, p. 6).

For this research, data collection is purposefully worded as witnessing, listening and exploring the group process, rather than “observing”; this is in line with the relational inquiry approach previously presented and attempts to reject the distinction between the researcher and participant, the self and other (Bellefeuille & Ricks, 2010). This purposeful choice of language is an attempt to limit the voyeuristic implications that observation may imply. In the context of witnessing and participating in a therapeutic social group, a constructionist approach focuses on the interactional processes of how therapeutic realities are constructed, the contextual factors that influence the therapy setting and the assumptions that are made (Miller & Strong, 2008). Since

the purpose of the research is to better understand the experiences of children with ASD in a therapeutic social group and how these experiences are constructed, the witnessing of group participants, as described above is considered an appropriate method of data collection. The way that this method is applied takes into account the theoretical framework and is congruent with the research questions.

**Rigor.** Caelli et al. (2003) discuss the inconsistencies in defining rigor in qualitative studies and suggest that qualitative researchers need to: clearly articulate their theoretical approach to rigor and select an approach that aligns with their theoretical and philosophical approach to the inquiry. Caelli et al. (2003) state:

The assumptions and principles that inform a generic study may not be based on the well-established theoretical traditions that inform each of the established approaches, but the research choices made in any generic study are still informed by a set of assumptions, preconceptions and beliefs. (p. 8)

In the current study, rigor was addressed by ensuring that a social constructionist and relational inquiry approach was used consistently in all aspects of the study with multiple opportunities to reflect upon the research design, data collection and data analysis. Providing a transparent approach to data analysis as described below further supports this.

**Analytic lens.** The analytic lens, as described by Caelli et al. refers to how the researcher engages with the data. In generic qualitative research, it is important to clearly articulate how and why data analysis is done, particularly since aspects of the analysis may be borrowed from established approaches with deeply rooted theoretical assumptions. In the current research, a thematic analysis was used with a further step to explore potential meanings in the context of the theoretical framework and the research topic. Data were analyzed through multiple readings of

the transcripts and field notes to identify patterns. These patterns were explored, viewed and reflected upon through the lenses of a social constructionist and relational inquiry approach, the literature and my personal position.

**Data Analysis.** The data were analyzed using an inductive process that took into account and acknowledged the co-construction of the information. The field notes, video recordings and verbatim transcripts were explored multiple times, with particular attention paid to how group interactions, language and socio-political factors contributed to the children's experiences. Data analysis focused on the research questions, exploring not only *what* children's experiences in a therapeutic social group were, but also *how* these experiences are brought into being. By engaging in this type of analysis, the experiences of children began to be understood while recognizing that these experiences are in constant flux, and can be interpreted in a variety of ways. The analysis follows some of the poignant themes and delves deeper into how these themes may be interpreted from a variety of perspectives.

## **Methods**

### **Site of Research**

The research took place at a community organization that provides a range of intervention services to children and youth with Autism Spectrum Disorder (ASD). The organization provides inter-disciplinary intervention services to children and youth diagnosed with Autism Spectrum Disorders and other developmental disabilities. Services include individualized services such as behavioural intervention, behavioural consultation, speech-language pathology, and occupational therapy. The organization is community based, with two physical centers, but also provides services at home or out in the child's community. Group

intervention services focusing on specific skills such as social cognition, gross motor or play skills are offered at both centers as a way for children to learn alongside similar aged peers.

**Funding.** The majority of services are accessed through individualized funding from the Ministry of Children and Family Development (MCFD). In British Columbia, children under the age of 6 with a diagnosis of Autism Spectrum Disorder receive \$22 000 per year and children over the age of 6 receive \$6000 per year to spend on eligible autism intervention services (MCFD, 2015). The majority of children attending programs have an autism funding agreement signed between MCFD and the organization. Children are not required to have a diagnosis or funding in order to access services at the organization and some families, without funding, pay for services privately or through their extended medical plans.

**Social Group.** Data collection occurred during an established therapeutic social group that runs once per week at the community organization. Children in these groups are typically similar to their same age peers in terms of cognitive and language abilities, but may struggle with social skills and abstract language concepts. The group that was engaged as part of this research consisted of five children, one group facilitator and a practicum student as a second group facilitator. Groups are offered to parents during the school year and in the summer months. During the school year, groups start in September and run throughout the school year, with breaks coinciding with winter and spring school holidays. During the summer, groups run in intensive, weeklong camps, rather than once per week. Participants are placed in groups based on a number of factors including social and cognitive functioning, their match or fit with existing group members (i.e. similar interests, personality), availability, and general interest in attending the group. Parents sign their children up for the group and consent to intervention and the organization billing for service. While there is no formal attempt from the organization to obtain

consent from the children participating in groups, many parents will discuss therapy options with their children prior to enrolling them. A typical group consists of a check-in activity for each of the group members, a lesson related to social cognition (eg. creating “friend files” as a way to remember information about other group members and start conversations) and then an activity to practice the lesson with other group members.

### **Recruiting Participants**

An application to the Human Research Ethics Board was submitted and ethics approval was received prior to recruiting any participants. Because of my relationship to the organization (I had previously worked individually and as a group facilitator with all of the participants and am a colleague of the current group facilitator), there was a potential or perceived power relationship. Therefore, a third party (the organization’s administration) assisted with recruitment and safeguards were put in place to mitigate any potential pressure to participate (see Appendix I). Having an existing relationship with the participants allowed for a deeper understanding of the children’s experiences as I have previous working knowledge of their group and learning goals. Conducting research with participants over whom I had a power relationship allowed me to analyze and reflect on how my own practice methods may contribute to the experiences of the children with whom I work. Consent from all members of the group, their parents and the group facilitators were required in order for the study to take place (see Appendices II, III and IV). A letter was provided to the organization’s Clinical Director requesting permission to conduct research at the organization prior to recruiting participants (see Appendix V). Permission from the Clinical Director was obtained; the Clinical Director assisted in setting up a third party for the recruitment of participants.

**Recruitment.** Initial contact for the study was done through e-mail via the third party for both group participants and group facilitators. Parents and group facilitators were first invited to attend an information session. Multiple opportunities to consider the research were given without my presence. Copies of the letters of consent were attached to the initial e-mail so that participants had an opportunity to review the forms prior to the information session. During the information session, the study was explained to the participants with opportunities to answer questions or clarify any information. Follow up regarding recruitment was done through the administrative office. Parents and facilitators were asked to fill out and hand in their consent form to the third party only once they had considered and understood the conditions of the study and they voluntarily consented to participate.

Upon receiving permission from all parents and the group facilitators, children were invited to participate in an information session on the study and given a developmentally appropriate consent form to review. Children were given opportunities to have their questions answered and asked to fill out and hand in their consent forms only once they had considered and understood the conditions of the study and that their participation was voluntary.

**Consent.** Informed consent was obtained from all parents, group facilitators and children prior to data collection, resulting in five children and two facilitators participating in the study. Informed consent was readily obtained from parents and group facilitators. One parent wanted to check with their spouse prior to signing the form, and brought the form in the following week. Two parents discussed the study with their children based on the initial e-mail and brought their signed consent forms in prior to the information session, including their children's signed consent forms; they did not seek to clarify any information or ask questions. The other two parents signed the consent forms shortly after the information session and did not seek to clarify

any information or ask questions. Although the Human Research Ethics Board does not require written consent for children under the age of 13, the study required that all children provide written consent in addition to their parental consent to participate. When obtaining consent, one child in particular, Andrew<sup>1</sup>, was unsure about giving consent, wanting to check with and talk it over with his parents and started a discussion with the group about informed consent and the protection of personal information. Some members of the group sought clarification about why it was important that their real names were not revealed; they expressed delight that they would be written about and might become “famous”. Andrew took the opportunity to speak to the group about the importance of protecting personal information and the group facilitator and myself were able to further clarify the importance of confidentiality in the context of the research. It was interesting to note how seriously the children took the research and its implications, asking questions and seeking further clarification prior to giving their consent. Informing participants of my presence during each data collection session, and reminding participants that they could withdraw their consent at any time obtained ongoing consent.

**Risks and Benefits.** Participants were informed that their participation in the study would give them an opportunity for their perspectives to be heard and understood. Additionally, participants were given opportunities to reflect on their group experiences. Participants were informed that they might have some feelings of self-consciousness by being videotaped and observed. However, it is common practice at the organization for consultants or students to observe therapy. Participants were informed that the presence of an additional person in the group environment might be distracting. The risks to participants in this study were considered minimal; participants were not required to engage in any activity that was not typical of their weekly therapeutic social group.

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<sup>1</sup> All names of participants have been changed to protect confidentiality

## **Participants**

**Children.** All five participants were between the ages of 10 and 13 years old. All participants were members of an established therapeutic social group. The children in this group had all participated in individual intervention and group intervention at the organization before. Although being male and having an ASD diagnosis was not a requirement for participation in the study, all participants in this social group were male and had a previously established ASD diagnosis with related MCFD funding.

**Group Facilitators.** Although the focus of the study was on children's experiences, group facilitators were included because their participation was an important aspect of the co-construction of children's experience in the group. The main group facilitator, Marie, has an educational background in Child and Youth Care and specific training in Autism Spectrum Disorders through professional development opportunities and clinical supervision from professional team members (Speech-Language Pathologist, Occupational Therapist and Behaviour Consultant) at the organization. The group facilitator has facilitated these types of groups at the organization for approximately seven years. The practicum student group facilitator, Ingrid has an educational background in communication disorders and had been participating in the group as part of the practicum requirements at her academic institution since April 2015.

**Confidentiality.** Because of the small group size and familiarity with the participants, anonymity was not possible. However, the focus of the research is on the group process, not individuals. Pseudonyms and changes in identifying information have been used throughout the study, wherever possible. Video recordings have been transcribed verbatim, and pseudonyms have been used for both children and facilitators throughout. Because of the association with the

site of research, the name of the organization has not been used as this may make it possible to identify individual participants.

### **Data Collection**

Data collection occurred over three group sessions in May and June 2015, towards the end of a yearlong therapeutic social group. The first two sessions were one-hour long, and the last session was two and a half hours long, for a total of 4.5 hours. At the time of data collection, the group's focus was on planning and participating in community and social outings. Data collection occurred approximately every two weeks. The group planned a community outing or social gathering that would occur the following week. Data collection did not take place when children were in the community. The last session was a year-end party at the organization, and was therefore longer than the other sessions.

Data collection consisted of witnessing and listening to participants engaging in their therapeutic social group activities through videotaping, and taking field notes. For the majority of the group, participants were not required to engage in any activity that was not typical of their weekly social group. The last ten minutes (approximately) of each session was dedicated to sharing my reflections with the group while making space for children to share their own reflections. This allowed for transparency in the research process, allowing participants to be informed on what I was listening for and giving participants opportunities to reflect on the session. Below are a few examples: I am listening to the group conversations and how the energy may change based on a specific topic; I am exploring how participants relate to one another in the group; and I am listening to how participants express their hopes and wishes for how best they learn and how they would like to be supported.

Field notes were taken during each group session. Field notes contributed to the data by providing written descriptions of the therapy environment and visual descriptions of verbal and non-verbal interactions occurring in the therapy group, including personal self-reflections. From a constructionist viewpoint, field notes were collected with the intension of capturing as much *in situ* verbatim detail as possible, recognizing the unavoidable transformation of data that occurs through preconceptions, conventions, framing and other forms of selectivity (Holstein & Gubrium, 2008). Each session was video recorded and transcribed verbatim, including the reflection sessions. The combination of these data collection methods allowed for a detailed account of the sessions that preserved “the opportunity to later ‘unpack’ talk-in-interaction for the constructive work entailed” (Holstein & Gubrium, 2008, p. 386).

### **Ethical Considerations**

Because of the nature of the research and my strong ties to the community agency and participants, ethical considerations were foremost when conducting this research. Obtaining approval from The Human Research Ethics Board allowed me to carefully consider many ethical factors in the design of this study. It was important for me to take these ethical considerations a step further and consider, as Mazzei and Jackson (2012) state, that power relations exist when interpreting other’s experiences, “we are always already shaping those ‘exact words’ through the unequal power relationships present and by our own exploitative research agendas and timelines (p. 747)”. While engaging in this research, I was cognizant of the inherent power inequity that existed, while attempting to privilege the perspectives of the participants. It was important for me to constantly “ask whose voices are present...and whose are absent or silent” (Gergen, 2009, p. 244). Greene and Hill (2005) emphasize the need to contextualize our own research activities and examine the reasons for carrying out research. The personal position section outlined

previously explores the importance of self-reflection, reflexivity and relational inquiry that was applied to this research.

### **Context**

The following section provides some additional context, including a detailed description of the therapy center written from the field notes and a detailed description of the therapy approach used in this particular group.

**The therapy center.** The therapy center was once a corner grocery store; it was converted into a one level house and used as a group day center for adults with developmental disabilities prior to the organization purchasing the property. Located in a residential area, the property lacks the aesthetic charm of the houses next door, which are surrounded by flowerbeds and manicured lawns. The front of the center consists of a graveled parking lot with enough room for about twelve cars, some double-parked behind one another. The parking lot is almost always full and parking can be difficult to find, with cars parked in front of the surrounding neighbors' properties.

The main part of the center contains a gym and a kitchen. The gym consists of a large, industrial metal frame with equipment hanging off of it; a flat, circular swing, a pocket swing, and a rope ladder. Underneath the metal frame are interlocking foam mats. The gym also contains a practice set of stairs, with three steps going up and three steps going down, a small rebounder trampoline and a variety of exercise balls in different sizes. The open concept gym leads into a fully equipped kitchen, with a large center island and a dining table. French doors lead into the fenced backyard, which consists of a concrete patio area followed by a large grassed area, and a single apple tree in the middle of the yard. Due to neighborhood noise complaints, children are not allowed to play in the large backyard, even though the screams and cries of

nearby neighborhood children can be heard throughout the neighborhood, especially in the Spring and Summer months. The kitchen and gym area leads onto a small hallway, which contains three therapy rooms. The first room on the left, often referred to as the sensory room, is meant as a quiet, safe space for younger children. It contains one table, the shape of a half-hexagon, a few chairs, and a foam matted area, similar to mats found in a gymnastics gym, which when put together build a small fort or cave-like structure. The cupboard is covered by a shower curtain and contains shelves with various toys (action figures, music toys etc.). The next room on the left, often referred to as the Team Meeting room, is meant as a meeting room, or room for older children. It contains two half-hexagon tables put together, with about five or six adult size chairs. Across the hallway is the room most often referred to as the Group Room. This room backs onto the backyard concrete patio, with backyard access via French doors. The room also contains two half-hexagon tables put together, with five or six adult size chairs, mixed in with coloured plastic blocks for sitting. The table and chairs take up most of the room, leaving little space to move around. The Group Room has an adjoining bathroom, separated by a pocket door, the bathtub, unused, is filled with parts of discarded toys and furniture. During the days of data collection, the room is quite warm and the window and French doors are open, providing a gentle breeze into the warm room.

**Therapy approach.** All children in the group have participated in some type of therapy from preschool age. While their early therapy was primarily based on the principles of Applied Behaviour Analysis, with input from Behavioural Consultants, Speech-Language Pathologists and Occupational Therapists, their current group draws from a therapy developed by Winner (2016), called Social Thinking®, which focuses on teaching social cognitive skills, and a therapy developed by Ward and Jacobson (2014), which focuses on teaching executive functioning skills.

Winner (2016) describes Social Thinking® as a methodology that was developed as a way to provide individuals with social learning issues “access to interventions and strategies based on both individual learning abilities and the demands of the community within which they participate” (para. 2). When applying this methodology to working with individuals, the goals are to teach children to think socially (think about the thoughts, intentions and emotions of themselves and others), problem solve in order to adapt social skills effectively, and recognize that social behaviours affect the emotions of those around them (including how we feel about ourselves) (Winner, 2016). The practice is founded on peer-reviewed, research-based theoretical concepts, which are then applied to conceptual frameworks, treatment frameworks, strategies, activities and motivational developmental tools which are expected to be adapted and individualized by practice professionals when working with children with social learning challenges. Social Thinking® has developed dozens of books and products that are available for purchase to use when working with children with social learning challenges; these materials are used frequently at the organization in the children’s therapeutic social group. Marie and myself have attended numerous conferences hosted by the creators of Social Thinking® as well as presented at their annual Providers Conference in June 2015.

Ward and Jacobsen (2014) describe their clinical model for developing executive function skills; in order to plan and execute a task we need to be able to stop our “own actions and thoughts to consider the what, where and when of the desired future, to compare this future with previous experiences, and to determine the value: why is it important, necessary, or motivating?” (p. 72). Individuals with weak executive functioning skills may have a limited ability to visually picture the future or sustain this visual representation over time in order to plan and execute a task (Ward and Jacobsen, 2014). Ward and Jacobsen use a visual model entitled

GetReady\*Do\*Done to help individuals develop awareness of the task or situation (situational awareness), have a visual representation of the end result and then integrate the materials, time and actions in order to complete the future task. Marie and myself have attended specific conference presentations by Sarah Ward in order to learn the specific techniques and theory behind this therapeutic approach.

The methodology and methods described in the above chapter work congruently to explore the experiences of children in a therapeutic social group, recognizing that no single or object truth exists. It is with this intention that the data were analyzed and findings presented. A social constructionist approach focuses on the interactional processes of how therapeutic realities are constructed, the contextual factors that influence the therapy setting and the assumptions that are made (Miller & Strong, 2008).

## **Chapter Four: Findings and Discussion**

This chapter explores the experiences of children in a therapeutic social group. More specifically, it examines how those experiences are constructed through relationships, language and socio-political factors. A social constructionist methodology guided the analysis and significant themes have been identified. While I as the researcher have selected certain themes to highlight, it is important to consider that my interpretation of the findings is filtered through my own experiences and socially situated in-between the knowledge of researcher and participants (Denzin & Lincoln, 2003). Data were analyzed based on a social constructionist and relational inquiry approach, with the literature on critical disability studies providing an additional theoretical lens. The findings presented below respond to the following research question: What are children's experiences in a therapeutic social group and how are these experiences constructed through relationships, language and socio-political factors? While many themes were identified throughout the analysis, the most salient themes are presented here and have been chosen based on multiple readings of the data, analyzing and re-analyzing how the experiences of children in the group are constructed, and making connections back to the literature.

### **Practicing for the “Real World”**

A main goal of the group was to teach children skills needed to function successfully in the “real world”. While this language was not explicitly used, language such as “life skills” and “social skills” were used frequently to describe goals. Within this broad theme, three key sub-themes were identified: Reliance on structure and time; unexpected skills; and safety. The highly structured materials and teaching methods were clearly aimed at teaching the children skills to be able to “pass” in the “real world” and the examples below show how this assumption influenced the children's experiences. Children also demonstrated unexpected skills that showed how they

are capable of functioning in the “real world” in their own way. Lastly, the concept of safety emerged as a central concern, bringing into question, is the “real world” a safe place for children with autism?

**Reliance on structure and time.** Time and structure were prominent themes throughout the group sessions. On the surface, it was clear that the concepts and methods of teaching Social Thinking® and Executive Functioning skills were beneficial and appeared to create positive experiences for the participants. The children were able to demonstrate how they learned and applied skills of time management, perspective taking, and problem solving. Group facilitators were able to break down complex social and executive functioning skills into concrete teaching methods that facilitated the group’s learning. At the same time, an over-reliance on structure and time within the sessions was observed, sometimes leading to redundancy and over-teaching within the sessions. The children often demonstrated unexpected social competence and frustration at the redundancy involved in some of the teaching methods. The rigid teaching methods were meant as a way for the children to learn skills needed for the “real world”. However, this brought into question: what exactly is the “real world” and how are these “real world” experiences being constructed?

Specific language was used in the group as a means of breaking down social complexities in order to give language to common social skills needed for the real world. For example, the vocabulary of “Group Plan” and “Own Plan” (Hendrix, Palmer, Tarshis & Winner, 2013) was used frequently to help the group stay on track and work together. As described by Hendrix et al. (2013), a Group Plan is when the group has the same thoughts and is focusing on the same thing and Own Plan is when you are having different thoughts from the group, or thinking about your own idea. The example below highlights some of the specific language being used by the

facilitator. In this example, the group members are in the process of working out when they would need to arrive at group in order to have enough time to go bowling during their next session. In the following verbatim transcripts, pseudonyms have been used throughout for all participants. GF is used for the group facilitator, Marie and SGF is used for the student group facilitator, Ingrid.

Christopher: By the way, where's Danny today?

Andrew: He's at, he's at like a school camp.

GF: Yeah, his class went camping.

Andrew: (waving hands) Ah, big bugs!

Evan: So, so, I guess, he just stay there overnight?

GF: Yup, he's been gone for...a couple of days now.

Evan: Yup, like I had something that is similar to that like twice...like...first like, it was like, it was like October 2014 and like we went to Camp Pringle, it was like a...band trip kind of, we only stayed there for one night.

GF: Oh yeah, he's there for three or four nights I think, so he's there for awhile...

Evan: Yeah, so –

GF: So, I think we're getting distracted I'm looking at the time and we don't have too much time to do the plan –

Andrew: Alright, Alright so we, so you gotta be back here at 5:30 –

GF: So I gotta be back here at 5:30, do you want a pen to figure it out? -

Evan: I'll make this quick. The other one we went to, it was another band trip, we went to Kelowna –

GF: Oh, so right now we need to (pointing at Andrew figuring out the math on paper) –

Evan: Uuuugggh!!!

GF: - think about the Group Plan, okay, and you can tell me about that later, okay? 'cause we have to figure this out, we only have....like twenty-five minutes, not even

Ben: Twenty, twenty-five minutes?

GF: We have, I think twenty minutes –

Evan: (Looking at clock) No, we have thirty (pointing at clock).

While there are benefits to teaching time management and keeping sessions highly structured, there were also moments when the importance of getting things done within the hour was apparent throughout the sessions. The importance of staying on track and watching the clock seemed to take away from the naturally occurring interactions of the group members. In the example above, Christopher is wondering about a missing group member and Evan is trying to relate his experience of going on a trip with Danny's experience. The group facilitator redirects the conversation back to the task at hand, keeping the structure and language very specific. Other goals of the group are to teach the children to think about one other, relate to one another and have topical conversations. The children are showing all of these skills in this example, but these skills are not being valued here because it is not "time" to demonstrate them.

While repetition for teaching skills to children with ASD can prove to be beneficial, redundancy, frustration and sometimes confusion on the part of the children was observed. For example, the group members spent half of their session (approximately 30 minutes) trying to figure out the timing and phone call for their bowling outing. When the correct answer was finally agreed upon after painstakingly going through each activity and working backwards, it was discovered that one of the group members had estimated the correct answer at the beginning of the session.

Evan: So it's 3:30?

GF: Yup!

Christopher: So, that's what I said. That's what we estimated at the beginning (half-laugh).

While deciding what type of pizza to get for their year-end party, redundancy was observed again. The group members had spoken to one another and decided that it would be easiest to just order cheese pizza. This agreement was made in a few minutes at the beginning of the session, even taking into account dairy allergies and asking about other preferences.

Danny: You know the safest bet would just be, would just be to order a cheese pizza.

Andrew: Yeah, that, that's the type I like best.

Danny: I like cheese...and...is anyone here allergic to dairy?

Evan: I don't really care what kinda pizza we're getting, like I'm okay with any one-

Andrew: Anybody else have a- anybody else have a preference besides...cheese pizza.

The group facilitator however wanted to ensure that everyone had a say in the type of pizza that they like in order to take the children through a structured process of deciding as a group.

Danny: Oh! Do you want?

Andrew: Cheese.

Danny: I'm okay with cheese.

Christopher: Everyone wants cheese.

Andrew: Is cheese pizza? Everyone? On paper?

Evan: Yeah.

GF: Okay so everyone wants cheese on their pizza? (writing down in notebook).

Danny: Well, uh...

GF: Are you just going to order cheese or will you actually order stuff on your pizza?

Christopher: I don't think, I don't really like anything.

GF: You don't like anything?

Danny: Well, uh, -

GF: So how would you know what the others like?

Danny: Well, I like pepperoni and maybe some like, uh, pineapple? Pineapples are pretty good.

GF: So you like pepperoni? (writing down in notebook)

Danny: Yeah.

GF: ...and....pineapple.

Danny: I thought we were going to be ordering a type of pizza, or are we making our own? Probably...

GF: Well, what do you usually do when you...order pizza with somebody.

Danny: Oh, you make your own, or you ask for certain toppings, or -

GF: Okay, guys? (to Evan and Danny) – so usually when you make a Group Plan for the pizza, you see what everybody likes on their pizza and then you try to decide from there what type of pizza that you order. Do you think you'll just order one pizza? Or two pizzas?

Even though the group members had independently decided that it would be easiest to order cheese pizza, the role of the group facilitator was to teach the children how to problem solve and negotiate. Although breaking down complex social skills and helping the children to problem solve was clearly beneficial in some situations, this technique had an artificial quality that lead to

redundancy in the teaching and over teaching of skills the children were already demonstrating. McLaughlin and Rafferty (2014) found similar practices when exploring the experiences of students with autism in a secondary school setting; students in their study expressed that educational assistants often helped them with tasks that they were capable of doing themselves. The group members were capable of deciding themselves, without needing to break down each component skill. The pizza example provides insight into redundancy of the teaching, but also into how the group facilitator performs the role of teacher. In the example below, Marie, the Group Facilitator is helping Evan and Danny to decide and negotiate ordering a pizza together, while taking into account the various toppings they would like.

Evan: Is this like one of those kinda pizzas when there's like one, there's like one, one side has like, like, like, both sides have different toppings on it?

GF: Yeah, but sometimes they don't do that so we'll have to problem solve where the pizza is all the same.

Evan: In case, in case they don't.

Christopher: Can't you pick off the things that you didn't like? Like, with mushrooms and stuff? You can just pick that stuff off.

GF: Okay, so Danny and Evan, you guys need to decide what type of pizza you want.

The group members are coming up with multiple solutions to the problem that would suit their needs (getting a half and half pizza, picking the toppings off that you don't like), but the group facilitator is getting stuck on the idea that she needs to teach them to negotiate how to order a single pizza and compromise. Children with autism are so often seen as inflexible, with idea perseveration as a common trait. It is somewhat ironic, then, that the group facilitator is showing inflexibility here, insisting that the decision be performed in a specific way.

There were a number of examples where it was clear that a specific answer was desired from the group facilitator. For example, when the group was deciding what board games to bring to their year-end party, it was clear that the group facilitator was trying to get them to bring “age-appropriate” games even though all group members agreed that the game sounded fun and they would like to play it.

Danny: I have this cool idea – I have this cool card game at home, called, uh, Moose in the House.

Andrew: Oh I’ve played that game.

Danny: Yeah, it’s basically, you have to, you need to, seal off doors with doors, set moose traps, and do other things to keep mooses from getting into the rooms of your house, uh, I’ll explain the rules further with the help of the real book, when I - if we bring the game there, but my family and I play it a lot and its really fun and I think you guys would...really like it.

Andrew: Yeah I’ve played that before.

GF: Okay so -

Danny: - Also, Moooooose (puts head down on table).

GF: So also what we want to think is, games that...boys, your age will play too right.

In the above example, there is a judgment that the game suggested is not age-appropriate based on the name of the game. However, when I looked the game up, the suggested age range is ages 8 and up (Gamewright, 2016). This was also observed when the group facilitator was teaching the group members about how to tip the pizza delivery person.

GF: So the person delivering the pizza to you, you need to give them a tip. So usually you give them 15 or 20%, depending on how well they did. So what would 15 or 20 % - Do you guys wanna pay 15% or 20%?

Danny: Uh, depends on quality.

Andrew: Yeah.

Danny: Depends on delivery quality and the quality of the pizza.

Christopher: I thought that we –

GF: - Okay but we won't know the quality of the pizza though.

Danny: Let's just give them a 20%.

GF: 20%? Okay, so what would 20% of thirty be?

In the above example, I was surprised that Marie suggested that a 15-20% tip is customary for pizza delivery. If I was teaching the group that day I probably would have suggested a lower percentage based on my own experiences and customs. Social Skills are highly nuanced, which makes it difficult to think of them as standardized or universal skills. As practitioners we can unintentionally incorporate our own values and judgments into the teaching process. Gruson-Wood (2016) describes some of these tensions when speaking about therapists in an applied behaviour analysis setting. There is a “strong desire of the therapists to succeed in modifying their kids’ performance, which is rooted in a strong desire to be judged a good behavioural therapist” (Gruson-Wood, 2016, p. 47). In my role as a group facilitator, I have felt these tensions as well, wanting to perform my role as teacher and feeling inadequate if the children perform a task in a way that I was not initially expecting. In therapeutic relationships it is important as professionals to understand how our values shape the experiences and identities of the clients with whom we work (Brownlow, 2010).

These examples bring into question, what is the “real world?” and who gets to decide what “normal” social skills are? Milton (2012) describes the normalization agenda that is imposed on autistic individuals, describing “The autistic person is thus constructed within this discourse as having no agency and simply the subject to be worked upon, to be socialized as best one can, so that one can ‘pass as normal’” (p. 9). Milton (2014) explains how autistic individuals are often described using a machine-like metaphor; that they show strengths in displaying knowledge and expertise using mimeomorphic actions (actions performed in the same way each time and thus can be reproduced mechanically). This understanding of autism contributes to how the learning environment of the group was structured. However, not all autistic displays of knowledge and expertise can be explained in this way. Additionally, this is not how “real world” social skills are enacted. In the “real world” a group deciding on what type of pizza might do so in much the same way as the children attempted to do, rather than painstakingly going through each group members likes and dislikes in order to decide. The experiences of the children in these examples are a paradox – the methods used to teach attempted to respond to autistic ways of thinking and learning, but the skills being taught cannot be enacted in this way, as they are highly nuanced and culturally situated. The children benefitted from highly structured teaching methods in some cases, but also showed unexpected skills in negotiating and problem solving as a group.

**Unexpected skills.** As mentioned previously, Milton (2014) describes how autistic individuals are often misinterpreted as understanding the world in a machine-like way of thinking. However, the experiences of the group members reinforced Milton’s views that autistic individuals are capable of understanding and enacting polymorphic actions (actions that require social understanding and flexibility to adapt to changing social contexts). This was demonstrated

in an earlier example when the children came up with multiple ways to solve the problem of ordering a pizza, suggesting getting a half and half pizza, or picking off the toppings you don't like. While the skills and vocabulary being taught in the group are beneficial, there were also a number of instances when the group members demonstrated skills such as perspective taking and empathy independently.

Ben: I wouldn't have volunteered if I knew it was right now.

GF: (laughing) It's okay that you're prepping for it so you'll be good, you can do it, you did a fantastic job last time you made a phone call.

SGF: You're very prepared already.

GF: So, what else might he ask?

Christopher: He or she.

GF: Yeah, so Andrew, what else do you think they might ask?

In the above example, Ben is getting prepared to do a phone call to the bowling alley.

Christopher shows that he has superior perspective taking skills by correcting the group facilitator's pronoun. He understands that we wouldn't know the gender of the bowling alley attendant on the phone. This occurs a second time, when Evan and Andrew are doing Rock, Paper, Scissors to decide who should make the next phone call. Evan and Christopher recognize that it is important to understand each person's motivation or thoughts before playing the game. If Evan and Andrew both want to do the phone call, then the winner would make the call, but if neither of them want to do the phone call, then the loser would do it. This is further complicated if one of the children wants to do the phone call and the other does not. In this particular situation, both children expressed later that they did not mind either way.

Evan: Rock, paper scissors (Andrew and Evan start doing rock, paper scissors).

Christopher: Who gets?

Evan: Wait, is it the loser that goes or the winner that goes?

GF: Oh, good one.

Christopher: Well it would makes sense if it's the – well...it depends on, if both of you guys want to do it, or if both of you guys don't wanna do it.

Ben: To be or not to be or not to be, that is the question.

The above example is a complex situation that requires understanding the motivation of both players and working out how to solve the problem. As the researcher, even writing a description of it felt complicated and required me to spend some time thinking about it in order to fully understand.

Group members independently demonstrated empathy and acceptance of one another on a number of occasions.

Danny: You okay Evan?

Evan: I don't wanna talk.

Andrew: That's fine, we don't have to.

(Group silence)

Danny: Do you believe it's the most painful (inaudible) ever?

Andrew: He doesn't, he doesn't wanna talk Danny, just leave him alone.

Danny: I thought that would cheer him up, I just wanted to try and make it better 'cause

Evan and I are pals (puts arm around on Evan's shoulder).

In the above example, both Andrew and Danny are showing empathy for their friend in different ways, Danny wanting to cheer him up, and Andrew wanting to let him have the space he thinks

he needs. Danny shows his ability to think about others and their feelings again during the pizza party.

Danny: Um, do you, um...even though I was with the team that ordered the...more exotic pizza does that mean, does that mean I can't have cheese, or...

GF: Um, I dunno you'll have to discuss it with the cheese pizza eaters.

Danny: Oh, uh actually I'm fine because, that would mean they would have less pizza so I'll just stick with this.

GF: That's good thinking, that's nice of you.

Lester and Paulus (2012) describe how the “embodied performance of another is ‘read’ as *normal, abnormal, autistic, and non-autistic*, in and through the process of cultural and discursive enactment” (p. 261). In the case of these unexpected skills, the children are demonstrating attributes (empathy and perspective taking) that are not normally associated with their diagnosis. If the children are being read as abnormal and autistic, then the skills they are demonstrating can only be attributed to the therapy. The demonstration of skills may be an indication that the lessons being taught are carrying over into unstructured time or non-teaching time as demonstrated in the study by Crooke, Hendrix and Rachman (2008). As I witnessed the group sessions, however, I couldn't help but wonder if these demonstrations of advanced and nuanced social skills were already there? Or, if given the opportunity to build relationships with peers with similar attributes allows for these skills to be demonstrated? It is often assumed that children with ASD are lacking these skills and need to be taught. Then, when they show the skills independently we automatically attribute them to therapeutic interventions without even considering that the skills already existed or were learned through other avenues such as school, family or friendships.

**Safety.** During the first session, while discussing a bullying issue that one of the group members was having, the group facilitator mentioned that the group was a “safe place” for the children to talk about problems or issues they might have.

GF: Mmm, yup...but, can Evan talk about it in group...is group a safe place to talk about stuff like that?

Ben: Yeah.

Andrew: Mmm...I guess so.

GF: Yeahup, ‘cause we know that everything kinda stays in the group right? -

Andrew: Yeah.

GF: And then, we’re here to help each other out so that we don’t struggle with stuff like that....

As the researcher, I was curious if the group members felt the same way and asked them if they considered the group a safe place. All group members agreed and provided examples of what made the organization a safe place.

Kerry: So, so Christopher you were saying it’s everything that makes it a safe place, what’s everything?

Christopher: Well...uh...

Andrew: Everything is just, they can help you feel...secure.

Ben: Well, the people, the place...

Kerry: The people?

Ben: It’s a Safe Zone.

Kerry: Can you guys tell me about the people? So what about, what people make you feel safe? It is?

Andrew: Your friends.

Christopher: Well, everybody in [Organization] is nice, so -

Ben: - The safeness, the safeness makes me feel safe.

Christopher: - And also like even the smell, it's kinda ridiculous.

The conversation around safety then led to a discussion about the length of time that each of the group members had been at the organization and how they had first met and formed friendships with one another.

Christopher: And I mean, it's not so safe on the first day because you don't know where anything is and it's scary.

Kerry: Right, okay, but how - you guys have been here, quite a while now?

Andrew: Uh, a few years actually for me.

Kerry: Yeah.

Christopher: I've been here for... -

Andrew: - In fact this is why I, this is where I, [Organization] Groups is where I first met Danny.

Feeling safe in a therapy environment is very important and it was clear that the children saw the value in having a setting where they could freely make "social mistakes" and learn from them. More importantly, the safety seems to have contributed to an environment where they could create long lasting relationships. The idea of safety, however, brings into question, is the "real world" not safe? Bagatell (2010) describes her role as a nondisabled, neurotypical researcher attending a meeting organized and run by autistic adults. Some of the members felt that her presence made them feel ill at ease and judged in their "safe" environment. Having an environment to engage with other children with autism seems to be an important component of

how children's experiences in the group are constructed, even though a non-autistic adult runs the group. The children clearly felt safe in this environment, but constructing this environment as a "safe" place implies that the outside world may not be a safe place. It brings into question how individuals with autism experience the "real world" and how the onus is so often put on the autistic individual to change and adapt to the non-autistic world, in order to keep themselves safe. This is seen by some of the advice the group facilitator and the other group members gave Evan when talking about a bully at school.

GF: I'm thinking that, um...the boy might do this because he knows it makes you angry....and...he thinks it's funny that you're getting angry, so...if you can, try to keep your anger inside and try to use a Social Fake, to pretend like it doesn't bother you.

Evan: Uh-hmm.

GF: and maybe you can say, "hey I found this on my desk, who's is this? And who's is this?" and then you can give it to them-

Evan: Uh-hmm.

GF: Instead of getting upset, so then they know, "oh, well Evan didn't do it because he's actually giving us the stuff".

Evan: Uh-hmm.

GF: Does that make sense?

Evan: Okay. But he does other various things...(inaudible) so I should probably like tell, like a teacher and then they'll probably like tell his parents and then...-

GF: - Maybe...but -

Christopher: - That usually gets people more angry...sometimes (quietly)-

Andrew: And it'll probably, it'll probably make him do worse things because he's mad at you for ratting on him.

Christopher: Oh yes.

Evan: Well, then I think he deserved it.

Christopher: I guess so...

Andrew: Well...mmm...maybe you could try to think of a way to communicate with him.

Evan: There's no way, he gives me no respect, I hate him.

While the advice given by the group members and the facilitator is sound (trying not to react to a bully, communicating and seeking help), it is clear that Evan is being targeted because of his strong reaction to the bully's actions. It reinforces the idea, that the "real world" may not be a safe place for the children, but also that it is up to him to change his behaviour in order to fit in.

The children in the group spent a significant time practicing for "real world" events in order to "pass" socially. However, an over-reliance on structure and time, the children showing unexpected social skills and issues around safety highlighted how this assumed lack of social insight "is both biologically and socially derived, and yet is also historically and socially situated in discourse" (Milton, 2012, p. 886). The children in the group showed significant insight into the non-autistic world, "real" world. It can be argued that they have gained a greater level of understanding into the non-autistic world than the group facilitators (myself included) have gained in understanding the autistic world, perhaps due to a need to survive and potentially thrive in a non-autistic culture (Milton, 2012).

### **Co-constructing Identities**

In the analysis, particular attention was paid to how experiences were constructed through relationships, language and socio-political factors. The children's experiences in the group contributed to how their identities were constructed within this setting. Bagatell (2007) describes how in a social constructionist perspective, individuals have "multiple, changing identities that are expressed in specific, though fluid social relationships" (p. 413). These multiple identities and how they were constructed were closely examined. Three overlapping themes are explored: assuming deficit; experiences making friends; and the label of autism. The nature of the group as a therapeutic intervention contributed to assumed deficits on the part of the children. The social nature of the group contributed to how the children constructed their identities as friends. Lastly, the unspoken label of autism, the elephant in the room, contributed to how the children constructed their identities as individuals on the autism spectrum.

**Assuming Deficit.** The group itself is aimed and advertised as a way to teach social skills in a group environment with similar aged-peers. Additionally, the group members are able to attend because of funding provided by MCFD. These factors alone situate the group and the group members in a deficit-based model of learning. Funding is provided in order to pay for interventions for children and youth with ASD, with the ultimate goal of changing behaviour and as described above, giving children skills they may need for the "real world". It is not surprising, then, that the group members and the group facilitator perpetuate this deficit based thinking as they co-construct the children's identities in their group experience. As described previously, children were taught skills needed for the "real world", and it was assumed that the children did not have the executive functioning and social skills needed to plan and engage in the community. While this was true in some cases (children needing the support to problem solve and make

plans), there were also many examples where children were able to show the skills independently and did not require support (as described in the unexpected skills section previously).

This assumed deficit carried over to how children constructed their own identities, assuming that they were wrong or making a mistake and relying heavily on adults to help them navigate situations. The children showed a strong desire to be “right” and often saw themselves as learners. The children in the group showed a lack of confidence in their social skills, assuming that what they were doing or saying was inappropriate or over-filtering their conversation. For example, Evan is unsure whether it is appropriate to share his story about being sick and checks in with the student group facilitator before continuing.

Ingrid: I’ve been getting sick a lot lately.

Evan: Same here.

Ingrid: Yeah?

Evan: But like, but, I don’t know if this is – may sound gross, I probably shouldn’t say it...should I say it?

The group members repeatedly checked in and referred to the group facilitator to ensure that they had permission or were doing the right thing, even when the facilitator had no control over the outcome.

Andrew: Okay, so each player needs a pencil and several response strips.

Christopher: Response strips?

Andrew: (holding up paper) these things, and what do ya know (to GF), there’s five on each sheet!

GF: Perfect.

Andrew: So I’ll, I’ll tear off a sheet every, every time we...every round?

GF: I dunno...it's your game.

Even when demonstrating skills appropriately, the children would often question themselves and assumed that their behaviour might be interpreted in the wrong way. In the example below,

Danny chooses his words very carefully:

Danny: - Like the – we both want to have pepperoni and I'm personally, I don't really mind if we have pineapple or not but I guess I think it's kinda cool, but Evan has a unique selection.

GF: (laughing) Okay.

Danny: I'm saying that – I'm not trying to be rude when I say that (putting hands up in “surrender” pose), please don't write me off as rude!

Danny filters himself and successfully uses a “Social Fake” when he carefully chooses the word “unique” to describe Evan's choice. However, he is still unsure that what he said is all right, being clear that he does not want to be perceived as being rude.

During the sessions, it became clear that the group facilitator was the primary leader of the group. During discussions and planning, most of the conversation went through the group facilitator, with group members taking turns responding to her questions. It was also noticed, that even when the group facilitator attempted to step back and let the group members engage together or problem solve together, the children often referred to the facilitator for validation and clarification. The group members seemed to accept their role as learners and the group facilitator's role as leader without question; they seemed to accept that they did not know everything and that the group facilitator was there to help them avoid mistakes. The group members were asked about these roles during the reflection time at the end of one of the sessions.

Kerry: One thing I noticed is that when you guys are doing your planning, you're often, um, between you and Marie, you guys are often kinda checking in with each other. Can anyone tell me, like, if that makes it easier to plan or if it makes it harder to plan?

Danny: Well –

Andrew: I hadn't really thought about it before actually.

Ben: It's just what we do.

Danny: Well, it's, it's to make sure that, we're making sure that what we're doing is okay with, with what's a, what someone is doing, is okay with everyone, if someone, making sure someone's okay with, what everyone else thinks is okay, making sure...everyone's...on the same page. Or at least that's how I feel.

Kerry: Okay.

Danny: It's only one opinion.

Ben: I say it's just what we do (shrugging).

Kerry: Anyone else? It's just what you do, that's how the group works?

Ben: Yeah.

Kerry: Christopher?

Christopher: - Well, mmm, I don't know, I just kinda think, it's if we made a mistake I guess.

Kerry: Okay, so if you made a mistake it kinda helps if you're checking in with Marie to make sure that, you're not making a mistake?

Christopher: Yeah.

In the above example, the assumed deficit continues as Danny attempts to get the “right” answer for me as the researcher, when Danny explains himself by saying “it’s only one opinion”. Lester and Paulus (2012) describe how there is a “tendency and the overarching pattern in the broader discourse to impose and privilege certain social conventions” (p. 267). In the group, the facilitator is seen as being an “expert”, with elevated expert knowledge, leaving the children to assume deficits in their own social skills. This elevated expert knowledge was also observed with myself as the researcher.

Andrew: By the way, I think you chose a good topic.

Kerry: What’s that?

Andrew: For your, uh, for your report thing.

Kerry: Oh yeah? Why’s that?

Andrew: Because, it, just, it just seems, you have a lot of experience with stuff like this.

It was interesting but not surprising that Andrew saw me as an “expert”. As a non-autistic researcher, doing research with autistic children, I felt a discomfort with this. One of my hopes for this research was to privilege the voices of the children in the group and learn from them. It brought into question: Can non-autistic researchers accurately depict the lived experiences of autistic individuals? Bagatell (2010) had similar concerns when engaging in research with autistic adults in a community organization that was run for and by adults on the spectrum. In Bagatell’s study, participants had mixed reviews to her presence; some felt hopeful and welcomed the opportunity for their stories to be heard while others showed significant resistance to her role as a non-autistic researcher entering an autistic space.

While group members assumed deficits about themselves, they also saw the value in personal growth and how they were proud of learning to navigate social situations.

Danny: I think the other group members would describe me as, as, a very nice person, with um, good ideas, he can be a – he can erupt sometimes, if you know what I’m talking about.

Andrew: Yeah but that’s normal for everybody, everybody has a temper.

Christopher: Yeah, I think it is.

Danny: Not to my degree! Although I’m going to be honest, I’ve...although not to brag I’ve been getting better at it over time, I’m better than I was in elementary school.

In a sense, the feelings of accomplishment come from starting out with a deficit-based model of thinking. However, the feelings also seemed to boost the children’s self-esteem and they felt truly proud of their accomplishments.

Andrew: It’s nice to know that I’ve adapted to groups, it feels like it was just yesterday that I was having problems with people reacting and all that stuff.

Bagatell (2010) had similar findings; individuals in her study benefitted greatly from having a space of open acceptance to attend but also saw the value in personal growth. One of Bagatell’s participants expressed similar views to the children, appreciating the help navigating situations that cause anxiety and depression.

By the very nature of the group, the children’s experiences were constructed through an assumed deficit. It brings into question what the purpose of intervention for this group is.

Bagatell (2010) proposes looking at the purpose of intervention and the ethics of intervention.

Sinclair (1998) takes the view that autistic people, like everyone else, need to be taught to behave in a way that does not intrude on other people’s boundaries or actively interferes with other people. However, if the student is engaging in behaviour that is deemed “weird” but does not affect anyone else, and the behaviour is not distressing to the student, then it does not need to be

changed by professionals. In the group, there were moments when one or more of the children would engage in hand flapping and this behaviour was accepted by both the group facilitator and the other group members without question. However, the underlying purpose of the group to target deficits remained, which contributed to how the children constructed their identities. I wonder how the children's experiences would be constructed if Sinclair's "rule" was followed consistently throughout the group, would this help create a group with a different purpose? Or, would the murky nuance of what individual social boundaries are make this task challenging?

**Experiences Making Friends.** An overwhelming theme throughout the group was the strong relationships the group members had with each other, the group facilitators and the organization. These relationships influenced how the children constructed their identities as friends.

One of the ways relationships formed between the group members was through shared interests and experiences. For example, the group members had opportunities to work together on creative projects in the group and developed an inside joke regarding a cartoon character that they created. The cartoon character and humour surrounding it was evident throughout all the sessions observed. Because I had not been present during the creation of the character I asked the group members to explain the origin of the cartoon.

Kerry: No, but I don't understand where the character came from.

Danny: Excuse me, Mr. Dopplemackle was created by I believe it was Ben-

Andrew and Ben: - Christopher (pointing).

Danny: Christopher, as a, he was one of the, we were adding like characters to the cartoon logo, Mr. Dopplemackle was one of the prototypes.

Kerry: Okay.

Danny: He was given the shaft, and pencil-man and eraser-man, pencil and eraser took his place.

Kerry: Oh okay, it was just that you guys kept talking about it, but I didn't know what it was-

Andrew: - And to this, and to this day, Ben and Christopher are doing some crazy stuff with Dopplemackle –

Kerry: So it's kinda like an inside joke?

Andrew: - and now we've apparently brought back his ancestor, Dopplemackle McCarkey.

The group demonstrated a unique sense of humour throughout the sessions, often playing with language and using puns.

Andrew: (pointing at something on the wall) Look, it's Mr. McTalky.

Danny: These are terrible puns.

Andrew: They aren't puns.

Ben: They're what?

Christopher: They're funs?

Andrew: Wait, funs? (giggling)

Ben: They're in for tax re-funs.

The humour, silliness and inside jokes observed throughout the sessions appeared to be bonding for the group. Bagatell (2010) had similar findings in her study, observing that the autistic individuals in her study enjoyed jokes, riddles and puns, many of which she did not understand. DePape and Lindsay (2016) also found that individuals with ASD seemed to place value on shared interests, such as video games as a means of creating and maintaining friendships.

Danny: So guys, (to Christopher and Ben) do you have (inaudible) video games?

Ben: I, I, I like video games.

Danny: I also have one and it, I also have a lot of things I want to add on, but I'm not quite sure what those things are to make it a very complete game. (Ingrid walks in and sits down) – Oh hey Ingrid!

Christopher: What video games?

Danny: Uh, I'm just, when I, when I grow up I want to make video games for a living. Because, I love playing video games, so, why not make a few?

The group members showed a strong desire to continue their friendships with one another and remain in the same group together, making specific reference to their length of time as friends.

GF: Yeah...so...it can be an end of the school celebration and end of this group celebration.

Evan: Oh, wait, oh wait, the group's ending as well?

Andrew: Yeah, it's a, it's a year – it's a group end party.

GF: Yep.

Ben: Who's going to the next one?

Christopher: Wait, is it just a theme end party or –

GF: - No, because then it's summer time, right? So, there's not groups, or there are groups in the summer time, but some people don't into join groups in the summer time

Andrew: Are we, are we all, are we all gonna get, are we all gonna get back together when's when summer's over? Or are there gonna be some, or are people, are some people gonna be gone and some new people gonna come?

GF: I dunno, what do you guys think? Do you guys like being a group together?

Danny: I do.

Ben: Yeah.

Christopher: I do.

Andrew: Yeah, we get along pretty well together.

Ben: We get along.

GF: Yep, you do.

Danny: We're all good friends.

Christopher: We've spent many years together.

When asked what their favorite part about group was, the theme of friendship and relationships continued. It was clear that the group members were happy with their ability to foster friendships in the group and wanted to continue to build upon those relationships in the future.

Andrew: What I really liked, was just being with all of you.

GF: Yeah.

Andrew: Having the group with all, having the group with all of my good friends.

GF: Yeah, it is a pretty good group. I really enjoyed every Thursday.

Andrew: Are we, are we all gonna be here in the next group?

GF: Um, I dunno we'll have to figure that out for next year.

Ben: Okay uh.

GF: - cause, I don't know what everybody's doing next year.

Ben: I'll be here, I'll be here.

The theme of relationships and friendships continued to build when the children were asked what they were most proud of accomplishing in the group over the year.

Kerry: So, but, what are you most proud of?

Danny: Well I'm personally proud of, well just – I'm just proud that I have a lot of friends, Andrew, [Kevin] a lot of very, very nice people who I can call my friends, I'm really proud of that.

Kerry: Okay, I'm, I'm wondering, what are you most proud of from this whole year, what are you the most proud of?

Andrew: Hmm-

Christopher: -well I made lots of friends-

Danny: - You mean in our personal lives?

Kerry: Sure, so Christopher you said you made lots of friends?

Christopher: Yeah.

It was also clear that some of the children saw the value in the way the skills were being taught, making specific reference to learning the skills needed to make friends.

Andrew: Getting new skills –

Danny: - I like um -

Kerry: - Okay, what kind of skills?

Andrew: Uh, just stuff like knowing how to do stuff and how to make friends and stuff like that, life skills you would say.

Reichow, Steiner and Volkmar (2012) reviewed the literature on the effect of social skills groups for children and youth with ASD and determined that children receiving treatment showed better social competence and reported better friendships than those not receiving treatment. The group members have clear friendships with each other that extend outside of the group, often getting together for birthday parties or spending time at each other's houses. Laugeson, Gantman, Dillon

and Mogil (2012) had similar findings, noting that hosted get-togethers outside of the treatment time improved as a result of their intervention.

Throughout the group, it was clear that the lessons and skills being taught were beneficial to the children. The relationships between the group members, the children and facilitators and the relationship with the organization appeared to be strong, enabling the children to feel like they were accomplishing personal growth and building friendships. While there is literature on social skills groups improving friendships and decreasing depression and loneliness amongst those with ASD, it can be questioned, are these findings due to increased social competence as described by Reichow, Steiner and Volkmar (2012), or could increased friendships be a result of simply being given the opportunity to be included in a group situation, with like-minded individuals? As Silberman (2015) describes, could these positive effects of social skills groups, be a result of “finding their tribe?” In his book, *NeuroTribes*, Silberman quotes Donna Williams, an individual on the autism spectrum upon meeting up with other autistic individuals: “Together we felt like a lost tribe. ‘Normal’ is to be in the company of one like one’s self. We all had a sense of belonging, of being understood” (p. 440). Silberman also describes the experience of Jim Sinclair “He realized that the same behaviours that had been viewed for so long as inherently antisocial could become social in a group of autistic adults, particularly if there were no clinicians around to pronounce them pathological” (p. 440). This speaks to the highly contextual nature of social skills. In the group, the children were highly attuned to one another, showing empathy and understanding and creating their own social context that incorporated their unique humour and interests. It brings into question the transferability of these skills to other social contexts. It is unclear if these skills would show up in the same way without the strong relationships and friendships formed over a long period of time. Crook et al. (2008) successfully

showed a transferability of social skills of a similar group from a clinical, group therapy setting to an unstructured setting (a social get together). However, the same group members and facilitators were all present in the unstructured setting, perhaps indicating that the relationships formed between individuals in the group contributed to the ability of the group members to navigate social situations in that context. What are considered “normal” social skills change based on the situation and can look quite different for autistic individuals. Bagatell (2010) describes how autistic adults in her study showed alternative ways of socializing that were considered “normal” for their community organization. For example, Bagatelle describes how autistic socializing in her study did not always involve conversation and sometimes involved merely being in proximity with others. Individuals in her study also spoke about how technology had enabled them to socialize using online forums and chat groups that were free from the constraints of “normal” social conventions. With the prevalence of autism approximately 1 in 68 (Center for Disease Control, 2014), perhaps it is time to start thinking differently about what “normal” social skills are, and for whom they are considered “normal”. Social conventions are in constant flux, especially as technology changes the ways in which we communicate. The challenge is learning how to navigate these ever changing contexts, while respecting, acknowledging and attempting to understand one another.

While the goal of the social group is therapeutic (aimed at improving social skills) the supportive and meaningful relationships with the organization, group facilitator and group members appear to be vital in contributing to the positive experiences and identities expressed by the children. The strong friendships formed between the group members were based on mutual interests and understanding of one another, and highlighted the possibility of alternative “normal” social skills based on context and autistic ways of being.

**Autism: The elephant in the room.** Gergen (2011) describes how the realities, rationalities and values created within a specific community have socio-political implications. In the context of this group and autism therapy, ableist ideals that dominate the field have been highlighted earlier in this chapter, speaking to the larger socio-political landscape. Specifically, how social interactions demonstrated by the children are not always acknowledged and deficits are assumed. Another area in the study that highlights this ableist ideal was the unspoken label of autism.

While analyzing the data and reviewing the literature on identity construction for individuals with autism, it became apparent that in 4.5 hours of video recording and over 100 pages of transcriptions the word “autism” does not occur a single time. While the group is not advertised specifically for children with autism, it is clear that it is aimed and tailored towards children on the autism spectrum. The funding provided by MCFD enables children with ASD to attend the group (as the cost of the group makes is prohibitive for most families who have a child without a diagnosis and attached funding). The Social Thinking® and Executive Functioning materials and resources are aimed at teaching children with autism, and the facilitators are specifically trained at working with children on the autism spectrum. All of these things combined position the children’s experiences in the group to be constructed around this particular identity. However, the identity of autism is never mentioned. The reason for this could be seen from two different perspectives. If we follow the person-first philosophy explained by Berger (2013) that comes with “person-first language” then the children’s identity could be being constructed from the perspective that the children are viewed as individual people first, and therefore naming their disability in the sessions is not necessary. There is some evidence to support this perspective; the children’s interests are encouraged throughout the sessions and their

strengths and interests are used in teaching social skills. For example, in previous sessions, the children designed a logo for a sister organization of [the organization], using their interests of cartoon characters and drawing to help them problem solve and work together on the project. Additionally, the group is not specifically advertised as a group for children with autism and occasionally, children with similar social challenges but no diagnosis, or a different diagnosis attend the groups. However, if we follow the perspective of identity-first language explained by Berger (2013), that the individual cannot be separated from their diagnosis, it could be perceived that by not naming this important identity, that there is shame in the diagnosis. By not speaking about the identity and owning the autism identity as part of who the group members are, this could lead to additional frustration of being different and never quite “measuring up” to social skill standards. In the current political climate, autism is seen as something that requires “intervention”.

While the word “autism” is not used in the group, there is some evidence to show that the group members identify with one another using a similar identity. This is seen through the incredible empathy the children showed toward one another, even during more difficult situations.

Andrew: Can you please (putting hand up in stop signal) I can't concentrate, Danny, I can't concentrate.

Danny: (singing) Sorry. I talk too much (puts head on table).

Andrew: Hey, that's one of, that's part of what you do (shrugging).

At one point in the group, Evan became upset and felt the student group facilitator was singling him out. Two of the group members showed empathy and understanding for how he felt and helped problem solve the situation together.

Evan: Like, I always get bashed on.

Danny: Uuuhhh.

Andrew: What's that suppose to mean?

Danny: He always gets, he always chooses things, like what he's trying to do is always getting shot down, I know how that feels dude (puts arm around Evan's shoulder)...sorry.

Evan: Like, I try not to do this kind of stuff and then people, will like point out to me.

Ingrid: I'm not pointing out anyone, I'm just talking in general that it's hard for me to form a group plan right now.

Andrew: (voice cracking, on the verge of tears) and Evan, this is normal for us.

GF: Yep, so –

Danny: (hand on Evan's shoulder) Sorry, so sorry, it's, it's my fault...for causing all this trouble, so sorry.

Andrew: It's not anyone's fault!

GF: Nope, we're just trying to...make a group plan, so we all need to focus, is it okay to get distracted at times?

(Ingrid nodding head)

Andrew: Of course, it's normal.

Evan: No.

GF: Yep, we're, we're all-

Andrew: - Of course, it's us!

In this example, Andrew points out the group identity, using “this is normal for us”, “Of course, it's us!”. The group members not only accept one another, but also construct their own identities

together. Is this because the group members have formed relationships with one another and therefore construct this solidarity based on their perception as a group? Or is this because they recognize, perhaps on an underlying level, their common strengths and challenges in relation to their shared diagnosis?

I wonder how the group's experiences may differ if their diagnosis was spoken about openly in the group as an important part of their identity? It is my understanding that all of the children in the group are aware of their diagnosis so it was interesting that the word autism was not mentioned once. As a group facilitator, I have felt discomfort using the word autism to talk about the identity of the children with whom I work. One of the reasons is that I am never sure whether the children have been made aware of their diagnosis. I also come from an educational and professional background that has taught me to view the diagnosis as separate from the child, and to focus on the individual and their strengths, rather than their diagnosis. As a group facilitator, I feel that it is not my place to explain the diagnosis as this is most often left up to the parents to decide when and how to discuss it. However, this positions the diagnosis in a shameful light, something to only be spoken about during specific times with specific people, perhaps only in private. While autism is not the children's only identity, and a diagnosis is not an identity in and of itself, I feel we are doing children a disservice by not speaking about it early and often in order to normalize and de-stigmatize the diagnosis. Brownlow (2010) discusses how living in a world organized around values that are predominantly non-autistic, especially the heavy emphasis on social skills is an area that is seen as problematic for both professionals and people with autism. A construction of autism that focuses on negative characteristics or that is deemed as something shameful needs to be renegotiated so that individual differences and positive traits are highlighted, making available a different construction of the label of autism (Brownlow,

2010). In British Columbia a diagnosis of autism is heavily funded and comes with funding that requires professionals to submit a Behavioural Plan of Intervention that outlines the child's current abilities, where they require intervention and strategies to achieve goals (MCFD, 2015). This emphasizes the assumption that autism is a diagnostic category that requires change on the part of the individual, highlighting the ableist ideal that dominates this field. This brings into question, how can we support individuals to embrace autism as part of their identity in a political climate that constantly advocates for change and growth "within" the individual?

## Chapter Five: Implications

In this chapter I discuss the implications of the study for future research, practice and education efforts in the field of Child and Youth Care.

### Research

The current study highlights the experiences of children with autism in a therapeutic social group. Specifically, how those experiences are constructed through relationships, language and socio-political factors. The research emphasizes the strengths and skills exhibited by the children, their strong friendships with one another and how they construct their identities. The study also examines how the highly structured learning environment produced an artificial quality to “real world” experiences and questions what “normal” social skills are. The research highlights how both children and facilitators assume deficits and explores the label of autism from a socio-political lens.

**Future Research.** This research was not designed to provide a concise truth on the experiences of children in a therapeutic social group. It has however, opened up a discussion on how children’s experiences are constructed through language, relationships and socio-political factors. Future research could take a few different paths. For example, a similar study could be undertaken with a different group of children and facilitators to see if similar themes might be identified. This study could also be used as a starting point for additional research on finding a balance of teaching social skills and accepting social differences. While the purpose of the research was to explore the experiences of children, the participation of the group facilitators emphasized the importance of practice professionals in the co-construction of experiences. Future research could explore the experiences of children in a therapeutic social group using a participatory action research model that would allow for the children to be central in the research

process from the very beginning all the way through, including the data analysis. This could include opportunities for the children to critically analyze the teaching methods and approach used by group facilitators.

**Limitations.** Although the study has important implications for research and practice, there are a number of limitations worth stating. While the children were able to build a workable social context in the group, allowing for friendships to be built and the ability to engage in group projects together, it is unclear how the children's experiences may differ in other contexts. The experiences of the children explored are limited to this particular context and assumptions cannot be made to other environments such as school and family experiences. The sample size for the study was small, and therefore offers a limited view on the experiences of a diverse group of children. One of the goals of this study was to privilege the voices of the children in the group and to better understand their experiences. While I have learned a great deal throughout the research process, it remains unclear if those voices have been privileged or fully understood. As Bagatell (2010) asks, as a non-autistic researcher, is it possible to accurately depict the lived experiences of autistic individuals? Throughout the research process, the design, data collection and data analysis have all been controlled and understood through my own personal lens. While this perspective may be valuable to other group facilitators wanting to reflect on their practice, and highlights some of the experiences of the children in the group, my interpretation of the research has been privileged by the simple fact that I am the one leading the study.

## **Practice**

Based on the above findings, the following recommendations for practice are offered. The participants saw the content of the lessons being taught in the group as valuable in many ways; they expressed personal growth in their social skills and the ability to form friendships with group members. However, the experiences of the children in the group also highlighted a few areas where possible changes to practice may be beneficial.

Moving the focus away from specific learning “goals” and being more reflective as practitioners may help facilitators become more in tune with the children’s strengths and needs. This includes the flexibility to suspend or change the “lesson” in the moment in order to respect and value the skills being shown by the children. Mattingly, Stuart and Vanderven (2002) describe the areas of flexibility and self-reflection as some of the core competencies that guide child and youth care work, and these should be incorporated as a regular part of practice when running a social group. Video taping sessions is common practice at the organization for children to view and reflect on their own behaviour and social skills. A concrete way that self-reflection and a move toward flexibility could be achieved is for group facilitators to watch their own practice with particular attention paid toward how they may be perpetuating deficit based thinking and incorporating their own biases. Giving the children an opportunity to reflect on the teaching methods used by the group facilitator and offer feedback to facilitators may also be beneficial, giving the group participants an opportunity to practice critical thinking and self-determination.

Continual self-reflection as practitioners related to our own biases in terms of what the “correct” social skill being taught in context will be an ongoing challenge. For this challenge, drawing on Sinclair’s (1998) “rule” may be beneficial; that autistic individuals, like everyone else need to be taught to respect personal boundaries, but that behaviour deemed as “weird” or

that is not distressing to the individual should not be changed. This idea, in the context of a social skills group, where there is an underlying assumption from parents, facilitators and funding providers that children are there to learn new skills could become problematic and seen as “doing nothing”. Perhaps, as a way to provide some balance to this, lessons could be framed in such a way as to help autistic individuals understand the predominantly non-autistic world. For example, highlighting to children that most non-autistic people use eye contact as a way to communicate, “what I’m looking at I’m thinking about”, without the pressure for autistic children to conform to this social norm. Re-framing it this way may help the children understand why non-autistic people do the things they do, or why they may be missing social cues (for example, “Oh, if I follow her eyes I can figure out what she’s thinking about”). Perhaps, a re-framing of teaching social skills without the pressure to conform may also help facilitators open up conversations that could lead to a better appreciation of how the children understand and view the world.

One of the most powerful experiences described by the children was their ability to form friendships and connections with peers and the group facilitators throughout their time in the social group. The connections that the children made with one another should continue to be fostered, as this was an important and powerful component of the positive experiences children described about the group. One area for improvement in practice would be to open up the discussion of how individuals co-construct their own identities in the context of the group and their shared diagnosis. The deficit based thinking influenced how the children viewed themselves, often assuming they were wrong or relying heavily on the group facilitators for guidance. Speaking about identity and using the label of autism as one component of the children’s identity may help children understand their challenges better and shift the focus away

from some of the deficit based thinking to help highlight individual differences and positive traits.

An ongoing challenge with this type of social group will be balancing the mandates of funding for therapeutic services, which advocate for change and growth within the individual, with the need for full acceptance of autism as a difference that does not require change. In a field that is predominantly dominated by a push toward evidence-based practices such as applied behaviour analysis or cognitive behaviour therapy that focus on compliance and behavioural change on the part of the individual, this is especially challenging. Orsini and Smith (2010) discuss how “autistic children and people with autism are seen as passive recipients of social services, rather than as agents or subjects in determining their own lives” (p. 43). Perhaps a balance can be found while working within the current system. Children should be given opportunities to recognize their own strengths and challenges and then determine their own goals within the group. Additionally, it would be beneficial for children to learn about the ways autism and disability are constructed within our society to better understand the problems of ableism and normativity.

### **Education**

Based on the research, the following recommendations to changes in education of Child and Youth Care practitioners are offered. Disability and atypical development are included as part of the curriculum in Child and Youth Care. While disability theories such as the social model of disability are included in the curriculum, critical disability studies are not. Critical disability studies focus on intersectional analysis, shifting attention away from the problems of disablism to the problems of ableism, or normativity. The current curriculum still largely includes an individualized focused of disability, which can be helpful when training for how best

to support individuals in the community. However, having a broader understanding of the intersections of disability with other factors such as sex, class, age and race may prove to be useful in creating practitioners who can critically reflect on their practice within the larger socio-political climate; something that the facilitators in the group may have found useful. Including critical disability studies in the curriculum may open space for shifting practitioners' views away from the disabled individual to exploring the complex nature of disability and the ableist ideals that dominate the field. O'Dell, Rosqvist, Ortega, Brownlow and Orsini (2016) describe the emerging field of critical autism studies, which parallels critical disability studies in many ways, but focuses on how autism specifically is constructed, challenging dominant understandings of autism as a neurological deficit and highlighting it as "an identity that is materially and discursively produced within specific socio-cultural contexts"(p. 167). Including readings that explore and challenge the dominant, individualized views in the field may prove beneficial in training practitioners to think critically and holistically about the ways in which they work with children and youth on the autism spectrum.

### **Concluding Remarks**

The entire research process has had a profound impact on my own practice. It has left me questioning how and why I work the way I do and has motivated me to explore and seek out alternative ways of working with children and youth with ASD. Throughout the data analysis I saw myself reflected in the actions and words of the group facilitator and was able to reflect upon my own biases in the teaching process. With the prevalence of autism continuing to grow it will be important to continually reflect on the ways in which we work with young people on the spectrum, highlighting strengths, understanding challenges and accepting differences. Most

importantly, moving away from providing services *to* children, and working *with* children towards self-determination.

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## Appendix I

### Invitation to Information Session E-mail: Parents and Participants

Hello,

You are invited to attend an information session regarding the opportunity for your child to participate in a study entitled Exploring the Experiences of Children in a Therapeutic Social Group that is being conducted by Kerry-Lynn Weatherhead.

Kerry-Lynn Weatherhead is a graduate student in the School of Child and Youth Care at the University of Victoria and you may contact her if you have further questions by e-mail at [mackayk@uvic.ca](mailto:mackayk@uvic.ca) or by phone at [REDACTED].

Ms. Weatherhead is a Senior Interventionist and Group Facilitator at [REDACTED], and you and your child may have a professional relationship with her. Joining the study is voluntary; you and your child should not feel obligated to participate based on your professional relationship with Ms. Weatherhead. Any services received from Ms. Weatherhead and [REDACTED] will not be impacted if you or your child does not elect to join the study.

For your convenience, the information session will be held on [DATE] at 5:15pm at the [REDACTED] location during your child's regular weekly Social Group. Please reply to this e-mail ([admin@\[REDACTED\]](mailto:admin@[REDACTED])) to let us know if you are able to attend the information session, or you can e-mail Kerry directly at [mackayk@uvic.ca](mailto:mackayk@uvic.ca). If you are unable to attend the information session, but are still interested in finding out more about the opportunity, you can reply to this e-mail or e-mail Kerry directly.

Attached, you will find two Consent Forms, A Parental Consent Form for you and a Participant Consent Form for your child. The consent forms will provide you with detailed information on the study prior to the information session in order to give you the opportunity to ask questions.

Thank you for your consideration,

[REDACTED] Administration

### Invitation to Information Session E-mail: Group Facilitator

You are invited to attend an information session regarding the opportunity to participate in a study entitled Exploring the Experiences of Children in a Therapeutic Social Group that is being conducted by Kerry-Lynn Weatherhead.

Kerry-Lynn Weatherhead is a graduate student in the School of Child and Youth Care at the University of Victoria and you may contact her if you have further questions by e-mail at [mackayk@uvic.ca](mailto:mackayk@uvic.ca) or by phone at [REDACTED].

Ms. Weatherhead is currently employed at [REDACTED], and may have a professional relationship with you. Joining the study is voluntary; you should not feel obligated to participate based on your professional relationship with Ms. Weatherhead. Your employment at [REDACTED] will not be impacted if you do not elect to join the study.

For your convenience, the information session will be held on [DATE] at [time] at the [REDACTED] location. Please reply to this e-mail ([admin@\[REDACTED\]](mailto:admin@[REDACTED])) to let us know if you are able to attend the information session, or you can e-mail Kerry directly at [mackayk@uvic.ca](mailto:mackayk@uvic.ca). If you are unable to attend the information session, but are still interested in finding out more about the opportunity, you can reply to this e-mail or e-mail Kerry directly.

Attached, you will find a Consent Form. The consent form will provide you with detailed information on the study prior to the information session in order to give you the opportunity to ask questions at the information session.

Thank you for your consideration,

[REDACTED] Administration

## Appendix II



**University  
of Victoria**

*Parent Consent Form*

**Exploring The Experiences of Children in a Therapeutic Social Group**

Your child is invited to participate in a study entitled Exploring the Experiences of Children in a Therapeutic Social Group that is being conducted by Kerry-Lynn Weatherhead.

Kerry-Lynn Weatherhead is a graduate student in the School of Child and Youth Care at the University of Victoria and you may contact her if you have further questions by e-mail at [mackayk@uvic.ca](mailto:mackayk@uvic.ca) or by phone at [REDACTED].

As a graduate student, I am required to conduct research as part of the requirements for a Master's degree in Child and Youth Care. It is being conducted under the supervision of Dr. Jennifer White. You may contact my supervisor by e-mail at [jhwhite@uvic.ca](mailto:jhwhite@uvic.ca) or by phone at [REDACTED].

**Purpose and Objectives**

The purpose of this study is to explore the experiences of children who have participated in a therapeutic social group. The research questions are: What are the experiences of children in a therapeutic social group? How are children's experiences in a therapeutic social group constructed? Specifically, how are these experiences constructed through their relationships with group members, including the facilitators? How are these experiences constructed through the language used in the group? How are these experiences constructed through socio-political factors?

**Importance of this Research**

The aim of this research is explore and honor the voices and perspectives of children participating in a therapeutic social group. By exploring children's perspectives, we will gain a deeper understanding of not only what those experiences may be, but also how they are constructed through language, relationships and socio-political factors.

**Participants Selection**

Your child is being asked to participate in this study because he/she is a member of an established therapeutic social group at [REDACTED]. Your child will have unique insights into his/her own experiences and will be able to offer unique perspectives on how these experiences are constructed.

**What is involved**

The research will take place at [REDACTED], during your child's regular weekly social group. The research will occur in up to five group sessions between May 2015 and June 2015.

For the majority of each group session, participants will not be required to engage in any activity that is not typical of their weekly social group. The last ten minutes of each session will be dedicated to sharing my reflections with the group while making space for children and the facilitator to share their own reflections. This will allow for transparency in the research process, allowing your child to be informed on what I am listening for and giving him/her opportunities to reflect on the session. Below are a few examples: I will be listening to the group conversations and how the energy may change based on a specific topic; I will be exploring how participants relate to one another in the group; and I will be listening to how participants express their hopes and wishes for how best they learn and how they would like to be supported.

As part of the research process, written notes will be taken during each group session. Video recordings of your child will be taken with your permission and later transcribed.

### **Inconvenience**

Participation in this study may cause some inconvenience to your child, including possible feelings of self-consciousness from being observed. Additionally, the presence of an additional person and video recording equipment in the group environment may be distracting for your child.

### **Risks**

There are no known or anticipated risks to your child by participating in this research.

### **Benefits**

The potential benefits of your child's participation in this research include having the opportunity for his/her experiences and perspectives to be heard. Participants will have opportunities to reflect on their group experiences. The relational process of the research will recognize and prioritize children's knowledge and how it is constructed.

### **Voluntary Participation**

Your child's participation in this research must be completely voluntary. If you and s/he decide to participate, you or your child may withdraw at any time without any consequences or explanation. In addition to obtaining your consent, your child's consent to participate will also be sought. If you or your child withdraws from the study, it will be impossible to remove his/her individual data, as it will be linked to the group data. If you do withdraw from the study your child's data will only be used in summarized form with no identifying information.

### **Researcher's Relationship with Participants**

The researcher may have a relationship to potential participants as an interventionist and previous group facilitator. To help prevent this relationship from influencing your decision to participate, the following steps to prevent coercion have been taken.

1. A third party (██████████ Administrative Staff) has been enlisted to approach you regarding your interest in participating. An information session will be held to outline the purpose, benefits and possible inconveniences in participating to ensure you are fully informed.
2. After the information session, the researcher will not be present to collect consent forms and any follow up will be done through the third party.
3. The researcher will not be facilitating any of the social groups or working with the children individually at any point in the recruitment and data collection process.
4. The researcher is aware that you and/or your child may feel pressure to participate because of the existing relationship. Your decision to have your child participate or not participate will have no influence on the services that your child is receiving currently or in the future, and there is no

disadvantage of not consenting. Your child will still participate in their social group regardless of your decision.

5. I have also informed the [REDACTED] Clinical Director of my intended research and should you feel that there are pressures or unanticipated consequences as a result of participating or not, you are free to contact the Clinical Director, [REDACTED], my research supervisor, Dr. Jennifer White, or the Human Research Ethics Office at the University of Victoria (250-472-4545) to have your concerns addressed.

6. If you wish to withdraw from the study at any time, you may contact the [REDACTED] Administration at [REDACTED] or e-mail admin@[REDACTED]

### **On-going Consent**

Data collection will occur in up to five sessions between May 2015 and June 2015.

To make sure that you continue to consent to participate in this research, I will send an e-mail prior to each session where data collection will occur to remind you of my presence in the group that day and remind you that you may withdraw your consent at any time.

### **Anonymity**

There are limits to protecting your child's anonymity. Because of the small group size and existing relationships the researcher will know who each participant is, even with the use of pseudonyms. However, the focus of the research is on the group process, not on individual data.

### **Confidentiality**

There are limits to protecting your child's confidentiality. The nature of the group activities makes it impossible to keep your child's data separate from the group data. Additionally, the small group size and association with [REDACTED] may make it possible to identify individual participants.

Efforts will be made to protect your child's confidentiality and the confidentiality of the data. The use of pseudonyms and changing identifying information in field notes and video recording transcriptions will be used. To protect your child's anonymity and confidentiality, only the transcribed video recordings and field notes will be used in the dissemination of results and the video recordings will only be used for the purposes of data collection. No visual or audio data of your child will be used in the dissemination of results. Because the association with [REDACTED] may make it possible to identify individual participants, the organization will not be referred to by name in the dissemination of results.

### **Dissemination of Results**

It is anticipated that the results of this study may be shared with others in the following ways: As a thesis paper accessible online through the University of Victoria, presentations at scholarly meetings, and/or as a published article, chapter, or book. Additionally, you will be provided with a written summary of the study results.

### **Disposal of Data**

Data from this study will be retained for five years and then disposed of. Written field notes will be stored in a locked cabinet and destroyed by shredding after five years. Electronic video recordings and verbatim transcripts will be stored on the researcher's computer using password-protected files and permanently deleted electronically after five years.

### **Contacts**

Individuals that may be contacted regarding this study include the researcher, Kerry-Lynn Weatherhead ([mackayk@uvic.ca](mailto:mackayk@uvic.ca) or [REDACTED]), my supervisor, Jennifer White

([jhwhite@uvic.ca](mailto:jhwhite@uvic.ca) or [REDACTED]), the [REDACTED] Clinical Coordinator, [REDACTED] ([REDACTED]) or the [REDACTED] Administrative Staff ([REDACTED]).

You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or [ethics@uvic.ca](mailto:ethics@uvic.ca)).

Please review the statement below carefully and then tick the box if you consent to your child's participation in this study:

**I agree** to my child's participation in this study. I understand that notes will be written about my child and that he/she will be video recorded. I understand that video recorded images will be collected for research purposes, but not for public dissemination.

Your signature below indicates that you understand the above conditions of your child's participation in this study and that you have had the opportunity to have your questions answered by the researcher.

---

*Name of Participant*

---

*Signature*

---

*Date*

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***

## Appendix III



**University  
of Victoria**

## *Group Participant Consent Form*

### **Exploring The Experiences of Children in a Therapeutic Social Group**

You are invited to participate in a study entitled Exploring the Experiences of Children in a Therapeutic Social Group that is being conducted by Kerry-Lynn Weatherhead. You may read this letter yourself, or have a parent or other adult read the letter with you.

Kerry-Lynn Weatherhead is a graduate student in the School of Child and Youth Care at the University of Victoria and you may contact her if you have further questions by e-mail at [mackayk@uvic.ca](mailto:mackayk@uvic.ca) or by phone at [REDACTED]

As a graduate student, I am required to conduct research as part of the requirements for a Master's degree in Child and Youth Care. It is being conducted under the supervision of Dr. Jennifer White. You may contact my supervisor by e-mail at [jhwhite@uvic.ca](mailto:jhwhite@uvic.ca) or by phone at [REDACTED].

We have to have **both** your parent/caregiver's permission **and** your permission before you can take part in this study.

This form contains a lot of important information about the study, any risks or benefits that you might experience if you decide to participate, and the steps we will take to make sure the information you share with us stays confidential. We're going to go through each section together, so if you have any questions feel free to stop us at any time.

#### **What is this study about?**

The purpose of this study is to explore the experiences of children, like you, who have participated in a social group. I want to learn more about and understand what your experiences in the group are like. I am interested in understanding how things like your relationships and friendships with other group members contribute to how you experience group. I am also interested in how the words and language used in the group might contribute to these experiences.

#### **Why is this research important?**

The aim of this research is to give your ideas and voice priority by listening to you, and giving you opportunities to give me your feedback while in your group.

#### **Why are you asking me to take part?**

You are being asked to participate in this study because you are a member of an established therapeutic social group at [REDACTED]. You will have unique knowledge that can be shared, that will help me to better understand how you experience the group.

### **What is expected of me if I agree to take part in this study?**



The research will take place at [REDACTED], during your regular weekly social group. The research will occur in up to five group sessions between May 2015 and June 2015.

For the majority of each group session, you will not be asked to do anything that is not typical of your weekly social group. As part of the research process, written notes will be taken during each group session. Video recordings of yourself and the other children will be taken, but you will not be personally identified when I write about my study. The last ten minutes of each session will be dedicated to sharing what I noticed during the group that day and give you an opportunity to share your own thoughts on the group. The kinds of things I might be listening for are your group conversation and how your reaction might change depending on the topic. For example, I might notice that you get excited sometimes or I might notice that you seemed bored. I will be listening for how you work together with your other group members and the group leader. I will be listening to how you might tell the group or myself your hopes and wishes for how best you learn and how you would like to be supported.

### **Will I be inconvenienced if I take part?**



Participation in this study may cause some inconvenience to you, including possibly feeling self-consciousness about being observed. Additionally, having an extra person and the video recording equipment in the group environment may be distracting for you.

### **Are there any risks associated with participating?**

There are no known or anticipated risks to you by participating in this research.

### **What are the benefits of my participation?**

The potential benefits of your participation in this research include having the opportunity for your experiences and perspectives to be heard. You will have an opportunity to share your unique knowledge about yourself and your group experience. Any information you provide while participating in the research conversation will help encourage practitioners and researchers to pay attention to children's' knowledge, ideas and values as they relate to Therapeutic Social Groups.



### **Is my participation in this study voluntary?**

Yes, your participation in this research must be completely voluntary. In other words, you have complete control over deciding whether you would like to participate or not. If you decide to participate, you can change your mind and choose to not be a part of the research anymore without having to explain why. You will not get in trouble for changing your mind or deciding you do not want to participate in the research. If you decide you do not want to participate anymore, it will be impossible to take you out of the video recordings as they are linked to the group video. If you decide to withdraw, your data (video recordings and notes) will only be used as a summary, and your individual data will not be used.

### **What if I change my mind?**

If you change your mind, and no longer want to be part of the research, the video recordings and my notes will still have your information on them because they are part of the group information. If you do withdraw from the study your information will only be used in summarized form and no one will know that you were part of the group.

### **How will you make sure that my participation is voluntary?**

You may know the researcher as your previous interventionist and/or group leader. Your decision to participate in this research needs to be voluntary and it is important that you do not choose to participate in the research only because you know me, or you feel that because you know me, you have to say yes.

To help prevent our relationship from influencing your choice to participate, I have taken the following steps to make sure you have the opportunity to make a decision on your own.

1. The [REDACTED] administrative staff has been asked to approach you and your parents to see if you are interested in participating. A meeting will be held with your parents to go over the purpose, benefits and possible inconveniences of participating to make sure that they are aware of what it means for you to participate in the research.
2. If your parents say it alright that you participate, I will meet with you to go over the purpose, benefits and possible inconveniences of participating to make sure you are aware of what it means for you to participate in the research. Please remember that even if your parents say that it is okay that you participate, it is important that you make the final decision about whether you would like to be part of the research or not.
3. I will give you the information about the research and give you opportunities to ask me questions before you decide. I will not be there when you are deciding whether or not to sign the consent form and if you do decide to participate, you can hand your form to the [REDACTED] administrative staff in the office.
3. I will not be running any of your social groups or working with you individually when you are deciding if you want to participate or during the recording sessions.
4. I am aware that you may feel pressured to participate because you know me. Your decision to participate or not participate will not affect your current group or any individual sessions we may have in the future. Your social group will still run regardless if you decide to participate in the research or not.
5. I have also informed the [REDACTED] Clinical Director of my research and if you feel pressured to participate or feel uncomfortable during the research process, as a result of participating or not, you are free to contact the Clinical Director, [REDACTED], my research supervisor, Dr. Jennifer White, or the Human Research Ethics Office at the University of Victoria (250-472-4545) to have your concerns addressed. You can also talk to your parents and have them contact the appropriate person if you feel more comfortable.
6. If you decide you no longer want to be in the study at any time, you can tell your parents or you may contact the [REDACTED] Office at [REDACTED] or e-mail [REDACTED]

### **How will you make sure I still want to participate?**

It is important that we check with you that you give your permission to take part throughout the entire study. It is anticipated that I will record up to five of your sessions between May 2015 and June 2015.

To make sure that you still want to participate in this research, I will ask you before each session if you still want to participate to remind you that I will be in the group that day video recording and taking notes, and remind you that you may withdraw your consent (change your mind) at any time.

### **Will anyone know that I participated in this study?**

Anonymity means that no one, including me can tell from my notes and video recordings that you are participating in my study. In this research, it will be impossible to keep your identity completely anonymous, because of the small group size and because you are working together with your group members. To help protect your identity, when I write my notes and type up the video recordings, I



will not use your real name or any identifying characteristics. As well, the focus of the research is on your group as a whole, rather than you and your responses individually.

### **Will my responses be kept confidential?**

Confidentiality refers to how I will protect your identity throughout the research process. There are limits to protecting your confidentiality. Because I will be taking notes and video recording the entire group, I will not be able to keep your ideas and responses separate from other group members. Additionally, the small group size and association with [REDACTED] may make it possible for someone reading my research to make a guess that the idea or response came from you. Because the association with [REDACTED] may make it possible to identify you, [REDACTED] will not be referred to by name when I share my results.

I will do a few things other things to protect your confidentiality and the confidentiality of what you say or do in the group. I will not use your name and will change any identifying information in my field notes and when typing up my video recordings. To protect your anonymity and confidentiality, only the typed up video recordings and field notes will be used when I share my research and the video recordings will only be used to help me remember what was said in the group. No one will see the video recordings or hear your voice when I share my results with other people.

### **Will I be able to read the results of the study?**

Yes, I will provide you with a summary of the results of the study. As well, you will be able to read the results of this study in the following ways: I will write a thesis paper for my degree that can be accessed online through the University of Victoria, I may make presentations about this study, and/or I might publish an academic article, chapter, or book.

### **Will you keep my responses forever?**

I will keep the field notes and video recordings from this study for five years before destroying them. Written notes will be stored in a locked cabinet and destroyed by shredding after five years. Electronic video recordings and typed notes from the video recordings will be stored on my computer using password-protected files and permanently deleted electronically after five years.



### **Who else can I contact for information?**

You can contact the following people if you have questions about this study include the researcher, Kerry-Lynn Weatherhead ([mackayk@uvic.ca](mailto:mackayk@uvic.ca) or [REDACTED]), my supervisor, Jennifer White ([jhwhite@uvic.ca](mailto:jhwhite@uvic.ca) or [REDACTED]), the [REDACTED] Clinical Coordinator, [REDACTED] ([REDACTED]) or the [REDACTED] Administrative Staff ([REDACTED]). You can also talk to your parents at any time and they can contact the appropriate person for you.

You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or [ethics@uvic.ca](mailto:ethics@uvic.ca)).

**If you have any questions or concerns, please don't  
hesitate to ask!**



*Here is where you can give permission to take part in this study. Remember, that **both you and** you parent/caregiver have to give permission for you to take part.*

Please review the statement below carefully and then tick the box if you wish to participate in this study:

**I agree** to participate in this study. I understand that notes will be written about my participation and that I will be video recorded. I understand that video recorded images will be collected for research purposes, but not for public presentations.

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

---

*Name of Participant*

---

*Signature*

---

*Date*

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***

## Appendix IV



**University  
of Victoria**

## *Group Facilitator Consent Form*

### **Exploring The Experiences of Children in a Therapeutic Social Group**

You are invited to participate in a study entitled Exploring the Experiences of Children in a Therapeutic Social Group that is being conducted by Kerry-Lynn Weatherhead.

Kerry-Lynn Weatherhead is a graduate student in the School of Child and Youth Care at the University of Victoria and you may contact her if you have further questions by e-mail at [mackayk@uvic.ca](mailto:mackayk@uvic.ca) or by phone at [REDACTED]

As a graduate student, I am required to conduct research as part of the requirements for a Master's degree in Child and Youth Care. It is being conducted under the supervision of Dr. Jennifer White. You may contact my supervisor by e-mail at [jhwhite@uvic.ca](mailto:jhwhite@uvic.ca) or by phone at [REDACTED]

#### **Purpose and Objectives**

The purpose of this study is to explore the experiences of children who have participated in a therapeutic social group. The research questions are: What are the experiences of children in a therapeutic social group? How are children's experiences in a therapeutic social group constructed? Specifically, how are these experiences constructed through their relationships with group members, including the facilitators? How are these experiences constructed through the language used in the group? How are these experiences constructed through socio-political factors?

#### **Importance of this Research**

The aim of this research is explore and honor the voices and perspectives of children participating in a therapeutic social group. By exploring children's perspectives, we will gain a deeper understanding of not only what those experiences may be, but also how they are constructed through language, relationships and socio-political factors.

#### **Participants Selection**

You are being asked to participate in this study because you are a group facilitator of an established therapeutic social group at [REDACTED]. Your knowledge and experience facilitating the group will contribute to the unique insights and perspectives of the children participating in the social group.

#### **What is involved**

The research will take place at [REDACTED] during your regular weekly social group. The research will occur over approximately five group sessions between May 2015 and June 2015.

For the majority of each group session, you will not be required to engage in any activity that is not typical of your weekly social group. The last ten minutes of each session will be dedicated to sharing my reflections with the group while making space for children and yourself as the facilitator to share your own reflections. This will allow for transparency in the research process, allowing you and the children to be informed on what I am listening for and giving opportunities to reflect on the session. Below are a few examples: I will be listening to the group conversations and how the energy may change based on a specific topic; I will be exploring how participants relate to one another in the group; and I will be listening to how the children express their hopes and wishes for how best they learn and how they would like to be supported.

As part of the research process, written notes will be taken during each group session. Video recordings of yourself and the children will be taken with your permission and later transcribed.

### **Inconvenience**

Participation in this study may cause some inconvenience to you, including possible feelings of self-consciousness from being observed. Additionally, the presence of an additional person and video recording equipment in the group environment may be distracting for you and the children in the social group.

### **Risks**

There are no known or anticipated risks to you by participating in this research.

### **Benefits**

The potential benefits of your participation in this research include having the opportunity for your experiences and perspectives to be heard. However, the relational process of the research will focus on recognizing and prioritizing the children's knowledge and how it is constructed.

### **Voluntary Participation**

Your participation in this research must be completely voluntary. If you decide to participate, you may withdraw at any time without any consequences or explanation.

If you withdraw from the study, it will be impossible to remove your individual data, as it will be linked to the group data. If you do withdraw from the study your data will only be used in summarized form with no identifying information.

### **Researcher's Relationship with Participants**

The researcher may have a relationship to potential participants as colleagues. To help prevent this relationship from influencing your decision to participate, the following steps to prevent coercion have been taken.

1. A third party (██████████ Administrative Staff) has been enlisted to approach you regarding your interest in participating. An information session will be held to outline the purpose, benefits and possible inconveniences in participating to ensure you are fully informed.
2. After the information session, the researcher will not be present to collect consent forms and any follow up will be done through the third party.
3. The researcher will not be facilitating any of the social groups or working with the children individually at any point in the recruitment and data collection process.
4. The researcher is aware that you may feel pressure to participate because of the existing relationship. Your decision to participate or not participate will have no influence on you employment currently or in the future, and there is no disadvantage of not consenting. You will still run the social group regardless of your decision.

5. I have also informed the [REDACTED] Clinical Director of my intended research and should you feel that there are pressures or unanticipated consequences as a result of participating or not, you are free to contact the Clinical Director, [REDACTED] my research supervisor, Dr. Jennifer White, or the Human Research Ethics Office at the University of Victoria (250-472-4545) to have your concerns addressed.

6. If you wish to withdraw from the study at any time, you may contact the [REDACTED] Administration at [REDACTED] or e-mail [REDACTED]

### **On-going Consent**

Data collection will occur in up to five sessions between May 2015 and June 2015.

To make sure that you continue to consent to participate in this research, I will send an e-mail prior to each session where data collection will occur to remind you of my presence in the group that day and remind you that you may withdraw your consent at any time.

### **Anonymity**

There are limits to protecting your anonymity. Because of the small group size and existing relationships the researcher will know who each participant is, even with the use of pseudonyms. However, the focus of the research is on the group process and children's experiences, not on your individual data.

### **Confidentiality**

There are limits to protecting your confidentiality. The nature of the group activities makes it impossible to keep your data separate from the group data. Additionally, the small group size and association with Little Steps Therapy Services may make it possible to identify individual participants, especially group facilitators.

Efforts will be made to protect your confidentiality and the confidentiality of the data. The use of pseudonyms and changing identifying information in field notes and video recording transcriptions will be used. To protect your anonymity and confidentiality, only the transcribed video recordings and field notes will be used in the dissemination of results and the video recordings will only be used for the purposes of data collection. No visual or audio data of you will be used in the dissemination of results. Because the association with [REDACTED] may make it possible to identify individual participants, the organization will not be referred to by name in the dissemination of results.

### **Dissemination of Results**

It is anticipated that the results of this study may be shared with others in the following ways: As a thesis paper accessible online through the University of Victoria, presentations at scholarly meetings, and/or as a published article, chapter, or book. Additionally, you will be provided with a written summary of the study results.

### **Disposal of Data**

Data from this study will be retained for five years and then disposed of. Written field notes will be stored in a locked cabinet and destroyed by shredding after five years. Electronic video recordings and verbatim transcripts will be stored on the researcher's computer using password-protected files and permanently deleted electronically after five years.

### **Contacts**

Individuals that may be contacted regarding this study include the researcher, Kerry-Lynn Weatherhead ([mackayk@uvic.ca](mailto:mackayk@uvic.ca) or [REDACTED]), my supervisor, Jennifer White ([jwhite@uvic.ca](mailto:jwhite@uvic.ca) or [REDACTED]), the [REDACTED] Clinical Coordinator, [REDACTED]

( [REDACTED] ) or the [REDACTED] Administrative Staff  
( [REDACTED] ).

You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or [ethics@uvic.ca](mailto:ethics@uvic.ca)).

Please review the statement below carefully and then tick the box if you wish to participate in this study:

**I agree** to participate in this study. I understand that notes will be written about my participation and that I will be video recorded. I understand that video recorded images will be collected for research purposes, but not for public dissemination.

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

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*Name of Participant*                      *Signature*                      *Date*

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***

## Appendix V



**University  
of Victoria**

*Community Organization Site of  
Research Permission*

**Exploring The Experiences of Children in a Therapeutic Social Group**

I am writing to request your permission to use [REDACTED] as site of research for the study entitled Exploring the Experiences of Children in a Therapeutic Social Group that is being conducted by Kerry-Lynn Weatherhead.

Kerry-Lynn Weatherhead is a graduate student in the School of Child and Youth Care at the University of Victoria and you may contact her if you have further questions by e-mail at [mackayk@uvic.ca](mailto:mackayk@uvic.ca) or by phone at [REDACTED].

As a graduate student, I am required to conduct research as part of the requirements for a Master's degree in Child and Youth Care. It is being conducted under the supervision of Dr. Jennifer White. You may contact my supervisor by e-mail at [jhwhite@uvic.ca](mailto:jhwhite@uvic.ca) or by phone at [REDACTED].

**Purpose and Objectives**

The purpose of this study is to explore the experiences of children who have participated in a therapeutic social group. The research questions are: What are the experiences of children in a therapeutic social group? How are children's experiences in a therapeutic social group constructed? Specifically, how are these experiences constructed through their relationships with group members, including the facilitators? How are these experiences constructed through the language used in the group? How are these experiences constructed through socio-political factors?

**Importance of this Research**

The aim of this research is explore and honor the voices and perspectives of children participating in a therapeutic social group. By exploring children's perspectives, we will gain a deeper understanding of not only what those experiences may be, but also how they are constructed through language, relationships and socio-political factors.

**Participants Selection**

The target population is all members of one of the established social group at [REDACTED] including the Group Facilitator. Children participating in these groups will have unique insights into his/her own experiences and will be able to offer unique perspectives on how these experiences are constructed.

**What is involved for [REDACTED]**

The research will take place at [REDACTED] during one of the regular weekly social groups. The research will occur over approximately five group sessions between May 2015 and June 2015.

Because of my existing relationship with the Group Facilitators as colleagues and the children as an Interventionist and previous Group Facilitator, I am requesting that the administrative staff at [REDACTED] act as a third party to aid in the recruitment of participants. This will involve having

administrative staff send an initial e-mail with letters of consent attached and inviting the facilitators and parents of potential participants to an information session regarding the research. After the information session, I will request that participants hand in their letters of consent and any follow up regarding consent (including the withdrawal of consent) be done through the [REDACTED] administrative office.

### **What is involved for Participants**

For the majority of each group session, participants will not be required to engage in any activity that is not typical of their weekly social group. The last ten minutes of each session will be dedicated to sharing my reflections with the group while making space for children and the facilitator to share their own reflections. This will allow for transparency in the research process, allowing the children to be informed on what I am listening for and giving him/her opportunities to reflect on the session. Below are a few examples: I will be listening to the group conversations and how the energy may change based on a specific topic; I will be exploring how participants relate to one another in the group; and I will be listening to how participants express their hopes and wishes for how best they learn and how they would like to be supported.

As part of the research process, written notes will be taken during each group session. Video recordings of the sessions will be taken with permission and later transcribed.

### **Inconvenience to [REDACTED]**

Having [REDACTED] as a site of research may cause some inconveniences to the organization, including the use of administrative staff to aid in the recruitment and follow up of obtaining or withdrawing consent by participants.

### **Inconvenience to Participants**

Participation in this study may cause some inconvenience to the children, including possible feelings of self-consciousness from being observed. Additionally, the presence of an additional person and video recording equipment in the group environment may be distracting for your child.

### **Risks**

There are no known or anticipated risks to children or group facilitators by participating in this research.

### **Benefits**

The potential benefits of the children's participation in this research include having the opportunity for his/her experiences and perspectives to be heard. Participants will have opportunities to reflect on their group experiences. The relational process of the research will recognize and prioritize children's knowledge and how it is constructed.

### **Voluntary Participation**

The children's participation and group facilitator's participation in this research must be completely voluntary. If participants decide to participate, they may withdraw at any time without any consequences or explanation. In addition to obtaining parental consent, the children's consent to participate will also be sought.

### **Researcher's Relationship with Participants**

The researcher may have a relationship to potential participants as an interventionist and previous group facilitator. To help prevent this relationship from influencing their decision to participate, the following steps to prevent coercion have been taken.

1. A third party ([REDACTED] Administrative Staff) has been enlisted to approach participants regarding their interest in participating. An information session will be held to outline the purpose, benefits and possible inconveniences in participating to ensure they are fully informed.
2. After the information session, the researcher will not be present to collect consent forms and any follow up will be done through the third party.
3. The researcher will not be facilitating the social group or working with the children individually at any point in the recruitment and data collection process.
4. The researcher is aware that participants may feel pressure to participate because of the existing relationship. The decision to have the child participate or not participate will have no influence on the services that they are receiving currently or in the future, and there is no disadvantage of not consenting. The child will still participate in their social group regardless of their decision. The decision to participate or not participate will have no influence on the group facilitator's employment currently or in the future, and there is no disadvantage of not consenting. The group facilitator will still run the social group regardless of their decision.
5. I will inform participants that you are aware of my intended research and should they feel that there are pressures or unanticipated consequences as a result of participating or not, they are free to contact you as the Clinical Director, [REDACTED]), my research supervisor, Dr. Jennifer White, or the Human Research Ethics Office at the University of Victoria (250-472-4545) to have their concerns addressed.
6. If you participants wish to withdraw from the study at any time, they may contact the [REDACTED] Administration at [REDACTED] or e-mail [REDACTED]

### **On-going Consent**

Data collection will occur over approximately five sessions between May 2015 and June 2015. To make sure that participants continue to consent to participate in this research, I will send an e-mail prior to each session where data collection will occur to remind them of my presence in the group that day and remind them that they may withdraw their consent at any time.

### **Anonymity**

There are limits to protecting the anonymity of the participants. Because of the small group size and existing relationships the researcher will know who each participant is, even with the use of pseudonyms. However, the focus of the research is on the group process, not on individual data.

### **Confidentiality**

There are limits to protecting your participants' confidentiality. The nature of the group activities makes it impossible to keep individual data separate from the group data. Additionally, the small group size and association with [REDACTED] may make it possible to identify individual participants.

Efforts will be made to protect confidentiality and the confidentiality of the data. The use of pseudonyms and changing identifying information in field notes and video recording transcriptions will be used. To protect your anonymity and confidentiality, only the transcribed video recordings and field notes will be used in the dissemination of results and the video recordings will only be used for the purposes of data collection. No visual or audio data of the participants will be used in the dissemination of results. Because the association with [REDACTED] may make it possible to identify individual participants, the organization will not be referred to by name in the dissemination of results.

### **Dissemination of Results**

It is anticipated that the results of this study may be shared with others in the following ways: As a thesis paper accessible online through the University of Victoria, presentations at scholarly meetings, and/or as a published article, chapter, or book.

**Disposal of Data**

Data from this study will be retained for five years and then disposed of. Written field notes will be stored in a locked cabinet and destroyed by shredding after five years. Electronic video recordings and verbatim transcripts will be stored on the researcher's computer using password-protected files and permanently deleted electronically after five years.

**Contacts**

Individuals that may be contacted regarding this study include the researcher, Kerry-Lynn Weatherhead ([mackayk@uvic.ca](mailto:mackayk@uvic.ca) or [REDACTED]), my supervisor, Jennifer White ([jhwhite@uvic.ca](mailto:jhwhite@uvic.ca) or [REDACTED]) or the Human Research Ethics Office at the University of Victoria (250-472-4545 or [ethics@uvic.ca](mailto:ethics@uvic.ca)).

Your signature below indicates that you understand the conditions of the research and the conditions of using [REDACTED] as a site of research for this study. Your signature below indicates that you have had the opportunity to have your questions answered by the researcher, and that you consent to the researcher requesting informed consent for the participation of your employees and clients in the above research.

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*Name of Clinical Director*

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*Signature*

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*Date*

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***