Health and Lifestyles Comparison of Youth with Autism and Their Siblings without Autism

BY

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THESIS

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### LIST OF ABBREVIATIONS

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<tr>
<td>APE</td>
<td>Adapted Physical Education</td>
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<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
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<tr>
<td>BMI</td>
<td>Body Mass Index</td>
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<tr>
<td>BMP</td>
<td>Beats Per Minute</td>
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<tr>
<td>CDC</td>
<td>Center for Disease Control and Prevention</td>
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<tr>
<td>HFASD</td>
<td>High Functioning Autism Spectrum Disorder</td>
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<td>IDEA</td>
<td>Individuals with Disabilities Education Act</td>
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<td>PE</td>
<td>Physical Education</td>
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SUMMARY

The nature of ASD presents significant challenges for the successful engagement in physical activity. In an effort to better understand the barriers and determinants of physical activity, this study compared health and lifestyle information of teens with ASD and their teen siblings without ASD. Parents and their teens with ASD and without ASD responded to a self-select online self-report survey. Findings were limited due to the small sample size. Results indicated similarities for teens with and without ASD in most physical activity indicators and participation in physical education or adapted physical education. A few differences were reported showing reduced participation in clubs and organizations outside of school or home and very limited participation with friends for teens with ASD. Parents reported a need to accompany their teens with ASD most of the time. Study results are discussed in terms of health promotion implications and methodological adjustments for increasing recruitment and sample size.
I. INTRODUCTION

Physical activity is centrally important to a healthy lifestyle. Everybody requires some form of activity for their well-being. This is particularly true for the estimated 54 million Americans with disabilities who appear to have dramatically lower levels of participation in physical activity in comparison to non-disabled persons (Rimmer & Wang, 2005). An important subgroup within the 54 million Americans with disabilities includes youths with Autism (Klepper & Giannini, 1994; McDonald, 2002) who represent special challenges because of the nature of their condition (Auxter, Pyfer, & Huettig, 1997). Autism which is associated with the deficits in social, communication, sensory and behavioral functioning presents numerous barriers to health and physical activity since the symptoms of this condition may predispose youth with autism to inactivity.

Autism Spectrum Disorder is represented by a group of developmental disabilities of neurobiological origin that can cause significant social, communication, and behavioral challenges (Center for Disease Control and Prevention, [CDC] 2010). It is a spectrum disorder with the associated impairments ranging from mild to severe, with some areas of development only being mildly impaired while others may be severely impacted (American Psychiatric Association, 2000). There are three different types of Autistic Spectrum Disorders: Autistic Disorder, Asperger Syndrome, and Pervasive Developmental Disorder – Not Otherwise Specified. Autistic Disorder or Autism typically involves significant language delays, considerable social deficits, displaying behaviors of rigidity, solitary play, difficulty in socializing with others, including a lack of understanding social cues and the perspectives of others, self-stimulating behaviors and often intellectual disability (CDC, 2010). Asperger Syndrome presents milder symptoms of autistic disorder. Individuals might have social
challenges and unusual behaviors and interests, yet typically do not have problems with language or intellectual disability. Pervasive Developmental Disorder – Not Otherwise Specified also includes some characteristics of autistic disorder or Asperger Syndrome, but not all characteristics. There are fewer and milder symptoms than those with autistic disorder that might cause only social and communication challenges.

The three types of Autistic Spectrum Disorders vary in terms of symptoms, yet there are common characteristics which cause problems with social, communication, sensory, and behavioral issues. Each of these issues make engaging in physical activity challenging. In addition, limited motor functioning, low motivation, difficulty planning and generalization impact the ability to successfully participate in physical activity (Reid, O’Connor, & Lloyd, 2003).

More recent research has expanded beyond the focus on behavior management to targeting the health related lifestyles of youth with autism. Studies have addressed a variety of topics: assessing the impact of parental activity levels and support on physical activity levels in youth with Autism (Pan & Frey, 2005), comparing the physical activity levels in youth with and without Autism (Rosser Sandt & Frey, 2005), and evaluating the usefulness of walking for fitness and reducing body mass index (BMI) among adolescents with severe Autism (Pitetti, Rendoff, Grover, & Beets, 2007).

The present study expands on these most recent studies in an effort to comparatively evaluate the relationship of physical activity levels and lifestyles between adolescent youth with and without Autism. Comparing physical activity levels provides necessary baseline data on the unique patterns of physical activity participation.
The specific question asked in this study is whether youth with Autism are less active than their siblings without Autism. The study utilized a survey to compare the health and lifestyle behaviors of adolescents (12-18 years) with Autism and their siblings without Autism to better understand patterns of physical activity and related issues.

While there is a substantial amount of research on physical activity in youth without disabilities, a parallel body of similar research on youth with disabilities, especially those with Autism, is lacking. We cannot plan programs or make a policy without adequate baseline of data on activities levels and choices of activity for this population.

This study utilized an anonymous online survey about health and lifestyle to ascertain the physical activity levels and activity choices of teens with Autism and their teen siblings. The survey questions included queries about social, psychological, health and environmental variables in addition to physical activity levels. Teens completed the survey independently or with their parent’s assistance if needed. Parents also completed the survey in order to independently assess their perspectives on health and activity and to provide basic demographic information.

Findings from this study were not conclusive due to the small number of participants. What did emerge from the results was the finding that recreation resources were less used by teens with ASD than teens without ASD. The data also indicated there was a difference in participation with friends with teens with ASD having fewer opportunities. However, results from video game playing and watching television data did not appear to be different between the groups nor did any large differences exist in the participation in physical education. These findings, although limited by sampling are consistent with observation in the literature. Limited participation in clubs and organizations has been reported among children with disabilities
Sedentary activity choices have been reported for both children with and without ASD (Rosser Sandt & Frey, 2005). Differences in participation involving friends are commonly seen in the literature: recreation activities are often pursued without companions or friends with limited or no peer relationships (Ormond, Krauss, & Seltzer, 2004).

The following chapters will introduce the topic of health and lifestyle behaviors of youths with Autism in order to provide a context for our discussion on physical activity. Chapter II provides a detailed review of literature summarizing the current state of research knowledge. Chapter III describes the study methodology and procedures. Study results are summarized in Chapter IV and discussed and interpreted in Chapter V. Included is a review of implications for future research.
II. LITERATURE REVIEW

The Center for Disease Control estimates that 1 in 110 children in the U.S. have an Autistic Spectrum Disorder (ASD), making ASD the second most common developmental disability in the nation (Center for Disease Control and Prevention, 2010). ASD is a group of developmental disabilities that can cause significant social, communication, and behavioral challenges. There are three different subtypes of ASD that vary in degree of severity: Autistic Disorder, Asperger Syndrome and Pervasive Developmental Disorder – Not Otherwise Specified. Autistic Disorder, also known as Autism, involves significant language delays, social and communication challenges, unusual behaviors and interests, and often intellectual disability. Asperger Syndrome presents milder symptoms of autistic disorder, typically without problems with language or intellectual disability. Pervasive Developmental Disorder – Not Otherwise Specified includes some characteristics of Autistic Disorder or Asperger syndrome, but not with fewer and milder symptoms that create social and communication challenges. Three out of four people with ASD are diagnosed with an intellectual disability. Among those with an intellectual disability, half will have an intellectual impairment in the severe to profound range (National Dissemination Center for Children with Disabilities, 2006). Because individuals with ASD often exhibit atypical behaviors, have limited socialization skills, repetitive behaviors and interests, challenges exist for their participation in physical activity and health promotion programs.

A. Secondary Conditions and Disability

The importance of physical activity for overall health and quality of life is well known. This is especially true for people with disabilities. According to Healthy People 2010 (U.S. Department of Health and Human Services, 2000), the national health agenda prepared by the United States Public Health Service, people with disabilities have increased health concerns, and
especially, an increased risk for developing secondary conditions. As defined by the Healthy People 2010 report, secondary conditions are a, “medical, social, emotional, family, or community problems that a person with a primary disablining condition likely experiences” (CDC, 2001, p. 3).

This broad definition of secondary conditions considers the physiological, psychological, and environmental barriers that impact the health of people with disabilities. Secondary conditions are health concerns that are not a direct result of the primary disability but rather, are acquired at a later time due to lifestyle changes associated with the disability (e.g., weight gain, falls, pain, fatigue, depression) (U.S. Department of Health and Human Services, 2000). Difficulties accessing transportation because of the disability for example, may exacerbate isolation and increase the risk for depression. Secondary conditions are largely preventable.

The impact of secondary conditions among people with disabilities is most of seen in a decline in physical, emotional and or social functioning resulting as part of deconditioning. Several reports have suggested that deteriorating function produces greater inactivity, which in turn increases both the number and severity of secondary conditions (Coyle, Santiago, Shank, Ma, & Boyd, 2000; Rimmer, & Shenoy, 2006; U.S. Department of Health and Human Services, 2000).

While participation in physical activity can have a positive impact on improving the health of people with disabilities as well reduce the risk for development of secondary conditions (U.S. Department of Health and Human Services, 1996), significant disparities in physical activity levels make this less likely for people with disabilities. The Healthy People 2010 reported 56% of people with disabilities do not participate in leisure time physical activity
compared to 36% for non-disabled people (U.S. Department of Health and Human Services, 2000).

Intensity of exercise was quite different with 13% of people with disabilities participating for 20 minutes in vigorous physical activity three times a week compared to 25% of non-disabled people (CDC, 2001).

1. **Physical activity and persons with disabilities**

   Physical activity decreases a person’s chances of contracting a number of diseases and conditions (National Center for Chronic Disease Prevention and Health Promotion, 2007). The Surgeon General recommends individuals participate in 60 minutes of moderate physical activity most days of the week. Engaging in physical activity can improve health and quality of life while reducing the risk of secondary conditions, including hypertension, diabetes, obesity, asthma, and other serious health problems including psychological disorders, such as depression (U.S. Department of Health and Human Services, 2010). The Centers for Disease Control and Prevention reports that physical activity can decrease pain, improve function and promote quality of life for people with arthritis, which is a common disability in the United States. Physical activity can also manage other secondary conditions, such as obesity and diabetes.

2. **Disparities in physical activity**

   People with disabilities remain one of the most physically inactive groups in society (Rimmer, 2005). The Healthy People 2010 report noted that the significantly lower rate of participation in physical activity among people with disabilities is likely due to barriers to their participation. People with disabilities often experience barriers to regular physical activity beyond those experienced by nondisabled persons, including finances, transportation, and lack of information, appropriate and accessible facilities and programs (Rimmer, 2005). Such barriers
effectively reduce personal choice options, inhibit participation in healthy, active lifestyles, and prevent people with disabilities from fully participating in their communities (North Carolina Office on Disability and Health, 2001). Some recent research suggests people with disabilities are often confronted with so many barriers to participating in the types of physical and recreational activities they need to maintain their health and well-being that they decide such pursuits are not worth their time and effort (Rimmer, 2005).

B. **Physical Activity and Autism**

Physical activity can positively impact fitness and the characteristics and associated conditions of autism (Levison & Reid, 1993). Studies on cardiovascular exercise and autism have found that participation in vigorous physical activity in combination with behavior therapy can be helpful in reducing inappropriate behaviors in children with autism (Lavay, French, & Henderson, 1997). Being physically active not only provides health benefits for individuals with autism, it may also help with reducing problematic behaviors, increasing desired behaviors, attention, productivity, fitness levels, muscle strength and endurance, promoting healthy weight loss and improving social skills for positive peer relationships (Pan & Frey, 2006; Sherrill, 1998).

1. **Physical activity and behavior**

Studies related to physical activity and ASD began with the Watters and Watters (1980) investigation which was based on their observations that the self-stimulating behaviors of students with ASD decreased after participation in gym and field trips. The focus of the research was to determine if exercise could be a successful technique for controlling behaviors. Self-stimulating behaviors, which can include hand flapping, spinning, rocking, outbursts, and similar type activities, will interrupt learning, socialization, or attending to the task at hand. In their
study, five elementary school age boys with ASD participated in a language training lesson, watched Sesame Street for 10-15 minutes or jogged for 8-10 minutes. After each of these conditions, the children’s behavior was observed and monitored for self-stimulating actions. Results of the study showed an average decrease of 32.7% in self-stimulating behaviors following exercise. No difference in behaviors was found after television watching or academics. These results indicated that exercising prior to classroom lessons might be a useful technique for classroom behavior management since it did not interrupt teaching.

Kern, Koegel, Dyer, Blew, and Fenton (1982) targeted physical exercise as an effective pre-activity for positively influencing behaviors and attention. This study examined the effect of jogging on subsequent self-stimulating behaviors and appropriate responding for seven children, ages 4 to 7, who were diagnosed with autism. The subjects’ self-stimulating behaviors significantly decreased following jogging. However, the reduction of behaviors was only temporary with a return to baseline within 75 to 90 minutes after jogging. In a follow-up study, Kern, Koegel, and Dunlap (1984) investigated the effects of different types of physical activity on stereotypical behaviors of children with autism ages 7-11. The children participated in vigorous continuous jogging or less vigorous exercise of ball playing for 15 minutes. Behaviors were observed and recorded following the physical activity for a period of 90 minutes. After the observation, the children participated in the second type of physical activity and were then observed for 90 minutes. The type of physical activity was alternated at the beginning of each day. Vigorous exercise appeared to have a positive effect on the children’s behaviors with a 40% decrease in stereotypical behaviors after jogging. No consistent changes were noted in behavior after ball playing. This was one of the first studies to suggest that physical activity may affect the underlying physiological process that impact behaviors.
Levinson and Reid (1993) also explored the effects of exercise intensity on the stereotypic behaviors of individuals with autism. Three students with autism walked for 15 minutes and engaged in vigorous exercise for 15 minutes over a period of five weeks. The frequency of stereotypic behavior was measured prior to exercise, immediately following exercise, and 90 minutes after completion of exercise. Results of the study showed that mild exercise had little effect on behaviors, but a significant reduction in stereotypic behaviors occurred after the vigorous exercise condition. The mean reduction of stereotypic behaviors between pre-jogging and post-jogging was 17.5. As in the Kern, Koegel, Dyer, Blew, and Fenton study (1982), the duration of these reductions was temporary. Stereotypic behaviors increased to pre-exercise levels after 90 minutes. Behavior involving motor control was the most common stereotypic behaviors observed. This was one of the first studies indicating that the mode of exercise correlates with the sensory feedback (motor), which is similar to what is gained from stereotypic behaviors of autism.

Reducing behaviors associated with autism also has implications for increasing the community integration of individuals with this condition. Elliott, Dobbin, Rose, and Soper, (1994) compared general motor training and vigorous aerobic exercise on the behavior of adults with autism. Participants living in a residential treatment program for people with autism and who had a history of severe maladaptive behavior were placed in one of three conditions: playing board games (non-exercise control), walking on treadmill at a slow pace (general motor activities) while maintaining their heart rate within 90-120 beats per minute (bpm), or walking fast on a treadmill with heart range averaging 130-144 bpm (vigorous exercise). Results showed that 4 out the 6 participants experienced decreased stereotypical behavior after antecedent aerobic activity. Little change in behaviors was observed after the non-exercise control and mild
exercise conditions. An improvement in behaviors following vigorous aerobic exercise was significant with reductions of 57% in maladaptive behaviors and a 65% reduction in stereotypic behaviors. A relationship was observed between age and the amount of benefit from aerobic exercise. The three oldest participants experienced the greatest reduction in behaviors. Additionally, two of the six adults who achieved significant consistent positive results with exercise participated in two vigorous exercise sessions and two periods without exercise prior to going to their jobs, which involved distributing advertising materials in the community. There was a decrease in stereotypical behaviors for both participants. These results suggested the potential for using vigorous aerobic exercise to assist with the community integration of adults with autism.

The generalizability and functional significance of antecedent vigorous exercise on stereotypical behaviors was investigated by Malek and Mitchell (1997). The effects of aerobic exercise on the self-stimulatory behaviors and academic performance of adolescents with ASD was assessed, as well as the generalization of exercise effects on task performance in a community based workshop situation. Five adolescent males with ASD who attended the same public school special education class and who participated in a community-based workshop program participated in the study. The program included jogging and academics prior to participating in academic or workshop tasks. The intervention conditions consisted of warm up stretches and mildly strenuous jogging performed independently for twenty minutes in a gym and routine assorted academic lessons. The conditions following exercise consisted of academic work or individualized workshop tasks for each student. Results supported the positive effect of aerobic activities being incorporated into a student’s day for both effective behavior management and improved classroom and workshop performance.
2. **Health effects of physical activity**

The Pitetti et al. (2007) study of treadmill walking is one of few research studies focused on the health benefits of physical activity for youth with ASD. Pitetti evaluated the usefulness of walking for fitness by measuring its impact on body mass index (BMI) reduction. Ten adolescents with ASD who attended a residential school were assigned to one of two groups: a treadmill walking program or a control group. The treadmill walking group walked on a treadmill for 15 to 30 minutes during their regular activity classes (three weekdays), non-activity days (two other weekdays) and the evening at their residences. The control group participated in leisure activities for 30 minutes, 3 times per week at a local gymnasium. The treadmill walking group gradually increased their walking duration to 5 times per week for 20 minutes a session, maintaining a speed between 3.7-4.1 miles per hour. The incline was slowly increased with a peak grade of 5%. Daily logs were maintained for each participant for treadmill walking progression in frequency, duration, grade and speed, caloric expenditure, and BMI. The treadmill walking group showed a significant decrease of 17.2% in BMI as well as a significant increase in exercise capacity and monthly caloric expenditure. The study did not attain the minimum recommendations for exercise duration or frequency, but did achieve the recommended levels of speed. The results of this study suggest that the treadmill walking group had a positive impact on reducing BMI, including two participants who were taking daily doses of risperidone, which has a side effect of weight gain. No significant changes in BMI and body weight were demonstrated in the control group. This study demonstrated that a treadmill walking program could improve or control persons with autism health profiles.
3. **Correlates of physical activity**

Orsmond et al. (2004) study investigated the role of friendships/peer relationships, environmental factors and participation in the social and recreational activities of 235 adolescents and adults with autism who lived at home. Mothers of participants provided data during home interviews or through self-administered questionnaires. Study measures of social or recreational activity focused on frequency of participation: quality of participation was not assessed. For the majority of subjects (74.5%), the most common activity that occurred at least once a week was walking. Recreation activities were pursued independently without companions or friends; 46.4% of the participants reported having no peer relationships, though results indicate that those with less severe impairments were more likely to have friends. Greater participation in social and recreation activities was associated with greater independence in activities of daily living, a greater number of internalizing behavior problems, less impairment in reciprocal social interactions skills, greater number of services received, and greater maternal participation in social and recreation activities. According to this study, three environmental factors that potentially could influence the level of participation in social and recreation were: 1) mother’s engagement in social and recreation activities, 2) the number of services which participants received, and 3) whether or not the participant was included with non-disabled peers while in school. It appeared that recreation activities, such as walking or other forms of exercise that do not necessarily require social interaction were the most commonly engaged in.

Social impairments associated with ASD limit opportunities for participation in physical activity with peers. Pan and Frey (2005) addressed the need to better understand how ASD may affect health behaviors. They assessed the impact of parental activity levels and parental support of children’s physical activity on the physical activity levels of youths with high functioning
autism spectrum disorder (HFASD). Thirty youth diagnosed with HFASD and their parents wore an accelerometer to measure physical activity for seven consecutive days for at least eight hours per day for a minimum of four days, which included three weekdays and one weekend. Data was recorded on log sheets. Time spent in light, moderate, vigorous, and very vigorous physical activity during 60 minute segments of the seven day monitoring period were measured. To measure parental support, parents completed the Social Support Toward Physical Activity Scale at the start and end of the seven day monitoring period. Results of the study demonstrated that youth with HFASD were more active than their parents with only 33% of mothers and 64% of fathers exercising for 30 minutes on most days and 47% of youth with HFASD exercising for 60 minutes per day. Parental support was not related to youth’s physical activity. Youth age and sedentary pursuits impacted activity levels, but not parent physical activity or support. These results may be indicative of the need for further supports to develop health behaviors of youth with autism beyond parental support.

Age is an important factor when considering the physical activity levels of children because health behaviors are established during childhood. It is unknown if children with ASD are developing physical activity habits early in life and as a consequence be at risk for health related conditions in later years. Rosser and Frey (2005) compared the time spent in daily physical education, recess, and the level of after school physical activity of five to twelve year old children with and without ASD. The children’s activity was monitored for five days (four weekdays and one day during the weekend). Fifteen children with ASD and 13 children without ASD wore an accelerometer for four school days and one day of the weekend over a 14 day period from 10:00 a.m. to 7:00 p.m. Direct observation of physical activity within physical
education and recess was assessed using a validated instrument, the Behavior of Eating and Activity for Children’s Health: Evaluation System (Thomas et al., 1991).

They found no differences between genders, time spent in vigorous and very vigorous physical activity. However, children without ASD spent more time in moderate to vigorous physical activity at recess than at other times. Children with ASD spent more time in moderate to vigorous physical activity in physical education compared to other settings. A majority of children from both groups went directly home after school, often participating in sedentary technology based activities indicating a potential for youth with ASD to develop unhealthy behaviors of participation in sedentary activities.

C. The Present Study

Research has established the positive effect of physical activity on self-stimulating behaviors associated with ASD, and while few studies have documented the health benefits, there is little question that greater levels of activity are important. We know little about the variables associated with increased or decreased physical activity among youth with ASD. As indicated in the preceding studies, environmental and especially family effects appear to be important to variations in physical activity.

The present study explored this issue by comparing children's activity levels with their siblings without autism. By comparing teen siblings, the study sought to control inter-family variations in activity levels and isolate variables related to autism that resulted in less physical activity than their non-disabled siblings.
III. RESEARCH METHODS

A. **Aim and Objectives**

The study was a self-report based online survey about health and lifestyle for teens with ASD. Only teens with ASD who had a non-ASD sibling were included in this study. Survey questions focused on factors that could potentially impact activity levels: lifestyle, environmental factors, and social opportunities. Data collection was based on a proxy (parents) reporting about both the teen with ASD and their sibling without ASD. In addition, the youths were invited to respond to the survey. Analysis of the data focused on: (1) determining if there were differences in participation in activities at home, at school, and in the neighborhoods between the siblings with and without ASD, (2) estimating the activity levels of the teens, and (3) identifying the activities and opportunities teens had available to them.

B. **Sampling**

Study participants were drawn from agencies and organizations in the Chicago area that serve individuals with ASD. The ASD related organizations that were contacted were: 1) Advocate Illinois Masonic Pediatric Developmental Center, 2) Arc of Illinois Life Span Project, 3) Autism Speaks, 4) Autism Society of Illinois, 5) Chicago Southside Autism Support Group, 6) Easter Seals Chicago Therapeutic Day School, 7) Kids Enjoy Exercise Now, and 8) Family Clinic, Department of Disability and Human Development, University of Illinois. The agencies and organizations included in the sampling were chosen because they served individuals with autism exclusively or had a relatively high proportion of individuals with autism represented in their consumer base. Agencies that approved the dissemination of study information for recruitment invited participants via a hardcopy flyer, website, or email from their organization.
1. **Sampling strategy**

Agencies and organizations serving individuals with ASD were contacted in March 2009 to request permission to recruit families into the study. Contact persons were identified for each agency and ranged from the agency directors to program secretaries. In April 2009, study participants received printed flyers from the following organizations: Advocate Illinois Masonic Pediatric Developmental Center, Autism Society of Illinois, Chicago Southside Autism Support Group, Easter Seals Chicago Therapeutic Day School, and the Family Clinic, Department of Disability and Human Development, University of Illinois. A website recruitment posting was provided by the Arc of Illinois Life Span Project. Email information was sent to parents served by Kids Enjoy Exercise Now. The survey was posted online on May 16, 2009 for the family volunteers. In August 2009, follow up phone calls were made to the participating agencies in order to prompt them to share study information with families. The last day for submitting a completed survey was October 31, 2009.

2. **Selection criteria and subjects**

To be considered for inclusion in this study, participants had to be adult (over 18 years of age) family caregivers of children with and without ASD. Their children had to be between the ages of 12 and 18 years. The total number of subjects approved by the Internal Review Board to participate was 300 (family caregivers, children with and without ASD). Families who did not have a child with ASD and a child without ASD in the age range of 12-18 years and who did not access the service recruitment sites were excluded from this study.

Only those families who visited an ASD related website or agency encountered information about the study information and invitations to participate as subjects. Thus the study sample was self-selected. Eligibility was determined with a single question asked prior to taking
the survey: “Are you the parent or guardian mainly responsible for giving care to a child between
the ages of 12 and 18 with Autism Spectrum Disorder (ASD) and a sibling without ASD both of
whom live with you?” If parents did not answer yes to the first question, they were thanked and
sent to the exit page without seeing the survey.

3. **Consent procedures**

Parents completed the initial survey. At the end of the survey, parents were asked
if they were willing to allow their children to complete the survey as well. Parental permission
was required in order for their children to participate. Upon approval, a code was provided for
their children to use to participate in the online survey. In addition to parent consent, the child’s
assent was required. The study’s protocol deferred to the parent’s judgment whether their
children’s ability or maturity was adequate to provide assent. If parents believed their children
did not have the necessary maturity to provide assent, the parent provided assent on their behalf.
If children needed assistance to complete the survey, parents were asked to provide assistance
with the questions. If a parent assisted one of their children, they were asked to assist the second
child in order to maximize consistency in responses. The data obtained from the survey was
recorded and stored on a secure server at the University of Illinois at Chicago for analysis.

C. **Instrumentation**

The survey was a modified version of the Health and Lifestyles of Teens with Disabilities
Survey (Yamaki, 2007). The original survey was used in an analysis of obesity-related secondary
conditions among adolescents with disabilities. Since the focus of the present study was not on
obesity, the tool was modified to omit obesity related questions, and instead emphasized physical
activity related questions. The parental survey included questions on recreation resources, such
as if the park or community center closest to where they live had programs for youth with
disabilities, and participation issues. New questions were not added. However, all disability references were changed to specifically refer to ASD. It was estimated that the survey would require 5 to 15 minutes to complete, depending on the person’s ability to read and respond to the questions.

The survey was organized around categories of activity, and response options included activity levels for activities where appropriate. The categories were: (1) availability of school based physical education or adapted physical education, (2) community based activity resources, (3) amount of time involved in activities, (4) transportation, (5) accessibility, (6) intensity of activity, (7) duration of activity, (8) participation in sedentary activities, (9) inclusiveness of activities and resources, (10) environmental factors (crime, traffic, etc.), and (11) specification of associated conditions, gender, age, and demographics. With the exception of four categories, the same questions appeared in both the parental and child survey versions. One category was specific to the child: physical activity in school. Participation in sports and recreation activities, concerns about public places and associated conditions to disability were specific to the parental survey. Question categories, number of items, and associated survey are summarized in Table I.
### TABLE I

<table>
<thead>
<tr>
<th>Question Category</th>
<th>Number of Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participation in sports and recreation activities</td>
<td></td>
</tr>
<tr>
<td>Youth</td>
<td>0</td>
</tr>
<tr>
<td>Parent</td>
<td>8</td>
</tr>
<tr>
<td>Physical activity opportunities in school</td>
<td></td>
</tr>
<tr>
<td>Youth</td>
<td>8</td>
</tr>
<tr>
<td>Parent</td>
<td>0</td>
</tr>
<tr>
<td>Physical activity resource</td>
<td></td>
</tr>
<tr>
<td>Youth</td>
<td>3</td>
</tr>
<tr>
<td>Parent</td>
<td>1</td>
</tr>
<tr>
<td>Accessibility of sports and recreation activities</td>
<td></td>
</tr>
<tr>
<td>Youth</td>
<td>1</td>
</tr>
<tr>
<td>Parent</td>
<td>2</td>
</tr>
<tr>
<td>Teens ability to get around various public places</td>
<td></td>
</tr>
<tr>
<td>Youth</td>
<td>1</td>
</tr>
<tr>
<td>Parent</td>
<td>5</td>
</tr>
<tr>
<td>Concerns about teen in public places</td>
<td></td>
</tr>
<tr>
<td>Youth</td>
<td>0</td>
</tr>
<tr>
<td>Parent</td>
<td>2</td>
</tr>
<tr>
<td>Teen’s physical activity habits</td>
<td></td>
</tr>
<tr>
<td>Youth</td>
<td>7</td>
</tr>
<tr>
<td>Parent</td>
<td>4</td>
</tr>
<tr>
<td>Associated conditions of teen’s disability</td>
<td></td>
</tr>
<tr>
<td>Youth</td>
<td>0</td>
</tr>
<tr>
<td>Parent</td>
<td>2</td>
</tr>
<tr>
<td>Background information</td>
<td></td>
</tr>
<tr>
<td>Youth</td>
<td>1</td>
</tr>
<tr>
<td>Parent</td>
<td>4</td>
</tr>
</tbody>
</table>

The survey was structured to incorporate ranked Likert responses that could determine degree of participation in activities beyond simple “yes” and “no” responses. There were 28 questions on the parental survey and 21 questions on each of the teens with ASD and sibling survey. The survey contained skip patterns. For example, if a parent responded no to the question, “Does the child with ASD use a wheelchair or another device to move around?”, then
they would skip question nine which related to accessibility. The surveys can be found at Appendices A, B, and C. The survey was designed to: 1) require a small amount of time to complete, 2) be easily accessible without restrictions so parents and their children could response at any time, 3) make it easy to share personal experiences, and 4) require no contact with the researcher or other families in order to maintain confidentiality.

Response data for the questionnaires were stored digitally on the University of Illinois at Chicago Academic Computing and Communication Center servers. The files contained survey questions, responses with corresponding numeric values of responses. Results were exported to a comma-separated values file, which is used for the digital storage of data structured in a table of lists form.

1. **Parent and teen surveys**

Two versions of the survey were utilized to capture both the parental response and the teen response to factors affecting teen participation in physical activities. The parental tool included questions about the participation in sports and recreation activities, accessibility of resources, concerns of public places, and the ability to get around the community. In contrast, the teen survey had questions related to physical activity opportunities in school and more questions on physical activity habits. The goal was to ascertain the unique perspectives of parents and teens.

2. **Procedures**

The surveys were posted online using the University of Illinois at Chicago servers on the domain registered to the National Center on Physical Activity and Disability. The original Health and Lifestyles of Teens with Disabilities Survey is also located at this same domain. Families linked electronically to the survey from the Arc Lifespan Project website or by entering
survey website urls listed on printed flyers that they had received from agencies (see Section B for the list of participating agencies). The Lifespan Project is the statewide information and resource site for services for people with developmental disabilities in Illinois. The website contains events, advocacy, referral, services, and an array of helpful information specific to developmental disabilities. Parents were the initial respondents. Once a parent or guardian answered the question confirming they had primary responsibility for child in the targeted inclusion group, they then received access to the full survey. Upon completion of the survey, parents were queried to provide permission for their teens to participate in the survey. Parents who permitted their teens to take the survey chose an access code to give their child which gave teens who provided assent access to the full survey. Respondents typically completed the survey within approximately ten minutes.

In March and April of 2009, agencies provided letters of support to disseminate survey information. On May 12, 2009, IRB approval was received for the protocol approval period from May 7, 2009 to May 6, 2010. Surveys were first posted in May 2009, but none were accessed until follow-up phone calls were made to agencies confirming dissemination of study information in June and August 2009. Flyers were provided to agencies in April, June, and again in August 2009 for multiple attempts to disseminate study information. October 31, 2009 was the final date for survey information.

D. Analysis

Data were imported into SPSS files and then tabulated using basic descriptive frequency summaries. The summaries described the pattern of responses as well as comparisons of distribution of responses between parents and between teens with ASD and their siblings. Respondents did not answer all questions.
IV. RESULTS

A. **Respondents**

Only a small number of families chose to respond to the survey and not all of those volunteering completed all surveys. The restricted sample severely limits the degree to which generalizations can be made about activity levels. Response levels among the volunteer families are shown in Table II.

### TABLE II

<table>
<thead>
<tr>
<th>Survey Type</th>
<th>Number of Respondents</th>
<th>Number of Completed Surveys</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Teens with ASD</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Teen Siblings</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

A total of seven parents accessed the survey, but only six parents elected to take it. Surveys were separately analyzed according to type of respondent: parents, teens with ASD or non ASD siblings. No identification connecting family member to a survey was made and results were tabulated as individual surveys. Thus for example, the two teen siblings who took the survey may or may not have been from the same family. The survey was not designed to provide information aggregated at the family level. Not surprisingly, teen siblings had the lowest response rate, perhaps reflecting their greater autonomy in making decisions to participate in the survey than their brothers and/or sisters with ASD.
B. **Parent Surveys**

Survey responses were tabulated to compare teens with ASD and non ASD siblings in Table III.

### TABLE III

**PHYSICAL ACTIVITY IN 12 MONTHS: ASD VS NON ASD SIBLINGS**

<table>
<thead>
<tr>
<th>Item</th>
<th>ASD</th>
<th>NON ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Play on a sports team?</td>
<td>16.7%</td>
<td>33%</td>
</tr>
<tr>
<td>Clubs or organizations?</td>
<td>16.7%</td>
<td>100%</td>
</tr>
</tbody>
</table>

The data show differences in participation in sports teams although note that the magnitude of the percent differences is distorted by the small sample size. Only one teen with ASD participated on a sports team compared to two teen siblings without ASD. Greater differences were reported between siblings on participation in clubs and organizations outside of school or home. Only one teen with ASD participated versus all six siblings without ASD participating in clubs.

As shown in Table IV, parents were evenly divided across the choices of activities being very accessible, moderately accessible and slightly accessible.

### TABLE IV

**ACCESSIBILITY OF SPORTS AND RECREATION ACTIVITIES**

<table>
<thead>
<tr>
<th>Rating</th>
<th>Number of Respondents</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very</td>
<td>1</td>
<td>33.3%</td>
</tr>
<tr>
<td>Moderate</td>
<td>1</td>
<td>33.3%</td>
</tr>
<tr>
<td>Slightly</td>
<td>1</td>
<td>33.3%</td>
</tr>
</tbody>
</table>
All parents (100%) indicated that the park district or community center closest to where they live had programs in which youth with disabilities can participate. This includes both programs specifically for youth with disabilities as well as inclusive programs in which both youth with and without disabilities participate together.

Table V summaries data on the ability of teens with ASD to get around public places.

<table>
<thead>
<tr>
<th>Rating</th>
<th>Special Transport</th>
<th>Need to Accompany Child</th>
<th>Available to Accompany Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>16.7%</td>
<td>66.6%</td>
<td>16.7%</td>
</tr>
<tr>
<td>Often</td>
<td>16.7%</td>
<td>16.7%</td>
<td>66.6%</td>
</tr>
<tr>
<td>Rarely</td>
<td>0</td>
<td>16.7%</td>
<td>16.7%</td>
</tr>
<tr>
<td>Never</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>N/A</td>
<td>66.6%</td>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

The majority of parents (66.7%) indicated that special transportation was not required for their family. However, 66.7% of parents responded that they always find it necessary to accompany their teens with ASD and 66.7% of parents reported that often someone is available to accompany their child.
**TABLE VI**

USE OF VIDEO ENTERTAINMENT AMONG TEENS WITH ASD

<table>
<thead>
<tr>
<th>Amount of Use</th>
<th>Watches TV</th>
<th>Plays Video Games</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ASD</td>
<td>NON ASD</td>
</tr>
<tr>
<td>4-5 Hours</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3 Hours</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2 Hours</td>
<td>16.7%</td>
<td>16.7%</td>
</tr>
<tr>
<td>1 Hour</td>
<td>16.7%</td>
<td>0</td>
</tr>
<tr>
<td>1&lt; Hour</td>
<td>66.7%</td>
<td>83.0%</td>
</tr>
<tr>
<td>Does Not</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table VI compares the use of video entertainment by teens with ASD and their siblings. Teens with ASD watched more TV than their siblings with 66.7% of teens with ASD reported to have watched less than one hour of TV compared to 83.3% of siblings. Playing video games was more common for their teen siblings. Two-thirds of the teens with ASD did not play videos while all their siblings were reported by their parents as video game players.

Parents were asked if the teens with ASD had associated conditions. Two-thirds (66%) indicated that there was an associated condition, and of these, 75% listed sleep apnea. The balance of parents (25%) identified a learning disability as the associated condition.

C. **Teen Survey**

Data from teen surveys is found in Table VII through IX. Survey responses revealed modest differences in most areas. It is important to note there were only two teen siblings who participated in the study. Table VII lists the physical activity opportunities in school for both teens with ASD and siblings non ASD. Fifty seven percent of teens with ASD completed the
survey on their own: 14.3% with help from their parent and 28.5% by parent on behalf of teen. All siblings completed the survey on their own.

There was a difference in the requirement of physical education (PE) in their educational programs. Six teens with ASD responded that physical education is offered at school compared to 100% or 2 teen siblings without ASD. However, only 20% or 2 of the 6 teens with ASD responded that they were required to take physical education compared to both (100%) of the teen siblings without ASD. While this difference may be merely due to the small sample of

<table>
<thead>
<tr>
<th>Item</th>
<th>ASD</th>
<th>NON ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Required to take PE or APE?</td>
<td>20%</td>
<td>100%</td>
</tr>
<tr>
<td>Location other than classroom</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Type of PE in School</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular PE</td>
<td>40%</td>
<td>100%</td>
</tr>
<tr>
<td>Adapted PE</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>N/A</td>
<td>60%</td>
<td>0</td>
</tr>
<tr>
<td>Days in PE per Week</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 or less</td>
<td>0</td>
<td>100%</td>
</tr>
<tr>
<td>4 or more</td>
<td>100%</td>
<td>0</td>
</tr>
<tr>
<td>Minutes in PE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30 or less</td>
<td>50%</td>
<td>0</td>
</tr>
<tr>
<td>31 or more</td>
<td>50%</td>
<td>100%</td>
</tr>
<tr>
<td>Time Exercising/Sports in PE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than half</td>
<td>50%</td>
<td>0</td>
</tr>
<tr>
<td>Most</td>
<td>50%</td>
<td>100%</td>
</tr>
<tr>
<td>Participate in Same Activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>50%</td>
<td>0</td>
</tr>
<tr>
<td>Most</td>
<td>50%</td>
<td>0</td>
</tr>
<tr>
<td>All</td>
<td>0</td>
<td>100%</td>
</tr>
</tbody>
</table>
teens, the reason is unclear. Teens with ASD may have less access to physical education due to differences in the curriculum requirements for the two groups. Three teens with ASD reported that they were not required to take PE. In terms of the type of PE, two (40%) of the teens with ASD responded that they took PE and three (60%) did not take PE compared to the one sibling (of the two siblings) who responded that PE was a required course. The two types of PE considered were physical education and adapted physical education. Physical education for individuals with disabilities was specifically noted in the Individuals with Disabilities Education Act (IDEA) in terms of Adapted Physical Education (APE) for children with disabilities. This accommodation was designed to ensure that children with disabilities receive equal opportunities for participation in physical education. In contrast to their siblings, Table VII shows differences between teen respondents with teens with ASD reported attending that they participated in PE more days than teen siblings without ASD. Although teens with ASD attend PE more frequently during the week, the time devoted to physical education is slightly less than their siblings. Time spent exercising or playing sports during PE in Table VII reflects how much of the class time actually devoted to physical activity is. Only one of the teens with ASD reported spending most of their time being physically active in PE. Teens with ASD reported taking part in all the same activities as their classmates at a much lower rate than their siblings.

Table VIII illustrates the use of community facilities such as parks or playgrounds and transportation access by teens and their siblings. In this instance, teens with ASD reported being heavier users of parks than their siblings. The question regarding the availability of a ride to participate in sports or physical activities was intended to represent transport access. Non ASD siblings reported that someone is always available compared to only 42.9% or three teens with
ASD. Finally, lack of accessibility did not appear to reduce participation for 42.9% or three teens with ASD. It had no effect on the teens without ASD (100%).

**TABLE VIII**

<table>
<thead>
<tr>
<th>Item</th>
<th>ASD</th>
<th>NON ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resources in the community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Park or Playground Available</td>
<td>83.3%</td>
<td>50.0%</td>
</tr>
<tr>
<td>Use Park or Playground</td>
<td>20.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>How Often</td>
<td>0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Ride Available?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td>42.8%</td>
<td>100%</td>
</tr>
<tr>
<td>Often</td>
<td>28.5%</td>
<td>0%</td>
</tr>
<tr>
<td>Some</td>
<td>14.2%</td>
<td>0%</td>
</tr>
<tr>
<td>Rarely</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Never</td>
<td>14.2%</td>
<td>0%</td>
</tr>
<tr>
<td>Lack of Accessibility Reduces Activity?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Great Deal</td>
<td>14.2%</td>
<td>0%</td>
</tr>
<tr>
<td>Lot</td>
<td>14.2%</td>
<td>0%</td>
</tr>
<tr>
<td>Moderately</td>
<td>14.2%</td>
<td>0%</td>
</tr>
<tr>
<td>Little</td>
<td>14.2%</td>
<td>0%</td>
</tr>
<tr>
<td>Not At All</td>
<td>42.8%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Table IX indicates that slight differences were seen in the level of activity teens with ASD compared to non ASD siblings during the week. On average, teens with ASD reported zero days with friends compared to three days for teen siblings without ASD. In terms of watching television (TV) and playing video games, similar amounts of time were expended by both groups though video game playing was slightly higher for teens with ASD. Both of the non ASD siblings in the sample reported playing video games less than one hour compared to two or
28.5% of teens with ASD playing for less than one hour and four or 57.1% of teens with ASD played video games for two hours and one or 14.3% of teen with ASD playing video games for four hours.

### TABLE IX

**PHYSICAL ACTIVITY HABITS**

<table>
<thead>
<tr>
<th>Item</th>
<th>ASD</th>
<th>NON ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average # of Days Exercised</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20 minutes</td>
<td>4.0 days</td>
<td>3.0 days</td>
</tr>
<tr>
<td>30 minutes</td>
<td>3.5 days</td>
<td>3.5 days</td>
</tr>
<tr>
<td>60 minutes</td>
<td>3.8 days</td>
<td>3.0 days</td>
</tr>
<tr>
<td>With Friends</td>
<td>.028 days</td>
<td>3.0 days</td>
</tr>
<tr>
<td>With Family</td>
<td>1.4 days</td>
<td>1.0 day</td>
</tr>
<tr>
<td><strong>Average # of Hours You:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Watch TV</td>
<td>.085 hours</td>
<td>1.0 hour</td>
</tr>
<tr>
<td>Play Video Games</td>
<td>1.71 hours</td>
<td>1.0 hour</td>
</tr>
</tbody>
</table>
V. DISCUSSION

The aim of this study was to determine if teens with ASD were less active than teens without ASD using siblings as the comparison group to control for inter family differences. The small number of participants recruited into this study makes this question impossible to answer at this time. Within the sample, however, there does appear to be consistent differences in degree of social integration and activity and participation in clubs and organization outside of the school or home for teens with ASD.

The hypothesis that teens with ASD would be less active than their siblings without ASD was impossible to test because of the low response rate. Comparing the data of seven teens with ASD to two teen siblings without ASD did not provide sufficient data or population representation to support any inferences about differences in activity levels. Nonetheless, modest differences were identified and appear consistent with the hypothesis. It was clear that parents felt some of the limitations in participation were a matter of safety; for example, most believed was necessary to accompany their teens with ASD most of the time. Findings from the teens with and without ASD data indicated there is a difference in degree of participation with friends; not expectantly, teens with ASD had many fewer opportunities. In contrast, results from video game playing and watching television data did not appear to be different between the groups nor did any large differences exist in their participation in PE.

A comparison of daily physical education, recess and after school physical activity levels of school aged (5 to 12 years of age) youth with ASD and non ASD youth resulted in no significant difference. Both groups of children reported going directly home after school and engaging in sedentary technology based activities. Results are consistent with other findings that age and sedentary pursuits are factors affecting physical activity (Rosser Sandt & Frey, 2005).
These findings, although limited by sampling are consistent with observations in the literature. Limited participation in clubs and organizations has been reported among children with disabilities (Connolly, 2008). Pan and Frey (2006) described the limited amount of community based recreation programs available to youth with ASD. This lack of recreation programs reduces opportunities for youth with ASD to recreate. Difference in participation involving friends is commonly seen in the literature; recreation activities are often pursued without companions or friends with limited or no peer relationships (Orsmond et al., 2004).

The critical limitation in this study was its extremely small sample size that was not adequate for drawing any generalizations or for allowing statistical analysis. There were no opportunities for the analysis of subgroups. The primary reasons for the small sample were a selection criterion that was limited only to families of teens with and without ASD, reliance on agencies to disseminate study information, the dependence on families to self-select participation, and the expectation that most families had access to a computer and internet service. The criterion was limited to adult family caregivers of children with and without ASD, who were ages 12-18 years and youth with ASD and without ASD in the age range of 12-18 years. All others were excluded from this study. This criterion proved to be too selective to produce enough study participants. Dependence on agencies to distribute study information was another factor that impacted the small sample size. Agencies are multifaceted, often requiring levels of approval for action. Gaining the approval of the agency to post the survey was complicated. Each agency differed in its approval process. A significant amount of time was required to contact agencies to explain the study, request permission from their boards, committees, chairperson, or executive directors. Repeated follow-ups were required to ensure that surveys were being disseminated. Most agencies provided permission to post flyers in
waiting areas, yet would not allow recruitment post on websites or recruitment via emails. Thus it was difficult to contact parents about the study, which directly affected the low response rate and sample size. Lastly the assumption that most families had access to a computer and were skilled in accessing an online survey could have affected the sample size. Few families actually accessed the survey, which could have been due to not having a computer and/or a lack of knowledge on how to use a computer to complete the survey. Additionally, families had to be motivated to initiate taking the survey as it was a self-selection design. This proved to a challenge. Families of children with disabilities are exceptionally busy as are the agencies that service them. This was evident in an anecdote shared by a professional from one of the agencies who noted that the timing of the study conflicted with the fiscal crisis in state funding for social services in Illinois. The funding crisis was a priority to agencies and to families as funding affected their survival, which significantly impacted the involvement of agencies and families in this study.

A. **Conclusions and Future Directions**

The need for continued research on physical activity and ASD and expansion of effective health promoting physical activity programs for this population is evident from the literature and suggested by the data (albeit limited) of this study. The nature of ASD presents numerous obstacles to successfully engaging in activities, especially group type activities. With the increasing number of individuals with ASD being diagnosed, it is critically important that programs are developed to appropriately address the needs of this growing population. There is general consensus that people with disabilities are less active, are at a greater risk for developing secondary conditions and have decreased opportunities to participate in health promoting programs or activities. The implications of physical inactivity are serious such disparities put
individuals with disabilities at greater health risk (Pan & Frey, 2005). Future research should replicate this study but with modifications of method for greater response rates. Expanding the age range from teens to all school age youth would widen the pool of potential study participants. Expanding the dissemination of the survey to include schools with special education services would increase the number of families informed and likely increase the potential sample size. Lastly, eliminating the online survey and replacing it with a paper survey could reduce the need for access to computers and computer skills. These modifications could enhance family access. Hopefully lessons drawn from present study can inform future study efforts focused on health promotion, recreation, adaptive recreation, and sports for youths with autism.
APPENDICES
APPENDIX A

Health and Lifestyles of Teens with Autism Spectrum Disorder (ASD) and Their Siblings without ASD

Parent Survey

The University of Illinois at Chicago
Department of Disability and Human Development
APPENDIX A (continued)

Parent Questionnaire
Are you the parent or guardian mainly responsible for giving care to a child between the ages of 12 and 18 with Autism Spectrum Disorder and their sibling without ASD who lives with you?

□ Yes
□ No

If you have marked no to the question above, thank you for interest in our survey. However, your response to this question has indicated that you and your teen are not eligible to participate in this study.

If you have marked yes, please proceed to the next page.
APPENDIX A (continued)

Informed Consent

This research is being conducted by the University of Illinois at Chicago and is made up of two surveys. This survey is for you, as the parent/guardian of the child with a disability. After you have completed this one, you will be taken to the youth questionnaire, which will be completed either by your child with or without your assistance, or by you on your child’s behalf. Before you start, we ask that you read the information on the next page about the rights and risks of participating in this research. Please read it on behalf of you and your teen.

Informed Consent

Purpose:

The purpose of this research is to better understand issues surrounding children with disabilities being physically active.

Participants’ Involvement:

You and your child are being asked to respond to a confidential online survey about lifestyle and health. The parent survey and the child survey will each take less than 15 minutes to complete. During the survey, you and your child will be asked about social, psychological, health, and environmental factors that may be related to children with disabilities.

Use of Data:

You and your child’s responses will be recorded and stored on a secure server at the University of Illinois at Chicago for analysis. The data will be kept for at least 5 years.

Privacy and Confidentiality:

Information collected from the survey will only be used for the purpose of this research. Information you and your child provide will be kept confidential. This means that you and your child’s identities will not be released to anyone outside the research team.

Risks and Benefits:

Potential risk of participating in this research includes loss of confidentiality. You or your child may feel uncomfortable when responding to questions related. There is no other known risk or discomfort associated with the survey. You or your child may not receive any personal benefit by participating in the survey. However, you and your child’s participation may help with understanding issues related to the health behaviors of children with disabilities.
APPENDIX A (continued)

Voluntary Participation:

Your and your child's participation in this research is voluntary. Your or your child’s refusal to participate in this research will not involve any penalty, result in any decrease in benefits to which you or your child are otherwise entitled to, or affect any current or future relationship between you/your child and the University. Neither you nor your child is required to respond to all of the questions in the survey. You and your child can refuse to answer a question and can stop participating at any time without any penalty or loss of benefit.

Availability of Researcher:

If you or your child has a question about this research, you may contact Sheila Swann-Guerrero at 773-699-6873 or swanngue@uic.edu. Faculty sponsor, Dr. James Rimmer at 312-413-9651 or jrimmer@uic.edu

UIC IRB information:

If you or your children have questions regarding your rights as a research subject, you may contact the University of Illinois at Chicago’s Office for Protection of Research Subjects at 312-996-1711.

Please read the statement below, and check one of the following boxes.

I have read the above statement and:

☐ I agree to participate in this research.
☐ I do not agree to participate in this research.
Reminder: Please note that the expression "your child" in this survey refers to your child of ages 12-18 with a disability.

Please tell us about your child’s participation in sports and other recreation activities.

1. Does the park district or community center closest to where you live have programs in which youth with disabilities can participate? This includes both programs specifically for youth with disabilities as well as inclusive programs in which both youth with and without disabilities participate together.

   □ Has programs
   □ Does not have programs
   □ Don't know

2. During the past 12 months, did your child play on a sports team or participate in sports lessons after school or on weekends?

   □ Played or participated in sports lessons
   □ Did not do either
   □ Not sure

3. Did your child participate in activities as a member of any clubs or organizations that took place outside of the school or home during the past 12 months?

   □ Participated
   □ Did not participate / Not a member
   □ Not sure

Please tell us about how easy it is for your child to get around various public places.

Public places can be designed so that people with disabilities can get around these places easily (for example, having ramps, sidewalks or other wheelchair-friendly building features); that is, these places can be made accessible. The next questions ask about the accessibility of places where your child can participate in physical and recreational activities.
APPENDIX A (continued)

4. Does your child use a wheelchair or another device to move around?

□ He/she does use
□ He/she does not use (skip to question 7)

The next few questions relate to youth that use a wheelchair or other device to move around. If you answered “Does not use” to the question above please proceed to question number 7.

5. How accessible are sports and recreation activities in the area in which you live for your child who uses a wheelchair or another device to move around?

□ Extremely accessible
□ Very accessible
□ Moderately accessible
□ Slightly accessible
□ Not at all accessible

6. Because of physical reasons associated with his/her disability, how often does your child need special transportation (such as a wheelchair-accessible van, etc.) or physical assistance (transporting to/from wheelchair to car, etc.) when he or she goes to places outside of the home, other than school?

□ Always
□ Often
□ Rarely
□ Never
□ Not applicable / Does not need assistance

7. How often does your child’s disability make it necessary for you or someone else to accompany your child to places other than school?

□ Always
□ Often
□ Rarely
□ Never

8. How often is someone available to accompany your child when he/she wants to go places other than school?

□ Always
□ Often
□ Rarely
□ Never
9. Besides getting rides from family members, are there any other ways in which your child is able to go to places outside of the house, other than school?

□ There are other ways
□ There are no other ways

The next two questions address concerns you may have about your child when he/she is out in public places.

10. When you consider allowing your child to go outside of the home, how concerned are you about crime in the area in which you live?

□ Not at all
□ A little
□ A moderate amount
□ A lot
□ A great deal

11. When you consider allowing your child to go outside of the home, how concerned are you about traffic safety in the area in which you live?

□ Not at all
□ A little
□ A moderate amount
□ A lot
□ A great deal

Please tells us about your child’s habits

12. On a typical school day, for about how many hours does your child watch TV or videos/DVDs?

□ Less than 1 hour
□ 1 hour
□ 2 hours
□ 3 hours
□ 4 hours
□ 5 or more hours
□ Not sure
13. **On a typical school day**, for about how many hours does your child play video/computer games or use a computer for reasons other than doing schoolwork? (exclude physically active video games and please round the number of hours to the nearest whole number, for example count 1 hour and 20 minutes as 1 hour, and 1 hour and 45 minutes as 2 hours.)

- □ Less than 1 hour
- □ 1 hour
- □ 2 hours
- □ 3 hours
- □ 4 hours
- □ 5 or more hours
- □ Not sure

---

### Please tells us about the additional condition associated with your child’s disability (ASD)

14. Are there additional conditions associated with your child’s ASD?

- □ Yes (if yes, Please refer to the following list to describe your child’s disabilities. Check all that apply.)
- □ No (skip to question 16)

If there is not an additional condition associated with your child’s disability please proceed to question 15

<table>
<thead>
<tr>
<th>Check all that apply</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention Deficit/Hyperactivity Disorder (ADHD)</td>
<td>O</td>
</tr>
<tr>
<td>Blindness or vision problems</td>
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</tr>
<tr>
<td>Cerebral palsy</td>
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<tr>
<td>Deafness or hearing problems</td>
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</tr>
<tr>
<td>Condition</td>
<td>Status</td>
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<td>-----------------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>O</td>
</tr>
<tr>
<td>Epilepsy or seizure</td>
<td>O</td>
</tr>
<tr>
<td>Head injury</td>
<td>O</td>
</tr>
<tr>
<td>Impairment or deformity of foot or leg</td>
<td>O</td>
</tr>
<tr>
<td>Impairment or deformity of arm, hand, or finger</td>
<td>O</td>
</tr>
<tr>
<td>Learning disability</td>
<td>O</td>
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<td>Mental retardation</td>
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<td>Mental or emotional problem/disorder</td>
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<tr>
<td>Missing legs, feet, arms, hands, or fingers</td>
<td>O</td>
</tr>
<tr>
<td>Paralysis of any kind</td>
<td>O</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>O</td>
</tr>
<tr>
<td>Spinal cord Injury</td>
<td>O</td>
</tr>
<tr>
<td>Asthma</td>
<td>O</td>
</tr>
<tr>
<td>High blood pressure</td>
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</tr>
<tr>
<td>High cholesterol level</td>
<td>O</td>
</tr>
<tr>
<td>Diabetes</td>
<td>O</td>
</tr>
<tr>
<td>Depression</td>
<td>O</td>
</tr>
<tr>
<td>Fatigue</td>
<td>O</td>
</tr>
<tr>
<td>Gastrointestinal problems</td>
<td>O</td>
</tr>
<tr>
<td>Joint or bone pain</td>
<td>O</td>
</tr>
<tr>
<td>Sleep apnea or other sleeping disorders</td>
<td>O</td>
</tr>
</tbody>
</table>
APPENDIX A (continued)

<table>
<thead>
<tr>
<th>Liver or gallbladder conditions</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Being overweight</td>
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</tr>
<tr>
<td>Low self-esteem</td>
<td>O</td>
</tr>
<tr>
<td>Preoccupation with weight</td>
<td>O</td>
</tr>
<tr>
<td>Blount’s disease</td>
<td>O</td>
</tr>
<tr>
<td>Pressure sores</td>
<td>O</td>
</tr>
<tr>
<td>Other—please specify:</td>
<td>O</td>
</tr>
<tr>
<td>______________________________</td>
<td></td>
</tr>
</tbody>
</table>

16. What is your relationship to the youth with a disability?

- Mother (biological, step, foster, adoptive)
- Father (biological, step, foster, adoptive)
- Sister (step, foster, adoptive)
- Brother (step, foster, adoptive)
- In-Law of any type
- Aunt
- Uncle
- Grandparent
- Other family member
- Female guardian (non-relative)
- Male guardian (non-relative)
- Other non-relative

Parental Permission for Youth Survey

You have just completed the parent survey. Now we would like to invite your teen (12-18 years) with a disability and your teen (12-18 years) without a disability to complete the second survey.

Please note that the survey and data will be kept in a password protected university server. The security of online surveys can never be 100% guaranteed.

Because your child is a minor (17 years of age or younger), we need your permission to enroll him/her in the survey. Do you allow your teen who is between 12 and 18 years old to participate in this research?
APPENDIX A (continued)

Please note that if the teen needs help with completing the survey, we ask that you help him/her by being present as he or she answers the questions. If he/she is unable to select answers by him/herself, please answer the teen survey on his/her behalf. If needed, parents may assist their children in completing the survey.

☐ Yes, I allow my child to participate in this research.
☐ No, I do not allow my child to participate in this research.

You can ask any questions you may have about the study by calling or emailing: Sheila Swann-Guerrero at 312-699-6873 or swanngue@uic.edu
Faculty sponsor, Dr. James Rimmer at 312-413-9651 or jrimmer@uic.edu

Thank you for allowing your child to participate in this research. To ensure that your child’s participation is voluntary, he/she will also be asked at the beginning of their survey whether he/she wishes to participate.

Please enter a password into the box below. We will ask that this password be entered again at the beginning of your child’s survey. This will enable us to link your responses on this survey to those of the child.

To assure that your password is unique to you and your child, we recommend that you use the name of the caregiver who is answering this survey, followed by the child’s birth date.

Example:
Parent's name: Carol
Child's Birth date: 6/5/85
Password: Carol060585

You're Done!

Thank you for taking the time to complete this survey.
APPENDIX B

Teens with Disabilities Physical Activity Survey

Teens Survey

The University of Illinois at Chicago
Department of Disability and Human Development
APPENDIX B (continued)

<table>
<thead>
<tr>
<th>Youth Assent</th>
</tr>
</thead>
</table>

I am a student at the University of Illinois at Chicago. I would like to invite you to take a study that involves teenagers like yourself.

Why are we doing this study?

We are asking you to help with our research because we want to learn more about how your amount and quality of opportunities for physical activity in life relates to your overall health. If you agree to participate, you will answer questions with your parent and/or caregiver on the computer about your activities at school, at home, and in your neighborhood. It will take about 15 minutes to complete the survey. If needed, your parents may assist you in completing the survey.

What will happen to you if you are in the study?

As you answer the questions, it is possible that you may feel uncomfortable because you will be asked to tell us about things related to your health, school life, relationship with your friends, and your feelings. However, your participation may help us to better understand important issues related to the health of young people like yourself.

Do you have to be in the study?

Please talk this over with your parent before you decide whether or not to participate. While your parent has already given us permission for you to take part in this survey, you can still choose not to participate. You do not have to do this survey if you do not want to. Remember, being in this study is up to you and no one will be upset if you don’t want to do it or if you change your mind later and want to stop.

Do you have any questions?

You can ask any questions you may have about the study by calling or emailing: Sheila Swann-Guerrero at 312-996-6053 or swanngue@uic.edu.

UIC IRB information:

If you have questions about your rights as a research subject, you can contact the University of Illinois at Chicago’s Office for Protection of Research Subjects at 312-996-1711 or uicirb@uic.edu.

Do you want to participate in this survey research?

☐ I want to participate
☐ I do not want to participate
APPENDIX B (continued)

THE QUESTIONS ON THE FOLLOWING PAGES ASK ABOUT PHYSICAL ACTIVITY OPPORTUNITIES AT SCHOOL AND IN YOUR NEIGHBORHOOD

1. Does your school offer physical education (gym) or adapted physical education class during the school day?

☐ Yes, it does offer
☐ No, it does not offer (skip to Question 8)
☐ I don’t know (skip to Question 8)

THE NEXT FEW QUESTIONS TALK ABOUT GYM CLASS, IF YOUR SCHOOL DOES NOT OFFER GYM CLASS PLEASE SKIP DOWN TO QUESTION 8

2. Does your school require you to take physical education (gym) or adapted physical education class?

☐ It is required
☐ It is not required
☐ I don’t know

3. Which type of physical education or adapted physical education class do you take?

☐ Physical education (PE)
☐ Adapted PE
☐ I do not take PE (skip to Question 8)

4. Do you generally participate in physical education or adapted physical education class in a somewhere other than your classroom?

☐ Yes
☐ No

THE NEXT FEW QUESTIONS TALK ABOUT GYM CLASS, IF YOU DO NOT ATTEND GYM CLASS PLEASE SKIP DOWN TO QUESTION 8

5. During a typical week when you are in school, on how many days do you go to physical education or adapted physical education class?

a.) ☐ Never (skip to question 8)
☐ 1 day/week ☐ 2 days/week ☐ 3 days/week
☐ 4 days/week ☐ 5 days/week
APPENDIX B (continued)

How many minutes per day is your physical education or adapted physical education class?

b.) □ 1-15 minutes/day □ 16-30 minutes/day
□ 31-45 minutes/day □ more than 60 minutes/day

THE NEXT FEW QUESTIONS TALK ABOUT GYM CLASS, IF YOU DO NOT ATTEND GYM CLASS PLEASE SKIP DOWN TO QUESTION 8

6. During physical education or adapted physical education class, how much of the class time would you say you spend actually exercising or playing sports?

□ None of it
□ Less than half of it
□ About half of it
□ Most of it
□ All of it

7. During physical education or adapted physical education class, how many of the same activities do you participate in compared to the others in your class?

□ I do not take part in any of the same activities as my classmates.
□ I take part in some of the same activities as my classmates.
□ I take part in most of the same activities as my classmates.
□ I take part in all the same activities as my classmates

8. Is there a park, playground, or other such space near your home that you can go to take part in physical activity?

a.) □ There is
□ There is not
□ Don't know

If there is, do you use it?

b.) □ Yes
□ No

If yes, how often do you use it?

c.) □ Daily
□ Weekly
□ Monthly
□ Yearly
APPENDIX B (continued)

9. When you need a ride to participate in sports or other physical or social activities, how often is someone available to give you a ride?

☐ Always  
☐ Often  
☐ Sometimes  
☐ Rarely  
☐ Never

SOME PUBLIC PLACES OR HOMES ARE DESIGNED SO THAT PEOPLE WITH DISABILITIES CAN GET AROUND THESE PLACES EASILY. THIS IS REFERRED TO AS THE “ACCESSIBILITY” OF A PLACE.

10. To what degree has a lack of accessibility or lack of supports at places where you can take part in sports, such as parks, gyms, or friends’ homes, reduced your opportunities to be as physically active as you would like?

☐ Has not reduced at all  
☐ Reduced a little  
☐ Reduced moderately  
☐ Reduced a lot  
☐ Reduced a great deal

THE FOLLOWING QUESTIONS ASK ABOUT YOUR PHYSICAL ACTIVITY HABITS.

11. During a typical week, on how many days do you exercise or do some type of physical activity for at least 20 minutes that makes you sweat and breathe hard?

☐ 0 days  
☐ 1 day  
☐ 2 days  
☐ 3 days  
☐ 4 days  
☐ 5 days  
☐ 6 days  
☐ 7 days
12. During a typical week, on how many days do you participate in physical activity for at least 30 minutes that does NOT make you sweat or breathe hard, such as fast walking, slow bicycling, skating, playing with friends or family, playing physically active video games (i.e. Wii Fit, Wii Sports, Dance Dance Revolution)?

- □ 0 days
- □ 1 day
- □ 2 days
- □ 3 days
- □ 4 days
- □ 5 days
- □ 6 days
- □ 7 days

13. During a typical week, on how many days are you physically active for a total of at least 60 minutes (60 minutes = 1 hour) per day? (Add up all the time you spend in any kind of physical activity that increases your heart rate and makes you breathe hard some of the time.)

- □ 0 days
- □ 1 day
- □ 2 days
- □ 3 days
- □ 4 days
- □ 5 days
- □ 6 days
- □ 7 days

14. During a typical week, how many days do you spend doing physical activities or playing sports with friends?

- □ 0 days
- □ 1 day
- □ 2 days
- □ 3 days
- □ 4 days
- □ 5 days
- □ 6 days
- □ 7 days
APPENDIX B (continued)

15. During a typical week, how many days do you spend doing physical activities or playing sports with family?

□ 0 days  
□ 1 day  
□ 2 days  
□ 3 days  
□ 4 days  
□ 5 days  
□ 6 days  
□ 7 days

16. On a typical school day, for how many hours do you... Watch TV or videos/DVDs?

□ Less than an hour  
□ 1 hour  
□ 2 hours  
□ 3 hours  
□ 4 hours  
□ 5 or more hours  
□ Not sure

17. On a typical school day, for how many hours do you... Play video or computer games or use a computer for something that is not school work? (exclude physically active video games)

□ Less than an hour  
□ 1 hour  
□ 2 hours  
□ 3 hours  
□ 4 hours  
□ 5 or more hours  
□ Not sure

18. You may have needed some assistance with answering our questions. Please indicate how much help you had while completing this survey.

□ I completed this survey on my own.  
□ A parent/guardian helped me complete this survey.  
□ A parent/guardian completed this survey on behalf of the teen.
APPENDIX B (continued)

Thank you for your participation
All Information you provided will be kept confidential.

If you have any questions about this study, please contact:

Sheila Swann-Guerrero
University of Illinois at Chicago
Department of Disability and Human Development
773-699-6873
APPENDIX C

Teens with Disabilities Sibling Physical Activity Survey

Teen Survey

The University of Illinois at Chicago
Department of Disability and Human Development
APPENDIX C (continued)

| Youth Assent |

I am a student at the University of Illinois at Chicago. I would like to invite you to take a study that involves teenagers like yourself.

**Why are we doing this study?**

We are asking you to help with our research because we want to learn more about how your amount and quality of opportunities for physical activity in life relates to your overall health. If you agree to participate, you will answer questions with your parent and/or caregiver on the computer about your activities at school, at home, and in your neighborhood. It will take about 15 minutes to complete the survey. If needed, your parents may assist you in completing the survey.

**What will happen to you if you are in the study?**

As you answer the questions, it is possible that you may feel uncomfortable because you will be asked to tell us about things related to your health, school life, relationship with your friends, and your feelings. However, your participation may help us to better understand important issues related to the health of young people like yourself.

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

Please talk this over with your parent before you decide whether or not to participate. While your parent has already given us permission for you to take part in this survey, you can still choose not to participate. You do not have to do this survey if you do not want to. Remember, being in this study is up to you and no one will be upset if you don’t want to do it or if you change your mind later and want to stop.

**Do you have any questions?**

You can ask any questions you may have about the study by calling or emailing: Sheila Swann-Guerrero at 312-996-6053 or swanngue@uic.edu.

If you have questions about your rights as a research subject, you can contact the University of Illinois at Chicago’s Office for Protection of Research Subjects at 312-996-1711 or uicirb@uic.edu.

**Do you want to participate in this survey research?**

☐ I want to participate
☐ I do not want to participate
APPENDIX C (continued)

THE QUESTIONS ON THE FOLLOWING PAGES ASK ABOUT PHYSICAL ACTIVITY OPPORTUNITIES AT SCHOOL AND IN YOUR NEIGHBORHOOD

1. Does your school offer physical education (gym) or adapted physical education class during the school day?
   □ Yes, it does offer
   □ No, it does not offer (skip to Question 8)
   □ I don’t know (skip to Question 8)

THE NEXT FEW QUESTIONS TALK ABOUT GYM CLASS, IF YOUR SCHOOL DOES NOT OFFER GYM CLASS PLEASE SKIP DOWN TO QUESTION 8

2. Does your school require you to take physical education (gym) or adapted physical education class?
   □ It is required
   □ It is not required
   □ I don’t know

3. Which type of physical education or adapted physical education class do you take?
   □ Physical education (PE)
   □ Adapted PE
   □ I do not take PE (skip to Question 8)

4. Do you generally participate in physical education or adapted physical education class in a somewhere other than your classroom?
   □ Yes
   □ No

THE NEXT FEW QUESTIONS TALK ABOUT GYM CLASS, IF YOU DO NOT ATTEND GYM CLASS PLEASE SKIP DOWN TO QUESTION 8

5. During a typical week when you are in school, on how many days do you go to physical education or adapted physical education class?
   a.) □ Never (skip to question 8)
       □ 1 day/week □ 2 days/week □ 3 days/week
       □ 4 days/week □ 5 days/week
APPENDIX C (continued)

How many minutes per day is your physical education or adapted physical education class?

b.) □ 1-15 minutes/day □ 16-30 minutes/day
    □ 31-45 minutes/day □ more than 60 minutes/day

THE NEXT FEW QUESTIONS TALK ABOUT GYM CLASS, IF YOU DO NOT ATTEND GYM CLASS PLEASE SKIP DOWN TO QUESTION 8

6. During physical education or adapted physical education class, how much of the class time would you say you spend actually exercising or playing sports?

□ None of it
□ Less than half of it
□ About half of it
□ Most of it
□ All of it

7. During physical education or adapted physical education class, how many of the same activities do you participate in compared to the others in your class?

□ I do not take part in any of the same activities as my classmates.
□ I take part in some of the same activities as my classmates.
□ I take part in most of the same activities as my classmates.
□ I take part in all the same activities as my classmates.

8. Is there a park, playground, or other such space near your home that you can go to take part in physical activity?

a.) □ There is
    □ There is not
    □ Don't know

If there is, do you use it?

b.) □ Yes
    □ No

If yes, how often do you use it?

c.) □ Daily
    □ Weekly
    □ Monthly
    □ Yearly
APPENDIX C (continued)

9. When you need a ride to participate in sports or other physical or social activities, how often is someone available to give you a ride?

☐ Always
☐ Often
☐ Sometimes
☐ Rarely
☐ Never

SOME PUBLIC PLACES OR HOMES ARE DESIGNED SO THAT PEOPLE WITH DISABILITIES CAN GET AROUND THESE PLACES EASILY. THIS IS REFERRED TO AS THE “ACCESSIBILITY” OF A PLACE.

10. To what degree has a lack of accessibility or lack of supports at places where you can take part in sports, such as parks, gyms, or friends’ homes, reduced your opportunities to be as physically active as you would like?

☐ Has not reduced at all
☐ Reduced a little
☐ Reduced moderately
☐ Reduced a lot
☐ Reduced a great deal

THE FOLLOWING QUESTIONS ASK ABOUT YOUR PHYSICAL ACTIVITY HABITS.

11. During a typical week, on how many days do you exercise or do some type of physical activity for at least 20 minutes that makes you sweat and breathe hard?

☐ 0 days
☐ 1 day
☐ 2 days
☐ 3 days
☐ 4 days
☐ 5 days
☐ 6 days
☐ 7 days
APPENDIX C (continued)

12. During a typical week, on how many days do you participate in physical activity for at least 30 minutes that does NOT make you sweat or breathe hard, such as fast walking, slow bicycling, skating, playing with friends or family, playing physically active video games (i.e. Wii Fit, Wii Sports, Dance Dance Revolution)?

☐ 0 days  
☐ 1 day  
☐ 2 days  
☐ 3 days  
☐ 4 days  
☐ 5 days  
☐ 6 days  
☐ 7 days

13. During a typical week, on how many days are you physically active for a total of at least 60 minutes (60 minutes = 1 hour) per day? (Add up all the time you spend in any kind of physical activity that increases your heart rate and makes you breathe hard some of the time.)

☐ 0 days  
☐ 1 day  
☐ 2 days  
☐ 3 days  
☐ 4 days  
☐ 5 days  
☐ 6 days  
☐ 7 days

14. During a typical week, how many days do you spend doing physical activities or playing sports with friends?

☐ 0 days  
☐ 1 day  
☐ 2 days  
☐ 3 days  
☐ 4 days  
☐ 5 days  
☐ 6 days  
☐ 7 days
APPENDIX C (continued)

15. During a typical week, how many days do you spend doing physical activities or playing sports with family?

☐ 0 days  
☐ 1 day  
☐ 2 days  
☐ 3 days  
☐ 4 days  
☐ 5 days  
☐ 6 days  
☐ 7 days  

16. On a typical school day, for how many hours do you... Watch TV or videos/DVDs?

☐ Less than an hour  
☐ 1 hour  
☐ 2 hours  
☐ 3 hours  
☐ 4 hours  
☐ 5 or more hours  
☐ Not sure  

17. On a typical school day, for how many hours do you... Play video or computer games or use a computer for something that is not school work? (exclude physically active video games)

☐ Less than an hour  
☐ 1 hour  
☐ 2 hours  
☐ 3 hours  
☐ 4 hours  
☐ 5 or more hours  
☐ Not sure  

18. You may have needed some assistance with answering our questions. Please indicate how much help you had while completing this survey.

☐ I completed this survey on my own.  
☐ A parent/guardian helped me complete this survey.  
☐ A parent/guardian completed this survey on behalf of the teen.
APPENDIX C (continued)

Thank you for your participation!

All Information you provided will be kept confidential.

If you have any questions about this study, please contact:

Sheila Swann-Guerrero  
University of Illinois at Chicago  
Department of Disability and Human Development  
773-699-6873
APPENDIX D

Dear (Agency)

My name is Sheila Swann-Guerrero and I am a master’s student at the University of Illinois at Chicago in the Department of Disability and Human Development. I am conducting research for my thesis, which is a study comparing the health and lifestyles of teens with Autism Spectrum Disorder (ASD) and their siblings without ASD.

The purpose of this study is to better understand issues surrounding teens with ASD being physically active. A population-based survey for teens (12-18 years) with disabilities, their siblings (12-18 years) and their parents (family caregivers) will be used to ascertain what lifestyle habits, environmental factors, activity and social opportunities impact the physical activity levels of youth with ASD. Non-disabled sibling’s responses will offer data to compare and determine if differences exist. Differences could identify areas in which health promotion efforts may need specific tailoring for youth with ASD. Please note that the survey and data will be kept in a password protected university server. The security of online surveys can never be 100% guaranteed.

Because health promotion questionnaires seldom include children with disabilities and the literature is very limited on this topic, the information learned through this research will increase the knowledge base in the area of health promoting behaviors of children with disabilities. The study finding is hoped to be beneficial for the field of disabilities, health promotion, recreation, adaptive recreation and sports, youth and settings that service children with disabilities.

I am asking if your agency would post a flyer on this study and/or send/post an email to families that you service to inform them of this opportunity. This study will only be helpful if families take the survey. Your help in disseminating study information to inform families is crucial. I have included the flyer and email invitation to participate.

Please feel welcome to contact me with any questions and with your decision. I will follow-up with you in a week for your response. The faculty sponsor is Dr. James Rimmer at 312-413-9651 or jrimmer@uic.edu. Thank you in advance for your consideration, time and effort.

Sincerely,

Sheila Swann-Guerrero, CTRS
swanngue@uic.edu
773-699-6873
APPENDIX E

Health and Lifestyles of Teens with Disabilities Study

Volunteer families of children with Autism Spectrum Disorder are asked to participate in a research study to learn what issues surround children with ASD leading physically active lifestyles. This study is being done for a thesis project of the University of Illinois at Chicago Department of Disability and Human Development to compare the health and lifestyles of teens with ASD and their siblings with ASD.

Who: Parents of children with Autism Spectrum Disorder (ASD) and their child with ASD who is 12-18 years and their child without ASD who is 12-18 years

What: You are invited to participate in an online confidential survey concerned with the health, and physical activity lifestyles of teens with ASD and their siblings without ASD.

How: Participation is simple. Both you and your children are invited to complete a 5 minute online survey, that’s it.

Why: Your information will help us better understand what factors are related to children with Autism Spectrum Disorder being physically active. All information is kept confidential.

To complete the survey go to:


For information or if you have difficulty accessing the survey please contact:

Sheila Swann-Guerrero 773-699-6873 or swannge@uic.edu.
Faculty sponsor, Dr. James Rimmer 312-413-9651 or jrimmer@uic.edu.

Thank you so very much for your consideration and potential participation! Your time and efforts are appreciated.
APPENDIX F

Health and Lifestyles of Teens with Disabilities Study

Who: Parents of children with Autism Spectrum Disorder (ASD) and their child with ASD who is 12-18 years and their child without ASD who is 12-18 years.

What: You are invited to participate in an online confidential survey concerned with the health, and physical activity lifestyles of teens with ASD and their siblings without ASD. This is a research project at the University of Illinois at Chicago.

How: Participation is simple. Both you and your children are invited to complete a 5 minute online survey, that’s it.

Why: Your information will help us better understand what factors are related to children with Autism Spectrum Disorder being physically active. All information is kept confidential.

To complete the survey go to:


For information or if you have difficulty accessing the survey please contact:
Sheila Swann-Guerrero: swanngue@uic.edu or 773-699-6873.

Faculty sponsor, Dr. James Rimmer jrimmer@uic.edu or 312-413-9651.
APPENDIX G

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1127 West Polk Street
Chicago, Illinois 60612-7221

Exemption Granted

March 13, 2012

Sheila Swann-Guerrero, MS
Disability and Human Development
426 N. Major Ave
Chicago, IL 60630
Phone: (312) 996-6053 / Fax: (312) 413-4058

RE: Research Protocol # 2012-0205
“Health and lifestyles comparison of youth with Autism Spectrum Disorder (ASD) and their siblings without ASD (Previously UIC Research Protocol #2009-0026)”

Sponsor: None

Dear Ms. Swann-Guerrero:

Your Claim of Exemption was reviewed on March 12, 2012 and it was determined that your research protocol meets the criteria for exemption as defined in the U. S. Department of Health and Human Services Regulations for the Protection of Human Subjects [(45 CFR 46.101(b)].

You may now begin your research.

Exemption Period: March 12, 2012 – March 11, 2015
Performance Site(s): UIC
Number of Subjects: 15 previously enrolled subjects (no additional subject enrollment or participation in the research)

Subject Population: All subjects previously enrolled in the research via UIC Research Protocol #2009-0026. The remaining research-related activities are limited to data analysis only.

The specific exemption category under 45 CFR 46.101(b) is:
(4) Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

You are reminded that investigators whose research involving human subjects is determined to be exempt from the federal regulations for the protection of human subjects still have responsibilities for the ethical conduct of the research under state law and UIC policy. Please be aware of the following UIC policies and responsibilities for investigators:

Phone: 312-996-1711 http://www.uic.edu/depts/ovcr/opens/ Fax: 312-413-2929
1. Amendments You are responsible for reporting any amendments to your research protocol that may affect the determination of the exemption and may result in your research no longer being eligible for the exemption that has been granted.

2. Record Keeping You are responsible for maintaining a copy all research related records in a secure location in the event future verification is necessary, at a minimum these documents include: the research protocol, the claim of exemption application, all questionnaires, survey instruments, interview questions and/or data collection instruments associated with this research protocol, recruiting or advertising materials, any consent forms or information sheets given to subjects, or any other pertinent documents.

3. Final Report When you have completed work on your research protocol, you should submit a final report to the Office for Protection of Research Subjects (OPRS).

Please be sure to:

⇒ Use your research protocol number (listed above) on any documents or correspondence with the IRB concerning your research protocol.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact me at (312) 355-2908 or the OPRS office at (312) 996-1711. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Charles W. Hoehne, B.S., C.I.P.
Assistant Director, IRB # 2
Office for the Protection of Research Subjects

cc: Tamar Heller, Disability and Human Development, M/C 626
    Glenn T. Fujiura, Disability and Human Development, M/C 626
CITED LITERATURE


VITA

Name: Sheila Swann-Guerrero

Education: B. S. Leisure Studies, emphasis in Therapeutic Recreation University of Illinois Champaign, Illinois, 1982

M.S. Disability and Human Development, University of Illinois Chicago, Illinois, expected 2012

Professional Experience: Ray Graham Association


Advocate Illinois Masonic Medical Group Pediatric Developmental Center. Coordinate Sibshop Program. Chicago, IL 2001-2011


University of Illinois, Department of Disability and Human Development Senior Information Specialist National Center on Physical Activity and Disability. Chicago, Illinois, 2002-2010.


**Honors**

Certified Therapeutic Recreation Specialist (NCTRC)

**Certifications:**

- Crisis Prevention Intervention
- Motivational Interviewing
- Certified American Association for Physical Activity Recreation Master Teacher of Adapted Aquatics
- Certified American Association for Physical Activity and Recreation Adapted Aquatic Instructor
- Water Safety Instructor
- Certified Special Olympics Coach in Alpine and Cross Country Skiing, Snow Shoeing, Aquatics, Basketball, Bocce, Horseshoes, Floor Hockey, Power Lifting, Soccer, Softball and Track and Field
- Certified Classifier and Coach for Adapted Sports (formerly known as, National Disability Sports Alliance)
- Very Special Arts Disability Awareness Presenter

**Funding:**

Illinois Department of Transportation, Safe Routes to School

Award amount: $48,100 and $45,500, 10/01/08 – 2/28/10

**Publications:**


Professional Memberships:

Illinois Park and Recreation Association

American Therapeutic Recreation Association