Participation in Recreational Activities in School Age Children with High Functioning Autism and Their Peers

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Statement of Authorship

I certify that I am the primary author of the manuscript contained in this these. I claim full responsibility for the content and style of the text included herein.

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List of Abbreviations

ABAS-2	Adaptive Behavior Assessment System, 2nd edition
ANOVA	Analysis of Variance
ASD	Autism Spectrum Disorder
CAPE/PAC	Children Assessment of Participation and Enjoyment/Preference for Activities of Children
CAPE	The 'Children Assessment of Participation and Enjoyment' component of the CAPE/PAC
PAC	The 'Preference for Activities of Children' component of the CAPE/PAC
CASL	Comprehension Assessment of Spoken Language (2 subtests)
CDC	Center for Disease Control
CSHN	Children with Special Health Care Needs
CP	Cerebral Palsy
DD	Developmental Disability
HFA	High Functioning Autism
HRQL	Health Related Quality of Life
GARS-2	Gilliam Autism Rating Scale, 2nd edition
ICC	Intra-class Correlation
ICF	The International Classification of Functioning, Disability and Health
ID	Intellectual Disability
MANOVA	Multiple Analysis of Variance
MID	Minimally Important Difference
PD	Physical Disability
PDD-NOS	Pervasive Developmental Disorder Not-Otherwise Specified
PedsQL	Paediatric Quality of Life 4.0 Generic Core Scales
PI	Primary Investigator
PTO	Parent Teacher Organization
QOL	Quality of Life
SD	Standard Deviation
SRS	Social Responsiveness Scale
TD	Typically Developing Peers
TONI-3	Test of Nonverbal Intelligence, 3rd edition
VABS-2	Vineland Adaptive Behavior Scales, 2nd Edition
VDH	Vermont Department of Health
WD	Without Disability
WHO	World Health Organization
WISC-3	Wechsler Intelligence Scale for Children 3rd ed.

Abstract

The patterns of recreational engagement and health related quality of life (HRQL) of school-aged children with High Functioning Autism (HFA) are not well understood. The objectives of this study of children with HFA and their typically developing peers were to: compare their recreational profiles; identify child-based factors related to recreational participation; and, estimate their HRQL in relation to recreational engagement. Additionally, the psychometric properties of the *Children's Assessment of Participation and Enjoyment/ Preference for Activities of Children* (CAPE/PAC) for this population were estimated.

A cross sectional study of a volunteer sample of children with HFA (n=30) and peers (n=31) recruited through multiple Vermont sources was conducted. Data collection took place during 2-3 home visits. Standardized and psychometrically sound tools were used to independently confirm diagnosis and ascertain children's characteristics. The CAPE/PAC and Pediatric Quality of Life 4.0 were the primary outcome measures.

The groups were similar on key characteristics except those related to the HFA attributes. Children with HFA differed from peers in terms of diversity ($p=.002$), social aspects ($p=.006$) and locations ($p<.001$) of recreational participation. The two groups were not statistically different in personal intensity ($p=.684$), enjoyment ($p=.239$) or preferences ($p=.788$) of recreation. Children with HFA had significantly poorer HRQL whether reported by themselves ($p<.001$) or their parents ($p<.001$), although disagreement (ICC=-.075) between children and parental scores suggested that they had different viewpoints about children's HRQL. The study results have value for parents, clinicians, teachers and administrators in understanding and supporting the recreational engagement of children with HFA.

Abrégé

Nous avons une compréhension limitée des habitudes de loisir et de la qualité de vie liées à la santé (QVLS) des enfants d'âge scolaire ayant un trouble envahissant du développement (TED) de haut niveau. Cette étude avait pour objectifs: de comparer les habitudes de loisir; d'identifier des facteurs chez l'enfant qui sont associés aux habitudes de loisir; et, d'estimer la QVLS et la relation de celle-ci avec les habitudes de loisir des enfants ayant un TED de haut niveau et de leurs pairs présentant un développement typique. De plus, la validité et la fiabilité du *Children's Assessment of Participation and Enjoyment/ Preference for Activities of Children* (CAPE/PAC) chez les enfants ayant un TED de haut niveau furent estimées.

Au Vermont, un échantillonnage volontaire d'enfants ayant un TED de haut niveau (n=30) et de leurs pairs (n=31) a été établi à partir de diverses sources afin de procéder à cette étude transversale. La collecte de données s'est faite lors de 2 ou 3 visites. Des outils d'évaluation standardisés, valides et fiables furent utilisés pour confirmer les critères d'inclusion. Le CAPE/PAC et le *Paediatric Quality of Life 4.0* étaient les deux outils d'évaluation des principaux concepts étudiés.

Les participants dans les deux groupes présentaient des caractéristiques similaires sauf celles reliées au diagnostic de TED. Les enfants ayant un TED de haut niveau participaient dans un nombre plus restreint d'activités de loisir ($p=.002$), avec un nombre plus limité d'autres personnes ($p=.006$) et généralement plus près de chez eux ($p<.001$). Cependant, les deux groupes n'étaient pas statistiquement différents en ce qui a trait à la fréquence de participation moyenne dans les activités de loisir ($p=.684$), leur plaisir à participer à ces activités ($p=.239$) ou leur désir d'y participer ($p=.788$). Les enfants ainsi que leurs parents ($p<.001$) jugeaient que les enfants ayant un TED de haut niveau avaient une QVLS significativement moindre que leurs pairs.

Malgré ce fait, l'accord entre la QVLS jugé par les enfants et leurs parents étaient presqu'absent (ICC=-.075) indiquant qu'ils évaluaient des aspects différents de la qualité de vie. Les résultats de cette étude pourront aider les parents, les cliniciens, les enseignants et les administrateurs à comprendre les habitudes de loisir des enfants ayant un TED et leur permettront de mieux soutenir les enfants dans cette participation.

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I would like to dedicate this thesis to my mother (1948-2009) who would have been so proud. She did not want anything, least of which her illness, to slow my progress. I love you always.

Preface

The life of those with disabilities has never been an easy one. In the Middle Ages, individuals with disabilities endured poor treatment including imprisonment, abuse, and sterilization. Many of these practices continued until the middle of the last century. In consequence, the willingness to include individuals with disabilities as fully participating members of western society is relatively recent, largely the result of a groundswell of advocacy and research. This paradigm shift over the last few decades has been linked with the civil rights movement, which expanded in the early 1970s to include individuals with disabilities. In 1975, the first United States special education law (i.e., Education of All Handicapped Children Act) was enacted. Since then, individuals with disabilities and their families have continued to advocate for their educational rights as well as for the right to participate in and have physical access to their communities. This struggle has included the fight for the right to participate in community recreational resources.

Recognized as a fundamental right in article 23 of the United Nations on the Convention on the Rights of the Child (1989) and included in the No Child Left Behind Act (2001), the Individual with Disability Education Improvement Act (2004) and the Rehabilitation Act (1992), recreation is an area of social participation that has been found to have great benefits in terms of quality of life and satisfaction with life. It includes involvement in activities in both formal and informal domains such as sports, going to the movies, crafts and reading. However, people with disability experience lifelong barriers to recreational participation. In children with disability, where play and recreation are primary experiences known to contribute to development, these barriers are most problematic.

Autism Spectrum Disorder (ASD), a condition characterized by difficulties in communication and social abilities, emerges in early childhood. Participation in everyday activities is affected. Children with ASD have language impairment, repetitive play schemes, difficulty with learning basic academics and unusual or disruptive behaviors. Even children with ASD with more advanced cognitive and language abilities may have difficulty carrying on reciprocal conversations, may misinterpret social situations and appear socially awkward or aloof. Even though they may have average or above average intelligence, as they grow older, these children with autism and high cognitive and linguistic abilities have trouble sustaining relationships, succeeding in higher education, living independently and securing long-term employment.

Difficulties with communication, social skills and interactions, and play skills are the characteristics of ASD, which are best scientifically understood. By contrast, difficulties experienced with participation in recreational activities are relatively unexamined. Parents, teachers and therapists have all observed that recreational participation is restricted in children with ASD. These children seem to have less varied and more solitary recreational pursuits than their peers. However, empirical knowledge of this important component of meaning in life is lacking. As a result, society remains unprepared to meet the needs of this growing group of citizens with disability.

ASD has received a great deal of attention in mass media from novels and TV shows, ranging from characters known or suspected to have the condition, to movie stars promoting ASD-focused interventions with limited evidence. The public is concurrently exposed to legitimate advertisement campaigns about the prevalence and signs of ASD. All work conducted about ASD in North America, whether it is intervention, education or research, is carried out in

the context of this media attention and resultant population awareness. Consequently, some of the issues found in mass media are briefly discussed here as a backdrop for the study conducted. Not all of these issues are strictly limited to the recreational participation of children with ASD.

ASD has had a rapid increase in prevalence from 1 per 10,000 live births in the mid 1990s to1 per 110 live births in 2006 in the United States (Center for Disease Control and Prevention, 2009). Alarmist websites have called this phenomenon an epidemic; however, the accuracy of this opinion is in question (Fombonne, 2001b; Wazana, Bresnahan & Kline, 2007). In an effort to explain this increase, experts in the field point to the intensification of efforts placed on early diagnosis. The use of expanded diagnostic criteria has also resulted in an increased rate of positive identification, particularly of those with milder symptoms, such as children with High Functioning Autism (HFA). In addition, the heightened awareness of parents and health professionals to the signs and symptoms of ASD has resulted in an increased rate of referrals for diagnostic inquiry. Unfortunately, the rationale presented above is only moderately reassuring, as it actually does not fully explain the apparent change in prevalence of ASD.

The cost of ASD to society is high. In Britain, the lifetime cost per individual with ASD is estimated at 1.23 million pounds and per individual with HFA at 800,000 pounds (Knapp, Romeo & Beecham, 2009). In the United States, Ganz (2007) estimated a lifetime per capita societal cost of $3.2 million for ASD. In Vermont, where this study was conducted, the cost of education in 2005 for 550 students with ASD was 11 million dollars, twice that for typically developing students (McFadden & Bruno, 2006; Vermont Department of Education, 2007). With an apparently rising prevalence, these figures point to the soaring societal financial costs to come.

With the increased attention on ASD, great efforts are being made to understand its etiology. A number of theories, many spurious, have been proposed. Current etiological research focuses primarily on the identification of a group of genes that, when coupled with environmental factors, result in the manifestation of the characteristics of ASD. To date, no definitive cause has been identified. Scientists are now referring to ASD as a syndrome.

A number of controversial interventions have arisen in relation to these suspected causes of ASD such as nutrition-based interventions (e.g., casein free and mega-vitamins doses), sensory-based interventions (e.g., auditory integration training and Wilbarger protocol) and chelation therapy. Although their theoretical foundations are questioned and their efficacy has not yet been established, these controversial interventions have found a following. Powerful organizations such as Defeat Autism Now (www.defeatautismnow.com) promote them, train clinicians in their use and bring awareness to families of their existence. Part of the difficulty with these unproven interventions is that they are not harmless; they can be costly to families financially and emotionally trying. As families' resources are finite, these unproven interventions can impact a family's ability to benefit from more proven interventions. More validated approaches include social stories, use of visual supports, peer-mediated interventions, discrete trial learning, joint attention training and exercise. Most of these focus on the functional characteristics of ASD and aim to improve activity and participation.

In this context of mass media awareness of prevalence, cost, etiology and intervention, this study was designed to address a missing component of the ASD puzzle. Its purpose was to contribute to our understanding of the complexities and unknowns surrounding the participation in recreational activities of children with ASD. Specifically, the study set out to describe the patterns of recreational participation of children with HFA as compared to their typical age-peers

and to begin to explore any pertinent child-related factors that might help parents, teachers and therapists expand these. Further, the health-related quality of life of these children was investigated in connection with their recreational participation. In this study, the children themselves were asked to describe their recreational participation, whereas, in the earlier literature, the report of parents or other adults has been relied upon to gather information on children with HFA.

This thesis is divided into seven chapters. Chapter 1 is the literature review providing the background to the study. It is an expansion of the literature review written for an article published by this author that describes methods to enhance recreational participation in children with ASD using a collaborative-family centered approach (Potvin, Prelock & Snider, 2008). It includes information about prevalence, etiology and characteristics of ASD and HFA; describes the importance of participation in recreation for all members of society including individuals with HFA; and links recreation and quality of life for the HFA population.

Chapter 2 describes the rationale or purpose for the study, the primary and secondary objectives as well as the hypotheses that were posed before the study was conducted.

Chapter 3 presents the methodology used, the inclusion criteria, the recruitment process, the measurement tools employed and the process used to collect data.

Chapter 4 contains the data analysis. Descriptive data are presented first, describing both groups, followed by statistical analysis presented according to the research questions.

Chapter 5 is a discussion of the implications of the results and their interpretation in relation to the literature. It also contains study limitations and suggestions for future studies.

Chapter 6 summarizes the thesis and Chapter 7 provides the overall conclusions of the project.

Chapter 1: Literature Review

The International Classification of Functioning Disability and Health (ICF), an inclusive model of health, highlights participation as an important outcome for medical, rehabilitation and educational interventions. Participation in recreation has been found to have great benefits, in terms of quality of life and life satisfaction, across society. As play and recreation are primary childhood experiences known to contribute to development, difficulties in these areas are more problematic for children with disability who typically experience difficulty with recreational participation throughout their life. Autism Spectrum Disorder (ASD), a disabling condition that emerges in childhood is believed to affect children's recreational participation. In truth, little is known about the patterns of recreational pursuits and interests of children with ASD.

This chapter provides the background literature to support the study conducted. Specifically, the literature defining HFA's characteristics, etiology, prevalence and impact are presented. The literature describing the importance and patterns of recreation, and factors affecting this in individuals with disability is reviewed with a focus on children with HFA. The literature describing health related quality of life (HRQL) in individuals with disability and those with HFA is included. Finally, a review of considerations about measuring recreational participation and HRQL in this population is discussed. Because of the limited literature on certain relevant constructs for school-aged children with HFA, when pertinent, the literature pertaining to children with ASD and, in some cases, to adults with HFA and ASD will be presented. As a whole, the literature provides the background and highlights the importance of this study, which set out to describe patterns of recreational participation in children with High Functioning Autism (HFA), a sub-group of ASD, as compared to typical peers and to begin to explore factors related to recreation in this population.

1.1 High Functioning Autism: Definition, Prevalence and Etiology

1.1.1 Definition: high functioning autism and autism spectrum disorder.

The American Psychiatric Association has described a group of five life-long conditions under the category of Pervasive Developmental Disorders (PDD): Autistic Disorder, Asperger's Disorder, PDD Not-Otherwise Specified (PDD-NOS), Childhood Disintegrative Disorder and Rett Disorder (American Psychiatric Association [APA], 2000). Three of these disorders, Autistic Disorder, Asperger Disorder and PDD-NOS are commonly referred to as Autism Spectrum Disorder (ASD) (Charman, 2002; Simpson, 2005). Children with ASD have, primarily, a triad of deficits in: (a) language, (b) social development, and (c) abnormal restrictive, repetitive and stereotyped behaviors and interests (APA, 2000).

ASD constitutes a highly variable neurodevelopmental syndrome (Geschwind, 2008). Children diagnosed with ASD differ significantly in the range of severity of autistic symptoms, (Geschwind, 2008; Rutter, 2003) and in measured intellectual abilities (Allik, Larsson, & Smedje, 2006). Clinically, the term High Functioning Autism (HFA) is used to describe individuals who exhibit less severe ASD symptoms and/or average or above average intellectual ability. In research, HFA is commonly used to portray individuals whose intelligence is assessed to be within or above the normal (Allik et al., 2006; Landa & Goldberg, 2005; Verté, Roeyers, & Buysse, 2003). Experts are debating whether Asperger Disorder and HFA are distinct disorders (Howlin, 2003; Nayate, Bradshaw, & Rinehart, 2005). In their review of the literature, Witwer and Lecavalier (2008) found that studies on the diagnostic features of Asperger and HFA did not support a distinction between these labels. The Neurodevelopmental Disorders Work Group revising the 5th edition of the *Diagnostic and Statistical Manual (DSM) of Mental Disorders* is

proposing the removal of Asperger Disorder from the upcoming DSM-V (Swedo, 2009). For the purposes of this literature review and this study, Asperger Disorder is grouped with HFA.

1.1.2 Prevalence of autism spectrum disorder and high functioning autism.

The DSM-IV notes a prevalence for autistic disorder of 1 in 2000 to 5000 (American Psychiatric Association, 1994). The Center for Disease Control and Prevention (CDC) estimated the 2000 prevalence of ASD at 1 in 150 (Center for Disease Control and Prevention, 2007) showing a large increase over 1994. The CDC surveillance report noted a further increase in prevalence of 60% for boys and 48% for girls between 2002 and 2006 with the most recent prevalence estimates of ASD being 1 in 110 (Center for Disease Control and Prevention, 2009). Researchers are investigating whether the rise in prevalence represents a true increase in the number of individuals with this condition. The literature explains part of the increase in prevalence through: diagnosis of ASD in people of normal intelligence; broadening of the diagnostic criteria; improved case ascertainment at an earlier age; diagnostic substitution; change in special education law eligibility categories; and, increased community awareness about ASD (Center for Disease Control and Prevention, 2009; Fombonne, 2001a, 2005; Leonard et al., 2010). Some studies, however, have suggested that changes in diagnosis practices do not explain fully the increased prevalence over the last two decades (King & Bearman, 2009; Wazana et al., 2007) suggesting that other factors contributed to the increased prevalence (Leonard et al., 2010).

The estimation of HFA prevalence is less precise as it is impeded by its different definitions. However, using intellectual abilities as the criteria for defining HFA, comparisons between studies can be made which indicate a rise in the proportion of HFA within ASD. Studies have estimated that in the 1990s, the percentage of HFA in ASD ranged between 20 and 25% (Fombonne, 2005; Gillberg, 1999; Rinehart, Bradshaw, Brereton & Tonge, 2002). Fombonne

(2005) has stated that after 1998 it increased to approximately 44%. The CDC found that in 2006 69% of children with ASD had an IQ>70, thus meeting the criteria for HFA (Center for Disease Control and Prevention, 2009).

1.1.3 Etiology and pathogenesis of autism spectrum disorder.

It is assumed that the etiology and pathogenesis of HFA mirrors that of ASD. Since substantially more research was undertaken to determine the etiology of ASD than HFA, that literature was reviewed for this section. ASD is viewed as a syndrome with many etiologies. Some of them are known, such as co-occurrence of ASD and a genetic disorder like Tuberous Sclerosis, whereas other etiologies are emerging (Benvenuto, Moavero, Alessandrelli & Manzi, 2009). There is considerable genetic heterogeneity in ASD with new unique-genetic mutations being found in a large number of individuals (DiCicco-Bloom, et al. 2006; Geschwind, 2008). A great number of chromosomes have been associated with ASD; some appear to directly cause the symptoms associated with this diagnosis (Abrahams & Geschwind, 2008). In other instances, environmental factors, such as toxins and viral infections, seem to interact with the chromosomal abnormalities to cause ASD (DiCicco-Bloom, et al. 2006; Pardo & Eberhart, 2007).

At this point, unique pathology at the molecular, cellular or system level has not been found across the population of individuals with ASD (Geschwind, 2008). There appears to be general agreement that, in many instances, the cause of ASD occurs early in gestation (Gillberg, 1999; Pardo & Eberhart, 2007; Rodier, 2002). Our understanding of the pathogenesis, from early injury to the brain to the symptoms of ASD, is growing. In review articles, scientists seem to agree that ASD is a disorder of neuronal-cortical organization with a combination of inter-regional disconnectivity, disruption of white matter tracts, synaptic dysfunction and signaling pathway disorder with pathogenesis potentially varying between individuals (Abrahams &

Geschwind, 2008; Benvenuto et al., 2009; Pardo & Eberhart, 2007). Some believe that ASD may not be a single disorder (Benvenuto et al., 2009), whereas others question whether the different etiologies of ASD have a common pathogenesis (Abrahams & Geschwind, 2008).

A thorough literature review of brain differences in ASD is beyond the scope of this chapter. Key findings are provided here as a foundation for the discussion of body functions and structures, activity limitations and restriction in participation, which is presented later. The anatomy of the brain of individuals with ASD has been studied extensively. Great variability in findings exists between studies. Stanfield and colleagues (2008) postulate that the heterogeneity of symptoms of individuals with ASD may explain some of this variation. Systematic reviews of the literature and meta-analysis also point toward patterns of usual brain differences in ASD.

A meta-analysis by Redcay and Courchesne (2005) found that, compared to same age peers, head circumference in individuals with ASD was slightly reduced at birth, enlarged in early childhood and followed by normalization by adulthood. Another meta-analysis of brain MRIs of individuals with ASD did not find a statistically significant relationship between age and total brain volume (Stanfield et al., 2008). There is also evidence that ASD is associated with increased cerebellar volume (Stanfield et al., 2008). Specifically, an increase in white matter volume (Courchesne et al., 2001), abnormal cerebellar lobules VI and VII (Stanfield et al., 2008), reduced amount of grey matter of the cerebellar vermis and decreased Purkinje cells (Amaral, Schumann & Nordahl, 2008) have been reported. The Purkinje cells provide information from the cerebellum to other parts of the brain (Nayate et al., 2005).

Abnormalities of the cerebral cortex including increased cerebral hemispheric volume (Stanfield et al., 2008), increased cerebral gray and white matter (DiCicco-Bloom et al., 2006), abnormal patterning of the mini-columns and differences in the frontal lobes are reported

consistently in the literature (Amaral et al., 2008; Polleux & Lauder, 2004). Similarly, brainstem differences in ASD are widely documented in individual studies. Gillberg (1999) noted that the brainstem-cerebellum circuitries were abnormal in ASD. Another recent study found decreased brainstem gray-matter volume (Jou, Minshew, Melhem, Keshavan & Hardan, 2009). Despite numerous early studies that found brainstem differences, these were not reported in two recent meta-analyses (Amaral et al., 2008; Stanfield et al., 2008). Thus, either the small number of studies or design flaws in these studies prevent them from demonstrating patterns of brainstem difference when grouped in a meta-analysis.

Finally, two recent meta-analyses identified differences in the amygdala, the caudate nucleus and the corpus callosum. A statistically significant increase in volume of the caudate was found (Stanfield et al., 2008). In younger children, enlargement of the amygdala and reduction in size of the corpus callosum was reported (Amaral et al., 2008; Stanfield et al., 2008).

In summary, considerable research has been conducted to determine the etiology and pathogenesis of ASD. It is clear that genetic differences that are heterogenic in nature are causes of ASD, however, it seems there are environmental factors that may be at play, at least in some cases. The characteristics of ASD at present are thought to be a disorder of neuronal-cortical organization with pathogenesis potentially varying between individuals. This heterogeneity is also found in the brain anatomy of individuals with ASD, although through meta-analysis, patterns of brain differences are emerging including differences in the amygdala, the caudate nucleus, and the corpus callosum.

1.1.4 Impairments associated with high functioning autism.

The ICF conceptualizes the relationships between body structures and functions, activities, and participation in the context of health-related states (WHO, 2002). At the level of

body structure, the differences in the relative size and volume of brain structures and head size found in individuals with HFA are described above. At the level of body functions, a large body of research describes the three core deficit areas of HFA: language, social development, and abnormal restrictive, repetitive and stereotyped behaviors. The key impairments of HFA that may impact recreational participation are described in the following paragraphs.

While the basic aspects of communication are largely preserved in children with HFA, (Blacher, Kraemer & Schalow, 2003), impairments in higher-level verbal and nonverbal communication skills such as pragmatic abilities have been observed (Harris et al., 2006; Landa & Goldberg, 2005). Pragmatic language "is the ability to use language in a specific context and for a specific purpose" (Young, Diehl, Morris & Hyman, 2005, p. 63). In combination with their other impairments, the impaired communication skills of children with HFA may impact their recreational participation.

HFA is also associated with impairments in social cognition, the ability to recognize, understand and act on socially relevant information and to act appropriately within a social situation (Adolphs, 2001; Bauminger, Shulman & Agam, 2003). This involves the ability to correctly interpret verbal and nonverbal social and emotional cues, as well as to accurately understand another person's mental state (i.e., theory of mind) (Bauminger, 2002). While individuals with HFA are able to initiate social interactions, they often struggle to sustain and integrate the affective and cognitive aspects of a social interaction (Bauminger, et al., 2003; Blacher et al., 2003). The quality of their social interactions is, therefore, limited compared to typically developing peers (Macintosh & Dissanayake, 2006). Impairments of social cognition impact the social relationships of children with HFA, in particular, their interactions with peers (Bauminger, et al., 2003; Blacher, et al., 2003).

Difficulties with components of executive function such as planning, flexibility and working memory have also been described (Landa & Goldberg, 2005). Some authors state that the impairment of executive function forms the basis for poor communication skills. This is related to social functioning (Landa & Goldberg, 2005) and difficulty with pragmatic language (Landa & Goldberg, 2005; Young, et al., 2005).

In addition to these differences in body structures and functions, individuals with HFA experience limitations in activities and participation, which include restrictions in recreational participation (Gutstein & Whitney, 2002). For example, a child's impairments in pragmatic, non-literal language and social cognition may limit his interpersonal interactions with peers and may be associated with difficulty in modulating his own behavior (Belini, 2004; Landa & Goldberg, 2005). This may result in restricted participation in group sports and clubs, fewer friendships and limited opportunities for outings with peers. Figure 1 illustrates the interactions between the core deficits of HFA and participation in recreational activities using the ICF model (WHO, 2001). The literature describing recreational participation in individuals with HFA follows.

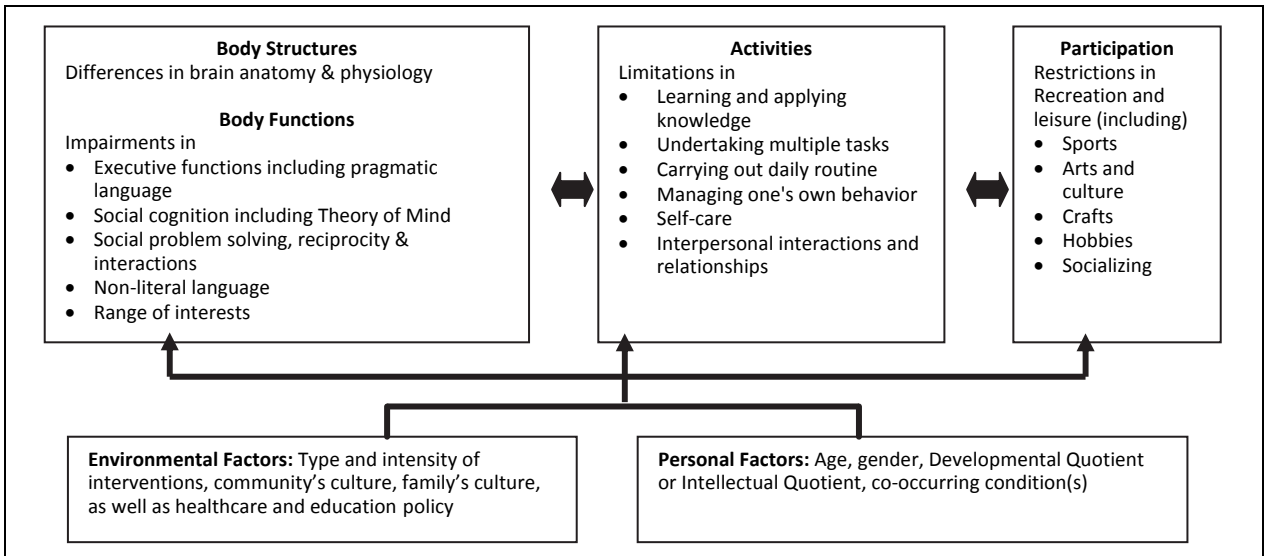

Figure 1. Model of participation in recreational activities in children with High Functioning Autism

1.2 Recreational Participation: Definition, Measurement and Experience of Individuals with Disability and High Functioning Autism

1.2.1 Definition and importance of recreation.

Participation represents "the complete range of domains denoting aspects of functioning from both an individual and a societal perspective" (WHO, 2002, p. 8). Recreation and leisure, a participation domain of the ICF, includes involvement in formal and informal activities such as play, sports, relaxation, going to the theater, crafts, playing music and tourism (WHO, 2001). Recreational participation is recognized as a fundamental right by the United Nations in article 23 of the Convention on the Rights of the Child, included as a complement to academic programs in the No Child Left Behind Act of 2001 (P.L. 107–110), included as a related service in the Individual with Disability Education Improvement Act of 2004 (P.L. 108-446), and mandated in the United States to be accessible for all individuals through the Rehabilitation Act (P.L. 102-569).

Recreational participation has extensive benefits for children with and without disability. In the general population of older children, recreational participation, primarily down-time and leisure activities that are social in nature, have a positive impact on mental health (Passmore, 2003). Recreation can reduce behavioral and emotional disorders, help develop social relationships and friendships, improve physical and mental health, and help children develop their interests (King et al., 2003; Mactavish & Schleien, 2004; Rae-Grant, Thomas, Offord, & Boyle, 1989; Wilson & Arnold, 1997). This is particularly beneficial for children with HFA who have a higher prevalence of anxiety, depression and loneliness than typically developing peers (Bauminger et al., 2003; Belini, 2004; Gillott, Furniss & Walters, 2001; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000).

Recreational participation is also associated with an improvement in family relationships and family life satisfaction (Mactavish & Schleien, 2004). This is of primary importance for families of children with HFA as mothers of these children report having poor physical and mental health (Allik et al., 2006; Gray, 2003) and their siblings report having poor quality of life (Verté et al., 2003). Moreover, participation in recreational activities is related to an increased quality of life and improved life satisfaction, both determinants of health and wellbeing (Law et al., 2004).

1.2.2 Experience of individuals with disability with recreational participation.

Studies report that both adults and children with disability experience participation restrictions (Bent, Molloy, Chamberlain & Tennant, 2001; Mancini, Coster, Trombly, Timothy, & Heeren, 2000; Wagner et al., 2002). Diminished and less varied recreational participation are found in children with disability, which negatively impacts children in the long-term (Faison-Hodge & Porretta, 2004; King et al. 2003; Mancini et al., 2000). A systematic review of studies of children with motor disability, found decreased social activities, social engagement and community-based activities compared to typically developing peers (Shikako-Thomas, Majnemer, Law & Lach, 2008). While children with motor disability differ from peers, the specific diagnosis and degree of disability are not statistically related to recreational participation. In contrast, demographic, environmental and functional characteristics do show a relationship to recreational participation (Law et al., 2004; Shikako-Thomas et al., 2008). In other disability groups, such as those with mental health disorders, recreational participation of childhood is less well understood, although a small body of research is emerging (Cowart, Saylor, Dingle & Mainor, 2004; Desha & Ziviani, 2007).

1.2.3 Patterns of participation in recreational activities in autism spectrum disorder and high functioning autism.

The body of literature about participation in recreation for those with ASD and HFA is meager although increasing. Considering that HFA is a subgroup of ASD, both bodies of literature describing recreational participation will now be presented.

Orsmond, Krauss and Seltzer (2004) conducted a cross-sectional study (n = 235) of adolescents and adults with ASD, although most participants (78.7%) were 21 years of age or less. They found that the mothers of these individuals with ASD reported walking or "getting exercise" as the most frequent recreational activity (Orsmond et al., 2004). They also noted that approximately half of the individuals with ASD engaged in a hobby and between one and two-thirds participated weekly in at least one recreational activity (Orsmond et al., 2004). In a population-based study, which surveyed parents of children with special needs, Wagner and colleagues (2002) found decreased participation in recreational activities for children with ASD as compared to peers with other disabilities. For example, one third of the children with ASD never visited friends, two-thirds never received phone calls and about 12% had no out-of-school interactions with friends (Wagner et al, 2002). A cross-sectional study based on a United State national sample found that children with ASD (n=82; ages: 3-17) were less likely to participate in religious services, organized activities, and community services than children with Attention Deficit Hyperactivity Disorder (ADHD; n=191) and typically developing peers (n=13398) (Lee, Harrington, Louie & Newschaffer, 2008). Another cross sectional study (peer n=90, ASD n=65, and intellectual disability (ID) n=30), based on parents' reports, found that children with ASD and ID participated in significantly fewer social and recreational activities than typically developing peers (Solish, Perry & Minnes, 2010). They also found that children with ASD were

engaged with fewer children when participating in social and recreational activities whereas they participated in significantly more social activities with their parents and other adults (Solish et al., 2010).

The construct of friendship is related to patterns of recreational participation. There is growing literature describing the difficulties of people with HFA in having meaningful friendships. Cross sectional studies found that children with ASD had fewer friends than children with other psychiatric diagnoses (Bastiaansen, Koot, Ferdinand & Verhulst, 2004), typically developing peers (Koning & Magill-Evans, 2001; Solish et al., 2010) and children with intellectual disabilities (Solish et al., 2010). This was also reported in a qualitative retrospective study (n=40) in which parents commented that none of their young school-age children with ASD had a deep reciprocal friendship whereas by middle school half of the children had a best friend (Church, Alisanski, & Amanullah, 2000). This was confirmed by the findings of Solish and colleagues (2010), noting that significantly fewer children with ASD had a best friend compared to typically developing peers and children with ID. In another study, half of the adolescents and adults with ASD are reported to have no peer relationships (Orsmond et al., 2004). Similarly, in a sample of adults with ASD (n=74), only 9% were reported by their parents as having friends (Saldana et al., 2009).

The studies published to date point to the restrictions in participation in recreational activities for children with ASD, primarily from the point of view of their parents. These studies did not estimate the broad range of recreational activities as they focused on describing friendships and social relationship of individuals with ASD. Two recently published papers have attempted to provide a comprehensive estimate of recreational participation in HFA (Hilton,

Crouch & Israel, 2008; Hochhauser & Engel-Yeger, 2010). A summary of these studies follows and a comprehensive critical appraisal of these articles is available in Appendix B.

Hilton and colleagues (2008) conducted a cross-sectional study of a convenience sample (HFA=52; peers=53; aged 6-12) in mid-western states that used the *Children's Assessment of Participation and Enjoyment/ Preference for Activities of Children* (CAPE/PAC) and *Social Responsiveness Scale* (SRS). The participants' IQ, being in the typical range, was determined by parents' report. On the CAPE component of the CAPE/PAC, a statistically significant difference was found between the two groups for the overall diversity and intensity scores. However, the enjoyment scores were not found to be statistically different. Statistical differences in diversity were found between the two groups in most types of activities (e.g., recreational, physical and social). The HFA group was divided into two groups according to the severity of the symptoms on the SRS and then compared to the typically developing peers. Once again, statistically significant differences were found for the overall scores across all categories (except enjoyment). The study method lacked rigor in not reporting whether the children actually had HFA, as parents' report of intellectual functioning was not confirmed. A limited description of the sample's functioning was provided (i.e., IQ, adaptive function, communication skills, etc.) limiting generalizability. Finally, the researchers did not administer the recreational preference dimension of the CAPE/PAC.

Hochhauser and Engel-Yeger (2010) also conducted a cross-sectional study of a convenience sample of children with HFA (n=25) and peers (n=25) to describe patterns of recreational participation as measured by the CAPE. They conducted their study in three schools in Israel and used a Hebrew translation of the CAPE whose psychometric properties were partially described. They modified the rating of two dimensions of the CAPE from a 5-point to a

2-point scale. Limited children and family characteristics are provided and those provided are not compared statistically, affecting generalizability. They found that peers participated in more activities than children with HFA, although no statistical test was reported. They found the two groups differed statistically on personal and general intensity, social aspect, location and enjoyment of recreational participation overall and for many activity types and domains. The statistically different enjoyment between groups with peers reporting great enjoyment is unlike findings by Hilton and colleagues (2008).

In summary, very few studies of patterns of participation in ASD included children with HFA. Of these, most examined a very limited breadth of recreational activities. Two recently published studies attempted to describe the patterns of recreational participation in children with HFA more broadly, but they both had methodological flaws and inconsistencies in results as described in the previous paragraphs and in details in Appendix B. However, these two studies highlight the importance of researching this topic. The paucity of information describing recreational activities in children with HFA is problematic considering the importance of recreation in human development and quality of life.

1.2.4 Measuring recreational participation in children with disability.

When measuring recreational participation in children with disability, it is essential to use a quantitative measurement tool that not only assesses actual participation but also the importance of and satisfaction of the children with the activity (Bedell & Coster, 2008). This tool should be developed from the perspective of people with disability (McConachie, Colver, Forsyth, Jarvis & Parkinson, 2006). Depending on the purpose of the assessment, the measurement tool can be completed by the child, family member, or other professionals or caregivers in the child's life (Bedell & Coster, 2008). If the child's opinion about their

participation is sought, a measurement tool that allows the child to self-report should be used (McConachie et al., 2006). This tool should be age appropriate and designed to be administered to individuals with various developmental strengths and challenges (McConachie et al., 2006).

A comprehensive review of recreational participation measurement tools yielded a dozen questionnaires, of which half could be used with children. For the present study, a psychometrically sound self-rated comprehensive measure of recreation that children with HFA would be able to complete with support was sought. Excluded were measurement tools requiring a high level of written or verbal language comprehension, having a narrow scope of recreational activities being measured and/or weak psychometric properties, such as, the *Leisure Questionnaire* (Passmore & French, 2001), the *Occupational Therapy Assessment of Leisure Time* (Soderback & Hammarland, 1993) and the *Godin Leisure Time Activity Scale* (Godin & Shephard, 1997). The *Paediatric Activity Card Sort (*Mandich, Polatajko, Miller & Baum, 2004) met most of the characteristics that were sought, but its psychometric properties were emerging at the time that the study was designed and it included fewer recreational activities than the *Children's Assessment of Participation and Enjoyment/ Preference for Activities of Children* (King et al., 2004), which was chosen as the best measurement tool of recreational participation.

The CAPE/PAC (King et al., 2004) is used to estimate a child's participation outside of school. The construct is measured from the child's perspective. The majority of the CAPE/PAC items (46 of 55) fall under the recreation and leisure sub-domain of the ICF. The items that fall outside this ICF sub-domain are generally related to the major life areas sub-domain (e.g., getting help for schoolwork, volunteer work, and paid jobs) or the domestic life sub-domain (e.g., doing chores, making food, shopping and taking care of pets). Thus, although the CAPE/PAC estimates some broader aspects of participation, it is primarily a measure of

recreational participation (Bedell & Coster, 2008; Hochhauser & Engel-Yeger, 2010; King, Petrenchik, Law & Hurley, 2009; Shikako-Thomas et al., 2008).

The CAPE/PAC was used in 12 published studies, primarily in children with motor disability, although children with HFA were included in two studies (Table 1). The CAPE/PAC's psychometric properties have been described for children with motor disabilities but not specifically for children with HFA. This is a necessary step since reliability and validity of a measurement tool's scores must be established for specific populations and interpretation (Cook & Beckman, 2006; Streiner & Norman, 2003).

1.2.5 Minimally important difference of the *Children's Assessment of Participation and Enjoyment/ Preference for Activities of Children*.

The minimally important difference (MID) of a tool is the smallest detectable difference important to a child, parent or clinician (Norman, Wyrwich & Patrick, 2007). The literature describes several methods to estimate MID including 0.5 effect size, half of one standard deviation (SD), half of a standard error of measurement, and use of a Delphi group (Beaton, Boers & Wells, 2002; Gross & Wyrwick, 2008; Klassen, Miller & Fine, 2004; Revicki, Hays, Cella & Sloan, 2008). Norman and colleagues (2003) demonstrated mathematically that these different approaches to measuring MID yield very similar values equating approximately a half SD. Their systematic review of the HRQL literature found that the mean MID value across studies was also approximately a half a SD (Norman et al., 2003). They suggest that this is a reflection of the minimal change that humans are able to detect and that it is likely similar in tools measuring other constructs (Norman et al., 2003). In collaboration with the CAPE/PAC developers, McNeil and colleagues (2009) determined that half a SD represented a meaningful difference for the CAPE/PAC.

Table 1

Overview of studies using the *Children's Assessment of Participation and Enjoyment/Preference for Activities of Children* as an outcome measure.

Reference	Population	n=	Design	Study Purpose	CAPE/PAC used as
Law, Finkelman et al., 2004	Motor disabilities	427	Cross-sectional	Diagnostic and participation	Primary outcome
Law, King et al., 2006	Motor disabilities	427	Cross-sectional	Describe participation	Primary outcome
Engel-Yeger, Jarus & Law, 2007	Jewish and Druze children	30	Cross-sectional	Culture and participation	Primary outcome
King et al., 2007	Motor disabilities	427	Cross-sectional	CAPE construct validation	Primary outcome
Law, Darrah et al., 2007	CP (GMFCS I-V)	104	RCT	Efficacy of rehabilitation intervention	Secondary outcome
Verschuren, et al., 2007	CP	30	RCT	Efficacy of exercise training	Secondary outcome
Hilton, Crouch & Israel, 2008	HFA vs. peers	52	Cross-sectional	Patterns of out-of-school participation	Primary outcome
Imms, Reilly, Carlin & Dodd, 2008	CP	108	Cross sectional	Participation	Primary outcome
Majnemer, et al., 2008	CP (GMFCS I-V)	67	Cross-sectional	Patterns of leisure participation	Primary outcome
Scholtes, et al., 2008	CP (GMFCS I-III)	21	RCT	Efficacy of lower extremities strength training	Secondary outcome
Engel-Yeger, Jarus, Anaby & Law, 2009	CP and Peers	52	Cross-sectional	Patterns of participation and gender's impact	Primary outcome
King, Petrenchik, Law & Hurley, 2009	PD and WD	781	Cross-sectional	Enjoyment and preferences of recreational participation	Primary outcome
Imms, Reilly, Carlin & Dodd, 2009	CP	108	Cross sectional	Factors impacting recreational participation	Primary outcome
McNeil, Wilson, Siever, Ronca & Mah (2009)	Children living in vulnerable neighborhoods	360	Longitudinal	Outreach support and recreational participation	Primary outcome
Hochhauser & Engel-Yeger (2010)	HFA vs. peers	50	Cross-sectional	Recreation and sensory processing	Primary outcome

Key. CAPE/PAC = *Children's Assessment of Participation and Enjoyment/Preference for Activities of Children*; CP = Cerebral Palsy; GMFCS = *Gross Motor Function Classification System*; RCT = Randomized Clinical Trial; HFA = High Functioning Autism; PD = Physical disabilities; and WD = without disabilities.

1.3 Factors Affecting Participation in Recreational Activities

King and colleagues (2003) organized the factors associated with the participation of children with disability in recreational activities into a comprehensive, strength-based and socio-ecological model. A visual depiction of this model, which identified factors in three categories: the child, the family and the environment, is presented in Figure 2. A very small number of studies identified factors affecting participation in recreation in children with ASD and none in children with HFA (Figure 3). This gap points to the need to explore determinants of recreational participation in children with HFA. One study cannot address all potential factors promoting or impeding recreation. As a first step, child-based factors affecting recreational participation in this population should be investigated with a focus on the interplay of the core deficits (communication and social skills) associated with this disorder.

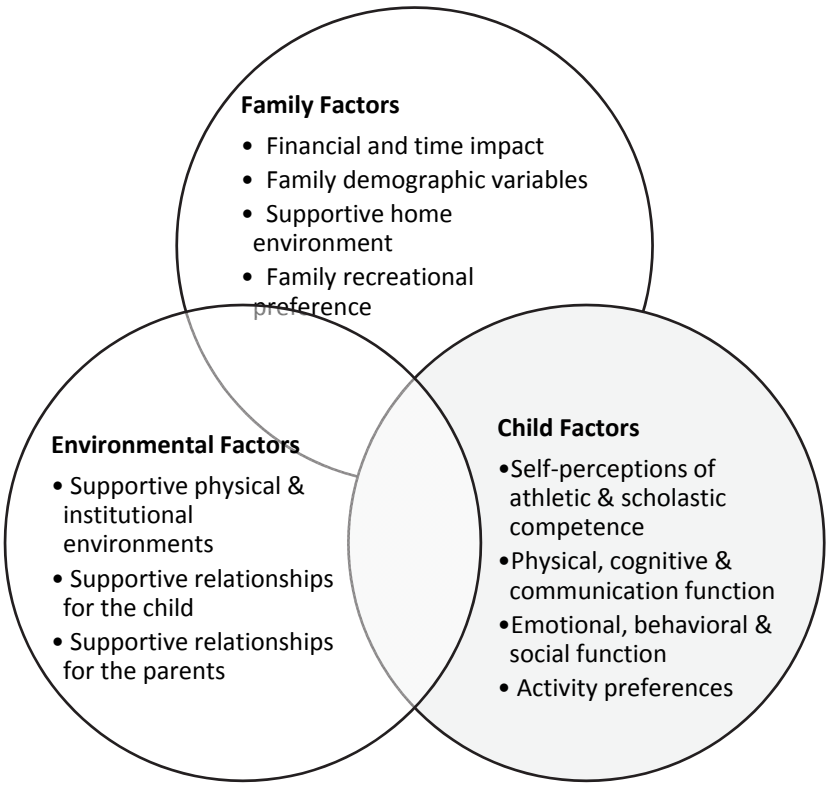

Figure 2. Factors Affecting Participation of Children with Disability (adapted from King and colleagues [2003])

Figure 3. Non-Exhaustive List of Factors Affecting Participation in Children with Autism Spectrum Disorder

1.4 Health Related Quality of Life

There is interplay between the constructs of quality of life and recreational participation. As noted previously in this chapter, participation in recreational activities is a determinant of wellbeing and it contributes to people's sense of living a life of quality (Law et al., 2004). On the other hand, as explained later in this section, recreation is a domain measured when researchers are estimating the quality of life of children with disability (Davis et al., 2006). Thus a study of recreational participation of children with HFA should include an exploration of their quality of life. The following section focuses understanding the construct of quality of life and the related

construct of health-related quality of life broadly and in children with disabilities including those with HFA.

1.4.1 Definitions of quality of life and health related quality of life.

Quality of life (QoL) is a construct whose importance is widely recognized. It has been studied in many fields including economics, social sciences and medicine (Cummins, 2005; Verdugo, Schalock, Keith & Stancliffe, 2005). Unfortunately, the breadth of meaning of the QoL construct in these fields has hindered the establishment of a single definition of QoL (Coghill, Danckaerts, Sonuga-Barke, Sergeant & ADHD European Guidelines Group, 2009; De Civita et al., 2005; Saxena & Orley, 1997). As a result, many definitions are found in the literature. The World Health Organization definition reads: "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHOQOL Group, 1997, p. 1). In spite of the lack of a single definition, domains of adult QoL have been agreed upon as: interpersonal relationships, social inclusion, personal development, physical wellbeing, rights, environment, family, recreation and leisure, and safety/security (Verdugo et al., 2005).

Within the field of medicine, the term health-related quality of life is more commonly used, narrowing the QoL construct to components that can be realistically influenced by health conditions and services, thus more easily measured (Wood-Dauphinee, 1999). HRQL suffers from the same lack of a single definition as QoL. However, scholars have listed the key principles of the HRQL construct stating that it "(1) is multidimensional and influenced by personal and environmental factors and their interactions; (2) has the same components for all people; (3) has both subjective and objective components; and, (4) is enhanced by self-determination, resource, purpose in life and a sense of belonging" (Cummins, 2005, p. 700).

The definition and domains of QoL in children are not identical to the adult domains (Ravens-Sieberer, Patrick and the CHI Consensus Group, 2002). Davis and colleagues (2006) systematically reviewed the pediatric literature identifying five distinct types of QoL definitions: functioning, position in life, functioning and feelings about functioning, existence measured objectively or subjectively, and discrepancy between actual and ideal self. De Civita and colleagues (2005) have broadly defined QoL in children as being comprised of their feeling about the impact of their conditions and treatment on different aspects of their life. There is a lack of agreement of QoL domains to be measured in children (Coghill et al., 2009). Davis and colleagues (2006) in their systematic review identified the most commonly used QoL domains: emotions, social interactions, medical/treatment, cognition, activities, school, family, independence/autonomy, pain, behavior, future, leisure, and body image. These authors noted that many pediatric QoL measures are actually measuring functional or health status. Dickinson and colleagues (2007) caution against using only function as measures of QoL in children. HRQL specifically measures health and functioning (Majnemer, Shevell, Law, Poulin & Rosenbaum, 2008). Thus, some of this apparent disagreement may be more related to which construct is being measured. It has been demonstrated that QoL and HRQL are related but different constructs which should be measured separately (Rosenbaum, Livingston, Palisano, Galuppi & Russell, 2007).

Even with the difficulties in defining the construct, HRQL has become one of the priority outcomes in health services delivery (Majnemer et al., 2008). In the following section, considerations for QoL and HRQL measurement in individuals with various diseases and disabilities are reviewed. Although many authors draw clear boundaries between QoL and HRQL, other authors group them together or use either term to measure the same domains. In the

following sections the term QoL will be used unless the literature reviewed makes a clear distinction between the two constructs.

1.4.2 Measuring Quality of Life.

Scholars agree that it is essential to measure QoL to understand the degree to which individuals, especially those with disability, experience a life of quality (Verdugo at al., 2005). However, the value of measuring this construct depends on whether it can be done reliably and with validity (Coghill et al., 2009). Consequently, there has been an attempt to determine the key aspects to consider in measuring the construct of QoL.

One aspect of measurement is the type of tool used. There is disagreement in the literature between using a generic or condition-specific measurement tool. Some authors state that condition-specific QoL measures should not be used as they focus on the disorder instead of the broad range of human experiences (Cummins, 2005). On the other hand, condition-specific measures allow for improved responsiveness and sensitivity (Coghill et al., 2009; Kirshner & Guyatt, 1985) and may more accurately capture the impact of intervention. The intended interpretation of the scores, rather than the type of measurement tool, is paramount in estimating the usefulness of tools from a validity point of view (Kane, 1992). A generic measure enables the researcher to compare people with different conditions amongst themselves and to the general population (Coghill et al., 2009).

Another aspect of QoL measurement is its subjectivity. A self-report of QoL is more closely related to what the respondents think and feel about a situation than to what they are able to do (Coghill et al., 2009). When self-reporting QoL, respondents seem to consider relevant experiences and judge these against an internal standard (Rapkin & Schwartz, 2004). The attitude toward a domain of QoL may change over time in relation to adaptation or coping

(Wood-Dauphinee, 1999). This response shift may reflect a change in an internal standard including values and an internal meaning of QoL (Rapkin & Schwartz, 2004).

In measuring QoL, determining the best respondent for a specific situation is essential. In view of its subjective nature, self-reporting of QoL, in contrast to proxy reporting, is preferred in all people including those with disability and children (De Civita et al., 2005; Rapkin & Schwartz, 2004; Ravens-Sieberer et al., 2002; Verdugo et al., 2005). The accuracy of proxy reporting in place of the reporting of the person with disability is questioned (Verdugo et al., 2005). The low correlation between self and proxy reporting may not denote a lack of accuracy in the proxy reporting but, rather, a difference in perspective or rating of different aspects of QoL (White-Koning, et al. 2005). Consequently, it has been suggested that obtaining ratings of QoL from multiple perspectives may be optimal as, for example, the insights of parents into their children's QoL can add depth to the information gathered from the children themselves (Coghill et al., 2009; De Civita et al., 2005; Verdugo et al., 2005; White-Koning et al. 2005).

A final consideration in measuring QoL in adults and children with disability is the type and degree of disability. Attention should be given to developmental age, motor skills and language abilities (Coghill et al., 2009; Ravens-Sieberer et al., 2002). The type and format of questions asked should maximize the individuals' abilities (White-Koning et al. 2005). When measuring QoL in people with intellectual disability, the assessor should use adaptations to allow the person to understand the questions and express his/her opinion (Verdugo et al., 2005). Individuals with specific impairments may have additional difficulties with reporting QoL in some domains. For example, children with autism may have difficulty reporting on peer relationships (Coghill et al., 2009).

Many aspects of QoL measurement found in the literature are directly applicable to the

doctoral study described in coming chapters. Specifically, since a comparison was to be made between children with HFA and their peers, a generic HRQL measure was chosen; to increase the depth of information obtained, both parent and child-self reporting of HRQL was obtained; and accommodations were made during the administration of the measure as the participants presented with varied levels of receptive and expressive language as well as reading abilities. After reviewing available pediatric HRQL measures, the *Pediatric Quality of Life Inventory* (PedsQL) was chosen as it had the key characteristics needed for this study. A number of studies have estimated MID and/or effect size for this measure in various populations but no one value was agreed upon (Huang et al., 2009; Limbers, Heffer & Varni, 2009; Seid et al., 2010; Varni, Burwinkle, Seid & Skarr, 2003). It was determined that Norman and colleagues' (2003) widely agreed upon MID estimate of half a SD for HRQL measurement tools would be used (Klassen, Miller & Fine, 2004; White-Koning et al., 2007) in this study.

1.4.3 Health related quality of life in children with disability.

Interest is growing for estimating QoL and HRQL in childhood (Guyatt, Juniper, Griffith, Feeny & Ferrie, 1997; Ravens-Sieberer et al., 2002), in particular, for children with medical conditions such as pain, cancer, and hemophilia (Bullinger, von Mackensen & Haemo-QoL Group, 2003; Chang & Yeh, 2005; Petersen, Hagglof & Bergstrom, 2009). QoL and HRQL are also being studied in children with varied disabilities. The complete review of this literature is beyond the scope of this chapter, however key studies whose findings contribute to understanding of HRQL in children with disabilities are reviewed.

Sawyer and colleagues (2002) conducted a population-based study (n=3597) of HRQL in children (aged 6-17 years) with mental health disorders based on parental report using the *Child Health Questionnaire*. They studied children with ADHD (n=308), depression (n=53), conduct

disorder (n=35), a combination of mental and physical disorder (n=80) and non-disordered peers (n=2507). They found that children with depressive disorder and ADHD were statistically different on all the HRQL domains measured compared to non-disordered peers. Children with conduct disorders had statistically different HRQL compared to peers in all domains excluding those related to physical health and activities. Children with mental disorders had significantly poorer HRQL in many domains than children with physical disorders. Finally, according to parents' perception, there was an additive negative effect on many domains of HRQL of children having a combination of mental and physical disorders.

Varni, Limbers and Burwinkle (2007) compared the HRQL of clinical samples of children with chronic conditions (n>2500) such as diabetes (n=331), asthma (n=165) and psychiatric disorders (n=310 including PDD n=28), and children with CP (n=245) using the PedsQL. They found that, per parent report, children with psychiatric conditions had the second lowest HRQL compared to ten other diagnostic groups, whereas per child-report, they were the fourth lowest (Varni et al., 2007). They did not find statistically different reports of HRQL by gender or ethnic/racial groups (Varni et al., 2007). They found no statistically different self-reported or parent reported HRQL between subgroups of children with psychiatric disorders (Varni et al., 2007). Finally, they found that, per parent reports, children with CP had significantly lower HRQL in most domains compared to children with psychiatric conditions (Varni et al., 2007) which differs from Sawyer and colleagues (2002).

Lau, Chow and Lo (2006) studied parent-reported HRQL in a random sample of children with developmental disability (DD; n=133) and typically developing peers (TD; n=132). The DD group included children with motor disabilities, sensory disabilities and others conditions such as

children with autism (n=32). They found that the children in the DD group had a significantly lower psychosocial health summary and overall PedsQL scores than the TD group.

Dickinson and colleagues (2007) conducted a European population-based study (n=500) using KIDSCREEN, a self-report measure of QoL. They found that children with CP reported QoL similar to neuro-typical peers for all QoL domains. Socio-demographic factors explained 4-13% of variation in QoL. Impairments (e.g., gross and fine motor) explained 3% of the variation in QoL and were not significantly associated with: psychological wellbeing, self-perception, social support and peers, school environment, financial resources, and social acceptance. Children with speech and language disorders reported poorer relationships with parents. Another study of QoL and HRQL in a cohort of 203 adolescents with CP of all motor function levels found that level of motor impairment was not related to degree of QoL but was related to HRQL scores (Rosenbaum et al., 2007). Varni and colleagues (2007) also found a decrease in HRQL with increased severity of impairments in children with CP.

These scientifically sound studies illustrate the depth of information that can be gained from studying QoL and HRQL in children with disability. HRQL reports appear to be different among children with different disorders. Consequently, limited inference can be made from studies of HRQL and QoL with other developmental disabilities to children with ASD and HFA. The studies reviewed reinforce previous literature noting that HRQL reports vary when parents or children are reporting on this construct. Although the majority of QoL and HRQL studies of childhood, which were developed early in the study of this construct, were proxy report questionnaires (Landgraf & Abetz, 1997, 2001, 2002; Landgraf, Abetz & Ware, 1999, 2003), more recent measures place children as the respondent in terms of rating their own QoL and HRQL (Iannaccone, 2002; Varni, Seid, Knight, Uzark & Szer, 2002).

1.4.4 Quality of life and health related quality of life in individuals with autism spectrum disorder.

There is little literature describing QoL in individuals with ASD (Burgess & Gutstein, 2007; Pimley 2007). An extensive review found four published studies in children and adolescents, and seven adult studies. Two of the articles discussed studies about children in broader diagnostic groups that included some children with ASD. The studies, both described in the previous section, did not analyze results for the children with ASD separately and thus were not included in this section.

A cross-sectional study of QoL in children (ages: 6-18) with various psychiatric disorders and peers without a diagnosis (total n=310; ASD n=28) found no difference in children ratings of QoL between diagnostic groups using the PedsQL (Bastiaansen et al., 2004). Like Sawyer and colleagues (2002), they found differences in QoL per parent reports for certain mental health disorders groups (Bastiaansen et al., 2004). Parents' rating of the QoL of their children with ASD's was statistically lower on psychosocial health than that of those 'without a diagnosis', and on psychosocial health and emotional functioning compared to those with other mental health diagnoses (Bastiaansen et al., 2004). This is similar to findings of Limbers, Heffer and Varni (2009) in their study of 22 children (ages 6-12) with Asperger Syndrome. These children had statistically significant lower HRQL than normative healthy children ($p<0.001$) with cognitive and social functioning domains showing the largest point difference between the two groups.

Three of the seven adult studies were poorly designed intervention studies using measurement tools akin to quality of life to estimate differences between employment and living milieu (Garcia-Villamisar, Wehman &Navarro, 2002; Gerber, Baud, Giroud & Galli Garminati,

2008; Persson, 2000). A study of a cohort of adults with moderate to severe intellectual disability (n=72) found that those with autism (71% of the sample) had significantly lower proxy-scored QoL on community satisfaction (Beadle-Brown, Murphy & DiTerlizzi, 2009). A cross-sectional study of adults with ASD (n=32; ages: 18.4-40.1) found that parents reported that material wellbeing and intimacy with the family were significantly more important and satisfactory than all other domains for their adult-children with ASD (Saldana et al., 2009). These parents reported that intimacy with friends was the least important of the domains (Saldana et al., 2009). Interestingly, only parents' reports were gathered, although 2/3 of the adults with ASD in this study could communicate effectively with their families, thus would likely have been able to self-report on QoL. A cross-sectional study of adults with HFA (n=58; ages: 18-53; IQ≥70) found that the degree of disability did not explain a significant amount of the variance in QoL whereas unmet formal support and perceived informal support did (Renty & Roeyers, 2006). A cross-sectional study of young adults with Asperger (n=12; ages 18-21) found that self-rated QoL was lower than for typically developing peers (n=13) and significant for the social and physical health domains (Jennes-Coussens, Magill-Evans & Koning, 2006).

To date, investigation of this construct in the ASD population is meager in childhood and adulthood. The studies had methodological limitations such use of a normative control group (i.e., confounding bias) and aggregating data of individuals with ASD with that of other mental health disorders which limits the interpretability and generalization of the results. The different QoL measurement tools used and the varied domains of QoL measured within these tools makes comparison between studies difficult. Emerging evidence seems to indicate that children with ASD have poorer QoL than children with other mental health disorders (Bastiaansen et al., 2004; Sawyer et al., 2002). There is also preliminary evidence that in ASD, like in motor disabilities,

the degree of disability does not explain a significant amount of difference in QoL (Renty & Roeyers, 2006; Rosenbaum et al., 2007). Children with ASD had the largest difference from their parents' scores with a correlation of 0.38, when compared to the six other mental health diagnosis groups (Bastiaansen et al., 2004). As theorized by White-Koning and colleagues (2005), this could represent parents and children rating different aspects of QoL. However, Pimley (2007) theorizes that quality of life characteristics may differ for individuals with ASD from those without this disorder. This could partly explain why children with ASD appear to have poorer QoL than those with other disorders. These preliminary findings, coupled with the methodological limitations noted, point to the need to further explore the QoL construct in individuals with HFA.

1.5 Conclusion

High Functioning Autism, a sub-group of ASD, is a life-long highly prevalent neurodevelopmental syndrome. Children with HFA differ from those with ASD in terms of the severity of autistic symptoms and higher measured intellectual abilities. The importance of recreational participation is widely recognized both in international and US laws as well as in the rehabilitation literature. Participation in recreational activities has the potential to support overall health and wellness as well as the development of function in the areas typically impaired in HFA, lessen the impact of HFA on the child, family and society, and promote quality of life and well-being. However, little is known about the broad range of recreational participation of these children. It is important to better understand the patterns of recreational activities (e.g., intensity, diversity and preference) of children with HFA as compared to their peers. Recreation has been found to have great benefits, in terms of quality of life and life satisfaction. However, the

literature about QoL in children with HFA and ASD is sparse; even fewer studies where children with these conditions were rating their own quality of life were found.

Identifying the child-based factors that influence patterns of recreational participation was important. To identify which child factors to investigate the complex array of abilities and impairments in communication, social, executive function and social cognition, the close interrelatedness of these constructs and the lack of agreement about the causal pathways between them were considered. A combination of broad based factors (i.e., communication and social skills) and a more narrowly focused factor (i.e., social cognition) were chosen for this study. It is thus essential to gain a deeper understanding of the recreational patterns, and factors affecting recreation and QoL of children with HFA. Chapter 2 expands on this providing the rational and objectives for this study.

Chapter 2: Study Rationale and Objectives

Children with High Functioning Autism are those who perform at the highest functioning range of Autism Spectrum Disorder, a lifelong developmental condition that adversely affects performance in social skills, communication and behavior. HFA results in participation restriction across a wide range of domains. One such domain, which may be affected in HFA, is engagement in recreation. Participation in recreational activities is an essential part of human performance, which provides benefits throughout the lifespan (Specht, King, Browwn & Foris, 2002). Preliminary evidence suggests that, in individuals with ASD, participation in recreational activities is limited (Bastiaansen et al., 2004; Wagner et al., 2002). Unfortunately, the literature describing specific patterns of recreation for individuals with HFA is sparse and methodologically weak. The opportunity to participate in recreational activities may support functional development in areas that are typically impaired (i.e., social skills, communication, behavior) and may promote quality of life and well-being. If so, the impact of the condition on both the child and family could be potentially lessened (Mactavish & Schleien, 2004; Wilson & Arnold, 199). Unfortunately, the factors that may impede or enable participation in recreational activities in children with HFA have yet to be identified. Furthermore, limited information about the quality of life of these individuals is available.

This thesis proposed that gaining knowledge about the patterns of participation in recreational activities of children with HFA was crucial to the comprehensive understanding of this condition. It postulated that obtaining this information from the children with HFA themselves was key, as adults may have misunderstood and/or misinterpreted their recreational engagement profile and preferences. Further, to guide strategies for intervention, it is essential to identify the child-based factors, which mediate participation in recreational activities in this

population. Finally, linking this information to children's reported quality of life provides a more comprehensive outlook. This knowledge can be used by teachers, clinicians and parents to address intrinsic as well as extrinsic barriers to children's participation in recreation (King et al., 2003).

2.1 Objectives

Primary objective: The primary objective of this study was to compare the patterns of participation in recreational activities, specifically in terms of the social activity-type, diversity, intensity and preference of elementary and middle school age children with HFA to those of typically developing peers. To further describe the recreational patterns of children with HFA, the study aimed to develop a recreational profile for these children. A recreational profile, that provides information beyond the statistical analysis, helps clinicians define typical patterns of recreational participation and guides their therapeutic interventions (Linden, Gehrke & Geiselmann, 2009).

Secondary objectives:

Objective 2. Identify child-based factors (i.e., communication skills, social skills and social cognition) related to diversity of recreational participation in children with HFA and typically developing peers.

To support the first two objectives, the study intended to estimate the appropriateness of making inference about the CAPE/PAC scores for children with HFA. Specifically, in children with HFA and their peers to,

Objective 3. Examine whether the CAPE captured the breadth of activities that children engage in (Content validity);

Objective 4. Estimate the test-retest reliability of the CAPE/PAC;

Objective 5. Examine the relationship of the CAPE to the *Paediatric Quality of Life 4.0 (*PedsQL*)* and the Play Time domain of the *Vineland Adaptive Behavior Scales* (VABS-2) (Convergent validity);

Considering the interplay between QoL and recreation, the study aimed to,

Objective 6. Compare the HRQL of children with HFA to that of peers

Objective 7. Examine the association between recreational participation and HRQL in children with and without HFA

2.2 Hypothesis

It was hypothesized that, when compared to peers, children with HFA would (a) participate in fewer socially-based activities (diversity of this activity type); (b) participate in significantly fewer activities (diversity); (c) partake in these activities more frequently (intensity) and (d) show a similar preference for various types of activities. Further, it was hypothesized that children with HFA and their peers would not have significantly different self-rated HRQL. Finally, it was hypothesized that social cognition, social skills and communication skills, in that order, would have the greatest impact on the diversity of recreational activities in children with HFA.

Chapter 3: Methodology

This chapter provides a description of the methodology used for this study. It describes the population under study and the inclusion criteria for participants (section 3.2). A breakdown of sample size estimation is given (section 3.3). Followed by the recruitment process (section 3.4) and summary of participant accrual (Table 2). The measurement tools selected for this study are then described (section 3.5) including an overview of the major characteristics of these tools, their known psychometric properties and use in research (Table 3). The method by which data was collected and analyzed are explained in section 3.6 and 3.7. Finally the ethical considerations of the study are conveyed in section 3.8.

3.1 Research Design

A cross sectional study was conducted to examine the patterns of and factors influencing recreational participation of school-aged children with HFA as compared to typically developing peers. Data were collected during a one-on-one interview with each family in their home or other location convenient to them. The project received ethics approval from the McGill University, Faculty of Medicine Institutional Review Board and the University of Vermont, Institutional Review Board. Addenda to the original protocol were submitted and approved in October 2007 and May 2008. Additionally, applicable ethical approval policies from recruiting agencies were respected.

3.2 Population and Eligibility

The population under study was elementary and middle school-age children with HFA. Children with HFA were eligible to participate in the study if they met the following criteria: (a)

had a diagnosis of Autism disorder, PDD-NOS or Asperger disorder given by a physician or a psychologist with expertise in the diagnosis of autism spectrum disorders; (b) had an intellectual quotient (IQ) of at least 80, or an adaptive functioning score of at least 60; (c) spoke English at home; (d) did not have neurodevelopmental co-conditions, specifically cerebral palsy, Down Syndrome, or other specific genetic syndromes; and, (e) were between 7 and 13 years of age when entering the study. The lower boundary of the age criteria was chosen so that children were older than the average age at diagnosis for children with HFA found in previous studies (Mandell, Listerud, Levy & Pinto-Martin, 2002; Smeeth et al., 2004). The upper boundary of the age criteria was selected so that recreational participation in childhood was specifically studied without venturing into adolescence. The adaptive functioning cut-off score selected was lower than the IQ one as suggested in the literature (Bölte & Poustka, 2002; Klin et al., 2007; Liss et al., 2001).

The comparison group was comprised of typically developing children schooled in Vermont (hereafter referred to as peers). The peers were eligible to participate in the study if they (a) had an intellectual quotient of at least 85; (b) were 7-13 years of age when entering the study; (c) spoke English at home; (d) did not have known neurodevelopmental conditions; and, (e) did not receive special education services[1], have a 504 Plan[2], nor had been followed by an educational support team[3] during the last or current school year.

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[1] Special education services are available to children whose disability interfere to a great extent with their ability to benefit from their regular education program (Individual with Disability Education Improvement Act [IDEIA], 2004).

[2] A 504-plan is a plan of accommodations to support students with disability to benefit from their regular education program which is mandated by the Rehabilitation Act of 1973 (Kaufman, 2002). It applies to students who do not qualify for special education services (IDEIA, 2004).

[3] An educational support team is mandated to assist "teachers in planning and providing accommodation to students in need of classroom supports" who do not qualify for special education or a 504-plan (Education Support Team Goals and Requirement, n.d., p.1).

3.3 Sample Size Estimation

Sample size estimation affects power or the "probability that a statistical test will indicate a significant difference when there truly is one" (Eng, 2003, p. 310). Sample size calculation is based on a number of factors including study design and type and number of outcome variables. The outcome instrument for this study was the CAPE/PAC. Performance on the CAPE/PAC is scored using dichotomous, ranked (i.e., ordinal variable), and discrete (i.e., nominal variable) scales, which are summed creating continuous variables. Summed scores are often treated statistically as normally distributed continuous variables although they may not be normally distributed (Walters, 2004). Considering the summed outcome scores to be continuous for the purpose of sample size estimation may result in an under-estimation of the sample size for the desired power in a study (Walters, 2004). Thus, the sample size estimation for this study was planned to be computed for ordinal variables, which is best done with pilot or historical data. Unfortunately, neither was available in 2006 when the sample size estimate was done. Alternatively, it can be estimated to be somewhere between the sample size needed for continuous and dichotomous variables from which an intermediate sample size is derived (R. Tamblyn, personal communication, May 11, 2006). Considering a power of 0.8, alpha of 0.05, a 5-point different between means and two distinct groups, the sample size for a dichotomous variable is 199 and for continuous variables 22 per group. Considering that there were two primary outcome measures, multiple statistical comparisons planed as well as a regression, an intermediate sample size of 50 children per group was chosen.

In May 2006, when the sample size estimation was conducted, data about the number of children aged 3-22 receiving special education services under the autism eligibility category in Vermont were available for the year 2004 (McFadden & Bruno, 2006). At that time, the

prevalence estimate for HFA in the ASD population was approximately 25% of children with ASD, thus there were approximately 135 students with HFA in Vermont. If all 135 families were invited to participate, considering a high response rate estimate of 65% (Sitzia & Wood, 1998), approximately 88 families would be expected to accept the invitation to participate in the study. However, not all of these families would have a child who met the age eligibility criteria (i.e., 7-13 years of age) to participate in this study. It was thus assumed that a sample size of 50 per group could be reached for this study.

3.4 Recruitment

The recruitment process for the children with HFA was initiated through contact with the agencies and groups in Vermont who diagnose, serve, or support children with HFA and their families. These included the Children with Special Health Needs (CSHN) program of the Vermont Department of Health and Parent-to-Parent of Vermont, and electronic mailing lists of health professionals, special educators and parent support groups for parents of children with ASD in Vermont (Appendix C). This strategy was used to identify a representative sample of children with HFA considering that no registry of children with ASD exists. The recruitment began in July 2007 and was closed in July 2010.

The director of CSHN compiled a list of eligible children using the criteria (a) and (e) described above. The professionals (e.g., psychologists, special educators, physicians, occupational therapists, physical therapists and speech language pathologists) contacted through the electronic mailing lists were asked to identify families who might be eligible to participate in the study. The person working within each agency and the professionals sent letters to the families either by email or mail (Appendix D). The letter described the study, invited families to

participate, and asked them to contact the primary investigator by phone or mail. A self-addressed postage-paid postcard was included with the paper copies of the letter for those who chose to indicate their interest in participating through the mail. The collaborator for each agency was asked to inform the investigator of the number of letters sent out. Families were asked to call or return the postcard even if they did not wish to participate in the study. The principal investigator (PI) telephoned those parents who expressed their intention to participate in the study to (a) answer questions about the study, (b) explain the consent and assent process, (c) screen for eligibility criteria, (d) schedule an appointment to collect data, and (e) assign them a study number for anonymity (Appendix E). The PI kept a record of the number of invitation letters sent out and postcards/phone calls.

Once a large portion of the group of children with HFA was identified, recruitment of peers who lived within the same county begun. Elementary and/or middle schools were selected at random (i.e., simple draw). The principals of the selected schools were contacted, and asked to assist in identifying peers of the same gender and age as the children with HFA for the control group. None of the school principals responded to the voicemail and letter sent to them over a two month period. The principals who were reached directly by phone (n=2) were unable to assist in recruitment for the study. Thus, as planned in the protocol, parents of recruited children with HFA were sent an email, or letter if no email address was available, asking them to share the letters of invitation with other parents of peers. This process yielded only three responses from parents of peers, two of whom were recruited into the study. The other parent, after learning more about the study did not have an interest in participating. The protocol was then amended with IRB approval to include “word of mouth” and organization such as schools’ Parent-Teacher Organizations (PTOs) and Boy Scout groups as a means to recruit peers. Further

amendment of the protocol was done so that recruitment of peers could be done through any county in Vermont not only counties where children with HFA recruited into the study lived. The PI shared information about the study with colleagues from various agencies across Vermont, some of whom shared the information with parents in their community directly and through electronic mailing lists. The families of peers expressed their intention to participate in the study by calling or e-mailing the primary investigator (PI). They were contacted to (a) answer questions about the study, (b) explain the consent and assent process, (c) screen for eligibility criteria by asking a few standard questions and (d) schedule an appointment to collect data.

The recruitment took place over a 36 month period during which a number of methods were used to invite families to participate: seven recruitment emails were sent to nine electronic mailing lists of parents and professionals; professionals requested 32 invitation letters to share with families; the Vermont Department of Education shared the recruitment letter with a tenth large electronic mailing list of parents and professionals working on legislation for children with ASD; a psychologist shared recruitment letters with 40 families of children with HFA who participated in a summer camp; and a mailing was done to 70 families who were identified through the Vermont Department of Health. Table 2 provides information about the number of families who responded to the recruitment invitation, the reason for which some did not participate or complete data collection and the number of participants who completed the study. In spite of the duration, variety and extent of the recruitment strategies we were unable to recruit 50 participants with HFA. The last 3 rounds of invitations yielded little interest to participate in the study. The last 2 participants who were recruited had been diagnosed after the previous recruitment email had been sent confirming that we had reached the maximum number of potential participants.

Two factors were impeded on the expansion of recruitment to additional states and provinces. First, to maintain the methodological strengths of the study, in those states and provinces we would have needed to be able to recruit a representative sample. Second, regional recreational participation patterns (e.g., rural vs. urban areas) may have confounded results. It was determined that the bordering state of New Hampshire which share resources, providers and sociodemographics with Vermont would be appropriate as a location for expansion of recruitment. However no families from New Hampshire responded to invitations to participate in the study. Recruitment was closed in June 2010.

Table 2

Summary of Recruitment, Data Collection Initiation and Data Collection Completion

High functioning Autism Group:	
Families who responded to the invitation by email, phone or postcard	57
- Parents who expressed interest in the study but did not respond to primary investigator follow-up phone calls to determine eligibility to participate	18
- After intake screening questions, child did not meet the intellectual quotient or diagnosis eligibility criteria	4
- Parents declined participation because of family reasons	1
- Child decline to participate	1
Families with whom data collection was initiated	33
- Data collection terminated because of the *Test of Nonverbal Intelligence, 3rd edition* score	1
- Data collection terminated because of the *Gilliam Autism Rating Scale, 2nd edition* score	1
- Parents withdrew from data collection because of increase in child maladaptive behaviors during the period of data collection	1
- Families who completed data collection	30
Peer Group:	
Families who responded to the invitation by email, phone or postcard	32
- Parents who expressed interest in the study but did not respond to primary investigator follow-up phone calls	1
Families with whom data collection was initiated	31
- Families who completed data collection	31

3.5 Description of Measurement Tools Used

The first four tools listed were the independent variables used to confirm participants' eligibility and describe the samples' characteristics. The last two tools were the primary outcome measures for this study and the dependent variables in the statistical analysis.

1. *Gilliam Autism Rating Scale, 2nd edition* (GARS-2) (Gilliam, 2006) is a screening tool developed for use with individuals aged three through 22 to identify autism and estimate the severity of the disorder. The GARS-2 has three subscales: communication, social interaction, and stereotypic behaviors. Each item is rated on a 4-point scale: "never observed", "seldom observed", "sometimes observed", and "frequently observed" with each point on the scale given a quantifiable definition. For example "frequently observed" is defined as "individual behaves in this manner at least 5-6 times per 6-hour period (Gilliam, 2006, p. 17). The recommended cut-off for "probability of autism: possible" is 70 and for "probability of autism: very likely" is 85 (Gilliam, 2006). Since children with HFA comprised the target population for this study, a cut-off score of 70 was chosen for inclusion into the HFA group. For the present study, typical peers scored 69 or less on the GARS-2 to be eligible.

The GARS-2 was normed on a representative sample of 1,107 individuals in the United States. Psychometric properties are adequate (Table 3). The internal consistency of the GARS-2 is excessively high as the optimum range for internal consistency is between 0.70 and 0.90 (Streiner & Norman, 2003). While this is an indication that there may be a great degree of redundancy in the items (Streiner & Norman, 2003), Gilliam (2006) justified the need for high internal consistency as this tool is designed to correspond to the categories of the DSM-IV. The test developer estimated the construct discriminative validity by comparing children with ASD to peers without disabilities, children with mental retardation and peers with multiple disabilities.

Table 3

Overview of the Major Characteristics of the Selected Measurement Tools

Measures	No. of items & scales	Time to complete (min)	Respondent	Time frame	Psychometric properties	No. of articles using tool with ASD
GARS-2	42 items 3 scales	5-10	Parent	Present	Test-retest: 0.88 Internal consistency: 0.94* Discriminative validity: p<0.01 Convergent validity: 0.64 Sensitivity: 0.84-1.00 Specificity: 0.84-0.87 Good content validity	11[#]
TONI-3	Varied number of items 1 scale	20	Child	Not Applicable	Test-retest: 0.91-0.92 Interrater: 0.96 Internal consistency: 0.93*** Good content validity Discriminative validity: significant when expected Concurrent validity: 0.63-0.76	6 TONI-3 = 3 TONI-2 = 3
VABS-2	Varied number of items 4 domains and 11 sub-domains	30-60	Parent	Present	Test-retest: 0.82-0.91[†] Interrater: 0.66-0.75[†] Internal Consistency: 0.80-0.97[†] Good content validity Convergent validity: r as expected Discriminative validity: p<0.01-0.05	68 VABS = 68 VABS-2 = 0 (2nd edition published in 2006)
CASL	Varied number of items 2 scales	20-25	Child	Not Applicable	Test-retest: 0.93 Internal Consistency: 0.64-0.94[^] Good content validity Discriminative validity: p<0.001-0.05 Convergent validity: r=0.72-0.80	3
CAPE/PAC	55 items 5 scales	45-65	Child	Past 4 months	Test-retest: 0.64-0.86** Internal consistency: 0.35-0.84* Good content validity	2
PedsQL	23 items 4 scales	15	Child and Parent	Past month	Internal consistency: 0.84*; ≈0.7* Good content validity Discriminative validity: p<0.05	6

Key. ASD: Austism spectrum disorder; CAPE/PAC: Children Assessment of Participation and Enjoyment/Preference for Activities of Children; GARS-2: Gilliam Autism Rating Scale, 2nd edition; TONI-3: *Test of Nonverbal Intelligence, 3rd edition*; VABS-2: *Vineland Adaptive Behavior Scales*, Second Edition; CASL: *Comprehension Assessment of Spoken Language*; PedsQL: *Paediatric Quality of Life Inventory 4.0* Generic Core Scales. Note. Statistical Tests Used: * Estimated by Cronbach's coefficient alpha; ** Estimated by Intraclass correlation; *** Estimated by Kuder-Richardson formula 20; [^] Estimated using the Rasch split-half method and Spearman-Brown formula; and [†] Range for domains and adaptive composite scale for the children of the age range include in this study; and [#] non-exhaustive list of articles in which the GARS was used as a tool for screening, diagnosis and/or estimating the severity of symptoms.

2. *Test of Nonverbal Intelligence, 3rd edition* (TONI-3) (Brown, Sherbenou & Johnsen, 1997) is a language-free measure of abstract problem solving, ideal for those with language impairments. The examiner primarily uses gestures to administer the tool although simple verbal directions can be given for the practice items. The child responds by pointing. The test items are large designs contained in a picture book printed one item per page. The TONI-3 was normed on 3,451 people residing in the United States. Tested extensively for its psychometric properties, it demonstrated strong correlations ($r < .90$) with broad-based tests of intelligence (Brown et al., 1997). The internal consistency of the TONI-3 can also be considered excessively high. Construct discriminative validity was established by comparing individuals categorized in a variety of groups (e.g. children with giftedness, attention-deficit disorder, reading disability and dyslexia). The TONI-3 is an appropriate measure of intelligence for children with ASD and has been used in research with this population (Edelson, 2005; Edelson, Schubert & Edelson, 1998).

3. *Vineland Adaptive Behavior Scales, Second Edition* (VABS-2) (Sparrow, Cicchetti & Balla, 2006) is a norm-referenced measure of adaptive functioning of individuals from birth to 91 years of age. The VABS-2 is composed of communication, daily living skills, socialization, motor skills, and maladaptive behavior domains. Scales have a mean of 100 and a standard deviation of 15 whereas subscales have means of 15 and standard deviations of three. Subscales can be scored individually, and a total developmental quotient is obtained by summing subscale scores. The VABS-2 does not have gross and fine motor skills norms for children older than 6:11 years old. The Motor domain cannot be computed and motor abilities are not included in the adaptive behavior composite for children older than 6:11 years of age. In this study, although children were 7:0 to 13:9 years old, obtaining information about their motor skills was deemed important. Thus, parents were asked to score the motor questions and for all participants, gross

and fine motor skills were compared to VABS-2 norms for children 6:9 to 6:11 years old. The motor scores were not aggregated into a motor domain nor included in the adaptive behavior composite.

The psychometric properties of the VABS-2 have been studied extensively (Table 3). The content validity of the VASB-2 was determined by various means including item response theory and factor analysis. The discriminative validity of the VASB-2 was estimated by comparing children who were classified in one of seven known impairment groups, including ASD and typically developing peers. To estimate the convergent and divergent validity of the VASB-2, the test developers compared it to a number of other tools including the first edition of the VABS, the *Adaptive Behavior Assessment System* 2nd edition (ABAS-2), *Wechsler Intelligence Scale for Children* 3rd edition (WISC-3), and the *Behavior Assessment System for Children*, 2nd edition. Generally, the VABS-2 correlated more strongly with tools and domains within tools that were measuring similar constructs. For example, the VABS-2 Adaptive Behavior Composite correlates at r=0.7 with the ABAS-2 General Adaptive Composite whereas the VABS-2 Socialization Domain correlated minimally with the WISC-3 Verbal IQ (-0.22).

Children with HFA have deficits in adaptive functioning that are more severe than would be expected from their intelligence scores (Liss et al., 2001). The discrepancy varies greatly between studies, partly as a function of how HFA is defined within the study. The average VABS and VABS-2 scores are between 3 and 40 standard points below the children's IQ scores with most of the studies placing the VABS composite standard score between 55 and 70 (Freeman, Del'PHomme, Guthrie & Zhang, 1999; Jonsdottir et al., 2007; Klin, Saulnier, Sparrow, Cicchetti & Volkmar, 2007; Liss et al., 2001; Sparrow et al., 2006).

4. *Comprehension Assessment of Spoken Language* (CASL) (Carrow-Woolfolk, 1999) is an assessment of oral language designed for those aged 3 to 21. It is comprised of four language categories: lexical/semantic, syntactic, supralinguistic and pragmatic. The supralinguistic category is comprised of four tests: nonliteral language, meaning from context, inference, and ambiguous sentences. The pragmatic category is comprised of one test (pragmatic judgment). The CASL has been normed on 1700 individuals matching the US census for children 3 to 17 years old. The psychometric properties are adequate (Table 3). Discriminative validity was estimated by comparing children who were classified in one of six known impairment groups to typically developing peers. Convergent validity was estimated against the *Test of Auditory Comprehension of Language-Revised*, the *Listening Comprehension* and *Oral Expression Scales*, the *Peabody Picture Vocabulary Test* and the *Kaufman Brief Intelligence Test*.

5. *Children's Assessment of Participation and Enjoyment/Preference for Activities of Children* (King et al., 2004) is used to evaluate a child's participation outside of school activities. It was designed for children with and without disabilities, ages 6 to 18 years old. The psychometric properties were studied in a sample of 427 children with limited physical functioning from Ontario (Law, King et al., 2006). The construct is measured from the child's perspective. In addition to the overall number of recreational activities (diversity) that children participate in, the CAPE/PAC provides other information about dimensions of participation: frequency of participation in the activity (intensity), with whom the child participates in the activity (social aspect), the location (where) the activity takes place, the child's degree of enjoyment in the activity and the child's desire to participate in the activity if he/she could "do anything in the whole world" (preference). Analysis of these dimensions of the CAPE/PAC

provides information about the patterns of recreational participation of children and contributes to their recreational profile.

The dimension of intensity as measured in the CAPE/PAC is a measure of general intensity of participation across all possible activities since the intensity score is divided by the total number of possible activities in which a child can participate (55) not the number of activities in which they actually participate. It is not a measurement of the intensity of their actual recreational participation in activities day to day. Following the example of Hilton, Crouch, and Israel (2008) and Hochhauser and Engel-Yeger (2010), a second measure of intensity (i.e., personal intensity) was computed in this study, where the child's intensity score was divided by the total number of activities the child participated in by report. This was the children's actual average intensity.

The scoring of the CAPE/PAC is designed to be performed in three ways: (a) overall scores, (b) scores by domains (i.e., formal and informal), and (c) scores by activity types (i.e., recreational, physical, social, skill-based and self-improvement activities) for all the measured dimensions (i.e., diversity, intensity, social aspect, location, enjoyment and preferences). However, the 55 activities of the CAPE/PAC are grouped into nine categories in the test booklet (i.e., organized sports, other skill-based activities, clubs, groups, and organizations, hobbies, crafts, and games, social activities, quiet recreation, active physical activities, entertainment and education, as well as jobs, chores, and employment). The CAPE/PAC developers state that in spite of the factor analysis deriving activity types, the original activity categories were retained in the published test booklet because they are a "meaningful way of introducing groups of activities to children" (King et al., 2004, p. 22). It can be argued that these categories would be useful in providing a complete Recreational Profile for children with HFA. To this end, a

category score sheet was created by the primary investigator, which replicated the scoring sheet for activity type. Because the primary investigator developed the score sheet, statistical tests were not performed during secondary analysis of the data. Rather, it was used to enhance the descriptive information presented.

6. The *Paediatric Quality of Life 4.0 Generic Core Scales (PedsQL) (*Varni, Seid & Rode, 1999*)* is a measure of health related quality of life comprised of physical, emotional, social and school functioning scales which are grouped into physical and psychosocial health summaries and a total HRQL score (Varni, Seid, Knight, Uzark & Szer, 2002). Rating is a five-point categorical scale *("never a problem" to "always a problem")* transformed to a 0-100 continuous value with higher scores indicating better HRQL (Varni et al., 2002). Multiple reliability and validity studies were conducted demonstrating the psychometric properties of the PedsQL as a measure of health-related quality of life (Table 3) (Varni et al., 1999; Varni, Seid & Kurtin, 2001). For example, the PedsQL construct discriminative validity discriminated between a group of healthy children and groups of children with acute and chronic health conditions (Varni et al., 2001). The PedsQL has been used both in self and proxy versions with children with ASD and their parents (Bastiaansen et al., 2004).

3.6 Data Collection

The PI conducted interviews and administered the measurement tools at a time and location convenient to the families. The data collection was done through two or three visits (Table 4). The PI used visual supports in the form of scripts containing simple directive and descriptive sentences, as well as pictures to assist the participating children in completing each part of the study.

Table 4

Summary of Assessment Timelines

Measurement Tools	Respondent		Visit		
	Parent	Child	1	2	3
Independent Variables					
• *Gilliam Autism Rating Scale*, 2nd edition	X		X		
• *Test of Nonverbal Intelligence,* 3rd edition		X	X		
• *Vineland Adaptive Behavior Scales*, 2nd edition	X		X		
• *Comprehension Assessment of Spoken Language* (2 subtests)		X	X		
Dependent Variables (Outcome measures)					
• *Children Assessment of Participation and Enjoyment/ Preference for Activities of Children*		X		X	X
• *Paediatric Quality of Life Inventory*	X	X	X		X

Visit 1 – This visit began with the informed consent and assent process. The PI shared the written consent form with the parents (Appendix F). The PI also explained the content of the consent form to the parent(s), answered their questions and gave them time to read the written document at their own pace. Then, for the children who were 11 years old or older the informed assent process began (Appendix G). The investigator explained the content of the assent form to the children, gave them time to read the form, and answered their questions. For children under the age of 11, the primary investigator explained the study but no assent form was used.

Following this, the data collection began. The parents were asked sociodemographic questions as well as questions about their beliefs toward recreational activities (Appendix H). Parents of the participants with HFA showed the PI a copy of the child's medical report documenting the diagnosis of ASD, Asperger disorder or PDD-NOS. With the PI present, each parent completed the *GARS-2* (Gilliam, 2006), the proxy *PedsQL 4.0 (*Varni et al., 1999) and the *VABS-2* (Sparrow et al., 2006) using the questionnaire procedure described in the test manuals.

While the parent completed the questionnaires, the PI invited the child to complete the child-based measurement tools. The *TONI-3* (Brown et al., 1997), the *PedsQL 4.0* child-self

report *(*Varni et al., 1999*)* and two subscales of the *CASL* (Carrow-Woolfolk, 1999) were administered to the child, according to the procedure in the test manuals. Short breaks were given to the children as needed. A follow-up visit within 2-4 weeks was scheduled.

The *GARS-2, VABS-2*, and *TONI-3* were scored immediately after the visit to ascertain the child's diagnosis and confirm group assignment. For two children, eligibility criteria were not confirmed during the first visit. The parents of the children were then advised and it was explained that they were not required to provide any further information. All peers met the inclusion criteria after completion of the measurement tools in the first visit.

Visit 2 – During the second visit, the *CAPE/PAC* was completed. Breaks were given to the children as needed. Although efforts were made to collect the information from the child within these two sessions, for three children with HFA an additional visit was scheduled.

Visit 3 – A sub-sample of participants with HFA (n=14) and typically developing peers (n=13) was selected for a repeated administration of the *CAPE/PAC* and *PedsQL 4.0* within one-month of the second visit to enable the estimation of the test-retest reliability and construct convergent validity of the *CAPE/PAC.* Considering the potential burden of this repeated assessment on the children, only those who completed the first two visits with relative ease were considered for the third visit. The children and parents of those who agreed to participate in the third visit then completed the *CAPE/PAC* and the *PedsQL 4.0* a second time. The parents were asked a transition question to ascertain whether the last four weeks were typical or whether unusual events had occurred.

During this last visit, steps were taken to determine the content validity of the *CAPE/PAC* for children with HFA. Further, following the completion of the *CAPE/PAC*, a brief probing interview of the children was conducted one-on-one. Cognitive debriefing interviews are

commonly used in tool development, including with children, to ascertain the participants' comprehension of the questions involved, what method they used to remember the necessary information to answer the questions, and how comfortable they felt answering the questions (Collins, 2003; Matza, Swensen, Flood, Secnik & Kline Leidy, 2004). Considering the challenges with abstract language experienced by children with HFA, this type of questioning could be challenging for some of the children participating in this study (Harris et al., 2006; Landa & Goldberg, 2005). To alleviate this potential challenge, the probing interview initially focused on concrete questions such as "Name any activities that you do that we have not talked about today." "How often do you do this activity?" "How did you know how often you do an activity?" "Name any activities that you would like to do that we have not talked about today". This was followed by two more abstract questions: "How did it feel to answer these questions in the book about the activities?" and "Is there anything else you want to tell me about the recreational activities that you do?" The interview lasted approximately 5 minutes.

3.7 Data Analysis

The data collected were analyzed according to the plan organized by study objectives, which is described below.

Objective 1 – A comparison of the two groups for social activity-type, diversity, intensity, and preference of recreational participation was conducted through a multivariate analysis of variance (MANOVA) with a $p \leq 0.05$ used to determined significance. This statistical test was chosen as the exposure variable was dichotomous, whereas the outcome variables were continuous once summed although they were rated by the children as dichotomous and ordinal types of data.

Subsumed within objective 1, statistical analysis were conducted to develop a comprehensive recreational profile. An exploratory comparison of the two groups in terms of patterns of recreational participation, beyond the specific hypothesis of objective 1, was conducted through a series of t-tests ($p \leq .01$). The recreational patterns of the two groups were also compared using the MID computation described in chapter 1. Descriptive data for percent of participation in individual activities and weighted absolute difference for activity-types and categories were also computed for visual comparison of recreational patterns of the two groups and within the HFA group. The relationship between reported 'diversity and preference', as well as between 'enjoyment and preference' for each activities were explored through t-tests, Hotelling's t-square test and repeated measures analysis of variance (ANOVA). Finally, parents' perception of children's recreation was explored in three ways: (a) t-tests comparison between the two groups of parents' perceived importance and satisfaction with their children's recreation; (b) Pearson Moment correlation of the association between parents' satisfaction and diversity of recreational participation; and (c) Pearson Moment correlation between the *Play and Leisure Time* (VABS-2) and some dimensions of recreational participation which may be related to play skills.

Objective 2 – A logistic regression analysis was used to estimate the magnitude of the effect between three child-based factors and diversity of recreational activities (CAPE/PAC). The communication domain of the VABS-2 was used as the communication factor (variable 1). The socialization domain of the VABS-2 was used as the social factor (variable 2). A composite variable comprised of the supralinguistic and pragmatic judgment scales of the CASL was used as the social cognition factor (variable 3).

Objective 3 – The content validity was interpreted qualitatively. Recreational activities mentioned by the children with HFA that were not included in the CAPE/PAC were recorded by the primary investigator. After the completion of all of the interviews, the comments of all of the participants were typed as a list and examined for their meaning (Rubin & Rubin, 1995; Seidman, 1998). This information was used to reflect on whether the content of the CAPE/PAC was valid for children with HFA. Additional information about the response process was gathered to ascertained whether children with HFA could complete the CAPE/PAC (section 4.4.4).

Objective 4 – An intra-class correlation coefficient (ICC) was calculated to estimate the test-retest reliability of CAPE/PAC in children with HFA and peers. Additional data were gathered as explanatory information of CAPE/PAC test-retest reliability. Parents' ratings of family changes were compared between the two groups through a Mann Whitney U. An ICC was also calculated for the PedsQL comparing the two administrations of this measurement tool.

Objective 5 –Pearson Moment correlations were computed to estimate the convergent validity of the CAPE/PAC with the PedsQL and the Play and Leisure Time (VABS-2). It was hypothesized that a correlation coefficient >0.40 between the CAPE/PAC and the PedsQL and >0.50 between the CAPE/PAC and Play and Leisure Time (VABS-2) would be found.

Objective 6 – The HRQL of the children in the two groups were compared through two MANOVA, one for children self-report and one for parent-proxy reports. To explore the degree of agreement between parents and children's ratings and the direction of this agreement, an ICC and repeated-measures ANOVA were conducted.

Objective 7 – To examine the association between HRQL and dimensions of recreational participation, Pearson Moment correlations were used for the HFA group.

3.8 Ethical Considerations

The study posed minimal risk to the participants and their families. No adverse events occurred as a result of participation in the study. This descriptive study did not, and was not intended to, have direct benefits for the participating families. A report summarizing patterns of and preferences in recreational activities of children in the study was shared with participating families. Data safety and participating families' anonymity was respected in this study. Each family was assigned a number placed on the consent form that was used on all other forms in the study. The consent forms were kept in a locked cabinet separately from other forms such as the measurement tools score sheets and socio-demographic data. The electronic data were stored in password-encrypted files. The primary investigator monitored quarterly the recruitment efforts, completeness of data collection tools and the data entry. One parent withdrew from the study after data collection was initiated by contacting the primary investigator by phone. This information was reported in an email to Dr. Laurie Snider. The PI conducted preliminary analyses of raw data when half and then three quarters of the participants had completed data collection to identify any problems that might have arisen.

3.9 Conclusion

This chapter explained the methodology used to conduct this cross-sectional study. The various methods of recruitment and repeated invitations to families to participate were described in detail. However, it was not possible to recruit the number of participants that was estimated to be needed although a review of prevalence and number of children receiving special education services for autism suggested that it would be possible. The implications are addressed further in Chapters 4 and 5. Information is provided about the six measurement tools used in the study to

confirm eligibility criteria, understand the characteristics of the children and collect information about the primary outcomes of the study. The PI collected the data and small deviations in data collection protocol were noted. No unexpected events or ethical problems arose during the study.

Chapter 4: Results

In this chapter, the results of the study are presented beginning with a description of the family and child characteristics of the participants (section 4.1), followed by the results of the study's primary objectives (Objective 1; section 4.2). Next, a Recreational Profile of the children with HFA (section 4.3) is introduced. A discussion of the relationships between child-based factors and recreational participation in children with HFA is then offered (Objective 2; section 4.4). Subsequently, an examination of the psychometric properties of the CAPE scores in these children is presented (Objectives 3-5; section 4.5). Finally, results related to children with HFA's HRQL compared to peers and the relationship between HRQL and recreational participation is provided (Objectives 6-7; section 4.6). Missing data are addressed in each section of the chapter when it affected the analysis. Overall, missing data for this study were minimal.

4.1 Participants Demographics and Characteristics

The sample was comprised of two groups of children: 30 children with HFA (26 boys [86.67%]; 4 girls) and 31 peers (27 boys [87.10%]; 4 girls). All parents of children in the HFA group showed the PI a medical report to confirm that the diagnosis was given by a physician or psychologist. Characteristics of the two groups (i.e., age, non-verbal intelligence, autism characteristics, non-verbal communication and adaptive behavior) were described and t-test comparisons are presented in Table 5. While statistically significantly differences were not found in age ($p=0.182$) or in non-verbal intelligence ($p=0.433$), there were significant differences between groups ($p<0.001$) on all other measured characteristics (i.e., autism characteristics, non-verbal communication and adaptive behavior composite) (Table 5).

Table 5

Child Characteristics of Participants

	HFA (n=30)		Peers (n=31)		p	95% CI	
	M	(SD)	M	(SD)		LL	UL
Age (in months)	111.03	(18.80)	118.26	(22.73)	.182	-17.93	3.49
GARS-2							
Stereotyped	8.27	(2.85)	3.26	(1.29)	<0.001*	3.88	6.14
Communication	8.13	(3.21)	2.55	(.93)	<0.001*	4.38	6.79
Social Interaction	8.03	(2.81)	1.97	(1.47)	<0.001*	4.92	7.21
Autism Index	83.50	(24.74)	53.19	(7.46)	<0.001*	21.01	39.60
TONI-3	105.53	(17.92)	109.81	(23.82)	.433	-15.01	6.55
CASL							
Non-literal language	89.00	(15.33)	109.55	(10.88)	<0.001*	-27.34	-13.76
Pragmatic judgment	71.57	(15.96)	96.19	(10.77)	<0.001*	-31.58	-17.67
VABS-2							
Communication	81.23	(9.80)	104.45	(10.67)	<0.001*	-28.47	-17.96
Daily Living Skills	77.13	(11.38)	99.58	(10.51)	<0.001*	-28.04	-16.85
Socialization	70.70	(9.56)	100.19	(9.15)	<0.001*	-34.29	-24.70
Gross Motor Skills	12.23	(2.58)	15.74	(.77)	<0.001*	-4.48	-2.54
Fine Motor Skills	12.83	(3.03)	18.00	(2.48)	<0.001*	-6.58	-3.75
Adaptive behavior composite	74.80	(7.65)	100.77	(8.99)	<0.001*	-30.26	-21.69
Maladaptive Behavior	19.90	(1.79)	15.55	(2.62)	<0.001*	3.20	5.50

Key. HFA: High functioning autism; GARS-2: Gilliam Autism Rating Scale, 2nd edition; TONI-3: Test of Nonverbal Intelligence, 3rd edition; VABS-2: Vineland Adaptive Behavior Scales, Second Edition; CASL: Comprehension Assessment of Spoken Language; SD: standard deviation; CI = confidence interval; LL = lower limit, UL = upper limit. Note. *Significant difference at $p < .05$ two-tailed.

The family characteristics of each group were compared using t-tests, Chi square, binominal or Mann Whitney tests according to the types of data. Considering the number of counties of residence and the few participants residing in some of the counties, no statistical test to compare county of residence was performed. Most participants resided in Chittenden County. This was expected since approximately half of the population of Vermont lives in this county. On some characteristics, specifically both parents living at home (p=0.961), number of children in the family (p=0.168), number of people living in the household (p=0.889) or family income (p=0.140; Table 6), families in the two groups were not different. Despite family income not

being statistically different, the highest level of education of a parent was statistically higher in the peer group ($p=0.019$). Specifically, 61.29% of families in the peer group had a parent with a professional degree or graduate studies as compared to 23.33% in the families of children with HFA. The two groups also differed on the number of people with disabilities in the family ($p<0.001$) since all the families in the HFA group had at least one person with a disability.

To estimate the representativeness of the sample compared to the Vermont population, the sociodemographic information of the sample was compared to the 2000 US Census data. The combined sample (i.e., HFA group and peer group) was statistically different from the US census data for the state of Vermont on the four measured characteristics: both parents living in the home ($p<0.001$), number of people living in the household ($p<0.001$), highest degree of parental education ($p<0.001$) and family income ($p<0.001$). The first two differences were expected as the US census data aggregates information for all types of households, including individuals living alone and without children, whereas the families participating in this study all had at least one child and were more likely to be living with a partner than the general population of Vermonters. The differences in income and level of education indicated that the study sample had higher socioeconomic status than the general population of Vermont.

4.2 Recreational Participation in Children with High Functioning Autism Compared to Peers

The CAPE/PAC provides information about children's recreational participation along six dimensions (section 3.5) summarized as: '<u>diversity</u>' is the number of activities out of 55 in which children participate; '<u>intensity</u>' is the frequency of participation in these activities; '<u>social aspect</u>' represents with whom they participate in activities; '<u>location</u>' is where they

Table 6

Characteristics of Participating Families

	HFA (n=30)		Peer (n=31)		p^a	p^b
	Frequency (percent)	M (SD)	Frequency (percent)	M (SD)		
Family Structure (in the home)						
Both parents	26 (86.67%)		27 (87.1%)		0.961	<0.001*
Number of Children		1.90 (0.55)		2.13 (0.72)	0.168	
Number of people		4.47 (1.50)		4.52 (1.24)	0.889	<0.001*
Number of people with disability		1.17 (0.38)		0.19 (0.40)	<0.001*	
County of Residence						
Addison	3 (10%)		2 (6.5%)			
Bennington	1 (3.33%)		0			
Caledonia	0		1 (3.2%)			
Chittenden	17 (56.67%)		21 (67.7%)			
Franklin	1 (3.33%)		1 (3.2%)			
Lamoille	0		1 (3.2%)			
Rutland	5 (16.67%)		0			
Washington	3 (10%)		5 (16.1%)			
Education- Parent Highest Level of Education					0.019*	<0.001*
High School Graduate	0		3 (9.68%)			
Some college, no degree	5 (16.67%)		2 (6.45%)			
Associate	6 (20%)		1 (3.23%)			
Bachelor	12 (40%)^		6 (19.35%)			
Graduate or professional Degree	7 (23.33%)		19(61.29%)^			
Family Income					0.140	0.001*
< $10,000	1 (3.33%)		0			
$10-14,000	0		0			
$15-24,999	2 (6.67%)		1 (3.3%)			
$25-34,999	2 (6.67%)		0			
$35-49,999	8 (26.67%)		4 (13.3%)			
$50-74,999	5 (16.67%)^		10 (33.3%)^			
$75-99,999	8 (26.67%)		11 (36.7%)^			
$100-149,999	3 (10%)		3 (10.0%)			
$150-199,999	0		0			
$200,000 >	1 (3.33%)		1 (3.3%)			
No answer	0		1 (3.3%)			

Note. HFA: High functioning autism; SD: Standard deviation; ^ Corresponds to the median for this variable; p^a value between the two groups; p^b value of both groups compared to US census; and *Significant difference at $p < .05$ two-tailed.

participate in activities; 'enjoyment' is the amount of pleasure reported from activities in which they participate; and 'preference' is their degree of interest in participating in activities in which they may or may not be currently participating. The 55 activities are grouped in 'activity-type', 'domains' and 'categories'.

The primary objective of this study, outlined in chapter 2, was to compare the patterns of recreational participation in terms of social activity-type, diversity, intensity and preference of the two groups. It was hypothesized that, when compared to peers, children with HFA would have significant differences in type, diversity and intensity of activity, but not in preference for activities as measured by the CAPE/PAC. Specifically, children with HFA would participate in 1) fewer activities overall and 2) fewer socially based activities. However, they would 3) partake in the recreational activities more frequently and 4) show a similar degree of interest for various types of activities in comparison with peers.

The results the MANOVA computed to test these hypotheses indicated (Table 7) that children with HFA did not differ from peers in their participation in the social-type of activity (activity-type; p=0.478; Table 8). However, there were differences in 'variety', that is, they participated in significantly fewer activities overall (variety; p=0.002). Contrary to our hypothesis, children with HFA did not show greater 'intensity' than peers whether general or personal intensity scores were used. Peers showed significantly greater general intensity (p=0.017). This was logical, since the peer group participated in significantly more activities, as their general intensity scores were also significantly greater. Finally, overall preference was not different between groups (p= .788), which confirmed our hypothesis regarding the degree of interest in recreational activities (Table 8).

Table 7

Recreational Participation across Activity Types and Domains: Comparison between Groups

	High Functioning Autism (n=30)		Peers (n=31)			
	Mean	SD	Mean	SD	F	p
Overall (55 activities)						
Diversity	27.53	5.25	32.45	6.54	10.455	*.002
Personal Intensity	4.58	.63	4.67	.92	.167	.684
General Intensity	2.33	.52	2.66	.55	6.090	*.017
Social aspect	2.17	.44	2.44	.30	8.026	*.006
Location	2.33	.37	2.79	.44	19.706	*<.001
Enjoyment	3.68	.67	3.87	.512	1.414	.239
Recreational Activity Type (12 activities)						
Diversity	8.90	1.84	9.45	2.06	1.209	.276
Personal Intensity	5.44	.75	4.86	.90	7.701	*.007
Social aspect	1.72	.54	2.01	.39	5.912	.018
Location	1.43	.39	1.90	.57	14.182	*<.001
Enjoyment	4.02	.64	3.95	.59	.186	.668
Physical Activity Type (9 activities)						
Diversity	3.30	1.86	6.00	2.70	20.601	*<.001
Personal Intensity	4.25	1.51	4.51	1.45	.470	.496
Social aspect	2.38	1.09	3.34	3.55	2.005	.162
Location	2.80	1.27	3.21	1.25	1.676	.200
Enjoyment	3.97	.98	3.91	.97	.067	.796
Social Activity Type (9 activities)						
Diversity	7.57	1.89	7.90	1.80	.509	.478
Personal Intensity	3.70	.73	3.86	.82	.620	.434
Social aspect	2.50	.45	2.72	.46	3.699	.059
Location	2.79	.64	3.12	.69	3.765	.057
Enjoyment	3.81	.80	4.16	.67	3.481	.067
Skill-based Activity Type (9 activities)						
Diversity	2.20	1.35	2.94	1.29	4.739	.033
Personal Intensity	4.03	1.58	4.36	1.17	.838	.364
Social aspect	2.67	1.23	3.20	.97	3.614	.062
Location	3.12	1.46	3.89	1.10	5.395	.024
Enjoyment	3.60	1.41	3.92	.80	1.217	.274
Self Improvement Activity Type (10 activities)						
Diversity	5.47	1.36	6.10	2.02	2.027	.160
Personal Intensity	5.01	.94	4.99	.66	.004	.951
Social aspect	1.99	.72	1.90	.58	.257	.614
Location	2.44	.59	2.50	.64	.153	.697
Enjoyment	2.80	.98	3.12	.94	1.653	.204
Informal Domain (36 activities)						
Diversity	24.07	4.65	27.74	6.15	6.896	.011
Personal Intensity	4.77	.75	4.61	.633	.846	.361

Social aspect	2.10	.47	2.30	.48	2.655	.109
Location	2.23	.43	2.67	.71	8.575	*.005
Enjoyment	3.81	.84	3.91	.59	.287	.594
Formal Domain (14 activities)						
Diversity	3.03	1.69	4.39	1.58	10.412	*.002
Personal Intensity	4.35	1.23	4.57	.89	.618	.435
Social aspect	2.93	1.05	3.36	.72	3.460	.068
Location	3.61	1.29	4.21	.91	4.464	.039
Enjoyment	3.60	1.18	3.93	.67	1.876	.176

Note. SD: Standard deviation; * Significant difference between groups at 0.01 or more.

Table 8

Comparison between Groups of Preference for Recreational Activities by Types and Domains

	High Functioning Autism		Peer		p
	Mean	SD	Mean	SD	
Overall	2.10	.34	2.12	.27	.788
Recreational Activity Type	2.35	.31	2.22	.38	.138
Physical Activity Type	2.03	.47	2.33	.37	*.007
Social Activity Type	2.35	.35	2.40	.35	.603
Skill-based Activity Type	1.91	.50	1.82	.38	.447
Self Improvement Activity Type	1.86	.44	1.80	.39	.594
Informal Domain	2.17	.31	2.23	.28	.439
Formal Domain	1.91	.49	1.89	.33	.876

Note. SD: Standard deviation; * Significant difference between groups at 0.01 or more.

4.3 Recreational Profile

To obtain a recreational profile of children with HFA, an exploratory analysis was conducted to compare the two groups to each other and to compare the HFA group to itself on various dimensions of the CAPE/PAC and other measurement tools.

4.3.1 Recreational profile: comparison between groups.

Further analysis of the CAPE/PAC using t-tests was conducted to develop the recreational profile for children with HFA. For this exploratory analysis an alpha of 0.01 was chosen in recognition of the number of statistical tests performed on the data in comparison to

the number of participants. MID was computed for diversity of participation across activity types extrapolating from McNeil and colleagues' (2009) definition of a meaningful change on this tool. Children with HFA were statistically different from their peers in terms of context of recreational participation; specifically, social aspect ($p=0.006$) and location ($p<0.001$; Table 7). This indicated that children with HFA participated more frequently in recreational activities either alone or with families and closer to home. In contrast, peers responded that they participated in recreational activities that involved other people more frequently and were located further from their home. Information about the type of recreational activities that children participated in is presented in Table 7. Statistical differences were found for diversity of participation in physical-type ($p<0.001$) and formal activities ($p=0.002$), for personal intensity of participation in recreational-type of activity ($p =0.007$) and for the location of participation for recreational-type activity ($p<0.001$) and informal domains ($p=0.005$). The participation diversity difference between groups was greater than the MID (i.e., ½ SD) for overall, physical-type and skill-based type activities. On the other hand, differences in preference for types of recreational activities were not found to be statistically significant and did not exceed the MID except for physical-type of activities ($p=0.007$), which was less preferred by children with HFA (Table 8).

Descriptive data for percent of participation in individual activities, regardless of the type, domain or categories in descending order for the HFA group were presented in Table 9. There were few activities (i.e., three) in which children with HFA reported engaging in more frequently by at least 10% than the peer group. There were 24 activities for which at least 10% more of the peer group reported participating in more frequently than the HFA group. Many of these activities with the largest differences in the percentage of the sample participation were physical-type activities such as *playing team sports*.

Table 9

Comparison of Percent Participation between Groups by Activity.

Activities name	Group Percent Participation		Activities name	Group Percent Participation		Activities name	Group Percent Participation	
	HFA	Peer		HFA	Peer		HFA	Peer
Playing computer/video games	***100.0%**	87.10%	Going on a full-day outing	63.33%	64.52%	Community organizations	*23.33%	41.94%
Watching TV or a rented movie	96.67%	96.77%	Making food	63.33%	67.74%	Fishing	*23.33%	41.94%
Reading	96.67%	93.55%	Doing snow sports	56.67%	45.16%	School clubs	20.00%	16.13%
Going to a party	93.33%	90.32%	Playing on equipment	*56.67%	67.74%	Horseback riding	16.67%	9.68%
Visiting	93.33%	93.55%	Doing puzzles	*53.33%	67.74%	Gardening	^16.67%	38.71%
Doing homework	93.33%	83.87%	Taking care of a pet	^53.33%	80.65%	Doing martial arts	13.33%	6.45%
Playing with things or toys	90.00%	83.87%	Writing letters	50.00%	58.06%	Taking music lessons	*13.33%	25.81%
Pretend or imaginary play	***86.67%**	67.74%	Going to the public library	*50.00%	67.74%	Doing volunteer work	^13.33%	38.71%
Shopping	86.67%	77.42%	Collecting things	46.67%	48.39%	Doing gymnastics	10.00%	9.68%
Doing crafts, etc.	83.33%	87.10%	Going to a live event	46.67%	51.61%	Taking art lessons	*10.00%	25.81%
Talking on the phone	83.33%	90.32%	Bicycling, etc.	~43.33%	80.65%	Racing or track & field	~6.67%	45.16%
Hanging out	83.33%	87.10%	Playing games	~43.33%	77.42%	Learning to dance	6.67%	9.68%
Playing board or card games	*80.00%	93.55%	Individual physical activities	*40.00%	58.06%	Doing water sports	^3.33%	32.26%
Playing with pets	80.00%	80.65%	Playing a musical instrument	36.67%	45.16%	Doing a paid job	~3.33%	41.94%
Doing a chore	*80.00%	96.77%	Dancing	*33.33%	48.39%	Learning to sing	0.00%	12.90%
Entertaining others	76.67%	80.65%	Playing non-team sports	^33.33%	54.84%			
Listening to music	76.67%	80.65%	Doing a religious activity	^30.00%	51.61%			
Going to the movies	73.33%	77.42%	Doing team sports	~26.67%	77.42%			
Swimming	66.67%	74.19%	Getting help for schoolwork	^**26.67%**	3.23%			
Going for a walk or hike	^66.67%	87.10%	Writing a story	*23.33%	35.48%			

Note. HFA: High functioning autism; * Represent a 10-19% difference between groups; ^ Represent a 20-29% difference between groups; ~ Represent a 30%+ difference between groups; and **Bolded** activities are those that the HFA group participate in more frequently that the peer group by at least 10%.

The weighted absolute difference between the two groups in percentage of participation was computed for each individual's activity within activity types and categories. Within activity-types, the peer group had greater participation for all types with physical being the most and social the least different between the two groups (Figure 4). Within activity-categories, active physical and job were most difference between the two groups, where as social activities, and education and entertainment showed the least (Figure 5). The HFA group showed greater percent participation for only one activity type or category: quiet recreation (Figure 5).

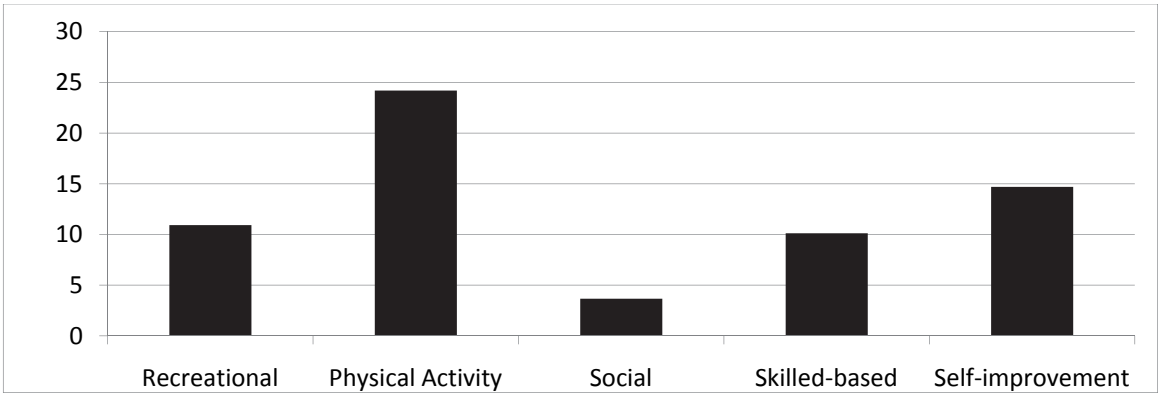

Figure 4. Between groups difference in diversity of activity participation by activity types.

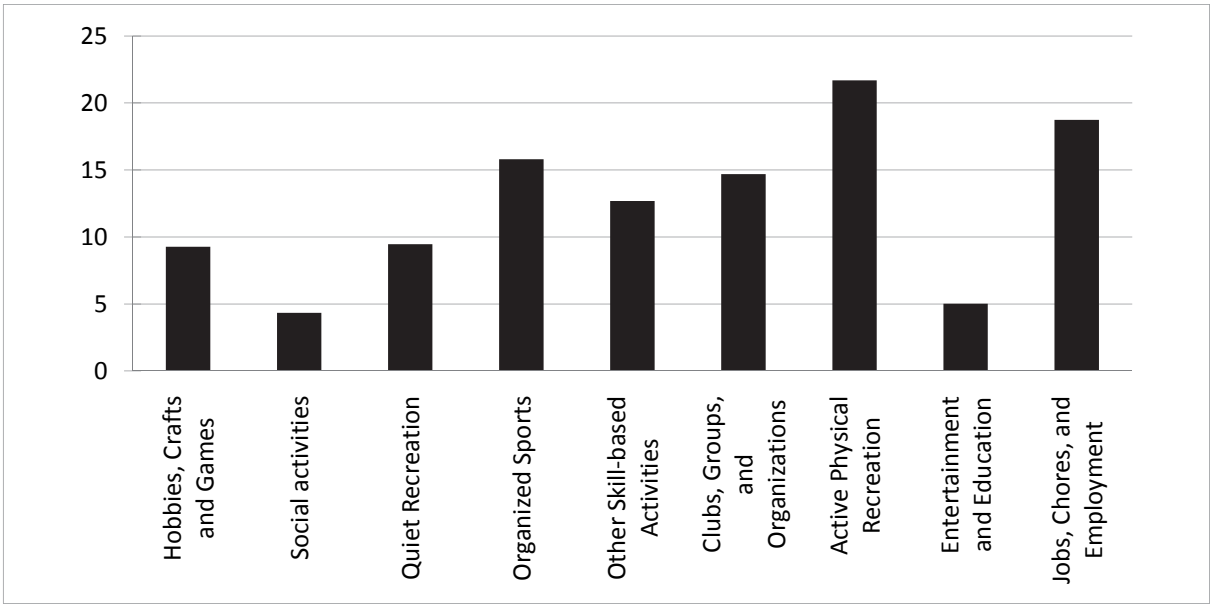

Figure 5. Between groups difference in diversity of activity participation by activity categories.

In further developing a comprehensive recreational profile for children with HFA, the relationship between activities in which children participate was compared to activities for which children indicated preference. This comparison was done pair-wise, activity by activity between preference in activities not engaged in and preference in activities participated in across all children in the group instead of an average preference across all activities. For both groups, a paired t-test revealed statistically significant difference with greater preference for activities in which children participate (Table 10). A repeated measures analysis of variance (ANOVA) showed children in both groups had a similar degree of difference between preference for activities in which they participated and those in which they did not (p=0.75).

Table 10

Relationship between Activity Preference and Participation in an Activity.

		Mean	SD	t	p
HFA	Preference for activities not participated in	1.83	.48	-7.52	<0.001
	Preference for activities participated in	2.40	.25		
Peer	Preference for activities not participated in	1.82	.32	-11.94	<0.001
	Preference for activities participated in	2.37	.23		

Key. HFA: High functioning autism; SD: Standard deviation.

Similarly, the relationship between enjoyment in an activity in which children participated and their preferences "if they could do anything in the whole world" for the same activity was explored (Table 11) using Hotelling's t-square tests and a repeated measures ANOVA. Children rated their preference for an activity using a three-point scale: "Would not like to do at all", "Would sort of like to do" and "Would really like to do". These were labeled as No Preference, Some Preference and Great Preference in Table 11. Children rated their enjoyment in activities in which they actually participated on a five-point scale. For the purpose

of this analysis, these were grouped into the following three categories: 1) “Not at all”, 2) “Somewhat, sort of” and “Pretty Much”, and 3) “Very much” and “Love it”. Children in both groups reported significantly more enjoyment for activities in which they expressed greater preference (Table 11, $p<0.001$). There was no statistical difference between the two groups in the degree of enjoyment expressed for the different level of activity preference ($p=.750$). In fact, in both groups, children reported greater enjoyment for activities for which they reported greater preference (Table 11).

Table 11

Relationship between Enjoyment and Preference.

		Mean	SD	F	p
HFA	Reported enjoyment for activities in which “no preference” was expressed	2.43	1.07	43.25	<0.001
	Reported enjoyment for activities in which “some preference” was expressed	3.40	.65		
	Reported enjoyment for activities in which “great preference” was expressed	4.28	.58		
Peer	Reported enjoyment for activities in which “no preference” was expressed	2.53	1.06	71.86	<0.001
	Reported enjoyment for activities in which “some preference” was expressed	3.58	.64		
	Reported enjoyment for activities in which “great preference” was expressed	4.48	.36		

Key. HFA: High functioning autism; SD: Standard deviation.

4.3.2 Recreational profile: variation in participation in children with HFA.

To further illustrate recreational participation within the HFA group, the percentage of children with HFA engaged in each activity was computed and mapped by activity type (Table 12) and categories (Table 13). Within each cell, activities were placed in descending order of the percentage of children with HFA who reported participation in the activity.

Table 12

Participation by Activity Types and Domains in Children with High Functioning Autism

Activity Types	Domains		
	Informal Activities (percent participation)		Formal Activities (percent participation)
Recreational	Playing computer/video games (100%) Watching TV or movies (96.67%) Playing with things or toys (90%) Doing pretend play (86.67%) Doing crafts, etc. (83.33%) Playing board or card games (80%)	Playing with pets (80%) Going for a walk or hike (66.67%) Playing on equipment (56.67%) Doing puzzles (53.33%) Taking care of a pet (53.33%) Collecting things (46.67%)	
Physical Activity	Doing snow sports (56.67%) Playing games (43.33%) Bicycling, etc. (43.33%) Individual physical activity (40%) Playing non-team sports (33.33%)	Fishing (23.33%) Gardening (16.67%) Doing a paid job (3.33%) Doing water sports (3.33%)	Doing team sports (26.67%) Participating in school clubs (20%) Doing martial arts (13.33%) Racing or track and field (6.67%)
Social	Going to a party (93.33%) Visiting (93.33%) Hanging out (83.33%) Talking on the phone (83.33%) Entertaining others (76.67%)	Listening to music (76.67%) Going to the movies (73.33%) Going on a full day outing (63.33%) Making food (63.33%) Going to a live event (46.67%)	
Skill-based	Dancing (33.33%)		Swimming (66.67%) Playing a musical instrument (36.37%) Community organizations (23.33%) Horseback riding (16.67%) Taking music lessons (13.33%) Doing gymnastics (10%) Taking art lessons (10%) Learning to dance (6.67%) Learning to sing (0%)
Self-improve-ment	Reading (96.67%) Doing homework (93.33%) Shopping (86.67%) Doing a chore (80%)	Writing a story (23.33%) Doing volunteer work (13.33%) Writing letters (50%) Going to the public library (50%)	Doing a religious activity (30%) Getting extra help for schoolwork (26.67%)

Table 13

Participation in Activities sorted by Activity Categories and Domains in the High Functioning Autism Group

Informal Activity by Categories		Formal Activity by Categories
Hobbies, Crafts and Games	Social activities	Organized Sports
Playing computer or video games (100.00%)	Going to a party (93.33%)	Swimming (66.67%)
Doing crafts, drawing or coloring (83.33%)	Visiting (93.33%)	Doing team sports (26.67%)
Playing board or card games (80.00%)	Talking on the phone (83.33%)	Horseback riding (16.67%)
Doing Puzzles (53.33%)	Hanging out (83.33%)	Doing martial arts (13.33%)
Collecting things (46.67%)	Entertaining others (76.67%)	Doing gymnastics (10.00%)
	Writing letters (50.00%)	Racing or track and field (6.67%)
Entertainment and Education	Jobs, Chores, and Employment	Other Skill-based Activities
Watching TV or a rented movie (96.67%)	Doing homework (93.33%)	Playing a musical instrument (36.67%)
Reading (96.67%)	Shopping (86.67%)	Help for schoolwork (26.67%)
Listening to music (76.67%)	Doing a chore (80.00%)	Taking music lessons (13.33%)
Going to the movies (73.33%)	Making food (63.33%)	Taking art lessons (10.00%)
Going on a full-day outing (63.33%)	Taking care of a pet (53.33%)	Learning to dance (6.67%)
Going to the public library (50.00%)	Doing volunteer work (13.33%)	Learning to sing (0.00%)
Going to a live event (46.67%)	Doing a paid job (3.33%)	
Active Physical Recreation	Quiet Recreation	Clubs, Groups, and Organizations
Going for a walk or a hike (66.67%)	Playing with things or toys (90.00%)	Doing a religious activity (30.00%)
Doing snow sports (56.67%)	Doing pretend play (86.67%)	Community organizations (23.33%)
Playing on equipment (56.67%)	Playing with pets (80.00%)	Participating in school clubs (20.00%)
Bicycling, etc. (43.33%)	Writing a story (23.33%)	
Playing games (43.33%)		
Doing individual physical activities (40.00%)		
Dancing (33.33%)		
Playing non-team sports (33.33%)		
Fishing (23.33%)		
Gardening (16.67%)		
Doing water sports (3.33%)		

Seventy-five percent or more of the children with HFA reported participating in more than half of the activities under the "Recreational" and "Social" activity types. The percentage of children with HFA who reported participating in the activities included in "Active Physical" and "Skill-based" activity types was small with none of the activities in these two types participated by at least 75% of the sample. The differences between groups by activity categories were less contrasting although "Organized Sports", "Other Skill-based Activities" and "Clubs, Groups, and Organizations" had low percentages of participation (<40%) except for swimming whereas "Social Activities" and "Quiet Recreation had high percentages of participation (>75%) except for writing letters and stories in the HFA group.

4.3.3 Parents' perception of their children's recreational participation.

The data about recreational participation on the CAPE/PAC were collected from the children themselves. Parents were asked two questions about their child's recreational participation which they rated on a Likert scale from "Strongly Disagree" to "Strongly Agree". These questions were: (a) In your family, the participation of children in recreational activities is important; and, (b) I am satisfied with my child's participation in recreational activities. The two groups were compared on these questions through t-tests. No statistical difference was found between groups on the importance of recreational participation ($p=0.082$); however, parents of the peer group had statistically significant greater satisfaction with their child's recreational participation than those of the HFA group ($p<0.001$). Pearson correlations were used to compare parents' satisfaction and diversity of recreational activities in which children reported participating. The correlation was very low for the HFA group ($r=0.209$) and low ($r=0.426$) for the peer group. The correlation coefficient interpretation proposed by Munro (2005) was used: .00-.25= little if any (herein referred to as 'very low'); .26-.49 =low correlation; .50-.69 =

moderate correlation; .7-.89 =high correlation; and .9-1 =very high correlation.

Another measurement tool, the VABS-2, captured a component of the construct of recreational participation from the parents' point of view. The VABS-2 *Play and Leisure Time* subdomain measures "how the individual plays and uses leisure time" (Sparrow et al., 2005, p. 3). The items of the subdomain appear to measure a child's skills in areas related to play and leisure with others. Children in the HFA group scored significantly poorer on this subdomain than peers ($p<0.001$; Table 5).

4.4 Selected Child-based Factors Related to Recreational Participation

The study intended to estimate the magnitude of effect between selected child-based factors and diversity of recreation through a regression with communication skills variable measured by the communication domain of the VABS-2, the social cognition variable measured by a composite of the supralinguistic language and pragmatic judgment scales of the CASL, the social variable measured by the socialization domains of the VABS-2 and recreational participation measured as the overall diversity score of the CAPE. It was hypothesized that social cognition, social skills and communication skills, in that order, would have the greatest impact on the diversity of recreational activities in children with HFA.

The regression showed that for the HFA group, the child-based factors included did not significantly contribute to the child's diversity of recreational participation (Table 14). Consequently, the study hypothesis related to these child-based factors was not confirmed. However, the PI recognizes that the sample size may have been too low to yield an effect as described below. To gain further understanding of the relationships between these three variables additional analysis were conducted.

Table 14

Regression of Selected Child-based Factors Related to Diversity of Recreational Participation

Model	HFA (n=30)				Peer (n=31)			
	B	SE	t	p	B	SE	t	p
Communication Skills	.167	.103	1.630	.115	25.098	17.655	1.422	.167
Social Skills	-.100	.106	-.944	.354	.027	.132	.208	.836
Social Cognition	-.063	.034	-1.854	.075	-.005	.153	-.032	.975

Key. HFA: High functioning autism; B: Coefficient; SE: Standard error; and t: t statistic.

First, the regression was repeated in the peer group with the same 2 variables included in the model. The three selected child-based factors did not predict diversity of recreational participation to a significant degree in the peer group. However, the degree of contribution of the social skills and social cognition factors in the peer group appeared to be lower than for the HFA group (Table 14).

Second, the association between the three child-based factors was analyzed through a Pearson Moment correlation. In the both groups, there was fairly constant low correlations (Table 15) between the three variables according to Munro's (2005) correlation interpretation.

Table 15

Correlation between Selected Child-based Factors

	High functioning autism		Peer	
	Social Skills	Social Cognition	Social Skills	Social Cognition
Communication Skills	.329	.305	.406	.319
Social Skills		.322		.296

Finally, to determine the impact of the current sample size on the result of the linear regression a computation was performed from the current results to determine the sample size that would be necessary in a future study to find a statistically significant difference in this

model. Since in the current study, the social cognition factor was closest to being statistically significant (p=.075) in the HFA group, the sample size necessary for this factor to become statistically significant at 0.05 with a power of 80% with the contribution of the two other factors (R^2=0.0860) remaining stable was computed. According to this computation, a minimum sample size per group of 62 participants would be necessary.

4.5 Psychometric Properties of the CAPE/PAC in Children with High Functioning Autism

This section provides the results of the estimation of the interpretability or psychometric properties of the CAPE/PAC for children with HFA, specifically, the test-retest reliability (section 4.5.1), convergent validity (section 4.5.2), content validity (section 4.5.3), and response process (section 4.5.4).

4.5.1 Reliability of the CAPE for children with high functioning autism.

The study was designed to estimate the test-retest reliability of the CAPE/PAC in a subgroup of participants with HFA and a subgroup of peers. To strengthen the interpretation of reliability of this tool for this population, the study also gathered data that provided explanatory information related to the test-retest reliability of the CAPE.

The test-retest reliability of the CAPE/PAC overall scores for all dimensions was estimated by ICC with a sub-sample in both groups (HFA n=14; peer n=13; Table 14). For the HFA group, the correlation between the two administrations was high (r>.7), according to a generally accepted standard (Streiner & Norman, 2003), for all dimensions of the overall CAPE/PAC except the social aspect dimension which was well below the standard (r=.196). For the peer group these test-retest correlations were moderate (r>.569) and overall slightly lower than for the HFA group, with the exception of the overall PAC correlation (r= .732).

In designing the study, it was planned that to gain an understanding of the meaning of potential correlation differences between the two administrations of the CAPE, the PedsQL was also administered both times. The association between the two PedsQL administrations was analyzed using an ICC (Table 16). For the HFA group the correlations between the two administrations on the psychosocial health summary and Total Score were high (r>.7) whereas for the physical health summary it was moderate. For the peer group these same correlations were low to moderate ranging from .212 to .426.

Table 16

Test-retest Reliability of the *Children Assessment of Participation and Enjoyment/Preference for Activities of Children* and *Paediatric Quality of Life Inventory*

		HFA Group	Peer Group
Children Assessment of Participation and Enjoyment			
Diversity	Time 1-2	.733	.654
Intensity	Time 1-2	.752	.649
Social Aspect	Time 1-2	.196	.651
Location	Time 1-2	.715	.550
Enjoyment	Time 1-2	.758	.563
Preference for Activities of Children	Time 1-2	.687	.732
Paediatric Quality of Life Inventory			
Physical Health Summary	Time 1-2	.489	.413
Psychosocial Health Summary	Time 1-2	.951	.210
Total Score	Time 1-2	.872	.220

Key. HFA: High functioning autism

To ascertain whether variation between the two administrations of the CAPE/PAC were due to true changes within the families' life, during the second assessment visit, parents were asked if the last four weeks had been typical for their family. A score of 'one' indicated strong disagreement and 'six' strong agreement with this statement. Eighty-six percent of parents in the

HFA group and 83% of parents in the peer group agreed or strongly agreed that the last 4 weeks had been typical for their family. Parents' rating of 'family change' was compared between groups using a Mann Whitney U test that was not statistically significant (p=0.752; Table 17).

Table 17

Parents' Rating of Family Changes between the Two Children CAPE/PAC Administrations.

		High Functioning Autism (n=14)		Peer (n=13)	
		Frequency	Percent	Frequency	Percent
Parents' ratings	1	0	0	0	0
	2	1	7.1	0	0
	3	1	7.1	2	15.4
	4	0	0	1	7.7
	5	6	42.9	3	23.1
	6	6	42.9	7	53.8
Median		5		6	
Mean		5.07		5.15	

When parents were present (46.67% of sample) as their child completed the CAPE/PAC, they were asked to rate on a six-point scale their degree of agreement with their child's self-rating on this measurement tool (Table 18). In the HFA group, for the CAPE 75% of parents and for the PAC 50% of parents agreed or strongly agreed with their child's rating with a median degree of agreement of 5 for the CAPE and 4.5 for the PAC. This information is not available for the peer group because too few parents in this group observed their children's completion of the CAPE/PAC (peer n=3).

In conclusion, both the CAPE/PAC and the PedsQL demonstrated generally better test-retest reliability for the children in the HFA group than the peer group. The HFA group demonstrated slightly higher test-retest reliability for the PedsQL than for the CAPE but for both measures they demonstrated sufficient test-retest reliability for the study results to be

trustworthy. The test-retest reliability of the PedsQL for the peer group raises some concerns about the generalizability of these scores for this group. Parents generally agreed with their children's self-rating of the CAPE.

Table 18.

High Functioning Autism: Parental Agreement with Child's Ratings of the *Children Assessment of Participation and Enjoyment* (CAPE) and *Preference for Activities of Children* (PAC)

		CAPE (n=16)		PAC (n=14)	
		Frequency	Percent	Frequency	Percent
Rating Scale	1 – Strongly disagree	0		0	
	2 – Disagree	1	6.3	0	
	3 - Slightly disagree	2	12.5	2	14.3
	4 – Slightly Agree	1	6.3	5	35.7
	5 - Agree	7	43.8	4	28.6
	6 – Strongly Agree	5	31.3	3	21.4
Mean		4.81		4.57	
Median		5.00		4.50	

4.5.2 CAPE convergent validity.

The convergent validity between the CAPE overall diversity and the PedsQL total score as well as the CAPE and the VABS-2 Play Time subdomain was estimated. The literature has described recreational participation as a domain of QoL (Verdugo, Schalock, Keith & Stancliffe, 2005). The PedsQL measures a subcomponent of QoL, specifically HRQL. Play is a component of recreational participation and was measured by the Play Time subdomain (Law et al., 2006; McHale, Crouter & Tucker, 1999). In the study protocol, it was hypothesized that the CAPE/PAC would be moderately correlated with both measures but most closely correlated with the Play Time subdomain ($r>0.50$).

A Pearson Product Moment correlation was computed for both pairs of variables for both groups separately. In the HFA group, the correlation between the overall diversity and the total PedsQL (r=.02) and between the overall diversity and the Play Time subdomain (r=-.23) were very low. In the peer group, these correlations were also very low (PedsQL r=.03; Play Time subdomain; r=.09). Thus, the study hypothesis of a moderate correlation between these measures was not confirmed. The study hypothesis of greater correlation of overall diversity with the Play Time subdomain than with the PedsQL was confirmed by a small margin.

4.5.3 CAPE content validity.

An examination of the content of the CAPE/PAC in terms of its appropriateness for use with children who have HFA was conducted using the qualitative information gathered from the children following the second administration of the CAPE/PAC. The children were asked to name recreational activities in which they participated that were not included in the CAPE (Appendix H). Ten of the children did not name additional activities; the others mentioned four additional activities (i.e., inventing things, play with a walkie-talkie, going on-line, and play battle with my sister). “Going on-line” and “inventing things” did not appear to belong to any of the current CAPE items but “play with a walkie-talkie” falls under “playing with things or toys” and “play battle with my sister” may belong to the CAPE activities “doing pretend play” or “playing games”. Thus, the 55 activities included in the CAPE qualitatively appeared to cover the broad range of recreational activities in which children with HFA participate.

Similarly, after completing the PAC, children were asked to name any other activities they would like to do “if they could do anything in the whole world”. Two children with HFA answered “none”. Children in this group named twenty-two other activities. Of these, 10 would fall under the activity “have a paid job” with mostly professions such as “pace car driver” and

"be the President" mentioned. Nine were either related to the child's own area of intense interest such as "getting actual Pokémon training" or they were the general wish of something the child would want if there were no rules such as "stay outside as long as I want" or "not go to bed" but were not a recreational activity per se. Three were recreational activities not listed on the PAC: "meeting a famous person", "learn to fly" and "be a hunter".

4.5.4 Response process.

The CAPE/PAC is a self-rated measure where children can complete the measurement tool independently or can be supported by an adult through adaptations when necessary. The test manual explains that for the factual questions (i.e., intensity, social aspect and location) a parent may answer the questions "if it is clear to the parent that the child is having difficulty answering a question" (King et al., 2004, p. 27). In this study, parents rated to what degree they answered the three dimensions of CAPE questions for their children using a five-point scale (Table 19). The two groups differed significantly on the number of questions answered by the parents for all three dimensions measured (Table 19, $p<0.001$) with parents of the children in the HFA group answering more questions for their children. In the HFA group, for intensity 44%, social aspect 37%, and location 37% of the parents answered 51% or more of the questions. During data collection, the PI kept notes of the adaptations provided to the children to assist them in completing the CAPE/PAC and PedsQL which are summarized by types of adaptations and a list of reasons for which these were provided in Figure 6.

Finally, the study explored the raters' thought process as they responded to the CAPE/PAC by asking them two questions following the second administration of the tool (HFA n=16). Children were asked "how they knew how often they did an activity?" to obtain information about their response process for the intensity dimension of the CAPE. The children

did not provide much depth off information; their responses were as follows: “I guessed” (n=2), “I just knew some of them” (n=2), “I thought about it” (n=2), “I tried to remember” (n=3), “I counted the number of times I did some things like going to the movies” (n=1), “I asked for help from mom” (n=1), and “I don't know” (n=1). Children were also asked to talk about how it felt to answer the questions in the CAPE/PAC more generally. The children provided limited information about this ranging from “fun”, “cool” and “felt good” (n=6), to “so-so” and they “sort of liked it” (n=2), to it was “boring” (n=2). One child stated that it was “hard to do” and one simply stated that he or she “did not know”.

Table 19

Parents Completion of Factual Dimensions of the *Children Assessment of Participation and Enjoyment*

	HFA (n=27) Frequency (Percent)	Peer (n=26) Frequency (Percent)	Mann Whitney U	p
Parents Answering “How Often” Questions			77.00	<0.001
None	4 (14.8)	23 (88.5)		
Up to 25%	9 (33.3)	2 (7.7)		
26-50%	2 (7.4)	1 (3.8)		
51-75%	1 (3.7)	--		
76-100%	11 (40.7)	--		
Parents Answering Social Aspect Questions			149.50	<0.001
None	10 (37.0)	24 (92.3)		
Up to 25%	6 (22.2)	1 (3.8)		
26-50%	1 (3.7)	1 (3.8)		
51-75%	3 (11.1)	--		
76-100%	7 (25.9)	--		
Parents Answering Location Questions			141.00	<0.001
None	10 (37.0)	25 (96.2)		
Up to 25%	5 (18.5)	--		
26-50%	2 (7.4)	1 (3.8)		
51-75%	3 (11.1)	--		
76-100%	7 (25.9)	--		

Key. HFA: High functioning autism.

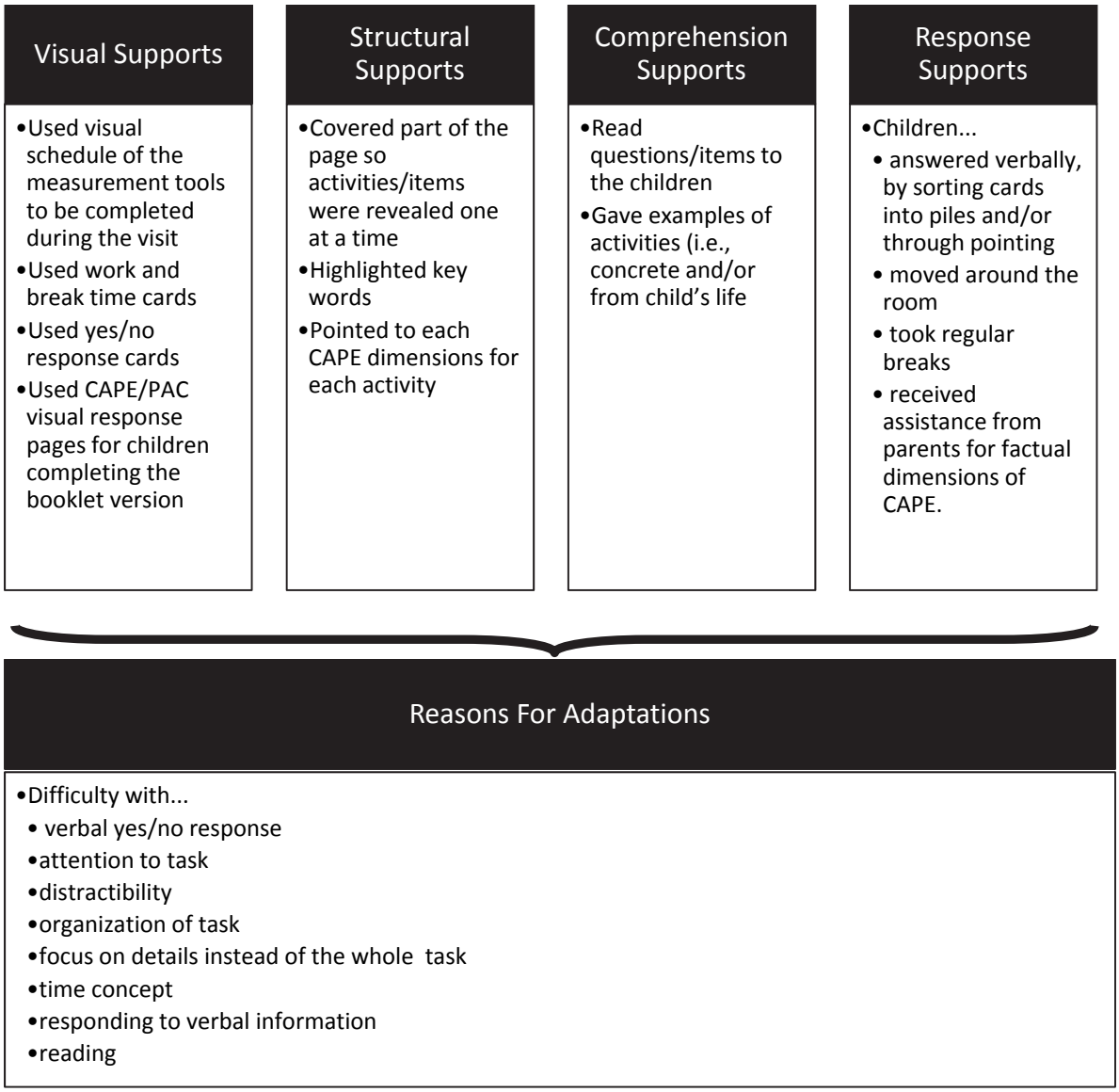

Figure 6. Adaptations provided to children for the *Children Assessment of Participation and Enjoyment/ Preference for Activities of Children* completion and rationale

4.6 Health-related Quality of Life

The objective of this study was to compare the HRQL of children with HFA and their peers as well as explore the relationship between the construct of HRQL and recreational participation in the HFA population. An exploratory analysis of the agreement between parental and child's rating of HRQL was also conducted. The child-self and parent-proxy reports of the

PedsQL were used to measure this construct. One parent in the HFA group did not complete the proxy-version of the PedsQL for their child after three attempts from the PI to obtain the information. Thus, the following analysis was conducted with an HFA group with an n=29 and the peer group with an n=31.

4.6.1 Between group comparison of HRQL.

A MANOVA was conducted comparing children-self and parents-proxy ratings separately between groups. It revealed a statistically significant difference between the two groups contrary to what was hypothesized (Table 20), with the peer group reporting greater HRQL. This statistically significant difference was true for the two summary scores and the total PedsQL score of the child-self and parent-proxy versions.

4.6.2 Agreement between raters about children's HRQL.

In addition to comparing the two groups HRQL, an exploratory analysis of the agreement between parental and child ratings of HRQL was conducted using three methods: ICC, percent agreement, and repeated measures ANOVA.

To estimate the inter-rater reliability between children and parents in both groups, an ICC was computed (Table 21). Low correlations between parents' and children's reports in both groups were found. This indicates that parents and children were not consistent with each other in rating the children's HRQL. Although Streiner and Norman (2008) argue against using standards of magnitude for reliability coefficients, such standards are given here tentatively for the clarity of the discussion. An ICC greater than 0.7 was considered to represent high agreement whereas an ICC between 0.5–0.7 was moderate, and below 0.5 was low (Majnemer, Shevell, Law, Poulin & Rosenbaum, 2008). Of note, two of the correlations were negative (Table 21). ICCs normally range from 0 to 1 (Norman & Streiner, 2008), however negative values are

possible and are indicative of low correlation (J. Bunn, personal communication, October 22, 2010; Taylor, n.d.).

Table 20

Comparison of Health-Related Quality of Life between Groups.

	Group	Mean	SD	F	p
Child-self					
Physical Health Summary	HFA	71.12	17.31	14.65	<0.001
	Peer	85.22	10.65		
Psychosocial Health Summary	HFA	60.86	13.50	31.21	<0.001
	Peer	79.09	11.75		
Paediatric Quality of Life Inventory Total	HFA	64.14	13.24	30.36	<0.001
	Peer	81.28	10.79		
Parent-proxy					
Physical Health Summary	HFA	63.03	21.59	48.13	<0.001
	Peer	92.04	8.46		
Psychosocial Health Summary	HFA	52.76	13.90	83.80	<0.001
	Peer	82.15	10.88		
Paediatric Quality of Life Inventory Total	HFA	56.10	13.58	100.98	<0.001
	Peer	85.54	8.75		

Key. HFA: High functioning autism; SD: standard deviation

Table 21

Paediatric Quality of Life Inventory: Inter-rater Reliability of Child and Parents' Ratings

		HFA Group	Peer Group
Physical Health Summary	Parent-child	.072	.218
Psychosocial Health Summary	Parent-child	-.134	.167
PedsQL Total	Parent-child	-.075	.125

Key. HFA: High functioning autism; and PedsQL: *Paediatric Quality of Life Inventory.*

Further estimation of the degree of agreement between parental and child ratings of HRQL was done by computing the mean absolute difference between scores for both health summary scores and the total PedsQL score divided by the minimally detectable difference of either the parent or child score – whichever showed the largest variability (White-Koning et al., 2007). In the HFA group, the percentage of rater agreement was 41.38% for 'physical health

summary' and 24.14% for the 'psychosocial health summary' and 24.14% 'total PedsQL'. For the peer group rater agreements were 25.81% for 'physical health summary', 22.58% for 'psychosocial health summary' and 74.19% for 'total PedsQL' (Figure 7).

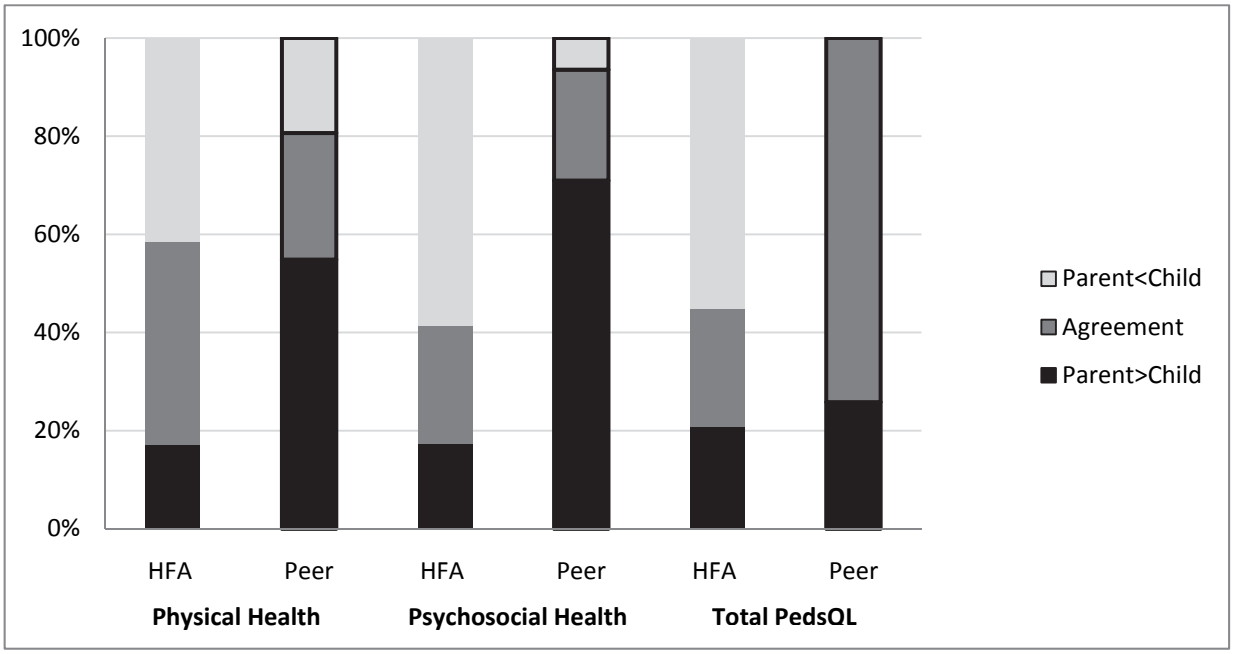

Figure 7. Distribution of rater agreement of the *Paediatric Quality of Life Inventory* (PedsQL).

To further investigate the interaction between raters and groups, repeated measures ANOVA were conducted (Portney & Watkins, 1993). One was done for the physical health and psychosocial health summaries and one for the total PedsQL score. There was a statistically significant interaction between the group (HFA/Peer) and the raters (Child/Parent) for physical health summary ($F= 7.971$, $p=.007$), psychosocial health summary ($F=5.014$, $p=.018$) and total PedsQL ($F=8.288$, $p=.006$). In all three instances, children in the HFA group rated their HRQL higher than their parents, while children in the peer group rated their HRQL lower than their parents, which is consistent with Figure 7. The combined parent-child scores for both summaries

and total PedsQL were statistically significant between groups ($p<0.001$) with the peer group having greater HRQL.

4.6.3 Relationship between recreational participation and HRQL.

In the HFA group, to explore the relationship between HRQL and recreational participation, Pearson's Moment Correlations were computed. All correlations between the children's report and dimensions of CAPE overall were very low to low (Table 22)). Low to moderate correlations between parent ratings of HRQL and CAPE dimensions were found, specifically with diversity and enjoyment having higher correlations but reverse directionality (Table 22).

Table 22

High Functioning Autism Group: Correlations between Health-Related Quality of Life and Recreational Participation Dimensions

	Diversity	Personal Intensity	Social Aspect	Location	Enjoyment
Child-self rating					
Physical Health	.18	.16	.09	.32	-.20
Psychosocial Health	-.05	.30	.24	.02	-.02
PedsQL Total	.02	.29	.19	.13	-.11
Parent-proxy rating					
Physical Health	-.34	.00	-.12	.29	-.41
Psychosocial Health	-.49	-.21	-.14	.16	-.37
PedsQL Total	-.47	-.14	-.05	.23	-.44

Key. PedsQL: *Paediatric Quality of Life Inventory*. Note.

4.7 Conclusion

To estimate the similarities between the groups and the generalizability of the sample to the population being examined, the study compared children with HFA and their peers in terms of child and family characteristics. The two groups were of similar age, intelligence and were

similar on most family characteristics. Both groups differed from the US Census data as participating families had greater education and family income than the average Vermont family.

The study results provided a depth of information about the participation of children with HFA in recreational activities. These children participated in significantly fewer recreational activities than their peers, but they did not express a preference in fewer activities. This discrepancy, however, between actual participation (diversity) and desired participation (preference) was not statistically significant between groups. Children in both groups expressed a similar degree of enjoyment for the activities in which they participated. The relationship between the enjoyment of an activity participated in (diversity) and the desire to participate in activities (preference) was similar between the two groups. Despite participating in fewer activities, children with HFA did not report participating in activities with greater intensity. These same children participated in recreational activities with a narrower range of other people than peers (social aspect). That is, they reported doing activities more frequently alone or with family as opposed to with friends or other people. Children with HFA also stayed closer to home when participating in recreational activities whereas peers participated in more activities in and beyond their communities. Additional details of the recreational participation of children with HFA are presented in the recreational profile section (4.3) of this chapter.

A secondary research endeavor was to contribute to the body of research on the psychometric properties of the CAPE/PAC for children with HFA. The CAPE/PAC showed high test-retest reliability in children with HFA and generally moderate reliability in the peer group. Furthermore, parents generally agreed with their children's self-rating of the CAPE. In terms of content validity, the activities included in the CAPE/PAC qualitatively appeared to cover the broad range of recreational activities in which children with HFA participate. Finally, data were

collected to provide information about the feasibility of children with HFA completing the CAPE on their own. As recommended in the CAPE/PAC test manual, the PI provided adaptations to facilitate the children's completion of the measurement tool (Figure 6). In addition, as also described in the CAPE/PAC test manual, some parents assisted their child in answering some or all of the factual questions. This occurred significantly more in the HFA than in the peer group.

A final component of this study was the estimation of the HRQL of the children in both groups. Children with HFA experienced statistically significantly lower HRQL than peers both on the child-self and parent-proxy ratings of the PedsQL. There was, however, low agreement between raters about children's HRQL.

In closing, multiple analyses of the data were conducted to meet the studies' objectives as planned in the study protocol. A second set of analysis was conducted to develop the recreational profile and to examine data collected that was not planned in the original protocol (i.e., protocol amendments) such as parental rating of children HRQL. In recognition of the number of statistical tests and correlations performed, a lower p-value (.01) was used for the secondary analysis and a more stringent guideline of correlation coefficient interpretation was used. This is considered throughout the discussion and interpretation of the results presented in Chapter 5 and elaborated upon in study limitations (Section 5.5).

Chapter 5: Discussion

This chapter provides a discussion of the study results and their interpretation in relation to the current body of literature about children with HFA. It includes an interpretative view of the characteristics of the sample in relation to the appropriateness of comparing the two groups and the generalizability of the study findings (section 5.1). It elaborates on findings that the two groups were similar on key characteristics and different from the broader Vermont population. It then summarizes the study's contribution to the body of research on the psychometric properties of the CAPE/PAC for children with HFA (section 5.2). It provides evidence that valid and reliable inferences can be drawn from this measurement tool for this population. An in depth examination of the recreational participation findings follows (section 5.3) highlighting similarities and differences between groups. Finally, the HRQL of children with HFA is scrutinized and implications of these results are presented (section 5.4). This chapter ends with a review of the limitations of this study (section 5.5.) and suggestions for future studies (section 5.6).

5.1. Characteristics of the Study Samples: Validity of Comparing the Groups and Generalizability of the Study

Elements of the sample characteristics were studied to determine whether (a) children in the HFA group indeed had HFA; (b) the two groups were comprised of samples of children representing distinct populations; (c) the participating families in the two groups were similar with the exception of the characteristics related to ASD; and, (d) the two samples were representative of the broader population they were intended to represent.

The HFA and peer groups' mean GARS-2 scores were respectively well above and well below the eligibility cut-off score of 70 (Table 5) confirming the appropriateness of group assignment. Intelligence of participants was assessed to be at or above the normal on standardized testing and not statistically distinct between groups (Table 5). This confirmed that the children in the HFA group met the criteria for having this label, that is they had an ASD diagnosis and normal intelligence (Allik et al., 2006; Landa & Goldberg, 2005; Verté et al., 2003). Since the two groups of children were not statistically different on the TONI-3, the differences between the groups in terms of the children's recreational participation and HRQL were not likely related to non-verbal intelligence.

It is interesting to note that within the HFA group, children had much lower adaptive behavior than non-verbal intelligence (Table 5). Thus, the children in the HFA group demonstrated more functional impairments than would be expected from their cognitive abilities confirming findings from the literature (Bölte & Poustka, 2002; Klin et al., 2007; Liss et al., 2001). Within adaptive function, the children with HFA had the highest scores, thus skills, for the communication domain were followed by the daily living skills domain and then the socialization domain. These results confirmed the findings of Klin and colleagues (2007) and Liss and colleagues (2001) who identified the same pattern of challenges.

The two samples in the study were similar on most measured family characteristics. This finding limited the risk of confounding bias of the outcome measured. As a combined group, the participants differed from the US Census data as participating families reported greater education and family income than the average family in Vermont. Rodriguez, Tuvemo and Hansson (2006) found that families with higher education were more willing to participate in studies. This was reflected in our study and two recent studies of participation in children with ASD (Hochhauser

& Engel-Yeger, 2010; Solish, Perry & Minnes, 2010). In one study, the parents' highest level of education was at least some college for 98.2% of peers and 85.9% of children with ASD (Solish et al., 2010). In comparison, in the present study this was true for 90.32% of the peer and 100% of the HFA group (Table 6). Hochhauser and Engel-Yeger (2010) reported high family income for 88% of their HFA group and 84% of their peer group. Direct comparison to the present study was not possible as the "high income" category was not stated for Israel, the country where the study was conducted. Further explanation of higher economic status in the HFA group may come from other investigations reporting a greater risk of having a child with ASD in families with higher socioeconomic status, although this finding was not consistent across studies (Bhasin & Schendel, 2007; Larsson et al., 2005; Maenner, Arneson & Durkin, 2009). These discussion points are conjectures as no direct inference could be drawn about the cause of the increased proportion of participating families with higher socioeconomic status in this study.

5.2 Psychometric Properties of the CAPE/PAC: Contribution to the Body of Literature

As described in Chapter 3, the psychometric properties of the CAPE/PAC were studied previously to allow valid and reliable inference of its scores for children with motor disabilities (Law, King et al., 2006). The developers of this measurement tool specify that it can be used with children with other disabilities (King et al., 2004). In addition to the initial psychometric testing performed by test developers, the psychometric properties of a measurement tool should be tested independently (Cremeens, Eiser & Blades, 2006). "This is especially true in the case of novel application of measures" such as using a measurement tool with a different population (Clausser, Margolis & Swanson, 2008; Upton, Lawford & Eiser, 2008, p. 911). Similarly, the reliability of a measurement tool "has meaning only when applied to specific populations"

(Streiner & Norman, 2003, p. 130). While the CAPE/PAC was used in studies with children with HFA, no discussion of the validity and reliability of drawing inference from the tool's scores for this population, was presented in those articles (Hilton et al., 2008; Hochhauser & Engel-Yeger, 2010).

Although estimating the validity and reliability of the interpretation of the CAPE/PAC in children with HFA was a secondary objective of this study, the soundness of the measurement tool's scores for this population must be addressed before the study's primary objective results can be discussed. In addition to referring to the traditional 'types' of reliability and validity (Streiner & Norman, 2003), the information is organized according to Cook and Beckman's (2006) classification of sources of validity: content, response process, internal structure, relations to other variables and consequences. It is acknowledged that the last source, 'consequences' is not included in this discussion as it would be premature to do so from the information available in the literature and inappropriate with this study's design.

5.2.1 Content validity.

To estimate the content validity of the CAPE/PAC for this population, the study endeavoured to determine whether children with HFA would report participating in recreational activities not captured by the measurement tool. Analysis of the study results revealed that the 55 activities included in the CAPE appeared to cover the range of recreational activities in which children with HFA participate. When asked to name additional recreational activities in which they participated, children named few activities that did not fall under one of the items included in the CAPE. Similarly, the 55 activities included in the PAC also appeared to cover the broad range of recreational activities in which children with HFA may want to participate. However, the more idiosyncratic activities related to an individual child's own area of intense or peculiar

interests, a hallmark of this diagnosis, might not be included on the lists of recreational activities provided by the CAPE/PAC. Clinicians should be aware of this when using this tool with this population.

5.2.2 Response process.

As noted in the literature review (Chapter 1), most previous studies of recreational participation in children and adults with HFA and ASD had parents or guardians reporting on behalf of the person with the disability (Church, Alisanski & Amanullah, 2000; Orsmond, Krauss & Seltzer, 2004; Saldana et al., 2009; Wagner et al, 2002). Several authors, however, have insisted on the importance of self-reporting in individuals with disability and questioned the accuracy of proxy reporting when measuring constructs related to recreational participation (De Civita et al., 2005; Rapkin & Schwartz, 2004; Verdugo et al., 2005). Bearing this in mind, this study was designed for children with HFA to self-report on their recreational participation and data was also collected about the feasibility of this approach (i.e., response process).

The CAPE/PAC is a self-rated measure of recreational participation that allows the person administering the tool to provide adaptations to the instructions and parents to be proxy-reporters for the factual questions included in the tool. This study noted the type of adaptations provided by the PI to enable the children to self-report (Figure 6) as well as the amount of proxy reporting that occurred (Table 19). For a number of reasons (Figure 6), children with HFA required a variety of adaptations to complete the CAPE/PAC. The adaptations included the use of visual, structural, comprehension and response supports. It is likely that similar adaptations would be necessary clinically when using this measurement tool with this population. All the children in the study were able to answer the diversity, enjoyment and preference questions of the CAPE/PAC. It should also be noted that parents were proxy reporters for the factual

dimensions of the CAPE with high proportion (Table 19). Clinically, this would indicate that although children with HFA should be supported in self-reporting for the CAPE/PAC, parents' input might also be necessary to complete the CAPE.

Finally, a reflection of the children's thought process as they completed the CAPE/PAC was conducted. In general, children with HFA lacked insight to share with the examiner about their ratings related to the intensity dimension of the CAPE. Furthermore, while the majority of the children with HFA were able to complete the CAPE/PAC as long as adaptations were provided, some children struggled even with adaptations. In using this tool with children with HFA, clinicians should have visual supports available and be prepared to provide 'structural support' (Figure 6) as these were commonly used in the study. When working with children with HFA who have more limited verbal language and/or more difficulty with attention to task, it is suggested that clinicians only use the parts of the CAPE/PAC that are necessary for their clinical application and that the task be broken up into small sections.

5.2.3 Internal structure: reliability.

To enable the estimation of test-retest reliability for this population, the CAPE/PAC was administered on two occasions one month apart. Between these testing sessions, both groups of parents rated family life as stable (Table 17). For the HFA group, the test-retest reliability was high (Table 16) for most CAPE dimensions and the PAC. In fact, the test-retest reliability was generally higher for the HFA group than for the peer group. It should be noted that in the HFA group, parents answered the factual questions, that is the intensity, social aspect and location dimensions of the CAPE for their children more frequently than in the peer group, which could facilitate better test-retest reliability in this group. However, further examination showed that the correlation coefficients for the factual questions were not systematically higher than for

questions answered by the children with HFA. Thus, parents answering more factual questions did not appear to explain the difference in reliability between the two groups. The test-retest reliability in the HFA group was similar to that reported in the CAPE/PAC manual for children with motor disabilities (King et al., 2004, p. 61) with the exception of the enjoyment dimension which showed higher test-retest reliability in our study. King and colleagues (2004) noted in the CAPE/PAC manual that the lower enjoyment dimension reliability might be related to children rating their enjoyment of their most recent experience. The higher test-retest reliability of enjoyment in our study may have indicated that this was not true of children with HFA.

As a final point of consideration it was noted that the test-retest reliability of the CAPE/PAC in children with HFA was only performed by a sub-group of children, those who after the first administration agreed, together with their parents, to repeat the administration. Analysis revealed that the group of children with HFA who agreed to repeat completion of the CAPE/PAC was not statistically significantly different then the other children in the HFA group on measured child characteristics except for non-literal language and non-verbal intelligence which were both higher. Thus, the reliability coefficient obtained in the HFA sub-sample may not have been representative of the of test-retest reliability in the sample as a whole.

Inter-rater reliability for the CAPE/PAC was not determined in this study, however parents' agreement with their children's self-reports was described (Table 16). The majority of parents in the HFA group agreed or strongly agreed with their children's reports, which supports the reliability of this measure's scores with this population.

5.2.4 Relations to other variables: convergent validity.

The study intended to estimate the convergent validity of the CAPE/PAC by comparing it to other measures whose constructs are related to recreational participation. Children with HFA,

with their unique triad of deficits, may have viewed the construct of recreational participation differently than typically developing peers or children with motor disability, for whom the CAPE/PAC was initially developed. In the present study, the convergent validity of the CAPE with the PedsQL and the CAPE with the Play Time subdomain of the VABS-2 were estimated. These were chosen because they have been shown in the literature to be related to recreational participation (Law et al., 2006; McHale et al., 1999; Verdugo et al., 2005). However, the study hypothesis for an expected moderate correlation between the CAPE/PedsQL and the CAPE/Play Time was not confirmed. This suggested that the two constructs, as measured by these tools, were not as closely related as expected. It did not suggest that the HFA group viewed the construct of recreational participation differently than typically developing peers since weak correlations were present for both groups.

5.3 Recreational Participation Profile of Children with High Functioning Autism

Overall, the present study found that children with HFA reported participating in significantly fewer recreational activities with a narrower range of other people and closer to home compared to peers. They did not participate in recreational activities with less intensity nor did they express less enjoyment in the activities they participated in than peers. This restriction in recreational participation in children with HFA is problematic as recreation is known to reduce behavioral and emotional disorders, help to develop social relationships and friendships, improve physical and mental health, and help children develop interests (King et al., 2003; Mactavish & Schleien, 2004; Rae-Grant, Thomas, Offord & Boyle, 1989; Wilson & Arnold, 1997).

The following sections will elaborate on these findings and highlight similarities and differences with two recently published studies (Hilton et al., 2008; Hochhauser & Engel-Yeger,

2010) that used the CAPE/PAC to estimate recreational participation in children with HFA. The methodological differences between studies bring caution in the interpretation of the results' similarities and differences. Specifically, Hilton and colleagues (2008) did not provide sufficient information about children and family characteristics or confirm the intellectual abilities of the children with HFA with a sound measurement tool. It is, thus, unclear whether the sample of children with HFA in their study and ours were drawn from a similar population. Hochhauser and Engel-Yeger's (2010) study used a Hebrew translation of the CAPE/PAC but the method of translation and the psychometric properties are not well described in the article. These authors used a convenience sample of children with HFA attending three inclusive classrooms. The Hochhauser and Engel-Yeger (2010) study was also conducted in a different country and culture where children with disability and recreational participation may be viewed differently. Complete critical appraisals of these two studies are provided in Appendix B. Thus, although there was value in contrasting the results of our study with these two previous studies as well as other studies of recreational participation in ASD discussed in Chapter 1, conclusions from these comparisons should be done with caution.

5.3.1 Diversity of recreational participation.

Profile of recreational activities diversity. Children with HFA showed less diversity of participation overall than did peers (Table 7). However, when activities were grouped by activity types and domains, only the physical-type activities and the formal domain were statistically different between groups. These results supported previous studies, which found similar diversity of recreational participation between children with HFA and their peers (Hilton et al., 2008; Hochhauser & Engel-Yeger, 2010). In addition to the physical activity type, the difference between groups was greater than the MID for the skill-based activity type. Although this latter

difference was not significant statistically, it may be important clinically for therapists, parents and teachers to be aware of this difference in participation in supporting children with HFA to participate in a wide-range of activities. In comparison to the results of Wagner and colleagues (2002) who found that 17.8% of children with HFA participated in school-sponsored groups, 45.6% in sports teams, 51.9% in religious groups, and 22.5% in Scouting, the present study found that 20% participated in school clubs, 26.7% in team sports, 30% in religious activities, and 23.33% in community organizations including Scouting.

Contrary to findings by Hilton and colleagues (2008) and Orsmond and colleagues (2004) children with HFA in this sample were more similar to typically developing children in terms of diversity of participation for informal activities than for formal activities. Previous assumptions that formal activities would be easiest for children with HFA to participate in were not confirmed (Hilton et al., 2008). Many activities in the formal domain would require a parent to sign their child up for a class or group such as art lessons or joining a sport's team. While there may be a cost associated with these formal activities, this should not have been a barrier for families in this study as their socioeconomic status was fairly high. Most of the activities in the formal domain, however, fall in the skill-based and self-improvement types of activities, which were the least preferred by the children in both groups. Thus, the disparate findings between this and previous studies may be related to regional differences. Possibly, children in Vermont have less interest in such activities, parents may be less inclined to sign them up for participation and/or the rural nature of the state may make these activities less available.

Participation in physical activities. Children with HFA reported participating in significantly fewer physical activities. This confirmed results by Hilton and colleagues (2008). Both formal and informal types of physical activities were very different between the groups,

with a greater than 20% difference in reported participation (Figure 4). These differences held true when physical activities were grouped into organized sports and active physical recreation (Figure 5). Children with HFA also expressed differences in preference for physical activities. This was a new finding, since Hilton and colleagues (2008) and Hochhauser and Engel-Yeger (2010) did not include the PAC in their study. For the physical activities in which the children with HFA reported participation, there was no statistically significant distinction in terms of intensity, social aspect, location or enjoyment.

Children with HFA in this study had poorer gross motor skills compared to peers. This could be related to the finding of decreased participation in the physical type of activities. Motor impairments in children with ASD and HFA have been well documented (Green et al. 2002; Molloy, Dietrich & Bhattacharya, 2003; Rinehart, Bradshaw, Brereton & Tongue, 2001; Rinehart et al., 2006) and children with HFA have a decreased sense of athletic competence (Williamson, Craig & Slinger, 2008). Furthermore, the degree of motor impairment appeared to increase with the degree of autistic characteristics (Hilton et al., 2007). However, no causal link can be drawn as other impairments associated with HFA such as poor social cognition (Adolphs, 2001; Bauminger, Shulman & Agam, 2003) may also have contributed to decreased participation in physical activity, specifically those that involved participation on a team. Children with HFA in this study had impairments in components of social cognition, specifically pragmatic and non-literal language as measured by the CASL.

Moreover, restriction in participation in physical activity could have a negative health and fitness consequence for children with HFA. A recent study found that these children have significantly poorer physical fitness than peers (Borremans, Rintala & McCubbin, 2010). In addition, a recent population-based study found that the odds of obesity in children with autism

who were 3-17 years of age, was 1.42 greater than in the general population (Curtin, Anderson, Must & Bandini, 2010). Obesity poses significant health concern in children (Curtin et al., 2010). Physical activity is known to alleviate the risk of being overweight or obese (Public Health Agency of Canada, 2010). It is recommended that children gradually increase their physical activity to 60 minutes of moderate and 30 minutes of vigorous physical activity per day (Public Health Agency of Canada, 2002). Considering the findings of this study, this may be difficult to achieve with children with HFA. Occupational and physical therapists could explore with teams barriers to participation in physical activities for these children promoting health and fitness (Potvin, Prelock & Snider, 2008).

Participation in pretend play. Children with ASD have consistently been found to have difficulties with pretend play showing "decreased frequency, complexity and novelty of spontaneous pretend play behavior" (Rutherford, Young, Hepburn & Rogers, 2007, p. 1024). Children in this study were found to have significantly poorer play skills as measured by the VABS-2 (Section 4.3.3) but pretend play skills were not specifically assessed. However, 86.67% of children with HFA reported engaging in 'pretend or imaginary play', almost 20% more than did the peer group. This may be partially explained by findings that children with ASD with higher non-verbal intelligence, as in this study, have better pretend play skills than children with ASD and lower measured intellectual abilities (Stanley & Konstantareas, 2007). Mazefsky and Oswald (2007) stated that in children with Asperger Disorder pretend play was observed but the content of play involved unusual objects or themes. This could have been the case in our sample of children with HFA, who may have been engaging in pretend play frequently but with a more limited range of pretend themes. Future studies could investigate the type of activities that

children with HFA would identify as pretend play and determine whether their play skills are more immature within those activities.

Parents' satisfaction with children's recreational participation. In the HFA group, parents were less satisfied with their child's recreational participation than parents of peers (Section 4.3.3). However, parent satisfaction was minimally explained (r^2= 4.37%) by the number of recreational activities in which these children participated. Future studies could explore with parents the causes for their dissatisfaction. This could lead to the development of strategies to increase the recreational participation of children with HFA.

5.3.2 Intensity dimension of recreational participation.

Peers reported greater overall general intensity of participation. However, there was no difference in overall personal intensity of participation, suggesting that the previous findings are related to the number of activities that peers undertake. For the recreational type of activities, there was a difference in personal intensity with children in the HFA group reporting a greater intensity of participation. These results mirrored findings by Hilton and colleagues (2008) who identified differences in personal intensity for 'recreational' type activities specifically, but no statistically significant difference in personal intensity overall. However, these results contrast with the findings of Hochhauser and Engel-Yeger (2010) who found that children with HFA had significantly lower personal intensity of participation (overall score). With the present sample, it can be concluded that despite participating in fewer activities, the intensity of the HFA group's recreational participation was not different than their peers.

5.3.3 Location dimension of recreational activities.

This study found that children with HFA participated in recreational activities in a narrower range of locations when compared to peers. This confirmed similar results from Hilton

and colleagues (2008) and Hochhauser and Engel-Yeger (2010). Specifically, children with HFA participated in 'recreational type' and the informal domain activities closer to home compared to peers. Although not statistically significant for all types and domains of activities, children with HFA systematically reported participation in activities in a narrower range of locations, such as at home or in a relative's home.

While this study did not systematically investigate the cause of this finding, parents of children with ASD previously reported refraining from participating in activities outside the home because of their child's behavior (Fox, Vaughn, Wyatte & Dunlap, 2002). The children with HFA in this study were reported to have significantly more maladaptive behaviors on the VABS-2 than typically developing peers (Table 5).

5.3.4 Social dimensions of recreational participation.

The CAPE measured the social nature of recreational activities in two ways: with whom the children participate in recreational activities (social aspect), and characteristics of participation in activities falling under the social activity-type. These are discussed separately in the following paragraphs.

The social aspect of recreational participation was statistically significant between groups overall. Children with HFA participated in recreational activities with a narrower range of other people than did typical peers, who reported more participation with friends and other children or adults. These findings confirmed those of Hilton and colleagues (2008) and Hochhauser and Engel-Yeger (2010). These findings were also in line with previous studies that found that children with ASD participated in fewer activities with peers (Solish et al., 2010), had fewer friends (Bastiaansen et al., 2004; Koning & Magill-Evans, 2001; Orsmond et al., 2004; Solish et

al., 2010), experienced social isolation from their peers (Macintosh & Dissanayake, 2006) and had limited out-of-school interactions with friends (Wagner et al., 2002).

Contrary to the study hypothesis, there was no statistically significant difference between groups on diversity of participation in social-type of activities. Actually, diversity in social-type activity was the least different between groups of all activity types and domains (Table 7 and Figure 4). This finding was contrary to that of Hilton and colleagues (2008), Hochhauser and Engel-Yeger (2010) and Solish and colleagues (2010). This study result was unexpected as social impairments are a hallmark of HFA (Koning & Magill-Evans, 2001). The social impairments of the HFA group were confirmed by the scores on the social domain of the VABS-2 and on the statistically lower psychosocial health summary of the PedsQL. Macintosh and Dissanayake (2006) reported that, despite their social impairments, children with HFA spent an important part of their free playtime engaged in social interactions. In addition, inspection of the activities included under social-type activities of the CAPE (e.g., going to a party, full-day outing, movie or visiting) revealed that these might have been parent initiated. This may have masked differences between groups. However, if this were true, it would be expected to have been true in the Hilton and colleagues (2008) and Hochhauser and Engel-Yeger (2010) studies since they also used the same measurement tool. A closer look at mean differences between groups (.33) and the greater variance within a group (SD=1.89) suggest that increasing the sample size of the current study would not have changed the finding. Exploration of this result contrasting with previous studies should be investigated further.

A possible explanation of this finding comes from Vermont's educational model promoting the inclusion of all students with disabilities in regular classes in their community schools, with additional supports for the last 20 years. Although the diversity of activities, the

social aspect and location of activity participation overall were more narrow in the HFA group, these children did report participating in diverse activities, many with peers and in their neighborhood and broader community. This may reflect the benefits of inclusive education in one's community where relationships can be established. This theory is supported by Orsmond and colleagues' (2004) finding that availability of inclusive recreational activities favored recreational participation in children with HFA. It may also reflect societal acceptance of individuals with disability and awareness of ASD in these communities. It would be interesting to study the impact of inclusive educational practices on the recreational patterns of children with HFA and other groups of children with disabilities.

5.3.5 Enjoyment and preference dimensions of recreational participation.

No statistical difference in reported enjoyment was found which supported the findings of Hilton and colleagues (2008), but was in contrast to the findings of Hochhauser and Engel-Yeger (2010). There is consistency between reported enjoyment expressed for activities in which children participated and the degree of desire (preference) to participate in an activity 'if they could do anything in the whole world', which supports the reliability of the children's responses.

With the exception of physical-type activities, which were statistically lower in the HFA group, children in both groups expressed a similar degree of activity preferences. This remained true when the MID was computed by activity-types and domains. Analysis showed that children in both groups participated more in activities in which they had a greater preference and less in activities for which they expressed less preference (Table 10). However, the HFA group had greater variability in the measurement of preference for activities in which they had not participated. Therefore, some children may have had an interest (preference) for activities in which they did not actually participate. This may partially explain the finding that, in spite of a

similar degree of preference for activities, children in the HFA group actually participated in fewer activities than the peer group. This finding suggests that parents are supporting children in participating in activities in which they have interest (preference) although there may be additional activities, which might be explored with families.

The preferences of the HFA group for recreational participation have not been previously reported in the literature. However, there is extensive literature, including the DSM-IV, describing these children as having circumscribed interests for specific topics; some usual for the child's developmental age, others unusual (American Psychiatric Association, 1994; Mazefsky & Oswald, 2007; South, Ozonoff & McMahon, 2005; Szatmari et al., 2005). These well-documented circumscribed interests were not reflected in the preferences expressed in this study by children with HFA. However, some were mentioned when children were asked to name additional activities in which they had a preference for the content validation component of the study. Consequently, it could be valuable when using this tool clinically to ask children about any additional recreational interests (preference) after completing the PAC.

5.3.6 Child-based factors related to recreational participation.

As a secondary objective, the study intended to identify child-based factors related to recreational participation. However, no significant effects could be identified in the factors selected. The sample size was likely too small to estimate the effect of such factors if indeed an effect was present. Moreover, the three factors selected for the analysis (i.e., communication skills, social skills and social cognition) could have been too closely related to reveal a factor that had a significant effect. From the results of this study, social cognition was the factor that seemed most likely to have a significant effect. Thus, future study of this factor with a larger sample size would be appropriate. King and colleagues (2003) grouped child-based factors as

'physical, cognitive and communication function' and 'emotional, behavioral and social' function. It is possible the child-based factors in children with HFA should be grouped differently to reflect their unique profile of disabilities as in this population communication and social functions are closely related.

5.4 Health-Related Quality of Life in Children with High Functioning Autism

The present study set out to gain knowledge about components of HRQL of children with HFA compared to peers, about the relationship between the parents and the child's viewpoints about children's HRQL, and about the association between HRQL and recreational participation. As a first step in gaining this knowledge, the soundness of the psychometric properties of the PedsQL was examined. The PedsQL test-retest reliability in the HFA group was high for the psychosocial health summary and total scores but only moderate for the physical health summary (Table 16). Thus, the PedsQL demonstrated suitable test-retest reliability for this population strengthening the interpretation of the study results about HRQL that follows.

5.4.1 Health-related quality of life in children with high functioning autism compared to typically developing peers.

Both parents and children reported that children with HFA had significantly poorer HRQL than their peers for physical health summary, psychosocial health summary and the total HRQL scores (Table 20). The range of reported HRQL was wider for the HFA group than the peer group suggesting greater variation in HRQL in the former group over the latter. The physical health summary showed the greatest variation for both child and parent ratings. This confirms findings from Limbers and colleagues (2009) in their study of 22 children with Asperger Syndrome who had significantly lower HRQL as measured by the PedsQL than

normative healthy children per parent report. On the other hand, it differed from Bastiaansen and colleagues (2004) who found no statistical difference in child-self ratings of HRQL between children with ASD when compared to children 'without a diagnosis'.

5.4.2 Health-related quality of life of children: self-rating compared to proxy rating.

The study found a statistically significant interaction between child-self and parent-proxy ratings of HRQL in both groups. The parents of children with HFA gave lower scores whereas parents of peers gave higher scores compared to their children's ratings. The percentage of agreement between raters using the MID as the cut-off for disagreement was in general quite low for both groups, although it was high for the total PedsQL scores of the peer group (Figure 7). The correlation between child and parent ratings for both groups was very low although it appeared to be lower for the HFA group (Table 21). In summary, parents and children of both groups did not agree on child HRQL and the direction of disagreement was different between groups.

The correlation found in this study appeared much lower than reported by Bastiaansen and colleagues (2004) who found correlations of 0.38 between child and parent ratings of HRQL in children of the similar age range with a variety of mental health diagnoses including ASD. They correlated the parent and child ratings of HRQL for the combined group of children in their study. When our two groups were combined, the correlation coefficient was 0.45, above that found in the Bastiaansen and colleagues (2004) study. No other studies comparing children and parents' ratings of HRQL in this population have been found. However, the broader literature on children's disability suggested that the degree of agreement between parents' and children's ratings of HRQL varied greatly (De Civita et al., 2005; Majnemer et al., 2008). Furthermore, a systematic review found that parents of typically developing children generally reported higher

HRQL whereas parents of children with disabilities tended to rate HRQL lower than their children (Upton et al., 2008), as was found in our study. The last two points bring to question whether combining groups when comparing child-self and proxy ratings of HRQL, as done in the Bastiaansen and colleagues (2004) study, is desirable.

In the present study, the weak correlation between parent and child's ratings indicated that parents of children with HFA were not good proxy raters of their children's HRQL. Since quality of life is a subjective construct (Colver, 2009), parents' ratings should, therefore, not take the place of the children's ratings as has been done in most of the studies of HRQL in the ASD/HFA population reviewed in Chapter 1. The very low correlation between parent and child ratings did not necessarily mean that parents were inaccurately rating their children's HRQL. Rather, this could represent a real difference between the two raters' points of view (Upton et al., 2008; White-Koning et al., 2005), which may provide an important additional clinical perspective (Coghill et al., 2009). Possible reasons for these different points of view were presented in the literature. These included parents' own negative feelings about their children's HRQL, the parent-child relationship and the differences in the importance raters attributed to different aspects of functioning (De Civita et al., 2005; White-Koning et al., 2005). In children with CP, higher parental stress as well as lower child behavioral and emotional health were determinants of parents ratings their children's HRQL lower than the children's own self-report (White-Koning et al., 2007). These determinants could be at play in our study as parental psychological QoL and stress has been identified in the literature as being increased in parents of children with HFA and ASD (Ingersoll & Hambrick, 2011; Mugno, Ruta, D'Arrigo & Mazzone, 2007; Rao & Beidel, 2009) and children had significantly higher levels of maladaptive behaviors as measured by the VABS-2 (Table 5). White-Koning and colleagues (2007) also found that high

parental education was associated with greater differences between child-proxy ratings of HRQL in either direction. This could partly explain the high differences found in our study, as most parents in both groups had some college education.

5.4.3 Exploration of the relationship between recreational participation and health-related quality of life in children with high functioning autism.

This study intended to explore the relationship between recreational participation and health-related quality of life. Participation in recreational activities could increase quality of life (Law et al., 2004). In the present study, the child and parental ratings of the children's HRQL had very low, to low correlation with dimensions of recreational participation (Table 22). The coefficient of determination was computed to determine the degree of covariance between HRQL and recreational participation. It was determined that diversity and enjoyment of recreational participation explained 22% and 19%, respectively of children's HRQL per parents' rating. In comparison, diversity and enjoyment of recreational participation explained .04% and 1%, respectively of children's self-rating of their HRQL. Thus, there was a greater association between children's diversity and enjoyment of recreational participation with parents' ratings of children's HRQL than the children's own rating however these were in reverse directions. This might be a reflection of difference in point of view between children and parents about children's HRQL as noted in the literature (Coghill et al., 2009). Actually, children's diversity of recreational participation was more closely associated with parents' rating of children's HRQL than parents' satisfaction with their children's recreational participation. The relationship between HRQL from both parents' and children's points of view, dimensions of recreational participation, and satisfaction with recreational participation should be further explored in future studies.

A final point to consider when interpreting this study's finding of children's patterns of recreational participation poorly correlating with child-rating of their own HRQL, is whether a narrower range of diversity and context of recreation is necessarily worse from the child's point of view. It was stated that "greater participation is not necessarily better" (Law et al., 2006, p. 342). Exploring this further, the study found a close relationship between the activity that children participated in and the expressed interest (preference) for activities suggesting the children are participating in the recreational activities in which they wish too engage. Thus, the observed restrictions in recreational participation could be a reflection of children's desired patterns of recreation (preference), which would explain the limited correlation between HRQL and recreational diversity. On the other hand, studies have found that individuals with ASD express a need for greater social interaction (Bauminger et al., 2003; Muller, Schuler & Yates, 2008). This could be true as well of their recreational engagement. Information is lacking but could be gathered through future studies.

5.5 Study Limitations

While steps were taken to recruit from multiple sources and reach the entire population of families who had a child with HFA within the defined catchment area, the study sample was made up of volunteers. Thus, there could be something different about the families who chose to participate in the study compared to those who did not. In fact, the participating families had higher income and greater education than the general Vermont population. Income may influence recreational opportunities. In addition, the study was conducted in one, mostly rural state whose educational inclusive practices may have impacted the recreational profile of the

participants. Consequently, generalization of the results to the entire population of families with a child with HFA should be done with caution.

The study was a descriptive analysis, which could describe patterns and illuminate relationships but did not permit causal inferences to be made. Further, the sample size was relatively small which limited the type and number of statistical analyses that could be done. To partially palliate this, a smaller p-value was chosen for the exploratory component of the analysis. A larger sample size would allow the investigation of determinants of recreational participation in the children, including family's recreational participation patterns, children's skill-based strengths and limitations as well as environmental opportunities for recreation. The study examined potential determinants by exploring the relationship between diversity of recreational engagement with children's 'play skills', parents' satisfaction with their child's recreational participation, and child self-reports of HRQL individually. It also investigated child-based (i.e., communication skills, social skills and social cognition) determinants of recreational participation without identifying a specific factor. Thus, much remains to be known about factors affecting recreational patterns in these children.

The characteristics of the children included in the study were thoroughly described and improved over previous studies as actions were taken to confirm their diagnosis independently. However, this could have been strengthened by using the *Autism Diagnostic Observation Schedule* (ADOS; Lord, Rutter, DiLavore & Risi, 1999) and the *Autism Diagnostic Interview-Revised* (ADI-R; Rutter, Lord & LeCouteur, 2003), the current gold standards in diagnosing children with ASD instead of a screening tool (i.e., GARS-2). Information about the degree of autism-related characteristics, an assumed determinant of recreational participation, may have been better captured by the ADOS or the *Social Responsiveness Scale* (Constantino & Gruber,

2005). Furthermore, although the TONI-3 has been found to correlate with broader measures of intelligence (Brown et al., 1997), it only estimates one component of intelligence directly. Future study should consider the feasibility of using a broader measure of intelligence such as the *Wechsler Intelligence Scale for Children* (Wechsler, 2003) as well as more sensitive measures of social cognition.

The study collected data about the validity and reliability of interpreting the CAPE/PAC and PedsQL scores for this population. In parallel, it also collected this information for the peer group. The test-retest reliability scores for the peer group on the CAPE/PAC and more importantly on the PedsQL were lower than what was desired. Until further studies of these tools are conducted, interpretation of the peer group results should bear this in mind.

5.6 Suggestions for Future Studies

This study and the two published since data collection started in July 2007 have begun to describe the recreational participation patterns of children with HFA in a comprehensive manner. A larger study that would build on the methodological strengths of this study, with a representative sample that is ethnically, socioeconomically and geographically diverse could be conducted to provide a population-based description of their patterns of recreation and their HRQL. It would be essential to begin to explore determinants of recreational participation in this population, which a larger sample would allow. Potential determinants to be studied were discussed throughout Chapters 4 and 5.

Although this study has demonstrated that children with HFA can report their own patterns of recreational participation using the CAPE/PAC, future studies could obtain parallel parental reports so that similarities and differences could be explored. Such study could also

scrutinize determinants of parental satisfaction with their children's recreational engagement. It would also be useful to learn about the children's satisfaction with their own recreation.

Studies should also examine the quality of the children's recreation beyond the concrete dimensions included in the CAPE/PAC. For example, children in the study reported participating in high percentages in pretend play but the quality, variety and creativity of this play were not explored. Similarly, depth of information could be gained about other activities such as those falling in the social-type of activities in which children appeared to participate more than expected from other studies.

To determine whether the profile of recreational participation found in HFA is unique to the disorder or related to the patterns of deficits and strengths, studies could be conducted comparing these children to other well-defined groups with social and/or behavioral difficulties, such as those with oppositional defiance disorder. Additionally, studies could identify the recreational profile for children with different severities of ASD characteristics. It would be essential to tie in the concepts of children's satisfaction with their recreational engagement to determine whether the observed differences are problematic from their point of view.

Future studies should also continue to investigate the validity and reliability of the inferences of the CAPE scores in children with HFA. It would be interesting to learn from individuals within this population whether the activities would be grouped within the same activity-type as was found with individuals with motor disability. It is suspected that children would focus on different aspects of the activity and may group them differently.

This study has found low agreement between raters about children's HRQL. Additional studies should be conducted to explore the perceptions of parents and children about the children's HRQL. Such study should also explore determinants of HRQL in children with HFA

and determinants in parents that alter their ratings of their children HRQL. Finally, the validity of using the PedsQL to infer HRQL in children with HFA should be further examined. Since, children with HFA generally think concretely, they may have interpreted the PedsQL questions differently than what was intended.

On a different note, this study highlighted the daily living skills impairments in this population in spite of normal or above average intelligence. This finding was consistently reported in the literature. However, the characteristics of the HFA diagnosis do not by themselves explain this finding. Future studies of the causes of daily living skills impairments in children with HFA should be undertaken so that interventions may be designed and tested. Studies could also explore the enabling role that occupational therapists currently hold in improving daily living skills in the children with whom they work.

5.7 Conclusion

This study builds on previous knowledge of recreational participation in HFA. Its rigor in describing the characteristics of children and families is unique compared to what has been published in this population. Key elements of findings and discussion are concisely described here followed by a thesis summary (Chapter 6) and a summative conclusion (Chapter 7).

Differences were found in patterns of recreational participation between the two groups: some confirmed the study hypothesis while others did not. Children with HFA reported participating in significantly fewer activities with a narrower range of exposure to other people and staying closer to home, but not with less intensity compared to peers. Their enjoyment and preferences did not vary significantly from those of peers. Although these findings of restricted recreational engagement are of concern considering the potential benefits of recreation, one

should keep in mind that more participation is not inherently better. Regional differences in activity participation may be interesting to investigate as well as factors causing the decreased participation in physical activity in this population.

This study also contributed to the body of literature about the validity and reliability of interpretation of CAPE/PAC scores for children with HFA. Its findings supported the use of this tool with this population looking at a broad range of psychometric properties; however, these were described using a relatively small sample.

The study did begin to address the need identified by Hilton and colleagues (2008) to examine the well-being of children with HFA in relation to recreational participation. It is the first to estimate HRQL in children with HFA as compared to peers, from the child's point of view. It also is the first study to compare the HRQL as measured by the PedsQL for these two populations using actual samples. Children with HFA reported having lower HRQL than peers, which was confirmed by parents. However, parents' and children's ratings showed poor agreement suggesting that the two sets of raters were scoring different aspects of HRQL. The possible reasons for these differences were not systematically studied in this project but the literature points to possible determinants. There was low to moderate association between HRQL and recreational participation in this study; however, there was a greater association between children's diversity and enjoyment of recreational participation with parents' ratings of children's HRQL than the children's own ratings.

Chapter 6: Thesis Summary

High functioning autism is a prevalent neurodevelopmental syndrome with associated core deficits that affect social participation and HRQL. The extent of involvement in recreational participation and HRQL of school age children with HFA have not been fully examined, although current evidence suggests that it is restricted. Participation in recreational activities is an essential part of human performance and offers wide ranging benefits across the life span. To date, studies of patterns of recreational participation and HRQL in this population have had important methodological limitations. Furthermore, studies describing the viewpoint of children with HFA about their HRQL compared to peers are missing. Greater understanding of the recreational engagement profile and HRQL of children with HFA could be used by teachers, clinicians and parents to address barriers to these children's participation in recreation.

This cross sectional study was conducted with the primary objective to compare the patterns of recreational participation of children with HFA compared to typically developing peers. To further elucidate these patterns, secondary objectives included the identification of child-based factors related to recreational participation; estimation of the HRQL of these children; and accumulation of knowledge about the interpretation of the CAPE/PAC scores in this population (psychometric properties).

A sample of children with HFA (7-13 years old; n=30) was recruited through multiple sources in an effort to achieve representativeness of the population. Peers (n=31) were recruited through the same e-mail lists as well as community e-mail lists. Children with HFA were eligible to participate in the study if (a) they had a current ASD diagnosis; (b) had an intellectual quotient of at least 80 or an adaptive functioning score of at least 60; (c) spoke English at home; and, (d) did not have neurodevelopmental co-conditions. The peer group was comprised of typically

developing children who met the same criteria except for a diagnosis on the autism spectrum. They also had not received special education supports during the last or current school year. Ethical approval was obtained from all appropriate institutions and agencies.

The data collection for each participant took place over two or three visits at a location convenient to the participants. The primary investigator conducted interviews and administered the following standardized measurement tools to the parents and children: GARS-2, TONI-3, CASL, VABS-2 as well as the two outcome measures: the CAPE/PAC and PedsQL. The data analysis included a combination of descriptive and inferential statistics. In addition to conducting the statistical analysis to answer the research questions, a recreational profile for children with HFA was developed.

The children in both groups (HFA: 26 boys, 4 girls; peer: 27 boys, 4 girls) and their families were similar on all measured key characteristics (i.e., child's age and IQ, family composition and income) except for highest level of educational attainment. Participating families had primarily an intact family unit and were from the middle to upper-middle class. Participating families in both groups, differed significantly ($p<.001$) from the broader Vermont population in socioeconomic status; consequently, this study's results should be interpreted cautiously when considering other social class.

The CAPE/PAC demonstrated adequate content validity, test-retest reliability ($r>.7$), agreement of parents with children's reports (mean= 4.81 out of 6), and response processes. This supported the appropriateness of interpreting the CAPE/PAC scores for this study and more broadly within this population.

Children with HFA differed from peers in terms of diversity of recreational participation overall ($p=.002$) and specifically for physical-type activities ($p<.001$) and formal-domain

activities (p=.002). They participated in these activities with a narrower range of individuals (social aspect; p=.006) and locations (p<.001). However, they did not participate in these recreational activities with less intensity (p=.684) nor did they enjoy them less (p=.239) than their peers. Children with HFA also did not express a desire to participate (preference) in fewer activities than their peers except for activities falling in the physical-type (p=.007). A profile of recreational participation was developed through descriptive statistics (Section 4.3). Parents' reported importance of recreational participation did not differ between groups; however, parents of children with HFA reported significantly lower satisfaction (p<.001) with their children's recreation. Children with HFA had significantly poorer HRQL whether reported by themselves (p<.001) or their parents (p<.001). That said, there was very low agreement between children and parental reports of HRQL in both groups, likely a reflection of difference in point of view between children and parents.

The study confirmed, refuted and expanded findings from existing literature about recreational engagement and HRQL in children with HFA. It contributed to the knowledge base about the extent of involvement of these children in recreation. These results, in the context of the study's limitations and the current literature of these topics bring to light conclusions which are summarized in Chapter 7.

Chapter 7: Conclusion

It is important to understand the impact of HFA on recreational participation and HRQL in order to provide services and supports to improve the lives of these children and their families. A positive finding is that children with HFA are participating in a variety of recreational activities, albeit fewer than typically developing children as hypothesized. This restriction was especially true for physical activities, which may have health and fitness consequences. Similarly, the children with HFA were participating in some activities with friends and away from their home but less so than peers. It is encouraging that the children with HFA like their peers enjoyed their recreational participation and expressed interest for a variety of activities. However, findings that children with HFA experience poorer HRQL, contrary to our hypothesis, is concerning. The study was the first to estimate the HRQL of children with HFA compared to peers from the perspective of the children.

Additionally, this study is unique as it ascertained the feasibility of gathering recreational participation and HRQL information from children with HFA. This actually proved essential, as parents and children appeared to regard these constructs from different perspectives. Both points of view should be sought clinically and in future research, with appropriate adaptations given to allow the children to self-report.

Further, the results of this study provide parents, rehabilitation professionals, teachers, and administrators an empirical understanding of the impact of the deficits associated with HFA on recreational participation. It confirmed, with greater methodological strengths, some of the findings of two recently published studies. The recreational profile reveals children's penchants and least liked activity types, such as pursuit of physical activity, which may require greater support. Clinicians and educators can use this information to guide their practice and program for

these children, including asking children for their activity preferences, which are likely to serve as motivators for engagement. The insight gained from this study will benefit families who are in the best position to promote their children's involvement in recreation.

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Appendix A

Collaborating to Support Meaningful Participation in Recreational Activities of Children with Autism Spectrum Disorder

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ABSTRACT

Participation in recreational activities is associated with higher quality of life and life satisfaction; it is essential to our lives. Individuals with Autism Spectrum Disorder (ASD) experience restriction in the range of recreational activities in which they participate. Complex factors impede participation in recreation activities for children with ASD, underscoring the need for professionals to work with parents to enhance participation in recreational activities. Given opportunity and adaptations, individuals with ASD can participate and enjoy the same recreation activities as others. This article describes the application of family centered care and collaborative teaming principles to maximize the participation of children with ASD in recreational activities.

KEYWORDS:

Autism Spectrum Disorders, Children, Recreation, Participation, and Collaborative Teaming

INTRODUCTION

Although participation in recreational activities is important (Coyne & Fullerton, 2004; Mactavish & Schleien, 2004), for many individuals with disabilities such participation is restricted by impairments associated with the disability (King et al., 2003). As an example, children with Autism Spectrum Disorder (ASD) are likely to have limited recreational opportunities considering their social, communication and behavioral impairments. Yet, planning for participation in recreational activities is seldom a focus in their educational programs. Further, considering the multi-faceted factors restricting participation for children with ASD, it is unlikely that parents, teachers, or therapists alone would be able to promote participation in a range of meaningful activities. Consequently, parents and professionals must collaborate in defining, planning and implementing participation in recreational activities.

This article describes the importance of participation in recreational activities and highlights the known and potential impact of ASD on children's recreational participation. Further, it offers an application of collaborative teaming and family-centered care principles to support the recreational participation of children with ASD.

PARTICIPATION AND THE IMPORTANCE OF RECREATION

Participation represents "the complete range of domains denoting aspects of functioning from both an individual and a societal perspective" (WHO, 2002, p.8). Recreation, a participation domain, includes involvement in formal and informal activities such as play, sports, relaxation, going to the theatre, crafts, playing music and tourism (WHO, 2001). Recreational participation is also recognized as a fundamental right in the United Nations on the Convention on the Rights of the Child [in article 23], included as a complement to academic programs in the No Child Left Behind Act of 2001 (P.L. 107–110), included as a related service in the Individual

with Disability Education Improvement Act of 2004 (P.L. 108-446) and mandated nationwide to be accessible for all individuals through the Rehabilitation Act (P.L. 102-569).

Unfortunately, children with disabilities participate in fewer recreational activities than typically developing peers with negative impact on long-term child outcomes (Faison-Hodge & Porretta, 2004; Mancini, Coster, Trombly, Timothy, & Heeren, 2000). This is problematic, as recreational participation has extensive benefits for children with disabilities. It can reduce behavioral and emotional disorders, help develop social relationships and friendship, improve physical and mental health, and help children develop their interests (King et al., 2003; Mactavish & Schleien, 2004; Rae-Grant, Thomas, Offord, & Boyle, 1989, Wilson & Arnold, 1997). Recreational participation is also associated with an improvement in family relationships and family life satisfaction (Mactavish & Schleien, 2004). Moreover, participation in recreational activities is related to an increased quality of life and life satisfaction, both determinants of health and wellbeing (Law et al., 2004).

RECREATIONAL PARTICIPATION OF INDIVIDUALS WITH ASD

ASD is characterized by core deficits in social skills, communication, and in restricted, repetitive and stereotyped patterns of behavior (American Psychiatric Association, 2000). The communication and social impairments associated with ASD have been studied extensively and a thorough review of that literature is beyond the scope of this article. Briefly, children with ASD have difficulties with pragmatic and paralinguistic language, social cognition, and executive function (Harris et al., 2006; Landa & Goldberg, 2005). Individuals with ASD may also have sensorimotor differences, such as difficulties with motor initiation and planning, and fine motor delays (Provost, Lopez & Heimerl, 2007; Rinehart et al., 2006). Each of these impairments has the potential to have an impact on participation in recreational activities.

ASD also has important psychosocial impacts on affected children and their families that can influence their ability to fully participate in recreational activities. For example, children with High Functioning Autism (HFA) have a higher prevalence of anxiety and depression than typically developing peers (Belini, 2004; Gillott, Furniss & Walters, 2001; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000). They also report feelings of loneliness to a greater degree than their peers (Bauminger et al., 2003). Similarly, mothers of children with HFA have reported poor physical and mental health (Allik et al., 2006) and siblings of children with ASD have reported poor quality of life as well (Verté et al., 2003). Notably, the literature has begun to suggest that such psychosocial impact can be reduced when children with disabilities and their families, such as those with ASD, participate in recreational activities (Mactavish & Schleien, 2004).

The literature indicates Orsmond, Krauss and Seltzer (2004) found that walking or "getting exercise" was the most frequent recreational activity mothers (n = 235) reported for their adolescent or adult child with ASD. They also noted that approximately half of the individuals with ASD engaged in a hobby and between one-third and two-thirds participated in at least one recreational activity weekly (Orsmond et al., 2004). In a population-based study of parents of children with special needs, Wagner and colleagues (2002) found decreased participation in recreational activities for children with ASD as compared to peers with other disabilities. For example, one third of the children with ASD never visited friends, two-thirds never received phone calls and about 12% had no out-of-school interactions with friends (Wagner et al, 2002). These participation restrictions were also seen in an observational study of 18 children with HFA who spent only about half of their time in social interaction with peers during unstructured time when compared to typically developing children (Bauminger et al., 2003). This social isolation

appears to worsen with age, as half of the adolescents and adults with ASD are reported to have no peer relationships (Orsmond et al., 2004).

In the context of the known and potential benefits of recreational participation for individual with disability, this emerging body of literature indicating that individuals with ASD have restrictions in recreational participation points to the need to include recreation as a critical program component of children's with ASD educational and rehabilitative programs.

ENHANCING RECREATIONAL PARTICIPATION OF CHILDREN WITH ASD

To successfully promote recreational participation it is essential to understand the factors influencing it. Participation restriction in individuals with disabilities is not based solely on their diagnosis and impairments; it is a complex and multi-determined phenomenon that includes environmental and personal factors (Forgeyrollas et al., 1998; King et al., 2003; Law et al., 2004). King and colleagues (2003) developed a comprehensive, strength-based and socio-ecological model, which categorizes the factors mediating the participation of children with disabilities (i.e., child, family & environmental factors). The factors identified so far as affecting participation in recreational activities in individuals with ASD are illustrated in Figure 1. The interplay is noted between the child's impairments, the family's style, preferences and demands, as well as environmental or community-based limitations in restricting a given child's ability to participate in an array of recreational activities. All of these factors need to be considered when an interdisciplinary team explores the possibilities for enhancing a child's participation in recreational activities.

To enhance participation in recreational activities for children with ASD, we propose that principles of collaborative teaming and family-centered care (FCC) be employed. Ultimately, the team should develop an intervention approach that embraces the strengths and interests of

children with ASD, takes into account evidence-based intervention strategies and builds on the strength of interdisciplinary service provision. Although these principles are not new, their application offers a useful framework for facilitating meaningful participation in recreational activities for children with ASD

In simplest terms, collaborative teaming can be defined as 2 or more people working cooperatively to achieve a common purpose (Rainforth & York-Barr, 1997). It is a voluntary relationship that requires equality among team members, depends on shared responsibility for decision-making and works to achieve a common goal. Collaborative teams evolve through 5 components: building team structure, learning teamwork skills, problem-solving and action planning, coordinating team action, and conflict resolution (Snell & Janney, 2005). Collaborative teams change and mature over time as team members change, as goals are achieved or adjusted, and as additional challenges present themselves. Family-centered care is an effective educational and health care service delivery approach, which emphasizes partnership between service providers, children and their families through respect, communication and collaborative participation in all aspects of service delivery from goal setting to implementation (Freitas & Shelton, 2005; Prelock, Beatson, Bitner, Broder, & Ducker, 2003). Collaborative teaming is a natural fit for services based in family-centered care as it espouses similar and complementary principles.

Therefore, a family-centered collaborative teaming approach is proposed to expand the recreational participation of children with ASD. This approach requires a series of interrelated although not necessarily sequential steps as illustrated in Figure 2. The team follows the parents' lead to determine a child's priority outcomes and to decide whether or not recreation falls within these priorities. The team, including the parents and child, then formulates the purpose or goal

for enhancing recreational participation for this child. To do this, and to later develop the action plan, the team may need to gather additional information about the child, family and environmental factors that have an impact on the child's recreational participation. The action plan generated from the objective will likely have several steps. These include identifying accommodations, developing instructional plans and/or providing direct interventions. Team members take responsibility for implementing specific parts of the plan, and establish a timeline and method of communication among team members. Finally, a method to determine when an action step is successful and when it needs to be modified is agreed upon.

Two hypothetical case examples follow that demonstrate the application of collaborative teaming and family centered care principles to ensure meaningful participation for children with ASD, specifically a child with ASD and limited verbal skills, and a more verbal child with ASD. Each example also identifies the child, family and environmental factors that impact participation.

FACILITATING PARTICIPATION FOR A CHILD WITH LIMITED VERBAL COMMUNICATION

In the first hypothetical example, a school team collaborates with a family to facilitate participation in recreational activities for a 7 year-old female (hereafter referred to as Jane) with ASD and limited verbal communication. Several factors influence the success of this collaboration in fostering recreational participation. Child factors include limited to no verbal skills (i.e., child points & uses pictures), expression of frustration through tantrums and self-injurious behaviors, and limited functional independence. Family factors include one younger sibling and an elderly grandparent living in the home, both parents working outside the home full-time, and family recreational preferences for sedentary activities (e.g., watching television

and reading) except for a weekly family swim time at the local public pool. Environmental factors affecting participation include Jane's attending a school committed to the integration of all students with disabilities into regular education classrooms. The Individual Education Plan (IEP) team, which includes Jane's parents, uses a family-centered, collaborative planning tool, *Choosing Outcomes and Accommodations for Children* (COACH), to develop the child's IEP.

COACH is a research-based, standardized process designed to identify outcomes for a child's educational program (Giangreco, Cloninger & Iverson, 1998). Families are asked to consider and identify areas of development, learning and life activities (i.e., communication, socialization, personal management, leisure/recreation, selected academics, home, school, community and vocational) they wish to be priority outcomes (Giangreco, Cloninger & Iverson, 1998). The COACH process is a strengths-based approach to intervention planning. It aligns with special education law requirements and promotes collaboration on the part of professionals involved with children with intensive special education needs (Giangreco, Cloninger & Iverson, 1998).

Through the COACH family interview, enhancing meaningful participation in recreational activities is identified as a priority outcome. Since the child's current independent activities are limited to watching videos and bouncing on a ball, the parents identify increasing her range of activities as a priority outcome. Therefore, an IEP goal could be written about recreational participation or the team might decides that additional information should be gathered prior to writing additional recreational goals. In this situation the team decides to gather additional information first. The occupational therapist (OT) completes an assessment of Jane's interests using the Hobbies and Sports cards of the *Pediatric Activity Card Sorting* (PACS) (Mandich, Polatajko, Miller, & Baum, 2004) and parent interview.

Various methods can be used to ascertain children's interests related to recreational activity ranging from interviews of parents, siblings and classmates, to observation during free play and the administration of standardized tools such as the PACS. The PACS is a self-report assessment composed of picture cards, each representing an activity that children sort into piles. Children rate both what they currently participate in and what they would like to do. Two other measurement tools assess the domain of participation from the child's point of view: *Children's Assessment of Participation and Enjoyment* (CAPE) (King et al., 2004) and the *Activities Scale for Kids* (Young, 2000); while others measure participation through parent, therapist and teacher ratings such as *the School Functional Assessment (*Coster, Deeney, Haltiwanger, & Haley, 1998).

Monthly team meeting are used to review the information regarding Jane's recreational interests, amend the IEP to include a recreational goal (see below) as well as develop and monitor an instructional plan to achieve this goal. Results of the PACS and an interview with a parent in this case reveal Jane's preference for activities in which she can move. The teacher identifies an afterschool gymnastics class Jane can attend in which she can have opportunities to interact with her peers with peer mediation support. The team then uses the information gathered to write an IEP goal related to recreation: Given needed support Jane will participate actively in 30-minutes of a weekly afterschool gymnastic program with 80% attendance. The team also develops objectives to enable Jane to meet her recreational goal. For example: 1) Jane transitions to gymnastics class with ease (i.e., without screaming or self-injurious behaviors) 70% of time given the use of a social story to prepare her for the class and a visual schedule indicating gymnastics was the next activity. 2) Jane waits for her turn to use each apparatus 80% of the time with a visual prompt and/or physical cueing from her paraeducator. 3) Jane responds to an initiation by at least one of her peers weekly using her communication board.

In keeping with the principles of family-centered care, IDEA and special education best practice, goals and objectives should be student-specific and discipline-free, provide a context for goal implementation, and be readily measurable by any observer. Goals and objectives should measure what the student is gaining as opposed to, for example, adult implementation of supports. Objectives should be sub-components of learning leading to goal achievement. As illustrated in Jane's situation, recreational participation can be included as an IEP goal although for other students, it may be more appropriate to include recreation as a related service or general support to achieve for example communication or social goals. Recreational participation goals can be activity specific as presented in this example or more exploratory in nature (e.g., Child will try 3 new recreational activities) depending on the identified individual child, family and environmental factors.

Using the information collected, team members then brainstorm supports and develop an action plan to ensure the success of the student in a given recreational activity. Responsibilities are assigned to each team member to maximize Jane's success in a gymnastics class. The physical therapist and physical education teacher introduce the gymnastics' equipment to Jane to prepare her for learning new motor tasks, following the routine of the gymnastics' class and interacting with peers. The SLP writes a social story describing the basic rules and expectations for the class and create a communication board for use in this new environment. The SLP also reviews with the team previously taught peer mediation techniques and provides applications in gymnastics class. The special educator writes an instructional plan for the paraeducator to implement. Both the special educator and SLP monitor the activity through observation during gymnastic class, brief conversation with the paraeducator and Jane's parents, and review of data collected for each objective. They respond to the mandate by the IEP team to adjust the plan in

the first month seeking input from other team members as needed, prior to the next team meeting to review any needed changes. Some evidence-based intervention strategies (e.g., social story, peer mediation) found to be useful with children with ASD are mentioned to demonstrate how they can be used to support recreational participation. A description of these strategies can be found in Prelock (2006).

This first hypothetical case example describes the actions of a mature, family-centered and collaborative team that functions in a supportive environment where teams are able to meet on a regular basis, fostering their collaboration. Team members share roles and responsibility for implementing and modifying action plans. Families' realities and preferences are respected. Parents and children (as appropriate) are involved in each step of the decision-making and implementation processes.

FACILITATING PARTICIPATION FOR AN ADOLESCENT WITH HIGH FUNCTIONING AUTISM

The second hypothetical example describes a school team who collaborates with a family to facilitate participation in recreational activities for a 15 year-old male (hereafter referred to as Tom) with High Functioning Autism. As part of the transition from middle to high school, Tom and his parents meet with both school teams to review Tom's IEP and discuss his successes, strengths and support needs as he moves to high school. During these meetings, the need to strengthen the secondary transition component of Tom's IEP, namely preparation to the transition to adulthood, arises. Assuming that Tom's IEP team, which includes himself, his mother and a select group of school team members, recognizes the importance of this transition they might choose to engage in a *Making Action Plans System* (MAPS) process with Tom and his mother.

Making Action Plans System is a collaborative process that brings a team of key people in a student's life together, to collect information and to create an action plan around the vision that families have for their children and that children have for themselves (Forest & Pearpoint, 1992). A MAPS plan is created through a facilitated discussion using probing questions focusing a team on the hopes and dreams for a child, what team members want to avoid or fear, the strengths and talents the child exhibits, and barriers to achieving the articulated dream (Forest & Pearpoint, 1992). Children, to the extent possible, are an integral part of their MAPS process.

Through the MAPS process Tom might indicate dreams of attending college, living on his own, developing close friendships, getting married and participating in more leisure activities outside his home. The IEP team proceeds by identifying priorities for Tom's upcoming school year as well as future years in high school, such as developing leisure activities that build on his strengths with the hope of fostering friendships and planning for a college education, both areas of participation.

Through the MAPS process factors potentially influencing recreational participation may arise. Such factors may also be documented in the Present Level of Performance section of the IEP. For students like Tom, child-based factors might include fluent expressive communication with difficulties with non-literal language and social cognition; increased ease of interaction with adults as compared to same-age peers; anxiety controlled through medication; sensitivity to sounds; restricted interests to computer games, television game shows, books, action movies and mathematics; and, grade-level performance in mathematics, history and computer science. Family factors include a single-working parent, limited financial resources, and limited natural supports. Environmental factors include attendance in a new school, living in a rural setting, educational support provided by a paraeducator for part of the day, and daily access to a quiet

independent work area.

This newly forming team struggles at first to collaborate in developing a cohesive plan to achieve Tom's priorities from the loosely formed plan that arises from the MAPS process. The team chooses to follow-up on the MAPS with its extension, the *Planning Alternative Tomorrows with Hope* (PATH) process, through which they collaboratively refine the action plan (Jonikas, Cook, Fudge, Hlebechuk & Fricks, n.d.). PATH allows the team to develop achievable long and short-term goals, provides clear timelines for achieving goals, and assigns team members to accomplish the steps toward a goal (Falvey, Forest, Pearpoint & Rosenberg, 1994).

Through the PATH process, the team determines that no additional IEP goals around recreation are required for Tom's IEP, as recreational activities may be part of the milieu where his communication and social goals are addressed. The first step of the action plan requires the school guidance counselor and occupational therapist (OT) to gather additional information about Tom's recreational interest and availability of recreational activities in the community. The OT asks Tom to complete general interest checklists and the CAPE.

The CAPE is a self-report tool used to document how children participate in everyday activities outside of their mandated school activities and to identify their activity preference (King et al., 2004). Children rate 55 activities on 5 characteristics such as frequency and location of participation in an activity, degree of enjoyment of the activities and interest in activities they may or may not have participated in. The 55 activities are then grouped into 5 categories: recreational activities, physical activities, social activities, skill-based activities, and self-improvement activities.

The IEP team then meets to review the information gathered. Through the CAPE, Tom has identified, in addition to his usual recreational interests, a desire to participate in school

clubs, hangout with friends and have a pet. Recognizing the family and environmental factors that impede recreational participation in the broader community, the team decides that an after-school program is the most appropriate first step. A team member, Tom's math teacher, proposes the school math club as a recreational activity that builds on Tom's strengths and interests. Tom, who is present during such a meeting, agrees that it is a good idea before the team continues planning. A conversation follows about challenges that Tom may experience while participating in this club. The need to provide support to facilitate positive social interactions during math club meetings and competitions, to learn the mechanics of the competition and to manage Tom's dislike of noises and busy places is discussed.

A plan to enable Tom's participation is generated. The SLP helps Tom understand the social interactions in the math club and teaches him appropriate responses through video modeling. Tom asks the Math Club advisor to teach him the mechanics of answering questions and the competition format with support from his special educator. The OT discusses self-management strategies (e.g., guided relaxation, wearing earplugs) with Tom to address his anxiety and sound sensitivities during the competition. The special educator charts the frequency with which the strategies are implemented during a few practices and games. After the first competition, modifications to the strategies are recommended such as the need for a teammate to touch Tom's arm gently when he needs to be reminded to focus on the game. The IEP team meets bi-monthly to discuss progress and modify the plan as needed. During this meeting, the school guidance counselor offers to meet a few times with Tom to explore further community recreation.

With older children, the inclusion of the student in the family-centered collaborative teaming process is essential to a successful outcome. Newly forming teams may have challenges

with working collaboratively and need to rely more heavily on specific processes such as PATH to develop and implement a plan to enhance recreational participation.

CONCLUSION

In summary, participation in recreational activities has the potential to support the development of function in the area of typical impairments in HFA (i.e., communication, social and executive function), lessen the impact of the symptoms of autism on the child and family, and promote quality of life and well-being. To enhance recreational participation for children with ASD, families and professionals must work collaboratively to determine the child's interests, identify barriers to recreation and develop a system of supports that allows the child to participate in a wide-range of meaningful recreational activities.

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Appendix B

Critical Appraisals of Studies about Recreational Participation in Children with HFA

Study 1 -

CITATION	Hilton, C. L., Crouch, M. C., & Israel, H (2008). Out-of-school participation patterns in children with high-functioning autism spectrum disorders. *The American Journal of Occupational Therapy*, *62*(5), 554-563.
STUDY PURPOSE Was the purpose stated clearly? ☒ Yes ☐ No	**Outline the purpose of the study. How does the study apply to your research question?** 1) In typically developing and HFASD children, compare patterns of participation in "out-of-school" activities specifically, diversity, intensity, whom they participate with, in which environments they participate, and their degree of enjoyment. 2) In 2 different age groups of HFASD children, compare patterns of participation in "out-of-school" activities specifically, diversity, intensity, whom they participate with, in which environments they participate, and their degree of enjoyment. 3) How those severity of autistic characteristics related to "out-of-school" participation as described above. **Reviewer's impression:** The first research question of this study is directly related to the primary research question in my doctoral study. The other 2 questions in this study are not addressed in my doctoral study. My doctoral study tackles 4 additional research questions, which were not included in this study.
LITERATURE Was relevant background literature reviewed? ☒ Yes ☒ No	**Describe the justification of the need for this study:** - "Participation is essential to the growth and development of children and continues to directly relate to a person's health and well-being" (Authors cited in Hilton, Crouch & Israel, 2008, p. 554) - In the general population, participate in leisure activities affects physical and mental health. - Mentions a few studies of participation in children with disabilities. **Reviewer's impression:** Reviews literature not relevant to their research question (e.g., motor ability and HFA) and does not thoroughly review literature available at the time of publication about recreational participation in ASD. Authors purport to review life satisfaction literature in HFASD but the 2 studies reviewed do not discuss this topic. Globally the literature review provides some relevant information but not in a comprehensive and cohesive fashion.
DESIGN	**Describe the study design. Was the design appropriate for the**

☐ Randomized (RCT) ☐ cohort ☐ single case design ☐ before and after ☐ case-control ☒ cross-sectional ☐ case study	**study question? (e.g., for knowledge level about this issue, outcomes, ethical issues, etc.):** Cross-sectional study with measurement tool administered to 2 distinct groups at one point in time. **Specify any biases that may have been operating and the direction of their influence on the results:** Selection bias: - Unclear whether parents could accurately report on their children IQ; more likely to affect HFASD group than peers; no way to determine if groups are similar related to IQ; IQ can affect patterns of recreational participation - Recruitment method did not attempt to identify a representative sample Information bias: - The CAPE has not been used with children with ASD; validity and reliability in this population not studied; could affect information gathered from its used. - There is the possibility of performance bias as no information is provided on who collected data and how. The person administrating the CAPE could influence children's response; if different individuals administered the CAPE to the two groups this could influence results.
SAMPLE N = 105 Was the sample described in detail? ☒ Yes ☐ No Was sample size justified? ☐ Yes ☒ No ☐ N/A	**Sampling (who; characteristics; how many; how was sampling done?) If more than one group, was there similarity between the groups?:** <u>Description of Sample:</u> - Children ages 6 to 12 years of age - 52 children with HFASD and 53 typically developing peers Per parent report: – All children were born full term, had an IQ of at least 70 and were proficient in English – All children did not have a diagnosis or history of cerebral palsy, major neurological condition, hearing problems and current non-corrected vision problems. – The typically developing peers did not have a diagnosis of autism spectrum disorder, attention deficit or hyperactivity disorder, Tourette syndrome, anxiety disorder or other behavioral disorder. <u>Recruitment:</u> - Voluntary convenience sample from five Midwestern states - HFASD Group recruited through parent and professional contacts of the principal investigator, parent support groups, information sent to newsletters and flyers posted at service providers sites. - Typically developing group recruited through information flyer

<table>
<tr><td></td><td colspan="2">shared with parent/professional contacts of research team.

<u>Sample Size:</u>
- No justification provided and no mention of power or minimally important difference.

Describe ethics procedures: Mentioned briefly in text (p. 556)</td></tr>
<tr><td>OUTCOMES
Were the outcome measures reliable?
☒ Yes - mostly
☐ No
☐ Not addressed

Were the outcome measures valid?
☒ Yes - mostly
☐ No
☐ Not addressed</td><td>Outcome areas:
- Social impairment
- Participation</td><td>List measures used:
- Social Responsiveness Scale
- Children Assessment of Participation and Enjoyment</td></tr>
<tr><td>INTERVENTION
Intervention described?
☒ N/A

Contamination?
☒ N/A

Cointervention?
☒ N/A</td><td colspan="2">Provide a short description of the intervention (focus, who delivered it, how often, setting).

This study was not an intervention study. No information about data collection procedure (e.g., location, who collected data, etc.) was provided in the study. The acknowledgments section mentioned “test sites” and list the names of 5 individuals related to “completion of data collection”.</td></tr>
<tr><td>RESULTS

Results were reported in terms of statistical significance?
☒ Yes
☐ No
☐ N/A
☐ Not addressed

Were the analysis method(s) appropriate?
☐ Yes
☐ No
☐ Not addressed</td><td colspan="2">What were the results? Were they statistically significant (i.e., p < 0.05)? If not statistically significant, was study big enough to show an important difference if it should occur? If there were multiple outcomes, was that taken into account for the statistical analysis?

<u>Demographic information:</u>
- No statistical difference in age/gender between groups (Chi-square)
- Statistical difference in income between group with control group higher (Chi-square); sub-divided groups by income (highest income vs. all other incomes) with no difference in patterns of CAPE differences between groups (Mann-Whitney U) so data was analyzed in 2 groups (HFASD/peer) discounting income difference. ➔ no mention of how many participants per income category groups so unclear if a difference would have been detected if truly present.
- No statistical difference within HFASD group for those with (N=29) and without (N=23) secondary conditions (Mann-Whitney U).

<u>Outcome Measure:</u></td></tr>
</table>

	- CAPE intensity measured two ways; one influence by number of activities subjects participated in (like in CAPE manual), other not influence. - Statistical difference on CAPE diversity, intensity and where dimensions between the three age groups for HFASD (MANOVA). - Statistically lower diversity, with whom, and where for HFASD group vs. peers. - Diversity of participation decreased as the children with HFASD got older in contrast to increasing in the typically developing peers. - No statistically different enjoyment between group - HFASD more similar to peers in number of formal activities participated in vs. informal but they enjoy participating in these activities significantly less than peers. -HFASD participate in fewer "social activities" and with less frequency than peers. - The largest difference between groups in terms of type of activities was for physical activities. - No statistical difference in participation in skill-based activity. **Reviewer's impression:** It is not always clear why the authors used non-parametric statistical tests. At times, sample size in sub-group is likely the reason but at other times not. Discussion of the findings appear adequate except for discussion about potential cause of decrease participation in physical activities which I feel is too narrow in its focus.
Clinical importance was reported? ☐ Yes ☒ No ☐ Not addressed	**What was the clinical importance of the results? Were differences between groups clinically meaningful?** This was not addressed. A thorough literature search showed that it has not been addressed for the CAPE in any of the published studies to date.
Drop-outs were reported? ☐ Yes ☒ No	**Did any participants drop out from the study? Why?** No information given
CONCLUSIONS AND IMPLICATIONS Conclusions were appropriate given study methods and results ☐ Yes ☐ No	**What did the study conclude? What are the implications of these results for practice? What were the main limitations or biases in the study?** <u>Authors' conclusions:</u> - Study provided a clear understanding of the difference in out-of-school participation patterns in children with HFASD and peers with differences noted in diversity, with "whom?" and "where?" but not enjoyment.

	- In terms of category of activities there is greater difference between the 2 groups for "physical, social, self-improvement, and recreational activities". <u>Study limitations and suggested for future research listed in the study:</u> - Descriptive analysis without causal inferences. - Reliability of data with self-rated questionnaires used - Convenient sample - Need to look at feeling of well-being - Need to look at areas of functioning such as motor skills in relation to participation

Study 2 –

CITATION	Hochhauser, M., & Engel-Yeger, B. (2001). Sensory processing abilities and their relation to participation in leisure activities among children with high-functioning autism spectrum disorder. *Research in Autism Spectrum Disorders*, *4*, 746-754.
STUDY PURPOSE Was the purpose stated clearly? ☒ Yes ☒ No	**Outline the purpose of the study. How does the study apply to your research question?** The study aimed to increase knowledge about specific sensory processing characteristics of children with HFA and their relationship to recreational participation.
LITERATURE Was relevant background literature reviewed? ☒ Yes ☒ No	**Describe the justification of the need for this study:** Authors review literature about characteristics of HFA, sensory processing generally and specifically related to HFA as well as participation broadly and applied to children with disabilities. **Reviewer's impression:** The literature review is brief and does not thoroughly consider literature available at the time of publication about recreational participation in ASD. The review of the literature related to sensory processing abilities in ASD is more complete although conclusions appear uni-dimensional.
DESIGN ☐ Randomized (RCT) ☐ cohort ☐ single case design ☐ before and after ☐ case-control ☒ cross-sectional ☐ case study	**Describe the study design. Was the design appropriate for the study question?** Cross-sectional study with measurement tool administered to 2 distinct groups at one point in time. **Specify any biases that may have been operating and the direction of their influence on the results:** Selection bias: - In HFA group IQ determine by psychological report and in the control group by parent report; no way to determine if groups are similar related to IQ; IQ can affect patterns of recreational participation

<table>
<tr><td></td><td colspan="2">- Recruitment method did not attempt to identify a representative sample

Information bias:
- The psychometric properties of the CAPE have not been estimated with children with ASD specifically.
- A Hebrew translation of the CAPE was used; method of translation was not described.
- Modified CAPE scoring of “with whom” and “where” to dichotomous without explanation for reason.</td></tr>
<tr><td>SAMPLE

N = 50
Was the sample described in detail?
☒ Yes
☐ No

Was sample size justified?
☐ Yes
☒ No
☐ N/A</td><td colspan="2">Sampling (who; characteristics; how many; how was sampling done?) If more than one group, was there similarity between the groups?:
<u>Description of Sample:</u>
- Children ages 6 to 11 years of age
- 25 children with HFA and 25 developing peers

Inclusion criterion:
− All children were born full term and had an IQ of at least 70
− HFA group: DSM-IV criteria reported by physician or psychologist.

Exclusion criterion:
− Any major neurological disorder, attention deficit or hyperactivity disorder or taking medication affecting the nervous system on a regular basis.

<u>Recruitment:</u>
- Voluntary convenience sample from three schools with inclusive classes for children with HFA.
- Letters of request to participate sent to all the parents.

<u>Sample Size:</u>
- No justification provided and no mention of power or minimally important difference.

Describe ethics procedures: Mentioned briefly in text (p. 749)</td></tr>
<tr><td>OUTCOMES
Were the outcome measures reliable?
☐ Yes - mostly

Were the outcome measures valid?
☒ Yes - mostly</td><td>Outcome areas:
- Sensory processing
- Leisure participation</td><td>List measures used:
- Short sensory profile
- Children Assessment of Participation and Enjoyment</td></tr>
<tr><td>INTERVENTION</td><td colspan="2">Provide a short description of the intervention (focus, who</td></tr>
</table>

Intervention described? ☒ N/A Contamination? ☒ N/A Cointervention? ☒ N/A	**delivered it, how often, setting).** This study was not an intervention study. At an occupational therapy clinic, the primary investigator administered the CAPE to the children while the parents filled out the Short Sensory Profile.
RESULTS Results were reported in terms of statistical significance? ☒ Yes ☐ No ☐ N/A ☐ Not addressed Were the analysis method(s) appropriate? ☒ Yes ☒ No ☐ Not addressed	**What were the results? Were they statistically significant (i.e., p < 0.05)? If not statistically significant, was study big enough to show an important difference if it should occur? If there were multiple outcomes, was that taken into account for the statistical analysis?** <u>Demographic information:</u> - Not statistical tests reported <u>Primary Outcome Measures:</u> - Significant difference in sensory processing abilities between groups (MANOVA) - Difference in terms of CAPE diversity (no statistical test reported) - Significant difference in general and personal intensity of participation (MANOV) - Significant difference in "with whom" dimension for 4 activity type, informal domain and overall. - Significant difference in "where" dimension for recreational activity type, informal domain and overall. - Significant difference in enjoyment between groups for all activity types, domains and overall. - Correlations are reported (r ranging between .39 and .54) between sensory processing abilities and CAPE dimensions, activity types and activity domains; and conclusions are drawn from these. No correlation table is available. No hypothesis about correlations are given thus it is unclear whether found correlations are important.
Clinical importance was reported? ☐ Yes ☒ No ☐ Not addressed	**What was the clinical importance of the results? Were differences between groups clinically meaningful?** This was not addressed.
Drop-outs were reported? ☐ Yes ☒ No	**Did any participants drop out from the study? Why?** No information given
CONCLUSIONS AND	**What did the study conclude? What are the implications of these results for practice? What were the main limitations or biases in**

IMPLICATIONS Conclusions were appropriate given study methods and results ☐ Yes ☐ No	**the study?** <u>Authors' conclusions:</u> - Recreational participation difference noted between children with HFA and peers in diversity, with "whom?" "where?" and enjoyment. - Study highlight the importance of considering the impact of sensory processing skills on participation - Study found that with more severe sensory processing impairments were associated with more limited diversity and intensity of participation. Additional specific association between characteristics of sensory processing skills and types of recreational participation are provided. <u>Authors' stated study limitations:</u> - Small convenience sample - Include families with broader ethnic and socioeconomic diversity. <u>Authors' suggestion for future research:</u> - Further investigate the relationship between sensory processing and participation.

The Critical Review Form – Quantitative Studies by Law, M., Stewart, D., Pollock, N., Letts, L. Bosch, J., & Westmorland, M. was used to conduct this review.

Appendix C

Methods of Recruitment

Parents Support Groups: Email Lists and Electronic Mailing List

- Parent-to-Parent
- Asperger's Parent Support Group
- Parents with children with Autism
- Parents supporting our children
- AAWARE of the NE kingdom
- AAWARE of Lamoille Valley
- Asperger's Association of New England
- Exceptional Parents of Exceptional children

Community Electronic Mailing Lists

- Front Porch Forum
- Green Mountain Council (Boy Scouts of America)

Professional Electronic Mailing Lists

- TRIPSCY electronic mailing list
- Autism Plan electronic mailing list

Rehabilitation Organization Requesting Recruitment Letters:

- Visiting Nurse Association of Chittenden and Grand Isle Counties
- Philo Center
- Kids on the Move

Appendix D

Recruitment Letter for HFA Group

Dear Parent(s)/Guardian(s),

There is a study being conducted in Vermont and New Hampshire to learn about the patterns of recreation of children with High Functioning Autism (HFA) and Asperger Disorder (AD). Participation in recreational activities supports the development of a wide range of skills, is associated with better family relationships and increased life satisfaction. Participation in recreational activities has the potential for being very beneficial for children with HFA/AD and their families. However, there is little to no research about the patterns and preferences of recreational activities of people with HFA/AD. This study will begin to fill this gap in knowledge.

Your participation would involve sharing some demographic information about your family and you and your child completing forms and assessments to gain information about your child's recreational activities, communication skills, and quality of life. The study requires 2 to 3 meetings with the researcher in a location that is convenient to you.

This study is designed to learn from a group of children with specific characteristics:

(a) They speak English at home.
(b) They have a diagnosis of Autistic Disorder, Asperger Disorder or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
(c) They are 7 and 13 years old.
(d) They have an intellectual quotient (IQ) of 80 or above.

This study is being conducted at the University of Vermont by Marie-Christine Potvin to meet the requirements of her doctoral program at McGill University under the supervision of Dr. Laurie Snider and with the support of Dr. Patricia Prelock.

If you have an eligible child and are interested in participating in the study, please contact me by phone or email. I am happy to answer any questions you may have.
Contact information: (802) 318-0603 or marie.potvin@uvm.edu.

Sincerely,

_____
Marie-Christine Potvin, PhD (candidate), OTR
Principal Investigator

Appendix E

Intake Checklist – Potential Participants with High Functioning Autism

Parent(s) have contacted the primary investigator by telephone or postcard on: _____

Contact Information of the Family
Parent Name: _____
Child's Name: _____ Child's D.O.B.: _____ Age:
Daytime Phone Number: _____
Home Address: _____
Addition Phone/Email Contacts:

_____
_____
_____

Primary investigator answered questions about the study:	⑦ YES	⑦ NO
The family meets the following eligible criteria:		
(a) English is the primary language spoken at home	⑦ YES	⑦ NO
(b) A child was given a diagnosis of Autistic Disorder, Asperger Disorder or Pervasive Developmental Disorder-Not Otherwise Specified by a health professional.	⑦ YES	⑦ NO
(c) Your child does not have cerebral palsy, Down Syndrome, or other genetic syndromes	⑦ YES	⑦ NO
(d) Your child is between 7 and 13 years old.	⑦ YES	⑦ NO
(e) As far as you know your child has an IQ of 80 or above.	⑦ YES	⑦ NO
The primary investigator explained the consent process to the parent:	⑦ YES	⑦ NO
The parent(s) are interested in participating in the study with the child:	⑦ YES	⑦ NO

The first visit is scheduled for: _____ at: _____

Location of visit: _____

Directions:

_____
_____
_____

Participant Number:

Appendix F

Informed Consent

Title of Research Project:	Participation in Recreational Activities in School Age Children with High Functioning Autism, Asperger Disorder and Peers
Project conducted at:	University of Vermont
Principal Investigator:	Marie-Christine Potvin
Faculty Sponsors:	Dr. Laurie Snider, McGill University
	Dr. Patricia Prelock, University of Vermont

You are being invited to take part in a research study conducted by the University of Vermont because either you have a child between the ages of 7 and 13 years of age who has High Functioning Autism (HFA) or Asperger Disorder (AD), or you have a child who is typically developing and lives within the same county as a child with HFA/AD. Throughout this document the word "you" refers to "you or your child". The abbreviation HFA/AD is used to refer to children who have High Functioning Autism or Asperger Disorder.

We encourage you to ask questions and take the opportunity to discuss the study with anybody you think can help you make this decision.

Why is This Research Study Being Conducted?

High Functioning Autism (HFA) and AD are developmental and behavioral conditions that affect communication and social skills. HFA/AD also affect a child's ability to participate in activities of everyday life such as recreational activities. Participation in recreational activities supports the development of social relationships and provides opportunities for children to gain skills. This suggests that participation in recreational activities has the potential of being beneficial for children with HFA/AD, and their families but we have no research information about the patterns, preferences and benefits of recreational activities for people with HFA/AD. We need to gain a better understanding of the factors that influence these patterns so as to help therapists, teachers, and parents to better support the children's participation in recreational activities. We also would like to know to what degree quality of life is related to participation in recreational activities.

How Many People Will Take Part In The Study?

50 families who have a child with HFA/AD and 50 families who have typically developing children are expected to participate in this study. All these families live in Vermont or New Hampshire.

What Is Involved In The Study?

If you decide to participate in this study, you will meet with the investigator 2 or 3 times at a time and location convenient for you. The investigator will use visual supports with simple sentences and pictures to help your child complete each part of the study. The table below summarizes your participation in this study.

Visit 1 – You will be asked a few background questions as well as a couple of questions about your child's participation in recreational activities. Parents of children with HFA/AD will also be asked to show the primary investigator a copy of the child's medical report documenting a diagnosis of Autistic disorder, Asperger disorder or PDD-NOS. Finally, you will fill-out the *Gilliam Autism Rating Scale, 2nd edition* (GARS-2) and the *Vineland Adaptive Behavior Scales, Second Edition* (VABS-2) with the assistance of the primary investigator. This part should take 45-60 minutes. During this time your child can play or participate in usual activity. You can also choose to complete these tools without your child being present, for example while your child is at school.

During the second part of the first visit, the investigator will complete the *Test of Nonverbal Intelligence, 3rd edition* (TONI-3) and two sections of the *Comprehension Assessment of Spoken Language* (CASL) with your child. This should take 45-60 minutes.

Summary of Procedures	**Who will be involved?**		**When will this occur?** Visit		
	Parent	Child	1	2	3(some)
Consent and assent process	X	X	X		
Medical record documenting diagnosis (children with HFA/AD only)	X		X		
Background information	X		X		
Questions about beliefs related to children's recreation	X		X		
Administration of Assessment Tools					
GARS-2	X		X		
TONI-3		X	X		
CAPE/PAC		X		X	X
VABS-2	X		X		
CASL (2 subtests)		X	X		
PedsQL	X	X		X	X
Transition question	X				X
Question about other recreational activities		X			X
Expected Duration of each session			**1.5-2 hours**	**1-1.5 hours**	**1.5-2 hours**

Visit 2 – The second visit will be scheduled within 2 to 4 weeks of the first visit. During the second visit, the investigator will complete the *Children Assessment of Participation and Enjoyment/Preference for Activities of Children* (CAPE/PAC) and the *Paediatric Quality of Life Scales (PedsQL)* with your child. You will also be asked to complete the parent report for children of the PedsQL. This should take approximately 60-90 minutes. Randomly, some children will do the CASL during the 2nd visit and the PedsQL during the 1st visit.

Visit 3 – Your child may be selected for a third visit *within* one-month of the second visit. During this visit, the investigator will re-administer the *Children Assessment of Participation and Enjoyment/Preference for Activities of Children* (CAPE/PAC) and the *Paediatric Quality of Life Scales (PedsQL)* to your child. You will also be asked to complete the parent report for children

of the PedsQL a second time. This time while your child is completing the CAPE/PAC, the primary investigator will note any comments and questions that your child raises. You will be asked a question to help the investigator know whether the last four weeks were typical or whether unusual events occurred during this time.

Finally after a short break, your child will be asked a few questions about recreation such as "Name any recreational activities that you do that we have not talked about today." "How often do you do this activity?" "How did you know how often you do an activity?" "Name any activities that you would like to do that we have not talked about today." "How did it feel to answer these questions in the book about the activities?" and "Is there anything else you want to tell me about the recreational activities that you do?" The interview will last approximately 15 minutes.

What Are The Risks and Discomforts Of The Study?
The study involves minimal risk to you and your child. Your child may find the change in routine of having the investigator come to your home bothersome. Your child may also experience some frustrations if they find some of the questions difficult to answer. The investigator will make every effort to minimize these as much as possible. You and your child may decide not to answer questions during the interview or during administration of questionnaires. If you or your child becomes fatigued during the interview or while completing questionnaires, you will be able to take breaks or complete the interview or questionnaires during another visit.

What Are The Benefits of Participating In The Study?
There is no direct benefit to you for participating in this study. However, a report summarizing patterns of recreational activities and interests in recreation in children with HFA/AD and who are typically developing living in Vermont will be shared with you and other families participating in the study. In addition, the information obtained in this study will provide insight about recreational activities patterns and preferences to therapists and teachers working with children with HFA and AD. This information can be used in planning intervention and educational programs for these children.

Are There Any Costs?
There is no cost for you and your child to participate in this study. The interviews will be conducted at a location convenient to you, which may be your family's home.

What Is the Compensation?
There is no financial compensation for your participation in this study.

Can You Withdraw or Be Withdrawn From This Study?
You may withdraw from the study at any time for any reason by contacting the principal investigator, Marie-Christine Potvin by telephone, email or mail at your convenience. There are no consequences to you or your child if you decided to withdraw from the study. The investigator may end you and your child's participation in the study if it is found that your child does not meet all the criteria to participate in the study.

What About Confidentiality?

You will be assigned a code number placed on the consent and assent forms. This number will be used on all forms used in the study so that no identifying information will be on any of these form. All forms will be kept in locked cabinet at the principal investigator's office at the University of Vermont. The consent forms will be kept in a separate cabinet from other forms such as the assessment tools score sheets and socio-demographic data. The electronic data will be stored in password-protected files on the principal investigator computer.

We do not plan to share your child's completed assessment measures with anyone outside of the research team unless required by law. A compilation of the scores of all the children in the study will be given to you at the completion of the study. The results of this study may eventually be published and information may be exchanged between investigators, but your confidentiality will be maintained.

Contact Information:

You may contact Ms. Marie-Christine Potvin, the principal investigator in charge of this study at (802) 656-1132 for more information about this study. If you have any questions about your rights as a participant in a research project or for more information on how to proceed should you believe that you have been injured as a result of your participation in this study you should contact Nancy Stalnaker, the Director of the Research Protections Office at the University of Vermont at 802-656-5040.

Statement of Consent

You have been given and have read or have had read to you a summary of this research study. Should you have any further questions about the research, you may contact the person conducting the study at the address and telephone number given below at any time. Your participation is voluntary and you may refuse to participate or withdraw at any time without penalty or prejudice.

You agree to participate in this study and you understand that you will receive a signed copy of this form.

This form is valid only if the Committees on Human Research's current stamp of approval is shown below.

Your signature below indicates your permission to allow your child, _____, to participate in this study.

_____

Signature of Legal Guardian or Legally Authorized Representative Date
(Applicable for children and subjects unable to provide consent)

_____

Name of Legal Guardian or Legally Authorized Representative (Printed)

_____

Signature of Principal Investigator or Designee Date

_____

Name of Principal Investigator or Designee (Printed)

Principal Investigator
Name: Marie-Christine Potvin
Address: University of Vermont, Center on Disability and Community Inclusion, Mann Hall 3rd floor, 208 Colchester Ave, Burlington, VT 05405-1757
Telephone: (802) 656-1132 Email: marie.potvin@uvm.edu

Faculty Sponsors
Name: Dr. Patricia Prelock
Address: University of Vermont, Communication Sciences, Pomeroy Hall Room 406, Burlington, VT 05401
Telephone: (802) 656-2529

Name: Dr. Laurie Snider
Address: McGill University, School of Physical and Occupational Therapy, Hosmer House, Montreal, Canada
Telephone: (514) 398-5863

Appendix G

Assent Form

Title of Research Project:	Participation in Recreational Activities in School Age Children with High Functioning Autism, Asperger Disorder and Peers
Project conducted at:	University of Vermont
Principal Investigator:	Marie-Christine Potvin
Faculty Sponsors:	Dr. Laurie Snider, McGill University Dr. Patricia Prelock, University of Vermont

Why are we doing this study?
You are being asked to be in a research study. This study will look at the kinds of recreational activities that kids in Vermont and New Hampshire like to do. We also want to know about what kinds of things make it easier or harder for kids to take part in recreational activities.

What will happen during the study?
If you decide to take part in this study, you will meet with the person conducting the study 2 or 3 times. Each visit will last 1 to 2 hours. During visit 1 and 2, you will answer some questions in writing about things like recreational activities, communication, and how happy you are with your life. The person doing the study will assist you in this task. You will be able to take as many breaks as you want.
Some children will meet with the person doing the study a third time to answer some of the same questions in writing and talk about how it felt to complete the questionnaires. This visit should also take 1 to 2 hours.

Are there good things and bad things about the study?
The goal of this study is to help parents and teachers be better prepared to help children participate in recreational activities. It may help you learn about the type of recreational activities that you would like to do. While you meet with the person doing the study, you will miss out on some of the usual activities that you would otherwise do. You may also find this study boring and feel tired by being asked to answer a lot of questions. You will be allowed to take breaks if you need too.

Who will know about what I did in the study?
If you agree to take part in the study your name and address will not be given to anyone. The answers you give to the questions will not be given to anyone outside the research team unless we are required to do so by law.

Can I decide if I want to be in the study?
You can choose if you want to be in this study or not. Both you and your parent have to agree to allow you to take part in the study. If you do not want to be in this study that's OK. Nobody will be angry or upset. If you say yes now but change your mind, you can say 'no' later and that will be OK. All you have to do is tell your parents or the person doing the study you don't want to be

in the study any more. If you have questions about the study you can ask your parents or the person doing the study. They will help you understand.

Assent

This research study has been explained to me and I agree to be in this study.

_____ _____

Subject's Signature for Assent Date

OR

I, _____ was present when _____read or

(Parent/caregiver name) (Child's name)

was explained this form and gave his/her verbal assent.

Check which applies (to be completed by person conducting assent discussion):

⑦ *The subject is capable of reading and understanding the assent form and has signed above as* documentation of assent to take part in this study.

⑦ The subject is not capable of reading the assent form, however, the information was explained verbally to the subject who gave verbal assent to take part in this study.

_____ _____

Signature of Person Conducting Assent Discussion Date

_____

Name of Person Conducting Assent Discussion (Print)

Person Conducting Assent Discussion

Name: Marie-Christine Potvin

Address: University of Vermont, Center on Disability and Community Inclusion, Mann Hall 3rd floor, 208 Colchester Ave, Burlington, VT 05405-1757

Telephone: (802) 656-1132 Email: marie.potvin@uvm.edu

Faculty Sponsors

Name: Dr. Patricia Prelock

Address: University of Vermont, Communication Sciences, Pomeroy Hall Room 406, Burlington, VT 05405

Telephone: (802) 656-2529

Name: Dr. Laurie Snider

Address: School of Physical and Occupational Therapy, McGill University, Montreal, Canada

Telephone: (514) 398-5863

Appendix H

Data Collection Summary Checklist

CONSENT/ASSENT PROCESS

Informed consent

- read ⑦ YES ⑦ NO
- explained ⑦ YES ⑦ NO
- form signed ⑦ YES ⑦ NO

Assent

- read ⑦ YES ⑦ NO
- explained ⑦ YES ⑦ NO
- form signed ⑦ YES ⑦ NO

Date of Scheduled Visits

Visit 1:

_____

Visit 2:

CONFIRM ELIGIBILITY CRITERIA

1. Viewed copy of medical report documenting Autism, Asperger or PDD-NOS
⑦ YES ⑦ NO (Children with HFA only)

2. Score on VABS-2: _____ Meet criteria? ⑦ YES ⑦ NO

3. Score on TONI-3: _____ Meet criteria? ⑦ YES ⑦ NO

4. Score on GARS-2: _____ Meet criteria? ⑦ YES ⑦ NO

MEASUREMENT TOOLS

	Planned					**Completed**							
Assessment Tools	**Respondent**		**Visit**			**1st Administration**				**2nd Administration**			
						Visit			**Date**	**Visit**			**Date**
	Parent	Child	1	2	3	1	2	3		1	2	3	
GARS-2	X		X										
TONI-3		X	X										
CAPE/PAC		X		X	X								
VABS-2	X		X										
CASL (2 subtests)		X	X										
PedsQL		X		X	X								
Parent PedsQL	X			X	X								

DEMOGRAPHIC DATA

Household Information

1. City/town of residence: _____
2. County of residence: _____
3. Number of children living in the household: _____
4. Is there a spouse or partner living with you and your children in your household?
   ⑦ YES ⑦ NO
5. How many other people are living in your household: _____
6. Number of people living in the household who have a disability: ____

7. Can you tell me what is your or your husband/wife/partner highest level of formal education (whichever is the highest)?

___ Less than 9th grade
___ 9th to 12th grade, no diploma
___ High school graduate (includes equivalency)
___ Some college, no degree
___ Associate degree
___ Bachelor's degree
___ Graduate or professional degree

8. If you want to tell me, what was your gross household income in 2006?

___ Less than $10,000	___ $35,000 to $49,999	___ $150,000 to $199,999
___ $10,000 to $14,999	___ $50,000 to $74,999	___ $200,000 or more
___ $15,000 to $24,999	___ $75,000 to $99,999	
___ $25,000 to $34,999	___ $100,000 to $149,999	

Did your **household income** include **supplemental security income**? ⑦ YES ⑦ NO
Did your **household income** include **public assistance income**? ⑦ YES ⑦ NO

QUESTIONS TO PARENT

Scale: 1 = strongly disagree 2 =disagree 3 = slightly disagree
4 = slightly agree 5 = agree 6 = strongly agree

1) In our family, the participation of children in recreational activities is important.
   Rating: _____
   Describe: _____
   _____

2) I am satisfied with my child's participation in recreational (both frequency and type) activities.
   Rating: _____
   Describe: _____
   _____

CAPE Degree of Parental Assistance In Answering Some of the CAPE Questions

	CAPE Questions		
Parental Assistance	How Often?	With Whom?	Where?
None			
Up to 25%			
26 to 50%			
51 to 75%			
76 to 100%			

Describe the type assistance: _____

Parents Degree of Agreement with Child's Answers

The parent was present when the child's answer the CAPE questionnaire: ⑦ YES ⑦ NO
My child's answers to the CAPE questionnaire are representative of my child's participation in recreational activity? (Circle one)

1 = strongly disagree 2 =disagree 3 = slightly disagree
4 = slightly agree 5 = agree 6 = strongly agree

_____

The parent was present when the child's answer the PAC questionnaire: ⑦ YES ⑦ NO
My child's answers to the PAC questionnaire are representative of what I think my child would like to do in terms of recreational activity? (Circle one)

1 = strongly disagree 2 =disagree 3 = slightly disagree
4 = slightly agree 5 = agree 6 = strongly agree

Investigator Record of Accommodations and Modification

CAPE

What modifications/accommodations were used?

Why?

Where the standardization procedures respected? ⑦ YES ⑦ NO

PAC

What modifications/accommodations were used?

Why?

Where the standardization procedures respected? ⑦ YES ⑦ NO

PedsQL

What modifications/accommodations were used?

Why?

Where the standardization procedures respected? ⑦ YES ⑦ NO

SUBGROUP 3RD VISIT

Parent Transition Question

Scale: 1 = strongly disagree
2 =disagree
3 = slightly disagree
4 = slightly agree
5 = agree
6 = strongly agree

In your opinion, the last 2-4 weeks (since the last visit) have been typical for you household?

Rating: _____

Child Qualitative Questions

Name any recreational or "fun" activities that you do that we have not talked about today.

How often do you do this or these activity? (Use visual support cards from CAPE/PAC)

How did you know how often you do an activity?

Name any recreational or "fun" activities that you would like to do that we have not talked about today.

How did it feel to answer these questions in the book about the activities?

Is there anything else you want to tell me about the recreational activities that you do?