

The Influence of Disclosure on Peer Engagement and Interactions for a Child with Autism in

Summer Camps: A Within Case Mixed Methods Study

by

Luan Fan

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

Master of Science

in

Rehabilitation Science

Faculty of Rehabilitation Medicine

University of Alberta

© Luan Fan, 2020

## **Abstract**

Autism Spectrum disorder (ASD) is often considered an invisible disability. Children with autism are at a particularly high risk of experiencing exclusion, stigma and bullying. Increasing social participation and engaging in community-based activities are one of the highest priorities for children with autism. According to previous hypothetical vignettes research, diagnostic disclosure and explanatory information of what the diagnosis means and how to engage with children with autism to their peers may increase engagement and inclusion for children with autism. However, no study has evaluated the effect of preventive disclosure in real life community contexts.

This study is a mixed-methods instrumental case study. We evaluated engagement states of a child with autism who participated in both disclosure and non-disclosure conditions at summer camp. The time-interval behavioral-coding system the Playground Observation of Peer Engagement (POPE) will be used to observe both the child and peers in the program, code their engagement states and reciprocal activities (both initiations and responses). To understand the perceived outcomes of disclosure from different perspectives, semi-structured qualitative interviews were conducted with the child with autism, camp leaders and peers in the disclosure camp. This study provides preliminary data to support that the use of simple disclosure protocol might be an easy and cost-efficient intervention to help improve peer engagement and understanding of children with autism in short-term community programs.

This thesis is presented in three chapters. The first chapter includes an introduction and discussion related to literature broader than that included in chapter two, which presents the original research contribution. The third chapter then presents a discussion, limitations, future

research directions, and conclusions related to the broader literature and practice. The detailed research abstract for the original research presented in chapter two is included below.

## **Preface**

This thesis is an original work by Luan Fan. The research project, of which the thesis is a part, was given research ethics approval from the University of Alberta Research Ethics Board, Project Name “Influencing inclusion for children with ASD in communities: Peer interaction and responses in context”, No. Pro00081598, Date: May 13, 2019.

Chapter 2 of this thesis has been submitted as Fan, Lu'an; Thompson-Hodgetts, Sandy; Shire, Stephanie Y.; Couture, Mélanie; Zwaigenbaum, Lonnie, "The Influence of Disclosure on Peer Engagement and Interactions for a Child with Autism in Summer Camps: A Within Case Mixed Methods Study" and is presently being given consideration for publication in *Disability and Rehabilitation*. I was responsible for the data collection and analysis as well as the manuscript composition. Dr. Sandy Thompson-Hodgetts was the supervisory author and supported secondary data analysis and contributed to manuscript edits. Dr. Stephanie Y. Shire, Dr. Mélanie Couture and Dr. Lonnie Zwaigenbaum was contributed to manuscript edits.

## Acknowledgements

I would like to begin by expressing my sincere gratitude to my supervisor for the continuous support of my study and research, for her patience, motivation, enthusiasm, and knowledge. Her guidance helped me in all the time of research and writing of this thesis. I could not have imagined having a better supervisor and mentor for my master's study.

I would also like to thank my committee: Dr. Lonnie Zwaigenbaum and Dr. Veronica Smith. Thank you for sharing your experience, knowledge and insightful comments with me, it has been incredibly valuable in the development and execution of this study.

To everyone in the SKIP lab and friends here in Canada, thank you for teaching me everything about North America, constantly cheering me on and helping me stay motivated. To my parents and friends in China, thank you for providing me with unfailing support and continuous encouragement throughout my years of study. Having all of you in my corner has made it possible to never lose sight of my goals even through the ups and the downs.

As a final note, I need to extend my gratitude to The Centre for Autism Services Alberta. My graduate school experience has been enriched by working with children with autism in real-life contexts.

I have been on a special journey these past few years. I firmly believe that my exciting achievement is never solely my own and are the culmination of the efforts of many people. The unwavering support from all of you has made this undertaking that much more achievable.

## Contents

Chapter 1 .....	1
1. Introduction.....	1
2. Literature Review.....	2
What is Autism? .....	2
Stigma and Autism .....	3
Theoretical Frameworks Informing This Study .....	6
Lived Experience of Diagnostic Disclosure for Persons with Autism .....	7
Social Participation.....	8
Social participation of Children and Adolescents with Disabilities .....	9
Social participation of Children and Adolescents with Autism .....	9
Social Participation at School for Children with Autism .....	12
Strategies Targeting Social Engagement and Participation.....	14
Disclosure .....	18
3. Summary .....	19
Chapter 2.....	31
Introduction .....	32
Methods.....	35
Results .....	45
Discussion .....	53
Conclusion.....	59
Chapter 3.....	66
1. Discussion .....	66
Language Use .....	66
Potential Alternative to a Disclosure Protocol .....	67
Adults Attitudes.....	68
Friendship .....	69
Limitations and Future Directions .....	70
2. Conclusion .....	71

## List of Tables

Table 1. Participant's ABAS-4 Global Adaptive Composite and Domain Scores .....	37
Table 2: Engagement States from the Playground Observation of Peer Engagement .....	41
Table 3: Engagement States and Peer Interactions for child with ASD in both conditions .....	46

## List of Figures

Figure 1: Stigma and Factors that Influence Disclosure or Non-disclosure in Chronic Illness.....	7
Figure 1: Intervals in which the Child with Autism was Jointly Engaged .....	46
Figure 2. Intervals in which the Child with Autism was not Jointly Engaged .....	47
Figure 3: Percentage of Successful Initiations .....	49
Figure 4. Percentage of Positive Responses.....	49



**List of Appendices:**

Appendix A. Playground Observation of Peer Engagement— Original Form .....88

Appendix B. Playground Observation of Peer Engagement— Revised Form .....89

Appendix C. Recruitment Poster.....90

Appendix D. Ethics Approval Letter .....91

Appendix E. Renewed Ethics Approval Letter .....92

Appendix F. Information Letter for Parents of Children with ASD .....93

Appendix G. Assent Form for Children with ASD .....97

Appendix H. Information Letters for Parents of Peers .....99

Appendix I. Email study announcement/recruitment that was distributed through existing  
listservs .....101

Appendix J. Interview Questions .....103

# Chapter 1

## 1. Introduction

Autism spectrum disorder is often considered an invisible disability. It is diagnosed based on deficits in social interaction, communication skills and restricted, repetitive behaviors (American Psychiatric Association, 2013). Children with autism are at a particularly high risk of experiencing social exclusion, stigma and bullying (Chambres, Auxiette, Vansingle, & Gil, 2008; Moyson & Roeyers, 2011b; Taheri, Perry, & Minnes, 2016). Negative effects associated with stigma, social exclusion and bullying largely affect the quality of life for both children with autism and their parents (Broady, Stoyles, & Morse, 2017; Kinnear, Link, Ballan, & Fischbach, 2016). According to previous hypothetical vignette research, sharing one's diagnosis in a planned way, with information about potential reasons for atypical behaviors and strategies for how peers can include a child with autism, might counteract stigma and increase social inclusion (Thompson-Hodgetts, Labonte, Mazumder, & Phelan, 2020). However, experiences with stigma and exclusion may affect parents' comfort with and desire to disclose an autism diagnosis to others (Lum, Garnett, & O'Connor, 2014; Thompson-Hodgetts et al., 2020). Therefore, evaluating if disclosure is associated with improved social inclusion could facilitate peer engagement and inclusion in real-life contexts.

This study is a part of my supervisor's larger project. The overall purpose of the larger project is to investigate the effects of diagnostic disclosure and explanatory information on social acceptance and peer engagement for children with autism in mainstream community settings. The purpose of my independent thesis project was to compare observed peer engagement and

social interactions for one child with autism who participated in two, one-week, summer camps, one in which he disclosed and one in which he did not disclose his diagnosis of autism to peers.

## **2. Literature Review**

To explore the broader literature related to this topic, I have reviewed literature related to autism, stigma, inclusion and participation in community recreation, strategies targeting social engagement and participation, and previous research on diagnostic disclosure, including people's lived experience and hypothetical vignette studies. Each of these topics is discussed separately below.

### **What is Autism?**

Autism spectrum disorder (hereafter called autism) is a complex neurological development disorder. It is diagnosed based on two core symptoms: deficits in social interaction and communication skills, and restricted, repetitive and stereotyped patterns of behavior (American Psychiatric Association, 2013). Characteristics of children with autism could include lack of awareness of others, difficulty with understanding and using non-verbal communication, unusual social play and marked distress over changes in the environment (Hyman, Levy, & Myers, 2020). The presence or absence of certain behaviours and developmental delays vary between each individual with autism. Because of the increased public awareness of autism and the more inclusive diagnostic criteria (Hyman et al., 2020), the prevalence of children with autism has increased over time. In 2018, the Autism and Developmental Disabilities Monitoring (ADDM) reported that the prevalence of children with autism was approximately 1 in 59 children aged 8 years old, which is slightly higher than the report published in 2016 (1 in 68)

(Baio et al., 2018b; Christensen et al., 2018). Autism is also four times more common among boys than in girls (Baio et al., 2018a).

### **Stigma and Autism**

Goffman (1963) first came up with the concept of stigma, and defined it as “an attribute, behavior, or reputation which is socially discrediting in a particular way”, with the stigmatized individual classified by others as “undesirable, rejected” rather than “accepted, normal”. He recognized that interpersonal ties with the person with a disability, for example their close friends and families, also experience stigmatisation, which was identified as “courtesy stigma”. Over time, an increasing number of scholars started to apply this paradigm to the experience of stigma with people with autism and their caregivers. Studies have shown that parents of children with autism experienced stigma, and mothers were more likely to encounter stigma from others than fathers (Farrugia, 2009; Gray, 1993, 2002).

Stigma towards individuals with autism and their families is prevalent and the negative effects of stigma influence their life in various aspects (Mazumber & Thompson-Hodgetts, 2019). In particular, stigma related to autism was summarized in four themes based on a scoping review of current literature in this area: social perceptions of autism, social isolation, well-being and responses to stigma, and stigma reduction (Mazumber & Thompson-Hodgetts, 2019). Social perceptions of autism refer to the invisible nature of autism and the diagnostic label of autism, which are associated with stigma. On the one hand, autism is often considered an invisible disability. Despite social and behavioral difficulties, this largely invisible nature also makes children at high risk of bullying, exclusion, and stigmatization (Chambres et al., 2008; Moyson & Roeyers, 2011b; Taheri et al., 2016). Because of the “normal” physical appearance, the general public and extended family may judge a child’s “abnormal” behaviors as a result of poor

parenting or bad behaviors, rather than interpreting these behaviours as a symptom of autism (Broady et al., 2017; Neely-Barnes, Hall, Roberts, & Graff, 2011). According to Gray (1993), “it is this combination of pervasive disability and apparent physical normality that gives the stigma experienced by families with autistic children its unique quality” (p.114).

On the other hand, autism is being increasingly recognized. Diagnostic labelling is often the key to access supports and services for a child with autism and their family, and some young people with autism have expressed an internalized sense of pride and belonging due to their unique attributes (Jones, Gallus, Viering, & Oseland, 2015; Mansell & Morris, 2004; Mogensen & Mason, 2015; Russell & Norwich, 2012). However, self-advocacy does not inoculate people with autism from struggling with a social stigma. Adolescents with autism have reported the negative social perceptions associated with their autism label, including persistent disabling attitudes in society and having their socially different behaviours misunderstood by others (Mogensen & Mason, 2015). Due to the negative stereotypes related to the autistic label, the perceived burden of having a child with a disability, and feelings of frustration with the fact that the autistic label was not understood by other people, the majority of parents resisted diagnosis initially and often delayed seeking a formal diagnosis (Mansell & Morris, 2004; Russell & Norwich, 2012).

Studies that have examined the consequences of frequent stigmatization among children with autism and their parents have reported their personal experiences with victimization, rejection and social isolation from broader social settings. In general, younger children were more vulnerable to be victimized than older children (Cappadocia, Weiss, & Pepler, 2012). Children with greater communication impairments were also at a higher risk of bullying and victimization (Cappadocia et al., 2012). Accordingly, children’s mental health problems may

have a bidirectional relationship with the risk of being victimized. High levels of victimization, exclusion and isolation may potentially cause mental health problems among children with autism, including anxiety, self-injurious behaviours, and being more vulnerable to aggressive peers. Correspondingly, children with mental health problems are also at a higher risk of being bullied and victimization (Cappadocia et al., 2012). In school, compared with children with other special educational needs and those without difficulties, children with autism reported fewer friendships and lower level of support from teachers and classmates, along with a higher frequency of bullying and exclusion (Campbell, Ferguson, Herzinger, Jackson, & Marino, 2004; Humphrey & Symes, 2010; Symes & Humphrey, 2010; Wainscot, Naylor, Sutcliffe, Tantam, & Williams, 2008). In the wider social context, nearly all parents also reported experiences of being isolated and excluded from their friends and families, especially when their child demonstrates disruptive or challenging behavior (Broady et al., 2017; Kinnear et al., 2016). Those negative effects of stigma can be challenging for parents of children with autism, which may increase the difficulty of raising children with autism, and also potentially contribute to extreme emotional distress, such as depression and anxiety (Gray, 1994; Kinnear et al., 2016).

Education may increase acceptance of autism and minimize stigma and discrimination towards children with autism. Previous studies indicated that parents of children with autism and adolescents with autism often try to reposition a diagnosis of autism in a more positive perspective (Farrugia, 2009; Jones et al., 2015; Russell & Norwich, 2012). In an effort to manage stigma, some parents also tried to actively educate others about autism, and advocate for the benefits of their child's unique characteristics and behaviors. By doing so, they successfully decreased stigmatisation to some degree (Farrugia, 2009; Russell & Norwich, 2012). However,

this type of education may require disclosure of one's diagnosis, which may or may not be desired by the person with autism and their family in public situations.

### **Theoretical Frameworks Informing This Study**

**Social Model of Disability.** This study was conceptualized with the lens of building an inclusive society, and decreasing discrimination and judgement, through targeting contextual factors, instead of focusing on the disability within the individual. Distinguished from the traditional medical or individual model, the Social Model of Disability (SMOD) defines disability as a social creation and argues that there is a relationship between people with impairment and a disabling society (Shakespeare, 2006). The SMOD indicates that environmental, political and psychological barriers (e.g., limited accessibility, restricted participation in mainstream social activities, oppressive social reactions, and so on), lead to people with different impairments becoming excluded by society. People who align with this model value attempts to build an inclusive society and advocate against discrimination and judgement.

**Theoretical Framework of Disclosure.** According to Joachim and Acorn's theoretical framework of stigma and disclosure, there are three options for potential disclosure for people with invisible chronic conditions, including disclosure (including protective disclosure or spontaneous disclosure), non-disclosure, and preventive disclosure. Both protective and spontaneous disclosure might increase social support and acceptance but may also lead to negative outcomes, like stigma, rejection and isolation. Non-disclosure means people choose to hide their disability from others. By doing so, there is a possibility that they are able to pass for "normal" and become a part of the group. But, hiding a condition can be stressful, and if they are found out by others, it might cause more negative outcomes. As a result, the authors advocate for

preventive disclosure and note that preventive disclosure might be able to counteract social stigma by preventing negative perceptions and ensuring help. Preventive disclosure is planned, people can control whether to conceal or disclose their condition and how much information they want to share.

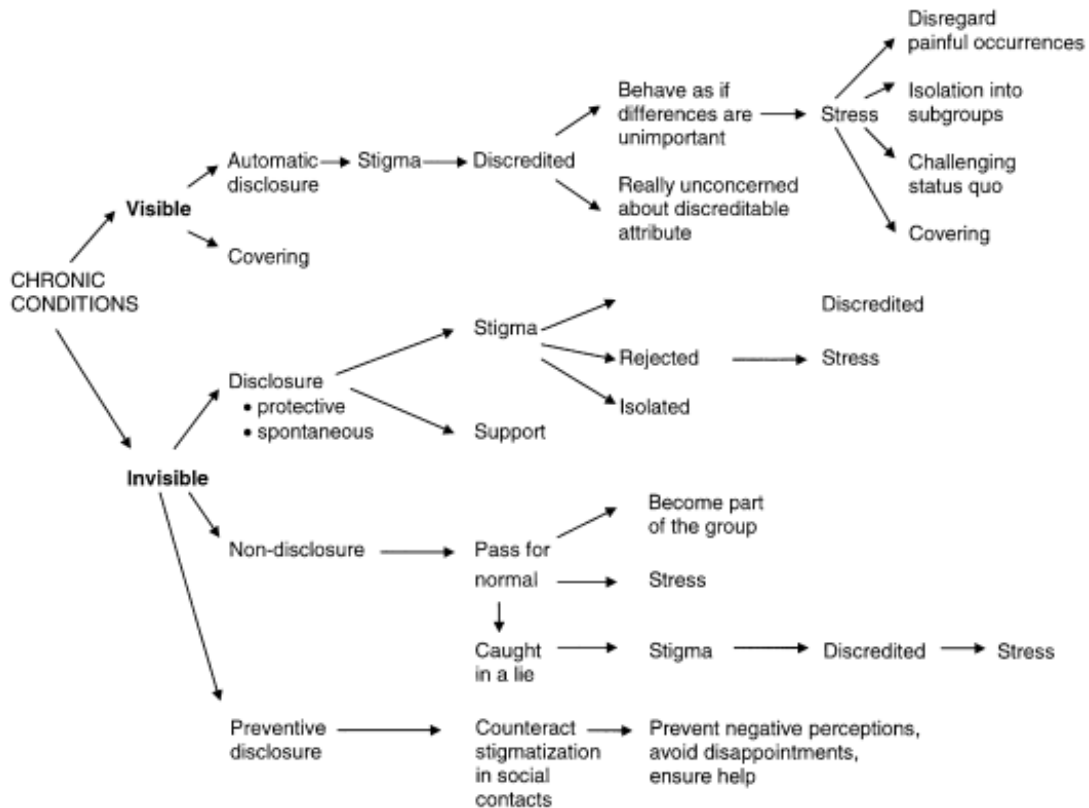


Figure 1. Stigma and factors that influence disclosure or non-disclosure in chronic illness.

Journal of Advanced Nursing, Volume: 32, Issue: 1, Pages: 243-248, First published: 25 December 2001, DOI: (10.1046/j.1365-2648.2000.01466.x)

### Lived Experience of Diagnostic Disclosure for Persons with Autism

Joachim and Acorn’s theoretical framework still requires evaluation for people with autism. However, there is a body of research on the lived experiences of disclosure that is relevant. Both parents with children with autism and adolescents with autism indicated a reluctance to share a diagnosis with others in order to avoid stigmatization (Russell & Norwich,



2012). People mostly limited their disclosure to certain circumstances, for example, when diagnostic disclosure was a requirement for them to receive disability support services at post-secondary institutions (Cai & Richdale, 2016). Otherwise, in order to avoid negative labelling from others, they often declined to disclose, even when talking to health care providers and police officers (Lum et al., 2014; Muskat et al., 2016; Thompson-Hodgetts et al., 2020). For example, both parents of children with autism and adults with autism reported a lack of understanding and negative responses towards their autism diagnosis from health care providers. A lack of wanting to disclose in front of the child with autism also made parents feel hesitant about disclosure (Lum et al., 2014; Muskat et al., 2016). Similarly, individuals with autism also report being uncertain about when to disclose, how much information to give, and to whom (Austin et al., 2016; Chambres et al., 2008). So, hypothetically, planned disclosure may be an appropriate strategy of reducing stigma and increasing opportunities for social participation for people with autism, but this requires further study.

### **Social Participation**

The World Health Organization defines participation as “a person’s involvement in a life situation”. Social inclusion and participation were identified as a vital part of health, development and quality of life (Currie et al., 2009; WHO, 2001). King et al (2003) defined children’s participation as “involvement in the formal and informal everyday activities of childhood in all types of non-school environments, including environments for play, sport, entertainment, learning, and religious expression” (p.65). Formal activities involve structured activities that include rules or goals with a designated instructor or coach, such as organized sports or board games, whereas informal activities are often initiated by children, with little planning and organizing, such as free play (King et al., 2003). Studies consistently emphasize the importance of encouraging children to participate in inclusive recreational and leisure-based

activities. Through participation, children acquire social skills and capabilities, such as communication and interpersonal skills; have opportunities for social interactions; build meaningful friendships; develop mental and physical health, and enhance self-identity and emotional wellbeing (King et al., 2003; Law et al., 2006; Solish, Perry, & Minnes, 2010).

### **Social participation of Children and Adolescents with Disabilities**

Despite the importance and benefits of social participation, results from a number of studies indicated that, compared with typically developing (TD) individuals, children and adolescents with disabilities were less likely to participate in social activities (Buttimer & Tierney, 2005; King et al., 2003; Orsmond, Krauss, & Seltzer, 2004). Social participation of children with disabilities was not significantly diagnosis-specific; instead, it was restricted by multifaceted factors, including environmental (both physical and social environment), family (e.g., family social-economic situations, family interest in recreational activities) and child (e.g., child's functional skills, communication skills) factors (King et al., 2003). Studies suggest that children and youth with developmental disabilities preferred to participate in sedentary and recreational activities at home, such as playing computer games and/or watching television, rather than engaging in active, physical and skilled-based activities in the community with friends, such as team sports (King, Shields, Imms, Black, & Ardern, 2013; Law et al., 2006). Low levels of social participation not only limited the development of social, emotional and cognitive skills for children with disabilities, but also contributed to higher the rates of obesity and poor health (King et al., 2003; Rimmer, Rowland, & Yamaki, 2007).

### **Social participation of Children and Adolescents with Autism**

Given the increasing prevalence of individuals diagnosed with autism, researchers started to describe and understand the level of social participation of individuals with autism in community contexts. A scoping review revealed that autism-related impairments (i.e., deficits in social interaction and communication skills, and restricted, repetitive and stereotyped patterns of behaviors), other potential co-occurring characteristics (such as aggressive behaviors), and problems in fine and gross motor ability were all considered as barriers to individuals' participation (Askari et al., 2015). In addition, similar to children and youth with other developmental disabilities, environmental factors were also influential, which included limited social supports from family and friends, lack of availability of programs, as well as negative social attitudes (Anaby et al., 2013; Askari et al., 2015).

Hilton, Crouch and Israel (2008) studied the diversity and intensity of participation in out-of-school activities, and the number of people they participated with, for children they defined as high-functioning autism (also known as Asperger syndrome) and typical development (TD) children. Children with high functioning autism participated in a more limited diversity and frequency of social activities, especially informal activities, and engaged with fewer people than TD children. As noted before, informal activities (such as going to movies with friends) often involve social initiation and motivation, while formal activities (such as art lessons or team sports) are planned and organized. Given the potentially increased contribution of social abilities, it was possible that these differences were related to the social impairments of children with autism. Moreover, due to deficits in motor skills, children with autism had the greatest limitation and the lowest frequency of participating in physical activities.

Research by Taheri et al. (2016) examined both social participation and friendship of children and adolescents among three matched groups: TD individuals, individuals with

intellectual disabilities (ID) and individuals with both ID and autism. They described that individuals with ID and ID + autism participated in fewer social activities and had fewer friends with poorer quality of friendship relative to their TD peers. In addition, those with ID + autism were reported to participate even less frequently in some special occasions (e.g., birthday parties) and had fewer school friends than those with ID only.

In terms of young adults, Orsmond et al. (2013) found that young adults with autism experienced significantly higher levels of social isolation in comparison with young adults with other disabilities (including intellectual disability, emotional disturbance and learning disability). In their study, almost 40% of youth with autism never saw friends, and close to 50% of young adults with autism never got called or invited to social activities by friends. The extent of social participation did not appear to change with the transition from school to college or work.

Although social participation is important and considered as a critical predictor of quality of life, studies consistently indicated that the participation of children and adolescents with autism in social activities is limited (Currie et al., 2009). Individuals with complex and challenging needs were most likely to be socially isolated (Hilton, Crouch, & Israel, 2008; Orsmond et al., 2013; Taheri et al., 2016). Communication and functional impairments (e.g., poor social and motor skills) are common deficits of autism, which can make social participation and establishing relationships with their peers more difficult for people with autism (American Psychiatric Association, 2013). However, many individuals with autism reported their desire of participating in various social activities as well as forming relationship with others (Bauminger & Kasari, 2000; Cowart, Saylor, Dingle, & Mainor, 2004; Humphrey & Lewis, 2008). Thus, it is important to find strategies to increase the social participation of individuals with autism. Research on social participation in school contexts, which is much more common than research

in community contexts, may provide important information related to promoting social participation in the community.

### **Social Participation at School for Children with Autism**

In order to enhance children's social and academic development, parents and professionals increasingly prefer to integrate their children with autism into mainstream schools (Humphrey & Lewis, 2008). As mentioned, children with autism participate at low rates across non-school environments (Hilton et al., 2008; Taheri et al., 2016). To understand the benefits or risks of involving children with autism in inclusive school settings, social networks in general education classrooms and peer engagement on the playground were considered as two major social outcomes (Kasari, Rotheram-Fuller, Locke, & Gulsrud, 2012; Kretzmann, Shih, & Kasari, 2015).

Social network analysis is commonly used to explore the social network involvement for both children with autism and matched typically developing peers in classrooms (Chamberlain, Kasari, & Rotheram-Fuller, 2007; Kasari, Locke, Gulsrud, & Rotheram-Fuller, 2011; Santillan, Frederick, Gilmore, & Locke, 2019). Participants were asked to identify the children they like to hang out with and do not like to hang out with, and also report their classmates who like to hang around together in groups. This free recall list of friends delineates social connections between each individual in the classroom's social structure, which also provides information of friendship reciprocity, qualities, and peer acceptance (Kasari et al., 2012; Kretzmann et al., 2015). Existing data suggested that only one-third of nominated friends reciprocated their friendship with the children with ASD at school, while for typical children from the same classroom, the percentage was approximately 60% (Chamberlain et al., 2007).

According to Carins and Carins (1994), there are four levels of social involvement, from isolation, peripheral, secondary to nuclear. Different levels were used to describe how well the children were integrated into peer networks. Compared to their typically developing peers and children with a non-autism disability, children with autism often reported being less centrally connected to other children in the classroom. In fact, children with autism were often peripheral in their classroom's social network, had low peer acceptance and low reciprocity of friendships (Chamberlain et al., 2007; Kasari et al., 2011; Locke, Kasari, Rotheram-Fuller, Kretzmann, & Jacobs, 2013). These data were consistent for children across the school year (Chamberlain et al., 2007; Kasari et al., 2011; Locke et al., 2013).

Different from the classroom context, the playground is an unstructured setting at school where children with autism have opportunities to engage in naturalistic play and develop their social skills during recess, as well as pre- and post-school (Lang et al., 2011). Recess, which often involves time on the playground, is considered as a more challenging environment than classrooms for children with autism due to their social impairments. Independent observations of children on the school playground provided some insights into the playground engagement and social interactions of children with autism. Studies have noted that children with autism on school playgrounds are mostly unengaged, even when a reciprocal friendship was observed in the classroom (Kasari et al., 2011; Locke, Shih, Kretzmann, & Kasari, 2016). Children with autism were only jointly engaged with peers in a reciprocal activity for about 40% of the recess period, whereas the matched peer models spent about 70% of recess jointly engaged (Locke et al., 2016).

In addition to social limitations, it is important to note that some kids with autism are rated as popular in social networks and also demonstrated several socially successful behaviors

with their classmates. For example, 20% of children with autism identified as high-functioning in first through fifth grade had reciprocal friendships and high social network status (Kasari et al., 2011). Moreover, children with autism had on average 75% of successful initiations towards their peers on the playground, with 82% of positive response rate (Locke et al., 2016). In general, some children with autism have high-quality social network inclusion and have high quality friendships, however, the majority of children with autism are on the periphery of their social networks across the school year and support is required for school involvement and keeping up with their peers, especially during recess period (Locke et al., 2013).

To date, one study by Santillan et al. (2019) demonstrated the association between social network inclusion in the classroom and playground engagement of children with autism. Children were more likely to be jointly engaged on the playground if they had higher classroom social network inclusion. Those results suggested the importance of facilitating social development and peer interactions for children with autism in both structured (e.g., classroom) and unstructured (e.g., playground) settings (Locke et al., 2013; Santillan et al., 2019).

### **Strategies Targeting Social Engagement and Participation**

There are a variety of strategies that are used to target social engagement and participation for children with autism. These are summarized below.

#### **Social Skills Interventions**

Clinicians and researchers often approach social engagement through social skills interventions targeted at improving social outcomes and building peer interaction skills of children with autism. Social skill interventions differ in strategy and format, which were divided into five categories: (a) child-specific interventions, (b) peer-mediated interventions, (c)

comprehensive interventions, (d) collateral interventions, and (e) environmental modifications (McConnell, 2002). Reviews of those studies indicated that those interventions were often conducted in group-based clinical settings, but social skills were not necessarily displayed in natural contexts (Bellini, Peters, Benner, & Hopf, 2007a; Rao, Beidel, & Murray, 2008; Williams White, Keonig, & Scahill, 2007). Generalization of skills from a clinical setting to real-world environments (e.g., home or school) is recognized as a major challenge for children with autism (Williams White et al., 2007). Thus, studies have recommended that interventions targeting social skills occur in multiple inclusive settings with multiple persons (Bellini et al., 2007a).

### **School-based interventions**

Given the amount of time children spend in school, school is considered as the ideal context to foster social development in both structured (classroom) and unstructured (playground) settings (Locke et al., 2013; Santillan et al., 2019). School-based interventions could add benefits to children's emotional, social and academic performances at school by facilitating peer engagements and social relationships for children with autism (Locke et al., 2013). Some interventions can also help develop children's ability to communicate with peers, and increase the frequency and duration of initiation and responding behaviors (Sutton, Webster, & Westerveld, 2019).

Child-specific intervention is the most common approach, often conceptualized as an adult-directed one-on-one intervention that provides direct social skills training to the child with autism (Bellini et al., 2007a; Kasari et al., 2012; Rao et al., 2008; Sutton et al., 2019). For example, the interventionist or teacher teaches the child social communication skills such as initiating and responding, or helps the child to build specific skills that may enhance participation in a particular game on the playground. The other commonly used approach is peer-



mediated intervention, which focuses on training peers without autism to act as the intervention agents to support social interactions of the child with autism (Bellini et al., 2007a; Kasari et al., 2012; Sutton et al., 2019). For example, peers may be given strategies on how to engage children with autism, encourage positive social interactions, and identify isolated children.

A randomized controlled trial that examined the efficacy of child-direct versus peer-mediated interventions for children with autism was done in mainstream schools (Kasari et al., 2012). Children with autism were randomized into four groups with different types of treatments: (a) only peer-mediated intervention on engaging isolated children; (b) only child-specific social skills intervention; (c) both types of interventions and (d) no interventions. After 12 sessions of treatments, with a 12-week follow-up, the peer-mediated groups showed greater improvements and maintenance in children's social network salience in the classroom and also less isolation on the playground. Alternatively, participants in the child-specific social skills intervention, which did not include peer training, demonstrated only minor and temporary changes in receiving friend nominations from their peers and had more solitary play on the playground. These results highlighted the positive effects of peer education to improve engagement and social integration for children with autism.

Researchers or clinicians, not teachers, were mainly responsible for implementing those school-based interventions. The gap between research and practice implementation negatively affects the treatment outcomes (Kasari & Smith, 2013; Sutton et al., 2019). Some novel interventions provided intervention training to school personnel in order to maintain the continuous supports to children with autism after professional support is withdrawn (Kretzmann et al., 2015; Santillan et al., 2019). Remaking Recess (RR) is one example of a low-dose, brief intervention that aims to improve playground engagement for children with autism by training

non-specialist school personnel on identifying children who need supports in engaging and interacting with peers, providing individualized strategies and activities to facilitate children's engagement and coaching the intervention through different situations (Kretzmann et al., 2015; Locke et al., 2019). Positive benefits of RR related to increasing peer engagement for children with autism have been demonstrated. Additional school-level implementation support on RR demonstrated more substantial gains in social network inclusion and friendship nomination, as opposed to the RR-only condition without the extra implementation support, as teachers were more likely to use RR throughout the day, and more school personnel were involved (administrators, staffs, and students) (Locke et al., 2019).

Intensive autism educational programs focused on raising autism awareness are also recommended as a strategy to increase understanding and inclusion of children with autism, typically targeted at school settings. For example, autism organizations may make resources widely available that incorporate information about educating peers about autism, exploring similarities and differences of children with autism, learning to treat everyone as equals, and practicing skills on how to interact with children with autism (Organization for Autism Research (OAR), n.d.). However, to my knowledge, outcomes related to the use of these resources and kits, which are widely available for use, have not been evaluated.

Despite meaningful results of school-based interventions, one study comprehensively addressed the barriers of implementing interventions in the school settings and found that school policies surrounding recess, staffing and prioritization of competing demands, level of respect and support for implementers, and the availability of resources impeded the generalizability and sustainment of the intervention (Locke et al., 2015). Thus, less intrusive, briefer and less costly strategies are needed.

## **Disclosure**

Simple diagnostic disclosure with explanatory information protocols could be considered as a brief educational intervention (Swaim & Morgan, 2001.). Empirical research to date has been based on studies that have used hypothetical vignettes to evaluate outcomes of this type of intervention. These studies examined the changes of children's and adult's attitudes and behavioral intentions towards children with autism by providing two types of information: (a) descriptive information, which focuses on highlighting similarities between the child with autism and typical peers without using the diagnostic label of autism, and (b) explanatory information that includes both diagnostic disclosure and additional information about autism and autism-related behaviors (Campbell et al., 2004). Videotaped analogue was the most commonly used method, and actors were asked to display autism-related behaviours or not.

Swaim and Morgan (2001) first attempted to examine the effects of this type of disclosure in improving peers' attitudes and behavioral intentions towards children with autism. They assigned 233 third- to sixth-grade children into one of the three experimental conditions, which were presented through video vignettes: (a) no autism condition, in which the child was described without any features of autism; (b) an autism condition with only descriptive information, in which the child displayed a few autistic behaviors, including stereotypic hand flapping, rocking in the chair and echolalic speech when responding to a female; (c) an autism condition with both descriptive and explanatory information, which provided the same information as condition (b) plus an explanation of the purpose of behaviors. This study showed that children at each grade level more positively rated the peer who presented without autistic features than the same peer presented with autistic features, and there was no difference in behavioral intentions between two autism conditions, regardless of whether explanatory

information was supplied. However, different findings were found in the study that extended the knowledge of Swaim and Morgan's study. Campbell et al. (2004) indicated that the combination of descriptive and explanatory information had positive effects on changing peers' perceptions and behavioral intentions towards the child with autism.

In many respects, there is a body of studies that have consistently reported positive outcomes related to disclosure, especially when the diagnostic label was combined with explanatory information about autism (Austin, Galijot, & Davies, 2018; Austin, Zinke, & Davies, 2016; Huws & Jones, 2008; Silton & Fogel, 2012a). In general, positive outcomes were evaluated related to improved behavioral intentions and reduced negative judgement from others about autistic behaviors (i.e., atypical or problematic behaviors) in public (Austin et al., 2016). Female students reported more positive attitudes than male students towards an unfamiliar student with autism (Campbell et al., 2004; Campbell, 2007) across grades. Chambres and colleagues (2008) assessed adults' attitudes towards a six-year-old child with autism and found that disclosure primarily helped adults to perceive the child as more capable, such as using a computer or talking in front of a camera. Moreover, if strategies on how to support a child with autism were provided along with information about the diagnosis, behavioral intentions improved more (Silton & Fogel, 2012a).

### **3. Summary**

There are many approaches that inclusion and social participation for children with autism. Educational interventions that focus on increasing the public's understanding and acceptance of autism, including disclosure and information-sharing strategies, is one potential way. However, although existing vignette studies appear to support this approach, lived experience of people with autism and their families have indicated different, often negative,

outcomes of disclosure (Thompson-Hodgetts et al., 2020). This discrepancy cannot be ignored, and research on outcomes of disclosure protocols in real-life environments is needed. Research on inclusion in participation in community contexts is also lacking. This study starts to fill these gaps.

## References

- Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A., & Law, M. (2013). The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disability and rehabilitation, 35*(19), 1589-1598.
- Askari, S., Anaby, D., Bergthorson, M., Majnemer, A., Elsabbagh, M., & Zwaigenbaum, L. (2015). Participation of children and youth with autism spectrum disorder: a scoping review. *Review Journal of Autism and Developmental Disorders, 2*(1), 103-114.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.
- Austin, J. E., Galijot, R., & Davies, W. H. (2018). Evaluating parental autism disclosure strategies. *Journal of autism and developmental disorders, 48*(1), 103-109.
- Austin, J. E., Zinke, V. L., & Davies, W. H. (2016). Influencing perception about children with autism and their parents using disclosure cards. *Journal of autism and developmental disorders, 46*(8), 2764-2769.
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., ... & Durkin, M. S. (2018). Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *MMWR Surveillance Summaries, 67*(6), 1.
- Bauminger, N., & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child development, 71*(2), 447-456.

- Bellini, S., Peters, J. K., Benner, L., & Hopf, A. (2007). A meta-analysis of school-based social skills interventions for children with autism spectrum disorders. *Remedial and Special Education, 28*(3), 153-162.
- Broady, T. R., Stoyles, G. J., & Morse, C. (2017). Understanding carers' lived experience of stigma: the voice of families with a child on the autism spectrum. *Health & social care in the community, 25*(1), 224-233.
- Buttimer, J., & Tierney, E. (2005). Patterns of leisure participation among adolescents with a mild intellectual disability. *Journal of intellectual disabilities, 9*(1), 25-42.
- Cai, R. Y., & Richdale, A. L. (2016). Educational Experiences and Needs of Higher Education Students with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 46*(1), 31–41. <https://doi.org/10.1007/s10803-015-2535-1>
- Campbell, J. M. (2007). Middle School Students' Response to the Self-Introduction of a Student With Autism: Effects of Perceived Similarity, Prior Awareness, and Educational Message. *Remedial and Special Education, 28*(3), 163–173.  
<https://doi.org/10.1177/07419325070280030501>
- Campbell, J. M., Ferguson, J. E., Herzinger, C. V., Jackson, J. N., & Marino, C. A. (2004). Combined descriptive and explanatory information improves peers' perceptions of autism. *Research in Developmental Disabilities, 25*(4), 321–339.  
<https://doi.org/10.1016/j.ridd.2004.01.005>
- Cappadocia, M. C., Weiss, J. A., & Pepler, D. (2012). Bullying Experiences Among Children and Youth with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 42*(2), 266–277. <https://doi.org/10.1007/s10803-011-1241-x>

- Chamberlain, B., Kasari, C., & Rotheram-Fuller, E. (2007). Involvement or isolation? The social networks of children with autism in regular classrooms. *Journal of autism and developmental disorders*, 37(2), 230-242.
- Chambres, P., Auxiette, C., Vansingle, C., & Gil, S. (2008). Adult Attitudes Toward Behaviors of a Six-year-old Boy with Autism. *Journal of Autism and Developmental Disorders*, 38(7), 1320–1327. <https://doi.org/10.1007/s10803-007-0519-5>
- Christensen, D. L., Braun, K. V. N., Baio, J., Bilder, D., Charles, J., Constantino, J. N., ... & Lee, L. C. (2018). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *MMWR Surveillance Summaries*, 65(13), 1.
- Cowart, B. L., Saylor, C. F., Dingle, A., & Mainor, M. (2004). Social Skills and Recreational Preferences of Children With and Without Disabilities. *North American Journal of Psychology*, 6(1).
- Currie C, Zanotti, C., Morgan, A., Currie, D., de Looze, M., Roberts, C., Samdal, O., Smith, O.R.F. & Barnekow, V. (2012). *Social determinants of health and well-being among young people. Health Behaviour in School-aged Children (HBSC) study: International Report from the 2009/2010 survey*. WHO Regional Office for Europe.
- Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness*, 31(7), 1011-1027.
- Gray, D. E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health & Illness*, 15(1), 102-120.



- Gray, D. E. (1994). Coping with autism: Stresses and strategies. *Sociology of Health & Illness*, 16(3), 275-300.
- Gray, D. E. (2002). 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness*, 24(6), 734-749.
- Hilton, C. L., Crouch, M. C., & Israel, H. (2008). Out-of-school participation patterns in children with high-functioning autism spectrum disorders. *American Journal of Occupational Therapy*, 62(5), 554-563.
- Humphrey, N., & Lewis, S. (2008). 'Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism*, 12(1), 23–46.  
<https://doi.org/10.1177/1362361307085267>
- Humphrey, N., & Symes, W. (2010). Perceptions of social support and experience of bullying among pupils with autistic spectrum disorders in mainstream secondary schools. *European Journal of Special Needs Education*, 25(1), 77-91.
- Huws, J. C., & Jones, R. S. (2008). Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual and Developmental Disability*, 33(2), 99-107.
- Hyman, S. L., Levy, S. E., & Myers, S. M. (2020). Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics*, 145(1).
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, 32(1), 243–248. <https://doi.org/10.1046/j.1365-2648.2000.01466.x>

- Jones, J. L., Gallus, K. L., Viering, K. L., & Oseland, L. M. (2015). 'Are you by chance on the spectrum?' Adolescents with autism spectrum disorder making sense of their diagnoses. *Disability & Society, 30*(10), 1490-1504.
- Kasari, C., Locke, J., Gulsrud, A., & Rotheram-Fuller, E. (2011). Social Networks and Friendships at School: Comparing Children With and Without ASD. *Journal of Autism and Developmental Disorders, 41*(5), 533–544. <https://doi.org/10.1007/s10803-010-1076-x>
- Kasari, C., Rotheram-Fuller, E., Locke, J., & Gulsrud, A. (2012). Making the connection: randomized controlled trial of social skills at school for children with autism spectrum disorders: Social skills intervention. *Journal of Child Psychology and Psychiatry, 53*(4), 431–439. <https://doi.org/10.1111/j.1469-7610.2011.02493.x>
- Kasari, C., & Smith, T. (2013). Interventions in schools for children with autism spectrum disorder: Methods and recommendations. *Autism, 17*(3), 254-267.
- King, G., Lawm, M., King, S., Rosenbaum, P., Kertoy, M. K., & Young, N. L. (2003). A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical & occupational therapy in pediatrics, 23*(1), 63-90.
- King, M., Shields, N., Imms, C., Black, M., & Ardern, C. (2013). Participation of children with intellectual disability compared with typically developing children. *Research in developmental disabilities, 34*(5), 1854-1862.
- Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the

- Role Stigma Plays in Families' Lives. *Journal of Autism and Developmental Disorders*, 46(3), 942–953. <https://doi.org/10.1007/s10803-015-2637-9>
- Kretzmann, M., Shih, W., & Kasari, C. (2015). Improving peer engagement of children with autism on the school playground: A randomized controlled trial. *Behavior Therapy*, 46(1), 20-28.
- Lang, R., Kuriakose, S., Lyons, G., Mulloy, A., Boutot, A., Britt, C., ... & Lancioni, G. (2011). Use of school recess time in the education and treatment of children with autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders*, 5(4), 1296-1305.
- Law, M., King, G., King, S., Kertoy, M., Hurley, P., Rosenbaum, P., ... & Hanna, S. (2006). Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine & Child Neurology*, 48(5), 337-342.
- Locke, J., Kasari, C., Rotheram-Fuller, E., Kretzmann, M., & Jacobs, J. (2013). Social network changes over the school year among elementary school-aged children with and without an autism spectrum disorder. *School Mental Health*, 5(1), 38-47.
- Locke, J., Shih, W., Kang-Yi, C. D., Caramanico, J., Shingledecker, T., Gibson, J., ... & Mandell, D. S. (2019). The impact of implementation support on the use of a social engagement intervention for children with autism in public schools. *Autism*, 23(4), 834-845.
- Locke, J., Shih, W., Kretzmann, M., & Kasari, C. (2016). Examining playground engagement between elementary school children with and without autism spectrum disorder. *Autism*, 20(6), 653–662. <https://doi.org/10.1177/1362361315599468>

- Lum, M., Garnett, M., & O'Connor, E. (2014). Health communication: A pilot study comparing perceptions of women with and without high functioning autism spectrum disorder. *Research in Autism Spectrum Disorders*, 8(12), 1713-1721.
- Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism*, 8(4), 387-407.
- Mazumder, R., & Thompson-Hodgetts, S. (2019). Stigmatization of Children and Adolescents with Autism Spectrum Disorders and their Families: a Scoping Study. *Review Journal of Autism and Developmental Disorders*, 6(1), 96–107. <https://doi.org/10.1007/s40489-018-00156-5>
- McConnell, S. R. (2002). Interventions to facilitate social interaction for young children with autism: Review of available research and recommendations for educational intervention and future research. *Journal of autism and developmental disorders*, 32(5), 351-372.
- Mogensen, L., & Mason, J. (2015). The meaning of a label for teenagers negotiating identity: experiences with autism spectrum disorder. *Sociology of Health & Illness*, 37(2), 255-269.
- Moyson, T., & Roeyers, H. (2011). The quality of life of siblings of children with autism spectrum disorder. *Exceptional Children*, 78(1), 41-55.
- Muskat, B., Greenblatt, A., Nicholas, D. B., Ratnapalan, S., Cohen-Silver, J., Newton, A. S., ... & Zwaigenbaum, L. (2016). Parent and health care provider perspectives related to disclosure of autism spectrum disorder in pediatric emergency departments. *Autism*, 20(8), 986-994.

- Neely-Barnes, S. L., Hall, H. R., Roberts, R. J., & Graff, J. C. (2011). Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualizations. *Journal of Family Social Work, 14*(3), 208-225.
- World Health Organization. (2001). *The World Health Report 2001: Mental health: new understanding, new hope*. World Health Organization.
- Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of autism and developmental disorders, 34*(3), 245-256.
- Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of autism and developmental disorders, 43*(11), 2710-2719.
- Rao, P. A., Beidel, D. C., & Murray, M. J. (2008). Social skills interventions for children with Asperger's syndrome or high-functioning autism: A review and recommendations. *Journal of autism and developmental disorders, 38*(2), 353-361.
- Rimmer, J. H., Rowland, J. L., & Yamaki, K. (2007). Obesity and secondary conditions in adolescents with disabilities: addressing the needs of an underserved population. *Journal of Adolescent Health, 41*(3), 224-229.
- Russell, G., & Norwich, B. (2012). Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. *Clinical child psychology and psychiatry, 17*(2), 229-245.

- Santillan, L., Frederick, L., Gilmore, S., & Locke, J. (2019). Brief Report: Examining the Association Between Classroom Social Network Inclusion and Playground Peer Engagement Among Children With Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, 34(2), 91-96.
- Shakespeare, T. (2006). The social model of disability. *The disability studies reader*, 2, 197-204.
- Silton, N. R., & Fogel, J. (2012). Enhancing positive behavioral intentions of typical children towards children with autism. *Journal of Cognitive & Behavioral Psychotherapies*, 12(2).
- Sutton, B. M., Webster, A. A., & Westerveld, M. F. (2019). A systematic review of school-based interventions targeting social communication behaviors for students with autism. *Autism*, 23(2), 274-286.
- Symes, W., & Humphrey, N. (2010). Peer-group indicators of social inclusion among pupils with autistic spectrum disorders (ASD) in mainstream secondary schools: A comparative study. *School Psychology International*, 31(5), 478–494.  
<https://doi.org/10.1177/0143034310382496>
- Taheri, A., Perry, A., & Minnes, P. (2016). Examining the social participation of children and adolescents with intellectual disabilities and autism spectrum disorder in relation to peers. *Journal of Intellectual Disability Research*, 60(5), 435-443.
- Thompson-Hodgetts, S., Labonte, C., Mazumder, R., & Phelan, S. (2020). Helpful or harmful? A scoping review of perceptions and outcomes of autism diagnostic disclosure to others. *Research in Autism Spectrum Disorders*, 77, 101598.

Wainscot, J. J., Naylor, P., Sutcliffe, P., Tantam, D., & Williams, J. V. (2008). Relationships with peers and use of the school environment of mainstream secondary school pupils with Asperger syndrome (high-functioning autism): A case-control study. *International Journal of Psychology and Psychological Therapy*, 8(1), 25-38.

White, S. W., Keonig, K., & Scahill, L. (2007). Social skills development in children with autism spectrum disorders: A review of the intervention research. *Journal of autism and developmental disorders*, 37(10), 1858-1868.

## Chapter 2

A version of this chapter has been submitted to *Disability & Rehabilitation*. I was responsible for the data analysis as well as the manuscript composition. Dr. Sandra Thompson-Hodgetts was the corresponding author and supported secondary data analysis and contributed to manuscript edits. The full author list includes Dr. Stephanie Shire, Dr. Mélanie Couture and Dr. Lonnie Zwaigenbaum, who are all part of the research team for the larger study and provided substantive feedback on the manuscript prior to submission.

### **The Influence of Disclosure on Peer Engagement and Interactions for a Child with Autism in Summer Camps: A Within Case Mixed Methods Study**

#### **Abstract**

**Background:** Little research has evaluated how disclosure of an autism diagnosis influences peer engagement and understanding of children with autism in community recreation and leisure programs. This study evaluated outcomes of disclosure for a child with autism participating in mainstream summer camps.

**Materials and Methods:** One participant, a 9-year-old boy diagnosed with autism participated in two camps, one in which he disclosed and one in which he did not disclose. Quantitative data on peer engagement states and reciprocal interactions was collected through video data recorded on the first, second and last day of each program. Semi-structured qualitative interviews about perceived outcomes of disclosure were completed with the child with autism, camp leaders and peers in the disclosure camp.

**Results:** Peer engagement and reciprocal interactions improved following the disclosure protocol and continued to improve on the final day of the camp, which was not observed in the non-disclosure camp. Thematic analysis of interview data revealed three themes related to perceptions of disclosure, peer engagement, and inclusion.

**Conclusions:** Disclosure is a personal choice. This study provides preliminary data to support that disclosure may be a simple intervention to improve peer engagement and understanding of children with autism in community programs.



**Keywords (max 6):** autism, diagnostic disclosure, peer engagement, community programs, children, inclusion

## **Introduction**

Social inclusion is a vital part of health, development and quality of life (Currie et al., 2009). People with autism desire social relationships and inclusion in their communities. However, autism-related behaviors can be obstacles to engaging in meaningful social activities. The core characteristics of autism, which include deficits in social interaction, communication and restricted, repetitive and stereotyped patterns of behavior (Association, 2013), and internalizing and externalizing behaviours that may also occur, may relate to the social challenges that many children with autism experience in real life (Cappadocia et al., 2012; Humphrey & Lewis, 2008). Stigma related to autism is prevalent, and increases the possibility of peer rejection and social isolation (Mazumder & Thompson-Hodgetts, 2019).

Compared to similar-aged peers, children with autism report significantly lower levels of acceptance and social support from peers, experience greater peer rejection and social exclusion, and experience more frequent bullying (Chambres et al., 2008; Humphrey & Lewis, 2008; Moyson & Roeyers, 2011a; Symes & Humphrey, 2010; Taheri et al., 2016). Healthy social relationships can improve emotional, social and academic outcomes for children (McClelland, Morrison, & Holmes, 2000). Inclusive opportunities can provide increased opportunities for social relationships (J. Locke, C. Kasari, E. Rotheram-Fuller, M. Kretzmann, & J. Jacobs, 2013). However, previous research, most of which has occurred in school contexts, has consistently shown that some children with autism are rated as popular in social networks and have high quality friendships; however, most children with autism struggle to achieve high quality friendships and multiple reciprocal friendships in the classroom (Chamberlain et al., 2007; C.

Kasari et al., 2011). In contrast to structured classroom time, recess or unstructured play at a playground typically provides opportunities for children to choose what and with whom they want to play, and engage with peers (J. Locke et al., 2013; Locke et al., 2016). However, children with autism are observed to primarily engage in solitary activities and have few initiations and responses towards their peers during these times, instead of being jointly engaged in a reciprocal activity, conversations, or games like most of their peers without autism (Kasari et al., 2012; C. Kasari et al., 2011; J. Locke et al., 2013; Locke et al., 2016).

Strategies to support social inclusion are critical for children with autism. Several interventions have been reported to improve peer interaction skills and social outcomes for children with autism. Many of these interventions involve direct training, which targets specific social behaviors and communication skills demonstrated by the child with autism and is often conducted in clinical settings. Because of the uncertainty of natural environments, some studies indicate that generalization and flexible skills use can be limited with this type of intervention (Bellini, Peters, Benner, & Hopf, 2007b; Williams White et al., 2007). Other social skills interventions incorporate peer-, parent- or other adult-mediated approaches. Several recent studies suggest that these approaches, especially brief peer-mediated interventions, can improve peer engagement and social interactions for children with autism in school contexts, and that those improvements persist over time (Kasari et al., 2012; Locke et al., 2016; Santillan et al., 2019). For example, Kasari and colleagues found that educating peers on strategies to include isolated children led to increase social connections in the classroom and decrease isolation on the playground for those children (Kasari et al., 2012). However, research outside of school and clinical contexts is limited, and none of these studies looked at how sharing the child's diagnosis influenced outcomes.

Given experiences of stigma and exclusion, the management of personal information, including sharing one's diagnosis, is important in the lives of people with autism. Parents often struggle with whether or not a disclosure of their child's autism diagnosis will increase others' understanding and acceptance of their child's autism-related behavior. Qualitative studies of the lived experiences of parents of children with autism, and of adolescents and adults with autism, have found that the outcomes of the disclosure are not always positive. In fact, many participants in these qualitative studies report feeling reluctant and cautious in disclosing their autism diagnosis to others, including peers, because of their fear of judgment, discrimination and stigma (Labonte, 2017, May 10-23).

There is also a body of research that has used hypothetical vignettes to evaluate outcomes of disclosure of an autism diagnosis from the perspective of people without autism. This research has primarily shown positive outcomes for children and youth with autism, particularly when a diagnostic label is combined with explanatory information (Austin et al., 2016; Campbell et al., 2004; Chambres et al., 2008; Labonte, 2017, May 10-23). In these studies, participants without autism often report less negative judgment towards someone's disruptive behaviors when they are informed about autism, and the attribution of cause for disruptive or atypical behaviors became more positive (Austin et al., 2018; Austin et al., 2016; Chambres et al., 2008). Providing both a diagnosis and explanatory information about that diagnosis appears to have the greatest impact on peers' attitudes and behavioral intentions of engaging with children with autism, including in situations that involve disruptive behaviors and severe autism symptoms (Campbell et al., 2004; J. M. Campbell, 2007; Labonte, 2017, May 10-23; Silton & Fogel, 2012b).

The differences in perceived outcomes of disclosure by individuals with lived experience compared to others' in the context of hypothetical vignettes are striking (Thompson-Hodgetts et

al., 2020). To our knowledge, no study has evaluated how disclosure of an autism diagnosis influences peer engagement of children with autism in ‘real-life’ (i.e., non-contrived settings, rather than within experimental paradigms or theoretical vignettes), including school and community-based programs. Our objectives were to compare observed peer social interactions for a child with autism who participated in two, one-week, summer camps, one in which he disclosed and one in which he did not disclose his diagnosis of autism to peers, related to: (1) the time spent jointly engaged with peers, and (2) the frequency of reciprocal interactions between the child and his peers. Our study also aimed to understand the perceived outcomes of disclosure from different perspectives, including the child with autism, peers and adults. Based on previous vignette research, in the disclosure condition, we hypothesized that: (1) the time spent jointly engaged with peers would increase after information about autism and how to engage with the child was provided, (2) frequency of successful reciprocal interactions with peers would also increase following disclosure, and (3) peers’ perceptions of the child with autism would be positively influenced by providing campers with the disclosure protocol and information about autism. We also hypothesized that the time spent jointly engaged with peers and the frequency of successful reciprocal interactions in the nondisclosure group would decrease over the data collection period because peers would not understand the function of the child with autism’s unique behaviors.

## **Methods**

This is a mixed-methods, instrumental, within-case, study. Case study allows for the generation of an in-depth examination of complex issues that occur in real-life contexts (Crowe et al., 2011). Instrumental case studies use one particular case to appreciate an issue in depth. This instrumental case study evaluated engagement states of a child with autism who participated

in both disclosure and non-disclosure conditions at summer camp. To our knowledge, this is the first study to evaluate the effects of disclosure in a real-life context, and not based on vignettes. As such, it is the first study to evaluate these effects in a community program. Data sources included structured behavioral observations of both the child with autism and peers in a mainstream summer camp program, including engagement states, reciprocal interactions with peers, and qualitative interviews with camp leaders, the child with autism, and peers. The qualitative interviews were descriptively analyzed to help provide explanatory data for the quantitative findings (Creswell & Plano Clarke, 2011). Research ethics approval was obtained from the University of Alberta (Study ID: Pro00081598).

### **Description of the Participant:**

Bob was a 9-year, 5-month-old child with a diagnosis of autism. He lived in a large urban centre. He had one younger sister, and divided his time between living with his mother and his father in separate residences. Before the summer break he attended his local elementary school, in a mainstream classroom supported by a part-time aide. His adaptive skills were assessed using the Adaptive Behavior Assessment System, third edition (ABAS-3) parent form, which was completed by his mother. The ABAS-3 is a questionnaire that covers three broad adaptive domains, including conceptual, social, and practical; and ten skills areas, including communication, community use, functional academics, health and safety, home or school living, leisure, motor, self-care, self-direction and social (Harrison & Oakland, 2015). His scores and descriptive performance levels on the ABAS-3 are reported in Table 1. The general adaptive composite (GAC) and domain scores including conceptual, practical and social adaptive were in the extremely low range. The rating scores suggested that Bob had relative strengths in the home living and functional academic skills areas, compared to his extremely low adaptive functioning

in other skill areas, such as communication, self-direction and social skills. Bob communicated verbally with his peers and camp leaders, and did not have an aide supporting him at camp.

Table 1: Participant’s ABAS-3 Global Adaptive Composite (GAC) and Domain scores

ABAS-3 Scores				
Score area	Standard score (95% CI)	Scaled Score	Percentile rank	Description
General Adaptive Composite (GAC)	65 (61-69)		1	Extremely low
Conceptual Domain	65 (59-71)		1	Extremely low
Communication		3		Extremely low
Functional Academics		6		Below Average
Self-Direction		3		Extremely low
Social Domain	67 (61-73)		1	Extremely low
Leisure		5		Low
Social		3		Extremely low
Practical Domain	70 (64-76)		2	Extremely low
Community Use		5		Low
Home Living		7		Below Average
Health and Safety		3		Extremely low
Self-Care		5		Low

## Procedures

Bob was initially recruited via his mother through an email sent to listservs of local autism advocacy and service organizations. His mother contacted the researchers to learn more about the study. Informed consent was obtained from Bob’s mother and camp leaders. Assent was obtained from Bob. The corresponding author verbally explained the study to Bob, answered any questions, and was confident that he agreed with the study process based on his verbal assent and positive affect about the study. His ongoing willingness to participate was reassessed verbally each day the researcher was present. Ethics approval was granted for opt-out approval for peers: all peers’ parents received the information letter in the mail prior to the start of camp,

and the researchers were present on the first morning of camp to describe the study to all peers' parents and answer any questions. In both conditions, peers' parents were informed that the researchers were looking at how children engaged with each other over the week of camp. Autism was never discussed at this stage of recruitment. No parent chose to have their child opt-out of the study.

For this case study, Bob participated in two different summer camps that occurred on different weeks (4 weeks apart) with no overlap in peers or camp leaders, one in which disclosure occurred and one in which disclosure did not occur. His mother originally consented to participate as a 'non-disclosure' participant, and then contacted the researchers a second time to ask if he could also participate as a 'disclosure' case, since she had enrolled him in another camp and then wanted to disclose his diagnosis to peers.

Both camps were week-long mainstream, community summer camps for children between 6 to 9 years of age, with the same camp leader to child ratio in each camp (1:12), held at a multi-purpose recreation facility. The first camp (non-disclosure) focused on cooking activities as the camp theme, and the second camp (disclosure) focused on a variety of sports activities as the camp theme. The first camp had two volunteers present, in addition to the camp leader. The second camp had one volunteer present, in addition to the camp leader. The extent of structure and adult direction was consistent between the camp conditions, and both camps gave equivalent and ample opportunities for peer engagement and interaction, such as snack time, lunch and semi-structured games and activities. Data were collected at the same time of day, and during the same activity within each camp. This occurred during a semi-structured, group cooking activity in the first (non-disclosure) camp in which the children were situated around a table together with minimal staff direction (we started video after the leader instruction, while children were

playing with food items and conversing with one another with minimal adult involvement), and during a time-limited snack break in the second (disclosure) camp, in which children were seated in a circle or small groups together with minimal staff direction. Camp leaders and volunteers were not seated with the campers during the video recording at either camp; rather, children interacting with each other without adult involvement. We observed during these activities because the camp leaders indicated that these would be the least intrusive times for the researchers to be present, and because they occurred in an isolated space where other children for whom we did not have study consent were not present.

For both camps, data were collected on the first (Monday), second (Tuesday) and last (Friday) day of the program. In the camp in which disclosure occurred, the information was shared on the second day, approximately one hour before the video was taken on that day. The corresponding author wrote the disclosure script with Bob's mother, and then Bob read and verbally approved it with this author before we read it to his peers. He verbally reconfirmed his support of the disclosure protocol while his peers sat down to listen, but decided to go for a walk with a camp volunteer while the script was read. The script disclosed his diagnosis of autism, described what autism looked like for him, some of his favorite activities, his unique behaviors and what they may mean, and provided some suggestions on how to engage with him. The script took approximately three minutes to read and peers were given an opportunity to ask questions, although none of the peers in this camp did so. The corresponding author, with extensive clinical experience working with children with and without autism, read the script. An anonymized version of his disclosure script is provided below.

*I look at how kids play, and how they are the same as each other and how they are unique. Unique is a big word – does anyone know what it means? It means how we are all different in our own special ways. We all have things that are unique about us. Some of us like carrots, and some of us don't (ask kids to raise hands so they see*



*this). Some of us wear glasses and some of us don't (point out this difference in the room). Some of us really love to play soccer and run all day, and some of us prefer to cuddle and read a book.*

*Bob is unique because he has something called autism. This means that he thinks a little bit differently than you, and may behave and talk a bit differently.*

*Just like many of you, he likes playing with Lego, reading books and singing. However, Bob is unique in the way that he may not realize if he is standing too close to you, and he may even hug you or touch you. Standing too close and hugging and touching you are his ways of showing you that he thinks you are really nice. You have learned about personal space, and it's okay to remind him to stop or gently step away. He may also try to play chase games with you, even if it isn't really a good time for chase games. You can say 'not right now'. Sometimes he will repeat what you say – this is his way of letting you know that he likes what you are saying. He may flap his hands when he is excited, or twirl his hair when he feels anxious. Bob is really excited to be at camp with you and make new friends. He wants to play with you at camp, and he understands everything that you say, even if he might not respond the same way you would. He may come close to you but he doesn't know how to say 'can I play?'. Please ask him if he wants to play with you when he comes close or just take his hand and lead him to the activity. He will really like this because he wants to be included, just like you.*

*Do any of you have any questions about autism or about how to help Bob be included?*

### **Children's social engagement measure**

The Playground Observation of Peer Engagement (POPE) (C Kasari, Rotheram-Fuller, & Locke, 2005) is a timed-interval behavior coding system. It has been used to evaluate the behavior of children with autism in school settings. The original POPE includes six mutually exclusive categories of engagement states. We used an adapted version of the POPE that included an additional category "on task" to ensure that we captured time when the child was appropriately engaged in an activity when peer engagement would not be appropriate (e.g., when directed to go wash hands at the sink away from his peers). Table 2 provides definitions and examples of each engagement state.

Table 2. Engagement States from the Playground Observation of Peer Engagement

Engagement states	Operational Definition	Example
Solitary	The child appears uninvolved with peers and plays alone with no other children.	At the table with his peers doing kitchen activities, but not engaged in any with peers.
Onlooker	The child has a one-way awareness of another child or group of children. No restrictions on proximity.	Looking at his peers cleaning the kitchen, but not engaged, just one-way watching.
Parallel	The child and peer are engaged in a similar activity but there is no social behavior. Not noticing others.	Making “pizza” at the table together with peers; but not looking around or mutually aware of each other
Parallel aware	The child and peer(s) are engaged in similar activity and mutually aware in each other, but weak in quality compared to JE.	Having snack with peers; looking around at them having snack too; following their conversations, but not active engagement
Joint engagement	The child and peer(s) direct social behavior with one another	Playing high five with his peers, and having reciprocal conversations
Games with rules	The child participates in an organized game with clear rules set by the child or his/her peers.	Not applicable in this study. An example would be board games
On task	Child participates as intended, and follows instructions, or prepares for activity without opportunity for peer engagement.	Washing his hands as requested, at sink away from table

Independent, trained, blinded to data collection condition (day one, two or five, and whether it was the disclosure or non-disclosure camp) observers coded videos in one-minute intervals. All videos were 10 minutes. This duration was chosen to align with the longest periods of uninterrupted unstructured times in each camp (i.e., time given for snacks, and time in

cooking camp in which children worked without adult instruction). Raters have demonstrated high reliability on the POPE with video coding (Kasari et al., 2012; C. Kasari et al., 2011; Locke et al., 2016). In this study, raters were trained to reliably code the POPE against an expert coder using a series of pilot videos, obtaining intra-class correlation coefficients of 0.80 or higher. Two raters then independently coded all six of Bob's videos for engagement states, with 100% agreement, and one rater coded the reciprocal interactions. Reciprocal interactions were straightforward to code, with only one uncertainty, which was also coded and agreed upon by the second rater.

**Children's peer engagement states.** Engagement states were coded using paper copies of the POPE for three-time points in each camp: days one, two and five (final day) of camp (which represented before disclosure, after disclosure and the final day of camp for the disclosure condition). Consistent with previous studies done by the original POPE authors, we dichotomized data related to peer engagement states into two categories which reflected joint engagement and not jointly engaged with peers, with the second category combining multiple POPE engagement states (Kasari et al., 2012; Locke et al., 2016; Santillan et al., 2019). Coding of joint engagement required that the child with autism and peer(s) display direct social behaviour with one another and receipt of responses. In other words, joint engagement requires a clear shared activity and/or referent. Data coded as not jointly engaged with peer represents when the child with autism was not involved in a shared activity and/or referent with peers (included solitary, onlooker, parallel and parallel aware categories from the POPE; see Table 2).

Each 10-minute video was divided into 10, one-minute intervals for coding. The percentage of intervals the child spent primarily in each category (not jointly engaged with peers or joint engagement) was used to express peer engagement states for each day. More specifically,

we recorded the amount of time spent in each engagement state within each 1-minute interval of video data, and the interval was coded as the engagement state with the most time. For example, if a child was not jointly engaged for 22 seconds, and jointly engaged for 38 seconds, the interval was coded as jointly engaged with a peer(s). We also provided data for the percentage of intervals in which that child was coded as on task or jointly engaged with adults (Table 3), to provide context for the full 10 minutes of video. The category ‘games’ is operationalized in the POPE definitions, but no instances of games occurred in our videos.

**Children’s peer interactions.** The frequency of reciprocal interactions (initiations and responses) between the child with autism and his peers were also coded. (C. Kasari et al., 2011; Locke et al., 2016). Four variables were analyzed: total initiations, which indicated that the child with autism directed a social gesture towards his peers (e.g., verbal or nonverbal gesture, including challenging behavior); successful initiations, which indicated that peers responded to the child’s initiations with a social gesture (e.g., verbal responses, high five, showing or pointing); total opportunities for responses where peers directed a social gesture towards the child with autism (e.g., invitation to play, verbal comment); and positive responses when the child with autism indicated reciprocity or acknowledgement to a peer’s initiation (e.g., head nod, verbal responses). Consistent with previous studies, if the child with autism had reciprocal conversations that involved more than two exchanges with peers during the interval, we only counted the first initiation and the first response within one conversation. For example, if Bob started the conversation and then also responded to the peer’s response, that would be coded as one successful initiation and one positive response. The frequency of initiations and responses would not be marked again unless there was a break in the conversation. The percentage of successful initiations (frequency of successful initiations/ total frequency of initiations) and the

percentage of positive responses from peers (frequency of positive responses/ total opportunities for responses) were computed.

### **Qualitative interviews**

To understand the perceived outcomes of disclosure from different perspectives (the child with autism, peers in the camp, and the camp leaders), semi-structured interviews were completed. The interviews ranged in duration from four to 11 minutes and took place in person in a quiet space away from the main camp group. Qualitative interviews only occurred in the disclosure condition, as we did not provide any indication of autism in the non-disclosure condition. On the last day of the disclosure camp, we interviewed Bob, five of his peers in the camp, his camp leader and the volunteer. The open-ended questions were designed to focus on straight-forward description of the phenomena (Sandelowski, 2010) focused on: (1) the impact of disclosing and sharing information about autism; (2) the information they remembered about autism after disclosure; and (3) the acceptability of the disclosure strategy. The interviews were audiotaped and later transcribed verbatim.

### **Quantitative and qualitative and quantitative data analysis**

Descriptive statistics were calculated for all POPE data, as described previously. Interview data were analyzed using a systematic approach to thematic analysis (Braun & Clarke, 2006), aligned with qualitative description (Sandelowski, 2010) . Two researchers independently (1) coded each interview by reading and re-reading each transcript (which were relatively brief), and highlighted key words or statements in the margin that related to the question (e.g., words that clearly reflected their perceived influence of disclosure, such as the word “understanding”); (2) collated codes within stakeholder groups when multiple interviews occurred (camp leader and volunteer; peers), came up with preliminary themes, and then met to refine and agree on

identified themes. Peer debriefing on codes and themes was done with a third researcher to support credibility. The interviewer, who was experienced in qualitative methods, did clarify the meaning of statements during the interviews. Interview participants were not able to participate in member checking after the interviews were transcribed because the camps were finished and we did not have contact information for these participants.

## Results

### Joint engagement during disclosure and non-disclosure camps:

The percentage of intervals that Bob spent jointly engaged with peers within the two camps are presented in Table 3 and Figure 1. Overall, there was an increase in the percentage of time spent in joint engagement for the child with autism in the disclosure camp following disclosure, but data for the non-disclosure camp was more variable.

Table 3. Engagement States and Peer Interactions for the Child with Autism in both Conditions

	Nondisclosure			Disclosure		
	Baseline	Day 2	Follow-up	Baseline	Post	Follow-up
<b>POPE</b>						
Engagement	60%	47%	7%	10%	20%	60%
Solitary	40%	47%	80%	50%	70%	20%
<b>Peer Interaction per minute</b>						
Successful Initiation Rate	0.37	0.16	0.03	0.02	0.25	0.49
Total Initiation Rate	0.40	0.23	0.13	0.02	0.25	0.54
% of successful initiation	0.94	0.66	0.20	1.00	1.00	0.91
Positive response rate	0.36	0.04	0.00	0.11	0.24	0.38
Total response rate	0.36	0.05	0.01	0.11	0.27	0.42
% of positive response	1.00	0.79	0.33	1.00	0.90	0.91

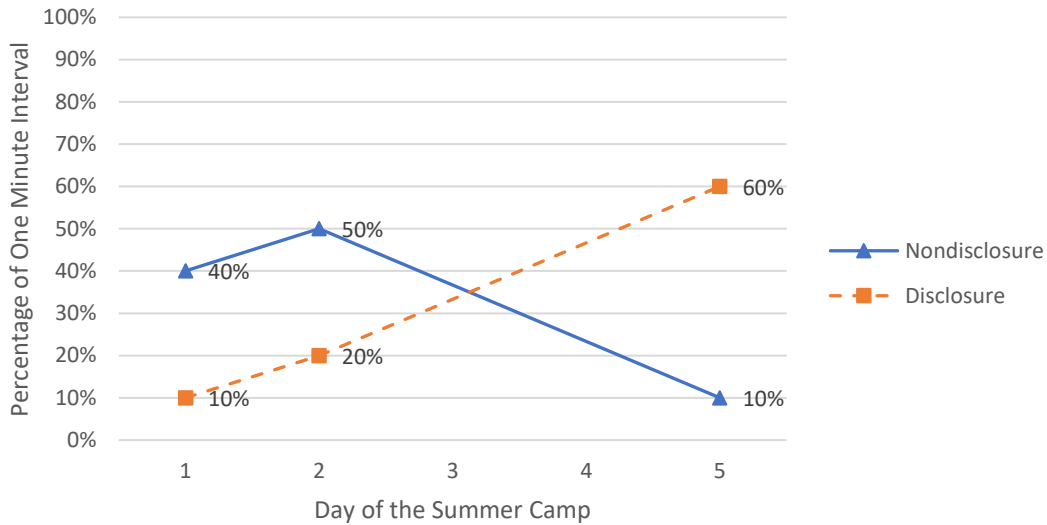


Figure 1. Intervals in which the child with autism was jointly engaged

There was a slight increase in the percentage of time spent in joint engagement for the child with autism between day one and two in both camps. However, there was a large decrease in joint engagement with peers by day five in the non-disclosure camp, whereas joint engagement with peers continued to increase in the disclosure camp by day five. The percentage of intervals in which the child with autism was not jointly engaged with peers in the disclosure camp also increased following disclosure, yet decreased on day two in the nondisclosure camp (see Figure 2). More specifically, on the first day, Bob spent 40% of the total intervals jointly engaged with his peers and 60% not jointly engaged in the nondisclosure camp, while he spent only 10% of the total intervals jointly engaged and 50% not jointly engaged with peers in the disclosure camp. The percentage of intervals in which Bob was jointly engaged with peers increased slightly in both camps (20% and 50% respectively) on the second day. On day five, the percentage of intervals in which Bob was jointly engaged was much higher in the disclosure camp than in the nondisclosure camp (60% and 10% respectively). Correspondingly, the

percentage of intervals of in which Bob was not jointly engaged with peers decreased to 20% in the disclosure camp, while it increased to 70% in the nondisclosure camp.

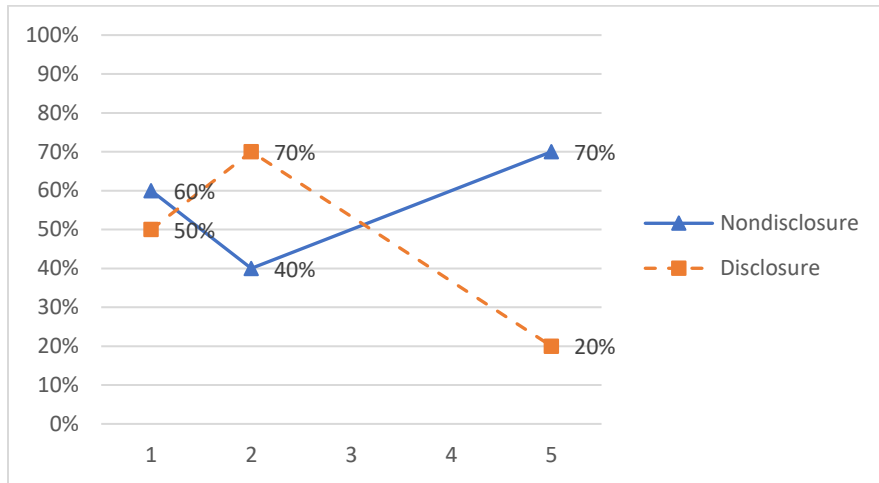


Figure 2. Percentage of Intervals the Child with autism spent in Solitary in both conditions

To better understand the nuances of these data, and the potential influence of disclosure on joint engagement, two independent coders made detailed qualitative comments for each interval's observation. Importantly, the activities in which Bob was engaged were consistent within each camp, and both camps provided equal opportunity for joint engagement. On day one in the nondisclosure camp, the observers noted that Bob spent most of the first four minutes (40% of the observed time) playing a hand-slapping game together with one of his peers. He only briefly interacted with other peers during this time. When others started to clean up the kitchen as a group, during which the other peers conversed with each other, Bob did not engage with them or help with cleaning up. Instead, he watched and was coded as an onlooker engagement state. In the disclosure camp, Bob primarily demonstrated onlooker engagement on the first day.



On the second day of the nondisclosure camp, campers were working collaboratively in preparing food, while chatting, at the beginning of the observed time. Bob was clearly engaged with his peers by passing materials back and forth, and adding sugar and baking powder into the bowl initially, but his peer engagement faded and he focused on playing with food on his own, and his peers did not try to re-engage him. On day two of the disclosure camp (after the disclosure protocol), Bob engaged with a variety of peers at the beginning of the video, which continued even after Bob walked to the other side of the room and his peers actively came to talk with him, leading to obvious short social behavior in some intervals.

Compared with the first two days of the nondisclosure camp, Bob was clearly less engaged with his peers on day five of that camp. This was especially apparent when campers were dividing into two groups voluntarily to make cookies, and Bob was isolated in the middle and not invited to participate in either of the groups. However, in the disclosure camp, more peers were observed to engage with Bob and high five with him when they were near on day five, which was an activity that Bob clearly enjoyed.

### **The influence of disclosure on reciprocal interactions**

Reciprocal interactions in the disclosure and nondisclosure camps are also provided in Table 3, Figure 3 and Figure 4. These data are presented as the frequency of total and successful initiations and responses to provide context for opportunity, as well as the overall percentage of successful initiations and responses.

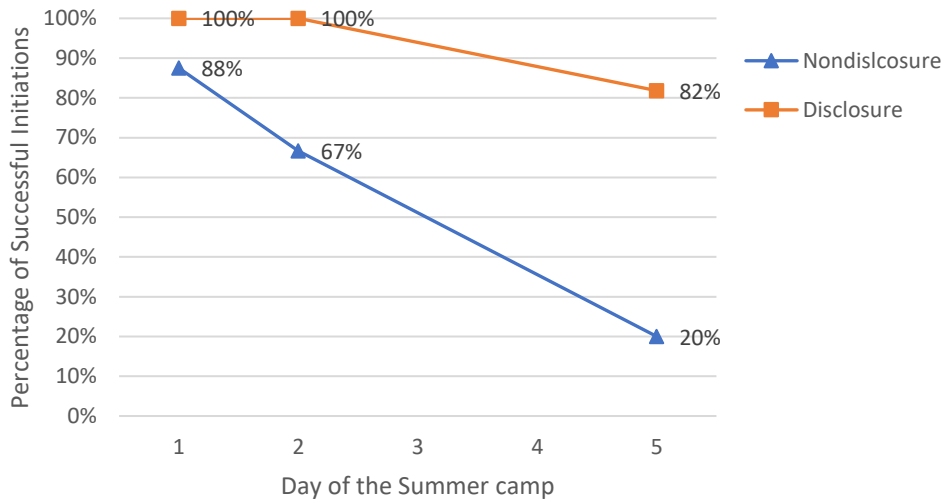


Figure 3. Percentage of Successful Initiations

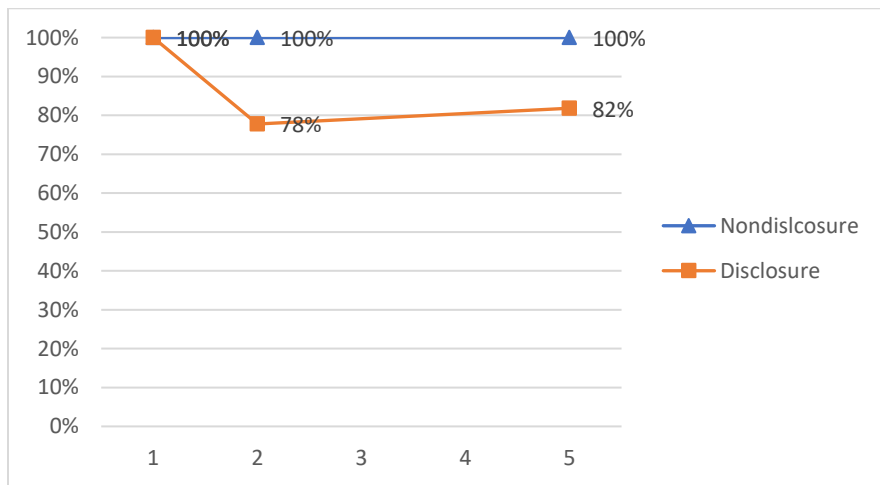


Figure 4. Percentage of Positive Responses

The frequency of initiations and responses in the disclosure camp were lower than those in the nondisclosure camp on day one. However, on day five this was reversed and Bob had more total initiations, more successful initiations, more opportunities to respond, and more positive responses in the disclosure camp than in the nondisclosure camp. More specifically, he had 11 total initiations of which nine were successful, and 11 opportunities for responses of which nine were positive, within the 10-min interval on day five of the disclosure camp. In the

nondisclosure camp, Bob had five total initiations with a variety of peers of which one was successful, and two opportunities for responses, from two different peers, both of which were successful within the 10-min interval on day five.

Overall, the percentages of successful initiations were high in both camps on the first day (100% in the disclosure camp and 88% in the nondisclosure camp), which remained high in the disclosure camp, but consistently decreased in the non-disclosure camp. On day five, this difference increased between conditions (82% and 20%, respectively). Bob's percentages of positive responses to peers' initiations were consistently high (78%-100%) across camps and days.

### **Qualitative findings**

One key theme emerged (theme three), which crossed peer and camp leader and volunteer interview participants, and two additional themes emerged that had data limited to one stakeholder group. We have included all three themes to ensure that we do not lose data that may be important to our understanding in this exploratory study. The first theme, *Autism is a Part of Who I Am*, highlights Bob's insights regarding his diagnosis. It also includes his acceptance of and support for the disclosure protocol that we used in this study. The second theme, *Unconditional Inclusion by Peers*, reflects some peers' intention of including the child before, or regardless of whether, they knew about his diagnosis, and the corresponding potential that the disclosure protocol was unnecessary. The third theme, *Changed Behavioral Attribution and Improved Inclusion*, encompasses a change in peers', the camp leader's and volunteer's perceptions and understanding of some of the child's behaviors, and intentions to include him more, following disclosure.

*Autism is a Part of Who I am*

Bob gave us positive feedback about the way we shared his diagnostic information with other camp members. He indicated that he would prefer to share this information in the same way, rather than not disclosing, in future camps. He stated his reason for sharing was “because I want everybody to learn how autism I am”. It should also be noted that he viewed his unique characteristics in a positive way. When talking about how he felt about his diagnosis of autism, he nodded his head and verbally agreed with the interviewer that “everyone can be special, and autism is just a part of who he is”.

#### *Unconditional Inclusion by Peers*

Bob indicated that one peer was most important to him. When asked if he had made any good friends at camp, Bob replied “one, yeah [name]”. When asked further if he wanted to make other friends, he replied, “I don’t think so, I think one is enough.” This peer also described Bob as his closest friend, and when the interviewer asked this peer what he learned from the script, he told us “I don’t remember anything”. Instead of using our information about what interests Bob and how to engage him, this peer described how other peers were “not really nice [to Bob]”, but he had already found mutual interests: “Bob was asking everybody to give him a high five, and I decided um, the high fives are just boring – a game of high five would be awesome and Bob liked it... the best part, when we first met, was when we were doing the high five game”.

Other campers also perceived that Bob appeared to be unconditionally included by some peers. For example, some female peers stated that none of the boys and girls tended to play regularly together, but, “the boys always like to play with him, they are, like, Bob come here, let’s play...like sometimes if he doesn’t have anything to do, the boys just go up to him and want to include him”.

#### *Changed Behavioral Attribution and Improved Inclusion*

Both peers and adults (camp leader, volunteer) described how they noticed some of the child's socially disruptive behaviors at the start of camp, for instance, having difficulty with listening, not understanding personal boundaries, making odd noises, and spitting. They described those behaviors negatively as "weird" and "annoying" before they knew about his diagnosis. These negative views were, however, revised to "fine" and "understandable" following disclosure. As noted by the camp leader, "people know that he isn't trying to be annoying, they know he doesn't want to hurt anybody." Taking the spitting behavior as an example, his peer stated, "the only weird thing was that he spitted". When asked if she still thought it was gross after they knew about his autism, she replied "No. No. Because sometimes people just can't [control]..." Learning about his diagnosis appeared to facilitate some campers to change their behavioral attribution and helped them understand some of Bob's behaviors.

The camp leader gave us some valuable information on how he perceived that the disclosure protocol positively impacted the level of peer engagement for the child with autism. Even though some of the female peers indicated that the boys in the camp always included Bob, our video data and interviews with the camp leader do not support these comments. Compared to pre-disclosure, a camp leader observed that the peers became nicer and gentler to him post-disclosure. "Everybody just, like, includes him more, after that information." He pointed out, "everyone just became nice that they wouldn't tell him to stop, they wouldn't tell him to, like, get off of me". Rather, they provided him a safe place to play and engage with them. The camp leader remarked that these interactions benefitted peers and the child with autism, "instead of, like, having to wait for the counselor to come, now he knows that he can just come in and feel safe around everyone". The camp leader also mentioned that the way we shared the information, as a "short, simple, presentation; its straight with the [information]", was appropriate for children

at that age. He concluded, “I did think it was good for everyone to know that he had autism, I think that was really important for everybody”.

## **Discussion**

This study describes how disclosure of an autism diagnosis may have influenced peer engagement and reciprocal interactions for a child with autism in the mainstream, community summer camps. Our participant, Bob, initially chose to not disclose his diagnosis of autism in one summer camp, but then disclose in a second camp, which created a unique opportunity to explore similarities and differences in the child’s social experience based on disclosure or nondisclosure. To our knowledge, previous research related to disclosure was based on hypothetical vignettes, and this is the first study to evaluate how disclosure may influence peer engagement in a real-life context.

Overall, the results suggest that disclosure may positively influence several outcomes. Bob tended to be more jointly engaged with, and have more reciprocal interactions with, his peers by the end of the camp week (day five) following the disclosure protocol compared to the nondisclosure condition. However, variability in the data on the second day of camp, which was collected soon after the disclosure protocol, suggests that gains in peer engagement and interactions may accrue over time as these improvements were most notable during the last day of the week of camp. Similarly, our data suggest that decreases in peer engagement and interactions may occur over a similar timeframe without disclosure. Our qualitative data provided insights to help us better understand the data and how disclosure may influence peer engagement and interaction.

Contrary to our expectations, at the first two time points, the percentage of intervals in which Bob was jointly engaged with peers increased under both conditions, and the percentage of intervals in which Bob was jointly engaged in the disclosure camp was lower than that in the nondisclosure camp. Similarly, the frequency of reciprocal interactions (total initiations, successful initiations, total opportunities for responses and positive responses) was increased in both camps on the first two days. There are several reasons why Bob seemed more socially engaged with his peers in the nondisclosure camp than in the disclosure camp at the beginning of the camp week. First, on day one, Bob was less jointly engaged with peers in the disclosure camp than in the nondisclosure camp. Qualitative observations and more detailed coding from the videos indicated that Bob and his peers were engaged in some mutually aware interactions in both camps, but Bob's engagement states were primarily coded as parallel aware in the disclosure camp (50% of the observed time). However, in the nondisclosure camp, campers were actively engaged with each other in more intervals (e.g., had more reciprocal conversations, passed things around and collaboratively cleaned up the kitchen). We chose to categorize parallel aware engagement as not jointly engaged with peers to align with previous research and because Bob's mom reinforced that Bob was capable of jointly engaged interactions with peers.

Another reason that the data in the disclosure camp may underestimate jointly engaged interactions with peers is that because the coding scheme for the POPE does not consider the length or number of the reciprocal interactions that occur within one exchange. Consistent with previous studies that used the POPE, when Bob had reciprocal conversations with his peers during the interval, we only counted the first initiation and the first response within one conversation, unless there was a clear break in the conversation. As such, the data indicates that Bob only had six successful initiations and seven positive responses on day two; however, there

were four reciprocal conversations among Bob and his peers, including two that lasted for the whole minute, one that lasted for 28 seconds, and one that lasted for 15 seconds. On the contrary, in the nondisclosure camp, there was only one reciprocal conversation on day two, which only lasted for 18 seconds. Thus, the length of the reciprocal interactions might need to be considered in future studies in order to better reflect the quality of the reciprocal interactions. Additionally, Bob maintained remarkable percentages of successful initiations (82%-100%) throughout the disclosure camp, while successful initiations decreased over the week in the non-disclosure camp. Bob also maintained high degrees of positive responses (higher than 78%) over time in both camps, which reflected his ability to reciprocally interact with others.

Although children were engaging in different activities within these two camps, they were able to choose what to do and with whom they wanted to interact independently in both camps, with limited leader involvement. The camp leaders' involvement was consistent within and between these two camps, with limited direct supervision and prompting of any children, including Bob. Indeed, overall trends indicate that peer engagement increased for Bob in the camp in which he disclosed, while there was an inverse trend for peer engagement in the nondisclosure camp. These results suggest that, overall, disclosure may have led to increased peer engagement for a child with autism in summer camps.

Qualitative observations by both video coders noted that they did not notice any change in Bob's social behaviors throughout these two camps. Bob demonstrated a variety of appropriate, as well as some less appropriate, initiations towards his peers in both camps. For example, he spit into materials, made atypical noises, and repeated the same sentence multiple times to a peer. His peers who received the disclosure protocol, in which they learned about the potential intent behind these behaviours and strategies to engage with Bob, appeared to approach



and start conversations with Bob, and respond to his initiations, more frequently and positively over the camp week. On the contrary, peers who did not receive the information appeared to become more passive about responding to his initiations, especially when they involved behaviors that appeared socially atypical, and rarely initiated to Bob by the last day of camp. As a result, the quality of reciprocal interactions decreased, and the frequency of initiation and response rates were extremely low on the last day of the nondisclosure camp. The consistent increases in total initiations and responses between day one, two and five in the disclosure condition suggest that disclosure may have helped to improve reciprocal peer interactions.

Both Bob and one peer in the camp talked about their reciprocal friendship in their interviews, which were conducted separately. Children with autism do typically desire friendships, and stable friendships could provide increased opportunities for joint engagement with peers in unstructured settings, such as at playgrounds and during recess (Frankel, Gorospe, Chang, & Sugar, 2011; Humphrey & Lewis, 2008; Locke, Williams, Shih, & Kasari, 2017; Santillan et al., 2019). In our study, Bob appeared to have a stable friendship with one peer as compared to other peers over the week of camp, based on when his peer discovered their mutual interests in high five on the first day of the camp (after our video was taken, but before the disclosure protocol on day two), and they kept playing this game for five days. However, we suspect that this friendship did not extend beyond camp. However, consistent interactions with this peer-facilitated almost all the campers to observe Bob's interest in high-fives. Notably, additional peers only actively participated in the high-five game after the disclosure protocol. We do not know if this increase in peer engagement would have happened without the disclosure protocol, although peers did report an increased understanding of Bob after this protocol. Bob did not appear to maintain a friendship in the nondisclosure camp, even though he did engage in

a hand-slapping game with a peer on day one, which they both appeared to enjoy. He also had some social interactions with another peer in the first two days of the non-disclosure camp, which was also not maintained on day five. These two peers rarely directed social gestures towards Bob when he was isolated later in the camp week.

To help develop peer reciprocal relationships, most studies have focused on delivering interventions to either children with autism or their peers and teachers in school settings, including peer- or adult- mediated treatments, manualized social skills interventions, and some novel interventions that provided education of isolated children to peers (e.g., *Remaking Recess* and *Circle of Friends*) (C. Newton; Hyman et al., 2020; Kalyva & Avramidis, 2005; M. Kretzmann, W. Shih, & C. Kasari, 2015). Those interventions were provided over two to 12 weeks duration, and have shown positive effects in improving peer social connections for children with autism in both classroom and playground contexts (Kalyva & Avramidis, 2005; Kasari et al., 2012; M. Kretzmann et al., 2015; Locke et al., 2016). Different from most previous studies, our study was conducted outside of the school context in week-long summer camps, which may not provide enough time to incorporate more intensive interventions or treatments like those identified above. It is important to note that our study targeted the social environment to help include the child with autism in community programs, rather than wanting the child with autism to adapt his social behaviour. Simple disclosure protocols could be a way to facilitate the acceptance and inclusion of children with autism within short-term programs that occur within many mainstream community settings, as it is simple, straightforward and time-efficient, and could be provided by anyone (e.g., parents, educators, program staff). Moreover, based on the varied social characteristics of children with autism, the disclosure scripts could easily be adapted and personalized.

Our findings suggest a potential practical value of disclosure in real-life settings. According to the camp leader, the combination of disclosure and explanatory information increased peer tolerance and understanding of the child's unique behaviors. Therefore, our findings are consistent with previous studies that used hypothetical vignettes, but with data collected in a real-life context, which found disclosure could enhance peers' behavioral intentions and decrease negative judgments towards children with autism (Austin et al., 2018; Austin et al., 2016; Campbell et al., 2004; Silton & Fogel, 2012b). Children with autism are vulnerable to victimization, and it is vital that they feel safe to access group activities without experiencing discrimination and stigma. Through healthy social relationships, community inclusion may be maximized (Cappadocia et al., 2012).

### **Limitations and Directions for Future Research**

There are some limitations that should be considered. First, this study involved only one child with autism, which limits generalizability beyond this case. However, this instrumental case study provides meaningful and novel data upon which to build future research. Future studies should employ larger samples to allow for causal inferences, and also analyse the effects of disclosure with other children with autism, including those who present with different skills and support needs. Because of the small sample size, descriptive statistics were used for all analyses. Involving larger samples of children with autism, in both disclosure and nondisclosure conditions, would provide power to determine whether an effect occurs beyond our case. Given the method, we also cannot infer causation or rule out other factors that may have influenced outcomes. Unfortunately, our day one baseline data was not equivalent, however, we did have the benefit of videos to re-watch for nuanced factors, such as length and quality of interactions. Although the camps were not identical in themes or activities, observing Bob in camps that

provided equal opportunities for engagement and interactions with peers, and conducting qualitative interviews with multiple stakeholders in the disclosure camp also provided meaningful data to help understand the nuances of potential changes.

Second, our data collection period was short as the summer camps only lasted for five days. We could not evaluate whether changes in peer engagement and interaction behaviors were temporary, or whether they persist over time. Future studies conducted in contexts that last longer, such as weekly programs that occur over months (e.g., Scouts), are needed to better understand if the effects of disclosure occur in these types of programs, and if they persist over time.

Finally, due to ethical reasons for potentially revealing a child's diagnosis, we were unable to conduct qualitative interviews in the camp in which Bob did not disclose his diagnosis and information about how to facilitate engagement. We were careful, in information letters, consent forms and personal interactions, to indicate that we were only looking at "how children engaged and interacted with each other over the week of camp". It would be interesting to gather qualitative data on peers and camp leader's perceptions of a child with autism who does not disclose their diagnosis.

## **Conclusion**

Engagement in community-based programs, such as summer camps, has many benefits for all children, including those with autism. However, children with autism participate in fewer community-based programs than their peers without autism. Some children with autism and their parents wonder if sharing their child's autism diagnosis within these programs would improve peer engagement and inclusion in these programs. This within-subject instrumental case study begins to address the gap in our knowledge about the experience of diagnostic disclosure and

how it may relate to peer inclusion and engagement for children with autism in one real life context, summer camp. Our results did not find any negative impact of disclosure, and appears to support previous vignette studies that suggest that the combination of diagnostic disclosure and explanatory information could efficiently increase the rates of peer engagement and reciprocal interactions for the child with autism in summer camp settings. It also appeared to help to develop peers' acceptance and understanding of autism and reduce judgments and discrimination towards autism related behaviors. Replication of this study, with larger samples, will provide important data on the effects of disclosure in real life contexts, with potential implications to increase peer engagement and inclusion for children with autism.

## References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.
- Austin, J. E., Galijot, R., & Davies, W. H. (2018). Evaluating parental autism disclosure strategies. *Journal of autism and developmental disorders, 48*(1), 103-109.
- Austin, J. E., Zinke, V. L., & Davies, W. H. (2016). Influencing perception about children with autism and their parents using disclosure cards. *Journal of autism and developmental disorders, 46*(8), 2764-2769.
- Bellini, S., Peters, J. K., Benner, L., & Hopf, A. (2007). A meta-analysis of school-based social skills interventions for children with autism spectrum disorders. *Remedial and Special Education, 28*(3), 153-162.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.
- Campbell, J. M. (2007). Middle School Students' Response to the Self-Introduction of a Student With Autism: Effects of Perceived Similarity, Prior Awareness, and Educational Message. *Remedial and Special Education, 28*(3), 163–173.  
<https://doi.org/10.1177/07419325070280030501>
- Campbell, J. M., Ferguson, J. E., Herzinger, C. V., Jackson, J. N., & Marino, C. A. (2004). Combined descriptive and explanatory information improves peers' perceptions of autism. *Research in Developmental Disabilities, 25*(4), 321–339.  
<https://doi.org/10.1016/j.ridd.2004.01.005>

- Cappadocia, M. C., Weiss, J. A., & Pepler, D. (2012). Bullying Experiences Among Children and Youth with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 42(2), 266–277. <https://doi.org/10.1007/s10803-011-1241-x>
- Chamberlain, B., Kasari, C., & Rotheram-Fuller, E. (2007). Involvement or isolation? The social networks of children with autism in regular classrooms. *Journal of autism and developmental disorders*, 37(2), 230-242.
- Chambres, P., Auxiette, C., Vansingle, C., & Gil, S. (2008). Adult Attitudes Toward Behaviors of a Six-year-old Boy with Autism. *Journal of Autism and Developmental Disorders*, 38(7), 1320–1327. <https://doi.org/10.1007/s10803-007-0519-5>
- Creswell, J. & Plano Clark, V. (2011). Designing and conducting mixed-methods research (2<sup>nd</sup> Ed.). Sage: Thousand Oaks, CA.
- Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A., & Sheikh, A. (2011). The case study approach. *BMC medical research methodology*, 11(1), 100.
- Currie C, Zanotti, C., Morgan, A., Currie, D., de Looze, M., Roberts, C., Samdal, O., Smith, O.R.F. & Barnekow, V. (2012). *Social determinants of health and well-being among young people. Health Behaviour in School-aged Children (HBSC) study: International Report from the 2009/2010 survey*. WHO Regional Office for Europe.
- Frankel, F. D., Gorospe, C. M., Chang, Y. C., & Sugar, C. A. (2011). Mothers' reports of play dates and observation of school playground behavior of children having high-functioning autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, 52(5), 571-579.
- Harrison, P. L., & Oakland, T. (2015). *ABAS-3: Adaptive behavior assessment system*. Los Angeles, CA: Western Psychological Services.

Humphrey, N., & Lewis, S. (2008). 'Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism*, 12(1), 23–46.

<https://doi.org/10.1177/1362361307085267>

Hyman, S. L., Levy, S. E., & Myers, S. M. (2020). Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics*, 145(1).

Kalyva, E., & Avramidis, E. (2005). Improving communication between children with autism and their peers through the 'Circle of Friends': a small-scale intervention study. *Journal of applied research in intellectual disabilities*, 18(3), 253-261.

Kasari, C., Locke, J., Gulsrud, A., & Rotheram-Fuller, E. (2011). Social Networks and Friendships at School: Comparing Children With and Without ASD. *Journal of Autism and Developmental Disorders*, 41(5), 533–544. <https://doi.org/10.1007/s10803-010-1076-x>

Kasari, C., Rotheram-Fuller, E., & Locke, J. (2005). The development of the playground observation of peer engagement (POPE) measure. *Unpublished manuscript, University of California, Los Angeles, Los Angeles.*

Kasari, C., Rotheram-Fuller, E., Locke, J., & Gulsrud, A. (2012). Making the connection: randomized controlled trial of social skills at school for children with autism spectrum disorders: Social skills intervention. *Journal of Child Psychology and Psychiatry*, 53(4), 431–439. <https://doi.org/10.1111/j.1469-7610.2011.02493.x>

Kretzmann, M., Shih, W., & Kasari, C. (2015). Improving peer engagement of children with autism on the school playground: A randomized controlled trial. *Behavior Therapy*, 46(1), 20-28.



- Locke, J., Kasari, C., Rotheram-Fuller, E., Kretzmann, M., & Jacobs, J. (2013). Social network changes over the school year among elementary school-aged children with and without an autism spectrum disorder. *School Mental Health, 5*(1), 38-47.
- Locke, J., Shih, W., Kretzmann, M., & Kasari, C. (2016). Examining playground engagement between elementary school children with and without autism spectrum disorder. *Autism, 20*(6), 653–662. <https://doi.org/10.1177/1362361315599468>
- Locke, J., Williams, J., Shih, W., & Kasari, C. (2017). Characteristics of socially successful elementary school-aged children with autism. *Journal of Child Psychology and Psychiatry, 58*(1), 94-102.
- Mazumder, R., & Thompson-Hodgetts, S. (2019). Stigmatization of Children and Adolescents with Autism Spectrum Disorders and their Families: a Scoping Study. *Review Journal of Autism and Developmental Disorders, 6*(1), 96–107. <https://doi.org/10.1007/s40489-018-00156-5>
- McClelland, M. M., Morrison, F. J., & Holmes, D. L. (2000). Children at risk for early academic problems: The role of learning-related social skills. *Early childhood research quarterly, 15*(3), 307-329.
- Moyson, T., & Roeyers, H. (2011). The quality of life of siblings of children with autism spectrum disorder. *Exceptional Children, 78*(1), 41-55.
- Santillan, L., Frederick, L., Gilmore, S., & Locke, J. (2019). Brief Report: Examining the Association Between Classroom Social Network Inclusion and Playground Peer Engagement Among Children With Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities, 34*(2), 91-96.

- Silton, N. R., & Fogel, J. (2012). Enhancing positive behavioral intentions of typical children towards children with autism. *Journal of Cognitive & Behavioral Psychotherapies*, 12(2).
- Symes, W., & Humphrey, N. (2010). Peer-group indicators of social inclusion among pupils with autistic spectrum disorders (ASD) in mainstream secondary schools: A comparative study. *School Psychology International*, 31(5), 478–494.  
<https://doi.org/10.1177/0143034310382496>
- Taheri, A., Perry, A., & Minnes, P. (2016). Examining the social participation of children and adolescents with intellectual disabilities and autism spectrum disorder in relation to peers. *Journal of Intellectual Disability Research*, 60(5), 435-443.
- Thompson-Hodgetts, S., Labonte, C., Mazumder, R., & Phelan, S. (2020). Helpful or harmful? A scoping review of perceptions and outcomes of autism diagnostic disclosure to others. *Research in Autism Spectrum Disorders*, 77, 101598.
- White, S. W., Keonig, K., & Scahill, L. (2007). Social skills development in children with autism spectrum disorders: A review of the intervention research. *Journal of autism and developmental disorders*, 37(10), 1858-1868.

# Chapter 3

## 1. Discussion

The results of the independent study are in-depth discussed in the previous chapter. This chapter will focus on the implications of the results and considerations related to language use, potential alternatives to disclosure protocols, adults' attitudes and reciprocal friendships of children with autism from a broader body of literature.

### Language Use

Language has notable power in influencing and shaping people's perceptions of autism. The most consistently used terms are "autism", "on the autism spectrum", "autistic" and "person with autism" (Kenny et al., 2016). Unlike professionals, including researchers and students, who endorse person-first language (person with autism), most adults with autism and their families and friends prefer using the term "autistic" (Kenny et al., 2016). However, none of the single statements is the universally accepted way of describing autism. Choosing different and individualistic words to use in a variety of situations when disclosing a diagnosis, for example, in the clinic, in schools and in community, may benefit those on the autism spectrum and improve society's understanding (Kenny et al., 2016). In this study, after getting the approval of the child and his mother, we used term "autism" in the disclosure protocol. As people prefer different terms to describe autism and autism community, it is plausible to change terminologies in different ways depending on respondents' (i.e., peers, the person with autism or their caregivers) preferences, if the child with autism and/or their caregiver is open to a variety of terminology. Rather, being attentive to peers' acceptance and understanding of what language to use in communication may also result in positive impression towards children with autism.

## **Potential Alternative to a Disclosure Protocol**

As discussed in the previous chapter, consistent with hypothetical vignette studies, the results of this independent case study indicated that simple disclosure protocols (diagnostic disclosure + explanatory information) could help facilitate the acceptance and inclusion of children with autism within mainstream community programs. Although these results are preliminary and limited to one participant, the potential benefits of simple disclosure protocols were emphasized, including that they are easily conducted, straightforward and time efficient. While research remains in the preliminary stage, this might be an alternative to peer-mediated interventions or child-directed social skill interventions within short-term programs, such as week-long summer camps.

However, what about children and parents who want improved peer engagement and inclusion, but do not want to disclose their child's autism diagnosis? Unlike disclosing with both diagnostic and explanatory information, some peer-mediated interventions did not directly identify the child with autism to typical peers (Chan et al., 2009; Kasari et al., 2012). Instead of using the term "autism", peers were taught to identify the isolated children in school (including appropriate and atypical behaviors the children performed), given the strategies on engaging and initiating an interaction or simple play with isolated children and also providing contingent reinforcement when necessary (Chan et al., 2009; Kasari et al., 2012). Positive effects of peer-mediated intervention were examined by researchers over decades, such as creating opportunities for children with autism to practice social skills with multiple peers, increasing the availability of intervention agents and fostering inclusion in general education settings (Bellini et al., 2007a; Chan et al., 2009; Kasari et al., 2012).

To date, no hypothetical vignette study has compared the effects of a disclosure protocol with, and without the diagnostic label of autism. Despite the potential benefits of information sharing, inherent concerns related to the autistic label should be considered. Use of this label might inadvertently strengthen stereotypes of the characteristics and deficits of children with autism, which has potential risk of stigmatization and exclusion (Mogensen & Mason, 2015; Russell & Norwich, 2012). In the qualitative interviews, both peers and camp leaders spoke about their understanding of some of the child's atypical behaviors after the disclosure protocol and their willingness to accept and include him within the group. Having explanatory information on the child's behaviors, highlighting similarities between the child and his/her peers, providing simple suggestions on how to engage with the child might be more helpful than sharing diagnostic information. In other words, the diagnostic label of autism might not be the 'active ingredient' in our disclosure protocol. Therefore, it would be interesting to compare the impact of disclosure protocols that include explanatory information and strategies to engage, with and without the autism label. Ideally, both conditions are needed to unpack what the 'active ingredient' (the part of the intervention that is most important in creating change) is. It is always important to consider the child with autism or the parents' choice in developing the disclosure protocol and deciding how much information they want to share.

### **Adults Attitudes**

Just as peers may benefit from additional information to engage with a child with autism, so might the adults who are responsible for conducting the mainstream summer camps. Many characteristics of children with autism, including socially atypical behavior and deficits in communication and socialization skills, may be poorly understood by facilitators (e.g., camp leaders), who may not best understand how to support the needs of children with autism. As

previously stated, inadequate staff knowledge and training about autism also makes parents of children with autism and adults with autism to have mixed feelings about disclosure in different settings (Lum et al., 2014; Muskat et al., 2016; Thompson-Hodgetts et al., 2020). To encourage meaningful participation in community-based programs, it might be helpful for camp staff to be well educated about autism, including children's behavior and specific needs. Positive outcomes were confirmed in our review of previous hypothetical vignette studies, which generally stated that informing adults about autism may help minimize their negative attitudes towards atypical behaviors and perceive a child as more capable, especially for female adults (Austin et al., 2016; Chambres et al., 2008; Thompson-Hodgetts et al., 2020). Therefore, it is critical to understand how disclosure and information sharing influences adults' attitudes and behavioral intention towards children with autism in "real life" community-based settings, such as summer camps.

### **Friendship**

Many individuals with autism reported their desire of "fit in" to various social activities as well as form relationships and friendships with others (Humphrey & Lewis, 2008). The children in our study participated in mainstream, community-based summer camps, which primarily included peers who would be classified as "typically developing" to our knowledge. Bauminger and Shulman (2003) examined the differences between "mixed" friendships (a child with autism and a typical developing peer) and "non-mixed" friendships (a child with autism and a friend with a disability). They indicated that compared with "non-mixed" friendship, advantages of having mix friendships are numerous. Bauminger et al. (2008) suggested that "participants in mixed friendship were more responsive to one another, had stronger receptive language skills, exhibited higher levels if positive social orientation and cohesion, and demonstrated a more complex level of coordinated play than those in non-mixed dyads" (p.

1224). Moreover, social skills, social acceptance and number of friends were positively correlated. Having more friends may provide youth with more opportunities to improve their social skills, which in turn results in greater peer acceptance from larger number of peers (Viecili, Weiss, Lunsky, & Shupak, 2010).

Of interest, in this independent study, a mixed friendship connection between the child with autism and one of his peers in the disclosure camp was established. Consistent with previous studies, both quantitative and qualitative results of the study showed the positive effects of friendship. Their consistent interactions and shared interests supported the child being less isolated throughout the summer camp. However, we suspect that this friendship did not extend beyond the camp. Using play dates and connecting peers with common interests as components of intervention have been suggested by some researchers (Koegel et al., 2012; Koegel, Werner, Vismara, & Koegel, 2005). One study indicated that having more play dates at home would positively affect the time that children with autism spent conversing with peers and participating in turn-taking activities on the school playground (Frankel et al., 2011). Hosting and inviting play dates at home might be a beneficial practise to help with friendship development and encourage positive peer interactions for the child in summer camps or even in school.

### **Limitations and Future Directions**

This mixed-methods, instrumental case study examined the effectiveness of diagnostic disclosure and explanatory information on increasing peer engagement and social interaction behaviors for one child with autism who participated in two different summer camps in Edmonton. The information we gained from this research is novel and informative. However, to address the limitation of our very small sample size and enhance the generalizability of the study results, it is important to extend the research to a larger sample of children with autism, and

potentially those from a broader age group and from a variety of community programs and areas. For example, future studies could start with comparing the effects of disclosure across different groups of children within similar community-based summer camps. Inclusion of a larger sample size would also allow for analysis of causal inferences and to rule out other factors that may have influenced outcomes. The larger project, which is recruiting a larger sample size of children with autism in both disclosure and non-disclosure conditions, will be continued.

Another significant limitation to understand peers' perceptions and acceptance towards children with autism is the absence of direct interview with staff from the non-disclosure camp. These participants may have different experiences with children with autism. Although integration of data from more comprehensive sources, including insight from camp leaders, peers and children with autism or their parents in the non-disclosure camp may enrich the information sharing experience and reinforce the development of disclosure protocol. They might provide important information about strengths, attributes and behaviors of the child with autism that were notable to campers, even though they did not tell about the child's autistic diagnosis. However, we do not see how this is possible as it carries of risk of inadvertently disclosing a child's diagnosis.

## **2. Conclusion**

The benefits of engaging in community-based programs are undeniable. The successful inclusion and peer participation of children with autism should not focus solely on the disability and improving social skills within the individual, but rather on building an inclusive and supportive environment without discrimination and judgement. Disclosure is one of the strategies that has been evaluated and suggested as beneficial in previous hypothetical vignette studies in facilitating others' acceptance and supports towards individuals with autism. The purpose of this



within-subject instrumental case study was to begin to address the gap in our knowledge about the effectiveness of disclosure and information sharing in a real-life context. Our study explored the different experiences a child with autism had when participating in two different camps, one in which he disclosed and one in which he did not disclose a diagnosis of autism. Consistent with previous vignettes studies, the combination of diagnostic disclosure and explanatory information could efficiently increase the rates of peer engagement and reciprocal interaction for the child in summer camp settings. The outcome of the larger project could be a foundational step in understanding outcomes of disclosure, to potentially support children and parents who want to develop an efficient disclosure protocol, and help them decide what information to give when they choose to share their autism diagnosis to others.

## References

- Austin, J. E., Zinke, V. L., & Davies, W. H. (2016). Influencing perception about children with autism and their parents using disclosure cards. *Journal of autism and developmental disorders, 46*(8), 2764-2769.
- Bellini, S., Peters, J. K., Benner, L., & Hopf, A. (2007). A meta-analysis of school-based social skills interventions for children with autism spectrum disorders. *Remedial and Special Education, 28*(3), 153-162.
- Chambres, P., Auxiette, C., Vansingle, C., & Gil, S. (2008). Adult Attitudes Toward Behaviors of a Six-year-old Boy with Autism. *Journal of Autism and Developmental Disorders, 38*(7), 1320–1327. <https://doi.org/10.1007/s10803-007-0519-5>
- Chan, J. M., Lang, R., Rispoli, M., O'Reilly, M., Sigafoos, J., & Cole, H. (2009). Use of peer-mediated interventions in the treatment of autism spectrum disorders: A systematic review. *Research in autism spectrum disorders, 3*(4), 876-889.
- Frankel, F. D., Gorospe, C. M., Chang, Y. C., & Sugar, C. A. (2011). Mothers' reports of play dates and observation of school playground behavior of children having high-functioning autism spectrum disorders. *Journal of Child Psychology and Psychiatry, 52*(5), 571-579.
- Humphrey, N., & Lewis, S. (2008). 'Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism, 12*(1), 23–46.  
<https://doi.org/10.1177/1362361307085267>
- Kasari, C., Rotheram-Fuller, E., Locke, J., & Gulsrud, A. (2012). Making the connection: randomized controlled trial of social skills at school for children with autism spectrum

- disorders: Social skills intervention. *Journal of Child Psychology and Psychiatry*, 53(4), 431–439. <https://doi.org/10.1111/j.1469-7610.2011.02493.x>
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462.
- Koegel, R. L., Fredeen, R., Kim, S., Danial, J., Rubinstein, D., & Koegel, L. (2012). Using perseverative interests to improve interactions between adolescents with autism and their typical peers in school settings. *Journal of positive behavior interventions*, 14(3), 133-141.
- Koegel, R. L., Werner, G. A., Vismara, L. A., & Koegel, L. K. (2005). The effectiveness of contextually supported play date interactions between children with autism and typically developing peers. *Research and Practice for Persons with Severe Disabilities*, 30(2), 93-102.
- Lum, M., Garnett, M., & O'Connor, E. (2014). Health communication: A pilot study comparing perceptions of women with and without high functioning autism spectrum disorder. *Research in Autism Spectrum Disorders*, 8(12), 1713-1721.
- Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism*, 8(4), 387-407.
- Mogensen, L., & Mason, J. (2015). The meaning of a label for teenagers negotiating identity: experiences with autism spectrum disorder. *Sociology of Health & Illness*, 37(2), 255-269.

Muskat, B., Greenblatt, A., Nicholas, D. B., Ratnapalan, S., Cohen-Silver, J., Newton, A. S., ... & Zwaigenbaum, L. (2016). Parent and health care provider perspectives related to disclosure of autism spectrum disorder in pediatric emergency departments. *Autism, 20*(8), 986-994.

Russell, G., & Norwich, B. (2012). Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. *Clinical child psychology and psychiatry, 17*(2), 229-245.

Thompson-Hodgetts, S., Labonte, C., Mazumder, R., & Phelan, S. (2020). Helpful or harmful? A scoping review of perceptions and outcomes of autism diagnostic disclosure to others. *Research in Autism Spectrum Disorders, 77*, 101598.

Viecili, M. A., Weiss, J. A., Lunskey, Y., & Shupak, S. (2010). The relationship between social acceptance, problem behaviours, and social skills as perceived by youth with autism spectrum disorders.

## Bibliography

- Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A., & Law, M. (2013). The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disability and rehabilitation, 35*(19), 1589-1598.
- Askari, S., Anaby, D., Bergthorson, M., Majnemer, A., Elsabbagh, M., & Zwaigenbaum, L. (2015). Participation of children and youth with autism spectrum disorder: a scoping review. *Review Journal of Autism and Developmental Disorders, 2*(1), 103-114.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.
- Austin, J. E., Galijot, R., & Davies, W. H. (2018). Evaluating parental autism disclosure strategies. *Journal of autism and developmental disorders, 48*(1), 103-109.
- Austin, J. E., Zinke, V. L., & Davies, W. H. (2016). Influencing perception about children with autism and their parents using disclosure cards. *Journal of autism and developmental disorders, 46*(8), 2764-2769.
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., ... & Durkin, M. S. (2018). Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *MMWR Surveillance Summaries, 67*(6), 1.
- Bauminger, N., & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child development, 71*(2), 447-456.

- Bellini, S., Peters, J. K., Benner, L., & Hopf, A. (2007). A meta-analysis of school-based social skills interventions for children with autism spectrum disorders. *Remedial and Special Education, 28*(3), 153-162.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.
- Broadly, T. R., Stoyles, G. J., & Morse, C. (2017). Understanding carers' lived experience of stigma: the voice of families with a child on the autism spectrum. *Health & social care in the community, 25*(1), 224-233.
- Buttimer, J., & Tierney, E. (2005). Patterns of leisure participation among adolescents with a mild intellectual disability. *Journal of intellectual disabilities, 9*(1), 25-42.
- Cai, R. Y., & Richdale, A. L. (2016). Educational Experiences and Needs of Higher Education Students with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 46*(1), 31–41. <https://doi.org/10.1007/s10803-015-2535-1>
- Campbell, J. M. (2007). Middle School Students' Response to the Self-Introduction of a Student With Autism: Effects of Perceived Similarity, Prior Awareness, and Educational Message. *Remedial and Special Education, 28*(3), 163–173.  
<https://doi.org/10.1177/07419325070280030501>
- Campbell, J. M., Ferguson, J. E., Herzinger, C. V., Jackson, J. N., & Marino, C. A. (2004). Combined descriptive and explanatory information improves peers' perceptions of autism. *Research in Developmental Disabilities, 25*(4), 321–339.  
<https://doi.org/10.1016/j.ridd.2004.01.005>

- Cappadocia, M. C., Weiss, J. A., & Pepler, D. (2012). Bullying Experiences Among Children and Youth with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 42(2), 266–277. <https://doi.org/10.1007/s10803-011-1241-x>
- Chamberlain, B., Kasari, C., & Rotheram-Fuller, E. (2007). Involvement or isolation? The social networks of children with autism in regular classrooms. *Journal of autism and developmental disorders*, 37(2), 230-242.
- Chambres, P., Auxiette, C., Vansingle, C., & Gil, S. (2008). Adult Attitudes Toward Behaviors of a Six-year-old Boy with Autism. *Journal of Autism and Developmental Disorders*, 38(7), 1320–1327. <https://doi.org/10.1007/s10803-007-0519-5>
- Chan, J. M., Lang, R., Rispoli, M., O'Reilly, M., Sigafoos, J., & Cole, H. (2009). Use of peer-mediated interventions in the treatment of autism spectrum disorders: A systematic review. *Research in autism spectrum disorders*, 3(4), 876-889.
- Christensen, D. L., Braun, K. V. N., Baio, J., Bilder, D., Charles, J., Constantino, J. N., ... & Lee, L. C. (2018). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *MMWR Surveillance Summaries*, 65(13), 1.
- Creswell, J. & Plano Clark, V. (2011). *Designing and conducting mixed-methods research* (2<sup>nd</sup> Ed.). Sage: Thousand Oaks, CA.
- Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A., & Sheikh, A. (2011). The case study approach. *BMC medical research methodology*, 11(1), 100.

- Cowart, B. L., Saylor, C. F., Dingle, A., & Mainor, M. (2004). Social Skills and Recreational Preferences of Children With and Without Disabilities. *North American Journal of Psychology, 6*(1).
- Currie C, Zanotti, C., Morgan, A., Currie, D., de Looze, M., Roberts, C., Samdal, O., Smith, O.R.F. & Barnekow, V. (2012). *Social determinants of health and well-being among young people. Health Behaviour in School-aged Children (HBSC) study: International Report from the 2009/2010 survey*. WHO Regional Office for Europe.
- Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness, 31*(7), 1011-1027.
- Frankel, F. D., Gorospe, C. M., Chang, Y. C., & Sugar, C. A. (2011). Mothers' reports of play dates and observation of school playground behavior of children having high-functioning autism spectrum disorders. *Journal of Child Psychology and Psychiatry, 52*(5), 571-579.
- Gray, D. E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health & Illness, 15*(1), 102-120.
- Gray, D. E. (1994). Coping with autism: Stresses and strategies. *Sociology of Health & Illness, 16*(3), 275-300.
- Gray, D. E. (2002). 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness, 24*(6), 734-749.



- Harrison, P. L., & Oakland, T. (2015). *ABAS-3: Adaptive behavior assessment system*. Los Angeles, CA: Western Psychological Services.
- Hilton, C. L., Crouch, M. C., & Israel, H. (2008). Out-of-school participation patterns in children with high-functioning autism spectrum disorders. *American Journal of Occupational Therapy, 62*(5), 554-563.
- Humphrey, N., & Lewis, S. (2008). 'Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism, 12*(1), 23–46.  
<https://doi.org/10.1177/1362361307085267>
- Humphrey, N., & Symes, W. (2010). Perceptions of social support and experience of bullying among pupils with autistic spectrum disorders in mainstream secondary schools. *European Journal of Special Needs Education, 25*(1), 77-91.
- Huws, J. C., & Jones, R. S. (2008). Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual and Developmental Disability, 33*(2), 99-107.
- Hyman, S. L., Levy, S. E., & Myers, S. M. (2020). Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics, 145*(1).
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing, 32*(1), 243–248. <https://doi.org/10.1046/j.1365-2648.2000.01466.x>
- Jones, J. L., Gallus, K. L., Viering, K. L., & Oseland, L. M. (2015). 'Are you by chance on the spectrum?' Adolescents with autism spectrum disorder making sense of their diagnoses. *Disability & Society, 30*(10), 1490-1504.

- Kalyva, E., & Avramidis, E. (2005). Improving communication between children with autism and their peers through the 'Circle of Friends': a small-scale intervention study. *Journal of applied research in intellectual disabilities*, 18(3), 253-261.
- Kasari, C., Locke, J., Gulsrud, A., & Rotheram-Fuller, E. (2011). Social Networks and Friendships at School: Comparing Children With and Without ASD. *Journal of Autism and Developmental Disorders*, 41(5), 533–544. <https://doi.org/10.1007/s10803-010-1076-x>
- Kasari, C., Rotheram-Fuller, E., & Locke, J. (2005). The development of the playground observation of peer engagement (POPE) measure. *Unpublished manuscript, University of California, Los Angeles, Los Angeles.*
- Kasari, C., Rotheram-Fuller, E., Locke, J., & Gulsrud, A. (2012). Making the connection: randomized controlled trial of social skills at school for children with autism spectrum disorders: Social skills intervention. *Journal of Child Psychology and Psychiatry*, 53(4), 431–439. <https://doi.org/10.1111/j.1469-7610.2011.02493.x>
- Kasari, C., & Smith, T. (2013). Interventions in schools for children with autism spectrum disorder: Methods and recommendations. *Autism*, 17(3), 254-267.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462.
- Kretzmann, M., Shih, W., & Kasari, C. (2015). Improving peer engagement of children with autism on the school playground: A randomized controlled trial. *Behavior Therapy*, 46(1), 20-28.

- King, G., Lawm, M., King, S., Rosenbaum, P., Kertoy, M. K., & Young, N. L. (2003). A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical & occupational therapy in pediatrics*, 23(1), 63-90.
- King, M., Shields, N., Imms, C., Black, M., & Ardern, C. (2013). Participation of children with intellectual disability compared with typically developing children. *Research in developmental disabilities*, 34(5), 1854-1862.
- Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Families' Lives. *Journal of Autism and Developmental Disorders*, 46(3), 942–953. <https://doi.org/10.1007/s10803-015-2637-9>
- Koegel, R. L., Fredeen, R., Kim, S., Danial, J., Rubinstein, D., & Koegel, L. (2012). Using perseverative interests to improve interactions between adolescents with autism and their typical peers in school settings. *Journal of positive behavior interventions*, 14(3), 133-141.
- Koegel, R. L., Werner, G. A., Vismara, L. A., & Koegel, L. K. (2005). The effectiveness of contextually supported play date interactions between children with autism and typically developing peers. *Research and Practice for Persons with Severe Disabilities*, 30(2), 93-102.
- Kretzmann, M., Shih, W., & Kasari, C. (2015). Improving peer engagement of children with autism on the school playground: A randomized controlled trial. *Behavior Therapy*, 46(1), 20-28.

- Lang, R., Kuriakose, S., Lyons, G., Mulloy, A., Boutot, A., Britt, C., ... & Lancioni, G. (2011). Use of school recess time in the education and treatment of children with autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders*, 5(4), 1296-1305.
- Law, M., King, G., King, S., Kertoy, M., Hurley, P., Rosenbaum, P., ... & Hanna, S. (2006). Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine & Child Neurology*, 48(5), 337-342.
- Locke, J., Kasari, C., Rotheram-Fuller, E., Kretzmann, M., & Jacobs, J. (2013). Social network changes over the school year among elementary school-aged children with and without an autism spectrum disorder. *School Mental Health*, 5(1), 38-47.
- Locke, J., Williams, J., Shih, W., & Kasari, C. (2017). Characteristics of socially successful elementary school-aged children with autism. *Journal of Child Psychology and Psychiatry*, 58(1), 94-102.
- Locke, J., Shih, W., Kang-Yi, C. D., Caramanico, J., Shingledecker, T., Gibson, J., ... & Mandell, D. S. (2019). The impact of implementation support on the use of a social engagement intervention for children with autism in public schools. *Autism*, 23(4), 834-845.
- Locke, J., Shih, W., Kretzmann, M., & Kasari, C. (2016). Examining playground engagement between elementary school children with and without autism spectrum disorder. *Autism*, 20(6), 653–662. <https://doi.org/10.1177/1362361315599468>

- Lum, M., Garnett, M., & O'Connor, E. (2014). Health communication: A pilot study comparing perceptions of women with and without high functioning autism spectrum disorder. *Research in Autism Spectrum Disorders*, 8(12), 1713-1721.
- Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism*, 8(4), 387-407.
- Mazumder, R., & Thompson-Hodgetts, S. (2019). Stigmatization of Children and Adolescents with Autism Spectrum Disorders and their Families: a Scoping Study. *Review Journal of Autism and Developmental Disorders*, 6(1), 96–107. <https://doi.org/10.1007/s40489-018-00156-5>
- McConnell, S. R. (2002). Interventions to facilitate social interaction for young children with autism: Review of available research and recommendations for educational intervention and future research. *Journal of autism and developmental disorders*, 32(5), 351-372.
- Mogensen, L., & Mason, J. (2015). The meaning of a label for teenagers negotiating identity: experiences with autism spectrum disorder. *Sociology of Health & Illness*, 37(2), 255-269.
- Moyson, T., & Roeyers, H. (2011). The quality of life of siblings of children with autism spectrum disorder. *Exceptional Children*, 78(1), 41-55.
- Muskat, B., Greenblatt, A., Nicholas, D. B., Ratnapalan, S., Cohen-Silver, J., Newton, A. S., ... & Zwaigenbaum, L. (2016). Parent and health care provider perspectives related to disclosure of autism spectrum disorder in pediatric emergency departments. *Autism*, 20(8), 986-994.

- Neely-Barnes, S. L., Hall, H. R., Roberts, R. J., & Graff, J. C. (2011). Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualizations. *Journal of Family Social Work, 14*(3), 208-225.
- World Health Organization. (2001). *The World Health Report 2001: Mental health: new understanding, new hope*. World Health Organization.
- Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of autism and developmental disorders, 34*(3), 245-256.
- Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of autism and developmental disorders, 43*(11), 2710-2719.
- Rao, P. A., Beidel, D. C., & Murray, M. J. (2008). Social skills interventions for children with Asperger's syndrome or high-functioning autism: A review and recommendations. *Journal of autism and developmental disorders, 38*(2), 353-361.
- Rimmer, J. H., Rowland, J. L., & Yamaki, K. (2007). Obesity and secondary conditions in adolescents with disabilities: addressing the needs of an underserved population. *Journal of Adolescent Health, 41*(3), 224-229.
- Russell, G., & Norwich, B. (2012). Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. *Clinical child psychology and psychiatry, 17*(2), 229-245.

- Santillan, L., Frederick, L., Gilmore, S., & Locke, J. (2019). Brief Report: Examining the Association Between Classroom Social Network Inclusion and Playground Peer Engagement Among Children With Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, 34(2), 91-96.
- Shakespeare, T. (2006). The social model of disability. *The disability studies reader*, 2, 197-204.
- Silton, N. R., & Fogel, J. (2012). Enhancing positive behavioral intentions of typical children towards children with autism. *Journal of Cognitive & Behavioral Psychotherapies*, 12(2).
- Sutton, B. M., Webster, A. A., & Westerveld, M. F. (2019). A systematic review of school-based interventions targeting social communication behaviors for students with autism. *Autism*, 23(2), 274-286.
- Symes, W., & Humphrey, N. (2010). Peer-group indicators of social inclusion among pupils with autistic spectrum disorders (ASD) in mainstream secondary schools: A comparative study. *School Psychology International*, 31(5), 478–494.  
<https://doi.org/10.1177/0143034310382496>
- Taheri, A., Perry, A., & Minnes, P. (2016). Examining the social participation of children and adolescents with intellectual disabilities and autism spectrum disorder in relation to peers. *Journal of Intellectual Disability Research*, 60(5), 435-443.
- Thompson-Hodgetts, S., Labonte, C., Mazumder, R., & Phelan, S. (2020). Helpful or harmful? A scoping review of perceptions and outcomes of autism diagnostic disclosure to others. *Research in Autism Spectrum Disorders*, 77, 101598.

Viecili, M. A., Weiss, J. A., Lunskey, Y., & Shupak, S. (2010). The relationship between social acceptance, problem behaviours, and social skills as perceived by youth with autism spectrum disorders.

Wainscot, J. J., Naylor, P., Sutcliffe, P., Tantam, D., & Williams, J. V. (2008). Relationships with peers and use of the school environment of mainstream secondary school pupils with Asperger syndrome (high-functioning autism): A case-control study. *International Journal of Psychology and Psychological Therapy*, 8(1), 25-38.

White, S. W., Keonig, K., & Scahill, L. (2007). Social skills development in children with autism spectrum disorders: A review of the intervention research. *Journal of autism and developmental disorders*, 37(10), 1858-1868.



## Appendix A

### Playground Observation of Peer Engagement – Original Form

#### Playground Observation of Peer Engagement

Int	State	Chi Initiations Gen = I, Peer R = +, Peer NR = -	Chi Responses App Res = + Miss opp = -	Comments (note affect, activity, atypical behavior, who the child engages with (aide, adult, peers) and anything of importance or interest)	
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					
14					
15					
STATES		S = Solitary	O = Onlooker	PA = Parallel Aware	G = Games with Rules
		X = Proximity	P = Parallel Play	JE = Joint Engage	

**Child Behavior Rating**

**Amount:**

- Initiated to another Child
- Responded to another Child
- Engaged in a Conversation (4+ exchanges) with another Child
- Engaged in a Game with another Child or Group of Children

**Amount Rating (BEHAM):** \_\_\_\_\_ (Sum the number of skills checked above)

**Quality:** The execution ability of observed skills

**1**=Poor implementation **2**=Less than Adequate **3**=Adequate, occasional difficulty **4**=Good, a couple small errors **5**=Excellent, flawless implementation

**Quality Rating (BEHQ):** \_\_\_\_\_

**Developmental Appropriateness:** Accuracy of matching strategies to child's developmental level in terms of **amount** and **frequency**.

- 1** = Poor matching of **amount** and **frequency** of strategies used.
- 2** = Isolated matching of **amount** and **frequency** of strategies used.
- 3** = Average matching of **amount** and **frequency** of strategies used.
- 4** = Good matching of **amount** and **frequency** of strategies used.
- 5** = Excellent matching of **amount** and **frequency** of strategies used.

**Developmental Appropriateness Rating (RESDA):** \_\_\_\_\_

Child ID:

Date:

Time point:

School ID:

Time:

Observer:

Kasari C, Rotheram-Fuller, Locke J. *The development of the playground observation of peer engagement (POPE) Measure*. Unpublished manuscript. Los Angeles, CA: University of California Los Angeles; 2005.

## Appendix B

### Playground Observation of Peer Engagement – Revised Form

Interval	Aide Present?	Overall State <u>PA JE G</u>	Interaction Partner	Partial Interval State <u>PA JE G</u>	Interactive Partner	Child with ASD responses to peer initiations (child with ASD responds = +) (child with ASD doesn't respond = -) (circle if aide prompted) (N = none) *put letter 'a' beside +/- if with adult	Child with ASD initiations towards peers (peer responds = +) (peer doesn't respond = -) (circle if aide prompted) (N = none) *put letter 'a' beside +/- if with adult	Notes
1		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			
2		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			
3		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			
4		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			
5		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			
6		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			
7		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			
8		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			
9		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			
10		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			
11		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			
12		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			
13		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			
14		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			
15		S O P OT <u>PA JE G</u>	P A	S O P OT <u>PA JE G</u>	P A			

STATES: S = Solitary/Unengaged O = Onlooker P = Parallel/Object PA = Parallel aware JE = Joint Engage G = Games with Rules OT = on task during adult led activity

Interaction Partner: A = adult, P = peer (can circle both if relevant)

Put 'off' somewhere on interval line if off camera for majority of interval

Appendix C

Recruitment Poster



# Influencing inclusion for children with ASD in communities: Peer interactions & responses in context

Will your child with ASD register in an Edmonton area summer camp? If so, we hope to hear from you!



If you want to learn more about this study or how to participate, please contact the study coordinator, Dr. Ashley McKillop or the primary investigator, Dr. Sandy Hodgetts at [skiplab@ualberta.ca](mailto:skiplab@ualberta.ca)  
Ethics ID#: Pro00081598

- We know that children with ASD participate in fewer community recreation activities than their peers, and may be left out by peers when they do.
- We want to observe how peers interact with and respond to children with ASD in these settings, and if sharing info about ASD to peers changes these interactions.
- We will not tell you whether to share information about ASD – that is your choice!

This study is generously funded by:



## Appendix D

### Ethics Approval Letter

---

#### RESEARCH ETHICS OFFICE

308 Campus Tower  
Edmonton, AB, Canada T6G 1K8  
Tel: 780.492.0459  
Fax: 780.492.9429  
www.reo.ualberta.ca

#### Notification of Approval

Date: June 12, 2018  
Study ID: Pro00081598  
Principal Investigator: [Sandra Hodgetts](#)  
Study Title: Influencing inclusion for children with ASD in communities: Peer interaction and responses in context  
Approval Expiry Date: Tuesday, June 11, 2019

Approved Consent Form:	Approval Date	Approved Document
	6/12/2018	<a href="#">Information letter &amp; consent professionals_June 9, 2018.docx</a>
	6/12/2018	<a href="#">Information letter parents of peers_May2018.docx</a>
	6/12/2018	<a href="#">Information letter &amp; consent parents of child_June 11, 2018.docx</a>

Thank you for submitting the above study to the Research Ethics Board 2. Your application has been reviewed and approved on behalf of the committee.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Sincerely,

Stanley Varnhagen, PhD  
Chair, Research Ethics Board 2

*Note: This correspondence includes an electronic signature (validation and approval via an online system).*

## Appendix E

### Renewed Ethics Approval Letter

#### RESEARCH ETHICS OFFICE

308 Campus Tower  
Edmonton, AB, Canada T6G 1K8  
Tel: 780.492.0459  
uab.ca/reo

#### Notification of Approval (Renewal)

Date: May 13, 2019  
Principal Investigator: Sandra Hodgetts  
Study ID: Pro00081598  
Study Title: Influencing inclusion for children with ASD in communities: Peer interaction and responses in context  
Sponsor/Funding Agency: Women and Children's Health Research Institute WCHRI

	Project ID	Project Title	Speed Code	Other Information
RSO-Managed Funding:	RES0040664	Preventative disclosure on peer engagement and inclusion of children with ASD in community contexts		

	Approval Date	Approved Document
Approved Consent Form:	6/12/2018	Information letter parents of peers_May2018
	7/16/2018	Information letter & consent professionals_June2018
	7/16/2018	Information letter & consent parents of child_June2018
	1/28/2019	Information letter consent professionals_Jan2019.docx
	1/28/2019	Information letter parents of peers_Jan2019.docx
	6/12/2018	Information letter parents of peers_May2018.docx
	6/12/2018	Information letter & consent parents of child_June 11, 2018.docx
	1/28/2019	Information letter consent parents of child_Jan2019.docx
	1/28/2019	Information letter parents of peers signature_Jan2019.docx
	7/16/2018	Information letter parents of peers signature_July 2018
	6/12/2018	Information letter & consent professionals_June 9, 2018.docx

Approval Expiry Date: Monday, May 11, 2020

Thank you for submitting this renewal application. Your application has been reviewed and approved.

This re-approval is valid for one year. If your study continues past the expiration date as noted above, you will be required to complete another renewal request. Beginning at 30 days prior to the expiration date, you will receive notices that the study is about to expire. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Sincerely,

Ubaka Ogbogu, LLB, BL, LLM, SJD  
Chair, Research Ethics Board 2

*Note: This correspondence includes an electronic signature (validation and approval via an online system).*

## Appendix F

### Information Letters for Parents of Children with ASD

**Study Title:**

Influencing inclusion for children with ASD in communities: Peer interaction and responses in context

**Principal Investigator:**

Dr. Sandra Hodgetts  
Department of Occupational Therapy  
University of Alberta  
780-492-8416  
[sandra.hodgetts@ualberta.ca](mailto:sandra.hodgetts@ualberta.ca)

**Research Coordinator:**

Dr. Ashley McKillop  
Supporting Kids Inclusion &  
Participation (S.K.I.P.) Lab  
University of Alberta  
[amckillo@ualberta.ca](mailto:amckillo@ualberta.ca)

---

**Background and Purpose:**

Your son or daughter is being invited to take part in this research study because he or she has a diagnosis of ASD and is participating in a community program. This study will look at how peers interact with and respond to children with ASD in community recreation programs, such as summer camps, and whether sharing information about ASD makes a difference.

**Description of the Research:**

All children will participate in all camp activities like normal. We will take videos of children interacting with each other during normal camp activities. Taking videos is helpful because we will not be intrusive at the camp, and we can look at behaviours in detail later. We will look at how peers initiate and respond to children with ASD at the beginning, middle and end of camp, including whether there is a difference after children share information about ASD.

*You do not have to share information about ASD – that is your choice.* If you do choose to share information, this will be done on the first or second day of camp. We will never share any information about your child to other children or their parents other than what you approve. Their letters and consent forms are different – they do not include the word autism. They just say that we are looking at how children play together.

You will complete a questionnaire to describe your child. This will help us understand whether things about the child, such as how they communicate, make a difference. We do not need any information about peers and will not show the videos to anyone other than our research team.

If you choose to share your child's diagnosis of ASD we will briefly talk to camp counsellors, your child (if able) and some other children after camp. We will ask them if and how they think this information made a difference to how they included your child. We will audio-record these conversations and type them out with all information that could identify any person or program removed. No one other than the researchers will hear what people said. We will not ask questions to other children if you do not share this information because they will not know that your child has ASD.

**Possible Risks:**

We do not expect that your child will experience any harm if he or she participates in this study. We do not expect negative outcomes from disclosing an ASD diagnosis. It is your choice

whether or not you choose to disclose your child's diagnosis. You can choose to do whatever you would do in normal everyday life.

**Possible Benefits:**

Parents in our previous research studies told us that they struggle with whether sharing their child's ASD diagnosis and information about ASD to peers will increase acceptance and inclusion, or exclusion and bullying. This is the first study to look at how sharing a diagnosis influences inclusion in these programs.

There may not be direct benefits for your child. We hope that this study helps us better understand outcomes of disclosure to help children with ASD and their parents. We expect that children who disclose may experience more interaction from their peers.

Your child will receive a small thank-you gift for his or her participation. You will receive a small gift-card to thank you for your time filling out the questionnaire about your child.

**Voluntary Participation:**

Participation in this study is voluntary. It is you and your child's choice to take part in this study. You can choose to withdraw from the study at any point **before** your child's camp is finished. If you withdraw you can choose whether or not to have your child's data destroyed. Your child's camp activities will not be affected in any way if your child takes part in this study.

**Confidentiality:**

No information about who you or your child is will be given to anyone or be published. Videos will only be watched in a locked room at the University. Only the researchers will see the videos.

If you share information about autism and we talk with camp counsellors, your child, and/or other children we will remove your all person and program names from the typed records of the interviews and in reports about the research. We will replace your child's name with a pseudonym that is known only to the researchers. All information will be kept in a secure and locked filing cabinet or in an encrypted computer that can only be entered through a password.

The results of the study may be printed in a newspaper or journal but you or your child will not be identified. The results from this study may be used in presentations or for teaching purposes but you or your child will not be identified.

We may use the data we get from this study in future research, but if we do this it will have to be approved by a Research Ethics Board. We will also keep your and your child's contact information to potentially participate in future research related to people with ASD and their families if you give permission below. If so, this information will be kept in an encrypted computer that can only be accessed through a password. You do not have to give permission to potentially be contacted in the future.

**What costs are there to you if you enter this study?**

We do not expect you or your child to have any expenses as a result of taking part in the study.

**Contact Information:**

Please contact Ashley or Sandy if you have any questions or concerns. Our contact information is at the top of page 1.

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For question regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.



## CONSENT FORM

**Project Title:** Influencing inclusion for children with ASD in communities: Peer interaction and responses in context

**Locally Responsible Investigator:** Dr. Sandra Hodgetts

Tel: (780) 492-8416

	<u>Yes</u>		<u>No</u>
Do you understand that your child has been asked to be in a research study?	<input type="checkbox"/>		<input type="checkbox"/>
Have you read and received a copy of the attached Information Sheet?	<input type="checkbox"/>		<input type="checkbox"/>
Do you understand the benefits and risks involved in your child taking part in this research study?	<input type="checkbox"/>		<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>		<input type="checkbox"/>
Do you understand that your child is free to withdraw from the study at any time without having to give a reason and without affecting your or your child's participation in the program?	<input type="checkbox"/>		<input type="checkbox"/>
Has the issue of confidentiality been explained to you?	<input type="checkbox"/>		<input type="checkbox"/>
Do you understand who will have access to the records?	<input type="checkbox"/>		<input type="checkbox"/>
Who explained this study to you? _____			
I agree for my child to be video recorded during the program activities	YES <input type="checkbox"/>		NO <input type="checkbox"/>
I agree for a researcher to talk with my child at the end of camp	YES <input type="checkbox"/>		NO <input type="checkbox"/>
I agree for my child to be audio recorded when interviewed	YES <input type="checkbox"/>		NO <input type="checkbox"/>
I would like my child's contact information added to a recruitment list for future research	YES <input type="checkbox"/>		NO <input type="checkbox"/>
Signature of Research Participant: _____			
(Printed Name): _____			
Date: _____			
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.			
Signature of Investigator or Designee _____ Date _____			

## Appendix G

Assent Form for Children with ASD

### **Study Title:**

Influencing inclusion for children with ASD in communities: Peer interaction and responses in context

### **Principal Investigator:**

Dr. Sandra Hodgetts  
Department of Occupational Therapy,  
University of Alberta  
780-492-8416  
[sandra.hodgetts@ualberta.ca](mailto:sandra.hodgetts@ualberta.ca)

### **Research Coordinator:**

Dr. Ashley McKillop  
Supporting Kids Inclusion &  
Participation (S.K.I.P.) Lab  
University of Alberta  
[amckillo@ualberta.ca](mailto:amckillo@ualberta.ca)

---

### **What is a research study?**

A research study is a way to find out new information about something. Children do not need to be in a research study if they don't want to.

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

You are going to summer camp with other children your age. We want to learn about how children play with each other. Some other children may not know about autism. If you and your parent want, you can share information about autism. We will see if this changes how other kids play with you. You do not need to share any information about autism. We will not share any information about autism.

### **What will happen if you take part in this study?**

You will play at camp like normal. We will take three short videos of you and the other children playing. We will look at these videos to see how other children play with you. If you choose to share information about autism, we will ask you if you think it changed how the other children played with you. We will also ask some other children if they think information about autism changed how they played with you.

### **Who will this study help?**

This study might find out things that will help other children with autism and their parents decide if they want to tell other children about autism.

### **Do your parents know about this study?**

This study was explained to your parents and they said that we could ask you if you want to be in it. You can talk this over with them before you decide.

### **Who will watch the videos?**

We will watch the videos on a computer in a locked room at work. Nobody else will see the videos. We will not share your name with anyone.

### **Who will hear what I say if you talk with me?**

The researchers will listen to the recording and type out what you said. We will not include your name or share what you said with anyone else. Your parents or camp counsellor will not hear what you say.

**What do you get for being in the study?**

You will receive a small present for being in the study.

**Do you have to be in the study?**

You do not have to be in the study. No one will be upset if you don't want to do this study. If you don't want to be in the study, you just have to tell us. It's up to you.

**What if you have any questions?**

You can ask any questions that you want. If you have a question later that you didn't think of now, you can email us at [sandra.hodgetts@ualberta.ca](mailto:sandra.hodgetts@ualberta.ca), call us or have your parents call (780-492-8416).

**Other information about the study?**

If you decide to be in the study, please write your name below. You can change your mind and stop being part of it at any time. All you have to do is tell the person in charge. The researchers and your parents won't be upset.

You will be given a copy of this paper to keep.

Please check your answers:

- Yes, you can include me in the video
- Yes, you can talk with me at the end of camp if needed
- No, I don't want to take part in the study

\_\_\_\_\_

Child's name

\_\_\_\_\_

Child's signature

\_\_\_\_\_

Date

\_\_\_\_\_

Person obtaining Assent

\_\_\_\_\_

Signature

\_\_\_\_\_

Date

## Appendix H

### Information Letters for Parents of Peers

**Study Title:**

Influencing inclusion for children in communities: Peer interaction and responses in context

**Principal Investigator:**

Dr. Sandra Hodgetts  
Department of Occupational Therapy  
University of Alberta  
780-492-8416  
[sandra.hodgetts@ualberta.ca](mailto:sandra.hodgetts@ualberta.ca)

**Research Coordinator:**

Dr. Ashley McKillop  
Supporting Kids Inclusion &  
Participation (S.K.I.P.) Lab  
University of Alberta  
[amckillo@ualberta.ca](mailto:amckillo@ualberta.ca)

---

**Background and Purpose:**

Your son or daughter is being invited to take part in this research study because he or she is a child participating in a community program. This study will look at how children interact with each other in community recreation programs, such as summer camps.

**Description of the Research:**

All children will participate in all camp activities like normal. We will take videos of children interacting with each other during normal camp activities. Taking videos is helpful because we will not be intrusive at the camp, and we can look at behaviours in detail later. We will look at how peers initiate and respond to each other at the beginning, middle and end of camp.

We do not need any information about your child and will not show the videos to anyone other than our research team.

At the end of camp, we may briefly talk to camp counsellors and some children. We will ask them how they think their interaction with other children changed over time. We will audio-record these conversations and type them out with all information that could identify any person or program removed. No one other than the researchers will hear what people said.

**Possible Risks:**

We do not expect that your child will experience any harm if he or she participates in this study.

**Possible Benefits:**

There may not be direct benefits for your child. We hope that this study helps us better understand how children interact with each other, and how this changes over time. If we talk with your child at the end of camp, your child will receive a small thank-you gift for his or her participation.

**Voluntary Participation:**

Participation in this study is voluntary. It is you and your child's choice to take part in this study. You can stop at any time by telling the researcher. We will then blur your child's face in our videos. If they have already participated in an interview, we will destroy their data. Your child's camp activities will not be affected in any way if your child takes part in this study or not. **If you and your child do not want to participate, you need to tell a researcher before your child's camp is finished.**

**Confidentiality:**

No information about who you or your child is will be given to anyone or be published. Videos will only be watched in a locked room at the University. Only the researchers will see the videos.

If we talk with your child at the end of camp, any names will be removed from the typed records of the interviews and in reports about the research. All information will be kept in a secure and locked filing cabinet or in an encrypted computer that can only be entered through a password.

The results of the study may be printed in a newspaper or journal but no child will be identified. The results from this study may be used in presentations or for teaching purposes but your child will not be identified.

We may use the data we get from this study in future research, but if we do this it will have to be approved by a Research Ethics Board.

**What costs are there to you if you enter this study?**

We do not expect you or your child to have any expenses as a result of taking part in the study.

**Contact Information:**

Please contact Ashley or Sandy if you have any questions or concerns. Our contact information is at the top of page 1.

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For question regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615

## Appendix I

*Email study announcement/recruitment that was distributed through existing listservs*

A new research study that is taking place in the Edmonton area related to inclusion of children with ASD in community recreation programs, such as summer camps. We sent this notice for the researchers – they do not know your names, emails or any other information about you. Please see the attached poster and the information below, and direct any responses or questions to the researchers.

Kind regards,

\*\*\*\*

Ethics ID#: Pro00081598

.....  
***Influencing inclusion for children with ASD in communities: Peer interaction and responses in context***

Ethics ID#: Pro00081598

### Research team:

Dr. Sandy Hodgetts, Assistant Professor, Department of Occupational therapy, University of Alberta.

Dr. Ashley McKillop, Research Coordinator, Supporting Kids Inclusion and Participation (S.K.I.P.) Lab, Department of Occupational Therapy, University of Alberta.

Email: [skiplab@ualberta.ca](mailto:skiplab@ualberta.ca)

### *What do we already know?*

Children with ASD participate in fewer community programs than their peers, and are often excluded by peers when they do. This study will look at how peers interact with and respond to children with ASD in community recreation programs, such as summer camps, and whether sharing information about ASD makes a difference.

### *What will we do?*

We will take videos of children interacting with each other during normal camp activities. Taking videos is helpful because we will not be intrusive at the camp, and we can look at behaviours in detail. We will look at how peers initiate and respond to children with ASD at the beginning, middle and end of camp, including whether there is a difference after children share information about ASD.

You do not have to share information about ASD – that is your choice. We do not need any information about peers and will not show the videos to anyone other than our research team.

We have already partnered with the City of Edmonton Neighborhood Recreation Experiences, which are the community-based summer camps. We can also approach other organizations if your child is registered in a different camp. Additional partners are the Centre for Autism Services Alberta and Inclusion Alberta.

*Why is this important?*

Parents in our previous research studies told us that they struggle with whether sharing their child's ASD diagnosis and information about ASD to peers will increase acceptance and inclusion, or exclusion and bullying. Previous research based on stories suggests that sharing information about ASD may improve inclusion, but no studies have been done in real life settings. This will be the first study to look at outcomes in real life settings.

## Appendix J

### Interview Questions

#### **Camp Leaders:**

1. Please talk about if and how you think sharing the diagnosis and information about ASD influenced how peers interacted with and included the child with ASD?
2. What did you think about how the diagnosis and information about ASD was shared (if disclosed)?
  - a. Who shared the information?
  - b. When?
  - c. How?
3. Did you find that the researchers were intrusive in any way? What would you recommend that we do the same? Differently?

#### **Children with ASD:**

1. Do you think your friends behaved differently once they learned about autism?
  - a. Which friends?
  - b. How did they behave differently?
2. Did you like how the information was shared? Would you want it done any differently?
  - a. Who shared the information?
  - b. When?
  - c. How?
3. Do you think you would want to share this information again if you go to a different program? Why/why not?

#### **Peers (disclosure group only):**

1. What did you learn about ASD?
2. Do you think that learning that \*\*\* has ASD changed how you played with him/her?
  - a. In what way?
  - b. How do you think you would have played differently if you weren't told that \*\*\* had ASD?
3. Did you like how the information was shared? Would you want it done any differently?
  - a. Who shared the information?
  - b. When?
  - c. How?
4. Did learning about ASD this week change how you might include other children in the future?
  - a. Would it matter if you were told outright that someone had ASD?