# Exploring Effects of Participation in Group Social Skills Interventions on the Self-Esteem of Autistic Youth

by

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# Abstract

Autistic youth[1] commonly participate in Group Social Skills Interventions (GSSIs) as social-communication difficulties are a core component of their diagnosis. In these groups, autistic youth spend many weeks gaining knowledge about neurotypical social expectations. However, the evidence for GSSIs to improve social competence is modest and inconsistent, and there is questionable meaningful impact on their daily lives outside the treatment setting. Autistic adults, as well as some researchers, suggest that behavioral interventions that are based on normative expectations, including GSSIs, are part of the *normalization agenda*, and may have long-term negative effects on mental health. How participation in a GSSI affects well-being, including self-esteem, is largely unexplored. Taking lessons learned from the autistic community who have raised concerns about potential harmful effects of early versions of behavioral interventions and who call to celebrate autistic differences, this study explores the impact of participating in a GSSI on the self-esteem of autistic youth. Semi-structured interviews were conducted with ten autistic youth to explore how participating in a GSSI within the last year influenced their self-esteem. Drawing on critical disability theory and through an inductive approach guided by Interpretive Description and Thematic Analysis, three major themes were identified: (1) Explicit and Implicit Teachings, (2) Balancing Authenticity and Camouflaging: Impact of PEERS on Self-Esteem, and (3) Navigating the Self. A call for clinicians and researchers to consider a more nuanced, sensitive approach to managing social differences in autistic youth is discussed.

1. Throughout this thesis, identity-first language is used to honor the preference expressed by the autistic community.

# Acknowledgments

First and foremost, I want to uplift and acknowledge my children. Learning how best to parent them, seeing them struggle, and seeing how society responds to and supports them elicited the questions and concerns that compelled me to do a master's thesis. I am thankful for how learning about disability theory, particularly critical understandings, during my graduate classes has broadened my understanding of disability. As I continue to love and support my children, I hope that I continue to learn and be critical of what is considered 'right' and 'wrong' ways of being and doing. I hope to instill in them the deep acceptance of diversity and appreciation of difference that they have instilled in me.

Secondly, I am thankful for the autistic teenagers I met during this project. I enjoyed hearing about their stories and how they have navigated the challenges that adolescence, stigma, and medicalized perspectives bring. I am grateful to the parents of these teens who, by engaging in this project, display a desire to care for their children well and to contribute to knowledge about how to do this. I want to thank my husband for taking on extra tasks around the home as I spent weekends and evenings reading, writing, and contemplating all things social skills, self-esteem, and autistic youth.

Finally, I consider myself lucky to have a kind and intelligent supervisor. Dr. Sandy Hodgetts likely had second thoughts about accepting a master's student who had been out of school for 20 years and never participated in any research apart from physics and chemistry, yet she embraced my research question with curiosity, patience, and enthusiasm. Her responses to the various projects I chose to engage in, from the 3-Minute Thesis to a massive shift in my medical career, showed only patience and encouragement. I always felt expertly supported.

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# Chapter 1

## Introduction

Autistic individuals frequently need to navigate the impacts of personal impairments in the context of stigma, medicalized and deficit understandings of autism, and a dominant neurotypical social landscape that offers little accommodation (Jamison & Schuttler, 2017). For autistic adolescents, this interplay exists in addition to the physical and psychological developmental requirements as they transition into adulthood (Pickhardt, 2023). Efforts to understand one's place in society, cultivate a sense of self and identity, and establish independence, make this transition challenging yet developmentally vital for youth (PickHardt, 2023). Parents recognize this as a vulnerable and important period for their children and strive to provide positive support to ensure a healthy transition.

Autistic youth and their parents often look to experts in the healthcare system for guidance on how to ensure emotional well-being and optimal self-actualization during this time (Attwood, 2015). In particular, many parents and their autistic children look for ways to support the social-communication and interaction challenges that define current conceptualizations of autism (American Psychology Association, 2020; Centres for Disease Control and Prevention, 2019). Acquiring and maintaining friendships is challenging for autistic youth, and addressing this challenge is considered of utmost importance, particularly for parents (McMahon & Solomon, 2015; Rankin et al., 2016). This goal is justifiable as friendship is associated with greater feelings of self-worth and decreased loneliness in autistic children (Bauminger & Kasari, 2000). Research shows that social acceptance is positively correlated with social skills and negatively correlated with depression and anxiety (Viecili et al., 2010) and that greater social capacity predicts greater thriving in autistic children (Simpson et al., 2022). Understandably, interventions to improve social skills are commonly accessed and are considered a valuable treatment by parents and clinicians alike (American Psychology Association, 2020).

There are a variety of training formats but in general, social skills interventions delineate and then teach components of normative social expectations and skills. Amongst these, group social skills interventions (GSSIs) are the most utilized form (Bottema-Beutel et al., 2018; Gates et al., 2017). GSSIs teach social skills in a group setting with several autistic individuals of a particular age-range who do not have co-occurring intellectual disability and who communicate through speech (Lerner et al., 2013). These interventions assume that the social skills learned in the group will successfully generalize beyond the intervention setting, demonstrated by displaying expected social behaviors, which will propel the autistic youth to improved academic, adaptive, and psychosocial functioning (Wolstencroft et al., 2018).

In addition to improving social skills, interventions such as GSSIs are expected to “have a significant lifelong impact” (Laugeson & Frankel, 2010, p. 12), implying that the mental health of the individuals they are designed for is maintained and protected. Protection of mental health is imperative as autistic individuals report poorer mental health, including higher levels of depression and anxiety, than their neurotypical counterparts (Attwood, 2015). Research regarding the effects of GSSIs on the social competence of autistic youth is substantial and ongoing, yet there is very little known about the impact of GSSIs on emotional well-being, specifically self-esteem, for autistic youth (Jamison & Schuttler, 2017; Jonsson et al., 2016). The impact of GSSIs, as with autism research more broadly, is largely measured from the outside (i.e., change in behavior) rather than from the inside (i.e., how the individual perceives that it affects them; Lerner et al., 2013).

Adverse effects of GSSIs have been largely ignored despite calls to address this in the literature (Gates et al., 2017; Gilmore et al., 2022; Lerner et al., 2013). Benevides et al. (2020) identified the investigation of adverse effects of social-behavioral interventions, particularly those that were applied in childhood, as a top priority for autistic adults. They emphasize that the evaluation of adverse effects, as reported by autistic individuals themselves, is largely neglected (Benevides et al., 2020).

The emphasis on behavioral changes and the lack of research on the adverse effects of GSSIs is of particular concern. GSSIs are behaviorally based interventions, albeit focused on social skills, that have some similarities to earlier 'normalizing' interventions, such as Applied Behavioral Analysis (ABA; Anderson, 2023; Bottema-Beutel et al., 2018; Gaylord-Ross et al., 1984). The goal of ABA, still widely used as a therapy, is to broadly minimize autistic behaviors and increase more socially accepted ones (Centres for Disease Control and Prevention, 2019). According to the Autistic Self Advocacy Network (ASAN, 2020), ABA has been linked to traumatic experiences. As with GSSI literature currently, efficacy was established for ABA in the 1980s and it is still considered evidence-based practice (Wong et al., 2015). In fact, according to a review of evidence-based practices for autistic children, Wong et al. (2015) found that early intensive behavioral interventions hold the most substantial evidence for efficacy among comprehensive treatment models. However, effects on participants' mental health were largely ignored in ABA research (Anderson, 2023; Gaylord-Ross et al., 1984). In Anderson's recent phenomenological study exploring the experiences of adults who did ABA therapy in their youth, participants perceived some benefits of the treatment, but they all spoke of adverse long-term mental health effects, and the majority found ABA traumatizing (2023). In response, self-advocates largely oppose interventions that aim to reinforce the appearance of a “normal or near-normal child” (Leadbitter et al., 2021, p. 2).

It appears that many GSSIs are informed by a deficit perspective of disability, situating behaviors associated with autism as undesirable and teaching social skills based on what is perceived as *normal* using a behavioral approach (Bottema-Beutel et al., 2018; Laugeson & Frankel, 2010). While the general concept that improving social skills may lead to benefits in social support seems appropriate (Viecili et al., 2010) and that programs are developed with this intention, there may be associated risks with teaching normative social expectations. Hiding autistic traits, referred to as camouflaging, has negative mental health effects that are independent of the severity of autistic traits (Beck et al., 2020). In part, this knowledge of negative mental health effects has motivated a shift within autistic culture that seeks to move away from indistinguishability as a goal of intervention toward learning about personal strengths, coping strategies, and self-advocacy (ASAN, 2020), which has been shown to improve their emotional well-being (Appelqvist-Schmidlechner et al., 2020; Cooper et al., 2017; Nguyen et al., 2020).

## Problem Statement

GSSIs are a common way that autistic youth and their families seek to address their social struggles relative to the demands of *normal* social behavior. While there is some evidence for GSSI efficacy on knowledge and skills associated with social competence, there is little information regarding the impact of participation in these groups on the emotional well-being of participants. The legacy of interventions aimed at *normalizing* behavior, the known mental health vulnerability of autistic youth, and the emerging ideas from the autistic community around autistic pride highlight the importance of ensuring GSSIs are health-promoting and relevant.

Specifically, more information about the impact of GSSIs on mental health is needed. Increasing understanding of how the self-esteem and emotional well-being of autistic youth are affected by participation in GSSIs is critical to ensure their care is compassionate and ethical. To address this gap, this study used qualitative methods and drew on a critical disability lens to explore how autistic youths' self-esteem and emotional well-being are affected by participation in GSSIs.

## Situating the Researcher and the Research

The researcher's values and assumptions are considered integral to qualitative research, particularly when using critical inquiry (Ponterotto, 2005). It is arguably even more important for this study as it was solely personal experience that compelled the researcher (me) to disrupt an established family/work routine and enroll in graduate studies. In other words, I clearly had strong feelings and a personal investment in doing research in this area. This section is situated at the start of this thesis to mirror the significance of the personal events that primed and set this study in motion.

I have two children (currently aged 15 and 17 years) who are autistic, and I often feel like they live on opposite sides of the spectrum. My son was diagnosed at four years old and communicates using verbal language but has a significant intellectual disability. He swings from contently reading a book for hours to experiencing terror from perseverative thoughts. He feels safest when he is in the vicinity of trusted supports. My daughter was diagnosed as an early teen, has comparatively high cognitive function, and operates only at high speed (both motor and cognitive). She is always looking for something to do with little capacity for quiet. Unlike my son, she feels safest when she can spend extended periods of time engaging in activities on her own.

Armed with years of education immersed in positivistic knowledge and medical school, I initially approached their diagnosis in a linear, biomedical fashion. Consequently, a wide range of interventions to mitigate the expression of their autism were pursued, from dietary adjustments to cognitive therapy to behavioral interventions along with a variety of medications. Social skills interventions were quickly recommended by allied health professionals, and given my (ongoing) respect for expertise, I enrolled my children in various social skills interventions that ultimately spanned many years. These interventions included Lego therapy, self-directed guidebooks, a theatre-based program, one-on-one social skills training, and two different formats of GSSIs.

One of the GSSIs was a locally developed peer-supported program that we participated in for two-to-three years, and overall, we only recall positive experiences from it. It was led by thoughtful and knowledgeable speech-language pathologists and supportive teenage peers. Neither myself nor my children developed negative attitudes towards GSSIs from this experience, and I have recommended the program to friends who also found benefit from it. Of note, I had no preconceived notions or experience with the Program for the Evaluation and Enrichment of Relational Skills (PEERS; Laugeson & Frankel, 2010), the GSSI from which participants were recruited in this study.

However, I recall that I was concerned with some of the deficit language used by instructors of the Lego-based program. After the weekly session, I would get debriefed by the coordinator about how much my son *stimmed* (self-stimulatory behavior) that evening, with more stimming clearly considered a setback. “He did a lot of stimming today; it was really bad.” When both children were a bit older (9 and 10 years), I enrolled them in a social skills program that involved weekly one-on-one sessions with a trained facilitator. It followed a curriculum developed by a well-established local psychologist. While again, at the time, I had no issues with the program, both my children were able to voice negative feelings because of their participation. This seemed merely related to general irritation and a low tolerance for recurring instruction.

It was the Superflex book series (Winner & Madrigal, 2012), a popular self-directed social skills curriculum, that my son reacted strongly to. Consequently, I began to view this program and then social skills training more broadly, differently. After going through several of the books, he said they made him feel bad about himself. On a more careful review of the book alongside my son, I appreciated that the idea that his brain was being occupied and controlled by villains (called the 'Unthinkables') who had the power to make him do socially *unexpected* things evoked fear in him. An ugly villain residing in his brain was obviously distressing, and at one point, he asked me if he could have surgery to "cut it out." It was cathartic for him in later years to be allowed to take his black Sharpie and make choice edits in the manual (Appendix F).

Beyond this concerning messaging, both I and my children recognized their ongoing difficulty in satisfying the goals of the curriculum that were informed by neurotypical social expectations. I began to wonder whether some social skills interventions might be misguided in their attempts to support autistic youth and unwittingly cause detrimental effects on their sense of self. I was particularly concerned about the impact on mental health because I perceived that it was my children's co-occurring mental health issues that disabled them most day to day. Certainly, I recognized that being poorly accommodated and accepted by society was a contributing factor, but I wanted to do what I could to protect them from additional insults to their mental health by helping them develop a healthy self-esteem. Following my children's lead and my desire to limit the repeated demands (from myself and professionals) to dwell on and 'treat' their deficits, I shifted my expectations of their behavior. For example, the demand to make eye contact when listening was abandoned as I began to recognize that my son typically attends better when not doing so.

In tandem with the shift in how I parented, without being fully aware, I experienced a growth in how I understood disability. The changes in societal understandings of disability, as described by Disability Studies and presented to me as part of my graduate studies, were instrumental in helping me make sense of these shifts. I embraced the framework and language of the medical, social, and critical understandings of disability to map my personal journey.

I realized that parenting my children pushed me from a medical understanding of difference to narratives incorporating social and critical perspectives. At times, one perspective may dominate, such as when battling attitudinal barriers of presumed incompetence at my son’s school, situating disability as societal. Most times, however, the ideas of critical disability studies are particularly welcome as they feel closer to my experience of a messy, joyful, humanity-expanding view of disability. Sometimes, if demanded in the moment, I can simultaneously access understanding from multiple models and hold them in tension. As a white, middle-upper-class professional, I have the resources to recognize and fight limiting societal forces, help treat a medical issue, or, more simply, appreciate different ways of being, and this is undoubtedly a privilege. I appreciate the time and capacity to be critically reflexive, allowing me to make these shifts and perspectives more visible (De Schauwer et al., 2016). I know that many of my parent-friends have not had the opportunity to do so.

As described, being a parent of disabled children uniquely positions me in this research. But, in addition to informing my initial medicalized approach to disability, being a physician has also taught me the value of person-centered care. During my 20-plus years of general medicine practice, I have seen medicine increasingly shift towards this approach to patient care. Person-centered care involves evidence-based treatment that respects patient values, goals, and individual needs (Epstein & Street Jr, 2011) and is considered vital in providing respectful and impactful care. I currently work as an addiction medicine doctor at my city's inner-city hospital and help care for medically unwell individuals who live far in the margins of society: houseless with substance use disorders and often co-occurring mental and physical disabilities. A core tenet of treatment for this vulnerable population is trauma-informed care, which involves fostering feelings of trust, safety, and choice. This is done by holistically considering the many elements that make up each person (i.e., physical, spiritual, and psychosocial) and engaging in individualized patient- (and one step further person-) centered care. Professionally and personally, I embrace any treatment that incorporates these elements.

My tendency to serve marginalized populations likely comes from my family's Mennonite heritage. Growing up, I observed that the purpose of one's days was to live out expressions of faith. This included working hard and providing service to others, and particularly for women, self-sacrifice. The work was for the community and not the self. This, too, contributes to my position in this research. Even though my personal experience propelled me to do this study, my desire is undoubtedly to contribute to person-centered care of this vulnerable community.

When reflecting on the various social skills programs our family has done, I worry about how my children internalized some of the messages they received. I certainly have no ill feelings toward the creators or facilitators of any of the programs we participated in; I know that they were offered with only good intentions. However, professional and personal experience has shown me that one should not stop at good intentions; it's only a starting point. While certainly not the reason for doing this study, I also cannot help but feel complicit in contributing to negative messages that my children might have felt, and I am thankful for evolving understandings that can accommodate their unique complexities.

Despite my best efforts, historical and societal forces have partly informed my children's reality, placing some of their social tendencies as *abnormal*. I question the common notion that the treatment goal for autistic youth should be to conform to neurotypical social rules. From my clinical experience in various mental health domains, a strong sense of identity, a realistic self-understanding, a healthy self-esteem along with a set of tools to navigate challenges, contribute to good mental health. This, and personal experience, have shown that being expected to behave differently with questionable capacity to do so is frustrating and demoralizing. I want to see my children and others flourish to their full, individualized capacity and experience intrinsic value and well-being along the way. I used my personal values and assumptions outlined here to enrich and inform the research process while being diligently reflexive about how these could influence the inquiry and was mindful to appreciate alternative perspectives and experiences.

## Structure of this Thesis

This thesis is laid out in five chapters. The first chapter, of which this is part, provides an overview of the topic area, leading up to the problem statement. It also situates me as the researcher in this work.

The second chapter is a literature review of GSSIs, including their outcome measures, efficacy, and current research limitations. The evidence around the impact of GSSIs on emotional well-being and self-esteem is reviewed. This is followed by a description of PEERS, the GSSI program from which participants were recruited for this study, to provide background information that will help situate some of the discussion and implications outlined near the end of the thesis. This chapter also outlines how self-esteem is understood as a construct, how autism influences one’s understanding of the self, and the known factors that influence self-esteem for autistic individuals. Finally, research regarding camouflaging and social relationships amongst autistic individuals, as well as the concepts of neurodiversity and the double empathy problem, are reviewed.

The third chapter describes the theoretical framework that anchors the study, the methodology of Interpretive Description and Thematic Analysis, recruitment, participants involved, data collection and management, and data analysis. Issues around trustworthiness, credibility, and ethics are reviewed. This chapter ends with plans for knowledge translation.

The fourth chapter outlines the results of the study. An overview of the general characteristics of the participants is provided. The themes generated from the analysis are described along with supporting quotes.

The fifth chapter discusses the themes in the context of the literature with interpretations provided by the researcher. This is followed by an outline of the clinical and research implications of this study, its limitations, and associated future considerations. This chapter ends with a summary of the reflections that were recorded and tracked during the research project and a conclusion.

# Chapter 2: Literature Review

## Group Social Skills Interventions (GSSIs)

### *What are GSSIs?*

GSSIs are the most widely used and studied form of social skills intervention for autistic youth (Wolstencroft et al., 2018) and are considered evidence-based treatment (Wong et al., 2015). Some GSSIs explicitly teach social skills and focus on knowledge, while others teach social skills more implicitly, using recreational or performance-based activities (i.e., drama or Lego-based programs; Lerner et al., 2013). Apart from varying teaching strategies, other key dimensions of GSSIs vary, such as the duration, intensity, and adherence to a manualized curriculum (Lerner et al., 2013). Most common, however, are GSSIs that follow a structured curriculum, using some combination of didactic teaching, role play, modeling, skills practice, and verbal feedback (Lerner et al., 2013; Wolstencroft et al., 2018). Curriculums typically cover non-verbal and verbal communication, social interactions, and social problem-solving based on normative expectations (Lerner et al., 2013). Commonly, GSSIs include a parent intervention group that runs parallel to the youth intervention group, providing educational support and resources to help practice learned skills outside of the intervention setting (Lerner et al., 2013).

### *How is Efficacy Assessed for GSSIs?*

Assessment of the efficacy of a GSSI is primarily accomplished using questionnaires that assess social competence (Lerner et al., 2013). Social competence is generally thought to consist of two distinct constructs: social performance (enacting a behavior) and social knowledge (knowing the expected behaviors), and questionnaires typically target at least one or the other (Gates et al., 2017; Lerner et al., 2013). Parents are the most commonly used informant, followed by participants themselves, and less often teachers or other observers (Gates et al., 2017; Lerner et al., 2013). Infrequently, clinicians or intervention staff use behavioral observation through a task-based assessment of specific skills (Lerner et al., 2013). To assess changes in social performance, the Social Responsiveness Scale (SRS; Constantino, 2013) or Social Skills Rating System (SSRS or its later version, SSIS; Elliott & Gresham, 2013) are the most commonly used questionnaires for parents and teachers (Lerner et al., 2013). SRS is a 65-item scale of the 'severity' of autistic traits, including social impairments, social awareness, social information processing, capacity for reciprocal communication, social avoidance, and autistic mannerisms (Constantino, 2013). SSRS/SSIS is a 52-item questionnaire rating the frequency and/or quality of social behaviors in the home or classroom over a set time frame (Elliott & Gresham, 2013). The Quality of Socialization (or Play) Questionnaire (QSQ/QPQ; Laugeson & Frankel, 2010), a 10-item self-report and parent-report measure, assesses the frequency and quality of get-togethers and is considered the closest proxy of using social skills in real life amongst the measures (Zheng et al., 2021). To assess social knowledge, the Test of Adolescent Social Skills Knowledge (TASSK; Laugeson & Frankel, 2010), which is a series of multiple choice and true or false questions that reflect the didactic instruction of its curriculum, is commonly used.

The validity of parent- and self-report measures has been questioned due to the potential for expectancy bias (Gates et al., 2017; Lerner et al., 2013; Wolstencroft et al., 2018). Further, a large discrepancy in reported social competence between parents and adolescents has often been noted in efficacy studies with youths' tendency to overestimate their social performance compared to their parents, particularly after an intervention (Gates et al., 2017; Lerner et al., 2013; Vuori et al., 2017). Teacher report is thought to be protected from expectancy bias and, therefore, potentially more helpful to inform generalizability (Lerner et al., 2013).

Despite their widespread use, the evidence supporting GSSIs is limited, with studies reporting benefits that are modest and mixed (Choque Olsson et al., 2017; Gates et al., 2017; Gilmore et al., 2022; Lerner et al., 2013). Making firm conclusions about efficacy is difficult (Wolstencroft et al., 2018). Interventions are considered efficacious if social competence improves after the intervention compared with beforehand, with assessments commonly administered just before and after the intervention (Lerner et al., 2013). In addition to concerns about measurement validity, only a quarter of the studies assessing efficacy employ a control group. These consisted primarily of a waitlist or non-treatment control, which even when used, calls into question claims of efficacy (Gates et al., 2017; Lerner et al., 2013).

### ***Outcomes of GSSIs***

The most recent meta-analysis of GSSIs for adolescents with disabilities assessed 16 randomized controlled trials (RCTs) and found that 15 of them included autistic adolescents (Gilmore et al., 2022). Results from studies that utilized a range of manualized GSSIs were pooled and organized by individual measures of social skills (i.e., SRS, SSIS, TASSK, QPQ) to optimize homogeneity in reported outcomes (Gilmore et al., 2022). They found gains in social skills (SRS, SSIS) based on parent ratings but not from teacher ratings (SRS, SSIS) nor self-report (SSIS, FQS - the quality of best friendships). There was an increase in hosted get-togethers (QPQ) but not invited get-togethers. Social knowledge (TASSK) based on adolescent self-report showed a strong treatment effect. No differences were seen at the three-month follow-up with either parent or teacher report. The authors concluded there was moderate certainty of evidence, downgraded due to serious risk of bias, for gains in social skills based on some measures (SRS, SSIS, TASSK), but low certainty of evidence for improvement based on others (QPQ). They highlighted that self and parent-report questionnaires are potentially influenced by expectancy bias and that positive impacts on social functioning were limited. They also identified that more information about participant goals is needed in GSSI research (Gilmore et al., 2022).

The largest meta-analysis is from 19 RCTs of differing GSSI strategies (both performance and knowledge-based), which organized pooled data by informant (i.e., all parent data pooled, all teacher data pooled, all participant data pooled, all observer data pooled; Gates et al., 2017). Overall, findings demonstrated moderate improvements in social competence, but results varied between sources. There was a small treatment effect according to parent and observer reports, no effect according to the teacher report, a medium effect for an observed task-based measure, and a large effect from adolescent self-report (Gates et al., 2017). However, the latter effect became negligible when social knowledge was excluded in a post-hoc analysis, suggesting the measured outcome was primarily driven by increased knowledge but not a change in social behavior (Gates et al., 2017). The authors found evidence for publication bias in the overall meta-analysis, suggesting that the actual effect of GSSIs may be smaller than reported and that given the complex nature of social competence, measurements of effect may be confounded by any number of variables (such as effects of group cohesion), that could not be teased apart when using waitlist or no-treatment control groups (Gates et al., 2017). They suggest that unpublished null self-report findings (i.e., without social knowledge measures) and teacher report findings may contribute to the observed bias.

To address concerns about the wide heterogeneity of interventions included in previous meta-analyses, Zheng et al. (2021) approached their meta-analysis and systematic review by pooling data from 12 studies (nine waitlist control, three repeated measures design) that utilized only the PEERS program. Like previous reviews, adolescent self-reported social skills knowledge (TASSK) demonstrated a large effect; parent-reported social functioning (SRS and SSIS) had a medium effect; and there was a small effect on parent- and adolescent-reported get-togethers (QSQ). Uncertainty as to whether gains in social knowledge confer benefit beyond the treatment setting, lack of blinding to intervention and active control groups, and the likelihood of expectancy bias of parent-report were highlighted (Zheng et al., 2021). Additionally, they conceded that it was difficult to make conclusions about the effect of GSSIs on get-togethers because planning to do them is expected homework during PEERS. Their study reinforced the pattern in the literature of decreasing effect size when going from knowledge to performance and that PEERS may be better at improving social knowledge than for applied use. They emphasize the need for higher-quality studies and more information about the effects on mental health (Zheng et al., 2021).

There is a wide range of GSSI formats and heterogeneity in participant characteristics (Lerner et al., 2013). A review of the literature reveals inconsistent findings as to which intervention and participant features confer the most effect (Gates et al., 2017). For example, there is some evidence that interventions that incorporate a parent group and of greater duration and intensity obtain larger effects (Wolstencroft et al., 2018), while another study showed no effect related to parent and teacher involvement (Dekker et al., 2014). No consistent effect related to co-occurring conditions (such as attention-deficit/hyperactivity disorder; ADHD), autism severity, age, gender, intellectual ability, verbal or social ability, social self-awareness, or parent satisfaction has been found (Gates et al., 2017; Lerner et al., 2013). There is a paucity of information regarding participant satisfaction or other attributes, such as motivation or sensory differences (Lerner et al., 2013). A relatively recent study found that improved outcomes with GSSIs were related to lower parent-perceived difficulty in social skills, higher verbal ability, and younger age (Dekker et al., 2021). Neutral effects were found related to gender, level of social performance at baseline, and autism symptom severity, and smaller effects with higher anxiety levels (Dekker et al., 2021).

### *Limitations of Current Research Related to GSSIs*

There are recurrent limitations in the majority of research assessing the efficacy of GSSIs, most notably the lack of blind observation and active control groups (Gates et al., 2017; Kaat & Lecavalier, 2014; Lerner et al., 2013; Reichow et al., 2013; Wolstencroft et al., 2018). Indeed, the effect of GSSIs is similar to that seen in any group treatment for youth, suggesting that a nonspecific factor, such as group cohesion, drives benefit (Gates et al., 2017). Other limitations include questionable generalizability, lack of effectiveness research (Jonsson et al., 2016), use of self- and parent-report assessments that are prone to expectancy bias (Wolstencroft et al., 2018), deficiency in adverse event reporting (Trembath et al., 2023), and outcomes that focus on reductions in autism characteristics as opposed to more meaningful measures such as well-being, quality of life or community participation (Trembath et al., 2023). Most relevant to this study is that very little attention has been paid to the experiences of autistic youth when participating in these programs, including perceived mental health outcomes (Wong et al., 2015).

Despite calls for a higher quality battery of assessments and outcomes (Kaat & Lecavalier, 2015; Lerner et al., 2013), there has been little change in how the impact of GSSIs has been measured. For example, the TASSK questionnaire, created by the founders of one GSSI, PEERS, primarily measures participants' rote memorization capacity of the PEERS program, yet is commonly used to assess social competence (Kaat & Lecavalier, 2014). In most manualized programs, parents are given lists of discrete skills being taught and may look for specific skills expected to be learned after their weeks of effort (Gates et al., 2017; Wolstencroft et al., 2018) without considering the quality and satisfaction of real-life relationships. Treatment allegiance and vulnerability to the placebo effect when using questionnaires such as the SRS suggest that parent reports are particularly susceptible to expectancy bias (Jones et al., 2017). Additionally, gains reported by parents are likely perceived in limited settings (at home), whereas some research has shown infrequent behavior change in naturalistic settings (Gates et al., 2017; Williams White et al., 2007). While not typically done, blinded behavioral observations in a natural setting would have the greatest validity (Lerner et al., 2013).

Longer-term follow-up beyond the duration of the GSSI is often lacking, affecting the ability to draw conclusions about long-term effects through meta-analyses (Gates et al., 2017; Trembath et al., 2023; Wolstencroft et al., 2018). In one study, parents felt that social functioning improved after a GSSI, but no further improvement was observed at six months follow-up (Dekker et al., 2019). The involvement of teachers and parents in the intervention was hypothesized to support maintenance beyond the treatment setting (Moody & Laugeson, 2020). However, this was not found (Dekker et al., 2019). In examining the durability of PEERS for preschoolers, parent reports of social function (SRS and SSIS on raw scores only) and engagement (QPQ) were maintained over one-to-five years of follow-up, while problem behaviors and parent stress returned to baseline (Tripathi et al., 2022).

It appears that the most robust effect of GSSIs is an increase in social knowledge among participants; however, a clear gap in the research exists about whether this knowledge is generalizable to real-life interactions (Gates et al., 2017; Jonsson et al., 2016; Lerner et al., 2013; Zheng et al., 2021). Systematic reviews have generally focused on internal validity, such as the quality of research design and analysis, to ensure results are valid for the studied population

(Jonsson et al., 2016). External validity (whether findings can be generalized across populations or environments) has been largely ignored (Jonsson et al., 2016). In their review of the external validity of GSSI studies, Jonsson et al. (2016) concluded that the generalization and maintenance of social skills beyond the intervention setting are unclear. Participants seem to have an awareness of improved knowledge of expected social skills despite not performing them (Gates et al., 2017). There is a need to shift from efficacy research to effectiveness research, including questions related to external validity to determine whether the demonstrated benefits of GSSIs are meaningful in the youth's life (Jonsson et al., 2016; Lerner et al., 2013).

Notably, there is little known about the impact of GSSIs on the emotional well-being of autistic youth, which has been repeatedly pointed out in the literature (Jonsson et al., 2016; Lerner et al., 2013; Reichow et al., 2013; Trembath et al., 2023). There are a handful of studies that have measured the effects of various GSSIs on mental health; however, results are conflicting. Generally, parents and children express overall satisfaction with GSSIs (Lerner et al., 2013). Some studies have suggested short-term improvements in depression (Schiltz et al., 2018; Yoo et al., 2014), although others showed no effect on depression (Reichow et al., 2013). One study showed improvement in social anxiety (Schohl et al., 2014), while others showed no significant change in anxiety symptoms (Hill et al., 2017; White et al., 2013). Using pretest-posttest designs, one study showed improvement in a global self-worth subscale among 6–14-year-olds (Weiss & Burnham Riosa, 2015), and another showed no change in loneliness among young adults (Honan et al., 2023). Overall, these studies have the same limitations as other efficacy studies of GSSIs, including expectancy bias of parent and self-report measures, lack of active control groups, and small sample sizes, leaving uncertainty about what is driving measured effects.

Adverse event data is similarly limited (Gilmore et al., 2022; Jonsson et al., 2016, 2019; Kaat & Lecavalier, 2014; Trembath et al., 2023) for GSSIs. This is the case for non-pharmacological interventions generally, despite them being the first (and sometimes only) intervention that families access (ASAN, 2020). Many studies report no adverse event data, and when they are rarely reported, they have included concerns about missed school, minor physical illness, or increased anxiety (Gilmore et al., 2022). Psychological treatments, in general, run the risk of causing harm (Duggan et al., 2014), and there is concern by several investigators that increased awareness of impairments that might be recognized during a GSSI warrant looking for unintended consequences such as evoking negative internalizing symptoms (Anderson, 2023; Bottema-Beutel et al., 2018; Cresswell & Cage, 2019; Gardiner, 2017; Howe et al., 2023; Leadbitter et al., 2021; Lerner et al., 2013; Trembath et al., 2023). In their umbrella review of systematic reviews of non-pharmacological treatment for autistic youth, Trembath et al. (2023) showed that, while there is a positive effect for behavioral interventions, "there is a concerning lack of reporting of adverse effects in the literature to date, including null or negative findings" (p. 287). They highlighted that meaningful outcomes such as well-being and quality of life are lacking and stress a need for more "stringent monitoring of the child and family progress to ensure safe and socially valid outcomes" (Trembath et al., 2023, p. 287).

Finally, as already outlined, the impact of GSSIs is typically measured quantitatively, assessing change in social behaviors and social knowledge, while the experiences of autistic youth are largely not explored (Choque Olsson et al., 2016; Lerner et al., 2013; MacLeod, 2019). Trembath et al. (2023) state more qualitative research that centers on the lived experience of the autistic community is needed to help generate knowledge that is meaningful to autistic children and their families. One qualitative study explored parents' and participants' perceived changes in social skills and opinions about the structure and content of a manualized GSSI (Choque Olsson et al., 2016). Parents and participants were satisfied with the treatment and felt positive about its structure and content, particularly enjoying the group play and atmosphere. They perceived positive social change, such as gains in verbal and nonverbal communication and managing conflicts, and other positive changes, such as increased feelings of independence and social confidence (Choque Olsson et al., 2016). Negative aspects of the GSSI, such as practical concerns (missing school), were infrequently reported, but one participant did report experiencing increased social fears. To the best of the researcher's knowledge, there are no other qualitative studies exploring the emotional and mental health consequences of GSSIs.

### ***Recent GSSI Research that Addresses Limitations***

Recent studies have addressed some of the recurrent limitations seen in GSSI studies. In their assessment of a Dutch adaptation of PEERS, an active control group (a psychoeducation training program for adolescents) of similar duration and structure was utilized to mitigate the confounding effect of group participation (Idris et al., 2022). An observational measure of social skill competence was used to address concerns about expectancy bias in parent and self-report questionnaires, with assessors blinded to treatment. Both approaches showed improvements in positive affect and observed social skills irrespective of condition, and no difference was observed in social skills using the observational measure. Like previous studies, a self-report questionnaire (SSIS) showed increased social skills, and a parent-report (SRS) showed decreased social skill impairment. Parents were more satisfied with PEERS than with the active control intervention, but no difference in satisfaction between groups was seen among teens (Idris et al., 2022).

Afsharnejad et al. (2022) undertook an RCT comparing a Swedish-adapted 16-session manualized GSSI (KONTAKT) to a cooking group as an active control. Attention was paid to establishing personally meaningful social goals amongst participants and capturing adverse effects and the impact on emotional health (social anxiety, loneliness, quality of life, daily emotional states) through questionnaires, in addition to the typical battery of social skill assessments. Both groups demonstrated significant and similar progress in their social goals. However, the intervention group showed greater progress at the three-month follow-up (Afsharnejad et al., 2022). Social anxiety was found to decrease in the GSSI group compared to the active control group. However, there were no between-group effects on parent- or self-reported social skills, self-reported quality of life, emotion recognition accuracy, or daily emotional states (such as degree of loneliness or confidence). Negative experiences were reported across both groups, including a lack of understanding as to why they needed to attend the group, anxiety and stress, feelings of hopelessness, a sense of failure, and feeling stigmatized. The authors suggest that being in a group is challenging and may have provoked insights into personal limitations. Despite this, most parents and adolescents reported being highly satisfied with their participation. Unexpectedly, at three months follow up, both groups reported a significant reduction in happiness, leading the authors to stress the importance of appreciating the potential of GSSIs to evoke adverse events in both short-term and long-term (Afsharnejad et al., 2022).

Honan et al. (2023) explored young adults' (age 17-23 years) experience of participating in an adapted PEERS program using a mixed methods study. Through focus groups at program end, participants expressed that they found the amount of information and the nature of topics and homework challenging. Still, they enjoyed it overall, particularly meeting and interacting with others in the group. Parents and participants found the information useful but acknowledged that essential areas in social interaction were still difficult. In the quantitative component of the study, they found no significant improvements in self-report of social functioning, although parents reported significant improvements using the same measure. As in previous studies, social knowledge was significantly increased after completing the program (Honan et al., 2023).

## PEERS

There is a wide variety of social skills programs, but all the participants in the present study had completed PEERS (Laugeson & Frankel, 2010). The program is offered by local autism service organizations with whom the research team has connections, and while COVID put a halt on many in-person groupings, some in-person PEERS programs restarted when recruitment for this study began.

The overarching goal of PEERS is to make and keep friends, resulting in *get-togethers* (Laugeson & Frankel, 2010). It has been widely utilized, having been translated into several languages, and is the most studied of the GSSIs (Zheng et al., 2021). PEERS offers a combination of didactic instruction, modeling, and performance practice. The program consists of 14 weekly 90-minute parent and teen sessions. It is behaviorally oriented, with material presented as a set of up to 27 rules/steps to be followed and practiced by parents and teens (Laugeson & Frankel, 2010). Inappropriate and appropriate versions of the targeted behavior are role-played by coaches, which the participants then practice with supervision and feedback. There is a dedicated time for a *teen activity*, such as sharing a special item with the group or playing a game. Each session ends with a homework assignment relevant to the skill learned, which is to be reviewed at the following week's session. Each week, points are tallied for each participant based on homework completion, group participation, and adherence to group rules. The sessions cover topics thought to be important to making and keeping friends, including conversation skills, entering/exiting a conversation, appropriate use of humor, handling bullying and disagreements, good sportsmanship, and how to change a bad reputation. Homework consists of weekly phone calls and/or get-togethers.

Before enrolling in PEERS, there is a screening process consisting of an intake interview with both the parent and teen. This process is undertaken to help assess verbal ability, intellectual ability, and youth and parent interest to ensure suitability to the program. Parents are considered vital to the program and are asked to commit to finding extracurricular activities and arranging get-togethers to complete homework requirements. They also must agree that social contact between PEERS members during the duration of the program is prohibited. Outcome assessments, including the SSIS, SRS, QPQ, and TASSK, are often administered prior to starting and at the end of the program.

## Self-Esteem, a Component of the Self-System

Self-esteem is an individual's evaluation of their worth as a person (Reitz, 2022). It is considered a fundamental psychological construct that captures broad interest from scientists and the public alike as it is generally accepted to be an essential component of personal thriving and happiness (Reitz, 2022). An accepted definition was expressed by Coopersmith (1967), during a time when self-esteem research was rapidly expanding, as "a personal judgment of the worthiness that is expressed in the attitudes the individual holds towards himself" (pp. 4-5). Characterized by this subjective sense of worthiness, someone with high self-esteem feels good about themselves (Donnellan et al., 2015). Self-esteem is considered a protective resource to help navigate life's problems (Donnellan et al., 2015). Low self-esteem is linked to depression, anxiety (McCauley et al., 2019), and alienation (Heatherton & Wyland, 2003).

According to psychology literature, self-esteem is a component of the self-system, along with self-concept and self-efficacy (Byrne, 1996). Self-concept is a comparatively broader construct, as it incorporates how one perceives their cognitive, behavioral, and affective characteristics and includes beliefs of self-worth and competencies (Byrne, 1996). It also includes those characteristics that one appreciates are shared with members of various groups (i.e., one's social identities; Cooper et al., 2017). Self-efficacy is a judgment of one's competence to do a task and is more performance-based (Byrne, 1996). Byrne (1996) demonstrates this difference with "I am good at science" as self-concept, while "I can solve this science problem" as self-efficacy (p.4). On the other hand, self-esteem is an emotional evaluation of one's self-worth and is considered distinct from other components of the self-system (Byrne, 1996; Juhasz, 1985). Byrne (1996) points out that a student may consider themselves to have low physical self-concept because they are not good at a particular sport (self-efficacy), but this may or may not impact self-esteem.

### *Nature of Self-Esteem*

There are ongoing debates about whether self-esteem is a result of psychological vs. social processes; if it is a trait (is stable) vs. a state (is fluctuant); if it is an independent vs. dependent variable (the cause of behavior or the result of it); and if it is a product of self-protection vs. motivation for self-actualization (Mruk, 2013). Additionally, there are several perspectives on how self-esteem is structured, such as whether it consists of a unidimensional/global self-evaluation or a multidimensional one, informed by several independent developmentally appropriate 'domains' (e.g., academic, physical, and social; Byrne, 1996; Heatherton & Wyland, 2003).

For this study, self-esteem is considered multidimensional in structure and is an internalized product of one’s social environment and interactions (Heatherton & Wyland, 2003; Reitz, 2022). Through a process of symbolic interactionism (Blumer, 1969), individuals internalize the attitudes and ideas expressed by important figures in their lives (Heatherton & Wyland, 2003). Self-esteem development is a dynamic process of interaction and comparison with others, constrained by the range of the meanings and understandings one has access to (Blumer, 1969).

As a multidimensional construct, self-esteem is composed of interrelated facets, each with its own measure of value depending on the individual, their stage of life, and context (Marsh & Shavelson, 1985). Some of these facets are more amenable to change than others. Dapp et al. (2022) conducted a meta-analysis on the prospective effects between global and domain-specific facets of self-esteem and found that they impact each other bidirectionally. So, global self-esteem affects social ability/acceptance, for example, and vice versa.

The framework developed by Rietz (2022) is particularly helpful in understanding how self-esteem can change from moment to moment and over a lifespan. Her integrated process framework for self-esteem change, informed by multiple theoretical perspectives, describes a temporal change sequence that is influenced by cognitive, emotional, and reflective factors. It is supported by a general understanding that self-esteem is both a state and a trait, where the trait is largely stable day to day but can change trajectories depending on momentary negative or positive experiences (Heatherton & Wyland, 2003). For example, repeated negative psychological experiences during a particularly vulnerable life transition can cause long-term decreases in self-esteem (Reitz, 2022). This mechanism theorizes how state self-esteem changes (a brief shift) can drive a change in trait (stable) self-esteem trajectory. She summarizes that state self-esteem is particularly sensitive to self-conscious emotions, such as pride and shame, and how one interprets life events based on one's identity narrative. As mentioned, she emphasizes that adolescence is a developmental period with less stability in self-esteem and, therefore, more vulnerable to a trajectory shift that can have long-lasting effects (Reitz, 2022).

### *Assessment of Self-Esteem in Autism*

The abstract nature of self-esteem has spurred scientific debate on how best to assess it (Byrne, 1996). One point of apparent agreement in the literature is that self-esteem, as a subjective experience, is best determined by self-report (Byrne, 1996; Harris et al., 2018). Byrnes (1996) states that proxy reporting, using parent and/or teacher rating instruments to measure inferred self-concept, is a “dubious” practice (p. 61). Still, she and others appreciate that weaknesses exist in self-reporting, particularly with questionnaires (Byrne, 1996). Even well-meaning subjects will give responses that are subject to various filters and limitations (Donnellan et al., 2015). Protection of self-esteem is thought to result in an overestimation of social skills based on self-report questionnaires among individuals with autism and ADHD (Lerner et al., 2013). Results can also be distorted by inadequate self-insight or careless responding (Donnellan et al., 2015). Heatherton et al. (2003) contend that pressure to respond in an expected manner might be easier with a measure than an interview. Interviewing, therefore, could mitigate these misleading factors as the interviewer can assess for hints of defensiveness or ask questions in different ways to ensure understanding or elicit nuanced responses.

Research on how autism affects understanding of the self-system is minimal, especially for youth (Huang et al., 2017). It is thought that autistic individuals might have difficulty with self-understanding (including self-esteem) because of issues in social communication, fragmented autobiographical memories, and theory of mind (Huang et al., 2017; McCauley et al., 2019). In their review of the research, Huang et al. (2017) conclude that autistic individuals are likely impaired in the psychological self, but there is disagreement about the degree and/or nature of this impairment. Some researchers believe that autistic individuals have generally limited awareness of self and that self-report cannot be relied upon heavily (Mazefsky et al., 2011). Others suggest that autistic youth demonstrate select areas of weaker self-concept that align with autistic characteristics, such as interpersonal and social aspects of the self, with global self-concept preserved (Farley et al., 2010; Nguyen et al., 2020). Goddard et al. (2017) assessed autobiographical memory capacity, thought to be vital in self-understanding, and found that autistic adolescents had similar abilities as non-autistic peers to recall and recognize self-defining memories but may not attribute the same importance to them and showed a bias toward negative memories. Lee and Hobson (1998) showed that autistic participants tended to talk less about their social experiences than their peers with intellectual disability, however, they were able to describe themselves perfectly in physical and psychological terms. Importantly, McCauley et al. (2019) found that autistic self-report of self-esteem was reliable and consistent when compared with non-autistic peers and concluded that self-esteem is a clinically relevant construct for autistic youth. They stated that “meaningful global self-esteem can be formed despite the social and cognitive limitations experienced by youth with ASD” (McCauley et al., 2019, p. 407).

Thus, limitations in self-understanding as outlined above are recognized, yet research suggests that autistic individuals have both awareness of their difficulties and the capacity to describe themselves (Williamson et al., 2008). For example, autistic children rate their competence in social and athletic domains (Capps et al., 1995; Huang et al., 2017; Nguyen et al., 2020; Vickerstaff et al., 2007; Williamson et al., 2008) and peer approval (Williamson et al., 2008) as lower than neurotypical peers. Relatedly, in their review of the efficacy of GSSIs described earlier, Gates et al. (2017) suggested that their findings contradict theories that autistic individuals have limited insight into their social competence as autistic youth seemed able to differentiate between “reflecting on their own knowledge of a behavior versus the enactment of it” (p. 174).

### ***Factors Influencing Self-Esteem in Autism***

Increasingly, the investigation of factors that influence self-esteem in autistic individuals is being pursued. This is in large part because of the increased risk for mental health problems (Attwood, 2015) and a greater understanding that both autistic adults (Tsermentseli, 2022) and youth (van der Cruijsen & Boyer, 2021) have lower self-esteem than their non-autistic peers. Discrimination, stigma, and concealment of autism are thought to be important drivers of this finding (Botha & Frost, 2020). Low self-esteem is related to negative mental health consequences, including depression in autistic adults and youth (McCauley et al., 2019; van der Cruijsen & Boyer, 2021), and is likely associated with greater difficulty in achieving goals, including employment and maintaining relationships (Nguyen et al., 2020). On the other hand, self-esteem is an important predictor of life satisfaction in autistic adults (Tsermentseli, 2022). Researchers, therefore, have stressed the importance of supporting autistic youth in holding positive views of themselves to protect against negative internalizing symptoms (McCauley et al., 2019).

Acquiring autism identity (sense of belonging to a group) is positively associated with personal self-esteem if the collective self-esteem (the perceived value of belonging to a group) is positive, such as in autism pride (Cooper et al., 2017; Corden et al., 2021; Rodriquez et al., 2023). On a more individual level, positive self-appraisal about one’s autism (i.e., greater perceived benefits such as a high level of focus or special interest) is significantly related to better self-esteem (Cooper et al., 2017; Nguyen et al., 2020). In contrast, greater dissatisfaction with autistic identity predicted lower self-esteem and a desire to distance oneself from the label (Corden et al., 2021). Perceptions of giftedness, power in relationships (ability to influence others), and emotional resilience were also important factors for self-esteem in adults (Nguyen et al., 2020). For autistic youth, social acceptance was negatively correlated with negative internalizing symptoms such as low self-esteem (Viecili et al., 2010).

On the other hand, higher cognitive ability (such as with age, higher IQ, or greater theory of mind ability) is associated with lower self-perceived social competence (Capps et al., 1995; Vickerstaff et al., 2007) and lower self-esteem (McCauley et al., 2019; Zimmerman et al., 2017). Researchers hypothesize that a greater capacity for social comparisons leads to increased awareness of social communication deficits and more critical self-appraisal, which increases the risk for emotional disturbances such as depression and decreased self-esteem (Capps et al., 1995; Hedley & Young, 2006; Huang et al., 2017; McCauley et al., 2019; Vickerstaff et al., 2007; Zimmerman et al., 2017). Davidson et al. (2017) argue that their study's findings of greater fear of negative evaluation and shame in autistic adults compared to neurotypical peers go against the notion that autistic adults have less awareness of others. Like their peers, autistic youth are motivated to participate in social comparison, which may result in negative internalizing symptoms (Huang et al., 2017). Supporting this, Hedley (2006) found that there was a positive relationship between autistic youths' perceptions of difference in comparison with others, based on a social comparison scale, and depressive symptoms.

### *Social Skills Training and Self-Esteem*

Research regarding the effect of GSSIs on self-esteem for autistic youth is scarce. The closest proxy to self-esteem assessment was the utilization of the global self-worth scale by

Weiss and Burnham Riosa (2015), who found an increase in global self-worth after the completion of an un-manualised, parent-involved GSSI. As with many studies of GSSI efficacy, there was no control group and the study was unblinded, decreasing certainty of what aspect of the intervention caused change.

While not a direct measure of self-esteem, it is important to consider that learning a skill deemed of low importance or value is not likely to be motivating or positively impact self-esteem (Tyrrell & Woods, 2020). The extent to which social skills change is meaningful to participants is related to the importance of pursuing GSSIs, yet importance ratings in studies of social skills are rarely used (Lerner et al., 2013; Rankin et al., 2016). Parents often consider social skills of paramount importance, yet studies have shown that youth view social skills as less important (McMahon & Solomon, 2015; Rankin et al., 2016). In fact, parent-rated importance is inversely related to youth's self-rated importance (McMahon & Solomon, 2015; Rankin et al., 2016). Parent-child discrepancies also exist related to the importance of specific social skills; youth consider empathy and cooperation important, while parents consider self-control the most important (Rankin et al., 2016). The best practice in supporting youth is to involve them in directing their care (NICE, 2021), and there is evidence that listening to individual goals and providing choices increases motivation, perceived competence, agency, and self-esteem, especially for youth with disabilities (Patall et al., 2008; Tyrrell & Woods, 2020). Therefore, the youths' value of social skills, either perceived or actual, might directly affect motivation and indirectly affect self-esteem.

Researchers hypothesize that social impairments inherent in autism drive autistic youths' lower perceived importance of social skills and that the parent-youth reported discrepancy in the frequency of social engagement (Vuori et al., 2017) is due in part to this perception, as well as inaccuracies in self-monitoring (McMahon & Solomon, 2015; Rankin et al., 2016). While these might be contributing issues, research reveals that autistic youth do have an awareness of their social difficulties and lack of peer approval, albeit to a lesser degree than their parents (Vuori et al., 2017). The parent-youth discrepancy in the perceived importance of social skills could also result from a protective mechanism (Juhasz, 1985). As described by Rosenberg (1979), individuals attempt to maintain their self-esteem by devaluing areas where they perceive themselves as less competent. Ultimately, however, it appears that questions about how social experience and/or skills relate to self-esteem in autistic individuals remain (McCauley et al., 2019).

## Adolescence, Autism, and Social Relationships

Adolescence is generally considered a vulnerable time in the cultivation of 'self' (Goddard et al., 2017), with essential milestones being the development of independence and identity (Pickhardt, 2023). It is a period of life with low self-esteem stability, making it vulnerable to shifts that can have long-lasting effects (Reitz, 2022). Autistic youth share these vulnerabilities, and some show a functional deterioration with the onset of puberty, which has been pejoratively called the *Two-Hit Model*, where autism is the first hit and adolescence is the second (Picci & Scherf, 2015). Autistic youth tend to report lower global self-esteem and higher levels of anxiety and depression than their neurotypical peers (Capps et al., 1995; Goddard et al., 2017; McCauley et al., 2019). Greater mental health issues for autistic teens are theorized to be due to internal factors such as genetics, sensory processing differences, and/or environmental factors such as bullying and lack of acceptance (Chapman et al., 2022).

Autistic youth grapple with an increased awareness of social differences and stigma as well as an increased desire to fit in (Cage et al., 2016; Cresswell & Cage, 2019; Hanai et al., 2021). There is evidence that autistic social differences increase their risk of victimization (Bernardin, Mason, et al., 2021; Cresswell & Cage, 2019; Hsiao et al., 2013). Despite these findings, autistic adolescents want to have and maintain friends (Black et al., 2022; Finke, 2023; Ryan et al., 2021) and are concerned about their reputation (Cresswell et al., 2019). They also desire to understand themselves and can undergo self-reflection, noticing changing feelings, emotions, and behaviors (Hanai et al., 2021).

Increasing social complexities in adolescence make maintaining friendships challenging, leaving some autistic youth to experience loneliness if they are unable to fulfill this desire (Cresswell et al., 2019). Tierney (2016) found that for autistic girls, friendships from younger years deteriorate during adolescence as peers develop different interests and social expectations become more challenging to sustain. Coping strategies of imitation and camouflaging result in feelings of anxiety, depression, and self-harm (Tierney et al., 2016). Similarly, while autistic youth report that lower quality friendships are associated with symptoms of depression, greater friendship quality (such as having fun and feelings of companionship) is associated with increased anxiety for autistic girls, suggesting that there is a cost in maintaining a good friendship (O’Connor et al., 2022).

Autistic youth have different understandings and goals for their friendships than non-autistic peers (Black et al., 2022; Cresswell et al., 2019; Finke, 2023). They report shared interests and activities as a priority as opposed to more relational qualities such as affection or emotional support, and many prefer autistic peers as friends, feeling greater ease and a sense of belonging (Black et al., 2022; Cresswell et al., 2019). They also report that following social expectations, even if they know them, is difficult, and they find group interactions particularly stressful (Cresswell et al., 2019). Social misunderstandings with neurotypical youth are perceived to make bonding difficult, and studies show that autistic individuals often shoulder the responsibility for peer rejection and even bullying (Cresswell et al., 2019).

Recent research shows that there are different preferences for qualities in a friend, and also differences in how autistic young adults prefer to behave or 'be' with friends (Finke, 2023). For example, autistic young adults showed greater preference than non-autistic adults to talk on the phone to arrange plans rather than simply chatting, or to engage in a specific activity together as opposed to simply 'hanging out.' They also enjoyed using virtual spaces to engage with others. Like their neurotypical peers, autistic individuals preferred congruence of personalities and interests in a friendship, but the elements of congruence differed. The authors call for these differences to be considered valid ways to experience friendship even though they fall outside the normative expectations of friendship (Finke, 2023).

## Camouflaging

Camouflaging consists of hiding or suppressing autistic characteristics and is an area of increased interest in recent years (Hull et al., 2017; Leaf et al., 2023). Studies demonstrate that camouflaging is a common practice amongst autistic individuals and is considered harmful to autistic adults (Hull et al., 2017, 2021). Rather than a tool for deception, autistic individuals see camouflaging as a context-dependent mechanism that is accessed to fit in (Hull et al., 2017; Ross et al., 2023). Examples of camouflaging include suppressing stimming behavior and maintaining eye contact (Hull et al., 2017). In adults, it has been associated with exhaustion, generalized and social anxiety, depression, and suicidality (Cassidy et al., 2018; Hull et al., 2017, 2021; Raymaker et al., 2020). It threatens self-perception and self-esteem as individuals feel inauthentic, conflicted, and unaccepted (Cooper et al., 2017; Cresswell & Cage, 2019; Hull et al., 2017). Drivers of these negative consequences may be related to having less physical and psychological reserves to manage day-to-day stress and a lack of recognition of needed accommodations by others (Cage et al., 2018; Hull et al., 2017).

Camouflaging is more commonly used by those with average or above average intelligence (Hull et al., 2017) and by females, despite them viewing the practice more negatively and experiencing the most harm (Beck et al., 2020; Bernardin, Mason, et al., 2021; Leaf et al., 2023). Hull et al. (2019) has conceptualized camouflaging as comprising of three dimensions: compensation (strategies to manage social and communication difficulties), masking (hiding autistic presentations), and assimilation (blending in). They suggest that there are some similarities between camouflaging and impression management or self-monitoring (i.e., manipulating behaviors to make a better impression; Hull et al., 2019), which is considered a typical developmental process. However, a significant difference is that camouflaging results in poorer well-being and mental health difficulties (Bernardin, Mason, et al., 2021). Self-monitoring generally has positive effects on well-being and maintains a sense of self-preservation (Bernardin, Mason, et al., 2021; Hull et al., 2017; Robinson et al., 2020). Despite its negative impacts, autistic individuals recognize the benefits of camouflaging, such as reduced discrimination and negative judgment, greater acceptance, and opportunities for strengthening relationships and employment prospects (Cage & Troxell-Whitman, 2019; Hull et al., 2017).

Camouflaging research has recently broadened to explore the phenomenon in autistic children and adolescents. Howe (2023) found that children as young as ten years old engage in camouflaging; Jedrezjewska (2022) found that the practice increases in adolescence. At younger ages, the main driver is to avoid negative consequences, such as judgment and teasing. In adolescence, gaining positive consequences, such as peer acceptance, increasingly drives camouflaging (Howe et al., 2023). Like adults, there are negative consequences including stress, fatigue, internal conflict, and confusion (Bernardin, Mason, et al., 2021; Howe et al., 2023). It also predicts depression and anxiety (Bernardin, Lewis, et al., 2021; Ross et al., 2023). Another qualitative study with adolescents showed that both non-autistic and autistic youth camouflage for different reasons and non-autistic youth feel better after camouflaging, but autistic youth report negative emotions and fatigue (Bernardin, Lewis, et al., 2021). The authors suggest this difference is because the process involves hiding fundamental aspects of oneself, greater emotional and physical strain, and possibly an awareness of being less effective at it for autistic youth (Bernardin, Lewis, et al., 2021).

Camouflaging is considered both an individualistic response to stigma (Chapman et al., 2022; Perry et al., 2022) and a driver of increased internalized stigma (Botha & Frost, 2020). Stigma is the social discrediting of attributes that causes individuals to feel unacceptable (Goffman, 1990), and internalized stigma is the “acceptance and application of negative stereotypes to one’s self” (Perry et al., 2022, p. 801). Robust research shows that non-autistic adults form negative first impressions of autistic individuals based on their social behavior within seconds (Sasson et al., 2017). In their qualitative analysis of autistic teens’ experience of camouflaging, Chapman (2022) found that it was driven by a variety of factors, including negative treatment (such as bullying), a negative self-image informed by previous experiences, and worry about impression management. In their attempt for greater connection, camouflaging reinforces feelings of disconnection, difference, and shame and decreases self-confidence and self-esteem (Chapman et al., 2022). Similar to camouflaging research in adults, it is associated with sadness, anxiety, and thoughts of suicide in autistic youth (Chapman et al., 2022). Camouflaging is not so much a choice but an anxiety-driven response to not being accepted, anxiety being both a motivating factor and a response (Chapman et al., 2022). The authors express concern about the implicit negative messages of behavioral interventions and highlight that more research is needed to learn whether they reinforce camouflaging. In particular, they state, “the long-term consequences of social skills training interventions for autistic young people need to be considered and interventions which encourage autistic young people towards masking and away from authenticity should be discontinued” (Chapman et al., 2022, p. 16).

How social skills interventions relate to camouflaging is largely unknown. There are claims that ABA results in harmful camouflaging (Anderson, 2023; Leaf et al., 2023). Leaf et al. (2023) performed a literature review on the subject, looking specifically for a relationship between ABA and camouflaging, and did not find evidence to substantiate this. However, the authors note that this relationship has not been directly assessed or discussed in research apart from one commentary on the topic by Bottema-Beutel et al. (2018). They concede that research around camouflaging is still in its infancy (Leaf et al., 2023). It appears, however, that efforts to use instructions from social skills interventions demand all components of camouflaging (compensation, masking, assimilation), based on questions in the Camouflaging Autistic Traits Questionnaire (CAT-Q), which was developed and validated in autistic and non-autistic adults by Hull et al. (2019). For example, question items under the compensation camouflaging factor include “I have researched the social rules of social interactions to improve my own social skills” and “I have developed a script to follow in social situations”; questions capturing the masking factor include “I monitor and/or adjust my body language or facial expressions so that I appear interested” and “I don’t feel the need to make eye contact with other people if I don’t want to” (reversed); and questions capturing assimilation strategies include “In social situations I feel like I am preforming rather than being myself” or “I rarely feel the need to put on an act in order to get through a social situation” (reversed; Hull et al., 2019).

Negative impacts of camouflaging vary across people and contexts; consequently, attitudes towards the practice vary (Cage & Troxell-Whitman, 2019; Hull et al., 2017). Questions remain about how best to use social camouflaging and to benefit from it with minimal risk. Attention to camouflaging is needed during interventions, especially for females, and greater individualization of programming might minimize the costs associated with camouflaging (Leaf et al., 2023). Hull et al. (2021) suggest that a better approach than broadly teaching neurotypical expectations might be to determine which specific strategies are beneficial, then offer components of camouflaging, taking care to evaluate impacts on mental health. For example, one person might find forcing themselves to make eye contact helpful and not too taxing, while another might find it distressing and too distracting to be worth the effort (Hull et al., 2021). In their research on the relationship between camouflaging and mental health in autistic youth, Ross et al. (2023) stress the importance of clinicians being on alert for camouflaging, engaging with youth early to increase awareness and reasons for camouflaging, and shifting expectations from individual behavior change to environmental supports and acceptance so youth feel they can be themselves.

## Neurodiversity

The neurodiversity movement is a reaction to the medicalized approach to neurobiological differences (O’Dell et al., 2016). The neurodiversity perspective describes autism as a neurological difference rather than a deficit; it is considered a component of normal human variation (O’Dell et al., 2016). Neurodiversity is a call to shift support away from indistinguishability as a goal toward promoting subjective well-being, adaptive functioning, and learning about personal strengths, coping strategies, and self-advocacy (ASAN, 2020). Beyond support for the individual, there is also a call for societal approaches such as increased awareness of autistic ways of being and promoting inclusivity and respect for neurodiversity more broadly (Benevides et al., 2020). This approach includes greater appreciation and tolerance of various characteristics or coping mechanisms that are typically considered “autistic” (such as hand flapping, echolalia, or avoidance of eye contact) that may serve as strategies to communicate, express emotion, and reduce stress (Prizant & Fields-Meyer, 2015).

Similarly, Brownlow (2015) argues that broader constructions of friendship beyond the dominant neurotypical expectations are needed. Instead of focusing on the failure of autistic individuals to form relationships with peers, she calls for research exploring alternative ways of being social and having friends, ideally in safe and supportive spaces (Brownlow et al., 2015). For example, a significant way for autistics to connect is via online platforms or autistic-led spaces where neurodiversity is embraced (Brownlow et al., 2015; Milton, 2012).

## Double Empathy Problem

The double empathy problem was first coined by Milton (2012). It is a concept that challenges the accepted notion that the communication limitations of the autistic individual predominantly cause social communication breakdowns. Rather, it is a bi-directional breakdown between autistic and non-autistic people. Parallel to neurodiversity understandings of autism, this concept emphasizes that autism leads to different ways of social interaction. Milton et al. (2022) suggest that instead of focusing on perceived social deficits and normative remediation, “a position of humility in the face of difference, the need to build rapport and understanding and not assume a lack of capacity for understanding” (p. 1903) is needed.

## Chapter Summary

Recurrent limitations in GSSI research have resulted in unanswered questions as to whether measured benefits of improved social knowledge are conferred to real-life situations and/or if they are maintained over time (Gates et al., 2017; Jonsson et al., 2016; Lerner et al., 2013). Research does show that increased capacity for social-communicative ability has positive effects on making friends, ability to learn, thriving (Weiss & Burnham Riosa, 2015), and employment (Chiang et al., 2013); however, it is not clear if GSSIs per se have these effects. There is also very little evidence regarding the impact of GSSIs on emotional health, adverse effects, and perspectives of participants regarding the experience of participating in a GSSI (Afsharnejad et al., 2022; Gates et al., 2017; Idris et al., 2022; Jonsson et al., 2016; Kaat & Lecavalier, 2014). This is of particular interest given the increasing understanding of the harmful effects of early behavioral interventions (Anderson, 2023) and camouflaging, a common practice amongst autistic youth (Bernardin, Mason, et al., 2021; Howe et al., 2023). Whether there is a convergence of these factors to aggravate the mental health vulnerabilities of autistic youth (van der Cruijsen & Boyer, 2021) is largely unknown. While there have been very recent gains in exploring participant experience of doing GSSIs with attention paid to potential adverse effects, there is little attention to the impact on self-esteem.

Research has shown that self-esteem is a meaningful construct for autistic youth and, despite theories suggesting otherwise, self-awareness and self-report are reliable in this group. Self-esteem, an evaluation of one’s worth, is understood to be a multifactorial construct informed by symbolic interactionism. One’s global self-esteem trajectory can be impacted by its constituent domains in a bidirectional manner and can shift based on momentary experiences, particularly in adolescence. Understanding how self-esteem can be protected in autistic individuals is important given their known mental health vulnerabilities. Recently, research has shown how camouflaging negatively affects the mental health of autistic individuals and has offered a greater appreciation of what authentic autistic relationships look like. Newer understandings of autism, including neurodiversity and the double empathy problem, challenge the validity and the ethics of demanding autistic youth to learn and conform to neurotypical social expectations. These understandings align with a critical theoretical understanding of disability, which serves to ground this study and is outlined in the next chapter.

## Research Gap and Present Study

The unknown effects of GSSIs on self-esteem for autistic youth present a clear gap in the research. Knowledge of how self-esteem is affected by participation in GSSIs is critical to inform best practices to support the mental health of autistic youth and to ensure their care is compassionate, relevant, and person-centered. Parents and clinicians need to be vigilant in managing social differences in this group. Camouflaging, increased awareness of, and pressure to conform to normative expectations are not without risks; these issues might set up autistic youth for a decline in self-esteem. In other words, the concern is that the adverse effects of interventions such as GSSIs might outweigh any positive impact.

This study aimed to understand the experience of autistic youth participating in GSSIs. Past research offers little sensitivity to participant experience since it approaches autistic ways of being and interacting with a deficit focus. Dominant assumptions regarding *good* behavior and a *good* life can neglect the attitudes and feelings of those who do not, choose not, and/or cannot meet these expectations. In this study, autistic youth are considered the experts of their experience, and the hope is to create knowledge that is meaningful to them and their community. Using a critical perspective, this study aims to draw attention to the voices of those often not heard because of negative bias.

# Chapter 3: Methodology

## Purpose and Research Question

The purpose of this project is to explore the perceived influence of GSSIs on the self-esteem of autistic youth. The specific research question was: *How does the experience of participating in GSSIs influence the self-esteem of autistic youth*?

## Theoretical Framework

An essential first step in qualitative research is identifying and elucidating the paradigm that anchors the inquiry (Mayan, 2016; Ponterotto, 2005). This ensures the coherence of the process from beginning to end. This study began as a personal response to concerns about treatments that situate autistic ways of being as something to be replaced by neurotypical ways. The hopeful endpoint is that more strength-based and accepting ways of support might be fostered by engaging autistic youth in dialogue about their experiences in interventions.

The critical theory paradigm most adequately encapsulates the origins and goals of this study. Critical theorists use their work to challenge dominant assumptions and ultimately make egalitarian changes in society (Mayan, 2016; Ponterotto, 2005). Throughout this study, I have endeavored to listen to the experiences of autistic youth that I acknowledge to be situated in the hegemony of *normal* ways of being.

Ontology refers to the nature of reality. My ontological position is relativist, which rejects the idea of a singular reality (Braun & Clarke, 2022). Instead, realities are constructed through lived experience and, using a critical lens, are mediated by unequal historical and/or social power relations (Mayan, 2016). Throughout this study, I aspired to understand autistic youths’ experiences from their point of view and to appreciate those experiences as a valid reality (Ponterotto, 2005).

My epistemology, or how we come to know reality, is constructionist. The relationship between researcher and participant, and consequently knowledge generation, is transactional, interpretive, and ultimately transformative for both parties (Ponterotto, 2005). Therefore, the process demands meaningful participant involvement (O'Dell et al., 2016) and, as per critical theory, hopes to promote their empowerment (Ponterotto, 2005). From this understanding of epistemology, language is considered a tool that shapes reality rather than just reflecting it (Braun & Clarke, 2022). I believe that access to certain language, which is related to contextual factors like family and/or societal attitudes toward disability, influences how autistic youth navigate their diagnosis and perception of themselves. In other words, ways of talking about difference and disability help to create their realities.

Axiology considers the relevance of values in the research process. A criticalist anticipates from the outset that their values will influence the entire research process (Mayan, 2016; Ponterotto, 2005) and that they will drive disruption of the status quo. My values of equity, fairness, meaningful acceptance of, and respect for diversity unapologetically guide this research.

## Methodological Approach: Interpretive Description and Thematic Analysis

Interpretive Description (ID) is an inductive research process to "answer complex experiential questions" (Thorne et al., 2004, p. 2). It is a methodology well suited to this study as it seems to strike the right balance of participant description and researcher interpretation. Some methodologies demand a higher level of abstract meaning-making, such as Interpretive Phenomenological Analysis; and while this was considered an option, it was thought to be unrealistic for some participants. In ID, Thorne (2004) emphasizes that the researcher must be prepared to direct and own the interpretative process, shifting the interpretive demands from participant to researcher.

ID is particularly suited to applied health research. It typically starts with research queries related to the patient experience, with the primary goal of creating new insights that can be translated into practice that impact people's lives (Thorne, 2016; Thorne et al., 1997). Thus, the process of ID starts with the individual, who is considered a source of expert knowledge, followed by interpretation beyond the data to capture commonalities and individual variation, resulting in the production of knowledge to be applied back to the individual (Thorne et al., 1997).

The practice orientation of ID, formed in response to the limitations of more theoretically oriented qualitative methodologies (i.e., phenomenology, ethnography; Thorne, 2016), suits the research question and my personal pragmatic style. The process involves a literature review to acquire a solid understanding of existing knowledge, critical reflection to situate oneself in the research, purposive sampling, gathering of data, analysis of data for themes and patterns, and the formation of interpretations bound in context but applicable to changing care in real-life (Thorne, 2016). Likewise, my question demands careful listening and noting, and patterning of subjective experience while considering personal and contextual understandings of disability.

ID is a constructivist approach that views reality as unique, valid, and complex, with knowledge generated through interaction between researcher and participant, informed by the researcher’s values and assumptions (Thorne et al., 2004). ID offers flexibility in research design as it guides the researcher in creating an interpretative account that encompasses thematic patterns and individual variations (Thorne, 2016; Thorne et al., 2004). To this end, Braun and Clarke’s (2022) method of Reflexive Thematic Analysis (RTA) was chosen to analyze and interpret data.

RTA is a method to develop, analyze, and interpret patterns across a data set to form themes (Braun & Clarke, 2022). Through an iterative process of engaging with the data, noting patterns of convergence and divergence across the data using coding, new interpretations arise. As suggested in the *reflexive* part of RTA, the researcher must intentionally reflect on and declare their perspectives and how they might affect the research project (Braun & Clarke, 2022). The researcher is encouraged to embrace reflexivity and creativity as tools in knowledge production (Braun & Clarke, 2022).

Thus, using ID as a guide and RTA as the method, I described, analyzed, and interpreted the accounts of autistic youth to inductively produce knowledge, ensuring a systematic process that is supported by theoretical coherence.

## Recruitment

Inclusion criteria were: (1) confirmed autism diagnosis, (2) no or minimal co-occurring intellectual disability, and (3) between 13-18 years old (the latter two criteria are also inclusion criteria for PEERS). I also chose only to recruit participants who had participated in an in-person, rather than online, PEERS program. I initially proposed a criterion for completing PEERS within the past 3-6 months to provide an opportunity to reflect on and apply the skills and knowledge learned in PEERS. Given the small number of in-person PEERS groups running locally shortly after COVID restrictions were lifted, recruitment proved challenging, taking nearly a year longer than anticipated. As such, I expanded the timeline for participation from 3-6 months to 1-12 months. Through purposive sampling, recruitment started in late 2021 through local autism service providers. Participant enrollment did not occur until the third round of recruitment one year later, in the fall of 2022, with the last interviews being completed in the summer of 2023.

Recruitment initially occurred solely through email that included an information letter and poster about the study (see Appendix B) sent by the Center for Autism Services Alberta (the Centre; Edmonton Alberta) or the ASERT Lab (University of Calgary; Calgary Alberta) on my behalf to maintain the confidentiality of potential participants. After two rounds of this form of recruitment with no expressed interest, I was allowed to introduce myself and present my research study during PEERS sessions at both the ASERT lab and the Center. The goal was to offer a more personal approach and opportunity to answer questions. Interested participants then emailed me to either enroll in the study or gather more information. Both youth and parent consent forms were sent and received through email (see Appendix B). A gift card of $25 was given for participating in the study.

## Participants

ID can be applied to almost any sample size with the number of participants driven by the research question (Thorne, 2016). For this study, our sample size of ten participants allowed time for in-depth interviews, sufficient breadth of description, and depth of interpretation. These participants were 13-16 years old and had completed the PEERS social skills program in the previous 1.5-9 months.

## Data Collection

Semi-structured interviews for each participant were completed virtually. According to their review on how best to elicit the views of autistic youth, Tyrrell et al. (2020) found that semi-structured interviews are commonly used and effective, particularly for older children with greater cognitive capacity, with care taken to adapt the wording of abstract concepts. While I have comfort with the interview process, I approached the interviews much differently than a typical clinical interview, which is steered towards a desired outcome. Rather, using my interview questions as a guide, I followed the youths' lead in going deeper into certain topics. I also have much experience interacting with autistic youth, which proved helpful in developing a rapport (for example, spending time discussing special interests) and rewording questions more concretely if clarity was needed.

The interview guide was developed by the researcher, reviewed by an autistic researcher, and piloted with an autistic young adult (18 years old). Feedback from the pilot interview resulted in rewording questions to make abstract concepts, such as self-esteem, more accessible. For example, asking "How much do you like yourself as a person?" was used first, and then self-esteem was introduced only if the participant demonstrated an understanding of the concept first.

Interviews started with general questions about attitudes around autism, followed by questions about the experience of attending PEERS sessions, and then, ultimately, how participation in PEERS was perceived to influence self-esteem (see Appendix C). Demographic information about each participant, including age, identified gender, pronouns, and age of autism diagnosis, was collected as part of the interview to describe the sample.

The interview duration depended upon perceived signs of engagement/attention or distress (such as increased fidgeting or stimming). They lasted between 16.5 and 40 minutes. Overall, I enjoyed talking with the participants and feel that most interactions were engaging for both parties.

## Data Management

All interviews were digitally recorded and transcribed using the Zoom cloud recording and transcription process. Recordings and transcriptions were uploaded to a double-encrypted folder on the researcher's laptop, which is password-protected. The researcher saved de-identified transcripts in an encrypted, password-protected folder. The accuracy of all transcripts was verified by comparing each with its corresponding audio/video recording. Edits were made as needed. Pseudonyms (numbers) were used for all participants during data analysis and interpretation. All data will be securely kept for five years following the final publication of research findings, after which time the electronic data will be destroyed.

**Data Analysis**

The data were analyzed in an iterative, non-linear fashion using Braun and Clarke's (2022) RTA framework. Using a critical orientation to analysis, where I asked questions about how and why participants' experiences and their descriptions had been created (Braun and Clarke, 2022), I proceeded with analysis using the following steps:

1. Dataset familiarization: After all interviews were completed, I watched the recordings and made notes related to generalities of the interview, such as level of engagement, the overall attitude of the participant as expressed by tone and body language, and my perceived impacts of their environment during the interview process. I also read each transcript two times, adding more general statements before starting the coding process.
2. Data coding: Each line of each transcript was carefully reflected on as a potential unit of data or code. While both semantic (explicit) and latent (implicit) coding were used, it was noted by my supervisor that my coding process tended to lean more towards latent coding, suggesting my tendency towards higher-level interpretations. Some similar initial codes were amalgamated so patterns could be more easily seen. Codes were organized into tables, initially according to each participant and then according to code labels and collated data excerpts. I was the only coder for the study, which is considered best practice for RTA (Braun & Clarke, 2022); however, the transcripts and codes were reviewed by my supervisor to ensure the data were accurately reflected. See Appendix D for examples of coding tables.

As Braun and Clarke (2022) described, my codes evolved, with some codes being parsed out and others being broadened to represent more data.

3. Initial theme generation: Visual mapping techniques were used for theme development as they supported exploring provisional themes and how they related to each other (Braun & Clarke, 2022). Thematic mapping and connections were initially undertaken on a whiteboard. The data were further layered and reorganized by printing and cutting codes into individual pieces of paper. I found using this type of visual map supported new insights and interpretations.
4. Theme development: Further interpretations and connections were made through three rounds of thematic development sessions with my supervisor. An autistic adult with experience supporting autistic youth attended and provided input at two of these sessions, adding a greater depth of understanding of some patterns seen in the data. See Appendix E for examples of visual thematic mapping.
5. Theme refining, defining, and naming: This step is a type of validity check where the themes and subthemes are refined to ensure they are sufficiently descriptive while encapsulating observed patterns of convergence and divergence within the data (Braun & Clarke, 2022). Importantly, themes were examined to ensure they effectively answered the research question.
6. Writing up: Once the themes were established and defined, further reflection and writing allowed another level of interpretation and consideration. In this final stage, I drew on existing research and my acknowledged perspectives to elicit new understandings and produced an account of experiential themes using excerpts of participants' own words (Braun & Clarke, 2022).

## Trustworthiness and Credibility

According to Mayan (2016), rigor (or trustworthiness) in qualitative research is maintained through methodological and theoretical coherence, appropriate sampling and data analysis, concurrent data collection and analysis, and researcher responsiveness. Methodological and theoretical coherence has already been considered and outlined, as have appropriate sampling and data analysis approaches. Here, other aspects of research quality are outlined in more detail.

Researcher responsiveness is crucial to trustworthiness and credibility (Mayan, 2016). It refers to the ability to be thoughtful, flexible, and sensitive with respect to the data (Mayan, 2016). When there was difficulty in recruiting participants, I changed my recruitment approach from only using email to personally introducing myself and my research to PEERS participants. I also demonstrated researcher responsiveness by thoughtfully reconsidering my initial methodological approach, interpretive phenomenological analysis (IPA), when I felt that the data from the first three participants were not rich enough. After consulting with an expert on IPA, I changed the methodological approach to one that I perceived to align with my goals, even though the remaining interviews proved to be quite rich in data.

Data collection and analysis occurred concurrently in this study, which is considered another core feature of qualitative rigor (Mayan, 2016). Unintentionally, I did the interviews in three sets, bundling three to four interviews at a time. After I completed the first set of interviews, I did preliminary coding, noting early patterns in the data. This helped to elucidate what concepts needed to be expanded on during the next set of interviews. After the second set of interviews, I performed an in-depth round of coding of all the data collected until that point. This provided a solid sense of what experiences began to emerge in repetition or contradiction before I completed the last three interviews. At that point, I completed the coding process with established, recurring codes. With coding occurring alongside data collection, my codes were refined to capture more fully the meaning I saw in the data as I interacted with it in an iterative fashion.

An autistic researcher and young adult reviewed the interview guide to ensure the questions were clear and relevant to this population. After each interview, time was spent journaling and noting the overall sense of participant trustworthiness based on engagement, depth of responses, and evidence of distraction (such as watching TV) during the interview. I checked for understanding of more abstract terms when used, such as “masking,” “neurodiversity,” and, as already mentioned, “self-esteem.”

Other components of trustworthiness in qualitative research are the ideas of saturation and member checking. Saturation is when data within the data set repeats itself (Mayan, 2016). Each participant shared nuanced experiences and unique perspectives, yet several core experiences emerged as similar and contradictory in the data set. Member checking is another means to ensure credibility (Shaw & Anderson, 2018). There was concern that this strategy might be confusing for some participants. Interpretation is a necessary part of the inductive process, and, given the level of interpretation of the data, it was not used. To ensure codes and themes represented participants’ experiences rather than my perspectives, my supervisor independently reviewed the data and coding process, and themes were developed collaboratively with a team consisting of myself, my supervisor, and an autistic adult.

While all the above contribute to rigor, researcher reflexivity is considered the most important (Mayan, 2016). Personal experience and attitudes informed this project, which both constrained and directed my sense-making. However, being intentionally reflexive as I held and molded these data was the primary strategy to respect participants and their generated data. Throughout this study, I wrote reflections, noting my initial attitudinal responses and ideas, and conscientiously acknowledging how my values and biases might influence the process and interpretation. As stated, while critical inquiry situates the participant as the expert, it also presumes unavoidable interpretation by the researcher based on their experiences and perceptions (MacLeod, 2019).

## Ethical Considerations

A starting point for an ethical study is to ensure it has a purpose and contributes meaningfully to existing knowledge. The present study sought to hear from autistic youth and how GSSIs might affect their self-esteem - an important, but so far neglected, focus of current research.

Informed consent was obtained from the youth and their parent before participating in the study. Each participant was advised of the purpose of the study, the adherence to confidentiality and its limits, the process, and their rights. I acknowledged the power differential between myself, and the youth being interviewed. In this regard, I decided not to share that I am a physician but I did disclose select personal facts (that I have a cat or that my children are autistic) when I felt it might help level this differential. I made every effort to communicate that they ultimately decided on what information they felt comfortable sharing. They were informed in advance that they had a right to pause or stop an interview at any time.

The needs of the participants were closely monitored by me, who has experience in recognizing cues of anxiety and overstimulation in autistic youth. As a result, two of the interviews were cut short. The researcher ensured a supportive adult (parent/caregiver) was available in case face-to-face support was required during each interview. Two youths had a parent visibly/audibly nearby. The interviews were conducted virtually with the option of having the camera on or off. Two participants chose to keep their cameras off.

Participants were not felt to be exposed to any unnecessary risks during their participation in this study. The semi-structured interview questions were carefully phrased in direct ways with concrete prompts as needed to support the discussion of abstract concepts. The interview was piloted with an autistic young adult to ensure it was suitable, accessible, and not too taxing. Each participant was treated equitably and offered an honorarium of $25 for their participation.

### Planned Knowledge Translation

If desired, study results will be shared with participants via email or follow-up meetings. Results will also be shared with the broader local autistic community, including the Centre for Autism Services Alberta, the ASERT Lab, and other organizations that offer PEERS or other GSSIs, through our local Autism Research Rounds (organized by the Autism Research Center at the Glenrose Rehabilitation Hospital), and through a written lay summary of findings and a presentation if they are interested. Study findings will be submitted for peer-reviewed publication in a relevant journal.

# Chapter 4: Results

## Participant Descriptions

A total of 10 autistic teens enrolled in the study, with interviews occurring between January and August 2023. Nine participants identified as having autism and one participant identified as having ADHD, although a co-occurring diagnosis of autism was confirmed. Two participants identified as non-binary, two as female, and six as male. All participants were able to engage in the interview using verbal language. Two participants had their parents present, and two chose not to turn on their cameras. All interviews were conducted over Zoom in a shared space (living room) or their bedroom. Below is a table outlining the ten participants and brief descriptions of some of their characteristics.

**Table 1**

***Participant Descriptions***

| Participant (pronouns) Age (years)/ Age at diagnosis | Motivation for PEERS | Engagement during interview | Attitudes toward autism | Perspectives of PEERS | Use of PEERS outside of program |
|---|---|---|---|---|---|
| P1* (he/him) 13/young | Mother's choice, no specific goals, did not feel it was necessary | Moderate, brief answers | Neutral (ADHD), but feels there is a 'normal' way to behave | Boring at first, but enjoyed meeting others. PEERS taught rules to follow | No clear use; difficulty recalling rules and their order |
| P2 (he/him) 15/young | Mother's choice, no specific goals | Minimal, very brief answers | Neutral | Generally enjoyed, no specifics provided | No clear use, no effect on social life |
| P3 (he/him) 13/6 | Mother's choice, no specific goals | Minimal, very brief answers | Neutral | Enjoyed meeting others with common interests | Conflicting answers |
| P4 (he/him) 15/4 | Parent's choice. | Moderate, some in- | Negative, desires to | Found irrelevant, does | No clear use, but takes |

| | | | | | |
|---|---|---|---|---|---|
| | Perceives that struggles with social skills, but did not feel need to do PEERS | depth answers | be 'normal' | not like perception of needing supports | responsibility for social failures |
| P5 (he/him/non-binary) 16/13 | Joint decision with mother. Motivated to learn tools to navigate conflict | Highly engaged, thoughtful answers | Evolved from negative to accepting/neurodiversity; frequently camouflages for safety | Affirmed by apparent capacity compared to others in PEERS, found rules basic and reinforcing | Understands neurotypical landscape, increased assertiveness, and self-advocacy |
| P6 (he/him) 16/11 | Parents enrolled him, no specific goals, hoping to be more 'normal' | Moderate engagement, but fatigued | Very negative and stigmatized | Helped decrease sense of isolation and personal acceptance | No specific skills used |
| P7 (they/them) 15/14 | Personally motivated, to meet other autistics and learn neurotypical landscape | Highly engaged, thoughtful answers | Positive, diagnosis helped to understand self and struggles; camouflages for safety | Enjoyed meeting others, felt increased pressure to conform to rules | Uses conversational skills (introducing self) |
| P8 (he/him) 15/13 | Mother enrolled him, personal goal is to be a better friend | Low-moderately engaged, distracted by computer | Negative and stigmatized, trying (but unable) to learn to camouflage | Enjoyed meeting others | Recalled specific skills, but does not use regularly |
| P9 (she/her) 16/13 | Joint decision with mother, goal to help with social anxiety and retain friends | Highly engaged, mother present, camera off | Positive/neurodiversity | Enjoyed learning rules, reinforced knowledge, generally a rule follower | Understanding expectations to manage anxiety, increase confidence |
| P10 (she/her) 14/13 | Initially enrolled by mother, but | Highly engaged, | Negative, but evolving; | Meeting others increased | Uses conversational |

| | | | | | |
|---|---|---|---|---|---|
| | motivated to learn conversation skills and meet others | thoughtful answers | camouflages but conflicts with desire for authentic acceptance | acceptance and understanding | skills (being respectful) |

*Did not identify with the diagnosis of autism, although the diagnosis was confirmed by staff at the organization that led PEERS. As such, terms related to autism were avoided through the interview.

## Themes and subthemes

Three themes were generated from the thematic analysis: (1) Explicit and Implicit Teachings, (2) Balancing Authenticity and Camouflaging: Impact of PEERS on Self-Esteem and (3) Navigating the Self. All themes, their descriptions, and subthemes are listed in Table 2.

**Table 2**

***List of Themes and Subthemes***

| Theme | Description | Subthemes |
|---|---|---|
| Explicit and Implicit Teachings | Participants discussed the explicit learnings that are intended with PEERS (social skills). However, they also discussed many unintended, implied learnings, often based on ableist, normative assumptions of appropriate and inappropriate ways of being. | “Tips and Tricks”: Explicit Learnings from PEERS<br>“A Chance to be Normal”: Implicit Messaging from PEERS |
| Balancing Authenticity and Camouflaging: Impact of PEERS on Self-Esteem | Participants described the tension they experience between wanting to be themselves and wanting to fit in or have greater control in social situations. This dynamic and how it was impacted by participation in PEERS, was perceived to variably influence self-esteem. | |
| Navigating the Self | Participants described shifts in their understanding of ‘self’ - their self-concept, identity, and self-efficacy based on their participation in PEERS. | “I’m Still Trying to Figure it Out”: Influence of PEERS on Identity Development |

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| | | A Place to Belong |

**Theme 1: Explicit and Implicit Teachings**

Participants discussed outcomes of participating in PEERS related to the social skills they learned, which were explicitly outlined in the PEERS program. This is captured by the subtheme “Tips and Tricks”: Explicit Learnings from PEERS. However, they also spoke to other learnings not explicitly part of the PEERS curriculum. Instead, participants perceived many implied messages within the PEERS expectations and teachings.  This is captured by the second subtheme, “A Chance to be Normal”: Implicit Messaging from PEERS.

***“Tips and Tricks”: Explicit Learnings from PEERS***

Multiple participants saw PEERS as a place to gather practical tools on how to navigate social situations. For example, P5 explained that he enrolled in the program because “figuring out social situations...has always been a bit of a challenge...and [PEERS] would be a really good way to get some more tips and tricks.” When asked about the impact of PEERS in their day-to-day lives, some participants spoke in very general terms, such as having “better communication skills” (P6). However, others described specific skills they learned and used after completing the program. These skills were related to discrete social skills such as, “I learned that whenever someone’s talking you shouldn’t interrupt them” (P10) and also skills that had broader consequences. For example, P5 felt that PEERS increased their capacity to be assertive in their relationships, resulting in empowerment and personal growth. P7 felt that “I’ve been able to introduce myself...and they've [peers] been reacting really well, so I've been able to accumulate more friends” (P7). They also felt that group participation during PEERS, which was tracked week by week, helped them to increase their participation in school, “It helped me be able to do that [raise my hand] in school as well...I went from raising my hand once or twice a week in school to raising it much more" (P7). Some participants felt that some of the skills taught were reinforcing concepts they already understood to be important and, therefore, did not effect change in their lives.

Participants who reported that they were able to generalize the skills they learned in PEERS were actively involved in the decision to enroll in PEERS, expressed motivation to do the program, and had pre-set, specific, achievable goals such as meeting others with autism, acquiring tools for conflict management and conversation skills, and understanding neurotypical expectations to help with social anxiety. P5, for example, found some sessions particularly salient, which motivated them to enroll in PEERS: "I was dealing with some relationship issues…that I didn't know how to handle, so we saw PEERS as a way to teach me how to get out of the issues". Sessions that addressed bullying and teasing resonated with several participants. Some found the strategy to stand up for yourself or to "tease the tease" surprising and empowering. Despite this, it was unclear if any participants had utilized this rule in their daily lives at the time of interviewing.

In addition to learning about practical tools, some participants appreciated that PEERS helped them better understand the dominant social landscape and what to expect in social situations. Through a greater understanding of the neurotypical landscape, they felt better equipped to navigate it. For example, P5 felt that "the point of it [PEERS] was to help you go day to day in a neurotypical world - just …how to understand what neurotypical people think". P9 felt that having an understanding of social 'norms' supported her relationship with others, "learning how to keep friends…just knowing what other people expect you to do in social situations", and also mitigated her social anxiety, which she perceived, in turn, helped her to remember to follow social rules.

Some participants were able to utilize the skills and tools taught in PEERS in their day to day lives, but many had not. The primary outcome of the program, making and keeping friends, was only realized by a minority of participants, while most described little or uncertain improvements in their friendships. Despite being able to recall that it is important to appreciate others' feelings, one participant offered little understanding of how to enact it when he said: "Anytime someone feels something I should know what the other person's feeling" (P8). Another participant was conflicted about broadly applying the learned rules and stated, "Not everyone's going to be the same, and not everyone's going to be perfect and…respectful and quiet and nice" (10).

### *"A Chance to be Normal": Implicit Messaging from PEERS*

This subtheme captures implied messaging that many participants alluded to when talking about the expectations of PEERS, the content of PEERS, and/or the lingering effects of PEERS. These implied messages were not explicitly taught during the program. They included the reinforcement of autism as a deficit, an increased pressure to camouflage, the notion that social interaction is prescriptive, and that autistic individuals carry the burden of social fractures.

Seven participants described their natural social tendencies as inferior to normative or expected behaviors. For example, P10 stated, "They [PEERS leaders] talk to me…about how to do stuff I would be weird at", and that there are "proper ways to respond in certain situations." Some participants felt that being in a program that taught basic social skills made them feel "stupid" and, therefore, reinforced their deficit understanding of autism, "… how did I not see this in the first place? Like it made me feel a little stupid sometimes, but I just reminded myself that this is a learning experience and that I can't expect the same things of myself than I can of someone who doesn't have autism" (P7).

Many participants (at least half) perceived that PEERS taught that social interactions are a prescriptive, ordered set of steps instead of something relational, fluid, and contextual. One teen stated, "I just accept I should be doing XYZ differently" (P4). Another participant was frustrated with how the social skills were taught in PEERS because he found it difficult to "remember everything...every single fact. Like I know the main idea, I just have trouble remembering the inner ones…like the order of it" (P1). The expectation of eliciting desired responses in social situations reinforces participants' perceptions that social skills are prescriptive:

> I've found a way to manipulate how others treat me, I've been able to keep a consistent self-esteem…I know how to change the way others around me are acting…so why should I feel bad about myself if they act differently than how I want them to? (P7)

Most expressed that PEERS taught them to camouflage or reinforced their existing camouflaging practice. With respect to teaching camouflaging, participants said that some of the skills felt unnatural but necessary. When asked if PEERS taught them to act in ways that felt unnatural, P10 said, "Yes, like ways that I don't really use basically", and when asked how that made them feel she said:

> I was, like, open to trying it, but…I'm just saying that I didn't like the fact it was different than how I act, because I'm, like…a loud, talkative person…and there was a lot of lessons about, like, how you should talk

> and act around people…so I kind of didn't like it...because…I'm, like, a self-absorbed type of person, basically, that's how I talk with people.

Another participant stated:

> It was a little surprising [being taught to camouflage], but at the same time it was things I knew but I just didn't practice because it didn't feel right. But because we were practicing…it became ingrained in my mind (P7).

Some participants were already well versed in camouflaging before enrolling in PEERS and felt empowered when the program served to reinforce their skills. One participant, who despite expressing shame about being perceived as needing to do PEERS and being irritated by the repetitiveness of the many social skills programs he had done, said that "it's nice to know when you're doing something right…when it's explicitly said here's how to do XYZ, but you're already doing XYZ" (P4). Another participant who felt his camouflaging ability was comparatively more sophisticated stated that "a lot of these skills I had already picked up as a way of blending into the crowd" (P5). However, there were also a few participants who did not feel PEERS increased pressure to engage in camouflaging at all. One participant simply enjoyed learning the rules and saw them as a roadmap around the social landscape. Others seemed to have very little motivation to camouflage in the first place; they held comparatively neutral attitudes toward autism, and the program minimally impacted their behavior or sense of self.

Seven of the participants felt they were to blame for social fractures once they realized they were not following normative social rules during these interactions. For example, P9 reflected that "understanding, like looking back and being like, oh so this is probably what made them [friends] uncomfortable." PEERS evoked feelings of shame and guilt for some participants, like P10 who felt that "[PEERS] made me feel bad about myself because…I realized my friends might have felt, having to, like, listen to me. I didn't like having to find out about that." P4, who "just want[ed] to be normal, whatever that means," berated himself several times during his interview:

> It's a bit of a lightbulb going off - oh, that's why people try to leave or get disinterested" and "It's just with most of the instructions...you just kind of realize, oh I've been doing this wrong, I must have come off rude.

These realizations made many participants feel a heavy responsibility in managing issues in social relationships.

### Theme 2: Balancing Authenticity and Camouflaging: Impact of PEERS on Self-Esteem

The theme is summarized by P10's statement: "I don't feel like I should hide it anymore…it's just sometimes I don't want to be autistic", which captures the tension between participants' desire to be authentic with the desire to blend in and be accepted, and how participation in PEERS impacted this tension. The perceived influence of the dynamics between authenticity, camouflaging, and PEERS on participants' self-esteem is also discussed in this theme.

Most participants expressed awareness of regularly hiding their autistic traits or a deep desire to do so. Most of those who talked about camouflaging described the toll it took on them physically and psychologically. When feeling pressure to mask in certain situations, one participant said:

> It's an added feeling of discomfort…I get more and more tired over time. Sometimes when I come home from school I would immediately run to

> my room…I would avoid eating or doing my homework. I would just do something that would make me feel more relaxed (P7).

Another participant described the negative feelings that camouflaging elicits as it reinforces disconnection with her authentic self and with peers, "that makes me feel horrible, it makes me feel like people don't like me for who I truly am...so that kind of hurts 'cause it feels like people won't like me if I'm actually myself" (P10).

This desire to be perceived as *normal* motivated some participants to enroll in PEERS, particularly those with a negative view of autism. For example, P6 participated in PEERS "under the promise of hoping it would make me more normal, I went along with it [PEERS]." However, one participant explained that attempting to camouflage, as taught in PEERS, was itself socially awkward. When asked if it is hard to use the social skills learned (such as exiting/entering a conversation), he said, "It's hard because you can't just stand there and think [of the PEERS rules] for 10 seconds, that's awkward" and "have you ever tried to process something and then just stand there and someone goes: 'Hello!?'" (P4).

Many participants experienced internal tension between self-acceptance and the desire to fit in. When talking about their view of autism, one teen expressed, "Sometimes I feel like I'm a benefactor of…knowledge, other times though I wonder if that could be viewed as being a nerd or freak" (P6). Another participant tried to justify being both authentic and needing to camouflage during her interview, revealing her ongoing struggle between the two ways of being, "I like the way I am, I don't really think I should hide it…but, like, when I'm around people in my school, I act like a different person because I don't want them to judge me or anything" (P10). After explaining that she liked her energetic, happy personality and that PEERS increased pressure to hide these characteristics, she stated:

> [PEERS] was basically…how to fit in a crowd and like what to do, like, if…you're being different. So that was kind of stressing…'cause I didn't wanna have to change who I was so that certain people would, like, you know, like me and fit in.

Contributing to the tension between being authentic and camouflaging, P6, who feared being judged as a "freak," expressed that the point of PEERS was "to help people like me integrate and blend in with society, while at the same time just still be ourselves" and P4's receipt of the message "you don't have to change, but here's how" at the first PEERS session. P7 reflected on the challenges of camouflaging and their hope to be more authentic in the future, "I can't exactly keep masking forever so I'm just going to be myself."

Part of the tension around camouflaging was because participants used it as an important tool for safety and control during uncertain social interactions. For example, P7 stated that by learning social rules through PEERS, "I've ensured my safety by using the proper social skills." Participants talked about being able to avoid judgment and bullying:

> It was one of the ways that I found to keep me safe…I had faced a lot of bullying so acting neurotypical was one of the ways that kept me safe and kept me from being a target just because it made me "normal" (P5).

Participating in PEERS impacted participants' self-esteem in different ways. One participant, who was perceived to have relatively higher verbal and social capacity, experienced a positive effect on their self-esteem. PEERS helped them understand themselves more and offered reassurance of their capabilities. After seeing others in the PEERS group, they felt they were a "minority amongst minorities" (P5), having comparatively greater social abilities, including the capacity to camouflage. They commented on their ability to quickly acquire tally marks (a measure of participation and homework completion in PEERS) during the sessions and how they found the skills quite basic. It seemed that PEERS leveraged many existing strengths for this participant; importantly, they took away specific tools to be more assertive, which proved beneficial in their relationships and for self-care.

However, three participants expressed that taking a social skills class highlighted their deficits and negatively impacted their self-esteem, at least temporarily. When asked about what it was like doing a social skills group, one participant compared it to taking a remedial math class, "If you have to take a remedial math class, something that may come to mind is 'I'm stupid,' I'm grouped to all the stupid people" (P4). Another stated that, while they enjoyed the group overall, "It didn't make me feel good about myself, like I appreciated the skills that I learned, but it made me question…what's really wrong with me?" (P7).

Two participants with a very negative view of being autistic used pejorative language when talking about themselves ('black sheep' or 'freak'), which may be indicative of low baseline self-esteem. For them, it was difficult to determine how PEERS impacted their self-esteem. They wanted to 'be themselves' but were also deeply concerned about eliciting negative judgment from others or embarrassing their family when acting more authentically. They wanted to hide their autism to avoid negative judgment but had little awareness of how to do so and hoped that participation in PEERS would give them these skills. Worried that others would perceive him as acting too "babyish," P8 said:

> I'm trying to learn what mature stuffs are and I don't know - I just feel like it's hard trying to know one of the things that I can do or sound that can…be [perceived] as baby-ish…and I don't wanna get, like, my mom or my family embarrassed.

P6, who was particularly fearful of showing his autistic traits, stated that PEERS helped with his confidence as he felt slightly more accepting of himself, however, not enough to share his diagnosis openly: “Denying I was on the spectrum, it soothed down a bit, not enough for me to admit it, but still enough for me to be at least content with it.” While it was unclear whether PEERS instructions helped his self-esteem, seeing others seemed to help him with self-acceptance.

Three participants seemed to have little incentive or conscious awareness to participate in camouflaging. They did not seem to be motivated to learn neurotypical skills and did not appear to experience any tension between acting authentically and hiding their autistic traits. Rather, they accepted being autistic as an integral part of themselves, and there was little impact on how PEERS affected their self-esteem. One of them wondered if they might be camouflaging but was not aware of or distressed by it most of the time, particularly in the school setting where her natural tendency to be a rule follower was rewarded and encouraged, “That’s the problem, I don’t know…necessarily when I’m masking or when I’m not…cause a lot of it feels like that’s just me!” (P9).

## Theme 3: Navigating the Self

Most participants described that their process of self-understanding was in flux. The components of the self (Byrne, 1996), understood as self-concept (the descriptive component that includes identity), self-efficacy (the capacity component), and self-esteem (the emotive value of oneself), were expressed by participants as actively shifting in varying directions. How PEERS is perceived to influence self-esteem is captured by theme two. The third theme, Navigating the Self, captures participants’ experience of managing self-concept, identity, and self-efficacy. The subtheme “I’m still trying to figure it out”: Influence of PEERS on Identity Development captures the evolution of self-concept and self-efficacy. This includes how participants understand difference, autism, individual identity, and their appreciation of personal capacity. The second subtheme, ‘A Place to Belong,’ is about how PEERS became a welcomed and needed space to meet like-minded peers to foster a feeling of belonging and an important step to establishing a positive collective identity.

### ***“I’m Still Trying to Figure it Out”: Influence of PEERS on Identity Development***

Most participants expressed that they were in the process of learning more about themselves, including how they see autism in general and as informing their identity and the recognition and management of stigma. Individual stigma management strategies included the acceptance of negative feelings, leveraging social comparison to elevate oneself, and distancing oneself from the autism label. In addition to how PEERS impacted this process, participants talked about family, friends, school, and, for some, intersecting identities of gender and sexual orientation as important formative factors.

Like what is seen in the literature (Cooper et al., 2017), participants in this study held different attitudes toward autism. Most participants saw a clear distinction between individuals with autism and those without, placing autistic individuals as inferior and neurotypical ways of being as the goal to strive for. This was clearly articulated by P4, who stated, “It’s the way the majority of the population are…and it’s right” and by P6, in his description of autism, “It makes you feel like a freak…because they’re [autistics] are not normal, like everyone else, they’re just like an outcast; the black sheep is the more appropriate term”. Other participants expressed similar sentiments about the neurotypical teachings of PEERS, “It just helps kids like me understand the ways of the world a little bit better” (P6), “Just help practice normal conversation” (P2), and “A lot of the things [PEERS] talk about…I don’t really do quite as normally as other people do” (P10). Participants who held a negative view of autism saw it as something needing to be fixed or changed and, for a couple of them, they hoped PEERS might be a path to *normalcy*. When talking about other autistic individuals, P5 revealed the perniciousness of society’s views of autism, “I think that it can be a reason as to why…they are delayed, but I don't think that it’s an excuse per se - it’s definitely something you can learn [social skills]”.

For others, their attitudes towards autism had undergone a significant shift from a negative one to a more positive one. This reinterpretation of autism offered new meaning and acceptance as part of their identity. For these participants, a later diagnosis challenged them to reconcile their previously held negative perspectives of autism. In particular, two participants felt a sense of relief when they received and embraced an autism diagnosis in their teens. Both expressed how getting the diagnosis explained many of the struggles they experienced and, therefore, led to greater self-understanding and compassion. Those with either positive attitudes or emerging positive attitudes towards autism were more motivated to do the program and able to experience perceived benefits from it (such as feeling a sense of belonging and learning skills), despite some participants’ feeling that their deficits were highlighted.

Some participants held neutral attitudes towards autism, reflected in their ambivalence with the PEERS program and its utility. These participants seemed more likely to express little insight into having social challenges despite being enrolled in several social skills programs. Conversely, others were keenly aware of social issues and expectations. They held on to memories of previous failed interactions, for which they felt responsible, especially after learning expected social skills in PEERS.

Many participants were aware that people often perceive them negatively and have felt stigma related to their diagnosis. Participants described experiencing infantilization, dehumanization, bullying, and exclusion through comments such as, “I don’t like…people thinking I am baby-ish” (P8), “They look at me like I’m an object rather than I’m a person” (P7), and “My friends kept leaving me and ignoring me…and then I didn't know why because they wouldn’t tell me” (P9). Participants also described a deep fear of judgment from others for appearing differently than neurotypical expectations: “I just don't want to be the person who gets looks regularly, like “what did you do?” (P4), and “[I have] jealousy of being normal, and the fear of being a freak [acting autistic] gets control of you” (P6).

Some participants suggested that they needed to expect and accept negative feelings related to social interactions. When discussing how self-esteem was impacted after recognizing social differences, P4 said, “You have to accept that [negative feelings]; you don’t want to be ridiculous.” Similarly, P7 accepted that “[Feeling bad about oneself] can come from an interaction with neurotypical people that doesn’t go well…but...that’s something I got to put up with”. As described earlier, PEERS seemed to reinforce that it is the participants’ responsibility to conform to neurotypical social norms to have successful social interactions.

Participation in PEERS also seemed to provide an opportunity for comparison to others as participants sought to understand their autistic identity. For example, some participants compared themselves with others on the spectrum in general terms, “There are people who function just fine [like me]…then there are people on the opposite side of the spectrum that can barely do anything for themselves” (P4). Others compared themselves with other participants in PEERS to bolster their sense of self: “There’s definitely a dilemma for social cues [personally], but it's definitely more advanced compared to the other members” (P5).

Some participants, like P4, wanted to distance themselves from their diagnosis as a way to manage stigma and mold their identity into something that felt less threatening, “I don’t want to have some diagnosis that makes me special or stand out,” whereas others reframed autism into something more positive, “In my head autism was this horrible thing that crippled you, so it took a fair amount of time to be like ‘look at all these people who have autism and they are millionaires and billionaires’” (P5). One participant actively chose to challenge stereotypes of autism as another way to manage their felt stigma: “I like to tell it like it is and be like ‘I have autism’…because it changes their mindset too” (P7).

How participation in PEERS influenced these personal shifts in identity was variable. PEERS had little apparent effect on personal identity for those who held neutral attitudes towards autism and did not seem to access stigma management strategies. For some participants, PEERS offered a greater understanding of autism and affirmation of capacity, which supported a positive shift in personal identity. For others, PEERS seemed to help elevate a collective identity by seeing “how autism worked” (P10) when meeting other autistic individuals. And yet, for some participants, PEERS served to highlight deficits on a collective and personal level.

Emphasizing and appreciating personal strengths associated with autism is important for positive outcomes (Cooper et al., 2021). When asked about perceived strengths, participant answers were comparatively limited. One participant went so far as to call the positive aspects of autism “side effects” (P6). Perceived strengths related to autism centered around memory skills and the capacity to acquire knowledge about unique subjects. Participants also reported that engaging in their special interests and sharing them with others were important ways to boost their self-esteem.

### ***A Place to Belong***

The PEERS manual states that the mandate of the program is to teach skills to make friends and that participants are “not allowed to socialize in any way with the other teens in the group for the 14 weeks of PEERS” (Laugeson & Frankel, 2010, p. 24). Despite this, nearly all participants expressed that the main positive of PEERS was meeting other autistic youth. In fact, for some participants, like P7, meeting other autistic youth was a predetermined goal:

> I was hoping to be able to reach out to more people with autism…because when you meet someone who is autistic, you're able to click with them immediately because you probably bring up your special interest. And you guys go back and forth about your interest and that just, like, automatically creates a bond.

For several participants, meeting others on the spectrum made them feel less isolated in their diagnosis and struggles. For example, P6 felt that “When I learned that there were others like me, I was a little…bit relieved to know I wasn't the only outcast” and P7 reflected that:

> [Attending PEERS] made me feel OK about it [being autistic] because there’s other people there too, like it made me feel more connected with others with commonalities, it just made me feel like I wasn't alone, which I greatly appreciated.

Similarly, P10 appreciated meeting other autistic people at PEERS because “it also doesn't feel like I’m alone and I’m like the only weird person. Because I know there’s, like, people that have the same hardships as me.”

Belonging to the PEERS group seemed to be an opportunity to help transcend stigmatization and help internalize a positive collective identity that persisted beyond the treatment setting. Even for those teens who felt that participation highlighted their deficits, being with other autistic youth fostered a sense of increased value for themselves and of others on the autism spectrum. Some participants took it upon themselves to provide leadership by offering support during the sessions. One participant proudly stated that “it gave me better initiative to help others, because if I got something really quickly, then there was other people who didn't get it as quickly so that way I was able to help them” (P7). One teen expressed that, even if they hadn’t learned anything in the program, having the opportunity to socialize would still make it worth going.

# Chapter Five: Discussion

Most studies reporting the effects of GSSIs are focused on changes in participant knowledge and/or external behaviors, with little attention given to what is going on internally (Leadbitter et al., 2021; Trembath et al., 2023). Adverse events are rarely reported, leaving autistic self-advocates and some researchers in the field concerned about the potential of GSSIs eliciting negative emotional responses that might result in long-lasting effects on mental health (Anderson, 2023; ASAN, 2020; Black et al., 2022; Bottema-Beutel et al., 2018; Cresswell et al., 2019; Gardiner, 2017; Howe et al., 2023; Leadbitter et al., 2021; Lerner et al., 2013a; Trembath et al., 2023). This study centers the voices of autistic youth to address this gap, and to the researcher's knowledge, is the first qualitative study exploring the effects of participating in a GSSI on the self-esteem of autistic youth. This study's goal is not to interrogate the efficacy of a GSSI. Rather, the goal is to explore how participation in GSSIs made participants feel about themselves - their intrinsic value, their understanding of autism and its intersection with society, and their identity - aspects related to their self-esteem. Substantiating the concerns voiced in the literature, the results of this study suggest that there were some positive impacts of participating in PEERS, yet there were also unintended negative messages that participants received. This warrants more attention from researchers and clinicians alike. This study helps to provide the needed insight to start addressing this gap in knowledge.

## Generalizations of the (Un)intended GSSI Teachings into Daily Life

There is evidence for the efficacy of GSSIs, albeit modest, in improving the social competence of autistic youth (Gates et al., 2017; Gilmore et al., 2022). However, there is little information about generalizability and maintenance, nor is it understood how social participation is impacted (Gates et al., 2017; Gilmore et al., 2022; Trembath et al., 2023). Some participants in this study perceived that they acquired skills that they found helpful in their day-to-day lives. This was particularly true for those who identified specific goals upon enrolling in the program, rather than hoping to acquire general social skills improvement and friendships. However, most participants could not recall much of the explicit strategies they learned in PEERS. Spanning 14 weeks, dozens of rules for a wide range of social skills were outlined and rehearsed. Many participants found the rules confusing, difficult to remember, or awkward to use. Cage (2016) also found that, despite autistic youth being concerned about their reputation, following social rules to be ‘cool’ in everyday life was beyond their reach. Similarly, this study suggests that the generalizability of a multitude of generic social rules taught in GSSIs is limited. Individualized goal setting, informed by personal experiences, may increase the benefit of GSSIs and promote the generalization of skills learned beyond the treatment setting. Increasing specificity by targeting individualized goals rather than teaching broad expectations also respects the self-determination and autonomy of autistic youth and would likely maximize benefits and minimize harm (ASAN, 2020; Hull et al., 2021).

Understanding the neurotypical landscape to learn about differences in social interactions without the expectation to conform to them, aligns with the neurodiversity perspective (Finke, 2023; Leadbitter et al., 2021). With a greater understanding of the social landscape, autistic individuals can feel empowered to choose social arrangements that make sense to them or advocate for needed accommodations to improve the goodness of fit with their environment (Bottema-Beutel et al., 2018; Leadbitter et al., 2021; Mandy, 2019). Bottema-Beutel et al. (2018) suggest using a critical approach to provide insight into the process of social interactions and that “unpacking social interactions, including the range of power structures inherent to every encounter, could be undertaken to provide insight and increase empowerment” (p. 961). In this study, only a couple of participants appreciated PEERS to understand the neurotypical landscape; most were lost in the details and order of the rules. This capacity to transcend the rules and use them as a map for social navigation improved awareness of expectations and decreased anxiety for these participants.

Despite the good intentions of instructors, this study suggested that PEERS exposed its participants to negative implicit messaging. Like autistic youth generally, our participants were aware that autism is often viewed negatively by society (Botha et al., 2022) and that they were perceived to have lower social capacity than their peers (Bauminger et al., 2004). These understandings likely increased their vulnerability to receiving several implied messages from PEERS. Participants shared that PEERS reinforced a deficit understanding of autism, the pressure to camouflage, the prescriptive nature of social interactions, and that it was their responsibility to remediate social fractures. None of these messages are part of the intended teachings of PEERS, as the manual states that PEERS "targets skills development rather than correction of social mistakes" (Laugeson & Frankel, 2010, p. 5), still these implied messages were received and resulted in negative emotional responses for some participants. These findings align with concerns raised by the autistic community about the potential for unintended consequences of behaviorally focused interventions (ASAN, 2020; Bottema-Beutel et al., 2018). In her exercise of critical reflexivity of rehabilitation practice, Phelan (2011) similarly expressed, "it is important to reflect on the meaning…and the message they [treatments] imply with respect to becoming closer to normal" (p. 166).

Most participants viewed autism as a deficit, and PEERS seemed to reify this understanding, situating neurotypical social skills as the ideal and autistic social tendencies as deficient. Many participants similarly described the social skills rules as the *right* way to be, and some hoped that PEERS would elevate them and make them more *normal*. Although our participants did not reference the pre- and post-outcome measures that are used as part of PEERS (the SRS and SSIS), the goal of using these outcome measures to demonstrate decreased autistic behaviors reinforces and contributes to the *normalization agenda* (Milton, 2012).

This study suggests that autistic youth feel they are the cause of social fractures. They felt responsible for peer rejection, judgment, and isolation and that they needed to learn normative social rules to form and maintain relationships. This perspective aligns with Bottema-Beutel et al.'s (2018) concern that the "inherent assumption in these programs is that there is a correct or expected way to interact with others, and that it is incumbent upon the individual with ASD to learn this pre-specified format if interactions are to lead to relationships" (p. 959). In their systematic review of peer relationships among autistic youth, Cresswell et al. (2019) also found that autistic youth take responsibility for social failures. Our findings corroborate concerns that GSSIs teach autistic youth to memorize social rules because they alone are responsible for enacting change to have effective relationships (Bottema-Beutel et al., 2018). Even though some social rules felt unnatural to our participants, they felt that these rules were valid and necessary and that any negative feelings elicited from failed social interactions were something they ought to accept. These sentiments oppose neurodiversity understandings that are inclusive of diverse social preferences and the double empathy problem theory that emphasizes social misunderstandings as being interactional and due to a neurological mismatch, not a deficit, which both parties are responsible for accommodating (Milton, 2012). Leadbitter et al. (2021) argue that "all intervention stakeholders need to understand and actively engage with the views of autistic people and with neurodiversity as a concept and movement" (p. 1) to ensure interventions are ethically sound and focus on improving mental health and quality of life.

Participants’ perceptions that PEERS implied that social interaction follows a set of prescriptive, ordered rules might be counterproductive to the program’s intent of increasing connection and friendship. For example, teaching social interactions as a set of steps to be followed led some participants to feel increased inauthenticity and awkwardness, and propelled them to act neither autistic nor non-autistic, resulting in an awkward attempt to be both (Bottema-Beutel et al., 2018). This idea is supported by research that shows that autistic individuals have less capacity than neurotypical peers to adjust social rules based on contextual conditions, as demonstrated by their judgment of various schoolyard transgressions (Shulman et al., 2012). Autistic adolescents find it difficult to keep track of social rules and how to use them (Cage et al., 2016; Cresswell et al., 2019), and this may result in attempts to change that feel unnatural and awkward (Bottema-Beutel et al., 2018). Bottema-Beutel et al. (2018) argue that the effort it takes to recall and deploy social rules, while managing stigma, sabotages authenticity and connection and leaves the autistic person isolated and exhausted.

Bottema-Beutel et al. (2018) used the science of conversational analysis to argue that GSSIs fall short of stated goals to promote meaningful friendships because social interactions are outlined and taught in ways that are not grounded in empirical and theoretical knowledge. They suggest that rigid social rules do not leave room for context or shared sense-making, which is fluid and has potential to proceed in different interactional trajectories that are impossible to specify in advance. The nuances of context and negotiation between parties are stifled by a top-down approach inherent in a stable set of social rules. For example, they argue that the purpose of a conversation is not purely to “trade information” about a topic of mutual interest as suggested in PEERS, but, according to conversational analysis, it is more often a bid for connection, such as when someone comments on the weather. They reason that the unintended consequences of teaching an incomplete portrayal of social interactions propels the cycle of stigma and inauthenticity. Indeed, participants in qualitative studies described the “years in which they tried and failed to fit in as misspent,” feeling “intense pressure...to assimilate, and how it never worked, making them feel like failures” (Botha et al., 2022, p. 439).

## Considerations of Interventions That May Reinforce Camouflaging

Reinforcement of the social hierarchy by programs such as PEERS may serve to increase the stigma autistic individuals feel, as well as increase their efforts to manage stigma through camouflaging (Bottema-Beutel et al., 2018). Stigma is increased through “reifying an ideology that there is a correct way to engage in an interaction and encouraging individuals with ASD to pass as non-autistic” (Bottema-Beutel et al., 2018, p. 961), which was a message reinforced to our participants and possibly those who support them. Several participants in this study perceived that PEERS increased their pressure to camouflage. Similarly, autistic adults who had participated in ABA perceived that instead of learning what was intended, they only learned “how to mask their autism” (p.745). Some participants in this study seemed to have more capacity to act on this felt pressure through camouflaging, such as those participants who were already regularly engaged in the practice, while others were either not aware of engaging in the practice or were left feeling confused and frustrated when they were unable to do it. Research shows that many autistic youth as young as ten years old engage in camouflaging, motivated by efforts to avoid negative reactions from others (Bernardin, Mason, et al., 2021; Howe et al., 2023). While not specifically explored, this study aligned with research that shows camouflaging is more readily accessed by females (Cassidy et al., 2018; Wood-Downie et al., 2021), who do it more successfully than males (Hull et al., 2017), and those with higher cognitive ability who have greater insight into their own difficulties and how others might perceive this (Cassidy et al., 2018; Wood-Downie et al., 2021). Similar to participants in this study, some autistic individuals camouflage out of learned habit or without conscious awareness (Howe et al., 2023).

Increasing the pressure to camouflage through interventions with normative agendas comes at a considerable cost and is being recognized as unethical (Leadbitter et al., 2021). Camouflaging is associated with lower self-esteem, exhaustion, burnout, depression, and suicidality (Bernardin, Lewis, et al., 2021; Bernardin, Mason, et al., 2021; Cresswell et al., 2019; Hull et al., 2017; Perry et al., 2022), independent of the degree of autistic traits (Beck et al., 2020). Some participants described negative consequences of camouflaging, including cognitive demand, feeling inauthentic, physical fatigue, and needed time for recovery in safe spaces, often at home. As described, some were less aware of the practice, or it had become so habitual that it did not feel demanding; still, risks persist as this may result in caregivers overlooking needed support (Mandy, 2019). There are benefits to camouflaging such as fitting in and avoiding judgment and bullying (Mandy, 2019), and some participants in this study described this. However, such benefits must be reconciled with the growing body of research that suggests that increasing pressure to engage in camouflaging needs to be managed with extreme care, and broadly encouraging the practice should be avoided.

Little is known about how to gain the benefits of camouflaging while avoiding the risks, making it important to shift messaging related to camouflaging from implicit to explicit. Openly discussing the concept of camouflaging is especially important for autistic adolescents who, due to developing a heightened awareness of social differences and concern about reputation management, are likely vulnerable to unwittingly internalizing the message to camouflage. Explaining camouflaging and its potential consequences should ideally happen before adolescence, given how early some autistic youth start engaging in the practice (Howe et al.,

2023) to mitigate threats to developing self-concept and self-esteem (Reitz, 2022). At the very least, this discussion should be part of all behavioral interventions that might increase pressure to camouflage. Teaching self-advocacy, sensory regulation, and self-care, all considered vital to learn among self-advocates but underrepresented in autism interventions (ASAN, 2020), would be essential to the camouflaging discussion. To mitigate autistic burnout, acceptance, lowered expectations, and being allowed to be authentic are needed (Raymaker, 2020). The participants described the importance of having a space to decompress and be themselves to help recover from the consequences of camouflaging.

In addition to threatening mental health, camouflaging may result in feelings of inauthenticity that erodes identity and impact self-esteem (Hull et al., 2017; Mandy, 2019). Half of the participants expressed conflict between feeling the need to camouflage to be accepted and wanting to be accepted for their authentic selves. They described feeling constrained, awkward, and sad when peers did not value their true selves. Authenticity felt thwarted when they suppressed sharing their special interests, controlled their energy levels or feelings of dysregulation, acted more maturely, or changed how they dressed. In Howe et al.'s (2023) qualitative study exploring camouflaging in autistic children, participants described a loss of identity, feeling confused, and even feeling deceitful. Like the participants in this study, they desired both authenticity and acceptance, with efforts for the latter thwarting the former. In this study, the teens felt they had things to offer, but worried they would risk rejection if done authentically. As mentioned earlier, authenticity, considered vital for connection and relationship satisfaction, may be impeded by replacing it with the very social rules that GSSIs purport will help improve social interactions and friendships (Bottema-Beutel et al., 2018).

Autistic individuals, including our participants, have a strong desire for authentic friendship (Black et al., 2022). Evidence suggests that this occurs most easily between individuals of similar neurotypes (Black et al., 2022; Cresswell et al., 2019), which aligns with the concept of the double empathy problem (Milton, 2012). Autistic individuals often have friendship preferences and behaviors that are different from neurotypical individuals (Finke, 2023), which may shed light on how to promote authentic and meaningful friendships. Finke (2023) suggests that autistic friendships should be accepted as simply different and valid, rather than needing remediation. How we support friendship outcomes, then, needs to consider the preferred patterns of behavior that autistic individuals want to have in their friendships. Instead of conforming to neurotypical expectations, as instructed in GSSIs, the authors suggest the emphasis should be placed on encouraging the match of preferences, values, and practices of a potential friend. Many participants in this study expressed comfort in being in a group of autistic peers, and some also articulated a preference for more broadly neurodivergent friends (such as those with ADHD) or friends that were different in other ways (such as gender diverse), because they experienced ease of connection and relief from the pressure to camouflage.

In comparison, research suggests that autistic individuals often experience friendships with neurotypical peers as mired in feelings of anxiety, preoccupation about being judged, and insecurity (Black et al., 2022). Maintaining these friendships is demanding and even threatening, and the authors suggest that any psychological benefit might be negated by the efforts required to maintain the friendships (Black et al., 2022). Positive, authentic friendship experiences are paramount in maintaining self-esteem and well-being in non-autistic youth (Theran, 2010), and this is likely the same for autistic youth. Research suggests that this is more likely to happen when there is congruence in values and behavior preferences (Finke, 2023). Consequently, emphasizing and positioning neurotypical interactions as integral to successful relationships and friendships might expose autistic youth to stressful experiences that have negative consequences and limited opportunities to create meaningful friendships. Black et al. (2022) summarize: “Interventions and supports to assist autistic individuals in developing friendships should emphasize the development of authentic friendships based on shared interests, mutual trust, respect, and understanding, and should seek to increase awareness in non-autistic populations” (p. 4).

## Perceived Influence of GSSIs on the Self-esteem of Autistic Youth

The perceived impact on self-esteem by some participants most closely aligns with a state shift in self-esteem, as outlined by Reitz’s (2022) framework for self-esteem change. She describes self-esteem as both a state and a trait, where state self-esteem fluctuates moment by moment, which in turn is manifested in trait self-esteem, and that state self-esteem is uniquely sensitive to the self-conscious emotions of shame and pride.

Several participants in this study described feelings of shame and regret from their participation in PEERS, which were associated with decreased self-esteem, at least temporarily. These feelings were evoked mainly by two factors: (1) others’ perception that they needed to do PEERS, which some viewed as simplistic and demoralizing, and/or (2) learning about how they did not meet normative social expectations. Shame is related to the perceived lack of power to meet one’s ideal self, giving rise to feeling flawed and unworthy (Miceli & Castelfranchi, 2018). Often compared to guilt, it is less likely to be adaptive or foster growth and more likely to impact self-esteem negatively (Miceli & Castelfranchi, 2018). Shame is further associated with helplessness and hopelessness if the discrepancy between one’s ideal and actual self is seen as uncontrollable (Miceli & Castelfranchi, 2018). Using newer understandings of autism, it has been argued that interventions such as GSSIs have conceptual and existential ramifications because they target traits that are a product of an incurable neurological difference and, if changed, would render the individual fundamentally altered (Leadbitter et al., 2021; Sinclair, 1993). Feelings of helplessness and hopelessness might compound the shame elicited by the lack of power an autistic individual has to change to an ideal self, informed by normative expectations and made operational by medicalized approaches.

The negative impact on self-esteem perceived by some participants corroborates research that shows that heightened awareness of social difference is associated with symptoms of depression in autistic youth (Vickerstaff et al., 2007) and negative self-concept and self-esteem in autistic adults (Zimmerman et al., 2017). Vickerstaff et al. (2007) found that it is youth's self-perceived understanding of social differences rather than their parents or teacher's reported social competence that resulted in negative internalized symptoms. This means that negative effects on mental health result from youths' self-perception of social competence, not how others view the teen's social competence. These findings, in addition to the results of this study, suggest that interventions that highlight differences may have risks to poor mental health, as theorized in the literature (Leadbitter et al., 2021; Lerner et al., 2013; Trembath et al., 2023). Receiving and internalizing messages that they are deficient socially may influence autistic teenagers' self-esteem, promote stigma, and drive camouflaging (Chapman et al., 2022), which in turn may further negatively impact mental health.

The unintended, implied messages from PEERS (including reinforcement of autism as deficit, the increased pressure to camouflage, the prescriptive nature of social interactions, and that autistic individuals carry the burden of social fractures) may contribute to ongoing state changes in self-esteem if these messages are internalized and inform participants' identity narratives that are then used to interpret life events (Reitz, 2022). Specifically, increased pressure to camouflage has been associated with negative impacts on self-esteem (Bernardin, Lewis, et al., 2021; Hull et al., 2017, 2021); attempts to use social rules in social interactions may lead to inauthenticity which impedes connection and belonging, both understood to be important in bolstering self-esteem (Cooper et al., 2017; Reitz, 2022); reifying autism as deficit and in need remediation serves to increase stigma which in turn impacts mental health and self-esteem (Botha et al., 2022; Botha & Frost, 2020; Bottema-Beutel et al., 2018); finally, the message that autistic individuals are responsible for learning neurotypical social rules and deploying them reinforces autism as deficit and inhibits acceptance of neurodiverse social interactions (Bottema-Beutel et al., 2018).

During adolescence, self-esteem is particularly unstable as it is vulnerable to positive and negative experiences (state change), which can have long-term impacts (Reitz, 2022). It is concerning that our findings suggest that participants' self-esteem was sensitive to the impact of PEERS. The bidirectional interaction between domain-specific and global self-esteem might explain how highlighting a deficit in the social skills domain negatively impacts global self-esteem (Dapp et al., 2022). Self-esteem is comprised of a complex array of interacting domains, with certain domains holding greater value and thus more strongly informing one's global self-esteem (Juhasz, 1985). Therefore, one way to protect global self-esteem is to place a lower value on domains that one has less competency or capacity to change (Juhasz, 1985). For autistic youth, research suggests that greater social skills deficit correlates with lower self-rated importance of social skills, while other domains, such as school achievement, are weighted more important (Rankin et al., 2016). This suggests that the often-cited discrepancy of the importance of social skills between youth and their parents, where youth weigh social skills as less important

(McMahon & Solomon, 2015; Rankin et al., 2016), might be a protective mechanism that should be respected. The solution of increasing the saliency of social skills in autistic youth to alleviate this discrepancy (McMahon & Solomon, 2015) should be cautiously broached as this might negate a protective mechanism and inadvertently lower self-esteem.

The discrepancy between parents and youth regarding the importance of social skills was evident in this study, as there appeared to be a conflict between some participants and their parents about the need to enroll in PEERS. Some participants did not hold the same value and importance in doing PEERS as their parents, which is relevant as research suggests that having to learn something that one perceives is of little value can indirectly impact self-esteem (Tyrrell & Woods, 2020). In their qualitative study of autistic adults' reflections on participating in ABA, Anderson (2023) surmised that "most of the time they either didn't value what they were taught or they felt that what they were taught was useless" (p 744) and that while some participants learned valuable skills, many found there was little attention to what they really wanted support for.

## The Influence of GSSIs on Autistic Identity and Belonging

Research suggests that the social identity process is important to autistic youth and, therefore, is considered an important avenue for providing support (Cooper et al., 2017). This is particularly relevant as autistic youth often construct their identity through a lens of limitations and negative experiences, such as social exclusion and stigma (Rodriquez et al., 2023). In this study, participants were grappling with their autistic identity, which was informed by their established or evolving understandings of autism. As seen more broadly, most participants held a more medicalized approach to their disability (Botha et al., 2022), and some placed hope in PEERS to provide necessary treatment. A minority of participants had established or emerging neurodiversity-affirming perspectives of autism, which seemed propelled by close family members as they came to accept the diagnosis. Participants diagnosed at a relatively older age often felt a deep sense of increased self-understanding, which compelled them to welcome and integrate their diagnosis into their identity. This was also reported by Tan (2018), who found that individuals diagnosed as teenagers or adults found “an explanation for their atypicality and developed a more valued self-concept” (p. 161) and reinterpreted personal struggles from “devaluation to redemption” (p. 164). While not experienced by participants in our study, new self-understanding offered permission to absolve themselves from personal expectations to ‘normalize’ and from feeling a sense of failure experienced when previously accessed treatments did not meet expectations (Tan, 2018). Embracing their autism diagnosis opened doors to communities of like-minded others, which further served to mold a more positive personal identity (Tan, 2018).

Autistic adolescents’ efforts to understand identity occur in the context of normative expectations, stigma, and a desire to be authentic. This interplay caused much internal conflict for some study participants, who expressed a deep desire to be authentic and feel accepted for who they were while at the same time wanting to fit in and avoid negative experiences such as judgment, isolation, and bullying. In their study about stigma and autism, Botha (2020) concluded that the experience of stigma is largely unavoidable for autistic individuals and is associated with poorer mental health. Understandably, internalized stigma drives stigma management that has variable impacts on personal identity, collective identity, self-esteem, and well-being (Botha et al., 2022; Botha & Frost, 2020; Cooper et al., 2017). Participants in this study described experiences of stigma and accessed a variety of individual strategies to mold their personal identity, including rejecting or distancing themselves from their diagnosis, engaging in camouflaging, and favourably comparing themselves with others in the group (Botha et al., 2022; Perry et al., 2022). Results of this study suggest that camouflaging is a strategy that PEERS reinforces. Driven by stigma, camouflaging impedes connection, authenticity, and positive self-esteem development (Bernardin, Lewis, et al., 2021; Botha & Frost, 2020; Bottema-Beutel et al., 2018; Cooper et al., 2017; Hull et al., 2017; Perry et al., 2022), and therefore is likely to contribute to conflict around identity development. In addition to driving individual stigma management strategies, behaviorally based normalizing interventions serve to promote the stigma of autism on a collective level, potentially negatively impacting collective self-esteem and identity (Cooper et al., 2017).

Some participants (albeit a minority) leveraged the neurodiversity movement to align themselves with a positive collective identity of autism. Research shows that a positive understanding of autism (i.e., a positive collective self-esteem) is an important avenue for improving personal self-esteem among autistic adults (Cooper et al., 2017). However, many participants in this study had difficulty describing positive attributes related to autism when asked to do so. Research shows that autistic individuals perceive attributes associated with autism as much more negative than positive (Cooper et al., 2021). For example, negative attributes such as social skills and emotional difficulties were reported far more than positive attributes such as being gifted or unique (Cooper et al., 2021). Collective identity is often mired in a deficit understanding of autism, making it less likely to buffer against stigma (Cooper et al., 2017). Additionally, this study suggests that GSSIs increase the perception that autism is something to be fixed, and this is likely to impede the appreciation of a positive collective identity. The restriction to not engage with others meaningfully during PEERS further constrained the opportunity to create a positive collective identity. Rather than putting up barriers in the process of developing a sense of identity and the promotion of personal and collective self-esteem, interventions should focus on “opportunities for autistic people to increase their collective self-esteem [that] are crucial to their personal self-esteem, and by extension, their psychological well-being” (Cooper et al., 2017, p. 851).

Participants in this study consistently reported that the sense of belonging they felt in being with autistic peers was a positive aspect of participating in PEERS. Belonging is the feeling of security and comfort when a person is valued as their authentic self (Finke, 2023). For many participants, the time spent playing games or sharing interests was the most enjoyable aspect of the program. Research shows that identifying with like-minded others promotes self-esteem for autistic individuals if mediated by a positive autistic collective identity (Cooper et al., 2017). As described above, aligning oneself with a positive collective identity, as in the neurodiversity movement for autism, is an important tool for navigating stigma and discrimination (Perry et al., 2022). Despite some of the negative perceptions related to GSSIs, our participants described that coming to PEERS let them see how others experienced autism and made them feel less alone in their journey to understand autism. They also expressed feelings of solidarity in seeing others struggle similarly to them. PEERS explicitly states that promoting friendships or a support group is discouraged to avoid interfering with its stated goals of learning social skills. Yet, despite this mandate, participants clearly had a deep desire to locate themselves in community and used PEERS as an opportunity to do so. This is perhaps related to the teenage years being a time of greater awareness of difference, stigma, and isolation. Indeed, autistic adults report that autistic suffering is mainly from being in a world that is not accommodating (Botha et al., 2022). So, spaces of acceptance and opportunity for authenticity have increasingly become a meaningful way to support autistic well-being. In Tan’s (2018) exploration of autism narratives, participants explain how a like-minded community that holds a positive perspective of autism enriched their social life and offered a sense of relief, self-compassion, acceptance, and self-understanding. Interventions that facilitate the development of a positive autistic identity can serve to help transcend societal stigma, and this collective strategy can, in turn, improve personal self-esteem (Cooper et al., 2017; Rodriquez et al., 2023).

Home is also an important place where adolescents can experience belonging. Parents are considered integral to the success of PEERS, with some research suggesting this practice increases generalizability because parents are also taught the social rules to support their use at home (Dekker et al., 2014). Whether they, too, receive unintended implied messages, such as reifying autism as a deficit, increasing the pressure to camouflage, that their teens are responsible for remediating social interactions, or that social change is prescriptive, is unknown. Research indicates that families likely influence disability identity and that students with more neutral or positive descriptions of autism had parents who discussed the diagnosis openly (Riccio et al., 2021). This study suggests that adolescents, and likely their parents, hold varying attitudes towards autism – some deficit-based, and others more neurodiversity-affirming. Reinforcing normative social rules as something their children can and should learn might set up some parents for disappointment when this is not realized, potentially threatening the development of a supportive space for autistic youth. This is a relevant concern as expressions of acceptance and the perception of social support increase self-esteem (Nguyen et al., 2020). Caregivers can help youth see the positives of being autistic and, therefore, have positive impacts on their self-esteem by presenting a balanced (not only deficit-based) understanding of autism. Additionally, protecting spaces where authenticity can be expressed is a critical way to prevent autistic burnout and mitigate the adverse effects of camouflaging (Raymaker et al., 2020).

## Implications for Clinical Care

### *Implications for Behavioral Interventions in General*

The ultimate goal of this study was to gain insight into how to support autistic youth to flourish and maintain well-being. Based on this study's results, several clinical implications can be extracted to help achieve this goal. General considerations for behavioral interventions are discussed, followed by considerations specifically related to GSSIs.

It is essential to consider the mental health consequences of behavioral interventions, including carefully weighing potential downstream risks against potential benefits (Lerner et al., 2013; Trembath et al., 2023; Hull et al., 2021). Discussing risks and benefits should be done alongside the youth and their family. If, after careful consideration, an intervention is deemed beneficial, clinicians and caregivers need to be vigilant for signs that mental health is being negatively affected and have open and ongoing mental health check-ins with participants and their parents. Before starting the intervention, an individualized plan should be established about how to address signs of worsening mental health and how to mitigate these effects (Hull et al., 2021). This might include pausing the intervention, revisiting the risk-benefit ratio, and adjusting programming as needed.

Interventions that create a space of belonging, which involves embracing and understanding autism to help develop a positive autistic identity, should be prioritized. Medicalized approaches have dominated in supporting autistic youth; however, strength-based approaches are emerging (Lee et al., 2023). In their technology-based program that offered accommodations for sensory needs, Lee et al. (2023) found high motivation and enthusiasm amongst autistic youth to attend the program. This was attributed to efforts to intentionally create a space of belonging and authenticity that aligned with the interests and strengths of participants.

Using this holistic approach, the program positively impacted well-being, self-esteem, perception of autism, and social relationships (Lee et al., 2023). Interventions that align with the neurodiversity framework, appreciate the double empathy problem, and encourage autistic self-advocacy, such as those that promote sensory and emotional regulation and an understanding of autism, would likely increase self-awareness and self-esteem (Leadbitter et al., 2021).

Educational programs to increase the understanding of autism need to be more broadly available to neurotypical society to decrease stigma. The social model of disability suggests that it is important to consider shifting some responsibility for the disability experience onto society (Shakespeare, 2013). For social interactions, this would involve shifting the burden of successful social situations from being solely shouldered by autistic individuals to being shared between both parties, as described by the double empathy problem (Milton, 2012). Destigmatizing education is effective in addressing misconceptions about autism, increasing understanding, and reducing the judgment of autistic individuals (Gillespie-Lynch et al., 2015). Such efforts would improve the goodness of fit between the individual and the environment and reduce the need for autistic individuals to utilize stigma management strategies such as camouflaging (Botha & Frost, 2020; Mandy, 2019; Perry et al., 2022). In addition to educational programs, decreasing the focus on normalizing autistic people would also serve to reduce stigma (Bottema-Beutel et al., 2018).

To ensure interventions are psychologically safe, autistic individuals advocate for the need for autistic people to be involved in the creation and implementation of autism-related services (ASAN, 2020). Self-advocates have led the way for new understandings of autism that have resulted in shifts in language, support, and research. They have raised ethical concerns about interventions that are done at the expense of valuable life skills and well-being (ASAN, 2020). According to the autistic community, important intervention goals include learning about autism, coping strategies for sensory overload, and strategies to improve self-care as opposed to mimicking neurotypical social behavior that might elicit shame and damage self-esteem (ASAN, 2020). By listening to the autistic community, intervention priorities can be identified, along with learning how best to avoid unintended harm (Leadbitter et al., 2021).

Finally, in a commissioned report to hear autistic perspectives on behavioral interventions, the ASAN (2020) concluded that treatments need to have the following values: emphasis on positive outcomes, prevention of harm, protection of autonomy, inclusion, trauma sensitivity, self-determination, and cultural competency. They suggest that autistic individuals should consider and ask the following questions to the service provider when exploring an intervention:

1. How will you help me function better?
2. How will you help me learn the skills I want to learn?
3. How will you help me learn about my disability?
4. How will you help me be accepted?
5. How will you make sure I agree to the goals of therapy?
6. How will you help address problem attitudes towards disability?

Additionally, the following questions are recommended based on the findings of this study:

7. How will you respect my autistic identity?
8. What are the potential negative consequences of this intervention? How do you mitigate these?

### *Implications for GSSIs*

This study suggests that participation in GSSIs results in participants receiving several implied messages that do not align with the goals of the programs. Some participants perceived that they gained benefits from the GSSI, such as understanding the neurotypical social landscape or addressing specific relationship issues. However, it is not known how youth can selectively experience the benefits of GSSIs while avoiding their potential adverse mental health effects. This is because it is largely unknown who would benefit most and who would be at most risk of adverse effects from GSSIs, as the influence of individual characteristics of youth enrolled in GSSI on outcomes is rarely examined (Trembath et al., 2023). Some autistic youth, for example, might find eye contact bearable and worth the effort, while another might find it takes away from being able to listen and leaves them feeling exhausted. Despite PEERS being considered applicable to a wide range of individuals, this study suggests that individual values, goals, and motivations influenced outcomes, including impact on self-esteem. Therefore, these factors need to be considered before engaging in treatments such as GSSIs.

Using social rules may have benefits for certain individuals and for specific situations. Targeted interventions that are chosen and considered valuable by participants, as opposed to expectations to broadly change social behavior, would likely improve generalizability and relevance while minimizing risk to mental health (Hull et al., 2021, Leaf). Self-determination when accessing support is considered of utmost importance among autistic self-advocates (ASAN, 2020) and has been shown to increase instructional efficacy in autistic youth (Toussaint et al., 2016). PEERS is designed as a structured program, but our participants who had specific goals that happened to be addressed during one of the sessions seemed to increase the generalizability of taught skills. Didactic instruction might be appropriate for targeting specific goals, but Bottema-Beutel et al. (2018) suggest that normative expectations should be balanced by being explicit about the hegemony that underpins most encounters, and that instruction should be presented as choices that are context-dependent rather than prescriptive. The ramifications of choosing not to conform to social norms in different contexts could be outlined and evaluated as a part of GSSIs to help facilitate decisions about when and where to apply the skills learned in the GSSI.

An open discussion about the practice of camouflaging and the evidence suggesting its adverse impacts on mental health should be prioritized before any instruction of normative social skills takes place, especially as the practice can already be ingrained and habitual by adolescence (Howe et al., 2023). Similar to GSSIs, there is little evidence about how to benefit from camouflaging while minimizing the risk (Hull et al., 2021). Increasing one's awareness of engaging in the practice, encouraging deliberate choice of when and how to use it, monitoring for its effects when used, and the importance of self-care should be addressed on an ongoing basis throughout the intervention (Leaf et al., 2023). This would be especially important for females who have increased vulnerability to the pressure to camouflage and suffer from its adverse effects (Beck et al., 2020; Bernardin, Mason, et al., 2021; Leaf et al., 2023). Using camouflaging as a context-specific tool, when benefits outweigh the risks, and balanced by spaces that support authentic expression, might empower autistic individuals (Leaf et al., 2023).

Incorporating a neurodiversity-affirming lens within social skills interventions might decrease reinforcement of a deficit perspective of autistic social interaction and, therefore, minimize negative implicit messaging. Using this lens, neurotypical social practice can be taught as one of many ways to approach a social interaction and that social fractures are an interactional process rather than the result of the autistic individual's social difference. Increased regard for the importance and benefits of personal and relational authenticity, even if this differs from normative friend preferences and practices, should be reinforced for participants who identify making and keeping friends as a goal (Finke, 2023). The potential benefits of friendships between neurodivergent people should also be incorporated. This approach would align with recent research that suggests that friendships are more enjoyable and effective between matched neurotypes (Finke, 2023), and mentorship programs that pair autistic youth and adults promote feelings of social connectedness (Tomfohrde et al., 2023).

A neurodiversity-informed social skills intervention would focus on providing information about the neurotypical social landscape without the expectation to broadly conform to it (Leadbitter et al., 2021). Rather than being framed as teaching skills considered necessary to make friends, it would be an opportunity to increase understanding of dominant social preferences. For motivated individuals, this roadmap would serve to help navigate spaces such as school or the workplace, where adhering to certain social conventions increases chances of success (e.g., maintaining physical boundaries). If deemed relevant by the participant, targeted instruction to address specific social situations could be pursued. Important would be a discussion about camouflaging and how to access this tool strategically to minimize threats to mental health. This would involve ensuring the participant has supportive spaces for respite. Encouraging authentic, autistic social interactions both within and outside the program would be imperative to support autistic identity and a sense of belonging. Measures would focus on well-being and satisfaction in relationships.

## Implications for Research

The effectiveness of behavioral interventions needs to consider both efficacy and downstream effects. The outcome measures typically used in GSSI research, such as the SRS and

SSIS, carry inherent value judgments about being autistic since efficacy is considered as a reduction in autistic traits (Trembath et al., 2023). Research aligning with the normalization agenda, such as those that use these outcome measures, is incompatible with the more balanced neurodiversity-affirming perspectives (Leadbitter et al., 2021). Therefore, there are calls that intervention research needs to realign itself towards the neurodiversity movement using intervention outcomes that are "verifiably beneficial, including autonomy, [and] quality of life" (Leadbitter et al., 2021, p. 6) and that can assess the compatibility between an autistic individual and their social, emotional and physical environments rather than the reduction of autistic traits (Leadbitter et al., 2021). Working with the autistic community to ensure meaningful involvement in research is vital to help guide this shift.

It is clearly important to look beyond observable behavior to internal experiences, which is best explored with qualitative research centering the experiences of autistic individuals. ASAN (2020) continues to call for more high-quality qualitative studies to ensure the experiences of autistic individuals can shape research and support. Moving away from deficit understandings of autism that drive ableist research practices, such as the outcome measures commonly used, towards learning about how to promote flourishing and well-being could inform services that pragmatically improve the lives of autistic individuals and families.

## Limitations and Future Directions

Consistent with any exploratory study, our findings will not represent the experiences of all autistic youth who have participated in GSSIs. Our sample size was relatively small, although this is deemed appropriate for qualitative studies (Morse, 2000). The inclusion criteria were constrained by eligibility to enroll in PEERS, which requires average intellectual ability and the use of spoken language, which does not represent all autistic people. Autistic people with co-occurring intellectual disabilities and who communicate in ways other than through spoken language are often underrepresented in autism research, including exploration of the impact of interventions on their well-being and self-esteem (Nicholas et al., 2019). Therefore, future research on the influence of interventions, even if different than GSSIs, is an essential area of study. However, our sample did represent other aspects of diversity relatively well, including gender and race/ethnicity.

Despite my experience in interviewing a broad range of individuals and familiarity with autistic youth, there was minimal engagement by some participants, which limited the depth of some data. It might have been beneficial to have asked the participants to complete a measure of self-esteem before the interview to prime their thoughts about the abstract topic or to have an orientation session to outline the concept of self-esteem as understood in this study. Some participants seemed not to understand the construct and therefore gave conflicting answers when asked about self-esteem versus how they felt about themselves. Adding a quantitative component to the study was considered in the early phases of the project; however, as self-esteem and GSSIs have been largely unexplored, a study focused on hearing the perspectives of autistic youth was thought to be the most impactful approach to answering the research question. Additionally, many self-report measures are validated using normative standards and would, therefore, not align with the critical perspective of this study. The incorporation of a measure of self-esteem, ideally one that is informed by a neurodiversity-affirming perspective and validated for autistic youth, would further increase understanding of the mental health impacts of GSSIs. Incorporation of an active comparison group, such as a social group with a similar time commitment and support, in future research would also increase understanding of the impact of GSSIs on self-esteem.

This study suggested that participating in PEERS impacted self-esteem in the short term, as most participants (apart from one) had completed the program within three months of interviewing. It would be important to assess for impact on self-esteem in the long term. Additionally, with the expansion of PEERS delivery onto the virtual platform, there is the potential of losing the benefits of participants being together to foster a sense of belonging. How this might further impact self-esteem would be worth exploring.

We did not collect detailed demographic information about the participants (such as intellectual ability), their family perspectives on disability, and information about the goodness of fit between the youth and their household, which are important elements when considering self-esteem in youth (Peng et al., 2021; Riccio et al., 2021). Autistic youth benefit from supportive and accepting spaces that emphasize strengths and positive identity, and the influence of how a normalization agenda impacts the development of such spaces, particularly in the home, has not been explored. Using a critical lens to assess the impact of normative implicit messages received by caregivers involved in GSSIs is another important avenue to learn how to support the thriving of autistic youth.

Most participants in this study expressed overall satisfaction with PEERS, and there have been calls for research to clarify what this exactly means (McMahon & Solomon, 2015). It is still unclear as to whether this perception relates to factors such as the degree to which the intervention is tolerated or liked, the increase in social skills, allegiance to the intervention, or hope for improvement (McMahon & Solomon, 2015), or as suggested in this study, because of the opportunity to feel a sense of belonging. Previous research has suggested that GSSIs may elicit satisfaction regardless of the training taking place (Gates et al., 2017; McMahon &

Solomon, 2015). A better understanding of what aspects of GSSIs contributed to this satisfaction also warrants further investigation.

## Reflections

### *Evolution of the Methodology*

I suspect with many novice researchers, the path to answer the research question is a meandering one, and this project was no exception. Early on, I thought a mixed-method approach was the best way to answer my research question. I considered using a self-esteem measure to be administered before PEERS and after to determine if, and to what extent, participating in PEERS would affect self-esteem. Much time was spent looking at different self-esteem scales and exploring which one might be the most applicable to autistic youth. A qualitative component, done concurrently or sequentially, would offer greater depth to the quantitative information obtained using self-esteem scales. I did not end up using any self-esteem scales. Still, this process had the benefit of increasing my knowledge of current understandings of self-esteem, which proved helpful in guiding the theoretical foundation of the study.

As the research question evolved to its final and current form, it became increasingly clear that a qualitative approach would be the best fit. The question concerns the subjective experience of autistic youth during and after their participation in PEERS. More than anything, I hoped to obtain data holistically and relationally to provide a deeper appreciation of their experience. I was looking for depth and nuance to capture the complexity of the disability experience in youth. Consequently, we decided that the best chance to satisfy this goal was to dedicate my time and effort to a purely qualitative approach instead of mixing it with quantitative data. I also wanted to be intentional about elevating autistic youths' voices and gain at least a cursory appreciation of the world in which they live, their perspectives of disability, and themselves, and to get a glimpse of their social tendencies. I wanted to incorporate all this information to help me understand and elucidate their experience.

Even after deciding to pursue a qualitative approach, the evolution of how best to approach the project continued. We initially agreed that IPA was the most appropriate method, given my desire to collect nuanced experiential information that I felt confident I could interpret further. Phenomenology is the study of lived experience (Shaw & Anderson, 2018), which certainly aligns with the goal of this study. IPA, in particular, is a *double hermeneutic* approach where the interpretation of the participant is then, in turn, interpreted by the researcher, each bringing their own “subjectivities to the endeavor” (MacLeod, 2019, p. 50). The opportunity to mitigate power imbalance by elevating the participant as an expert (MacLeod, 2019), with the researcher tasked to use experience alongside existing knowledge (Howard et al., 2019), suited my goal to represent autistic youth.

However, recognized limitations of IPA in literature (Howard et al., 2019) became a reality early in data collection. The reliance on language and expression of internal thoughts and feelings for some autistic people may be limited. The idea that IPA would best serve the analysis and interpretation to answer the research question began to falter after the first three interviews. This was significant because we were aiming for a sample size of three. While willing to do the interview and appearing to have adequate verbal skills and capacity to attend and understand the questions being posed, the first few participants provided mostly concrete, descriptive answers with little depth or richness. I was left with very little story about their experiences to interpret with any depth. I certainly did not get the rich descriptions that are called for in an IPA approach.

In returning to the literature, I learned that Dewinter et al. (2017) also encountered this challenge, finding that the limited expressive language of autistic individuals restricted the richness of some participants' data. Further, despite the rise in IPA studies in the autism field, only three of 33 studies in DePape and Lindsay's (DePape & Lindsay, 2015) meta-synthesis of the lived experiences of autistic people employed IPA as their analytical framework. By contrast, most studies used thematic analysis, indicating that IPA is perhaps not yet recognized as a strong qualitative approach for research with the autistic community. Alase (2017) states that IPA depends on sense-making on the accounts that participants provide, which reflect their attempts to make sense of experience. Thus, in the early stages of this study, it seemed that IPA, demanding rich sense-making and articulate verbal description of that sense-making, was not well suited as a methodology for this study and that a different approach would be needed.

Additionally, there were emerging patterns across the data that seemed important to explore to provide insights into the research questions more effectively than analyzing data in a case-by-case fashion, as done in IPA. RTA offers a way to lift out patterns from the data without necessarily sacrificing the uniqueness of participants. Finally, practically speaking, while IPA may have been appropriate at some levels, RTA was more familiar to my supervisor.

During this period of uncertainty about how best to pursue my research project, I felt vindicated when I read that data collection and early analysis are expected to inform one another in an iterative manner in qualitative research, especially with ID (Thorne et al., 2004). Therefore, after understanding that IPA may not serve my research project as well as I initially thought, my attention turned to ID. ID, as described earlier, demands less depth of interpretation and sense-making by participants and places more weight on researcher interpretation, and therefore seemed to strike a more realistic balance of responsibility between researcher and participant for this study (Thorne et al., 2004).

### *Interviews*

As mentioned, the first three participants seemed minimally engaged during their interviews and offered limited sense-making around their experience of doing PEERS. This seemed to extend to their attitude towards PEERS and social skills generally, as they provided little reflection on the teachings and their impact on their day-to-day lives. For this reason, it was felt that some participants may not have been engaged enough to identify benefits from or concerns about the program, nor reflect on impacts on their self-esteem. In an intentional effort to minimize power differential with participants, the pace and sense that some participants were not engaged were respected. So, while some effort was made to make a personal connection, like commenting on a pet or reframing some questions, this was only done if the participant seemed to respond to increased bids for engagement.

Some participants could describe their experience of participating in PEERS in much more detail and with more evidence of sense-making. There were a couple of participants who had navigated gender diversity before their diagnosis of autism. Interestingly, they seemed primed to accept the diagnosis and incorporate neurodiversity understandings into their identity. While not explicitly explored, already grappling with a marginalized experience may have increased their capacity to accommodate intersecting identities.

Often, it was felt that participants answered questions in a socially desirable or expected way, at least at first. This was observed when, after there was perceived comfort in the process and the interaction was happening more easily, answers became more genuine and sometimes shifted from what would be expected to what was felt. For example, when asked if they liked the program, most participants initially said, “Yes, I liked it,” but when asked more probing questions, some participants provided answers that conflicted with the initial sentiment.

As a result of my children's experience with social skills interventions, I intentionally bracketed my personal bias about the expected impact of PEERS on study participants' sense of self and self-esteem. I asked open-ended questions and offered affirmations when participants stated that PEERS positively impacted their sense of self, such as saying, "I'm glad that you felt that!". I am also biased in that I think it is important for adolescents to be aware of their diagnosis, as I feel this has been a way to support my children's understanding of themselves and to promote self-advocacy. I was intentional about hiding my surprise when one participant was not aware of their diagnosis, and I quickly shifted the language of the interview to respect that this was not openly discussed in that participant's home.

### ***Data analysis***

During the coding process, I spent a lot of time reflecting on the language that participants used. Most participants used language that reflected a deficit understanding of autism. There were three participants in particular whose language was firmly deficit-oriented and even derogatory, which left me wondering about the attitudes they were exposed to in their homes. This led me to consider how the normative instruction of PEERS might send implicit messages not only to participants but also to the parents involved in the program.

### ***Results***

The results of this study have led me to reflect on some experiences I have had with my children, which seems fitting as their experience compelled me to do this study in the first place. I recently supported my daughter in navigating a social situation that reinforced the process of thoughtfully engaging in a risk-benefit evaluation when deciding to engage in camouflaging. My daughter is often unaware of the non-verbal messages she displays, and during her weekly extra-curricular drama class, she could not hide the growing frustration she felt for her teacher. Her nonverbal display made the teachers and other students feel uncomfortable to the point that it threatened her being asked to leave the program. After explaining her options and outlining the risks and benefits of changing the non-verbal messages she was sending (which she was unaware of), she decided to camouflage as she wanted to stay in the group. The effect was positive in that she was allowed to remain in the group. She did not feel the experience was too taxing, but she was offered the space and time to help recover from the effort at home afterward.

I have also been rethinking how I support my children's friendships. Years ago, I shifted my expectations regarding their need to always conform to normative social standards, reinforced by more nuanced understandings of disability that include social and critical perspectives. However, this study has highlighted that I still expect meaningful friendships to align with neurotypical preferences and behaviors. I want my children to experience diversity in their friendships and to be able to be friends with both autistic and non-autistic individuals. However, I appreciate that what they want from their friendships might be different than what I want for them in their friendships and that more meaningful friendship experiences may be more likely to happen with others who are also autistic.

My children are currently navigating adolescence. The research on the fragility of self-esteem during this time of life and the importance of bolstering and protecting self-esteem for autistic youth resonates with my efforts to support their well-being. This study, in part, has clarified how best to do this. For years, our family has embraced a neurodiversity-affirming approach to autism. Still, I better appreciate the need to intentionally communicate and expose my children to positive autistic identity to increase their self-esteem. I also want to emphasize their strengths while being realistic about the extent to which they can address struggles and limitations. Creating or joining spaces where autism identity is validated and celebrated will continue to be a priority in our family.

## Conclusion

Parents, clinicians, researchers, and the autistic community agree that the goal of interventions for autistic youth is to help them thrive and realize their full potential (Leadbitter et al., 2021), but what this means differs among these groups. Parents and clinicians prioritize normative social skills and social interaction, and there are calls for research entrenched by the medicalized perspective to be reconciled with and informed by the neurodiversity movement. Autistic self-advocates call for a shift away from interventions that minimize autistic behaviors towards ones that promote well-being and preserve mental health.

The goal of GSSIs is to improve friendships by teaching normative social skills to be used by the participant in their day-to-day life. While autistic individuals can gain knowledge from GSSIs (Gates et al., 2017), the normative agenda inherent in GSSIs, the internalized stigma that autistic individuals strive to navigate, and the unique vulnerabilities of autistic youth may set them up for unintended negative consequences of GSSIs that have long-lasting effects. The acknowledged impacts of early behavioral interventions provide a cautionary tale of the potential adverse effects that professionals and parents should pay attention to. For example, our findings suggest that autistic youth receive implied messages from GSSIs. Reinforcing the hegemony of neuro-normative ways of being, increasing pressure to conform to and be responsible for neurotypical expectations, and the prescriptive nature of social interaction are potential unintended messages from GSSIs that may both exacerbate and mask mental health problems, and promote inauthenticity and stigma (Bottema-Beutel et al., 2018).

Adolescence is a time of uncertainty and vulnerability; important milestones are developing identity and independence. It is a time when self-esteem is particularly sensitive to experiences, and shifts in self-esteem, such as those elicited by feelings of shame, can have long-term consequences. Stigma and associated personal and collective management strategies, a strong desire to both fit in and be authentic in the face of a deficit understanding of autism, make it imperative that interventions that autistic youth and their families access serve to protect self-esteem. Consequently, the unintended consequences of teaching normative expectations need to be acknowledged openly, and how difference is managed in this population needs to be handled with more care. Listening to the autistic community, including our participants, makes it clear that interventions that prioritize the development of a positive autistic identity and authentic relationships and offer targeted and participant-directed supports balanced by a strength-based approach are needed.

For GSSIs, current evidence does not allow a proper assessment of the risks and benefits. GSSIs primarily target social differences with the notion that remediation of these differences will improve function (Lee et al., 2023). However, GSSIs and other similar interventions may inadvertently devalue and stigmatize youth. Addressing a clear gap in the research, this study helps increase understanding of autistic youth's experience of participating in a GSSI and how this impacts well-being and self-esteem. By listening to the voices of autistic youth as experts, clinicians, researchers, and caregivers alike, we will better understand how to support their needs in a relevant and respectful way.

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# Appendix A: Ethics Approval

UNIVERSITY OF ALBERTA

| | |
|---|---|
| Date: | December 2, 2021 |
| Study ID: | Pro00115547 |
| Principal Investigator: | Sheri Klassen |
| Study Supervisor: | Sandra Hodgetts |
| Study Title: | Exploring Perceived Influence of Participation in Social Skills Group Intervention on the Self-Esteem of Autistic Youth |
| Approval Expiry Date: | Thursday, December 1, 2022 |

Thank you for submitting the above study to the Research Ethics Board 1. Your application has been reviewed and approved on behalf of the committee.

**Approved Documents:**

| ***Recruitment Materials*** |
|---|
| Recruitment Poster |
| ***Consent Forms*** |
| Youth Assent form |
| Study Information |
| Adult Consent form |
| ***Questionnaires, Cover Letters, Surveys, Tests, Interview Scripts, etc.*** |
| Interview Guide |

Any proposed changes to the study must be submitted to the REB for approval prior to implementation. 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 REB does not constitute authorization to initiate the conduct of this research. The Principal Investigator is responsible for ensuring required approvals from other involved organizations (e.g., Alberta Health Services, Covenant Health, community organizations, school boards) are obtained, before the research begins.

## Appendix B: Recruitment Documents and Consent Forms

# Participate in autistic self-esteem research

**We want to learn about how social skills groups affect the self-esteem and identity of autistic youth.**

**Participation involves an interview.**

**We expect the interview to take less than 30 minutes of your time.**

**You will receive a $25 Amazon gift card for your time.**

## How can I participate?

**We are looking for autistic youth who have completed a PEERS program in the last year.**

If you are interested, please respond to this email (saklasse@ualberta.ca) for more information.

**Study Title:** Exploring Perceived Influence of Participation in Social Skills Group Intervention on Self-Esteem of Autistic Youth

**Ethics ID**: Pro00115547 Research Ethics Board, University of Alberta (780) 492-2615

**Principal Investigator:**

Sheri Klassen, MD, MSc student

Faculty of Rehabilitation Medicine

University of Alberta

saklasse@ualberta.ca

**Supervisor:**

Dr. Sandy Thompson-Hodgetts

Department of Occupational Therapy

University of Alberta

780-492-8416

sandra.hodgetts@ualberta.ca

**Background:**

Social skills groups (such as PEERS) are commonly used for autistic youth. The goal of this intervention is to teach neurotypical social skills to be used in real-life situations. There is little research on how participation in these interventions affects sense of well-being, including self-esteem and identity, of participants.

**Why is this research important?**

We need to hear from autistic youth about how they think learning typical social skills affects their self-esteem in their day-to-day life.

**Who can join this study?**

Autistic youth (age 13-18 years old) who have completed PEERS within the last 1-12 months.

**What will happen during this study?**

You will be asked questions by the researcher, who has experience with autistic youth, through an interview over Zoom. We expect the interview to take about 20 minutes.

**What are the benefits of this study?**

What we learn will help us understand how to best support a positive sense of self for autistic youth. You will receive a gift-card for your participation.

**What are the risks of this study?**

We do not expect that you will experience any harm if you participate. You may get tired during the interview. You can ask for a break at any time. You can also tell us you do not want to answer a question or stop the interview at any time.

**Will my privacy be protected?**

The data from the zoom interviews will only be shared with people on our research team. We will all sign forms agreeing to keep all information private. We will remove your name from all data. We will not share your name at all when we talk about the study. The information that you share with the research team will be kept for at least five years after the study is done. All information will be kept in a secure and locked filing cabinet or on an encrypted computer that can only be entered through a password.

If you have any questions, please contact Sheri via email at saklasse@ualberta.ca or her cell at 780-901-4174.

## YOUTH CONSENT FORM

**Project Title:** Exploring Perceived Influence of Participation in Social Skills Group Intervention on the Self-Esteem of Autistic Youth

**Locally Responsible Investigator**: Sheri Klassen Tel: (780) 901-4174

| | Yes | No |
|---|---|---|
| Do you understand that you have been asked to be in a research study? | ☐ | ☐ |
| Have you read the attached Information Sheet? | ☐ | ☐ |
| Do you understand the benefits and risks involved in taking part in this research study? | ☐ | ☐ |
| Have you had an opportunity to ask questions and discuss this study? | ☐ | ☐ |
| Do you understand that you are free to withdraw from the study at any time | ☐ | ☐ |

without having to give a reason?

Has the issue of confidentiality been explained to you? ☐ ☐

Do you understand who will have access to the records? ☐ ☐

Who explained this study to you? ______________________________________________

---

I agree to participate in the research activities YES ☐ NO ☐

I would like my contact information added to a recruitment list for future research YES ☐ NO ☐

I agree to have anonymized (no names) Zoom audio clips used for presentation purposes YES ☐ NO ☐

Signature of Participant: ______________________________________________

(Printed Name): ______________________________________________

Date: ______________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to take part.

Signature of Investigator or Designee ________________________________ Date __________

## PARENT CONSENT FORM

**Project Title:** Exploring Perceived Influence of Participation in Social Skills Group Intervention on the Self-Esteem of Autistic Youth

**Locally Responsible Investigator**: Sheri Klassen Tel: (780) 901-4174

| | Yes | No |
|---|---|---|
| Do you understand that your child has been asked to be in a research study? | ☐ | ☐ |
| Have you read the attached Information Sheet? | ☐ | ☐ |
| Do you understand the benefits and risks involved in your child taking part in this research study? | ☐ | ☐ |
| Have you had an opportunity to ask questions and discuss this study? | ☐ | ☐ |
| Do you understand that your child is free to withdraw from the study at any time without having to give a reason? | ☐ | ☐ |
| Has the issue of confidentiality been explained to you? | ☐ | ☐ |
| Do you understand who will have access to the records? | ☐ | ☐ |

Who explained this study to you? ____________________________________________

| | | | | |
|---|---|---|---|---|
| I agree that my child participates in the research activities | YES | ☐ | NO | ☐ |
| I would like my child’s contact information added to a recruitment list for future research | YES | ☐ | NO | ☐ |
| I agree to have my child’s anonymized (no names) Zoom audio clips used for | YES | ☐ | NO | ☐ |

presentation purposes

Signature of Parent/Guardian: ______________________________________________

(Printed Name): ________________________________________________

Date: __________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to have their child take part.

Signature of Investigator or Designee ___________________________ Date __________

## Appendix C: Interview Guide

What is your identified gender? How old are you?

Being autistic:

1. Do you remember when you learned you were autistic?
2. How do you feel about being autistic? What does it mean to be autistic? Why do you think that?
    a. What do you like most about being autistic?
    b. Anything you not like about being autistic?

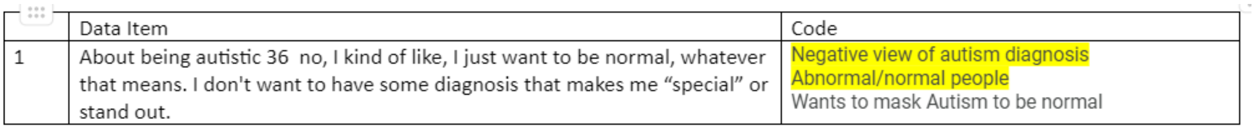
Participation in PEERS:

3. How/why did you decide to do the PEERS program?
    a. Was your decision?
    b. Did you feel like you needed to do it?
    c. Have you done other groups that teach social skills?
4. Tell me what did you hope PEERS could do you for you? What do you think the point was?
5. As much as you can, tell me what was it like being in the sessions for you?
    a. Did you like the program? The sessions?
    b. Was anything you learned surprising or unexpected?
    c. What was frustrating? What was easy?
    d. What was a positive about PEERS?
    e. What was a negative?
6. Do you remember when the leader talked about the whole point of PEERS? What did she say? What did you think about what she said?

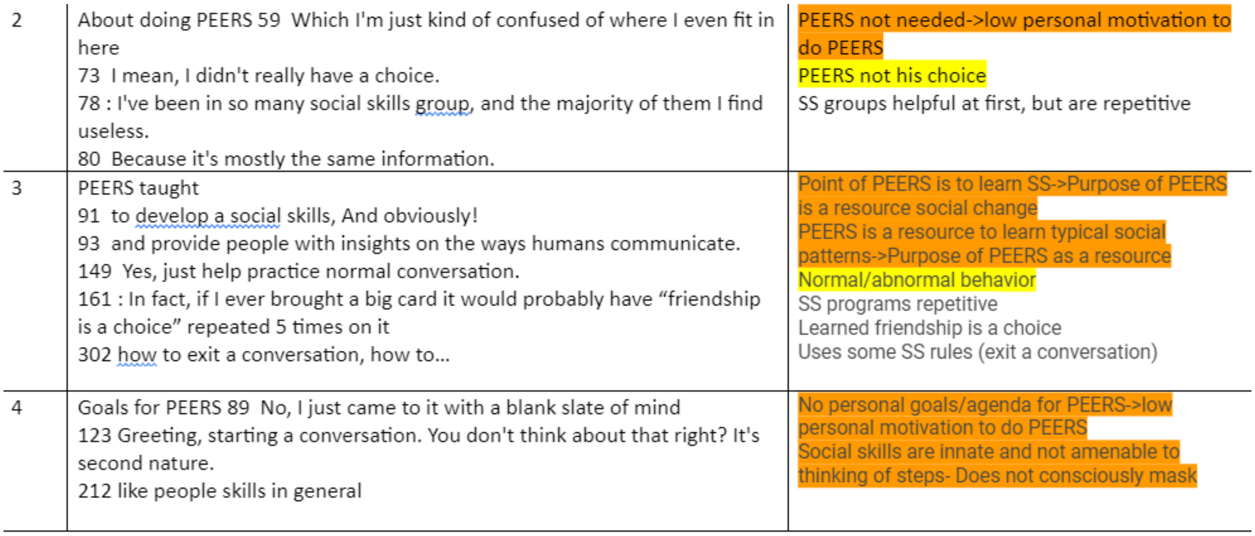
PEERS and self-esteem/self-worth/identity:

7. Tell me about how PEERS made you feel about yourself? About being autistic?
8. Did you feel that during PEERS you are taught to act in ways that were not natural to you? What is that like? Do you think being autistic means you have poor social skills?
9. How does that make you feel? Why?
10. Is acting non-autistic important to you?
    a. Do you feel that is the right way to be?
    b. Or does it feel not right for you?
11. Since finishing PEERS has anything changed for you? When interacting with friends for example? Do you have more friends since doing PEERS? Do you use what you learned in PEERS at school or with friends? How does that make you feel? Is it hard?
12. Tell me how do you think the program influenced how much you like yourself as a person? Change the sense of who you are?
13. Tell me about when you get to be your real, authentic self? How does that feel? Would you like to be able to do that more? Do you prefer to hang out with a group of autistics or non-autistics?
14. Self-Esteem: What makes you feel good or happy about yourself?

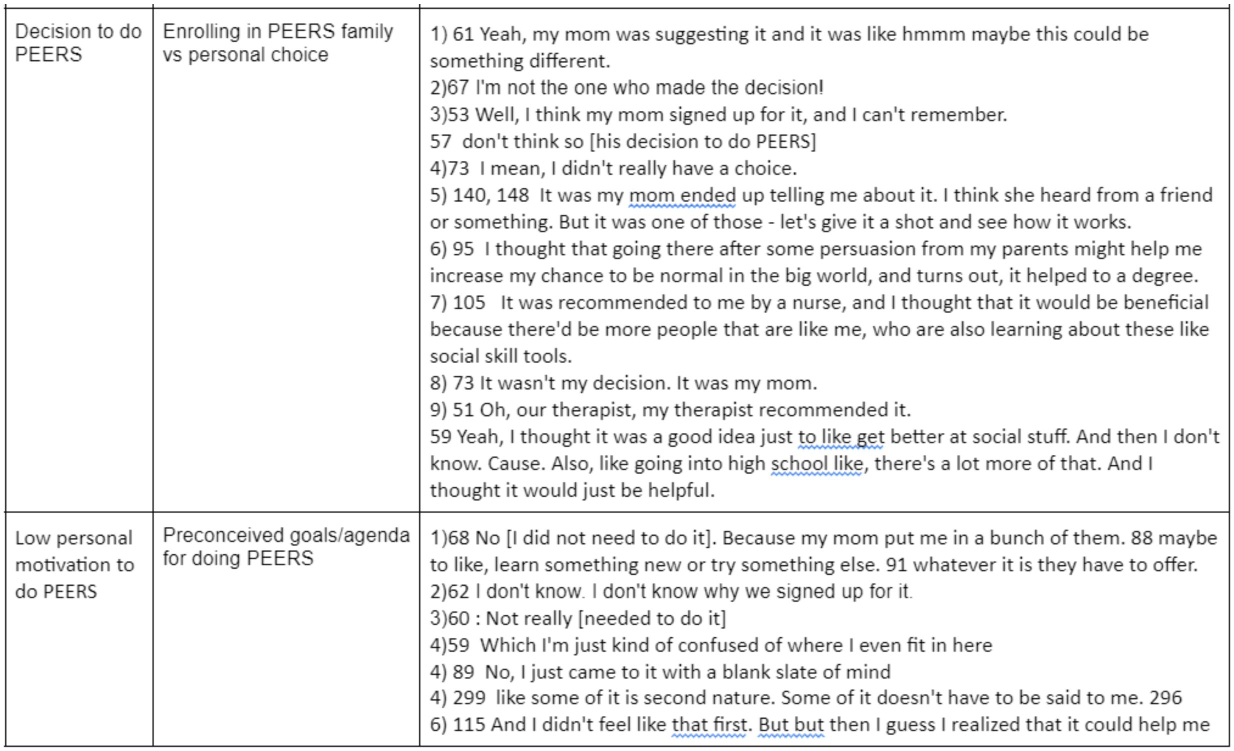
# Appendix D: Example of Coding tables



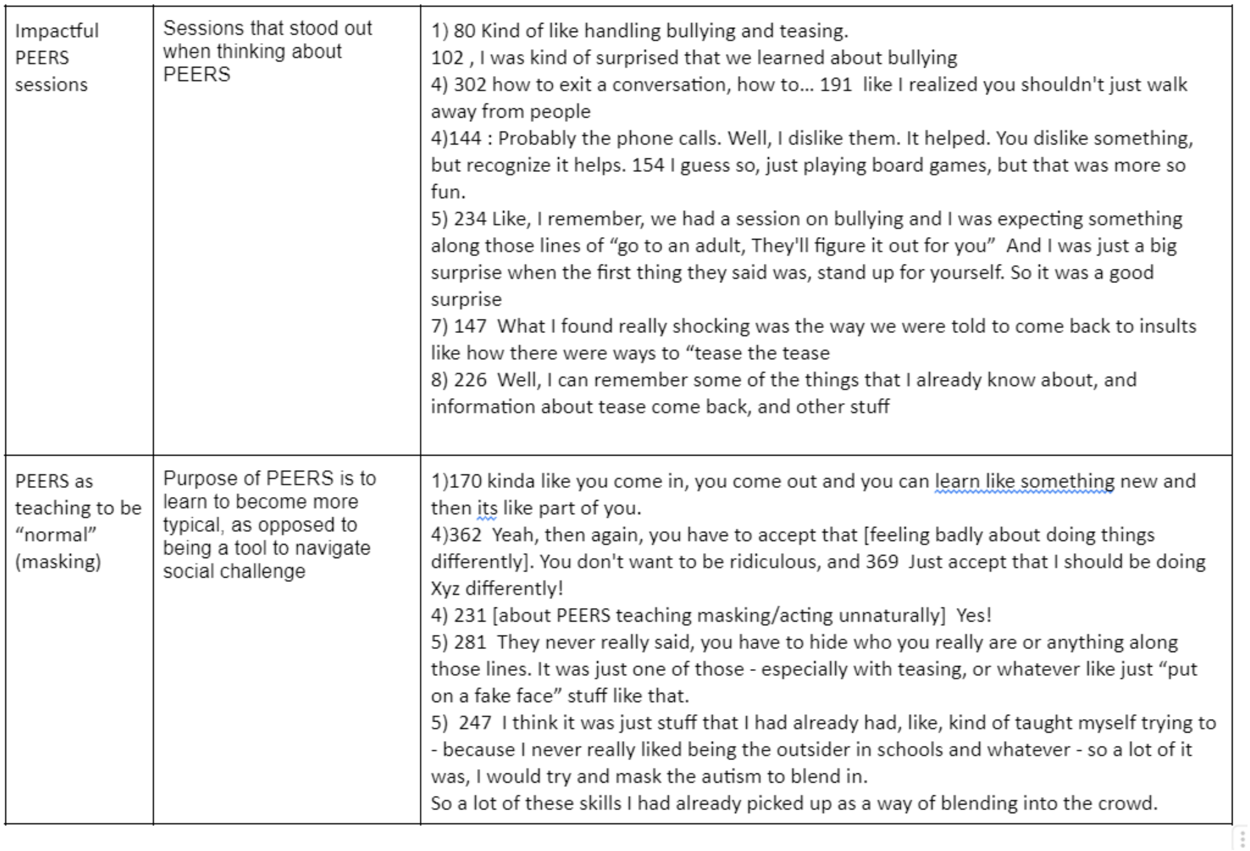
| | Data Item | Code |
|---|---|---|
| 1 | About being autistic 36 no, I kind of like, I just want to be normal, whatever that means. I don't want to have some diagnosis that makes me "special" or stand out. | Negative view of autism diagnosis<br>Abnormal/normal people<br>Wants to mask Autism to be normal |



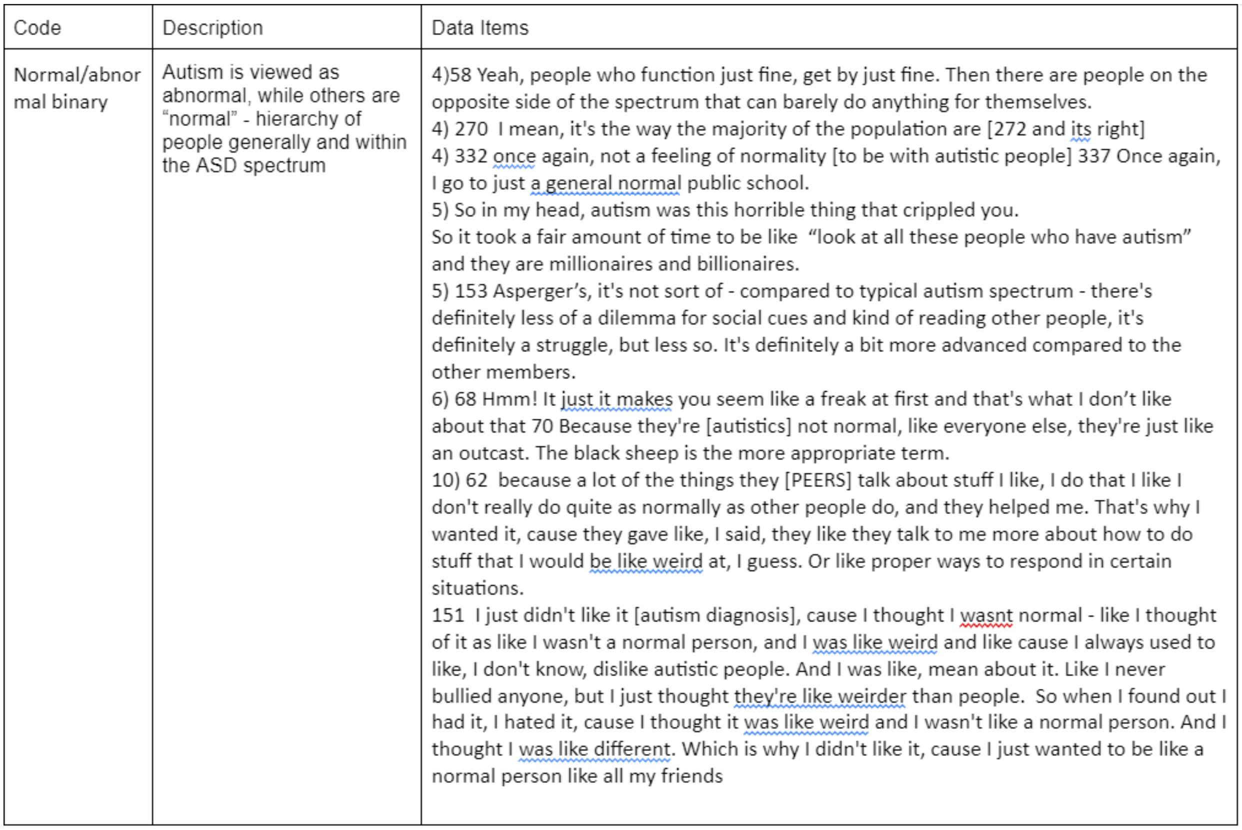
| | | |
|---|---|---|
| 2 | About doing PEERS 59 Which I'm just kind of confused of where I even fit in here<br>73 I mean, I didn't really have a choice.<br>78 : I've been in so many social skills group, and the majority of them I find useless.<br>80 Because it's mostly the same information. | PEERS not needed->low personal motivation to do PEERS<br>PEERS not his choice<br>SS groups helpful at first, but are repetitive |
| 3 | PEERS taught<br>91 to develop a social skills, And obviously!<br>93 and provide people with insights on the ways humans communicate.<br>149 Yes, just help practice normal conversation.<br>161 : In fact, if I ever brought a big card it would probably have "friendship is a choice" repeated 5 times on it<br>302 how to exit a conversation, how to... | Point of PEERS is to learn SS->Purpose of PEERS is a resource social change<br>PEERS is a resource to learn typical social patterns->Purpose of PEERS as a resource<br>Normal/abnormal behavior<br>SS programs repetitive<br>Learned friendship is a choice<br>Uses some SS rules (exit a conversation) |
| 4 | Goals for PEERS 89 No, I just came to it with a blank slate of mind<br>123 Greeting, starting a conversation. You don't think about that right? It's second nature.<br>212 like people skills in general | No personal goals/agenda for PEERS->low personal motivation to do PEERS<br>Social skills are innate and not amenable to thinking of steps- Does not consciously mask |



| | | |
|---|---|---|
| Decision to do PEERS | Enrolling in PEERS family vs personal choice | 1) 61 Yeah, my mom was suggesting it and it was like hmmm maybe this could be something different.<br>2)67 I'm not the one who made the decision!<br>3)53 Well, I think my mom signed up for it, and I can't remember.<br>57 don't think so [his decision to do PEERS]<br>4)73 I mean, I didn't really have a choice.<br>5) 140, 148 It was my mom ended up telling me about it. I think she heard from a friend or something. But it was one of those - let's give it a shot and see how it works.<br>6) 95 I thought that going there after some persuasion from my parents might help me increase my chance to be normal in the big world, and turns out, it helped to a degree.<br>7) 105 It was recommended to me by a nurse, and I thought that it would be beneficial because there'd be more people that are like me, who are also learning about these like social skill tools.<br>8) 73 It wasn't my decision. It was my mom.<br>9) 51 Oh, our therapist, my therapist recommended it.<br>59 Yeah, I thought it was a good idea just to like get better at social stuff. And then I don't know. Cause. Also, like going into high school like, there's a lot more of that. And I thought it would just be helpful. |
| Low personal motivation to do PEERS | Preconceived goals/agenda for doing PEERS | 1)68 No [I did not need to do it]. Because my mom put me in a bunch of them. 88 maybe to like, learn something new or try something else. 91 whatever it is they have to offer.<br>2)62 I don't know. I don't know why we signed up for it.<br>3)60 : Not really [needed to do it]<br>4)59 Which I'm just kind of confused of where I even fit in here<br>4) 89 No, I just came to it with a blank slate of mind<br>4) 299 like some of it is second nature. Some of it doesn't have to be said to me. 296<br>6) 115 And I didn't feel like that first. But but then I guess I realized that it could help me |



| | | |
|---|---|---|
| Impactful PEERS sessions | Sessions that stood out when thinking about PEERS | 1) 80 Kind of like handling bullying and teasing.<br>102 , I was kind of surprised that we learned about bullying<br>4) 302 how to exit a conversation, how to… 191 like I realized you shouldn't just walk away from people<br>4)144 : Probably the phone calls. Well, I dislike them. It helped. You dislike something, but recognize it helps. 154 I guess so, just playing board games, but that was more so fun.<br>5) 234 Like, I remember, we had a session on bullying and I was expecting something along those lines of “go to an adult, They'll figure it out for you” And I was just a big surprise when the first thing they said was, stand up for yourself. So it was a good surprise<br>7) 147 What I found really shocking was the way we were told to come back to insults like how there were ways to “tease the tease<br>8) 226 Well, I can remember some of the things that I already know about, and information about tease come back, and other stuff |
| PEERS as teaching to be “normal” (masking) | Purpose of PEERS is to learn to become more typical, as opposed to being a tool to navigate social challenge | 1)170 kinda like you come in, you come out and you can learn like something new and then its like part of you.<br>4)362 Yeah, then again, you have to accept that [feeling badly about doing things differently]. You don't want to be ridiculous, and 369 Just accept that I should be doing Xyz differently!<br>4) 231 [about PEERS teaching masking/acting unnaturally] Yes!<br>5) 281 They never really said, you have to hide who you really are or anything along those lines. It was just one of those - especially with teasing, or whatever like just “put on a fake face” stuff like that.<br>5) 247 I think it was just stuff that I had already had, like, kind of taught myself trying to - because I never really liked being the outsider in schools and whatever - so a lot of it was, I would try and mask the autism to blend in.<br>So a lot of these skills I had already picked up as a way of blending into the crowd. |

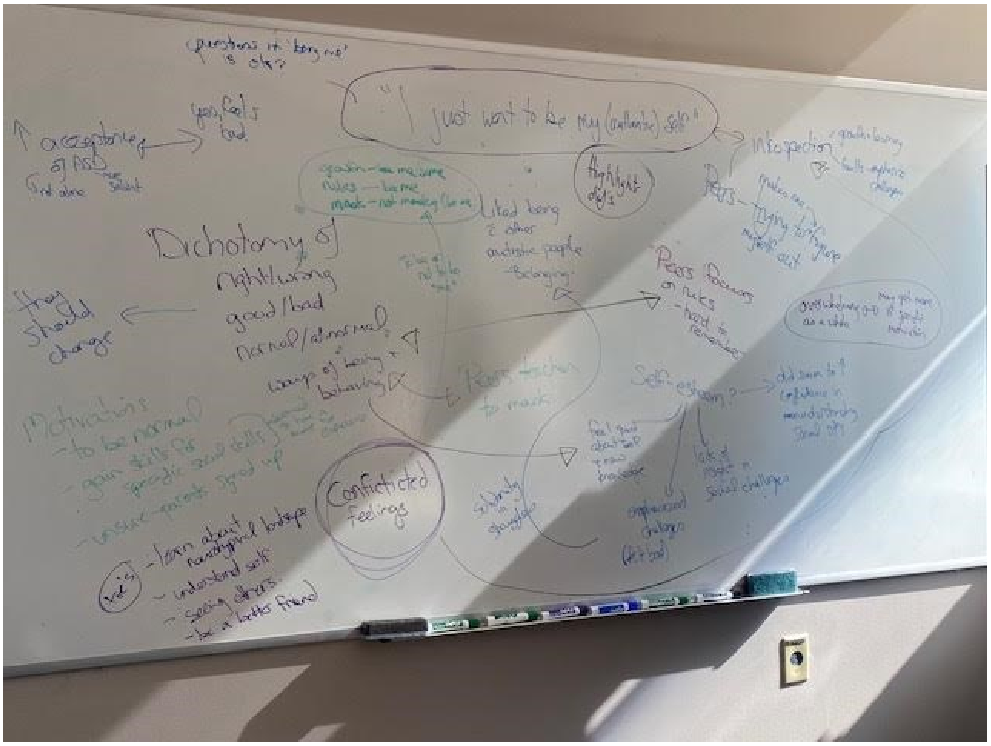


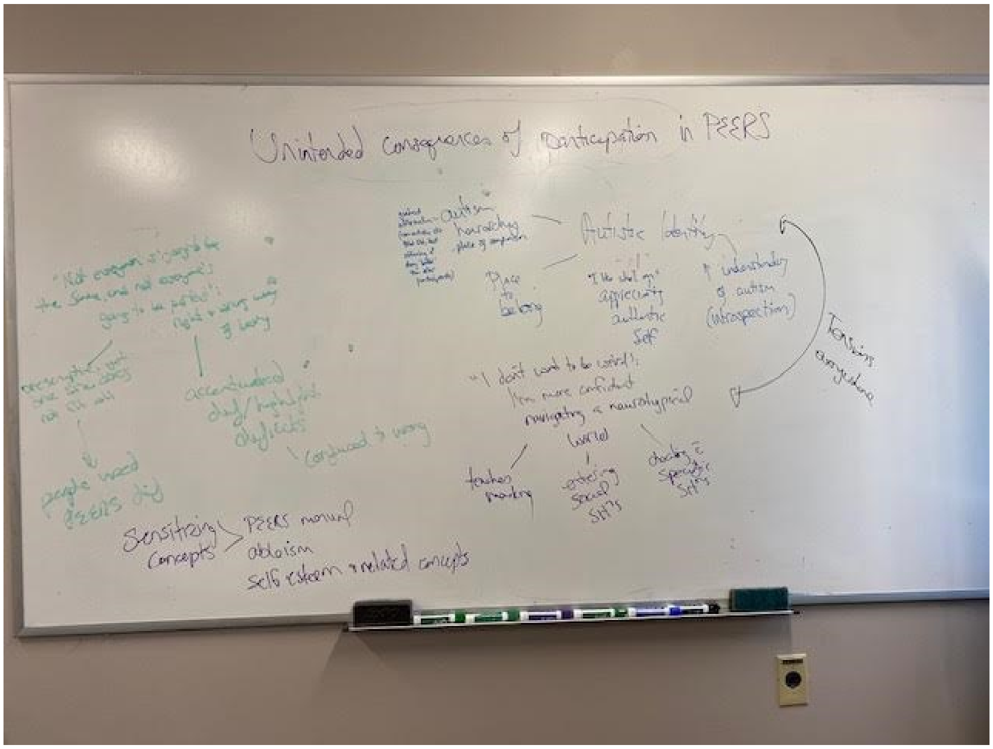
| Code | Description | Data Items |
|---|---|---|
| Normal/abnormal binary | Autism is viewed as abnormal, while others are "normal" - hierarchy of people generally and within the ASD spectrum | 4)58 Yeah, people who function just fine, get by just fine. Then there are people on the opposite side of the spectrum that can barely do anything for themselves.<br>4) 270 I mean, it's the way the majority of the population are [272 and its right]<br>4) 332 once again, not a feeling of normality [to be with autistic people] 337 Once again, I go to just a general normal public school.<br>5) So in my head, autism was this horrible thing that crippled you.<br>So it took a fair amount of time to be like "look at all these people who have autism" and they are millionaires and billionaires.<br>5) 153 Asperger's, it's not sort of - compared to typical autism spectrum - there's definitely less of a dilemma for social cues and kind of reading other people, it's definitely a struggle, but less so. It's definitely a bit more advanced compared to the other members.<br>6) 68 Hmm! It just it makes you seem like a freak at first and that's what I don't like about that 70 Because they're [autistics] not normal, like everyone else, they're just like an outcast. The black sheep is the more appropriate term.<br>10) 62 because a lot of the things they [PEERS] talk about stuff I like, I do that I like I don't really do quite as normally as other people do, and they helped me. That's why I wanted it, cause they gave like, I said, they like they talk to me more about how to do stuff that I would be like weird at, I guess. Or like proper ways to respond in certain situations.<br>151 I just didn't like it [autism diagnosis], cause I thought I wasnt normal - like I thought of it as like I wasn't a normal person, and I was like weird and like cause I always used to like, I don't know, dislike autistic people. And I was like, mean about it. Like I never bullied anyone, but I just thought they're like weirder than people. So when I found out I had it, I hated it, cause I thought it was like weird and I wasn't like a normal person. And I thought I was like different. Which is why I didn't like it, cause I just wanted to be like a normal person like all my friends |

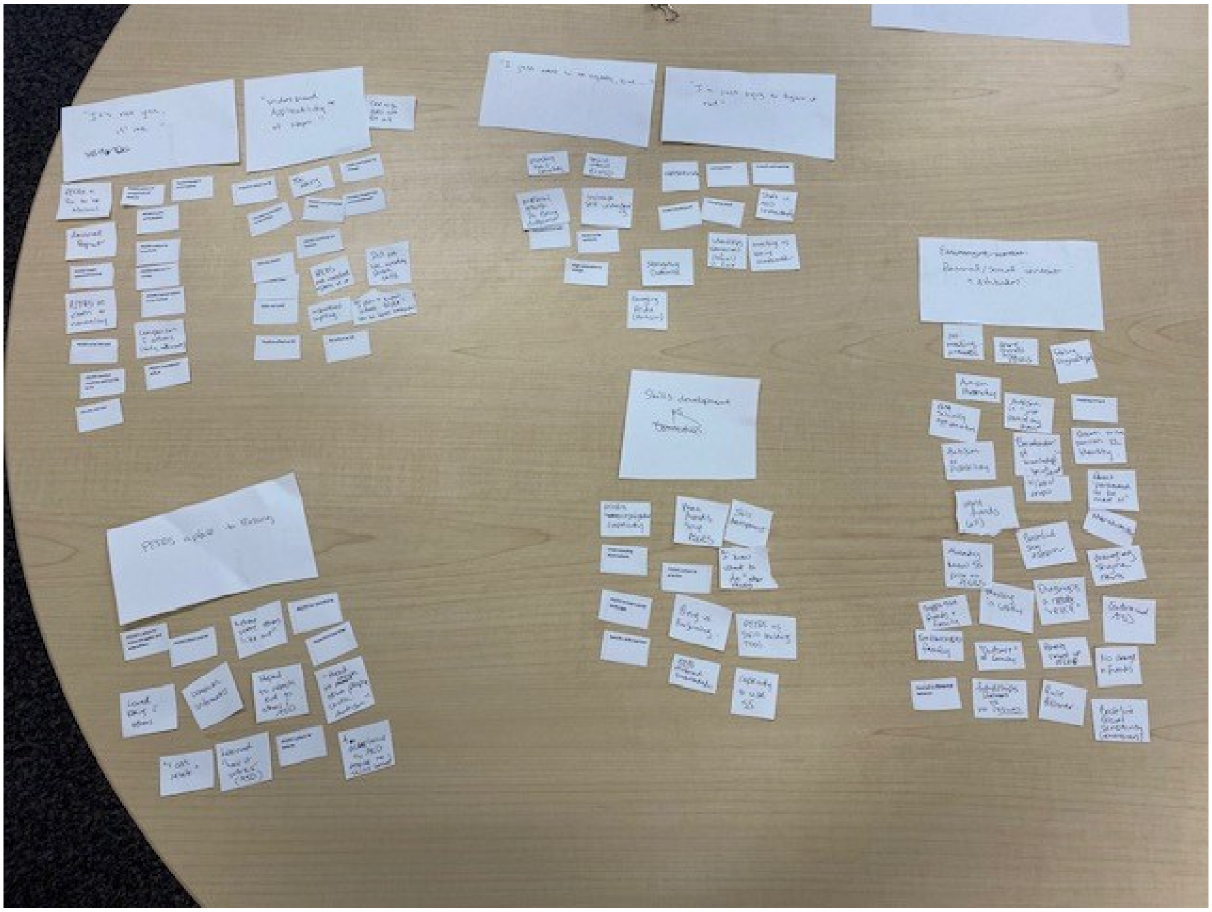
| | | |
|---|---|---|
| Benefits of masking | There are benefits to masking when used as a tool: such as safety with certain people, avoiding bullying, greater control of social interaction | 5)351 But it was one of the ways that I found kept me safe. Because up until this year of school I had faced a lot of bullying so getting acting neurotypical was one of the ways that kept me safe and kept me from being a target, just because it made me “normal”.<br>7) 211 . I didn't like being the weird kid in school, so I would try to pretend to be like others like try to dress like others, or try to like understand why people were reacting so negatively to me.<br>7) 251 But I do feel like my real self, because I'm able to express that with people who I'm closer to. But I'm also able to express that with others who I'm not close to by first, making sure that they're like not one of those people that ableist or anything. Once I feel safe with someone it doesn't - I'm able to be myself, but I'm able to feel safer with people now like. I'm able to be myself more because I know that I've ensured my safety by using the proper social skills |
| PEERS creating internal conflict around masking | | 5)169 Youth: kind of neutral. I: I think I'm just fine [PEERS teaching to change].<br>231 [about PEERS teaching masking] Yes!<br>Youth: It's hard [to be taught to mask].<br>6) 84 I think as long as you know, if I like the jealousy of being normal and the fear of being a freak get control of you, the side effects do break things.<br>6) 172 It was a little bit rough at first, but it slowly taught me the value of being different and at the same time just being with society.<br>144 eventually under promise of hoping that it would make more normal, I went along with it.<br>10)81 I think it was more to understand how things were, because I don't think they actually ever wants to like change how we are. But cause that would be like, I guess, like lowering to self esteem. But it was basically just to change your actions, to make sure |

| | | |
|---|---|---|
| PEERS is a place to belong | | 6) 161 when I learned that there were others like me, I was a little I was confused, but a little bit relieved to know that I wasn't the only outcast.<br>7) 105 It was recommended to me by a nurse, and I thought that it would be beneficial because there'd be more people that are like me, who are also learning about these like social skill tools<br>7) 127 I was hoping to be able to reach out to more people with autism, and to also be able to learn how to talk to other people who aren't autistic. Because when you meet someone who's autistic, you're able to click with them immediately because you probably bring up your special interest. And then you guys go in like a back and forth about your interest, and that just like automatically creates a bond. But with neurotypical people it's harder to just like mention, “hey! I like Anime” and start a conversation that way!<br>7) 120 it also gave me like, it gave me a better initiative to help others to, because if I bought something really quickly, then there was other people who didn't get it as quickly so that way I was able to help them.<br>157 positive was that it was giving me a place to socialize and it was teaching me things as well as it just fun like doing role plays and making inside jokes with the group. It was honestly just a fun experience like, even if I went and I didn't learn anything, I would still enjoy it because of other people who are in it, who are able to make jokes about the situations or be able to put their input in. Like one day we just spent the whole time |

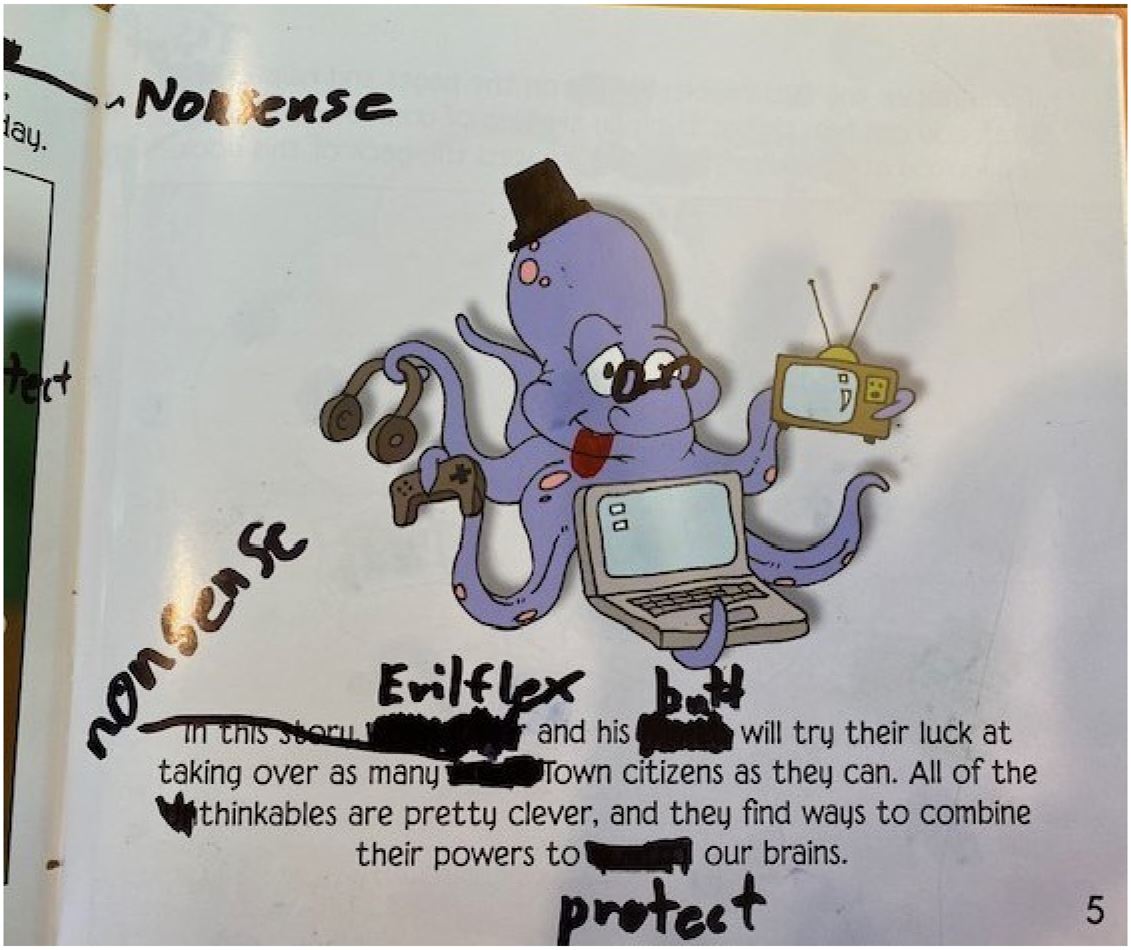
# Appendix E: Thematic Mapping







# Appendix F: Researcher's son's annotation of social skills book



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~~In this story~~ [redacted] and his [redacted] will try their luck at taking over as many [redacted] Town citizens as they can. All of the [redacted]thinkables are pretty clever, and they find ways to combine their powers to [redacted] our brains.

protect

5