

THE LIVED EXPERIENCES OF PARENTS OF CHILDREN WITH AUTISM  
SPECTRUM DISORDER IN AN ADAPTIVE SPORTS PROGRAM:  
A QUALITATIVE EXPLORATION

by

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The Lived Experiences of Parents of Children with Autism Spectrum Disorder in an Adaptive Sports Program: A Qualitative Exploration

Dissertation directed by Associate Professor Sylvia Mendez.

### **ABSTRACT**

The purpose of this phenomenological study is to develop an understanding of the lived experiences of parents whose children with autism realized a sense of belonging through participation in adaptive youth sports. This research centers on children with autism who participated in a successful sports program. Parents discussed the benefits of participation and the sense of belonging the program helped their children realize. The essence of the findings revealed the parents experienced their children's existence as one of innocence, beauty, and challenges cloaked behind an armor of coping mechanisms and defenses. This enigmatic existence was accepted at this sports program from day one. That acceptance was key to the children realizing a sense of belonging, which gave them the ability and freedom to drop the armor, be their authentic selves, and grow socially and physically over time.

This qualitative research is intended to add to the body of literature exploring the benefits realized by children and youth with autism spectrum disorder (ASD) who participate in adaptive youth sports and the challenges faced by those who seek to participate. Additionally, educators, administrators, and policymakers should consider the profound impact of belonging on a child and should increase efforts to achieve an outcome of belonging as a metric of program success in the future.

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## CHAPTER I

### INTRODUCTION

*I'm sorry kiddo, but you just don't fit,  
there are metrics and standards that teachers must hit,  
hypocrites, I admit, and your grit is legit,  
isn't fair, not a bit Kiddo, you just don't fit.  
You get points for courage, being different is rough,  
you give them your best, and it has to be tough,  
for you to believe, that you've got the right stuff,  
when you're told every day, your best isn't enough.  
They wish they could teach you, but you just don't fit,  
you are too far behind, so just quietly sit,  
they don't expect much, so that's what they'll get,  
it isn't your fault buddy; you just don't fit.*

The Autism and Developmental Disabilities Monitoring (ADDM) Network conducts studies on autism spectrum disorders (ASD) on behalf of the Centers for Disease Control and Prevention (CDC) and describes ASD as “a group of developmental disabilities characterized by impairments in social interaction and communication and by restricted, repetitive, and stereotyped patterns of behavior” (CDC, 2012, p. 2) . The specific symptoms and their severity can be drastically different among those with the disorder; therefore, for the purposes of this study, autism and ASD are used interchangeably to represent any recognized variations on the autism spectrum. Much progress has been made in recent years to address the prevalence and challenges of ASD. Public awareness of the disorder has been on the rise since the United Nations General Assembly adopted a resolution to recognize World Autism Awareness Day in 2007 (Morse, 2017); public education has increasingly integrated students with ASD into mainstream classrooms (Snyder et al., 2016); and annual research funding has increased by more than 60% since 2008 (Interagency Autism Coordinating Committee, 2016). Despite the progress that has been made, children with ASD and their parents often find

themselves in a world in which they do not appear to belong, one filled more with more questions than answers and a future that appears uncertain.

In 2018 the CDC reported the prevalence of ASD to be 1 in 59, and the nature of the spectrum disorder illuminates symptoms that vary dramatically among those with the diagnosis. This disparity creates challenges for educators as they attempt to include ASD students in mainstream classrooms. While the transition away from segregated learning environments has shown positive outcomes for neurotypical and some disabled students, placement in mainstream classrooms relegates many with ASD to the bottom of a social and/or academic hierarchy (Allen et al., 2018), which increases anxiety; decreases social acceptance (Mahadevan et al., 2016); leads to isolation; and raises the likelihood of being bullied (Morewood et al., 2011). To further complicate the matter, anxiety is common for individuals with ASD but often is displayed differently and results in treatment of the symptoms rather than the causes of the underlying anxiety (Kerns et al., 2014).

Physical activity is a proven mediator for anxiety and stress, and sports can be sources of friendships that create a sense of belonging for participants (Petitpas et al., 2005; Prichard & Deutsch, 2015; Ratey, 2010). The primary sources of physical activity for elementary school students include recess and physical education class. A 2002 study examined the benefits of recess and physical activity in light of the pressure faced by schools to reduce or eliminate recess time in favor of additional instructional time (Waite-Stupiansky & Findlay, 2002). In addition to the reported benefits in the form of higher self-esteem, increased social and emotional skills, imagination, and creativity, the authors reported, “breaks in structured learning activities help humans learn better. Students who spend more of their school day engaging in physical activity (recess and

physical education class) perform better academically than those who spend more time in instruction” (Waite-Stupiansky & Findlay, 2002, p. 23).

However, as many as one third of youth with disabilities do not fully participate in recess activities (Simeonsson et al., 2001), and integrating students with ASD into mainstream physical education classes can pose serious challenges to educators. A 2011 study on integrating ASD students into general physical education classes reported a total of 225 teacher-identified challenges among nine themes: (a) inattentive and hyperactive behaviors, (b) social impairment, (c) emotional regulation difficulties, (d) difficulties understanding and performing tasks, (e) narrow focus, (f) inflexible adherence to routines and structure, (g) isolation by classmates, (h) negative effects on classmates' learning, and (i) need for support (Obrusnikova & Dillon, 2011). Although 89% of parents of children with ASD surveyed want their children involved in organized physical activity programs a minimum of two hours per week, challenges with communication and social skills make this difficult to achieve (Alexander & Leather, 2013). Unfortunately, similar to public schools, youth sports and recreation programs have struggled to integrate children with ASD (MacDonald et al., 2011; Reid, 2005; Schleien et al., 2014).

Sports Plus Group, Inc. (Sports Plus) is an example of a youth program that has successfully managed these challenges and has created a sense of belonging for many participants. A sense of belonging is a basic human need (Maslow, 1968), yet too often it is elusive for individuals with ASD. Sports Plus is a non-profit organization that began in 2005 and is based in Montgomery County, Maryland. It offers year-round sports and social programs for participants with mild to moderate ASD ages 5-25. Siblings of this targeted group are encouraged to participate, and it is common to see several in

attendance. The Sports Plus leadership screens all coaches and volunteers to ensure they are patient, caring, and coachable. The organization assists the coaches and volunteers by reviewing the individual needs, challenges, and history of each participant prior to program sessions.

The general lack of successful participation in recreational activities for youth with ASD raises important questions about the success of Sports Plus, the methods implemented by the organization to foster success, and the meaning of those experiences for the parents of participants. Through this study, the researcher seeks to understand and characterize the essence of that meaning for parents when they observe their children realizing a sense of belonging through participation in Sports Plus programs. This understanding could benefit facilitators of other programs serving ASD youth, as well as teachers, parents, and caregivers facing similar challenges.

### **Problem Statement**

Parents of children with autism and other developmental disabilities agree inclusive recreational programs can provide an outlet for satisfying social and physical needs and can reduce stress in their children (Schleien et al., 2014). However, parents also have expressed significant difficulties in gaining access to programs and concerns over safety and poorly trained staff members (Schleien et al., 2014; Shields & Synnot, 2016). These concerns and perceptions of the benefits of participation are supported by similar studies specific to inclusive programs that have focused on physical activities (Kodish et al., 2006; Menear & Neumeier, 2015).

Specific barriers for children with developmental disabilities who participate in youth sports have included multiple physical, emotional, and social challenges

(MacDonald, 2011; Reid, 2005). The lack of participation for children with autism and other developmental disabilities has been associated with higher rates of obesity (Curtin et al., 2010); depression (Stewart et al., 2006); and social isolation (Iqbal, 2002). Despite the growing body of research suggesting psychosocial comorbidities, such as anxiety disorders, are frequently present in children with autism and other developmental disabilities, little research has focused on intervention strategies toward these challenges (Ghaziuddin et al., 2002; Kerns et al., 2014; Kerns et al., 2015; Lugnegård et al., 2011; Sukhodolsky et al., 2008; van Steensel et al., 2011) or on their potential connection to status hierarchies or sense of belonging. Researchers hypothesize that a major hurdle in targeting anxiety in individuals with ASD involves the difficulty in separating anxiety symptoms from stereotypical autism traits (Folstein & Carbajal, 2012; Kerns et al., 2015; Renno & Wood, 2013). A number of commonly accepted autism-related behaviors have been found to positively correlate with levels of stress and anxiety. These include restricted, repetitive behavior (RRB) (García-Villamizar & Rojahn, 2015; Rodgers et al., 2012); disruptive behavior (de Bruin et al., 2007); self-injurious behavior (Turygin et al., 2013); and challenging behavior (Mayes et al., 2011; Turygin et al., 2013).

Researchers argue that an additional factor leading to the under-reporting and under-diagnosing of anxiety in individuals with ASD is the clinical definition of anxiety (Kerns et al., 2014; White et al., 2015). *The Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), published in 2013 by the American Psychiatric Association (APA), categorizes anxiety into six broad groups for diagnostic purposes: generalized anxiety disorder, panic disorder, specific phobias, agoraphobia, social anxiety disorder, and separation anxiety disorder. Those anxiety groups defined by DSM-5 fail to capture a

number of atypical anxiety presentations that have been identified in individuals with ASD. The additional presentations include interfering worry and fear surrounding routine, novelty and restricted interests, unusual fears, social fear without concern for social rejection, and compulsive/ritualistic behaviors (Kerns et al., 2014).

### **Purpose of the Study and Research Questions**

The purpose of this study was to develop an understanding of the lived experiences of parents whose children with autism realized a sense of belonging through participation in adaptive youth sports. This dissertation utilizes a hermeneutic phenomenological research methodology in order to capture an understanding of the meaning or essence of those lived experiences (Gadamer, 1989). Data were collected via semi-structured interviews with parents of program participants.

The scope of this qualitative phenomenological study involves the parents of students with ASD who experienced a sense of belonging through the adaptive youth sports program implemented by Sports Plus. The primary research question for this study is: What are the lived experiences of parents whose children with autism realized a sense of belonging through participation in adaptive youth sports? The primary research question is supported by the following sub-questions:

1. What are the lived experiences of parents as they observe their children interacting with similar children?
2. What are the lived experiences of parents as they observe their children engaging in social relationships?
3. What are the lived experiences of parents as they observe their children negotiating meaningful roles in the community?

4. What are the lived experiences of parents as they observe their children finding a good fit through navigating norms and expectations?

## **Theoretical Framework**

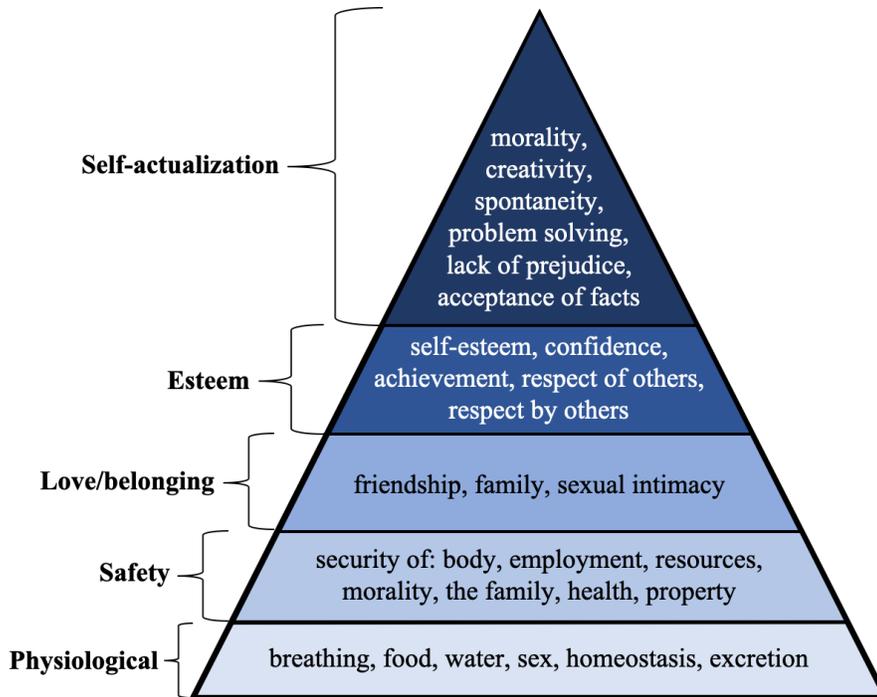
### **Belonging**

The concept and importance of belonging is well established as a basic human motivation or need and is captured as foundational to Maslow's (1943) hierarchy of needs pyramid in his theory of human motivation, as seen in Figure 1. The understanding of the term historically has been assumed or defined in subjective ways (Antonsich, 2010). This study utilizes a definition adapted from Goodenow and Grady (1993) in their analysis of school belonging. "Belonging" is defined as "the extent to which group members feel personally accepted, respected, included, and supported by others—especially [coaches] and other adults in the [group] environment" (pp. 60-61).

Although belonging is typically an implicit goal of inclusion programs, the terms "belonging" and "inclusion" should not be used interchangeably on the assumption that the goal of creating a sense of belonging has been or will be met. Educational inclusion is defined as "working in the school and/or working in the same classroom and/or working from the same curriculum . . ." (Imray & Colley, 2017, p. 1). Critics of educational inclusion programs assert that requiring special education students to be educated in mainstream classrooms can hinder rather than foster a sense of belonging for some students (Hornby, 2011; Imray & Colley, 2017; Kauffman & Badar, 2016; Kauffman et al., 2018; Morewood et al., 2011).

**Figure 1**

*Maslow's Hierarchy of Needs*



*Note.* This figure is a visual representation of Maslow's hierarchy of needs (Maslow, 1943).

While social and educational inclusion have focused primarily on environment, settings, affiliation, and social contact (Baumeister & Leary, 1995; Imray & Colley, 2017), belonging implies the existence of social bonds formed through supportive and caring relationships (Baumeister & Leary, 1995). This narrower definition of belonging is consistent with Maslow's (1943) theory of human motivation, which states that in the absence of friends, an individual "will hunger for affectional relations with people in general, namely, for a place in his group" (p. 381). Research is emerging that draws an important distinction between the terms in relation to inclusive education settings for students with developmental disabilities (Hornby, 2011, 2014; Imray & Colley, 2017; Kauffman & Badar, 2016). Connectedness, affiliation, and companionship have been

identified as variables that contribute to belonging, and a sense of belonging has been closely linked to social connectedness (Lee & Robbins, 1995); as well as social acceptance (Mahadevan et al., 2016); and can be achieved through social inclusion (Hall, 2010).

In 2009, the government of Australia took the lead in emphasizing the importance of belonging for students and adopted the Early Years Learning Framework (EYLF) based on the values of belonging, being, and becoming (Commonwealth of Australia, 2009). The guiding document for EYLF defines belonging as:

Experiencing belonging – knowing where and with whom you belong – is integral to human existence. Children belong first to a family, a cultural group, a neighbourhood and a wider community. Belonging acknowledges children’s interdependence with others and the basis of relationships in defining identities. In early childhood, and throughout life, relationships are crucial to a sense of belonging. Belonging is central to being and becoming in that it shapes who children are and who they can become. (p. 7)

In 2016, researchers explored school-based intervention strategies intended to reduce the risk and prevalence of mental health problems such as anxiety and depression for adolescents with ASD. They found the two most important mediators are a sense of belonging (school connectedness) and resilience (Shochet et al., 2016). Failing to create a sense of belonging for individuals can result in significant and measurable costs. A lack of social bonds has been linked to loneliness, unhappiness, depression, and anxiety (Baumeister & Leary, 1995). These effects are consistent with hierometer theory, which

holds that a lack of social bonds signals low social status in a group and is likely to result in isolation and higher levels of anxiety and depression (Mahadevan et al., 2016).

Closely related to belonging is the theory of self-concept, which has been defined as "the totality of the individual's thoughts and feelings with reference to [the] self as an object" (Rosenberg, 1989, p. 34) or is synonymous with self-worth (Byrne, 1996). The theory began to gain acceptance in the 1940s with the increasing popularity of Gestalt psychology and phenomenology (Rosenberg, 1989). During this period, prominent psychologists such as Donald Snygg began to publicly challenge behaviorism, the dominant paradigm in psychology at the time. Snygg argued for a phenomenological paradigm that focused on an understanding of the mind, consciousness, thoughts, and feelings of the individual and, ultimately, one's self-concept (Rosenberg, 1989; Snygg, 1941; Snygg & Combs, 1949). A 2002 study of academic self-concept (Skaalvik & Skaalvik, 2002) reported: "people come to view themselves as they believe they are viewed by others" (p. 234), and "students' judgments of their own achievements are major determinants of academic self-concept" (p. 233). The authors clarified that academically disadvantaged students have lower academic self-concept in mainstream classes than in special education classes, which has been further supported by subsequent research (Marsh, 2004; Skaalvik & Skaalvik, 2002).

A 2019 study by Renwick et al. developed a theoretical framework for belonging in youth with intellectual and/or developmental disabilities. The researchers analyzed feedback from 24 participants between the ages of 13 and 24 with an intellectual or developmental disability. Participants described belonging as:

Belonging was connected to friendship and feelings of being included in groups within communities and universally described as desirable. It was something participants felt was important to them or something that they wished for in their lives. . . . Belonging was tied to the quality of interaction and acceptance by others, rather than simply being included or invited. (pp. 8-9)

As shown in Figure 2, the authors found a sense of belonging is experienced in four ways: (1) interacting with similar people, (2) negotiating meaningful roles in the community, (3) engaging in social relationships, and (4) finding a good fit–navigating norms and expectations (Renwick et al., 2019).

**Table 1**

*Theoretical Framework of Belonging*

<u>Belonging</u>	<b>Interacting with similar people</b>
	Shared interests or experiences
	<b>Negotiating meaningful roles in the community</b>
	Being a member of a community
	Contributing to the community
	<b>Engaging in social relationships</b>
	Having people to talk to
	Having people to do things with
	<b>Finding a good fit – Navigating norms and expectations</b>
	Recognizing differences with peers
The self as a "friend"	
Negotiating support	

*Note:* This table is a visual representation of a theoretical framework of belonging featuring the four paths identified for realizing a sense of belonging for youths with intellectual or developmental disabilities (Renwick et al., 2019).

***Interacting with Similar People***

Participants in a study by Renwick et al. (2019) reported a sense of belonging is strengthened by spending time with those who share interests or experiences, and many

expressed value in having friends with a similar disability or in being part of a disabled community. This desire is consistent with a 2004 study that found interactions with people who share similarities create positive emotions (Burger et al., 2004). This route to a sense of belonging has potential similarities with prior research on well-being, which found relationships between individuals with intellectual disabilities protect against feelings of helplessness (Emerson & Hatton, 2008).

### ***Negotiating Meaningful Roles in the Community***

Being part of a community has been identified as a factor in feeling a sense of belonging. One participant in the Renwick et al. (2019) study described feeling a part of the community through being seen and recognized regularly in the local neighborhood. Communities are defined as schools, social groups, disability groups, workplaces, and churches. Having defined roles in the community gives individuals a sense of belonging and contributing in those roles provides an important sense of purpose. Employment and volunteer work are particularly significant for those who transition into adulthood (Renwick et al., 2019). This is consistent with previous research that found a high prevalence of social isolation after high school for young adults with ASD (Anderson et al., 2018; Lounds Taylor et al., 2017).

### ***Engaging in Social Relationships***

The majority of participants in the Renwick et al. (2019) study identified social relationships as a primary driver in feeling a sense of belonging. It was important for them to have someone to talk to or people with whom to do things. When this desire was not met, participants reported loneliness and isolation. It is noteworthy that the brain

structures of lonely individuals have been found to have less gray matter in a region linked to basic social perception (Kanai et al., 2012).

### ***Navigating Norms and Expectations***

Renwick et al. (2019) reported individuals realize a sense of belonging when they negotiate the type and volume of support they need, the expectations others have of them, and the increasing independence they desire as they age. The participants were aware of the importance of being a friend to others and discussed concepts such as reciprocity. The final subcategory of navigating norms and expectations is the recognition and acceptance that differences with peers exist in substantive ways. These differences include levels of independence, autonomy, opportunities, and aptitude in understanding and navigating social situations.

### **Status**

The hierometer theory of self-regard (self-esteem) supports research that suggests the theory is a more accurate explanation of human behavior than either sociometer or dominance theories. Hierometer theory proposes that status hierarchies exist in formal and informal groups, and self-regard covaries independently with the perceived status and belongingness of an individual in a particular group. The theory further suggests a low self-regard predicts conciliatory versus compensatory behavior. The lower the perceived status or sense of belonging of the individual, the less likely that individual will work to increase status or belonging (Mahadevan et al., 2016), which is a departure from the behavior predicted by sociometer and dominance theories.

Sociometer theory asserts self-esteem is largely a reflection of an individual's experience of social inclusion or belonging. The theory further suggests negative feelings

of exclusion are driven by the evolutionary needs of procreation and survival, prompting an individual to increase their efforts for social acceptance (Leary et al., 1995). Thus, individuals who experience lower levels of social inclusion are expected to adopt a more affiliative behavioral style in order to increase social inclusion and to raise self-esteem (Mahadevan et al., 2016). Dominance theory proposes self-esteem is the result of an individual's social dominance or prestige within a group. It suggests a fall in social status results in lower self-esteem, which prompts compensatory behavior in the form of assertiveness in order to increase social dominance (Barkow et al., 1975).

### **Significance of the Study**

This qualitative research is intended to add to the body of literature exploring the benefits realized by children and youth with ASD who participate in youth sports and the challenges faced by those who seek to participate. Eighty-five percent of all students in the US between grades 3-12 have participated in organized youth sports (Sabo & Veliz, 2008). In addition to the enjoyment derived from these activities, research has shown significant benefits are possible in the areas of physical fitness, psychosocial development, and motor skills acquisition (Fraser-Thomas & Côté, 2006; Seefeldt et al., 1993; Wells et al., 2008; Wiersma, 2000). Despite the documented benefits of youth sport participation, individuals with developmental disabilities often face a number of physical, emotional, and social challenges that prevent them from participating (Alexander & Leather, 2013; MacDonald et al., 2011; Reid, 2005).

This study intends to shed light on the essence of feeling a sense of belonging for individuals with ASD. Through understanding the lived experiences of parents who observe the impact on their children as they realize an often elusive sense of belonging, it

is the researcher's hope that educators, administrators, and policymakers will increase efforts to ensure children realize a sense of belonging and will use belonging as a metric of program success in the future.

## **CHAPTER II**

### **LITERATURE REVIEW**

This chapter presents literature related to parenting children with autism who participate in adaptive youth sports. Few published studies exist that are related to the specific topic being researched in this study. Therefore, in order to orient the reader to the experiences of these parents, the literature on autism, the prevalence of anxiety in individuals with ASD, typical and adaptive youth sports, and the concept of belonging, are reviewed.

#### **Autism and Other Developmental Disabilities**

The term “autism” was coined by psychiatrist Eugen Bleuler in 1908 to describe a symptom of schizophrenia (Matson, 2016). The clinical definition of the disorder has evolved and broadened since being uncovered separately by Leo Kanner in 1943 and Hans Asperger in 1944 (Silberman, 2015). It was not included as a recognized disorder in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) until the third edition was released in 1980, and the diagnostic criteria has changed significantly in subsequent editions (Silberman, 2015). In DSM-IV, ASD encompassed the subclasses of autistic disorder, Asperger’s disorder, and pervasive developmental disorder—not otherwise specified (PDD-NOS) (APA, 1994). The current version, DSM-5, combines the three subclasses into a single, more general diagnosis of ASD (APA, 2013).

The inclusion of autism in DSM-III (APA, 1980) increased awareness of the prevalence of ASD that continues to grow today (Silberman, 2015). A 2011 study based on CDC data found between 1999 and 2008, the prevalence in children with ASD ages 3 through 17 increased by 289% (Boyle et al., 2011). The increase in prevalence is

supported by the 2018 CDC report on children with ASD the US. Additionally, the number of students diagnosed with ASD between the ages of 3 and 21 receiving services under the Individuals with Disabilities Education Act (IDEA) in public schools has grown from 137,000 in 2002 to 498,000 in 2012, reflecting an increase of 264% (Snyder et al., 2016).

The symptoms and impairments attributed to ASD are varied, and many have been found to lower the quality of life for those with the diagnosis (Kuhlthau et al., 2010). A 2009 study using health-related quality of life (HRQoL) measures, as defined by the work of Peter Fayers (Fayers & Machin, 2007), compared the HRQoL of neurotypical children to those with ASD. The study found children with ASD have lower HRQoL scores in total and in every subcategory of physical health, psychosocial health, emotional functioning, social functioning, and school functioning (Kuhlthau et al., 2010). The authors concluded:

Our results . . . suggest that HRQoL is associated with a variety of behavioral challenges associated with ASD. . . . Interventions targeted at improving these aspects of ASD likely have the potential to make the greatest improvements in HRQoL. Improved HRQoL suggests greater happiness and overall well-being for children with ASD and other individuals in their environment. (p. 728)

### **Developmental Disabilities**

A developmental disability is defined by the U.S. Department of Health and Human Services (HHS) (Developmental Disabilities Assistance and Bill of Rights Act of 2000) as:

A severe, chronic disability of an individual that—

(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(ii) is manifested before the individual attains age 22;

(iii) is likely to continue indefinitely;

(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

(I) Self-care.

(II) Receptive and expressive language.

(III) Learning.

(IV) Mobility.

(V) Self-direction.

(VI) Capacity for independent living.

(VII) Economic self-sufficiency.

(v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated. (pp. 1683-1684)

Among the multiple, separate diagnoses that fall under the category of developmental disabilities, the most common include ASD, Fragile X, Down syndrome, cerebral palsy, and Intellectual Disability unspecified (Anderson et al., 2011). The diagnosis of ASD has received a great deal of attention in recent years due to the rapid increase in prevalence.

## **Autism Spectrum Disorder and the Brain**

Researchers at the University of California, San Diego (UCSD) analyzed 586 longitudinal and cross-sectional MRI brain scans of individuals with ASD from 12 months of age to 50 years (Courchesne et al., 2010). The authors concluded that not only do ASD brains differ significantly from the general population, but also the differences change with age. This study found evidence of cerebral overgrowth from ages 2 to 4 in the areas of the frontal and temporal cortices and limbic overgrowth in the amygdala. After 12 years of age, ASD brains show slower growth in overall brain volumes than neurotypical brains. The frontal cortex is responsible for motor control and social awareness, the temporal cortex is responsible for vision and hearing, and the amygdala is responsible for emotional regulation and responses to fear (Carter, 2019). The findings from the UCSD study are supported by research at Yonsei University in Seoul, South Korea. Xiao et al. (2014) found a similar pattern of brain growth in individuals with ASD and identified functional and structural connectivity abnormalities in the brain that are consistent with the deficiencies commonly found in individuals with ASD.

Several studies have found abnormal levels of neurochemicals in individuals with ASD, including high levels of serotonin (hyperserotonemia), norepinephrine, and cortisol and low levels of oxytocin (Kidd et al., 2012; Lam et al., 2006; Putnam et al., 2015). Serotonin is a neurotransmitter associated with well-being and has been shown to mediate anxiety and depression (Lam et al., 2006; Ratey, 2010). Norepinephrine acts as a stimulant and plays a role in regulating levels of neurotransmitters in the brain (Lam et al., 2006; Ratey, 2010). Cortisol is considered a primary stress hormone in humans, and research findings have revealed the cortisol levels from a stress response are significantly

higher and remain elevated significantly longer for the ASD samples compared to neurotypical peers (Spratt et al., 2012). Additional research has shown the ASD stress response sensitivity increases with age, which is hypothesized to explain a decreasing willingness to initiate social interaction (Schupp et al., 2013). The neuropeptide oxytocin plays an important role in mediating the stress response and increasing the ability to interpret social cues (Carter, 2019; Falougy et al., 2019).

### **Anxiety in Individuals with ASD**

Studies have associated anxiety and fear with autism since as early as 1975. A typical trait in children with pervasive developmental disorder (PDD) was first noted as an unusual fear of commonplace items and a lack of fear from dangerous situations (Wing, 1975). This view was supported in 1985 by a systematic study on adults with PDD. The findings indicated participants display anxiety symptoms as defined by DSM-III (APA, 1980) to a greater extent than individuals without PDD (Rumsey et al., 1985). The authors were not surprised by the findings because expert consensus at the time held that anxiety symptoms are concomitant with PDD and autism. The prevalence of fear and the assumption that fear and anxiety are concomitant with autism rather than comorbid conditions have been reflected in the literature (Marks, 1987; Matson & Love, 1990).

The first study that challenged the concomitant assumption occurred in 1998. This ground-breaking research studied 44 children with PDD and not only found that anxiety was distinct from the PDD diagnosis, but also that 84.1% of the sample displayed at least one symptom of an anxiety disorder (Muris et al., 1998). The research was supported in a 2007 comorbidity study with children diagnosed with the similar, but more narrowly defined, condition of PDD-NOS (de Bruin et al., 2007). The authors agreed with Muris et

al. (1998) that psychiatric disorders are comorbid and found that 80.9% of participants displayed such comorbidity. The study also found evidence to suggest 55.3% of subjects met the DSM-IV (APA, 1994) criteria for an anxiety disorder (de Bruin et al., 2007).

The research was narrowed further in 2008 in a study comparing differences in prevalence among four subgroups with developmental disabilities: high-functioning autism, PDD-NOS, autism, and intellectual disabilities (Davis et al., 2008). The authors reviewed the research on the topic and concluded anxiety was likely under-diagnosed among all four subgroups, and substantial numbers of individuals with developmental disabilities have comorbid anxiety disorders. The study further found evidence to support the notion that anxiety was positively correlated with cognitive ability among the four groups studied. The hypothesis of this cognitive correlation was supported by a similar study that found language ability to be positively correlated with anxiety (Sukhodolsky et al., 2008). The authors reported 43% of subjects with PDD met the criteria for an anxiety disorder, as defined by DSM-IV (APA, 1994).

A 2009 review of the research on ASD and anxiety prevalence reported findings of anxiety prevalence range between 11-84% (White et al., 2009). All of the reviewed research reported anxiety rates higher than that found in similar populations without ASD. The heterogenous nature of ASD has prompted researchers to stratify samples by the informal classifications of high-functioning autism (HFA) or low-functioning autism (LFA). No clear definitions exist of these unofficial classifications; therefore, Dr. Peter Szatmari (2000) attempted to clarify definitions based on practical usage in the literature. He indicated HFA typically refers to individuals on the autism spectrum who have verbal and cognitive abilities in a range consistent with neurotypical, same-aged peers; LFA

refers to individuals on the autism spectrum who have verbal or cognitive abilities below the range found in neurotypical, same-aged peers.

Researchers in 2011 compared anxiety prevalence between LFA and HFA subjects and found children with LFA displayed fewer symptoms and showed lower symptom severity than comparable HFA subjects, but those differences diminished with age and were no longer evident by adolescence (Mayes et al., 2011). It was further reported the overall prevalence of anxiety for both groups increased through adolescence when 88% of LFA subjects and 89% of HFA subjects were found to display anxiety symptoms. The researchers additionally noted 72% of HFA subjects ages 11-17 displayed symptoms of depression. The positive correlation of anxiety and age through adolescence was supported by a study examining the correlation over a lifetime. The research found that while anxiety increased through adolescence, it decreased in adulthood and increased again in the elderly (Davis et al., 2011). A meta-analysis conducted the same year identified age and cognitive functioning as anxiety correlates and reported an average prevalence of 39.6% for ASD subjects with at least one anxiety symptom as defined in the DSM-IV (APA, 1994; van Steensel et al., 2011).

Researchers typically use IQ scores and/or a measure of verbal ability as a proxy for symptom severity to categorize LFA and HFA samples (Szatmari, 2000). The lack of a clearly defined IQ score that separates HFA from LFA has led to significant variation in the research. A study in 1990 defined the HFA group as those with an IQ score above 50 (Stone & Caro-Martinez, 1990), while a 2011 study established an IQ cut-point for separating HFA and LFA samples at 80 (Ahuja et al., 2011).

A 2018 study called into question the validity of using common IQ assessment tools on children and youth with ASD (Grondhuis et al., 2018). The study compared the IQ scores derived from the Stanford-Binet Intelligence Scales, 5th Edition (SB5) with scores derived from the Leiter International Performance Scale–Revised (Leiter-R) on a sample of 80 subjects with ASD. Although these assessments have been validated as accurate and interchangeable for neurotypical individuals, the findings in this study suggest IQ scores could vary significantly for individuals with ASD. The scores among the sample varied by as much as 47 points, and more than 62% of study participants would have been assigned to a different IQ category based on the assessment tool utilized.

### **Anxiety Symptoms**

Clinical support of the 2007 comorbidity study by de Bruin et al. (2007) was provided by a physician in the field who reported success in treating ASD patients with anti-anxiety medication once the presence of anxiety was recognized (Folstein & Carbajal, 2012). Support for the hypothesis that the prevalence of anxiety in ASD populations is likely under-identified due to the DSM definition of anxiety symptoms (APA, 1994, 2013) was provided in a 2014 study by Kerns et al. The authors suggested while some with ASD display typical anxiety symptoms, many display atypical symptoms due to their disorders. The authors subsequently developed an anxiety measure that accounted for atypical and typical anxiety presentations. The list of atypical anxiety presentations added by the researchers to the list of symptoms included four categories: (1) anxiety around routine, novelty, and restricted interest; (2) unusual specific fears; (3) social fearfulness; and (4) compulsive or ritualistic behaviors. Under this new measure,

63% of the sample displayed at least one symptom on the expanded list, 15% displayed only atypical symptoms, 17% displayed only typical symptoms, and 31% displayed symptoms of both (Kerns et al., 2014).

A core trait identified in ASD is RRB (CDC, 2012) . Evidence is growing that traits such as RRB, which are largely considered concomitant with autism, are strongly correlated with anxiety. It was first suggested by Muris et al. (1998) that at least some of the behaviors are attributable to anxiety. Subsequent research has supported this theory and has shown a positive correlation between RRB and anxiety (García-Villamizar & Rojahn, 2015; Joyce et al., 2017; Rodgers et al., 2012). Anxiety also has been correlated with general autism severity (Renno & Wood, 2013) and self-injurious behavior (Kerns et al., 2015).

### **Anxiety and the Brain**

Anxiety and stress are closely related. Anxiety is the anticipation of a stressor, and stress is the physiological reaction to a stressor. Cortisol levels reflect reactions to stressors but also have been shown to increase in response to acute anxiety (Simon & Corbett, 2013). An anxiety disorder either triggers a stress response at inappropriate times or inhibits the stress response from turning off. In a stress response, the pituitary gland produces adrenocorticotrophic hormone (ACTH), which stimulates the production of cortisol and epinephrine (adrenaline) in the adrenal glands, and the body prepares for fight or flight (Carter, 2019). Prolonged stress in youth has been shown to increase sensitivity to stress and to inhibit the generation of new neurons (neurogenesis) when those individuals become adults (Karten et al., 2005). Additionally, chronic or repeated stress has been shown to increase anxiety; shrink dendrites; and impair memory,

cognition, mood, and judgment, which can negatively impact behavior (McEwen, 2016). One of the most common and effective interventions for reducing anxiety symptoms involves psychopharmacological approaches such as administration of the drug sertraline, which increases the effective level of serotonin in the brain (White et al., 2009).

### **Youth Sports and Physical Activity**

Eighty-five percent of all students in the US between grades 3-12 have participated in organized youth sports (Sabo & Veliz, 2008). The benefits of physical activity include psychosocial development, motor skills acquisition, improved cognitive functioning, longer life expectancy, improved communication skills, a sense of belonging, increased independence, and improved social skills (Fraser-Thomas & Côté, 2006; Memari et al., 2017; Seefeldt et al., 1993; Smith & Patterson, 2012; U.S. Department of Health and Human Services, 2018; Wells et al., 2008; Wiersma, 2000). Physical activity also has been found to be an effective mediator for anxiety and depression (Blumenthal et al., 2007; Ratey, 2010). A 2013 report from the Committee on Physical Activity and Physical Education in the School Environment of the Institute of Medicine (IOM) included a review of the status of physical education and physical activity for students in a school environment and found only half of all students met the minimum recommendation of 60 minutes of moderate to vigorous physical activity (MVPA) each day. The IOM Committee recognized that “Physical activity in youth also can improve mental health by decreasing and preventing conditions such as anxiety and depression and enhancing self-esteem and physical self-concept” (p. 4). The daily standard of 60 minutes of MVPA was supported for children ages 6-17 in *Physical*

*Activity Guidelines for Americans* (U.S. Department of Health and Human Services, 2018).

Youth sports organizations have offered additional benefits to participants when properly administered. Research has consistently identified the crucial role of coaches in the realization of benefits to participants. A 2013 study compared the approaches of the most and least effective coaches in youth programs (Flett et al., 2013). The researchers found the least effective coaches justified a negative style aimed at toughening participants and failed to use developmentally appropriate strategies. The most effective coaches were open minded about their own coaching education, created a positive team environment, promoted autonomy, challenged players in supportive ways, and attempted to transfer the lessons from the sport to life.

A 2015 study found programs with a focus on individual improvement and mastery were far more likely to result in participant enjoyment, positive relationships, higher academic performance, and a higher likelihood of college enrollment (Prichard & Deutsch, 2015). Programs focused primarily on winning, however, increased performance anxiety and compromised relationships with other participants. The importance of focusing on mastery over performance was identified in a 1997 study that showed the tendency for those at the bottom of the performance hierarchy to avoid demonstrating ability through performance (Middleton & Midgley, 1997).

The concept of physical literacy refers to the development of motor control and movement competence over time. It has many definitions, but its importance has been on the rise, and sport has consistently been shown to be crucial to that process. The Aspen Institute (2015) defines physical literacy as “the ability, confidence, and desire to be

physically active for life” (p. 9). The organization’s 2015 report on physical literacy in the US recognized the acquisition of movement skills to be correlated with increased time engaged in MVPA (Aspen Institute Sports & Society Program, 2015). In a 2017 review of physical literacy (Edwards et al., 2017), the authors synthesized the general consensus of the term as “the interactive and simultaneous consideration of competence in physical skills, confidence, motivation towards physical pursuits, and the valuing of physical movement and/or interacting with the physical world” (p. 121). A 2018 study by Faigenbaum and Rial Rebullido found if children were not given the opportunities to gain proficiencies in physical skills, they were less likely to become physically literate (Faigenbaum & Rial Rebullido, 2018). The study described the following:

If youth have ongoing opportunities to gain confidence and confidence [*sic*] in different physical activities while experiencing the mere joy of moving and learning, they will likely enhance their physical literacy. However, if participants lack competence and confidence in their physical abilities and perceive physical activity to be embarrassing, discomforting, or simply not fun, they will likely become disengaged in nonessential physical activity and more engaged in sedentary leisure pursuits. (p. 91)

### **Youth Sports, Physical Activity, and Children with ASD**

Early research on the impact of aerobic activity on individuals with ASD was focused on reducing stereotypical self-stimulatory behaviors such as spinning, flapping, and rocking with the goal of easing the mainstreaming of those individuals. A 1997 study confirmed prior research that showed significant reduction of these behaviors after

aerobic activity and an increase in academic performance (Rosenthal-Malek & Mitchell, 1997).

Although 76% of parents of children with ASD reportedly want their children to be involved in sports up to six hours per week, difficulties with communication and social skills make this a challenge (Alexander & Leather, 2013). Including students with ASD in mainstream physical education classes also can pose serious challenges to educators. A 2011 study reported a total of 225 challenges among nine themes: (a) inattentive and hyperactive behaviors, (b) social impairment, (c) emotional regulation difficulties, (d) difficulties understanding and performing tasks, (e) narrow focus, (f) inflexible adherence to routines and structure, (g) isolation by classmates, (h) negative effects on classmates' learning, and (i) need for support (Obrusnikova & Dillon, 2011).

Despite the association between the benefits of youth sports participation and HRQoL measures, as well as the findings that children with ASD have lower HRQoL than neurotypical children (Kuhlthau et al., 2010), those with intellectual and developmental disabilities, including ASD, are significantly less likely to participate in youth sports or physical activities due to a variety of challenges including deficient motor skills (MacDonald, 2011); the need for extensive social cues; and a lack of opportunities (Reid, 2005). Research in 2011 on the effect of jogging on classroom behavior for students with HFA showed that after 12 minutes of jogging, subjects displayed increased academic engagement, and effect size was positively correlated with intensity (Nicholson et al., 2011). These findings are consistent with prior studies on the effect of physical exercise on reducing self-stimulatory behaviors and increasing academic engagement (Evans et al., 1985; Kern et al., 1982; Rosenthal-Malek & Mitchell, 1997).

A 2010 systematic review was conducted to analyze 18 published studies on the impact of physical exercise on individuals with ASD (Lang et al., 2010). The review found evidence to suggest physical activity for individuals with ASD may reduce stereotypical behavior, aggression, or self-injury; increase the amount of time spent on task; increase academic accuracy; and increase physical endurance or strength, as well as time spent engaged in exercise. A 2012 meta-analysis on the behavioral effects of physical exercise on individuals with ASD included 16 studies published between 1991 and 2011 (Sowa & Meulenbroek, 2012). The authors found an overall effect size of 37.5% for positive behavioral improvement. Individual interventions showed greater overall improvements than group interventions, 48.57% versus 31.54%, respectively.

A study on the Heilpädagogical Station, which was the name of the Children's Clinic at the University of Vienna from 1911-1944, reported their program incorporated an hour of gymnastics or exercise prior to academic coursework six days per week (Michaels, 1935). The purpose was to study the motor skills and behaviors exhibited by the children. The Heilpädagogical Station was the clinic where Hans Asperger developed his understanding of autism; it was unique in its individualized approach and philosophy of identifying strategies that were effective for each patient.

A 2014 study involved parents of children with ASD describing their experiences with inclusive recreational activities. The seven themes identified were (a) parents believe recreational activities are important for the quality of life for their children, (b) there is limited access to programs, (c) parents are fatigued by having to actively support their children while they participate, (d) parents experience feelings of isolation, (e) parents have dreams and desires of their children being accepted for who they are, (f)

parents are torn between the desire for their children to be included with mainstream children and the safety associated with segregated programs, and (g) the current lack of access is unacceptable (Schleien et al., 2014). A father in the study stated the following:

We were restraining [child's name] every day to prevent him from doing property damage or harm to himself. When we started a program of very intensive physical activity, those things melted away. It's really hard to explain how important the benefits are. It has truly changed our lives. (p. 66)

Childhood obesity has more than tripled since 1980, and the efficacy of physical activity in reducing obesity is well documented (Aspen Institute Sports & Society Program, 2019; Davis et al., 2012; Fraser-Thomas & Côté, 2006; Hedstrom & Gould, 2004; Pan & Frey, 2006; Prichard & Deutsch, 2015; Sowa & Meulenbroek, 2012; Ullrich-French et al., 2012; Warren et al., 2018; Wittberg et al., 2012; Wójcicki & McAuley, 2014). Although little research has compared obesity rates between children with and without ASD, a 2010 study found children with ASD between the ages of 3 and 17 had an obesity rate that was 29% higher than those without ASD (Curtin et al., 2010). Research in 2014 examined unhealthy weights of adolescents with developmental disabilities. The authors found adolescents with a developmental disability had a 60% higher obesity rate than those without, and the obesity rate of those with ASD was more than double the rate of those without a developmental disability (Phillips et al., 2014). In 2015, the Aspen Institute reported youth with disabilities are less active and participate in recess activities, playground games, and organized school sports less frequently than children without disabilities.

Physical literacy for individuals with ASD has practical significance beyond that which has been previously mentioned. A study by Guan and Li (2017a) on injury mortalities for individuals with ASD found premature death by injury was nearly three times as high for individuals with ASD than for the rest of the population. Drowning accounted for nearly 20% of all fatal injuries for this group, and the rate of drowning fatalities was nearly 40 times higher for individuals with ASD than for those without. Additional research on injury mortalities by drowning for individuals with ASD found the fatal injury was most likely to occur with boys ages 7-8 who wandered away from their homes in the afternoon (Guan & Li, 2017b). Swimming is considered an essential skill in physical literacy (Aspen Institute Sports & Society Program, 2015), and a national study found 85% of all drowning victims between the ages of 5 and 9 did not know how to swim (Safe Kids Worldwide, 2016). Guan and Li (2017b) recommended children with ASD be provided swim lessons as soon as a diagnosis of autism is made.

### **Sports, Physical Activity, and the Brain**

In his seminal book on the topic, John Ratey (2010) provided evidence for the positive and significant impact of aerobic activity on anxiety, depression, focus, obesity, learning, stress management, and overall mental health through neurotransmitter regulation. Researchers at Duke University compared aerobic exercise to the serotonin-related antidepressant drug sertraline (Zoloft) in a four-month trial on subjects diagnosed with major depressive disorders. The results showed the effect of exercise was comparable to sertraline in reducing depression symptoms (Blumenthal et al., 2007). Recent studies have confirmed aerobic exercise stimulates the production of serotonin (Pietrelli et al., 2018; Zimmer et al., 2016).

Wittberg et al. (2012) conducted a study to compare standardized test scores of fifth graders who participated in aerobic activity over a two-year period. Results revealed aerobic capacity is associated with higher test scores. In 1993, a study of 18 head baseball coaches and 152 male players ages 10-12 examined the impact of a coach education model on the self-esteem of players (Smoll et al., 1993). Eight of the coaches took part in training intended to increase their supportiveness and coaching effectiveness. Findings showed significant increases in the self-esteem of boys coached by those who received the training compared with similar boys with coaches who did not receive the training. The authors of a 2009 study on physically active play and cognition wrote, “physically strenuous play synthesizes the neural benefits of both exercise and play by simultaneously providing physical, social, and intellectual stimulation” (Sattelmair & Ratey, 2009, p. 366). The authors concluded evidence exists to suggest school-aged students benefit mentally and physically from regular physical activity.

The brain’s hippocampus is responsible for spatial awareness, recall, and memory formation (Carter, 2019). A widely accepted theory holds that new brain cells are no longer generated after adolescence (Ratey, 2010). This belief began to change in 1998 after neuroscience research emerged with evidence that neurogenesis occurs in brains of adult humans (Gage et al., 1998). A great deal of research now supports the theory that exercise and physical activity stimulate neurogenesis (Olson et al., 2006; Sah et al., 2017; van Praag, 2008; Voss et al., 2013), as well as prevent cognitive decline (Ma et al., 2017). A 2000 study found aerobic exercise increases levels of norepinephrine in the hypothalamus (Dishman et al., 2000). This increase is thought to more effectively regulate the release of ACTH, which triggers the production of cortisol by the adrenal

glands. Salivary cortisol volumes were compared between youth with high levels of physical activity and those with low levels. Results showed much higher volumes of stress-induced salivary cortisol in the low physical activity group when compared with the high physical activity group (Eriksson et al., 2013).

Additional research has found salivary levels of the mediating stress hormone oxytocin increase after high-intensity martial arts training, with the highest increases associated with grappling activities (Rassovsky et al., 2019). These findings are consistent with a 2013 report from the IOM that concluded the following:

Although evidence is less well developed for children than adults, a growing body of scientific literature indicates a relationship between vigorous-and moderate-intensity physical activity and the structure and functioning of the brain. Both acute bouts and steady behavior of vigorous and moderate-intensity physical activity have positive effects on brain health. More physically active children demonstrate greater attentional resources, have faster cognitive processing speed, and perform better on standardized academic tests. (p. 4)

### **Belonging**

Social exclusion leads to loneliness and is a common cause for anxiety.

Loneliness is negatively correlated with social inclusion and acceptance. Additionally, deprivation of belonging has been shown to be stressful, while being part of a supportive social network reduces stress (Baumeister & Leary, 1995). A study using functional magnetic resonance imaging (fMRI) compared the brain activity of adolescents with ASD to those without after experiencing social rejection. The authors found that although both groups were aware they had experienced peer rejection, neuroimaging revealed

differences in the way in which subjects in each group processed those feelings. Results indicated the control group was much more sensitive to rejection than the ASD group (Masten et al., 2011). These results are consistent with the findings of Kerns et al. (2014) suggesting an atypical presentation of anxiety in individuals with ASD involves social fear without concern for social rejection.

A 2003 conceptual framework for quality of life for children with developmental disabilities included factors that influence being, belonging, and becoming, with a focus on occupational therapy application (Renwick et al., 2003). The authors posited the framework is significant because it focuses on the entire life of the individual rather than the specific deficit areas. The terms “being,” “belonging,” and “becoming” were defined in a more temporal, modern vernacular than that which would be in keeping with their ontological application from thinkers such as Descartes (1956), Heidegger (1962), or Kant (1964). Renwick et al. (2003) defined these terms as “(a) Being -- who the child is perceived to be; (b) Belonging -- the child's connections to people and places; and (c) Becoming -- the child's nurtured growth and development” (p. 111).

A 2012 study by Kanai et al. found loneliness is negatively correlated with gray matter volume of the left posterior superior temporal sulcus (pSTS), which plays an important role in social perception, such as accurately processing eye-gaze information. The study also concluded loneliness is negatively correlated with social perception and social competence and positively correlated with anxiety. In addition to mediating the brain's stress response, the neuropeptide oxytocin plays an important role in processing social cues (Carter, 2019). In 2010, researchers were interested in the outcome of administering supplemental oxytocin to subjects with ASD (Andari et al., 2010). Their

findings showed an increase in social competence in the subjects who were treated with oxytocin. More recent studies support the potential for oxytocin to be a safe treatment option for promoting social behavior in individuals with ASD (Cai et al., 2018; Falougy et al., 2019).

This literature review reveals that significant research has been conducted in a variety of disciplines relevant to this study. The fields of neuroscience, psychology, education, medicine, exercise science, and sociology have contributed to various aspects in various degrees, but the review reveals a gap in cross-disciplinary or interdisciplinary research that could impact the lived experiences of individuals with ASD and their families. This study attempts to fill that gap.

## **CHAPTER III**

### **METHODOLOGY**

Through research into adaptive sports programs for children diagnosed with ASD, one program stood out. Sports Plus is unique in terms of the large number of participants, the variety of sports programs offered throughout the year, and the growth of the organization since its inception. This organization is reported to offer a sense of belonging to the participants, which has been identified as important to parents but often elusive in the lives of children with ASD (Ashby, 2008; Barrow, 2017; Hornby, 2015). Given the apparent paucity of a successful sports program that fosters belonging for children with ASD, I chose as my research topic the lived experiences of parents whose children with autism realized a sense of belonging through participation in adaptive youth sports. I desired to understand the meaning of this parental experience, and the use of a hermeneutic phenomenological methodology was the most effective approach to achieving that goal.

Documented challenges are associated with participation in recreational activities for youth with developmental disabilities, including a lack of available options (Kodish et al., 2006; Menear & Neumeier, 2015; Schleien et al., 2014; Shields & Synnot, 2016). These challenges are particularly problematic for the large numbers of youth with ASD who already fail to realize a sense of belonging in inclusive educational settings (Hornby, 2015; Imray & Colley, 2017; Kauffman & Badar, 2016). Therefore, understanding the success of the Sports Plus organization in Montgomery County, Maryland, was particularly interesting and important. Through parental interviews, I sought to understand the meaning of lived experiences from the parents of program participants.

Identifying the essence of that phenomenon could benefit administrators of other programs serving youth with ASD, as well as teachers, parents, and caregivers facing similar challenges. The policies of schools, programs, and communities have a direct impact on the quality of life of children and their families (Renwick et al., 2003), and parents are able to provide insight into this impact.

This chapter includes the methodological plan for the study. The organization of the chapter is structured with the following topics: (1) research design, (2) research site, (3) research questions, (4) data sources, (5) population and sample selection, (6) data collection process, (7) data analysis procedures, (8) trustworthiness, (9) ethical considerations, (10) limitations, and (11) delimitations.

### **Research Design**

This study involved a qualitative methodology with a hermeneutic phenomenological research design (Creswell & Poth, 2018; Moustakas, 1994) embedded with thematic analysis (Guest et al., 2013). Individuals begin an experience from a unique reference point based on previous experiences, knowledge, and ideas; that reference point informs the lived experience. This also is true for phenomenological researchers and is the root of much philosophical debate. Edmund Husserl dealt with this reality by practicing the concept of epoché, or phenomenological reduction, which is the idea that researchers should suspend or “bracket” all judgments and pre-understandings when conducting a study (Husserl, 1983). The ability to effectively practice epoché has been challenged, and other philosophers have addressed the problem through disclosure, intentional openness, and incorporation of the researcher’s beliefs and pre-understandings (Dahlberg et al., 2008). This controversy eventually has led to two primary approaches to

phenomenological inquiry: transcendental and hermeneutic. Transcendental phenomenology is descriptive in nature and follows the teachings of philosophers such as Edmund Husserl (1983), Maurice Merleau-Ponty (2002), and Amedeo Giorgi (2009). In contrast, hermeneutic phenomenology is interpretive in nature, seeks to understand (Vagle, 2018), and accepts a researcher's pre-understandings as an unavoidable aspect of learning that should be disclosed, restrained, and utilized in the process. Practitioners of hermeneutic phenomenology generally follow the teachings of philosophers such as Martin Heidegger (1962), Hans-Georg Gadamer (1989), and Max van Manen (2014).

The hermeneutic approach was selected for this study due to my desire to understand the lived experiences of the parents in the study and skepticism of my ability to bracket my own judgments and pre-understandings to a Husserl level. This approach also resonated with me due to its pragmatic nature and its parallels with research in behavioral economics (Kahneman, 2011). Behavioral economics notes rational consumer behavior is not static for all individuals but depends upon the perspective and reference point of individual consumers; a change in wealth is a better determinant of happiness than simply reviewing current wealth (Kahneman, 2011). Gadamer (1989) understood the concept and suggested, "Every experience has implicit horizons of before and after, and finally fuses with the continuum of the experiences present in the before and after to form a unified flow of experience" (p. 246).

### **Hermeneutic Phenomenology**

Van Manen (1984) described phenomenology as ". . . a philosophy of the unique, the personal, the individual which we pursue, against the background of an understanding of the logos of Other, the Whole, or the Communal" (p. ii). He later described

phenomenology as the science of phenomena, rooted in reflected experience and described through written text (van Manen, 1997). In delineating the hermeneutic phenomenological research process, Creswell (2012) explained researchers first select a phenomenon in which they have deep interest and then reflect on the nature of the lived experience:

They write a description of the phenomenon, maintaining a strong relation to the topic of inquiry and balancing the parts of the writing to the whole.

Phenomenology is not only a description, but it is also an interpretive process in which the researcher makes an interpretation of the meaning of the lived experience. (pp. 79-80)

Hermeneutics is concerned with interpreting the meaning within texts (Guest et al., 2013). Hermeneutic phenomenology includes both methodologies and is based on the philosophy that when descriptions of experiences are captured in language, interpretation is necessary and unavoidable (van Manen, 1997).

### **Parental Perspective**

Parents' experiences when observing their child attending public education inclusion programs or mainstream sports programs provided a valuable comparison to the Sports Plus adaptive sports program in this study because the groups are expected to maintain different social status hierarchies. The experiences of parents observing their children in inclusive educational or sports programs shaped their horizons prior to the lived experiences being studied and informed their unified flow of experience.

Hierometer theory suggests relative status in social hierarchies and belongingness contribute to self-regard, and individuals adopt behaviors that reflect this (Mahadevan et

al., 2016). A hermeneutic lens informed the experiences as reported from the parents and contributed to the textual interpretations. By analyzing the experiences of participants' parents, I expected to reveal the meanings of the lived experiences of parents whose children with autism realized a sense of belonging through participation in adaptive youth sports (Moustakas, 1994). Qualitative data were collected through in-depth interviews with the parents, which is a typical method used in phenomenological data collection (Moustakas, 1994). The type of hermeneutic interview is classified by van Manen (2014) as methodology-interpreting.

This phenomenon was chosen because although a sense of belonging for children with ASD frequently has been reported as a desire of parents, often it is elusive (Ashby, 2008; Barrow, 2017; Bauminger et al., 2008; Hornby, 2015). Understanding the static phenomenology or *ti estin*—the “what” of phenomena, and the genetic phenomenology—the “how” of phenomena, through the lived experiences of participants' parents could be valuable to large numbers of individuals beyond those involved with this study (van Manen, 2014).

### **Research Site**

Sports Plus is a Maryland based 501(c)(3) non-profit organization that provides year-round sports programs for children and young adults between the ages of 5 and 25 with mild to moderate ASD and/or other developmental disabilities. Tom and Natalie Liniak, parents of a son with ASD, founded the organization in 2005. The programs, including swimming, track and field, and soccer, are designed to teach athletic skills in a fun, positive, and social environment tailored to the skill level and challenges of each participant. Sports Plus grew from six participants in 2005 to as many as 200 active

participants in 2019 and the organization reports 96% of first-time participants return to participate in additional programs. Additionally, 98% of Sports Plus participants were reported to be able to participate in mainstream physical education classes without support and 25% have advanced to mainstream sports programs.

### **Research Questions**

The primary research question for this study was: What are the lived experiences of parents whose children with autism realize a sense of belonging through participation in adaptive youth sports? The primary research question was supported by the following sub-questions:

1. What are the lived experiences of parents as they observe their children interacting with similar children?
2. What are the lived experiences of parents as they observe their children engaging in social relationships?
3. What are the lived experiences of parents as they observe their children negotiating meaningful roles in the community?
4. What are the lived experiences of parents as they observe their children finding a good fit through navigating norms and expectations?

### **Data Sources**

After approval of an application submitted to the UCCS Institutional Review Board (IRB), which can be found in Appendix A, the administrators of Sports Plus assisted in identifying potential interview participants (COVID-19 required a second IRB approval to complete remaining interviews virtually, which can also be found in Appendix A). Those who met the participation criteria were invited to be interviewed.

## **Semi-Structured Interviews**

Data were collected through semi-structured interviews. The methodology used to inform the interview protocol was based on the Interview Protocol Refinement (IPR) method. This method ensured interview questions were aligned with research questions, fostered an inquiry-based conversation, and included receiving feedback and piloting the interview protocol prior to utilization (Castillo-Montoya, 2016). The research-specific questions were guided by the theoretical framework of belonging, which identified four main areas: (1) interacting with similar people, (2) engaging in social relationships, (3) negotiating meaningful roles in the community, and (4) finding a good fit—navigating norms and expectations (Renwick et al., 2019). The inquiry approach was informed by van Manen (2014) and was limited to concrete experiences while avoiding perceptions, opinions, or beliefs. The semi-structured interviews involved open-ended questions about the experiences of parents with their children who realized a sense of belonging through participation in Sports Plus programs. The interviews also inquired as to the way in which those experiences compared with other events related to their children realizing a sense of belonging. The questions used to guide the interviews can be found in Appendix B. The use of semi-structured interviews allowed for the flexibility to follow up on interviewee responses for clarification and a deeper understanding of the original response (Rabionet, 2011). Further, hermeneutic phenomenology relied on dialogue between the researcher and the participant to reach a shared understanding of the phenomenon (Gadamer, 1989; Heidegger, 1962).

Each interviewee was required to sign an informed consent form prior to the interview, which provided participants with information about the study, confidentiality,

and the withdrawal process. The identities of the interviewees were concealed through the assignment of unique identifiers and alterations to some non-essential details that concealed potential identifiers. I provided my contact information to interviewees and invited them to follow up with any questions or concerns.

### **Population and Sample Selection**

The sampling scheme for this hermeneutic phenomenological study was a stratified purposeful strategy (Creswell & Poth, 2018; Guest et al., 2013) with the aim of identifying those who have experienced the phenomenon of interest. Individuals who share the diagnosis of ASD have conditions that vary radically; therefore, the criteria for sample selection was narrowed intentionally. Interview participants were limited to parents who reported their children had a diagnosis of ASD, suffered from some level of anxiety, and experienced a sense of belonging through participation in Sports Plus programs. An invitation was sent to 30 families and 17 agreed to participate. Three of those who agreed to participate were unable to schedule time to be interviewed, resulting in 14 participating families and a response rate of 46.7%.

The strategy for sample selection criteria and sample size is different for hermeneutic phenomenological studies than for those utilizing other qualitative methods. One suggested guideline is that as the complexity of the phenomenon of interest increases, more participants are needed (Dahlberg et al., 2008). Another is that the number of participants should be inversely correlated with the depth at which the researcher intends to pursue with each participant (Vagle, 2018). It is not possible to achieve saturation in a phenomenological study, so the goal is to locate examples of experientially rich descriptions of the phenomenon (van Manen, 2014).

The study sample shared the following demographic attributes: all interviewees spoke English, were over the age of 18, and were the married, biological parents of Sports Plus participants. All were classified as middle- to upper-income, college educated, and lived in the Montgomery County, Maryland, metropolitan area. The full list of sample characteristics can be found in Table 2.

### **Data Collection Process**

A stratified purposeful sample of 19 parents of 14 Sports Plus participants was generated through a survey distributed by the administrators of the Sports Plus organization. The strategy for sample selection was to locate examples of experientially rich descriptions of the phenomenon (van Manen, 2014). Survey respondents confirmed their child had a diagnosis of ASD, suffered from anxiety, and experienced a sense of belonging while participating in Sports Plus programs. The potential interviewees were sent informed consent forms to review and were instructed to sign an acknowledgment prior to the interviews. The Sports Plus program is geared toward youth with mild to moderate ASD. The administrators acknowledged they do not have the capacity to accommodate the more severe cases in which violence and self-harm can be common. It was not surprising, therefore, that the parents in this study described their children as either moderate or high functioning. The children of the interviewees were between the ages of 9 and 21, had participated in Sports Plus programs for at least three years, and 13 of 14 were male. The full list of child characteristics as reported by their parents can be found in Table 3.

**Table 2***Individual Parental Characteristics*

Characteristic	Parent ( <i>N</i> = 19)	
	<i>n</i>	%
Gender		
Female	12	63
Male	7	37
Relationship to Child		
Mother	12	63
Father	7	37
Race/Ethnicity		
White	15	79
South Asian	2	11
East African	2	11
Age Range		
30-34	1	5
35-39	0	0
40-44	0	0
45-49	8	42
50-54	4	21
55-59	5	26
60-64	1	5
Education Level Completed		
BA/BS	3	16
MA/MS	14	74
Professional Degree	1	5
PhD	1	5
Socioeconomic Status		
Middle	4	21
Middle/Upper	7	37
Upper	8	42

**Table 3***Characteristics of Sports Plus Participants*

Characteristic	SP Participant (N = 14)	
	<i>n</i>	%
Gender		
Female	1	7
Male	13	93
Race/Ethnicity		
White	11	79
South Asian	2	14
East African	1	7
Age Range		
9-12	3	21
13-16	4	29
17-20	3	21
21-24	4	29
Years Participating in Sports Plus		
3-5	6	43
6-10	3	21
>10	5	36
Functional Level		
Low	0	0
Moderate	7	50
High	7	50

*Note.* Anonymity was important to the parents, thus all quotes contributed by the parents of the one female Sport Plus participant were masked in terms of the child's gender.

The semi-structured interviews began with a casual greeting, and the researcher shared his appreciation for their time and reflections before posing questions individually to the interviewees. After consent of the participants, the researcher captured the audio recordings of each interview with a microphone, a laptop computer, and Adobe Audition 2020 software. The interview questions (see Appendix B) were formed with the goal of soliciting answers to the primary research question and supporting sub-questions. The

relationship between the research questions and the specific interview questions can be found in Table 4.

**Table 4**

*Research Questions in Relation to Interview Questions*

Research question	Interview question
1) What are the lived experiences of parents whose children with autism realize a sense of belonging through participation in adaptive youth sports?	S1, S2, S3, S5, S6, S7, S8 F1, F2, F3, F4, F5, F6, F7, F8, F9, F10
a) What are the lived experiences of parents as they observe their children interacting with similar children?	S1 F1, F2
b) What are the lived experiences of parents as they observe their children engaging in social relationships?	S1 F3, F4
c) What are the lived experiences of parents as they observe their children negotiating meaningful roles in the community?	S1 F5, 56
d) What are the lived experiences of parents as they observe their children finding a good fit through navigating norms and expectations?	S1 F7, F8, F9, F10, F11

*Note.* Interview questions S1-S8 represent the Study-Related questions in Appendix B. Interview questions F1-F11 represent the Belonging Framework questions in Appendix B.

Interviewees spoke as long as they wished, and the interviews were between 33 and 110 minutes in length. The interviews were transcribed verbatim using Microsoft Word, and confidentiality was maintained by storing the audio and transcription files in a password-protected encrypted folder on the researcher’s personal computer. After the interviews were transcribed, they were sent to the respective interviewee via electronic

mail for member checking. Interviewees were asked to review the transcripts and validate the content accurately reflected, to the best of their recollection, the intent of their responses. Any and all inaccuracies were corrected to reflect the interviewee feedback.

### **Data Analysis Procedures**

As the purpose of this study was to collect and analyze interview data regarding the experiences of parents whose children realized a sense of belonging through participation in adaptive youth sports, hermeneutic phenomenological research methodology was utilized to capture an understanding of the meaning or essence of those lived experiences (Gadamer, 1989). Phenomenological reflection was used to analyze the transcription data and to conduct the thematic analysis (van Manen, 1984, 1997, 2014). The researcher personally transcribed each interview and read the transcript of each repeatedly, reflecting on the meanings of those experiences. Van Manen (1997) described three methods for isolating thematic aspects from text: wholistic, highlighting, and line-by-line approaches. The wholistic approach was used in this study, although particularly revealing sentences were highlighted as transcripts were read multiple times. This process helped to inform the emergence of themes that captured the fundamental meaning of the text. Themes were then narrowed by combining those that were similar and deleting those that were not essential to understanding the phenomenon at hand or were not central to the research questions posed (van Manen, 1984). The themes helped to identify similarities among the lived experiences of participants. The final phase of the hermeneutic phenomenological process involved a series of interpretive writings and rewrites with the goal of accurately capturing the lived experiences of interview

participants. This writing process continued until a sound interpretation of the phenomenological experiences was achieved (van Manen, 1997).

The themes were then viewed through a hierometric lens to determine whether any social, psychological, or behavioral themes had been identified that were consistent with hierometer theory (Mahadevan et al., 2016). This theory holds that a positive perception of group status and a sense of belonging are reflected in higher self-esteem, increased confidence, and decreased anxiety. Viewing the analysis through an additional lens gave new dimensions to the meaning of the phenomenon of interest (Dahlberg & Dahlberg, 2019).

### **Trustworthiness**

As suggested by Lincoln and Guba (1985), the steps of the research process were clearly documented, including the various decisions made during the data analysis process. Additionally, the researcher employed the trustworthiness strategies of member checking, disclosing researcher bias, and providing thick, rich descriptions of the findings through direct quotes of participants (Creswell & Poth, 2018). Interviewees were asked to review a draft of their transcript, interpretive writings, and anecdotes to ensure that an accurate reflection of their original experiences were captured (van Manen, 2014). Member checking increases accuracy and credibility (Creswell & Poth, 2018) and validates “the quality of the experiential accounts” (van Manen, 2014, p. 348). The researcher is a parent of a child with ASD and has developed opinions about intervention approaches, youth sports, and inclusion programs. He is of the opinion that today’s inclusive educational environments often fail to create a sense of belonging for students. The disclosure of this researcher bias or pre-understanding of the phenomenon (Gadamer,

1989; Heidegger, 1962) allows the reader to have a full understanding of possible motivations and assumptions that may have influenced the data analysis process and the results (Creswell & Poth, 2018).

Providing thick, rich descriptions of the phenomenon experienced through the inclusion of direct quotes provides context to the readers, which is important for analyzing the quality of the interpretive reflection (van Manen, 2014). Trustworthiness also was increased by the sustained engagement of the researcher through all phases of the study (Vagle, 2018).

### **Ethical Considerations**

Recruitment of interviewees was initiated only after IRB approval from UCCS and permission was granted from the Sports Plus organization. Interviewees were required to sign an informed consent form prior to the interview. This form included a study overview, procedures, risks and discomforts, benefits, and confidentiality. All interviewees agreed to participate after reading the informed consent document, sharing understanding that participation was voluntary, and affirming that they were over the age of 18.

The identity of participants was concealed by assigning unique identifiers for each individual. Interviewees were provided contact information of the researcher and were invited to follow up with any questions, concerns, or to withdraw from the study. No participants withdrew from the study. The collected raw data were placed into a password-protected folder of which the researcher has sole access. Three years after completion of the study, the raw data and digital recordings will be permanently deleted and destroyed.

### **Limitations**

A limitation to this research is that a diagnosis of autism includes a broad range of possible traits and cognitive abilities. It is possible higher functioning children and their parents experience the phenomenon differently than lower functioning children and their parents. Another limitation to this study is potential researcher bias. The researcher is a parent of a child with ASD and has experienced situations in which his son realized a sense of belonging, which has the potential to influence the interpretive reflection if the epoché is not effectively applied.

### **Delimitations**

Delimitations narrow the scope of study (Creswell, 2014). One delimitation of the study is that parent participants were limited to those who reported their children had ASD and participated in programs through Sports Plus in Montgomery County, Maryland. A second delimitation is that only parents who agreed to be interviewed were selected for the study. The researcher used purposeful sampling to ensure rich, descriptive experiences of the phenomenon (Creswell & Poth, 2018), thereby limiting the scope of the study.

## CHAPTER IV

### RESULTS

The purpose of this phenomenological study was to develop an understanding of the lived experiences of parents whose children with autism realized a sense of belonging through participation in adaptive youth sports. A purposeful sample of 19 parents of 14 children who participated in Sports Plus programs was included in this study. The data represented the experiences of parents within the Sports Plus community. Data collection consisted of one-on-one or one-on-two semi-structured, open-ended interviews. The transcribed data were analyzed and interpreted to reflect the parents' lived experiences of observing their children as they realized a sense of belonging while participating in Sports Plus programs. This chapter describes the results of the phenomenological analysis conducted on that data. The interview questions were informed by the research questions. The primary research question was: What are the lived experiences of parents whose children with autism realize a sense of belonging through participation in adaptive youth sports? This research question was supported by the following sub-questions informed by the theoretical framework of belonging (Renwick et al., 2019):

1. What are the lived experiences of parents as they observe their children interacting with similar children?
2. What are the lived experiences of parents as they observe their children engaging in social relationships?
3. What are the lived experiences of parents as they observe their children negotiating meaningful roles in the community?

4. What are the lived experiences of parents as they observe their children finding a good fit through navigating norms and expectations?

### **Themes**

After a thorough analysis of the transcription data from the parental interviews, initial codes were isolated and further condensed into conceptual groups as the meaning of the experience surfaced. The final iteration resulted in a narrative description of the essence of the findings, which emerged from three major themes: (a) meet them where they are, (b) let them be themselves, and (c) see how high they climb. All findings are discussed in this chapter. The development of the initial codes to the conceptual grouping of codes into themes concerning the essence of the phenomenon can be seen in the code map in Table 5.

Agreement exists among researchers of both psychology and belonging that acceptance of a person is a critical step in creating a sense of belonging (Baumeister & Leary, 1995; Leary et al., 1995; Renwick et al., 2019; Rogers, 1961). The critical role of acceptance in creating a sense of belonging is supported by the findings of this study. The present existence of an individual, or being, encompasses the whole of the individual at each moment in time. Parents identified five concepts related to that which must be accepted as part of the whole being of their child, forming the first major theme of the essence, “meet them where they are.” Realizing a sense of belonging is a foundational human need and once met reduces anxiety and accords people the confidence to be themselves (Maslow, 1943). Four concepts discussed by parents that related to a sense of belonging comprised the second major theme of the essence, “let them be themselves.” Realizing a sense of belonging influences a child’s development (Commonwealth of

Australia, 2009), which was the final major theme of the essence, “see how high they climb.” This theme included four concepts related to the growth, development, and potential of their children.

**Table 5**

*Code Mapping–Primary Research Question: Codes–Themes–Essence of the Phenomenon*

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<u><b>Initial Codes</b></u>		
Likes being around people	Is accepted at SP	More confident at SP
Most don’t see their value	Can be themselves at SP	Growing physically at SP
Doesn’t have any friends	Is happy at SP	Trust leads to growth
Wants friends	Is growing social skills at SP	Anxiety is lower at SP
Was happier when younger	These kids are wired differently	Tries to bond with NT peers
Is rejected often	Is accepting of others	Never underestimate potential
Is forced to persevere a lot	Admins meet them where they are	SP peers more like future friends
Is uncoordinated physically	Sports Plus accommodates needs	We trust the leaders at Sports Plus
Socializes at SP	Applies new social skills outside SP	Is not a happy person Outside SP
Is only social with family	Interacts with like children at SP	One-way conversation

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<u><b>Conceptual Grouping of Codes into Themes</b></u>		
Meet them where they are	Let them be themselves	See how high they climb
Doesn’t have any friends	Is accepted at SP	Improving socially at SP
Wants friends	Can be themselves at SP	Improving physically at SP
Likes being around people	Interacts with like children at SP	Gaining confidence at SP
Most don’t see their value	Socializes at SP	Never gives up
Deals with anxiety		

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**Essence of the Phenomenon**

Parents experience their children’s existence as one of innocence, beauty, and challenges cloaked behind an armor of coping mechanisms and defenses. This enigmatic existence is accepted by Sports Plus from day one. That acceptance was key to the children realizing a sense of belonging, giving them the ability and freedom to drop the armor, be their authentic selves, and grow socially and physically over time.

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*Note.* SP = Sports Plus; NT = neurotypical.

The two thematic statements that were consistent with the belonging framework questions were: (a) interacts with like children at Sports Plus, and (b) socializes at Sports Plus. These statements were repeated several times in the transcripts, warranting their inclusion. However, it should be noted that interaction with similar children was to be

expected for most children who participate in Sports Plus due to the nature of the programs. The additional belonging framework codes and statements that were rejected were meaningful to the individual but were not representative of the majority of the sample. Given the heterogeneity of the individuals who comprise the autism population, it was not surprising that many of the children in this study experienced belonging differently than that described by Renwick et al. (2019) in their theoretical framework. Two important distinctions can be seen between this dissertation research and the study that generated the belonging framework. The first is that only eight of the 24 participants with a developmental disability in the earlier study had a diagnosis of ASD. The second is that one of the selection criteria for participation in the framework study was, “Will be able to communicate their own perspectives (i.e., must be able to understand and be understood by the project coordinator who will screen potential participants for eligibility to participate)” (Renwick et al., 2019, p. 5). These two distinctions suggest the samples of the two studies are substantively different, which may explain the variation in the findings that are discussed further in Chapter V.

### **Meet Them Where They Are**

Several parents spoke of the Sports Plus defining philosophy of “meet them where they are,” which signifies a pedagogy based on an individualized approach to instruction and intervention. This approach is in contrast to the standard group education model found in a typical classroom (Ness & Middleton, 2012), as well as the sequential instructional coaching model found in most youth sport programs that often is based on age or skill level (Seefeldt et al., 1993). The Sports Plus pedagogy eliminates the need to

“catch up” or “keep up” because both the starting point and the pace of mastery are dictated by the ability of the individual.

To “meet them where they are” is to accept the whole being and all it entails. It is to accept who they are and that which makes them uniquely “them.” This describes the starting point of strengths, challenges, and interests for each child when they first arrive at Sports Plus, as well as those factors that influence acceptance in the program at any point in the journey. Some parents noted the non-sport challenges often necessitated the individualized approach at Sports Plus. One mother shared the experience of her first day in her son’s participation in the program:

I was floored at how well they were able to handle him. . . . [R]ight on cue, he was moving at his own pace and he had his own agenda. But they were great . . . and I quickly recognized . . . that, OK, they do know what they’re doing, and they got this. I was thrilled. I went home and raved about it. Like, this is amazing, this is absolutely fantastic. And that feeling that I had, I feel almost every time I leave, because I see something amazing.

That mother was justified in her initial concern. The research relative to children with developmental disabilities who participate in youth sports and extracurricular activities has revealed high attrition and low participation rates. One of the causal factors identified by the researchers in the study was an unmet need for extensive social cues (Reid, 2005).

A number of parents compared the experience at Sports Plus with that of mainstream sports programs. A father explained why the approach at Sports Plus was important to the success of his son:

The thing with Sports Plus is, they know what they're dealing with, so the other day when my son left the group and ran around on the side, it didn't derail them. They were like, "OK, he's not gonna participate today, well then, just let that be. And, you know, he can come check in if he wants or he can do his own thing today," but with most mainstream programs, you either comply or you're out. And that kind of rigidity does not work for these kids.

Only recently have researchers begun to understand stereotypical behaviors for individuals with ASD and the correlation between those behaviors and anxiety (Folstein & Carbajal, 2012; Kerns et al., 2015; Renno & Wood, 2013). The father in the previous example correctly pointed out the desired outcome was unlikely to be achieved through rigidity in the form of restricting anxiety-related behaviors without addressing the underlying anxiety.

Another father discussed his experience the first day his son tried Sports Plus. He and his wife were interested in the swimming program because they desperately wanted their son, Luke, to learn to swim. They arrived at Sports Plus after Luke's father, an accomplished swimmer, was unsuccessful in teaching him to swim:

I sat there and watched. . . . I wanted to see how they handled the kid who could already swim really well . . . [and] the kid who was terrified of the water. And they had a very different approach for each kid. . . . A lot of them seemed to be paired really well with the people they work well with. Tom . . . was always trying to pair him with an instructor who would work well with him. And you won't find that in other programs, I assure you. . . .

This father was drawing attention to an advantage of individualization that is rarely an option for programs based upon group instruction.

A mother compared her child's experience with a mainstream soccer program to that of Sports Plus:

Mainstream soccer was just stressful. Mikey was confused by the directions they gave him and really didn't understand the game. That was stressful for us because we wanted him to be like other kids and just fit in and enjoy it. It quickly became an unenjoyable experience for everyone, so we stopped. He's made a lot of progress in his swimming, though . . . it's been very slow progress. This Sports Plus program has really helped; the ongoing, patient work. They meet him where he is.

Mikey's experience in mainstream soccer was another example of that which Reid (2005) identified as the need of ASD youth for extensive social cues. Another mother explained why the group instruction of a mainstream sports program did not work for her son:

For us, the drawback was less the autism and more the anxiety. Billy was so overwhelmed and overstimulated by the number of people around him that he really couldn't access the program. He was just stuck on making sure the other 30 kids were doing what they were supposed to be doing. He really couldn't concentrate on what was *his* job.

Individuals with ASD commonly struggle with anxiety (Kerns et al., 2014; White et al., 2015). The behavior described by Billy's mother was consistent with research findings that show stereotypical autism traits in individuals with ASD to be positively correlated

with anxiety (de Bruin et al., 2007; García-Villamizar & Rojahn, 2015; Mayes et al., 2011; Rodgers et al., 2012; Turygin et al., 2013).

As difficult as it may be for neurotypical people to understand, only eight of the 14 children were reported to be interested in having friends. However, four of the six who had no interest still enjoyed being around others. Additionally, only two of the seven children who had no friends actually wanted friends. One father explained that while his son spent a great deal of time interacting with people on multi-player video games, he was not interested in having friends or being physically around others. The father stated the following:

People don't understand. Other kids try to bond with him, and they're genuine, and it's just not in him. It's not his thing. We see them engage; they try to engage; they keep asking questions, but he's told us over and over; he just doesn't care. It's just not in his wiring.

The son's experience was not unique among those on the spectrum. A 13-year-old author with ASD explained a similar view when giving advice to parents of children with autism (Jackson & Attwood, 2002). In his book, *Freaks, Geeks, and Asperger Syndrome: A User Guide to Adolescence*, Luke Jackson wrote:

I think parents and teachers and adults in general have a big problem with the fact that AS kids like to be alone and don't mix with other people much. My answer to that one is—get over it! Just because one person would feel unhappy or lonely or sad, without a crowd of people around them or at least one or two people to chat to, that doesn't mean we have to be all the same. (p. 168)

The loner mentality among individuals with ASD is prevalent to the extent that medical personnel consider it an autism trait in the assessment process (Matson, 2016).

A number of parents expressed a specialness in their child that most individuals do not have an opportunity to see. Jeremy's mother talked about her son's magnetic personality. She explained her experience with his extraordinary empathy and kindness:

He's an exceptionally kind person. It's a very unusual thing because I know a lot of the kids on the spectrum aren't known for having empathy, but he has an exceptional amount of empathy. He's a vegetarian because once he figured out where meat comes from, he's like, "I can't eat an animal." He doesn't say mean things about people; he's one of the kids who's just never mean. He gets irritated for sure . . . but he's just a very kind kid.

Jeremy's mother shared her experience of watching his peers being drawn to him; she felt his likability was connected with his kindness and empathy. He was a child who reportedly wanted friends, had friends, and enjoyed being around people. A similar story of a unique personality for a child with ASD was told by Luke's mother, who explained, "Luke is . . . amazing, he's bright and charismatic, which you don't usually hear from kids with autism, but he is. He can charm the pants off of anybody, but that's just his internal nature." His mother pointed out that his happy and charismatic nature sometimes masked his struggle to regulate his emotions. Experience taught her to be especially alert to his rising energy level, which frequently signaled a forthcoming meltdown.

The transcripts of the interviews often failed to capture the emotions that accompanied the descriptions related to this concept. The love the parents felt for their

children was palpable for most, and a joy was salient for many when reflecting on some of the experiences. One parent described her child in this way:

[He] is the love of my life, because he is the most beautiful person. He's unique, and he's kind, and he is honest, and he is loving, and he is funny . . . but most people don't see that—unless you really get to know him. Because he doesn't interact in a way that neurotypical people do. It's different for him. . . .

She radiated with pride when she talked about her son, and it was apparent she would do anything in her power to help him. She described the remarkably high level of empathy and kindness he displayed:

I'll never forget when my mom was dying of cancer. We were going someplace, and they were both in the back seat together. She was having a really bad day. He didn't generally hold hands anymore, but he initiated holding her hand and he held her hand the entire 30-minute trip. He just held her hand, and I just . . . I think with him, it's instinct. He doesn't have to think about being kind in that way.

The descriptions of the special characteristics of these children frequently were accompanied by an explanation that the traits were either rare or unexpected for those on the spectrum.

Just as common was the notion that these special traits often are unseen or unrecognized. One such example was from a mother who attributed her son's anxiety to keeping the better part of her son hidden from most people. She shared, "Once he gets past his anxieties, he can be very friendly, very funny, and very outgoing. But it's a challenge getting to that point where he feels comfortable enough in an environment or

community to relax and be himself.” Anxiety was commonly mentioned by parents as a barrier to accessing the best part of their child’s personality. One parent explained how anxiety has obstructed her son’s better nature:

He’s extremely bright. He’s talkative and personable, but only in the right settings, so the way his behaviors manifest . . . he really requires comfort. Without comfort he goes into a fight or flight behavior, and that’s what sort of led us to Sports Plus.

This parent described her son as happy and engaged at Sports Plus, without his usual anxiety symptoms. Research has shown anxiety is lower in individuals who feel a sense of belonging (Baumeister & Leary, 1995), and physical activity is a natural anxiety mediator (Petitpas et al., 2005; Prichard & Deutsch, 2015; Ratey, 2010).

### **Let Them Be Themselves**

The second major theme of the essence of the phenomenon involved an outcome of realizing a sense of belonging. Although all parents discussed their experiences in observing their child while they realized a sense of belonging at Sports Plus, it became clear most children in the study grasped a sense of belonging differently than that suggested by the theoretical framework of belonging (Renwick et al., 2019). Parents commonly expressed the notion that the various obstacles to acceptance in previous programs for these children were accepted at Sports Plus. One parent believed having a child on the spectrum gave the Sports Plus administrators a unique perspective and an understanding that acceptance of unique personality traits goes with the territory. This parent described the concept of acceptance as follows:

Because Natalie and Tom have a child with autism, they understand that you can't sweat the small stuff and the little things—you try to laugh at them and not let them bother you, and I think that really helps. Even people there that don't have their own kids understand that these kids learn differently and a trigger for one kid is harmless to another. I thought a really positive thing about Sports Plus was acceptance of our kids and all their quirkiness.

Some evidence exists to support the idea that parents of children with ASD are particularly attuned to their unique needs. A 2010 study of home-schooled students with special needs found more than two thirds of parents removed their child from mainstream education because they believed the school was failing to meet the unique needs of their child (Parsons & Lewis, 2010).

A parent explained it simply as, “Sports Plus accommodates his needs. Nowhere does he feel as at home and welcome as he does in Sports Plus.” Some parents felt being accepted was the key to their children's ability to feel comfortable being themselves. One father described it in this way:

So, he's out on the field with a bunch of kids, having a great time and fitting in. For [him] belonging is, “hey, I'm just happy being me. I'm just out here having fun.” For him, belonging is just being able to be himself and not feeling weird and just having fun. And just being accepted by people around you—not necessarily because you have autism, but because you're just part of the group.

This example did not support the theoretical framework of belonging (Renwick et al., 2019). However, it was one of several examples in this study of children with ASD who felt a sense of belonging merely by being part of a group.

A parent described the first time she observed her child being comfortable enough to be himself at Sports Plus:

He was actually participating and following the instruction and we knew we were good. He's got a smile on his face, he's giggling, he's happy, and you knew it.

Like, he's good here right now. Sports Plus is so special, because it is so inclusive. Everyone plays, everyone gets a chance, everyone supports each other.

It is inspiring and amazing.

Similar to this mother, a number of parents remarked their own anxiety was lowered as a result of their child realizing a sense of belonging at Sports Plus. Studies have shown parents of children with ASD experience anxiety more frequently than those of neurotypical children. One study found nearly half of all parents feel stretched beyond their limits between one and five times per month (Sharpley et al., 1997).

Mikey's parents described the differences between their son socializing in a mainstream program versus the Sports Plus program. His mother discussed that which she viewed as a downside to interacting with primarily neurotypical kids:

The other kids were great with him, but he simply couldn't keep up. The friendships he was developing weren't natural, it was different. They looked out for him and took care of him, which was really nice, but Sports Plus is a place where he can be himself and do his own thing—and he's not getting helped by other kids the whole time.

Mikey's father added:

Even in the best mainstream inclusive programs he is getting lots of help to keep up. So, Mikey learned he didn't have to do much work. But in Sports Plus, he's

expected to do things on his own, at his own pace. And he's doing it and he's learning. He's also very hard on himself because he's very aware. He doesn't want someone telling, "good job" if he doesn't feel like he did a good job. Now, he actually feels proud of his accomplishments.

Mikey's parents characterized him as independent, enjoys working hard on topics in which he has interest, and can be alone without feeling lonely.

### **See How High They Climb**

The final major theme was related to the forward progress made by these children and their development for the future. The Commonwealth of Australia (2009) summarizes the connection of belonging with a child's identity and how the child develops with the statement, "*Belonging is central to being and becoming in that it shapes who children are and who they can become*" (p. 7). The majority of parents expressed an increased confidence in their children, as well as in their physical and social growth, while participating in Sports Plus programs. One parent described her experience in the following way:

But I thought it was just like . . . doing sports and that sort of practice every week –of whatever activity it was, he just developed so many great skills, physically. Got stronger, got more coordinated. And they challenged him in a good way, so I definitely saw him develop physically that way. I think he found the whole thing extremely fun.

Another parent talked about the swimming program and explained her amazement in her son's skill development:

If you could see where he started compared to now . . . he couldn't swim at all, he just wanted to bounce in the water. Now, he's wanting to do full laps in the pool. It's just amazing to watch the progress. And track and field has been great for his running endurance. He can run all day, now. That part of it's great, but I think the biggest thing is just that he feels so successful from it. Sports Plus does a great job of making every child feel successful.

The experiences shared by these parents are supported by the research on youth sports. Studies have found youth sports and physical activity can enhance psychosocial development, increase motor skills acquisition, improve cognitive functioning, advance communication skills, create a sense of belonging, increase independence, and augment social skills (Fraser-Thomas & Côté, 2006; Memari et al., 2017; Seefeldt et al., 1993; Smith & Patterson, 2012; U.S. Department of Health and Human Services, 2018; Wells et al., 2008; Wiersma, 2000).

One mother summed up her experience relative to observing her child's social development in this way:

It's comforting, and it's also sort of heart-warming in that, it kind of makes you optimistic. What Sports Plus does, is, they're helping these kids gain social skills through sports. They're learning how to follow instructions, learning how to work with other people, they're learning how to interact with people they don't know in situations that they can't control. . . . I find it very comforting.

Physical activity has been found to improve social functioning in children with ASD (Memari et al., 2017). Another mother saw advantages to watching her son socialize because of the teachable moments it offered:

He can't wait to get there and see who's there and who's not. It's helped us because it's really the only place where we get to watch him make an effort socially, so we can see where the deficit is and what we need to work on. We're able to coach him in real time and watch him apply the skills in real time.

As with several other parents, this mother explained that her son desired more privacy as he approached adulthood, so she had fewer opportunities to observe his social interactions. A number of parents pointed out their children were involved in Sports Plus only one day per week; therefore, it was important to find additional sources of social modeling and training.

A father remarked on Sports Plus serving as one part of a larger whole that built confidence in his son and reinforced important social lessons:

My son's social anxiety has gone down, but as a function of being in the right school and having things like Sports Plus, right? So, the more he's in settings that are comfortable for him, the more he's willing to adapt to settings not comfortable and he can kind of deploy the skills that he's been taught or used over here, to this setting.

That father pointed out the importance of his son being able to apply the lessons learned in school and Sports Plus to real-life settings. A mother of a child who had been with Sports Plus for more than a decade spoke of the advantages of the children learning and growing together:

I think a lot of the kids are really trying to socialize and when they were younger, they were just doing their own thing, you know, the parallel play. But now, when

he goes to the social groups, I've taken him and seen it, they're all like, "hi, hi, hi," and it's kind of nice. It's kind of a little tribe.

The child being described in this example was one of a small group that began with Sports Plus at the time of the organization's creation. This mother shared the view of other parents that the familiarity of this small group had been socially beneficial to their sons.

The final aspect of this theme was the general notion of the resilience parents observed in their children and the belief they would never give up on them. One mother spoke at length of the resilience she has seen in her son, as well as her pain in witnessing it:

One of the big qualities my son has is; he perseveres a lot. People don't realize and could never imagine how much you have to persevere in the face of constant rejection. His behavior and conversations are often not in line with people's expectations, so they reject him. That's part of life, like it or not. And, it's very, very hard to see that as a parent. He is struggling now in college, but we are hopeful that he will finish and . . . maybe get a job and a more satisfying life.

This mother recognized a contrast between Sports Plus and most other areas of her son's life outside the home. In many ways Sports Plus offered a break from the environments that required a great deal of resilience.

A second mother talked about how Sports Plus gave her hope for the future:

As a parent, you always wonder if there is going to be something for my child . . . to stay fit, to stay social, to stay happy? And this program has taught me not to be as worried anymore. I believe there will always be something for my son to do. I

needed to believe that. Maybe it's the area of the country we live in, but as a parent of a child with disabilities, it's important to know there will always be options for him, so this is very, very, very comforting.

A third mother agonized over her child's continuous failed attempts at friendships and social connections outside of Sports Plus. She expressed an undying belief in her child and described her support with simple resolve: "Times go up and down, but we will never give up."

### **Hierometer Lens**

The themes were viewed through a hierometric lens in order to assess the social, psychological, or behavioral variables that were identified and consistent with the predictions of hierometer theory (Mahadevan et al., 2016). This view holds that a positive perception of group status and a sense of belonging are reflected in increased confidence and decreased anxiety. Hierometer theory proposes that if children realize acceptance or a sense of belonging in a group, their confidence is expected to increase, and they should be more comfortable being themselves in the group. The argument also asserts confidence is necessary in order to apply newly acquired social skills.

The children in this study were found to have realized acceptance, a sense of belonging, an increase in confidence, and increased social skills. It should be noted factors other than belonging could have led to an increase in confidence, such as the acquisition of physical skills (Institute of Medicine, 2013). Therefore, while not conclusive, the findings offer support to hierometer theory. The behaviors reported by parents were in line with and did not contradict the theory. A more convincing approach for viewing the themes in this qualitative study through a hierometer lens involved

delving deep into the transcripts of three parents, two of whom had children with a desire for friends but had none, and one with a child who remained cheerful and confident despite peer rejection. Fortunately, each parent discussed life beyond the Sports Plus experience. In addition to analyzing the behavior of individuals who appeared similar to those used in the sample for the hierometer study, some value existed in reviewing the behavior of a child with ASD whose social awareness differs radically from those neurotypical individuals used in the hierometer research.

Chris was reported to be a happy, fun-loving, and playful child when younger; but today, at age 20, he struggles to connect with peers. With age, Chris's peers spent more time in conversation, bonded over shared views, and discussed ideas; but the gap between him and his peers grew. Chris's silliness that was previously effective in gaining acceptance from peers was now viewed as immaturity and frequently met with rejection. Chris's mother described it in this way:

When Chris was younger . . . big smile, running around, you know, fun, fun, fun all the time. Unfortunately, over time, we noticed that that disappeared. That fun-loving kid disappeared. Today, you see a Chris that's overly serious. Too sad and too serious. I don't know why. I hope that changes. Chris is young and has many years left. We live only once, and I want Chris to be happy.

The example of Chris exemplified the behavior expected by hierometer theory that calls into question sociometer theory, which would predict behavior that would signal an increase in effort on the part of Chris. Hierometer theory predicts the type of conciliatory behavior described by Chris's mother (Mahadevan et al., 2016).

Jordan is a 21-year-old male who was characterized as a lovable, happy child with limited speech who desperately wanted friends. Over the years, Jordan's parents arranged a number of play dates with the children of their friends in an attempt to satisfy his desire for friendship. Jordan's mother discussed one of the arranged meetings:

Jordan sat with them, and looked at them, but didn't interact with them. Jordan just didn't feel any sense of belonging with them . . . so we tried community gatherings and Jordan just focused on food or whatever else. I think it is more social anxiety and shyness, but we don't see much interest coming from Jordan's side. That's the hardest part because we know [Jordan] wants friends.

Jordan's example was less clear than that of Chris, but the lack of initiative in developing friendships is consistent with hierometer theory. It is noteworthy that Jordan's example is inconsistent with sociometer theory, which would have predicted an increase in effort from Jordan to pursue the friendship opportunities presented (Mahadevan et al., 2016).

Sean is a 21-year-old male of average intelligence who has participated in Sports Plus programs for more than 10 years. He is described as affectionate, likeable, and carefree. Although he enjoys being around people, his social awareness is very limited. He does not have, nor does he desire to have any friends. Although he has been rejected by peers, he does not appear to be aware of it when it occurs. His mother explained the following:

He's independent, he does everything independently. He loves to be social with his grandparents. . . . And then with peers, I see that brief interaction. He likes being around them, but I don't see a ton of back and forth conversations and I don't think that's anything new. I don't think he has a sense that he has ever not

belonged to any group. . . . So, for him, he's kind of in his own little happy world—no self-consciousness, no nothing.

According to hierometer theory, Sean should have experienced a loss of confidence and an increase in anxiety when rejected by peers. This example demonstrated a limitation to the theory that individuals are expected to possess the capacity to track their relative social status (Mahadevan et al., 2016). Given the proclivity of individuals with autism to struggle with social interaction and relationships, a large percentage of those with the disorder likely would not reflect the typical behavior to support the theory (Matson, 2016).

### **Essence of the Phenomenon**

The essence of the lived experience of parents whose children with autism realized a sense of belonging through participating in Sports Plus programs was best expressed through a representative narrative: Parents experience their children's existence as one of innocence, beauty, and challenges cloaked behind an armor of coping mechanisms and defenses. This enigmatic existence is accepted by Sports Plus from day one. That acceptance was the key to the children realizing a sense of belonging, which gave them the ability and freedom to drop the armor, be their authentic selves, and grow socially and physically over time.

A rather well-known quote prevails in the autism world that is credited to Dr. Stephen Shore (2018): "If you've met one person with autism, you've met one person with autism" (para. 1). This quote speaks to the heterogeneity of challenges, gifts, traits, coping strategies, interests, and personalities among those on the spectrum, as well as the very modes of being that parents referenced in their interviews.

This heterogeneity prompted several parents to remark on the importance of the Sports Plus philosophy to “meet them where they are.” Only through acceptance of the most challenging aspects of a child’s existence can the best and often hidden parts of that child be revealed. A sense of belonging begins with acceptance; once children feel that sense of belonging, they can truly be their authentic selves. The parents in this study made clear the importance of their children feeling comfortable to the extent that they showed a side of themselves that too often was revealed only in the safe and trusting confines of the home environment. The realization of a sense of belonging accomplished more than simply opening the door to learning sports skills from a coach. For many parents it represented hope, optimism, and promise for their child’s future.

I asked a remarkably optimistic mother about her positivity and that which gave her hope about the future for her child. She responded with the following:

He’s able to experience happiness, so that gives me hope . . . but for the most part, I just worry all the time. One hundred percent of the time. Like you. What’s gonna happen when we’re not here? Like all parents with kids on the spectrum worry about; what’s gonna happen when we’re not here?

Her words did not startle or confuse me, and I was confident she knew I would understand them before they were spoken. A connection, whether verbal or understood, often can be seen between parents with children on the spectrum whose chances of living as independent adults are in question. This mother and I both have children who fit that description, and the worry she expressed was rooted in the reality that parents are expected to die before their offspring. As a researcher, I was curious to understand the essence of her optimism given the challenges she had discussed. However, as a parent

who shares this painful connection, I am forced to ask whether that question was partly a self-serving search for hope regarding my own son's future.

### **Summary**

In Chapter IV, the data collection and analytical process was described, the findings of the thematic analysis were reported, and the essence of the phenomenon was presented. The purpose of this study was to develop an understanding of the lived experiences of parents whose children with autism realized a sense of belonging through participation in adaptive youth sports. This study utilized a hermeneutic phenomenological research methodology in order to capture that understanding (Gadamer, 1989). The interview responses from 19 parents were analyzed, and three major themes of the essence of the phenomenon emerged.

The first theme consisted of those concepts related to the essence of the child's being and included: (a) does not have any friends, (b) wants friends, (c) likes being around people, (d) most people do not see the child's value, and (e) deals with some level of anxiety. The second major theme consisted of concepts related to parents observing their child as they realized a sense of belonging and included: (a) is accepted at Sports Plus, (b) can be themselves at Sports Plus, (c) interacts with similar children at Sports Plus, and (d) socializes at Sports Plus. The third major theme consisted of concepts related to the forward progress made by these children, as well as their development, to include: (a) improving social skills at Sports Plus, (b) improving physically at Sports Plus, (c) gaining confidence at Sports Plus, and (d) never giving up. The essence of the findings was that parents perceived their children's existence as one of innocence, beauty, and challenges cloaked behind an armor of coping mechanisms and defenses. This

enigmatic existence was accepted by Sports Plus from day one. That acceptance was key to the children realizing a sense of belonging, which gave them the ability and freedom to drop the armor, be their authentic selves, and grow socially and physically over time. In Chapter V, the interpretation and implications of the findings is discussed as well as recommendations for future research.

## CHAPTER V

### CONCLUSION

The purpose of this study was to develop an understanding of the lived experiences of parents whose children with autism realized a sense of belonging through participation in adaptive youth sports. Growing bodies of research can be found around the psychosocial comorbidities of anxiety and autism (Ghaziuddin et al., 2002; Kerns et al., 2014, 2015; Lugnegård et al., 2011; Sukhodolsky et al., 2008; van Steensel et al., 2011); the benefits of youth sports and physical activity (Blumenthal et al., 2007; Fraser-Thomas & Côté, 2006; Memari et al., 2017; Ratey, 2010; Sabo & Veliz, 2008; Seefeldt et al., 1993; Smith & Patterson, 2012; U.S. Department of Health and Human Services, 2018; Wells et al., 2008; Wiersma, 2000); and the concept of belonging (Allen et al., 2018; Anderson et al., 2006; Baumeister & Leary, 1995; Blum, 2005; Craggs & Kelly, 2018; Hornby, 2011, 2014; Mahadevan et al., 2016; Maslow, 1943; Renwick et al., 2003; Shochet et al., 2016; Ullrich-French et al., 2012). However, little interdisciplinary research has been conducted on how their interrelationship impacts the lives of individuals with ASD.

This study was proposed because parents are uniquely positioned to reflect and communicate this wholistic interrelationship from the perspective of their own lived experiences. Semi-structured interviews with parents of children with autism were the primary source of data used to document those parental experiences and to answer the following main research question: What are the lived experiences of parents whose children with autism realized a sense of belonging through participation in adaptive youth sports? That primary research question was supported by the following sub-questions:

1. What are the lived experiences of parents as they observe their children interacting with similar children?
2. What are the lived experiences of parents as they observe their children engaging in social relationships?
3. What are the lived experiences of parents as they observe their children negotiating meaningful roles in the community?
4. What are the lived experiences of parents as they observe their children finding a good fit through navigating norms and expectations?

### **Summary of the Findings**

During the interviews, participants shared their lived experiences relative to parenting children with autism and observing them as they realized a sense of belonging through participation in Sports Plus programming. This data were then reviewed and analyzed using hermeneutic, qualitative methods to develop an understanding of the lived experiences. The summary of the findings is organized according to the three major themes that emerged from the research questions: (a) meet them where they are, (b) let them be themselves, and (c) see how high they climb.

#### **Meet Them Where They Are**

A common phrase used by parents when describing Sports Plus is that they “meet them where they are.” This implies acceptance of the child and all the quirks, challenges, and oddities that are part of the whole being of that child, and an individualized approach to sports instruction and intervention. One of the advantages of this approach is that it ensures the coaches at Sports Plus approach each child in a way that is developmentally appropriate, which is a key to effective coaching (Flett et al., 2013). This approach also

enables the coaches and volunteers to relate to each child in a manner that encourages effort and while maintaining an atmosphere of playfulness and fun. Additionally, the individualized approach to instruction is consistent with a focus on mastery versus performance, as confirmed by previous research that found a mastery orientation results in increased athlete enjoyment, decreased attrition in the program, and a reduction in anxiety (Dweck, 2006; Prichard & Deutsch, 2015). These findings also confirm research on well-being that found individual success increases emotional well-being, while placing individuals in a high-achieving group often has been shown to hurt well-being (Pekrun et al., 2019). This study on the big-fish-little-pond effect cited the natural tendency of individuals to rank themselves based on the abilities of others in their reference group. By defining success through individual goal achievement, or mastery, Sports Plus reduces the likelihood of reference group comparisons and increases the number of children who achieve success.

All the children of the study participants were reported to have experienced some level of anxiety. The interviews revealed that this was commonly seen as an obstacle to participation in previous sports programs. Prior research has suggested that physical activity has a mediating effect on anxiety, and this research supports those findings (Pietrelli et al., 2018; Ratey, 2010; Zimmer et al., 2016). Regular involvement in Sports Plus is likely to have contributed to the decreases in anxiety reported by parents.

### ***Interpretation***

The current educational model is one based on a normal distribution bell curve developed from samples of primarily neurotypical children. The vast majority of those with ASD are outliers on many distribution curves and are constantly reminded of their

differences, implicitly or explicitly. Many of these differences are identified as deficiencies that need remediation or correction. The resulting message that is far too often sent and received is that children with ASD are not accepted “where they are” because “where they are” is not good enough. This perceived lack of acceptance can quickly become a barrier to belonging, reduce confidence, and increase anxiety. For children who experienced a lack of acceptance in prior groups, the acceptance experienced at Sports Plus understandably was welcomed, refreshing, and salient for both the children and their parents.

### **Let Them Be Themselves**

When children realize a sense of belonging, they are able to put their defenses down and be themselves. The second major theme of the essence of the phenomenon was closely related to a sense of belonging: “let them be themselves.” The acceptance that began the day children arrived at Sports Plus continued throughout their time in the program. Acceptance is an early, critical step in creating an environment that fosters a sense of belonging (Baumeister & Leary, 1995; Leary et al., 1995; Renwick et al., 2019; Rogers, 1961). To “let them be themselves” is to recognize when the children are comfortable participating in an authentic manner; willing to be vulnerable in the group while taking direction and exerting effort. The data reveal that the ASD children of the study participants perceived a sense of belonging while participating in Sports Plus programs, but that perception was experienced in different ways and from different sources than that suggested by Renwick et al. (2019). The findings in this study fail to confirm the results in the research that developed the theoretical framework of belonging for individuals with developmental disabilities (Renwick et al., 2019).

An important difference between this study and the Renwick et al. (2019) framework of belonging research is that this study focused exclusively on experiences of children diagnosed with ASD. The sample in the Renwick et al. (2019) study consisted of 24 individuals with developmental disabilities and included only eight with diagnoses of ASD. A second important difference is that all eight individuals with ASD were able to communicate directly with the researchers, which suggests an even milder form of ASD than that found in this study. Similar to other areas in the lives of individuals with ASD, belonging appears to be unique to the individual. All children in this study needed acceptance prior to realizing a sense of belonging, and acceptance alone was enough for some to come to that realization. Others needed to feel part of a group, and some confirmed the criteria that were defined in the belonging framework study. Further research is needed in this area if a theoretical framework is to be defined for all individuals with ASD. While it was a worthy aim of Renwick et al. (2019) to focus on belonging and attempt to define a framework, this study demonstrates the theory is incomplete with regard to those on the spectrum.

One of the outcomes of an individualized approach to coaching is that athletes are less competitive with one another because they possess individual goals. When athletes focus on competition with other athletes rather than on their individual goals, they find less enjoyment and are more likely to quit the sport (Hedstrom & Gould, 2004; Sánchez-Miguel et al., 2013). It is also likely that sport organizations with a mastery orientation that focuses on individual goals have fewer hierarchical structures based on athletic performance. Several parents spoke of the lack of competitiveness of their children, but none discussed how their child ranks athletically among the other children. If an athletic

hierarchy was apparent at Sports Plus, hierometer theory would predict that those at the bottom of the hierarchy would tend to withdraw from the group and would be less comfortable being themselves (Mahadevan et al., 2016). The findings in this study are either in contradiction to hierometer theory, or Sports Plus has effectively flattened the athletic hierarchy through their individualized approach, thereby making the theory inapplicable to this study group. Further research is necessary to understand the discrepancy.

### ***Interpretation***

This research explored the sense of belonging realized by children with ASD; however, in order to completely understand the impact, one must also explore the absence of realizing that sense. When these children receive the message that “where you are is not good enough,” they are less prone to be confident in being themselves in front of others. This increases anxiety for most and prompts them to hide who they are. Evidence of that outcome likely presents as increased stereotypical autism behavior, which increases the prospect of ostracization and bullying from peers, further increasing intentional isolation. The need for belonging appears just after the basic needs of survival and security on Maslow’s (1943) hierarchy of needs. While there is evidence to suggest many human motivations manifest differently in individuals with ASD, no evidence exists to suggest that belonging, for them, is not a human need.

### **See How High They Climb**

The interview data revealed a consistent message of growth. Parents were keenly aware of their role in fostering the growth of their children, and Sports Plus served a purpose in helping to achieve that outcome. While parents universally loved and accepted

their children and the whole of their being, they did not accept the notion that their children's education or growth was remotely close to complete. The majority of parents observed growth in their children's confidence, social skills, physical strength, and athletic skills while participating in Sports Plus programs.

Progress is an expectation of coaches, parents, and children in the Sports Plus program. A guiding principal of the organization is that coaches must have an honest belief in the ability of the children to achieve. The children are reported to have a keen sense of whether or not that belief is present in a coach and this is reflected back in the children's belief in themselves. The age of the child tended to influence the focus areas discussed by the parents. Social skills were more important for parents of teenagers and young adults. The transition process after high school was of critical importance. The organization views the programs as a continuum from sports skills to life skills and increase the peer modeling and interactions of neurotypical same-aged volunteers for the older children. Regardless of the functional level of the child, none of the participants expressed the slightest hint that they had given up on their child or their child's ability to grow into a happy, productive adult. Many remarked on the resilience of their child.

### ***Interpretation***

Parents of ASD children often express uneasy sentiments regarding the future. This concern is a disconnect between parents who are hopeful about how high their children eventually will climb and others who seem to expect very little additional growth from their child. This disconnect occurs between those who have not given up on their child and those who have. The parents and coaches at Sports Plus have not given up, and they accept that the path is longer, slower, and generally less direct than the path

taken by neurotypical children. This dynamic simply does not allow engaged parents to give up hope or to stop trying to help their children to grow, progress, and master their world.

If a common undercurrent can be found in this study regarding those with ASD, it is the idea of difference that exists between these individuals and their neurotypical peers as compared to others on the spectrum. This idea is salient for parents early in their child's life. Most of what is taught about parenting is based on generalizations. If a parent of a neurotypical child learns what is happening at the mean, it usually applies to their child, which is likely to be true in many areas for a child with ASD as well. However, there are some areas in which knowing what is happening at the mean gives no useful information about a child on the spectrum. This discovery can be frightening and stressful for parents as they engage in trial and error to solve the mystery. The process of solving mysteries about their child generally continues with each new phase of the child's life, becoming the norm for these parents and quite possibly influencing their expectations about their child's future. When discussing a current challenge or deficit in their child, the parents in this study did not refer to it as something their child "could not do"; the parents referred to it as something their child "could not do, yet."

### **Implications for Practice**

From a practice and policy perspective, the findings should be of interest to those who make decisions about instruction and intervention for individuals with ASD. The results also should be of interest to coaches, teachers, policymakers, administrators, and families that desire to create a sense of belonging for the outliers among us. With the rising prevalence of ASD (CDC, 2018) and growing expectations for inclusive settings

(Snyder et al., 2016), the need for effective approaches to connect with this demographic are expected only to increase.

The findings in this study have implications within adaptive youth sports and beyond. The psychosocial and physical outcomes achieved through the approaches of Sports Plus suggest potential solutions to the documented challenges faced by other programs that struggle to service the ASD community (MacDonald, 2011; Obrusnikova & Dillon, 2011; Reid, 2005). The individualized approach to instruction and intervention potentially has far-reaching implications for many individuals with autism. For those on the spectrum who are aware of their relative status, ability, maladaptive, or stereotypical behaviors, an individualized approach could open doors that inclusive environments have failed to open (Hornby, 2011; Imray & Colley, 2017; Kauffman & Badar, 2016; Kauffman et al., 2018; Morewood et al., 2011). Meeting these children “where they are” involves allowing them to progress at an individual pace they can handle. While this method is more resource intensive, it has allowed many in the program to advance much farther than they otherwise would have. Some in the program have progressed to the point to earn spots on their mainstream high school swim teams. Those individuals did not show exceptional talent when they first started at Sports Plus; however, because the program keeps the sport fun and challenging, the children continued to improve over time and eventually became very good swimmers. This result calls into question the wisdom and cost of a standardized pace commonly found in schools and in youth sports.

Mainstream youth sports could learn much from the findings of this study. In recent years there has been an increase in sport specialization and a focus on elite athletes (Aspen Institute Sports & Society Program, 2019), which has resulted in less enjoyment

for the participants and a corresponding decrease in participation (Witt, 2018). Parents in this study reported they know immediately whether their child is not enjoying an activity. If Sports Plus fails to offer an enjoyable experience for a child, it is very likely that child would not be seen again. The message here is that it is possible to create programs and policies that engage even those program participants who are the most at risk of quitting the program. When done effectively, programs can help individuals with ASD realize a sense of belonging and benefit from programs in the same way as neurotypical children benefit.

### **Recommendations for Future Research**

A growing trend can be seen in the research to include those with developmental disabilities as much as possible to ensure they have a representative voice. This should be seen as a positive step for those capable of participating at the necessary level required for research, although it risks skewing the data even further toward those considered high functioning and away from those with verbal or intellectual deficits. This current study includes data from individuals who would not meet the criteria used in the Renwick et al. (2019) study precisely for that reason.

As the differences are vast among individuals who share the ASD label, those differences pale in comparison to individuals who are labeled as developmentally disabled. The research on developing a framework of belonging for individuals with developmental disabilities faces a daunting task if the goal is an all-inclusive framework. If such an endeavor is excessively cumbersome for meaningful findings, future research should consider separate frameworks for each segment under the developmental

disability umbrella. This study demonstrates the need for future research to develop a separate framework of belonging for individuals with ASD.

The research on physical activity has found several benefits that likely contributed to those realized by the children in this study. The potential benefits include psychosocial development, a sense of belonging, improved social skills, and a reduction in anxiety (Blumenthal et al., 2007; Fraser-Thomas & Côté, 2006; Memari et al., 2017; Ratey, 2010). The relative contribution to benefits from physical activity are unknown; therefore, future research on recreational programs that have implemented similar instruction and intervention strategies not involving physical activity would provide a valuable model with which to compare.

Despite having some neurotypical siblings in attendance, the participants in the Sports Plus programs would be considered a segregated versus inclusive group. This is not intentional based on a philosophy of the organization, but rather the outcome of programs designed to serve a unique and underserved demographic. It is noteworthy that belonging was experienced in a segregated group, but segregation is not thought to have been necessary for participants to realize belonging. This finding requires further attention in future research. The review of the literature elucidated a vast dearth of interdisciplinary research surrounding the subject of ASD. For example, individuals in the field of education have conducted a great deal of research on inclusive pedagogy and intervention strategies, but we have yet to understand the psychological or neurological impact of the same methodologies or their impact on the health-related quality of life for those students outside the classroom. Research in the field of psychology has only recently discovered the unique presentation of anxiety in individuals with ASD (Kerns et

al., 2014); however, these findings have not been included in DSM-5, and it is unclear if they will be included in the next edition (APA, 2013). The long-term psychological or neurological impact of an individual with ASD whose anxiety disorder goes undetected is currently unknown. That type of research would certainly inform the speed at which this new information is shared with those connected with individuals on the spectrum.

Researchers in the field of physical education have studied the behavioral impact on students with ASD after physical activity, but it is unclear to what extent changes in behavior are due to neurological, physiological, or psychological factors. Studies in this area would inform potential intervention strategies for parents and educators.

The latest CDC research shows that males are four times more likely to be diagnosed with ASD than females (CDC, 2018). Researchers have not ruled out the possibility that symptoms manifest differently between the genders, which could impact the accuracy of diagnoses among the female population. Future research should explore gender to ensure that females are not being underdiagnosed.

The concept of acceptance was critical in establishing a sense of belonging in this study. The general nature of acceptance and how it is experienced by children with ASD would further inform the topic of belonging. Research on acceptance could be complimented by exploring the nature of the attrition that has occurred at Sports Plus. Although the attrition percentage for first time participants is reportedly less than 5%, the nature of the attrition for this group is unknown.

This qualitative research focused on the meaning of parents observing their children realizing a sense of belonging, but additional research is needed to understand the impact of belonging on the lives of individuals with ASD. What is the impact to

academics in a classroom that fosters a sense of belonging versus one that does not? How does such a classroom impact a child with anxiety? Does this classroom impact a student's social skills, friendships, and view of school in general? How does an entire academic career with such classrooms impact a student's future? These questions are worthy topics for future research.

### **Conclusion**

The benefits realized through youth sport participation are exceedingly important to a child's development. As such, the large and vulnerable population of those with ASD should not be excluded. From an economic perspective, overwhelming evidence can be found that a demand exists for such programs by parents of children with ASD. A 2013 study by Alexander and Leather found that 89% of such parents want their children to be involved in organized physical activity programs more than two hours per week. Unfortunately, similar to public schools, youth sports and recreation programs struggle to integrate youth with ASD (MacDonald et al., 2011; Reid, 2005; Schleien et al., 2014). The result is a supply/demand disconnect in which as few as 12% of children with ASD are physically active (Memari et al., 2015). Parents, or their children with ASD, can do little to fit into programs that fail to accommodate their unique needs; therefore, it is imperative programs "meet them where they are."

This research sheds light on the profound impact of a sense of belonging on a child with ASD. While they experience belonging differently and from different sources, realizing a sense of belonging allows them to be themselves and to be vulnerable in the group in order to learn new skills and to grow as individuals. This research also elucidates the sad reality that environments in which these children and young adults

realize a sense of belonging are the exception rather than the norm. This disproportionate reality contributes to increasing rates of isolation with age, which reduces physical activity even further (Ayvazoglu et al., 2015).

Generalizability of the findings in a quantitative sense is not appropriate; however, it is expected that the findings would be transferrable to most children and youth, whether or not they have ASD. Additionally, the body of research in this area could be advanced if the sample of participants was expanded to be representative of other geographic areas and the socioeconomic status and education levels of the general population. The literature also would be enhanced if individuals who are at lower functional levels with more severe symptoms are more broadly included in research conducted with children with ASD.

This qualitative research adds to the body of literature exploring the benefits realized by children and youth with ASD who participate in youth sports and the challenges faced by those who seek to participate. The findings confirm previous research that youth sports can provide benefits of enjoyment, physical fitness, psychosocial development, and motor skills acquisition (Fraser-Thomas & Côté, 2006; Seefeldt et al., 1993; Wells et al., 2008; Wiersma, 2000). This study also reveals the essence of a parent who observes their child with ASD realizing a sense of belonging. Educators, administrators, and policymakers should review the profound impact on a child and increase efforts to achieve an outcome of belonging to use as a metric of program success in the future.

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## APPENDIX A

### IRB APPROVAL LETTERS



University of Colorado  
Colorado Springs

APPROVED

Expiration Date: Exempt  
2020-073-01

Institutional Review Board (IRB) for the Protection of Human Subjects

Date: 01/21/2020

**IRB PROTOCOL NO.:** 2020-073

**Protocol Title:** THE LIVED EXPERIENCES OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN AN ADAPTIVE SPORTS PROGRAM: A QUALITATIVE EXPLORATION

**Principal Investigator:** Darrin Steele

**Faculty Advisor if Applicable:** Sylvia Mendez

**Application:** New Submission

**Type of Review:** Exempt 2

**Risk Level:** Minimal

**Renewal Review Level (If changed from original approval) if Applicable:**

**This Protocol involves a Vulnerable Population:**

**Expires:** Exempt

\*Note, if exempt: If there are no major changes in the research, protocol does not require review on a continuing basis by the IRB. In addition, the protocol may match more than one review category not listed.

**Externally funded:**

**OSP #: Sponsor:**

Thank you for submitting your Request for IRB Review. The protocol identified above has been reviewed according to the policies of this institution and the provisions of applicable federal regulations. The review category is noted above, along with the expiration date, if applicable.

Once human participant research has been approved, it is the Principal Investigator's (PI) responsibility to report any changes in research activity related to the project:

- The PI must submit all protocol, recruitment, advertising, and consent form amendments/revisions to the IRB for approval.
  - The IRB must approve these changes prior to implementation.
- Changes in funding status must be reported to the IRB as quickly as possible to ensure funding requirements are met.
- If you are a student, note that it is required to include the IRB approval letter to the library when you submit the dissertation/thesis.
- The PI must promptly inform the IRB of all unanticipated serious adverse events (within 24 hours). All unanticipated adverse events must be reported to the IRB within 1 week (see [45CFR46.108\(a\)\(4\)\(i\)](#)). Failure to comply with these federally mandated responsibilities may result in suspension or termination of the project.
- The PI must submit a Continuing Review/Renewal application to the IRB at least **10 business days prior to expiration** to continue projects beyond the expiration date (if applicable).
- Notify the IRB when the study is complete.

If you have any questions, please contact Research Compliance Program Director in the Office of Sponsored Programs and Research Integrity at 719-255-3903 or [irb@uccs.edu](mailto:irb@uccs.edu)

Thank you for your concern about human subject protection issues, and good luck with your research.

Sincerely yours,

Zek Valkyrie, Ph.D.  
IRB Reviewer

**Institutional Review Board (IRB) for the Protection of Human Subjects**

Date: 04/03/2020

**IRB PROTOCOL NO.:** 2020-073  
**Protocol Title:** THE LIVED EXPERIENCES OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN AN ADAPTIVE SPORTS PROGRAM: A QUALITATIVE EXPLORATION  
**Principal Investigator:** Darrin Steele  
**Faculty Advisor if Applicable:** Sylvia Mendez  
**Application:** Request for Change  
**Type of Review:** Exempt 2  
**Risk Level:** Minimal  
**This Protocol involves a Vulnerable Population:**  
**Expires:** Exempt  
\*Note, if exempt: If there are no major changes in the research, protocol does not require review on a continuing basis by the IRB. In addition, the protocol may match more than one review category not listed.  
**Externally funded:**  
**OSP #: Sponsor:**

Thank you for submitting your Request for IRB Review to **use remote platform (video or telephone) for interviews**. The protocol identified above has been reviewed according to the policies of this institution and the provisions of applicable federal regulations. The review category is noted above, along with the expiration date, if applicable.

Once human participant research has been approved, it is the Principal Investigator's (PI) responsibility to report any changes in research activity related to the project:

- The PI must submit all protocol, recruitment, advertising, and consent form amendments/revisions to the IRB for approval.
  - The IRB must approve these changes prior to implementation.
- Changes in funding status must be reported to the IRB as quickly as possible to ensure funding requirements are met.
- If you are a student, please note that it is required to include the IRB approval letter to the library when you submit the dissertation/thesis.
- The PI must promptly inform the IRB of all unanticipated serious adverse events (within 24 hours). All unanticipated adverse events must be reported to the IRB within 1 week (see [45CFR46.103\(b\)\(5\)](#)). Failure to comply with these federally mandated responsibilities may result in suspension or termination of the project.
- The PI must submit a Continuing Review/Renewal application to the IRB at least **10 business days prior to expiration** to continue projects beyond the expiration date (if applicable).
- Notify the IRB when the study is complete

If you have any questions, please contact Research Compliance Program Director in the Office of Sponsored Programs and Research Integrity at 719-255-3903 or [irb@uccs.edu](mailto:irb@uccs.edu)

Thank you for your concern about human subject protection issues, and good luck with your research.

Sincerely yours,

Samantha Christiansen Ph.D.  
IRB Reviewer

## APPENDIX B

### INTERVIEW PROTOCOL

Script prior to interview:

*I'd like to thank you for taking the time to participate in the interview aspect of my research. As I have mentioned, my study seeks to understand the essence of a parent experiencing their child realizing a sense of belonging while participating in Sports Plus programs. The aim of this research is to document the experience and what that experience means to parents of these kids. Our interview today will last approximately 45–60 minutes, during which I will be asking you about your experiences with your child as it relates to a sense of belonging. [review aspects of consent form]*

*I sent you a consent form indicating that I would like your permission to audio record our conversation. Are you ok with me recording our conversation today? \_\_Yes \_\_No*

*If yes: Thank you! Please let me know if at any point you want me to stop recording or keep something you said off the record.*

*If no: Thank you/or letting me know. I will only take notes of our conversation.*

*Before we begin the interview, do you have any questions? (Discuss questions]*

*If any questions (or other questions) arise at any point in this study, you can feel free to ask them at any time. I would be more than happy to answer your questions and I will provide you with my personal contact information before I leave today.*

Interview questions:

#### Demographics

*Youth Participants:*

- 1. Gender*
- 2. Age*
- 3. ASD classification*
- 4. Comorbid conditions*
- 5. Public or private school*
- 6. Traditional or specialized school*
- 7. Race/ethnicity/religion*
- 8. Number of programs with Sports Plus*
- 9. Regular physical activity outside of Sports Plus*

*Parents:*

- 1. Gender(s)*
- 2. Age*
- 3. Marital status*
- 4. Socioeconomic status (SES)*
- 5. Education level(s)*
- 6. Race/ethnicity/religion*

### Study-Related

1. *Can you tell me a little about your child?*
2. *Why did you decide to enroll your child in Sports Plus?*
3. *What, if anything, does your child say about Sports Plus?*
4. *What does 'belonging' look like for your child?*
5. *You indicated that your son/daughter experienced a sense of belonging with Sports Plus. Can you recall the first time you witnessed this?*
  - a. *Can you describe it?*
  - b. *How did that make you feel?*
  - c. *What were you thinking as you watched?*
  - d. *Did you discuss it with anyone? How did you describe it?*
6. *Has your son/daughter participated in any other youth sports programs?*
7. *Did you see the same sense of belonging?*
8. *What was different?*

### Belonging Framework Questions

1. *What are the ways in which you have experienced your child interacting with individuals with similar interests as him/her?*
2. *What are the ways in which you have experienced your child interacting with individuals with similar experiences as him/her?*
  - a. *Does your child have any friends?*
  - b. *Has your child expressed a desire to have friends?*
3. *What are the ways in which you have experienced your child engaging in social relationships through conversation?*
4. *What are the ways in which you have experienced your child engaging in social relationships through doing things with others?*
5. *What are the ways in which you have experienced your child contributing to the Sports Plus community?*
6. *What are the ways in which you have experienced your child being a member of the Sports Plus community?*
7. *What are the ways in which you have experienced your child being a friend?*
8. *What are the ways in which you have experienced your child recognizing differences between themselves and peers?*
9. *What are the ways in which you have experienced your child effectively communicating the kind of support he/she needs from coaches in Sports Plus?*
10. *What are the ways in which you have experienced your child effectively communicating the support he/she needs from administrators in Sports Plus?*
11. *What are the ways in which you have experienced your child effectively communicating the kind of support he/she needs from peers in Sports Plus?*