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Occupational Therapy Practice Trends for Occupations
Impacted by Puberty in Children with ASD

by

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an Independent Study

Submitted to the Occupational Therapy Department

of the

University of North Dakota

in partial fulfillment of the requirements

for the degree of

Master's of Occupational Therapy

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APPROVAL

This Independent Study, submitted by Sydney Larson and Kelsey Hemberger in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

Sarah Nelson, PhD, OTR/L

Faculty Advisor

4/19/18

Date

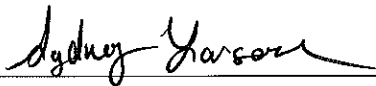
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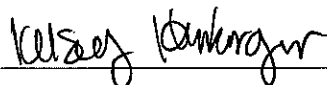
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Department: Occupational Therapy

Degree: Master's of Occupational Therapy

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~ Sydney & Kelsey

TABLE OF CONTENTS

ABSTRACT	vii
CHAPTER	
I. INTRODUCTION	1
II. LITERATURE REVIEW	7
III. METHODOLOGY	33
IV. DATA ANALYSIS	41
V. DISCUSSION	55
APPENDICES	65
A. IRB Letter of Approval	66
B. Occupational Therapy for Autism and Puberty Survey (OT-APS)	67
C. Postcard Format	78
D. Format for Post on OT Connections	79
E. Email Format	80
REFERENCES	81

LIST OF TABLES AND FIGURES

TABLE 1: <i>Number of Occupational Therapy Practitioners Working in Each Context...</i>	37
TABLE 2: <i>Percentage of Occupational Therapy Practitioners' Caseload Comprised of Children and Adolescents Ages 8-16 with ASD</i>	37
TABLE 3: <i>Percentage of Responses for Continuing Education</i>	42
TABLE 4: <i>Percentage of Participants Trained in Each Type of Intervention</i>	42
TABLE 5: <i>Percentage of Participants Using Each Assessment with Children and Adolescents Ages 8-16.....</i>	43
TABLE 6: <i>Mean Percentages of Sub-Challenges Selected for Each Overarching Challenge and Percentage of Responses to Each Sub-Challenge.....</i>	46
TABLE 7: <i>Percentage of Respondents Who Selected the Intervention for Each Challenge.....</i>	49
TABLE 8: <i>Mean Number of Interventions Selected for Each Challenge</i>	50
TABLE 9: <i>Mean Number of Times Each Intervention was Selected</i>	50
TABLE 10: <i>Percentage of Responses for Who Most Often Initiates Discussion About Puberty-Related Concerns</i>	51
TABLE 11: <i>Percentage of Responses for How Often Parents and Children/Adolescents Identify Puberty-Related Goals</i>	51
TABLE 12: <i>Percentage of Responses to Types of Assistance Requested by Parents for Puberty-Related Concerns</i>	52
TABLE 13: <i>Percentage of Responses for Comfort Level in Discussing Puberty-Related Concerns With Children/Adolescents and Parents</i>	53
FIGURE 1: <i>Practitioners' Comfort with Addressing Puberty-Related Challenges</i>	53
FIGURE 2: <i>Practitioners' Comfort Using Evidence-Based Interventions with Children and Adolescents with ASD</i>	54

ABSTRACT

Introduction: Adolescents face physical, social, cognitive, and emotional changes during the developmental stage of puberty. Pubertal changes can be difficult for neurotypical adolescents to cope with, but especially for individuals with autism spectrum disorder (ASD). Specifically, adolescents with ASD experience challenges with adapting to physical and emotional changes, managing new hygiene routines, abiding to social norms, and inappropriate sexual behaviors (Beddows & Brooks, 2016; Cridland, Caputi, Jones, & Magee, 2015; Cridland, Jones, Caputi, & Magee, 2014). While occupational therapy plays a role in helping adolescents with ASD, a lack of occupational therapy literature on this topic leads to unknown practice trends for practitioners to address puberty-related challenges in individuals with ASD. The purpose of this independent study was to understand the trends of occupational therapy practitioners in addressing developmental changes during puberty for adolescents with ASD.

Methodology: A descriptive survey design was used. The Occupational Therapy for Autism and Puberty Survey (OT-APS) was developed based upon a literature review to understand best practices in ASD. Stratified random sampling and convenience sampling were employed with 71 occupational therapy practitioners responding to the descriptive survey.

Results and Conclusions: Practice trends gleaned from the survey include: a) The most common assessments used were the Sensory Profile 2 (69.0%), the Sensory Processing

Measure (63.4%), and the BOT-2 (62.0%). b) The most common interventions practitioners have been trained in were behavioral strategies (94.4%), sensory processing integration (81.7%), and social learning approaches (80.3%). c) The interventions most often used included social learning approaches ($M = 5.30, SD = 2.86$) and behavioral strategies ($M = 5.28, SD = 2.65$). d) Practitioners were most comfortable addressing emotional regulation (54.9%) and personal hygiene and self-care (58%) and least comfortable addressing masturbation (88.7%) and menstruation (42.8%). e) Practitioners were most comfortable using behavioral strategies (56.3%) and social learning approaches (46.5%).

Significance: This research study provided evidence regarding the training completed, challenges addressed, interventions used, and comfortability of occupational therapy practitioners to address puberty related changes and challenges with children and adolescents age 8-16 with ASD. The findings provide an understanding of current practice trends and can be compared with best practice approaches and help identify evidence-based interventions that are being more or less utilized. Further research is needed better understand how these interventions are being provided in practice and why interventions are more often or rarely used. The information can be used in determining whether occupational therapy practitioners require further training in and understanding of puberty related changes and challenges within this population.

CHAPTER I

Introduction

Adolescents face physical, social, cognitive, and emotional changes during the developmental stage of puberty. According to MedlinePlus (2017), puberty is defined as a point in an adolescent's life when they experience physical changes and become sexually mature. All adolescents experience a growth spurt, excess hair growth, and may get acne, but pubertal changes affect boys and girls differently (MedlinePlus, 2017). Girls ages 10 to 14 begin menstruation and develop breasts while boys ages 12 to 16 experience enlargement of the testicles and penis, muscle growth, and deepening of the voice (Medline Plus, 2017). In addition to physical changes, Yurgelun-Todd (2007) identified that when youth transition into adolescence, they experience increased cognitive capacity and function as well as increased attention and ability to control emotional behavior in a goal-directed manner. Adolescents place more of a priority on social relationships and become more adept at noticing social and emotional cues (Yurgelun-Todd, 2007). These changes can be difficult for neurotypical adolescents to cope with, but especially for individuals with autism spectrum disorder (ASD).

ASD is a neurodevelopmental disorder in which an individual experiences deficits in social communication and interaction as well as restricted and repetitive behaviors, interests, or activities (American Psychiatric Association [APA], 2013). Individuals with

ASD follow normal developmental stages of puberty (Beddows & Brooks, 2016); however, they are at risk of experiencing increased difficulty. Adolescents with ASD may lack social skills, have difficulty understanding social norms, be inflexible with routines, and experience sensory processing deficits (APA, 2013).

Neurotypical adolescents often gain knowledge and understanding of sexual behaviors and social norms from their peers, but adolescents with ASD lack the skills to accurately interpret and respond to social cues (Beddows & Brooks, 2016). Adolescents with ASD experience challenges with adapting to physical and emotional changes, managing new hygiene routines, and abiding to social norms (Cridland, Caputi, Jones, & Magee, 2015; Cridland, Jones, Caputi, & Magee, 2014). Beddows and Brooks (2016) found a high prevalence of a variety of inappropriate sexual behaviors among adolescents with ASD. Cridland et al. (2014) discussed that parents and caregivers experience apprehension when anticipating pubertal changes and related sexual behaviors.

Occupational therapy practitioners can play a role in helping adolescents with ASD develop skills to increase success in daily occupations, including activities of daily living, education, and social participation (American Occupational Therapy Association [AOTA], 2014). A lack of occupational therapy literature on this topic leads to unknown practice guidelines for occupational therapy practitioners to address puberty-related issues in individuals with ASD. Related literature provides general recommendations for working with adolescents with ASD, such as providing adolescents with ASD and their families social support and individualized education addressing social skills, technical aspects of puberty, social norms, physical changes, personal boundaries, and healthy strategies for expressing sexuality (Beddows & Brooks, 2016; Cridland et al., 2014).

Despite the existence of these guidelines, it is important for occupational therapy practitioners to understand and be prepared to intervene with puberty related changes and challenges in adolescents who have ASD. A beginning understanding of practice is required to provide occupational therapy practitioners with recommendations and guidelines for evidence-based practice.

Purpose

The purpose of this independent study was to understand the role of occupational therapy practitioners in addressing developmental changes and challenges during puberty for children and adolescents with ASD. A descriptive survey design with exploratory inquiries was used. A quantitative survey instrument, Occupational Therapy for Autism and Puberty Survey (OT-APS), was developed using a thorough literature review and administered to occupational therapy practitioners to gather the data for this study.

Research Questions

Through the study, the researchers sought to answer the following questions: 1. What were the demographics and educational backgrounds of pediatric occupational therapy practitioners working with children and adolescents ages 8-16 with ASD? 2. What assessments and interventions are used in the occupational therapy process to address issues related to puberty for children and adolescents ages 8-16 that have ASD? 3. How prepared to occupational therapy practitioners feel to address occupational issues related to puberty for children ages 8-16 with ASD?

The researchers anticipated that the findings of this study would contribute to the literature addressing the needs of children and adolescents with ASD as they face developmental changes and challenges. The research results provided descriptive data

that will contribute to occupational therapy practice guidelines and suggest appropriate assessments and interventions to aid in the therapy process with this population. Additionally, the findings inform the profession of current practice trends, potential areas of focus for occupational therapy education and training, and further research in this topic area.

Population

Stratified random sampling and convenience sampling were used to recruit participants for this study. The population of interest was occupational therapists and occupational therapy assistants in the United States working with children and adolescents ages 8-16 with ASD. A total of 71 occupational therapy practitioners agreed to participate in the study and responded to the survey.

Theory

Due to the exploratory nature of this study, the researchers used an atheoretical approach to guide the research process. The *Occupational Therapy Practice Framework: Domain and Process*, 3rd edition (OTPF; AOTA, 2014) was used as a guide to complete the initial literature review. The researchers used the OTPF to determine the areas of occupation most impacted by puberty, performance skills and patterns, and client factors related to the occupations most impacted as well as identify interventions consistent with the occupational therapy domain.

Definitions

The following definitions are important in interpreting the nature of this study and to ensure consistency among respondents:

- **Adolescence:** For the purpose of this study, adolescence will be described as between the ages of 8-16. This age range was selected based on the National Institute of Health (NIH, 2017) and MedlinePlus (2017) definition that puberty occurs during adolescence between the ages of 8-14 for girls and 9-19 for boys.
- **Autism Spectrum Disorder (ASD):** a neurodevelopmental disorder in which individuals experience deficits in social communication and interaction as well as restricted and repetitive behaviors, interests, or activities across multiple contexts (APA, 2013).
- **Puberty:** the natural stage of maturation and the development of primary and secondary physical and sexual characteristics (NIH, 2017).

Summary

In Chapter I, the researchers presented an introduction to this study, including an overview of supporting literature, listed the research questions that guided this study, provided information on the participants involved in this study, discussed the guiding principles, and defined important terms. Chapter II presents a thorough literature review covering the definition of puberty, the definition of ASD, the disparity between puberty and ASD, evidence-based interventions to address puberty in children and adolescence with ASD, occupational therapy's role for children and adolescents with ASD, and evidence based occupational therapy interventions for individuals with ASD. Chapter III presents a description of the research methodology used for this study including research design, sources of data, instrumentation and data collection. In Chapter IV, the researchers report the results from the study, presenting and discussing the descriptive

data. Chapter V includes a summary of the researchers' findings, conclusions, limitations, and recommendations.

CHAPTER II

Literature Review

Society recognizes puberty as a transitional stage between childhood and adulthood marked by physical and hormonal changes. However, puberty and the developmental progression into adolescence also includes behavioral, emotional, social, and cognitive changes. This phase of development can be difficult for children as they transition into adolescence and learn to cope with new changes and increasing demands.

The National Institute of Health (NIH, 2017) defines puberty as the natural stage of maturation and the development of primary and secondary physical and sexual characteristics. All adolescents experience a growth spurt, excess hair growth, and may get acne, but pubertal changes affect boys and girls differently (MedlinePlus, 2017; NIH, 2017). Girls between the ages of 8-14 begin menstruation and develop breasts, while boys between the ages of 9-16 experience enlargement of the testicles and penis, muscle growth, and deepening of the voice (Medline Plus, 2017; NIH, 2017). A physical exam performed by a healthcare professional is the most common method for determining level of pubertal maturation (NIH, 2017), but it is not necessarily the most precise (Shirtcliff, Dahl, & Pollak, 2009). In fact, Shirtcliff et al. (2009) concluded

the most accurate measure of development and maturation may depend on which aspect of puberty is of interest to the analyzer.

During adolescence, individuals develop and gain personal insight and abstract thinking about the world, but become preoccupied with themselves and self-evaluative regarding personal attractiveness (Radizik, Sherer, & Neinstein, 2002). Self-report measures can be utilized to acquire a rough estimate of the pubertal development stage a child is in, as they are moderately accurate for neurotypical adolescents (Shirtcliff et al. 2009), but are not significantly reliable to determining the appropriate stage of development. Shirtcliff et al. (2009) found that adolescents overestimated maturation when at lower stages of development relative to peers and underestimated maturation when at higher stages than peers—indicating that adolescents desire to fit in and appear to be what is most typical for their age.

Ayres and Mailloux (1983, p. 540) proposed that puberty is the “neuro-biological development of the child during the early critical period for maturation of sensory integrative mechanisms,” suggesting there is more occurring during this stage of life than what most people are familiar with. In fact, puberty does not solely involve physical changes of maturation, but also social and behavioral changes, such as emotional reactivity and self-regulation. During adolescence, individuals become more reliant on peer support and friendships. Adolescents gain information about sex, relationships, behavior, and social norms from peers and everyday social interactions (Radizik et al., 2002). Carlo, Crockett, Wolff, and Beal (2012) found that pubertal maturation leads to higher levels of prosocial behaviors at home and increased popularity among peers. Adolescents are likely to engage in risky behaviors due to a discrepancy between

refinement of judgement, a desire to have a sense of belonging, and acquiring more adult-like roles (Vroman, 2015). Adolescents face increasing demands during puberty, such as managing complex social situations and development of personal identity (Cridland, Caputi, Jones, & Magee, 2015).

Because adolescents encounter a wide variety of physical, emotional, and developmental changes during puberty and the transition into adolescence, coping with these changes can be challenging. Adolescents require support throughout pubertal maturation to learn about their bodies and sexuality as well as understanding that their feelings are average among their peers (Rembeck & Hermansson, 2008). Early education and the development of healthy relationships can help adolescents manage feelings of confusion, excessive anxiety, and emotional turmoil (Vroman, 2015). Pubertal maturation and coping with developmental changes can be difficult for neurotypical adolescents to deal with and understand, making it especially challenging for non-neurotypical adolescents, such as individuals with autism spectrum disorder (ASD).

Definition of Autism Spectrum Disorder

ASD is a neurodevelopmental disorder in which individuals experience deficits in social communication and interaction as well as restricted and repetitive behaviors, interests, or activities across multiple contexts (American Psychiatric Association [APA], 2013, p. 50). According to the Centers for Disease Control (Centers for Disease Control and Prevention [CDC], 2016), approximately 1 in 68 children had ASD in the United States with boys being 4.5 times more likely to be diagnosed than girls. This number has continued to climb since 2007 when it was estimated that 1 in 150 children were diagnosed with ASD (CDC, 2016).

According to APA (2013), individuals with ASD most specifically have deficits with social and emotional reciprocity, commonly lacking the ability to initiate interactions or respond and engage in reciprocal conversations. People with ASD also experience challenges with nonverbal communication, such as abnormalities in eye contact and body language as well as understanding facial expressions and gestures. The deficits can be related to difficulty with developing and maintaining relationships with others. Children with ASD commonly experience problems engaging in imaginative play as well as sharing interests and emotions with their peers (APA, 2013).

Individuals with ASD frequently have restricted and repetitive behaviors and interests (APA, 2013). According to APA (2013), these experiences may be expressed as stereotyped motor movements and speech, strong attachment or preoccupation with specific objects, or abnormally restricted and fixated interests, which tend to be abnormal in intensity and focus. Individuals with ASD may also experience a desire for sameness, have ritualized patterns of behavior, and tend to be inflexible to change in their routines. People with ASD commonly have difficulty with processing sensory input, either responding as hyporeactive or hyperreactive, and may have abnormally intense or focused interests in specific aspects of the environment (APA, 2013).

The severity of ASD can vary immensely among individuals with the diagnosis, however the APA (2013) identifies three levels for discerning severity. Level one is the mildest level, identified as “requiring support,” level two is described as “requiring substantial support,” and level three, being the most severe form of ASD, is indicated as “requiring very substantial support” (APA, 2013, p. 52). Each level is accompanied by descriptions of the characteristics and symptoms regarding social communication and

restricted, repetitive behaviors. Additionally, ASD can be further described considering intellectual impairment, language impairment, associated medical conditions, or associated neurodevelopmental, mental, or behavioral disorders. People with ASD can lie anywhere on the spectrum making symptoms, challenges, and strengths unique among individuals, between contexts, and over time. The current ASD diagnosis includes the disorders previously known as “infantile autism, childhood autism, Kanner’s autism, high-functioning autism, atypical autism, pervasive developmental disorder, childhood disintegrative disorder, and Asperger’s disorder” (APA, 2013, p. 53).

The symptoms of ASD must be present during the early developmental period and cannot be better explained by an intellectual disability or any other condition (APA, 2013). These symptoms commonly last throughout the person’s life (CDC, 2016). The symptoms must cause a significant impairment in important everyday occupations and areas of functioning; however, the individual can learn strategies and use resources to manage the symptoms for improved engagement in daily life. The stage at which functional impairment becomes apparent varies depending on the individual, activities, and environment. According to the CDC (2016), determining a definite ASD diagnosis can be difficult because there is not currently a medical test to confirm an ASD diagnosis. Skilled professionals use standardized assessments and questionnaires to analyze the child’s development and behavior. Children can be diagnosed as early as eighteen months old, but often are not diagnosed until much older (CDC, 2016).

The symptoms of ASD can cause challenges for the individual when engaged in everyday tasks and experiences. Individuals with ASD have difficulty with social interaction and communication in all contexts, impacting success in everyday situations

and amount of assistance required. People with ASD also struggle to make social connections and form meaningful relationships, which includes family members, peers, teachers, and community members. Restricted and repetitive patterns of behavior or interests experienced by individuals with ASD may lead to difficulty coping with contextual changes, trouble managing variations in routines, and challenges with adjusting to sudden modifications of familiar spaces, people, or objects. According to Watling and Hauer (2015), sensory processing difficulties have been found to be associated with challenges specifically with adaptive skills, social engagement, academic performance, grooming, bathing, bedtime, sleep, eating and mealtime, play, and motor skills. The characteristics associated with ASD can impact all areas of daily life and result in functional deficits related to social interaction, self-care, independent living, as well as school and work performance.

Disparity Between Puberty and ASD

Children with ASD often experience developmental delays and challenges throughout their lifetime. These children may not learn to walk, talk, or become potty-trained as early as typically developing children. They often have difficulty playing with peers and might retain immature interests for a longer period of time. However, children with ASD generally experience pubertal maturation at the same rate as their typically-developing peers. Individuals with ASD follow the normal developmental progression of puberty, including maturation of physical characteristics, psychosocial changes, and sexual curiosity and desire (Beddows & Brooks, 2016; Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007).

Social and behavioral challenges that children and adolescents with ASD already possess can make changes in puberty and sexuality during adolescence even more complicated than the typically developing adolescent may experience (Klett & Turan, 2012). In particular, adolescents with ASD have difficulty adjusting to and coping with pubertal changes, including understanding and managing physical characteristics, sexuality, and expressing emotions (Cridland, Jones, Caputi, & Magee, 2014; Cridland et al., 2015; Pecora, Mesibov, & Stokes, 2016). Adolescents with ASD are more likely to have a greater amount of adverse reactions to pubertal changes, including anxiety, disgust, confusion, distress, anger, and aggression (Bagatell, 2016; Cridland et al., 2015; Pecora et al., 2016).

Neurotypical adolescents gain education about social and sexual norms through typical peer interactions, however adolescents with ASD miss out on these experiences due to their lack of social skills and peer relationships (Beddows & Brooks, 2016; Pecora et al., 2016). The deficits of ASD prevent the natural development of meaningful relationships and appropriate sexual behaviors for adolescents with ASD (Beddows & Brooks, 2016). Adolescents with ASD cope better with a logical approach to sexuality and tend to generally be open to puberty issues; however, Cridland et al. (2014) found that they struggle abiding to social norms, socializing with neurotypical peers, understanding what is socially appropriate, and being aware of boundaries.

Puberty brings about additional roles and responsibilities that an adolescent must learn to manage and cope with, including the increasing demands of a hygiene routine, sex-specific pubertal changes, and understanding appropriate behaviors. The onset of puberty and the changes it brings result in new challenges and dynamics for the family of

an adolescent with ASD, such as shifting routines and accommodating for behavioral changes (Bagatell, 2016). Parents of children with ASD report feeling apprehensive when anticipating new aspects of hygiene that emerge during puberty, including management of the practical aspects of menstruation, safe and appropriate guidance of masturbation, and emphasizing the importance of overall hygiene and grooming practices (Ballan, 2012; Cridland et al., 2014; Hamilton, Marshal, & Murray, 2011). In addition to management of physical changes and hygiene, parents of children with ASD also fear unpredictable emotional reactions, new self-stimming behaviors, and an increase in inappropriate or sexual behaviors, especially in public places (Ballan, 2012; Beddows & Brooks, 2016). Parents of children with ASD have concerns about community attitudes and perceptions about their child's sexuality because sexual versus non-sexual behaviors of children with ASD are often misunderstood, misinterpreted, and stigmatized by others (Ballan, 2012; Holmes, Himle, & Strassberg, 2015).

Children with ASD exhibit inappropriate sexual behavior and inattention to issues of privacy and modesty (Ballan, 2012). Beddows and Brooks (2016) found that adolescents with ASD display a variety of inappropriate behaviors, including masturbation, intimate relationships, inappropriate arousal, exhibitionism, gender identity problems, obscene gestures, non-consensual hugging, and inappropriate comments with sexual connotations. Additionally, adolescents with ASD often present with obsessive and compulsive behaviors, excessive discussion of sexual topics, and a lack of modesty. (Ballan, 2012; Hellemans et al., 2007). Adolescents with ASD often have difficulty with inappropriate sexual behavior due to a lack of appropriate puberty and sexual education, misinterpretation of social situations, problems with sensory processing, media and

pornography, curiosity, previous sexual abuse, and misunderstanding of personal space (Ballan, 2012; Beddows & Brooks, 2016). All of these additional challenges can disrupt daily living performance at home, school, and in the community.

While there are themes for inappropriate behaviors among adolescents with ASD, girls and boys tend to have differences in presentation of difficult behaviors. Aggressive, repetitive, and obsessive behaviors intensify with the menstrual cycle in girls (Hamilton et al., 2011). Hamilton et al. (2011) found that dysmenorrhea and PMS interfered with daily activities at home, but neither caused significant absence from school and other activities. Boys typically engage in masturbation in the presence of others, incorrect masturbation techniques, hyper-masturbation, and touching their genitals in public (Bagatell, 2016; Hellemans et al., 2007). Dewinter, Vermeiren, Vanwesenbeeck, and Nieuwenhuizen (2016) found that parents of boys with high-functioning ASD had a tendency to be unaware of their child's sexual habits, including masturbation and engaging in sexual acts with a partner. This puts boys with ASD at an increased risk of engaging in risky or unsafe sexual behaviors.

Adolescents with ASD exhibit behaviors that can be misinterpreted by others as inappropriate or sexual in nature, leading to vulnerability and involvement in dangerous situations. Additionally, adolescents with ASD can misinterpret the media as acceptable social norms, putting them at an increased risk for vulnerable situations and bullying (Pecora et al., 2016). Parents of children with ASD have significant concerns about vulnerability, sexual exploitation, and potential physical and sexual abuse (Beddows & Brooks, 2016; Cridland et al., 2014; Holmes et al., 2015). Individuals with ASD are vulnerable to sexual situations due to their inability to judge the negative intentions of

others, limited communication skills, and dependence on multiple caregivers (Ballan, 2012). For instance, Ballan (2012) discussed that parents struggle to provide their children with accurate information regarding the conflict between privacy and safety versus accepting personal assistance with self-cares.

Parents play a big role in assisting children who have ASD with the transition through puberty (Cridland et al., 2014); however, parents tend to avoid sexuality-related topics (Dewinter et al., 2016; Holmes et al., 2015). Parents often prefer to communicate with their children about sex and puberty, but they do not know how or when to engage in that conversation (Ballan, 2012). During discussions regarding puberty and sexuality-related changes and challenges, parents question their child's ability to understand and apply the knowledge or skills as well as speculate whether their child is interested or behaviorally mature enough to consider the topics (Ballan, 2012). Additionally, parents anticipate inappropriate, intense, or aggressive overreactions, overgeneralizations, perseverations, and fixations following the discussion of puberty and sexuality-related topics with their child with ASD. When parents initially introduce puberty and sexuality-related conversations with their child, it is most often related to their child's safety, sexual abuse prevention, social acceptance, and personal hygiene issues (Ballan, 2012).

In multiple studies, parents of children with ASD expressed a desire to receive additional guidance for providing puberty and sexuality-related knowledge to their child as well as strategies for managing self-care and inappropriate sexual behaviors (Bagatell, 2016; Ballan, 2012; Cridland et al., 2014; Cridland et al., 2015; Dewinter et al., 2016; Holmes et al., 2015). Parents of children with ASD have significant concerns about their child's future romantic relationships (Holmes et al., 2015); however, "with proper

supports and knowledge, many children with ASD develop into adolescence and adulthood with the ability to form and maintain mature and healthy sexual relationships” (Ballan, 2012, p. 682).

Evidence Based Interventions to Address Puberty in Children and Adolescents with ASD

Many disciplines may assist adolescents with ASD and their families through the pubertal transition. Healthcare workers, mental health professionals, and educators can use a variety of strategies to provide education, mediate and manage behaviors, and help adolescents with ASD understand and cope with the phases of change. During adolescence, individuals with ASD require interventions to address deficits with social skills, communication skills, challenging behaviors, academic skills, vocational skills, independence, self-cares, and physical development (McDonald & Machalicek, 2013).

McDonald and Machalicek (2013) reviewed effective interventions for adolescents with ASD, including behavioral strategies, antecedent manipulations, exercise, parent training, augmented and alternative communication (AAC), peer mediation, social skills training, self-management, teacher implemented, technology-based, parent training, and naturalistic interventions. Behavior and antecedent approaches were used most often and were frequently implemented simultaneously (McDonald & Machalicek, 2013). Through the comparison of a variety of intervention types within their study, McDonald and Machalicek (2013) indicated that while one intervention strategy may benefit some individuals, another strategy may be a better fit to another.

Behavioral interventions are widely used to support individuals who have ASD. Behavioral approaches involve the use of positive and negative reinforcement for

changing behavioral outcomes. Applied behavioral analysis (ABA) is the gold-standard for behavioral reinforcement in children with ASD. ABA involves teaching parts of a task in order to gain full mastery of a skill, reinforcement of desired behaviors, and manipulation of a controlled environment (Ballan & Freyer, 2017; Veazey, Valentino, Low, McElroy, & LeBlanc, 2016). McDonald and Machalicek (2013) found that using ABA strategies for adolescents with ASD is effective. Behavioral approaches can always be implemented when working with adolescents who have ASD; however, it has also been indicated to be effective for remediation of difficult behaviors related to sexuality and hygiene. Ballan and Freyer (2017) emphasized that ABA is an ideal strategy for providing proactive sexuality education, including normal and socially acceptable behaviors. Matson, Hattier, and Belva (2012) identified that self-care, independent living, and hygiene skills, such as oral care and toilet training, were mastered through the use of ABA techniques, such as modeling, reinforcement, and graduated guidance. Veazey et al. (2016) implemented chaining techniques to teach adolescent girls with ASD to manage feminine hygiene. The researchers found that chaining is an effective strategy that can be generalizable (Veazey et al., 2016).

Social skills training uses behavioral strategies, such as identification of appropriate and inappropriate behaviors, role-playing, and modeling to improve specific social skills such as reducing aggressive behavior, nonverbal communication skills, and maintaining social boundaries (Ballan & Freyer, 2017; Mathews, Erkfritz-Gay, Knight, Lancaster, & Kupzyk, 2013). Mathews et al. (2013) found that social skills training, especially when implemented as a group intervention, is significantly effective to improve social functioning in children and adolescents with ASD. Behavioral

interventions are based on the reinforcement of understanding social norms and sexual behaviors, leading to limited comprehension and generalizability of social skills (Ballan & Freyer, 2017). Ballan and Freyer (2017) discussed social behavior mapping, a cognitive behavioral strategy used with individuals who have ASD to facilitate differentiation between expected and unexpected behaviors as well as understanding reactions and consequences of a behavior. Social behavior mapping can be used within a variety of situations and contexts among children and adolescents with ASD (Ballan & Freyer, 2017).

Social learning theory is a practice guideline designed by Bandura that emphasizes observation, modeling, and reinforcement of behaviors for application and generalization of social skills (Stoffel & Tomlinson, 2011). Social learning theory strategies include modeling, prompting, coping skills, feedback, coaching, role-playing, and social stories (Ballan & Freyer, 2017; Berezna, Ayres, Mechling, & Alexander, 2012; Klett & Turan, 2012; Stoffel & Tomlinson, 2011). Social stories can be utilized to increase socially appropriate behavior and decrease problem behavior through description of a situation, concept, or skill from the perspective and comprehension level of the target individual (Ballan & Freyer, 2017). In relation to puberty and sexuality, social stories are individualized and can be used proactively to prepare for upcoming issues or in response to emerging behaviors (Ballan & Freyer, 2017). Klett and Turan (2012) found that social stories were an effective strategy for teaching adolescent girls with ASD menstrual hygiene care, concluding the participants were able to generalize their skills and problem-solve new situations related to menstrual hygiene. Berezna et al. (2012) found that video

modeling, with the use of chaining, was an effective intervention for individuals with ASD to learn an independent living skill.

The use of technology is often an effective strategy for children and adolescents because it is motivating—making them more likely to engage. Technology is being developed and used, but there is limited research to support its use. Bimbrahw, Boger, and Mihailidis (2012) looked at the efficacy of a device designed to guide children with ASD through common self-care activities called the COACH (Cognitive Orthosis for Assisting aCtivities in the Home). COACH has potential for teaching self-care skills to children and adolescents with ASD while providing a valuable service to families, caregivers, and clinicians to increase independence and decreasing caregiver burden. An iPhone can be an effective self-prompting device to teach daily living skills using video modeling and chaining strategies for adolescents with ASD (Bereznak et al., 2012).

The evidenced-based interventions and strategies discussed can be implemented by a variety of professionals that interact with children and adolescents who have ASD. These professionals can include people such as educators, mental health workers, and occupational therapists. Interventions tend to be most effective when used in conjunction with other strategies (McDonald & Machalicek, 2013). Several studies have analyzed the effectiveness of a curriculum or program designed to educate adolescents with ASD about puberty and address their needs. These curriculums integrate a variety of interventions and strategies for behavior management and acquiring appropriate skills.

Corona, Fox, Christodulu, and Worlock (2016) presented a program that educated adolescents with ASD and their parents about sexuality, puberty, masturbation, privacy, hygiene, friendships, relationships, dating, physical activity, and safety. Strategies

implemented included verbal and visual instruction, activity schedules, reward systems, behavioral supports, and group learning. Parents were provided with additional strategies for continued reinforcement of learning in the home. The results indicated that parents were highly satisfied with the program and adolescents with ASD required individualized teaching strategies to meet their educational needs about complex and abstract topics (Corona et al., 2016).

Visser et al. (2015) introduced Tackling Teenage Training (TTT), an individualized psychoeducation program that provided adolescents with ASD knowledge and strategies to manage puberty, sexuality, and intimate relationships. The TTT program involved structured sessions, take-home assignments, visual aids, behavioral rehearsals, quizzes, mock interviews, parent involvement, and contact reports. The results showed a significantly greater increase in psychosexual knowledge, and parents reported significantly improved insight regarding interpersonal boundaries (Visser et al., 2017).

Jamison and Schuttler (2016) presented Girls Night Out (GNO), a program designed to address social skills and self-care performance needs of adolescent females with ASD to improve social-emotional health. The GNO program addressed relating to others, self-care, and self-determination through a variety of social and behavioral learning strategies, such as peer mediation, modeling, role play, visual supports, video modeling, reinforcement of target skills, goal setting, in-vivo coaching, specific feedback, token economy, and planned generalization. The results indicated significant improvements in overall social competence and self-perception of the adolescents with ASD, and all participants (females with ASD, peers, families) were highly satisfied with the activities of the program (Jamison & Schuttler, 2016).

Occupational Therapy's Role for Children and Adolescents with ASD

Occupational therapy is the therapeutic use of occupations or meaningful daily activities to enable participation in routines, habits, and roles through improvement in client factors and performance skills with the goal of successful engagement in all areas of life (American Occupational Therapy Association [AOTA], 2014). Tomchek, LaVesser, and Watling (2015) reported on a study by the Interactive Autism Network, which showed that occupational therapy is the second most utilized service for individuals with ASD in the United States after speech-language pathology. Occupational therapy has a role for promoting functional performance with all populations across all contexts. When addressing the needs of children and adolescents who have ASD, occupational therapists use a variety of meaningful activities and strategies to facilitate improvement in client factors or performance skills as well as to promote successful engagement in all important daily occupations. With this population, important occupations typically include play, education, social participation, sleep, activities of daily living (ADLs), such as dressing, bathing, toileting, and feeding, or instrumental activities of daily living (IADLs), such as community mobility and safety (AOTA, 2014; Scott, 2011).

Occupational therapists work with children and adolescents who have ASD, their families, and other professionals in multiple contexts throughout the community where they typically engage to provide a variety of services and resources (Scott, 2011; Tomchek et al., 2015). Within the school system, occupational therapy is a related service under Part B of IDEA and a primary service under Part C of IDEA. Therefore, occupational therapy must be provided for a child with ASD in the school systems if the

services will promote performance in education and engagement in school-related activities (Tomchek et al., 2015). If necessary, services may be provided in a child's daycare or preschool setting. Occupational therapists can also provide services in the home, community, clinic, or residential setting depending on which setting will have the most impact on the child's success and engagement in meaningful daily activities (Scott, 2011).

The activities, roles, and stages of life of children and adolescents are constantly changing, which indicates the importance of occupational therapists to facilitate and promote successful transitions between settings, situations, roles, and stages of life as well as address challenges that occur during transitions (Scott, 2011). According to Canaboy et al. (2008), occupational therapists require extensive knowledge regarding task analysis and education of the various skills needed throughout contexts and activities. This knowledge enables occupational therapists to assume a vital role in transition services. Occupational therapists can assist an individual with ASD transition throughout all life stages including preschool, elementary school, high school, college, independent living, and work. Activities and skills occupational therapists address to support life transitions include self-advocacy skills, prevocational skills, time management, community mobility, self-care, job coaching, social communication skills, environmental accommodations or adaptations, and assistive technology (Canaboy et al., 2008). Therefore, occupational therapy services can benefit children and adolescents with ASD throughout their lifespan in order to fulfill meaningful roles, achieve functional independence, and engage in daily activities.

Occupational therapists apply the practice guidelines outlined in the *Occupational Therapy Practice Framework: Domain and Process*, 3rd edition (AOTA, 2014) to evaluate, plan, and carry out occupational therapy services for each individual. A comprehensive evaluation of the individual is completed upon initiation of occupational therapy services. This begins with an occupational profile to determine history, contexts, occupations, routines, social supports, motivations, strengths, and client factors, such as values, beliefs, and body functions (AOTA, 2014; Crabtree et al., 2017). An analysis of occupational performance is completed through observation and assessment of strengths, challenges, body functions, and performance skills during participation in important occupations and activities (AOTA, 2014; Crabtree et al., 2017). Individuals with ASD present with a wide variety of unique symptoms and everyday struggles, making it necessary for occupational therapists to guide assessment and intervention through identification of strengths, challenges, skills and abilities, environment, barriers, priorities, and desired goals of the client and family (Crabtree et al., 2017; Scott, 2011; Tomcheck, LaVesser, Watling, 2015). Parents, caregivers, family members, and educators should be involved throughout the occupational therapy process to ensure collaboration, positive communication, and client-centered practice (Tomcheck et al., 2015).

The *Occupational Therapy Practice Framework: Domain and Process*, 3rd edition (AOTA, 2014) provides occupational therapists with specific guidelines for identifying and defining functions, skills, and patterns required for engaging in occupations. Body functions include mental functions (i.e. higher-level cognition, attention, perception, thought, emotion, energy, temperament, and personality), sensory

functions (i.e. vision, hearing, vestibular, proprioception, and pain), and neuromusculoskeletal functions. Performance skills include motor skills, process skills, and social communication and interaction skills. Motor skills involve moving one's self or objects within the environment, such as reaching, manipulating, coordinating, lifting, transporting, calibrating, and enduring. Process skills involve the use of mental functions to engage in the environment, such as attending, choosing, locating, initiating, sequencing, and accommodating. Social interaction skills are required for engagement with others and include producing speech, gesticulating, turning toward, regulating, questioning, replying, expressing emotion, transitioning, matching language, empathizing, and disclosing (AOTA, 2014; Crabtree et al., 2017).

Upon completion of observation and informal assessment of performance skills, occupational therapists may choose from a variety of standardized assessments to further evaluate specific skills or areas of concern. Miller-Kuhaneck (2015) and Crabtree et al. (2017) identified several assessment tools and standardized assessments used for children and adolescents with ASD such as the Sensory Processing Measure (Parham, Ecker, Kuhaneck, Henry, & Glennon, 2010), Sensory Profile-2 (Dunn, 2014), Social Responsiveness Scale (Constantino, 2012), School Function Assessment (Coster, Deeney, Haltiwanger, & Haley, 1998), Kohlman Evaluation of Living Skills (Kohlman Thomson & Robnett, 2016), Pediatric Evaluation of Disability Inventory (Haley, Coster, Ludlow, Haltiwanger, Andrellos, 1992), Bruininks-Oseretsky Test of Motor Proficiency (Bruininks & Bruininks, 2005). Using this information, the occupational therapist will formulate individualized goals and a client-centered, holistic intervention plan to guide occupational therapy services (AOTA, 2014; Crabtree et al., 2017; Tomchek et al., 2015).

Specific occupational performance areas typically addressed for children and adolescents with ASD include social interaction and participation, play, education, activities of daily living (ADLs) or self-care, instrumental activities of daily living (IADLs), and sleep (Crabtree et al., 2017). Children and adolescents with ASD experience unique challenges with a variety of performance skills, which may inhibit engagement in many everyday occupations. Common skills and activities that are targeted during intervention for children and adolescents with ASD include emotion regulation, sensory processing, process skills, feeding and eating, communication and interpersonal skills, toileting, dressing, gross and fine motor skills, bedtime routines, and hygiene (Miller-Kuhaneck, 2015; Crabtree et al., 2017). However, occupational therapists may administer interventions to address all relevant areas of occupation. Tomcheck et al. (2015) reported that the ultimate purpose for occupational therapy services for an individual with ASD “is to promote engagement in and performance of daily activities, personal satisfaction, adaptation, health and wellness, role competence, quality of life, and occupational justice for individuals with ASD within the contexts of their families and communities” (p. 3).

According to Miller-Kuhaneck (2015), specific occupational therapy interventions commonly used with children who have ASD are Applied Behavioral Analysis (ABA), the Cognitive Orientation to Daily Occupational Performance Approach (CO-OP), Ayres Sensory Integration, Floortime, Animal Assisted Therapy, Reciprocal Imitation Training (RIT), Relationship Development Intervention (RDI), Social Communication, Emotional Regulation and Transactional Support (SCERTS), and Pivotal Response Training (PRT). General strategies and interventions commonly used include sensory integration, sensory

based strategies, modeling, visual supports, social stories, behavioral approaches, cognitive approaches, technology, environmental modifications, and routine formation (Crabtree et al., 2017; Tomchek et al., 2015).

Strategies used to assist with sleep include calming sensations and bedtime routines (Miller-Kuhaneck, 2015). To address ADLs and IADLs, occupational therapists use behavioral, cognitive, motor, and sensory strategies such as visual supports, video demonstration, CO-OP, sensory integration, modification of tasks, routine formation, and rewards/reinforcement (Miller-Kuhaneck, 2015). To improve educational performance, occupational therapists may utilize academic alterations, visual supports, technology, social supports, social stories, behavior supports (i.e. reinforcers and rewards), sensory supports such as sensory diets, and motivational supports (Miller-Kuhaneck, 2015). Lastly, when addressing play, occupational therapists use tools such as video modeling, peer mediated interventions, Integrated Play Groups, RIT, imitation, use of preferred toys, and integration of ritualistic behaviors (Miller-Kuhaneck, 2015).

Evidence Based Occupational Therapy Interventions for Individuals with ASD

Occupational therapy interventions to address the challenges and barriers faced by individuals with ASD have limited support from evidence-based research. Recently, AOTA completed an Evidence Based Practice Project to generate a number of systematic reviews using multidisciplinary scientific literature between 2006 and 2013 to address evidence-based interventions to support those with ASD (Tanner, Hand, O'Toole, & Lane, 2015; Watling & Hauer, 2015; Weaver, 2015). Although some of the articles may include methods used by multiple disciplines and they are not all exclusively

occupational therapy studies, the results of the systematic reviews reflect the scope of occupational therapy practice.

Within the literature, researchers found evidence to support occupational therapy interventions that address challenges with ADLs, IADLs, education, work, social participation, and play/leisure (Tanner et al., 2015; Watling & Hauer, 2015; Weaver, 2015). Several interventions and strategies have been shown to be effective for improving performance within these occupations for children and adolescents with ASD. Occupational therapy-based evidence consistently supports behavioral strategies, CO-OP model, technology, contextual changes, family involvement, among others—which have been implemented by occupational therapists to accomplish functional outcomes in individuals who have ASD (Weaver, 2015).

Sensory integration and sensory-based interventions have gained increased support in literature, especially occupational therapy-based research, which have indicated that Ayres Sensory Integration and multisensory strategies had a significant impact on improving functional performance skills for engagement in everyday activities for children and adolescents who have ASD (Watling & Hauer, 2015). Effectiveness of single-sensory strategies, such as sound therapies, dynamic seating, and weighted vests were found to have mixed results to address sensory processing difficulties in individuals with ASD (Watling & Hauer, 2015). Hippotherapy, or equine-assisted therapy, has gained recent attention within occupational therapy for individuals with ASD, showing a significant impact on engagement (Llambias, Magill-Evans, Smith, & Warren, 2016) as well as improving performance skill for increased participation in self-care, leisure, and social interaction (Ajzenman, Standeven, & Shurtleff, 2013).

Weaver (2015) reported on effectiveness of a variety of interventions for addressing ADLs, including self-care tasks, feeding and eating, and routines with children and adolescents who have ASD. Technology-based interventions and sensory integration strategies, specifically the use of an individualized sensory integration intervention (OT-SI), were found to decrease the need for assistance with self-care tasks among the ASD population. Multidimensional positive behavioral supports and behavioral skills training were effective in improving feeding behaviors in children with ASD. Additionally, the CO-OP model was also found to improve feeding and eating for children with ASD, which utilizes a systematic approach and caregiver-guided discovery to master functional outcomes (Weaver, 2015).

While the evidence supporting valuable interventions addressing IADLs is scarce within occupational therapy research, the CO-OP model was found to be effective in improving performance in IADL tasks as well, such as tying shoes, making the bed, using utensils, keyboarding, playing sports, riding bike, and bedtime routines. Weaver (2015) identified positive results on improving participation and independence with shopping and cooking tasks for individuals with ASD using a community-based training group, technology-based interventions, and behavioral strategies. Some intervention studies showed notable progression toward meeting home and health management outcomes—especially keyboarding, making the bed, and playing sports—through parental coaching and contextual interventions, which involve authentic activity settings, family daily routines, and sensory processing patterns (Weaver, 2015).

Evidenced-based occupational therapy interventions can improve attainment of education-related outcomes in the school setting for individuals with ASD. School

interventions found to be effective in decreasing challenging behaviors with children who have ASD include exercise, contextual changes, differential reinforcement, self-management interventions, and antecedent manipulations (Tanner et al., 2015). Children with ASD demonstrated significant improvements in mastery of educational tasks through implementation of an in-class sensory activity schedule (Mills, Chapparo, Hinitt, 2016). Weaver (2015) identified evidence to support daily yoga for improved classroom behavior, such as the Get Ready to Learn yoga program

Individuals with ASD benefit from evidence-based occupational therapy interventions for improving overall work performance. Independence with job tasks improved with video-modeling and Behavioral Skills Training strategies, including instruction, practice, feedback, modeling, token systems, and picture prompts (Weaver, 2015). Using technology, such as a mobile phone, tablet, or PDA can be motivating as well as promote skill development and guidance through tasks through video prompts and modeling (Weaver, 2015). Rosen, Weiss, Zancanaro, and Gal (2017) identified a favored video modeling tool called Ready, Set, Work! to improve work performance and job readiness skills in adolescents with ASD. Supported employment, such as on-the-job supports or a job coach, have been shown to increase rates of employment and retention as well as improve overall quality of life for individuals with ASD (Weaver, 2015).

Tanner et al. (2015) identified effective occupational therapy interventions for addressing social participation in children and adolescents with ASD, including group-based social skills training programs, peer-mediated interventions, activity-based interventions, computer-based interventions, and social stories. Group and activity-based interventions included Topobo (a constructional activity), LEGOs, exercise, and

computer work. Computer-based interventions implemented video modeling and virtual reality training strategies to assist children with developing social skills. The effectiveness of social stories for increasing positive social behaviors and decreasing challenging behaviors demonstrates mixed evidence within the literature. Tanner et al. (2015) determined effective occupational therapy interventions to address social communication, including Picture Exchange Communication System (PECS), naturalistic behavior interventions, DIR/floortime, parent-mediated intervention, imitation training, and joint attention training. DIR/floortime has been shown to especially improve social skills such as communication, relationships, and skills required for daily living for children with ASD (Liao et al., 2014).

Evidence-based interventions and strategies to support play and leisure in children and adolescents with ASD are limited within the occupational therapy literature. Tanner et al. (2015) identified potential interventions for enhancing performance in play, including adult modeling and prompting, DIR/floortime, and child-led play. Additionally, occupational therapy strategies for improving leisure participation include recess interventions, leisure groups, CO-OP model, water exercise, and social stories (Tanner et al., 2015).

Conclusion

Children and adolescents ages 8-16 with ASD experience many changes and challenges during development and pubertal maturation. Such challenges may include coping with puberty-related changes, menstruation, masturbation, personal hygiene and self-care, family routines, safety, emotional regulation, behavior management, and social participation. Occupational therapists have a role in addressing puberty-related changes

and challenges among the ASD population; however, there is limited literature to determine practice trends and evidence-based interventions for occupational therapists to fulfill this role. Current literature identifies a variety of occupational therapy and multidisciplinary intervention strategies, including behavioral strategies, Behavioral Skills Training, cognitive strategies, social learning approaches, technology-based, Ayres Sensory Integration Treatment Approach, sensory processing integration, exercise, parent training approaches, equine-assisted/hippotherapy, and specifically designed curriculums for puberty and sexual education. These intervention strategies have strong support from the literature for addressing challenges experienced by children and adolescents with ASD. However, evidence-based limitations exist in determining effective strategies for addressing puberty-related changes and challenges with the ASD population—especially within occupational therapy research.

CHAPTER III

Methodology

Research Design

A descriptive survey design (Gay, Mills, & Airasian, 2006) was used to explore and understand the practice trends of occupational therapy in assisting children and adolescents age 8-16 with autism spectrum disorder (ASD) address developmental changes and challenges during puberty. A survey design "determines and describes the way things are" and is used to illustrate how groups view topics or issues typically addressing factors such as demographics, opinions, and practices (Gay et al., 2006, p. 159). All factors of which are present in this study. There is limited information regarding the practice of occupational therapy to address puberty related challenges and changes for adolescents ages 8-16 with ASD. Therefore, the first step in understanding these practice trends was to employ a descriptive survey design to gather descriptive data to represent current practice trends of occupational therapy practitioners.

Sources of Data

Locale of the Study

The research study was approved by the University of North Dakota (UND) Institutional Review Board (IRB) on September 12, 2017 (see Appendix A for approval letter). The research study then ensued during the fall of 2017 to spring of 2018 academic

year. The Occupational Therapy for Autism and Puberty Survey (OT-APS) was distributed to collect the data (see Appendix B for sample of survey). The survey was distributed online through Qualtrics® (2018). It was chosen to be circulated online instead of hard copy for ease of data collection and analysis. The survey could be completed on any preferred device such as a smartphone, tablet, or computer and in any place of their choosing, such as at work or home. Prior to beginning the survey, a statement of informed consent was provided. By continuing with the survey, the occupational therapists and occupational therapy assistants consented to participate in the study. The survey design was chosen to increase the possibility of gathering a large amount of descriptive information from occupational therapy practitioners across the United States.

Population and Sampling

Two forms of sampling were used to gather participants to complete the online survey. Stratified random sampling (Gay et al., 2006) was utilized as the researchers obtained a randomized mailing list of specified subgroups of occupational therapy practitioners from the American Occupational Therapy Association (AOTA) to send postcards to 500 AOTA members most likely to work with children and adolescents ages 8-16 with ASD (see Appendix C for format of postcard). The specified subgroups included practitioners involved with the AOTA Special Interest Sections of developmental disabilities, sensory integration, as well as early intervention and school systems working primarily in outpatient clinics, private practice, the school system, mental health settings, and community-based practice.

Convenience sampling (Gay et al., 2006) was also utilized to obtain participants as the researchers used any available subjects willing to participate by posting an invitation to the study in four AOTA online occupational therapy blog posts on OT Connections (see Appendix D for format of post). Only occupational therapists and occupational therapy assistants who are members of AOTA have access to OT Connections. Therefore, this sampling method targeted licensed occupational therapy practitioners who work or who have worked in settings related to this research study.

Following the first two attempts for recruiting respondents, the response rate to the survey was less than desired. The researchers used convenience sampling (Gay et al., 2006) to invite additional participants for the study through the UND occupational therapy fieldwork database. The researchers sent 106 emails to pediatric fieldwork coordinators to forward onto occupational therapy practitioners at each site (see Appendix E for email format). This sampling method targeted occupational therapy practitioners the UND occupational therapy department has contact with who work specifically in pediatric settings. The researchers utilized the online blog posts on OT Connections, mailed postcards, and sent emails to invite and inform pediatric occupational therapy practitioners of the survey.

The target population of this study was licensed occupational therapists and occupational therapy assistants in the United States who worked with children and adolescents age 8-16 with ASD. To participate in the survey, individuals had to meet the inclusion criteria which included being an occupational therapist or occupational therapy assistant and that they had experience working with children and adolescents who have ASD. In total, 77 participants responded to the online Qualtrics® (2018) survey

during the three-month time frame the survey was available. Six of these respondents reported that they do not work with children and adolescents ages of 8 to 16 who have ASD, so they were dismissed from the survey. Therefore, only 71 survey responses were utilized in the data analysis. All participants were occupational therapists or occupational therapy assistants in the United States. Occupational therapists comprised of 88.7% ($n = 63$) of the responses. A majority of the participants were female ($n = 68, 95.8\%$), and most of the participants identified as only White ($n = 68, 95.8\%$). A large portion of participants resided in Minnesota ($n = 15, 21.1\%$) or North Dakota ($n = 11, 15.5\%$). Participants from 22 other states represented the remaining survey responses ($n = 45, 63.4\%$). The mean age of survey respondents ($n = 69$) was 42.64 (standard deviation [SD] = 12.096) with a range of 22 to 65 years. The mean amount of experience working as an occupational therapy practitioner was 15.63 ($SD = 11.41$) years with a range of 1 to 42 years. The mean amount of experience working as a pediatric occupational therapy practitioner was 13.28 ($SD = 10.64$) with a range of 1 to 40 years. The majority of participants worked in schools ($n = 46, 64.8\%$) and outpatient clinics ($n = 35, 49.3\%$). See Table 1. A majority of participants reported that 0 to 25 percent ($n = 33, 46.5\%$) or 26 to 50 percent ($n = 25, 35.2\%$) of their caseload was comprised of children and adolescents age 8-16 with ASD. Refer to Table 2. Participants who responded to the survey, reported working with adolescents with ASD who have an identified severity level 1 ($n = 64, 90.1\%$), severity level 2 ($n = 64, 90.1\%$), and severity level 3 ($n = 61, 85.9\%$).

Table 1

Number of Occupational Therapy Practitioners Working in Each Context

Context	n	%
School	46	64.8%
Outpatient Clinic	35	49.3%
Community	5	7.0%
Outpatient Hospital	3	4.2%
Inpatient Hospital	2	2.8%
Group Home	2	2.8%
Home Health	1	1.4%

Table 2

Percentage of Occupational Therapy Practitioners' Caseload Comprised of Children and Adolescents Age 8-16 with ASD

Caseload %	%
0-25%	46.5%
26-50%	35.2%
51-75%	12.7%
76-100%	5.6%

Note. N = 71.

Instrumentation and Data Collection

The OT-APS was created by the researchers for completion of the study. To develop the survey, researchers first completed a thorough literature review and identified the challenges children and adolescents ages 8-16 with ASD experience during development and pubertal maturation as well as the intervention approaches being utilized to address these challenges. Next, survey questions were developed based upon the themes that emerged from the literature. Challenges experienced by children and

adolescents age 8-16 with ASD include coping with puberty-related changes, menstruation, masturbation, personal hygiene and self-care, family routines, safety, emotional regulation, behavior management, and social participation. On the OT-APS, each challenge is further broken down into several subtopics from the literature that more conclusively encompass puberty-related complications for children and adolescents with ASD. Current literature also identified a variety of occupational therapy and multidisciplinary treatment approaches used with children and adolescents who have ASD. These evidence-based intervention strategies included behavioral strategies, Behavioral Skills Training, cognitive strategies, social learning approaches, technology-based, Ayres Sensory Integration Treatment Approach, sensory processing integration, exercise, parent training approaches, equine-assisted/hippotherapy, and specifically designed curriculums for puberty and sexual education.

The OT-APS gathered information to describe practice trends of occupational therapy practitioners when addressing puberty-related changes and challenges for children and adolescents ages 8-16 with ASD. The OT-APS was designed to gather demographic information and specific data addressing the identified problems and interventions found in the literature to provide the researchers with the results related to the purpose of the study. Participants were asked to identify treatment approaches they have been trained in as well as interventions and strategies they used to address each specific challenge. Additional items on the OT-APS gather information about the comfort level and preparedness of occupational therapy practitioners to address puberty-related challenges for children and adolescents with ASD.

The OT-APS was launched using Qualtrics® (2018), an online platform for consumer-centered survey generation, administration, and distribution. Occupational therapy practitioners gained access to the OT-APS through a direct link or QR code and were encouraged to complete the survey at their own convenience before a given expiration date. After the deadline for open access to the survey, the researchers analyzed the data using SPSS software. Descriptive and inferential statistics were used to analyze the data.

Validity is concerned with the amount that an instrument measures what it was designed to measure and, therefore, whether the instrument allows for an appropriate interpretation of scores (Gay et al., 2006). In order to address content validity, the researchers first completed a literature review to ensure that the depth and breadth of puberty related challenges and intervention approaches were included in the survey. The researchers addressed both item and sampling validity by designing the OT-APS questions and answer choices based off the literature found. Researchers used puberty related challenges and interventions for adolescents with ASD found throughout the literature making items related to the focus of the study and covering a variety of challenges and interventions. Criterion-related validity was not assessed, because, to the researchers' knowledge, there is not a similar instrument that measures puberty related practice trends for occupational therapy.

Reliability is concerned with the amount that an instrument consistently measures what it is measuring making it dependable and trustworthy (Gay et al., 2006). In order to address internal consistency reliability, the researchers calculated Cronbach's Alpha to analyze the reliability of the questions addressing challenges experiences and

interventions utilized in practice for children and adolescents age 8-16 with ASD. Internal consistency of the questions related to challenges was high ($\alpha = 0.895$). The questions related to interventions utilized in practice also had high internal consistency ($\alpha = 0.922$).

CHAPTER IV

Data Analysis

Research Question 1: "What is the continuing education background of pediatric occupational therapists working with children and adolescents ages 8-16 with autism spectrum disorder (ASD)?" The researchers calculated descriptive statistics to represent the data, including frequencies, ranges, percentages, means, and standard deviations.

Seventy-one respondents to the survey were utilized for data analysis. When analyzing ASD continuing education of participants, 45.1% ($n = 32$) completed both self-study courses and in person trainings/seminars and 38% ($n = 27$) completed only self-study courses. Refer to Table 3. The mean number of ASD continuing education courses attended by participants ($n = 59$) was 9.73 (standard deviation [SD] = 11.79). For continuing education in puberty related changes and challenges for ASD, 73.2% ($n = 52$) completed no continuing education courses. See Table 3. The mean number of continuing education courses attended by participants ($n = 19$) were 1.53 ($SD = 1.43$). The most common interventions that participants were trained in included behavioral strategies ($n = 67, 94.4\%$), sensory processing integration ($n = 58, 81.7\%$), and social learning approaches ($n = 57, 80.3\%$). Refer to Table 4. The mean number of interventions participants were trained in was 5.70 ($SD = 2.32$). Respondents were allowed to respond in an 'other' box. A range of interventions were listed, but no commonalities were found.

Table 3

Percentage of Responses for Participants Continuing Education

Type of Course	ASD Courses	ASD & Puberty Courses
None	15.5%	73.2%
Only In-Person	1.4%	8.5%
Only Self-Study	38.0%	12.7%
Both In-Person and Self-Study	45.1%	5.6%

Note. N = 71.

Table 4

Percentage of Participants Trained in Each Type of Intervention.

Intervention	%
Behavioral Strategies	94.4%
Sensory Processing Integration	81.7%
Social Learning Approaches	80.3%
Technology-Based	64.8%
Exercise	54.9%
Behavioral Skills Training	49.3%
Cognitive Strategies	46.5%
Ayres Sensory Integration Treatment Approach	39.4%
Parent Training Approaches	35.2%
Equine Assisted/Hippotherapy	12.7%
Specifically Designed Curriculums for Puberty and Sexual Education	2.8%

Note. N = 71.

Research Question 2: "What assessments are used in the occupational therapy process to address issues related to puberty for children and adolescents age 8-16 with ASD?" The researchers calculated descriptive frequencies and percentages.

The majority of participants utilized the Sensory Profile-2 ($n = 49, 69.0\%$), the Sensory Processing Measure ($n = 45, 63.4\%$), and the Bruininks-Oseretsky Test of Motor Proficiency (BOT-2) ($n = 44, 62.0\%$). Refer to Table 5. Overall, the mean number of assessments participants were utilizing for adolescents with ASD was 3.63 ($SD = 1.96$). Respondents were allowed to respond in an 'other' box. A variety of assessments were listed, but no commonalities were found.

Table 5

Percentage of Participants Using Each Assessment with Children and Adolescents Ages 8-16

Assessment	%
Sensory Profile 2	69.0%
Sensory Processing Measure	63.4%
Bruininks-Oseretsky Test of Motor Proficiency (BOT-2)	62.0%
Adolescent/Adult Sensory History	43.7%
School Function Assessment	38.0%
Pediatric Evaluation of Disability Inventory (PEDI)	22.5%
The Goal Oriented Assessment of Lifeskills (GOAL)	14.1%
The Vineland Adaptive Behavior Scales, 2nd ed.	11.3%
The Motivation Assessment Scale (MAS)	5.6%
Kohlman Evaluation of Living Skills (KELS)	4.2%
Adaptive Behavior Assessment System (ADAS-3)	2.8%
Social Responsiveness Scale, 2nd ed.	1.4%
Tool to Measure Parenting Self-Efficacy	1.4%
Assessment for Mothers of Children with Autism (AMCA)	0.0%
Autism Treatment Evaluation Checklist (ATEC)	0.0%
Vocational Fit Assessment	0.0%

Note. $N = 71$.

Research Question 3: "What interventions are used in the occupational therapy process to address issues related to puberty for children and adolescents ages 8-16 with ASD?" The researchers calculated descriptive frequencies, percentages, means, and standard deviations.

Nine puberty related challenges were identified from the literature. Each challenge was further defined using sub-challenges. In total, the mean number of sub-challenges addressed by participants was 22.27 ($SD = 11.61$). The most common challenges addressed regarding coping with puberty related changes were social expectations ($n = 45, 63.4\%$), parent concerns ($n = 41, 57.7\%$), and physical changes ($n = 37, 52.1\%$). See Table 6. In regards to menstruation, the most common challenges addressed included none ($n = 34, 47.9\%$) and hygiene management ($n = 31, 43.7\%$). Refer to table 6. For masturbation, the most common challenges addressed were touching genitals in public ($n = 43, 60.6\%$) and engagement in the presence of others ($n = 33, 46.5\%$). See Table 6. The most common challenges addressed regarding hygiene and self-care included dressing ($n = 50, 70.4\%$), using deodorant ($n = 49, 69.0\%$), and hair grooming ($n = 47, 66.2\%$). Refer to Table 6. In regards to family routines, the most common challenges addressed were transitioning from dependence to independence ($n = 41, 57.7\%$) and hygiene routines ($n = 39, 54.9\%$). See Table 6. The most common challenges addressed for safety included having healthy relationships ($n = 35, 49.3\%$) and avoiding vulnerable situations ($n = 25, 35.2\%$). See Table 6. In regards to emotional regulation, the most common challenges addressed included anxiety ($n = 63, 88.7\%$), aggression ($n = 59, 83.1\%$), and anger ($n = 56, 78.9\%$). Refer to Table 6. The most common challenges addressed regarding behavior management were appropriate versus

inappropriate behaviors ($n = 61, 85.9\%$) and self-stimming behaviors ($n = 57, 80.3\%$). Refer to Table 6. In regards to social participation, the most common challenges addressed included awareness of boundaries ($n = 58, 81.7\%$) and social norms ($n = 52, 73.2\%$). See Table 6. Overall, the overarching challenges with the largest percent of sub-challenges selected as being addressed with this population included emotional regulation (mean [M] = 66.43, $SD = 28.10$) and personal hygiene and self-care ($M = 47.36, SD = 31.55$). Refer to Table 6. Respondents were allowed to respond in an 'other' box for each overarching challenge. Commonalities were found for emotional regulation, personal hygiene/self-care, and safety. Refer to Table 6.

Table 6

Mean Percentages of Sub-Challenges Selected for Each Overarching Challenge and Percentage of Responses to Each Sub-Challenge

Challenge	M	SD	%
Emotional regulation	66.43	28.10	
Anxiety			88.7%
Aggression			83.1%
Anger			78.9%
Unpredictability			73.2%
Moodiness			69.0%
Other: impulsivity			2.8%
None			4.2%
Personal hygiene and self-care	47.36	31.55	
Dressing			70.4%
Hair grooming			66.2%
Washing face, acne treatment			52.1%
Bathing			52.1%
Shaving			35.2%
Genital cleansing			23.9%
Deodorant			69.0%
Other: brushing teeth			7.0%
None			11.3%
Behavior management	40.85	23.07	
Appropriate vs. inappropriate behaviors			85.9%
Self-stimming behaviors			80.3%
Obsessive and compulsive behaviors			60.6%
Obscene gestures			26.8%
Sexual behavior			22.5%
Exhibitionism			7.0%
None			2.8%
Social participation	40.69	25.88	
Awareness of boundaries			81.7%
Social norms			73.2%
Nonverbal communication			63.4%
Developing/maintaining relationships			57.7%
Interaction with the opposite sex			35.2%
Sexual comments			26.8%
Excessive discussion of sexual topics			14.1%

Intimate relationships			12.7%
None			7.0%
Family routines	40.56	32.24	
Transitioning from dependence to independence			57.7%
Hygiene routines			54.9%
Behavioral management			49.3%
Privacy and modesty			35.2%
None			19.7%
Coping with puberty-related changes	35.61	26.22	
Social expectations			63.4%
Parent concerns			57.7%
Physical changes			52.1%
Sex-specific maturation			25.4%
Sexual changes			21.1%
Sexuality			18.3%
None			14.1%
Masturbation	25.63	22.22	
Touching genitals in public			60.6%
Engagement in the presence of others			46.5%
Hyper-masturbation			18.3%
Incorrect technique			0.0%
None			28.2%
Safety	24.51	28.32	
Healthy relationships			49.3%
Avoiding vulnerable situations			35.2%
Sexual harassment and bullying			18.3%
Sexual abuse prevention			14.1%
Other: elopement/preventing escape			2.8%
None			33.8%
Menstruation	18.87	21.35	
Hygiene management			43.7%
Feminine hygiene products			32.4%
Tracking menstrual cycle			9.9%
Birth control			1.4%
None			47.9%

Note. $N = 71$.

For each of the nine overarching challenges areas, participants selected interventions they have utilized to address these puberty related challenges for adolescents with ASD. Participants had twelve interventions to choose from. For all nine challenge areas, the two most commonly used interventions were behavioral strategies and social learning approaches. For six of the nine challenge areas – coping with puberty related changes, menstruation, masturbation, hygiene and self-care, family routines, and safety – parent training approaches was the third most common intervention utilized among participants. Two interventions that were rarely used by participants to address these challenges were equine assisted therapy or hippotherapy and specifically designed curriculums for puberty and sexual education, refer to Table 7. Respondents were allowed to respond in an 'other' box. A range of interventions were reported for each challenge, but no commonalities were found. The overarching challenge areas with the most number of interventions utilized included emotional regulation ($M = 4.37$, $SD = 2.55$) and behavior management ($M = 4.17$, $SD = 2.38$). See Table 8. Overall, the interventions most commonly utilized by participants to address all challenges related to puberty for adolescents with ASD was social learning approaches ($M = 5.30$, $SD = 2.86$) and behavioral strategies ($M = 5.28$, $SD = 2.65$). Refer to Table 9.

Table 7

Percentage of Respondents Who Selected the Intervention for Each Challenge

	Behavioral strategies	Behavioral skills training	Cognitive strategies	Social learning approaches	Technology-based	Ayres Sensory Integration Treatment Approach	Sensory processing integration	Exercise	Parent training approaches	Equine assisted/hippotherapy	Specifically designed curriculums for puberty and sexual education
Emotional regulation	81.7%	38.0%	33.8%	74.6%	23.9%	21.1%	59.2%	53.5%	32.4%	5.6%	0.0%
Personal hygiene and self-care	63.4%	32.4%	18.3%	57.7%	15.5%	9.9%	15.5%	5.6%	42.3%	0.0%	2.8%
Behavior management	83.1%	43.7%	35.2%	73.2%	14.1%	23.9%	54.9%	42.3%	36.6%	5.6%	0.0%
Social participation	69.0%	33.8%	29.6%	78.9%	16.9%	12.7%	28.2%	19.7%	26.8%	1.4%	0.0%
Family routines	57.7%	18.3%	21.1%	47.9%	15.5%	5.6%	18.3%	11.3%	45.1%	0.0%	4.2%
Coping with puberty-related changes	64.8%	21.1%	14.1%	67.6%	14.1%	14.1%	26.8%	21.1%	35.2%	0.0%	5.6%
Masturbation	47.9%	15.5%	8.5%	50.7%	2.8%	4.2%	11.3%	4.2%	18.3%	0.0%	5.6%
Safety	29.6%	9.9%	14.1%	47.9%	11.3%	1.4%	5.6%	2.8%	23.9%	0.0%	1.4%
Menstruation	31.0%	9.9%	7.0%	31.0%	2.8%	2.8%	5.6%	7.0%	18.3%	0.0%	1.4%

Note. N = 71.

Table 8
Mean Number of Interventions Selected for Each Challenge

Challenge	M ^a	SD
Emotion regulation	4.37	2.55
Behavior management	4.17	2.38
Social participation	3.20	2.20
Coping with puberty-related changes	2.89	2.15
Personal hygiene and self-care	2.68	2.03
Family routines	2.48	2.14
Masturbation	1.72	1.73
Safety	1.54	1.83
Menstruation	1.21	1.65

Note. $N = 71$.

^aRange of possible selection = 0-11.

Table 9
Mean Number of Times Each Intervention Was Selected

Intervention	M ^a	SD
Social learning approaches	5.30	2.86
Behavioral strategies	5.28	2.64
Parent training approaches	2.79	3.21
Behavioral skills training	2.62	2.39
Sensory processing integration	2.25	2.53
Cognitive strategies	1.82	2.66
Exercise	1.68	1.97
Technology-based	1.17	2.01
Ayres Sensory Integration Treatment Approach	0.96	1.86
Specifically designed curriculums for puberty and sexual education	0.21	0.86
Equine assisted/hippotherapy	0.13	0.51

Note. $N = 71$.

^aRange of possible selection = 0-9.

Respondents reported that parents ($n = 27, 38.0\%$) and third parties such as teachers, counselors, or physicians ($n = 19, 26.8\%$) most often initiate discussion about puberty related concerns. Respondents were allowed to respond in an 'other' box, but no commonalities were found. However, six participants did not respond to this question. See Table 10. A majority of participants reported that parents and children seldom ($n = 43, 60.6\%$) identify puberty related goals. However, five respondents did not respond to the item. Refer to Table 11. Participants reported that the type of assistance parents most often request were strategies to implement in the home ($n = 55, 77.5\%$). Participants were allowed to respond in an 'other' box, but no commonalities were found. Refer to Table 12.

Table 10

Percentage of Responses for Who Most Often Initiates Discussion About Puberty-Related Concerns

Response	%
Parent(s)	38.0%
Third-Party: teacher, counselor, physician	26.8%
Therapist	14.1%
Other	11.3%
Child/Adolescent	1.4%

Note. $n = 65$.

Table 11

Percentage of Responses for How Often Parents and Children/Adolescents Identify Puberty-Related Goals

Frequency	%
Never	12.7%
Seldom	60.6%
Often	18.3%
Always	1.4%

Note. $n = 66$.

Table 12

Percentage of Responses to Types of Assistance Requested by Parents for Puberty-Related Concerns

Response	%
Strategies to implement in the home	77.5%
Direct intervention/treatment with the child	56.3%
Educational materials	40.8%
Other	5.6%

Note. $N = 71$.

Research Question 4: "How prepared do occupational therapy practitioners feel to address occupational issues related to puberty for adolescents age 8-16 with ASD?" The researchers calculated descriptive frequencies, percentages, means, and standard deviations.

Using a 5-point Likert scale from 0 ("not at all comfortable") to 4 ("extremely comfortable"), participants ranked their comfort discussing puberty-related changes and challenges with adolescents and parents. A majority of participants reported being "somewhat comfortable" discussing puberty-related changes and challenges with children and adolescents ($M = 3.16$, $SD = .811$) and with parents ($M = 3.33$, $SD = .811$). However, 16 participants did not respond to comfort with children and adolescents, and 10 participants did not respond to comfort with parents. Refer to Table 13. The majority of respondents reported being 'most comfortable' addressing challenges of emotional regulation ($n = 39$, 54.9%) and personal hygiene and self-care ($n = 38$, 53.5%) and being 'least comfortable' addressing challenges of masturbation ($n = 63$, 88.7%) and menstruation ($n = 30$, 42.3%). Refer to Figure 1. The majority of participants reported being 'most comfortable' utilizing behavioral strategies ($n = 40$, 56.3%) and social learning approaches ($n = 33$, 46.5%) and being 'least comfortable' utilizing specifically

designed curriculums for puberty and sexual education ($n = 46, 64.8\%$) and equine assisted therapy or hippotherapy ($n = 36, 50.7\%$). Refer to Figure 2.

Table 13

Percentage of Responses for Comfort Level in Discussing Puberty-Related Concerns with Children/Adolescents and Parents

Comfort Level	Children/Adolescents ($n = 55$)	Parents ($n = 61$)
Not at all comfortable	0.0%	1.4%
Not so comfortable	16.9%	11.3%
Somewhat comfortable	33.8%	33.8%
Very comfortable	23.9%	36.6%
Extremely comfortable	2.8%	2.8%

Figure 1

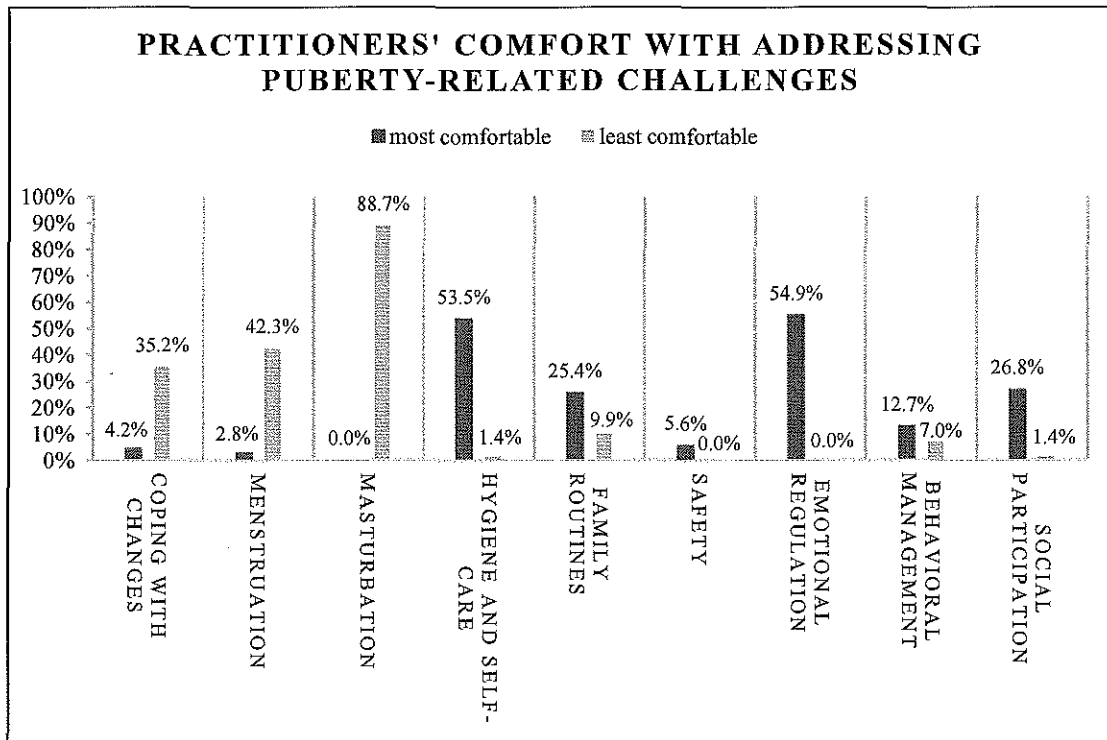
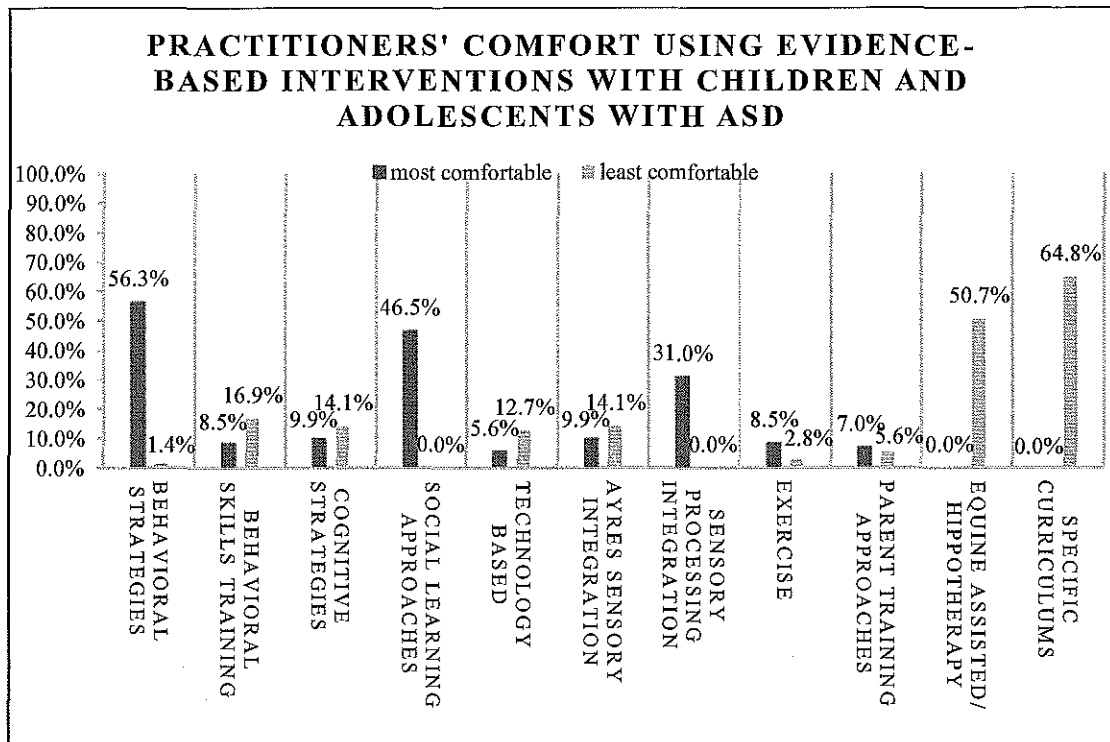


Figure 2



CHAPTER V

Discussion

The purpose of this study was to understand the trends of occupational therapy practitioners in addressing developmental changes and challenges during puberty for children and adolescents age 8-16 with ASD. The researchers utilized a descriptive survey design. Seventy-one occupational therapy practitioners responded to the survey.

Summary and Conclusions

Occupational therapy practitioners working with children and adolescents age 8-16 with autism spectrum disorder (ASD) attended a limited number of continuing education courses on pubertal changes and challenges for ASD with a majority of participants attending none. Participants most commonly were trained in interventions of behavioral strategies, sensory processing integration, and social learning approaches. Assessments most often utilized by occupational therapy practitioners for children and adolescents with ASD included the Sensory Profile-2, the Sensory Processing Measure, and the Bruininks-Oseretsky Test of Motor Proficiency (BOT-2). This compares to what was identified in the literature by Crabtree et al. (2017) as standardized assessments commonly used for adolescents with ASD. However, no respondents reported utilizing the Autism Treatment Evaluation Checklist (ATEC) and the Assessment for Mothers of Children with Autism (AMCA) identified by Miller-Kuhaneck (2015) as assessment tools for children and adolescents with ASD. These findings indicate that occupational therapy

practitioners are utilizing assessments that correlate with what is recommended in the literature. However, occupational therapy practitioners in this study are not utilizing ASD specific evaluations and are not specifically assessing changes and challenges related to puberty with adolescents who have ASD.

Overall, the most common puberty-related challenges identified by respondents were emotional regulation and personal hygiene/self-care. Although adolescents with ASD are likely to experience adverse emotional challenges and difficulty managing hygiene routines during puberty, (Bagatell, 2016; Cridland, Caputi, Jones, & Magee, 2015; Pecora, Mesibov, & Stokes, 2016) adolescents with ASD also struggle to cope with and understand physical and sexuality changes related to puberty (Cridland, Jones, Caputi, & Magee, 2014; Cridland et al., 2015; Pecora et al., 2016). Adolescents with ASD also experience challenges with appropriate social interaction and knowledge of social norms, causing them to be at an increased safety risk of vulnerability, sexual exploitation, and abuse (Beddows & Brooks, 2016; Cridland et al., 2014; Holmes, Himle, Strassberg, 2015). Families of adolescents with ASD experience increased challenges during this time, such as altering routines and accommodating to behavior and emotional changes, managing hygiene, menstruation, and masturbation needs (Bagatell, 2016; Ballan, 2012; Cridland et al., 2014; Hamilton, Marshal, & Murray, 2011). Consistent with the lack of occupational therapy literature, respondents were less likely to address unique issues to puberty, including coping with puberty related changes, masturbation, safety, and menstruation. Therefore, occupational therapy practitioners may be neglecting to address other important challenges and changes that children and adolescents with ASD and their parents experience during the pubertal transition.

Based on the results of the study, the researchers gleaned that occupational therapy practitioners are most commonly utilizing behavioral strategies, social learning approaches, and parent training approaches to address puberty-related challenges for children and adolescents with ASD. Within the survey, descriptions of behavioral strategies and social learning approaches were provided for clarification to the participants. Behavioral strategies included interventions of reinforcement, positive behavioral supports, picture prompts, visual supports and aids, and activity schedules. Social learning approaches included interventions utilizing social stories, modeling, peer mediation, and social skills training. Behavioral strategies, social learning approaches, and parent training approaches were found throughout the occupational therapy and non-occupational therapy literature, indicating that these interventions are commonly employed with children and adolescents who have ASD in occupational therapy and other disciplines. Therefore, occupational therapy practitioners may be neglecting to use additional evidence-based interventions unique to occupational therapy with children and adolescents who have ASD to address puberty-related challenges, including cognitive strategies such as Cognitive Orientation to Daily Occupational Performance Approach (CO-OP), Ayres Sensory Integration Treatment, sensory processing integration, forms of behavioral skills training such as shaping and chaining, and equine assisted or hippotherapy (Ajzenman, Standeven, & Shurtleff, 2013; Llambias, Magill-Evans, Smith, & Warren, 2016; Tanner, Hand, O'Toole, & Lane, 2015; Watling & Hauer, 2015; Weaver, 2015).

Furthermore, none of the occupational therapy evidence found in the literature review discussed interventions for specifically addressing pubertal changes and

challenges for children and adolescents with ASD. The non-occupational therapy literature showed support for utilizing Applied Behavioral Analysis (ABA), chaining, social stories, and specifically designed curriculums to address changes and challenges specific to puberty for adolescents with ASD (Ballan & Freyer, 2017; Corona, Fox, Christodulu, & Worlock, 2016; Jamison & Schuttler, 2016; Klett & Turan, 2012; Veazey, Valentino, Low, McElroy, & LeBlanc, 2016; Visser et al., 2015). However, researchers found that occupational therapy practitioners are rarely utilizing behavioral skills training techniques, such as ABA and chaining, or specifically designed curriculums that show evidence of effectively addressing puberty-specific challenges with adolescents who have ASD. Moreover, occupational therapy practitioners are neglecting to use other evidence-based interventions such as technology and exercise with adolescents who have ASD (Bimbrow, Boger, and Mihailidis, 2012; Berezna, Ayres, Mechling, & Alexander, 2012; McDonald & Machalicek, 2013; Tanner et al., 2015; Weaver, 2015).

Based on the results of the study, the researchers found that a majority of the occupational therapy practitioners do not initiate discussions about puberty and more often, the parents are initiating this discussion. Furthermore, the survey results gleaned that parents and children seldom identify goals related to puberty. However, throughout the literature, it was found that parents of children and adolescents with ASD express a desire to receive additional guidance related to pubertal changes and challenges (Bagatell, 2016; Ballan, 2012; Cridland et al., 2014; Cridland et al., 2015; Dewinter, Vermeiren, Vanwesenbeeck, & Nieuwenhuizen, 2016; Holmes et al., 2015). Therefore, parents may not be identifying puberty related goals because occupational therapy practitioners are

not initiating the discussion and informing parents that puberty-related changes and challenges are within the occupational therapy scope of practice.

The researchers found that occupational therapy practitioners are most comfortable addressing emotional regulation and personal hygiene and self-care challenges, and practitioners are least comfortable addressing masturbation and menstruation. Emotional regulation and hygiene/self-care were also the challenges occupational therapy practitioners addressed more often in therapy, and menstruation and masturbation were two of the three challenges practitioners least often addressed in therapy. Therefore, occupational therapy practitioners may only be addressing puberty-related challenges they are most comfortable with and neglecting to address areas they identified as less comfortable.

Researchers found that occupational therapy practitioners are most comfortable utilizing behavioral strategies and social learning approaches. Based on this survey, behavioral strategies and social learning approaches were also two of the three most common interventions occupational therapy practitioner respondents were trained in and the two most often utilized interventions for addressing pubertal challenges with adolescents who have ASD. Behavioral strategies such as reinforcement, positive behavioral supports, and visual supports and social learning approaches such as social stories, modeling, social skills training, and peer mediation were found throughout the non-occupational therapy literature as effective interventions to utilize for puberty specific challenges for adolescents with ASD (Ballan & Freyer, 2017; Klett & Turan, 2012; Mathews, Erkfritz-Gay, Knight, Lancaster, & Kupzyk, 2013). However, other

interventions such as ABA (Freyer, 2017; Matson, Hattier, & Belva, 2012; McDonald & Machalicek, 2013).

Occupational therapy practitioners were least comfortable utilizing equine assisted/hippotherapy and curriculums specifically designed for puberty and sexual education. Curriculums specifically designed to address puberty education were identified throughout the non-occupational therapy literature as effective interventions for adolescents with ASD (Corona et al., 2016; Jamison & Schuttler, 2016; Visser et al., 2015). Equine assisted/hippotherapy and curriculums specifically designed for puberty and sexual education were also the interventions practitioners were least commonly trained in and the interventions least commonly utilized to address pubertal challenges for adolescents with ASD. Therefore, occupational therapy practitioners may be most comfortable with interventions in which they have more training and least comfortable utilizing interventions in which they have less training. Furthermore, occupational practitioners are more often utilizing the interventions in which they are most comfortable and underutilizing the interventions in which they are least comfortable.

Implications for Clinical Practice

These findings provide an understanding of the current occupational therapy practice trends when addressing puberty related changes and concerns with children and adolescents age 8-16 with ASD. Overall, the results from this survey revealed that puberty related change and challenges may be an underserved area for occupational therapy practitioners working with adolescents who have ASD. The occupational therapy profession may need to develop an assessment or screening tool that evaluates the pubertal and sexuality changes and challenges found throughout the literature for

adolescents with ASD. Occupational therapy practitioners working with adolescents who have ASD might also adapt current assessments being used in practice to assess these pubertal challenges were appropriate such as when assessing activities of daily living (ADLs) or self-care, social participation, safety, emotional regulation, or behavior management. In addition, occupational therapy practitioners need to ask additional questions during the initial evaluation that address and open discussions about puberty related changes and challenges with adolescents who have ASD and their parents. Practitioners must evaluate and initiate discussions so adolescents and parents are open to identifying puberty related goals.

These results indicated that certain evidence-based interventions are being less utilized by occupational therapy practitioners to address these challenges, and occupational therapy practitioners are more often utilizing other evidence-based interventions. Occupational therapy practitioners are encouraged to consider and utilize other evidence-based interventions with this population to address pubertal challenges. There may also be a need for the occupational therapy profession to develop a program or curriculum that specifically addresses puberty related changes and challenges for adolescents with ASD.

Lastly, there is a need for increased continuing education courses and programs for addressing puberty and sexual challenges with children and adolescents with ASD. Many participants had attended a limited number or no continuing education courses on pubertal challenges with the ASD population. Increasing continuing education opportunities in this area would prepare practitioners to better address these challenges

and, therefore, may increase comfort to initiate these discussions and address all the challenges that puberty poses for adolescents with ASD and their parents.

Implications for Education

During occupational therapy schooling, there is a need for further training in and understanding of puberty related changes and challenges for children and adolescents with ASD. Occupational therapy students need increased exposure to the challenges that may accompany puberty as well as increased training on additional evidence-based interventions to utilize in this context. Increased training and understanding in formal education may increase comfort in addressing these challenges and intervening by utilizing an array of evidence-based interventions.

Implications for Research

From the literature review, the researchers found a lack of occupational therapy literature for effective interventions to address puberty specific challenges. This study supports further research in the area of puberty related challenges and interventions for children and adolescents age 8-16 with ASD. Further research is needed to better understand why certain evidence-based interventions, such as behavioral strategies and social learning approaches, are being utilized more often and other evidence-based interventions are not being utilized by occupational therapy practitioners to address pubertal challenges with adolescents who have ASD. Further research is also needed to better understand how these interventions are being utilized in practice. Furthermore, research is needed to determine effectiveness and validity of interventions in addressing pubertal challenges with adolescents who have ASD.

Limitations

The survey was developed specifically for this study and did not go through procedures to establish psychometrics. This was the first time utilizing the survey and researchers may make changes to the survey if it was to be used again. Because this descriptive survey was a self-report survey, researchers did not observe participants completing interventions to determine if reporting was accurate based off intervention descriptions. The age range of 8-16 years old used to define adolescents was large, and practitioners may address pubertal changes and challenges differently throughout this age continuum.

The survey had a limited number of participants. Also, there was a low response rate to the initial random sample, so researchers sent the survey to pediatric therapy facilities within the University of North Dakota Occupational Therapy Fieldwork Sites databases, which resulted in a large number of responses from North Dakota and Minnesota practitioners. Therefore, these results may be more representative of practice in these states. A majority of respondents reported as being female ($n = 68, 95.8\%$) and white ($n = 68, 95.8\%$). While this is a limitation of the study, these percentages closely reflect the occupational therapy discipline as a whole, where approximately 90.9% of practitioners are female and 85.3% of practitioners are white (American Occupational Therapy Association [AOTA], 2015).

A majority of respondents also worked in schools ($n = 46, 64.8\%$) which may have affected outcomes of the survey as there may be less opportunities for school-based therapists to address puberty challenges as goals must be education focused. Also, a high majority of school therapists may have provided less information on practice trends in

other settings such as outpatient clinics and hospitals. However, this is also closely reflective of the occupational therapy discipline. As of 2014, schools were the second ranked practice setting of the total occupational therapy workforce for both occupational therapists (19.9%) and occupational therapy assistants (15.2%) (AOTA, 2015). Therefore, these percentages reflect the work setting trends of the profession as a whole.

APPENDICES

Appendix A

IRB Letter of Approval



DIVISION OF RESEARCH & ECONOMIC DEVELOPMENT

UND.edu

Institutional Review Board
Twamley Hall, Room 108
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September 12, 2017

Principal Investigator(s):	Kelsey Hemberger and Sydney Larson
Project Title:	Occupational Therapy Practice Trends for Occupations Impacted by Puberty in Children with ASD
IRB Project Number:	IRB-201709-040
Project Review Level:	Exempt 2
Date of IRB Approval:	09/12/2017
Expiration Date of This Approval:	09/11/2020

The application form and all included documentation for the above-referenced project have been reviewed and approved via the procedures of the University of North Dakota Institutional Review Board.

If you need to make changes to your research, you must submit a Protocol Change Request Form to the IRB for approval. No changes to approved research may take place without prior IRB approval.

This project has been approved for 3 years, as permitted by UND IRB policies for exempt research. You have approval for this project through the above-listed expiration date. When this research is completed, please submit a Termination Form to the IRB.

The forms to assist you in filing your project termination, adverse event/unanticipated problem, protocol change, etc. may be accessed on the IRB website: <http://und.edu/research/resources/human-subjects/>

Sincerely,

Michelle L. Bowles, M.P.A., CIP
IRB Coordinator

MLB/sb

Cc: Sarah Nielsen, Ph.D., OTR/L

Appendix B

Occupational Therapy for Autism and Puberty Survey (OT-APS)

The survey was built and distributed via Qualtrics.

The University of North Dakota Consent to Participate in Research

Title: Occupational Therapy Practice Trends for Occupations Impacted by Puberty in Children with ASD

Project Director: Kelsey Hemberger, MOTS and Sydney Larson, MOTS, Advisor Sarah Nielsen, PhD, OTR/L

Phone: (701) 777-2208

Department: Occupational Therapy

Statement of Research

A person who is to participate in the research must give his or her informed consent to such participation. This consent must be based on an understanding of the nature and risks of the research. This document provides information that is important for this understanding. Research projects include only subjects who choose to take part. Please take your time in making your decision as to whether to participate. If you have questions at any time, please ask.

What is the Purpose of this Study?

You are invited to take a survey in which the data will be analyzed for a research study about occupational therapy interventions to address puberty-related issues for individuals with autism because you are identified as an occupational therapy practitioner working with children and adolescents ages 8-16 with autism spectrum disorder.

The purpose of this independent research study is to understand the role of occupational therapy in addressing developmental changes during puberty for children and adolescents ages 8-16 with autism spectrum disorder.

How Many People will Participate?

Five hundred people are being asked to complete the survey.

How Long Will I Be in this Study?

The survey will take approximately 15 minutes to complete.

What Will Happen During this Study?

The survey consists of approximately 30 questions, involving multiple choice, multi-select answers, ranking, and short-answer. You are encouraged to answer all questions as accurately as you are able; however, you are free to skip any questions that you would prefer not to answer. The data gathered from the study will be analyzed using descriptive statistics to determine practice trends of occupational therapy practitioners when addressing puberty-related changes and challenges with children and adolescents ages 8-16 with autism spectrum disorder.

What are the Risks of the Study?

There are no foreseeable risks from participation in this study.

What are the Benefits of this Study?

You may not benefit personally from participating in this research study. However, we hope that, in the future, other people might benefit from this study because we will gain a fuller understanding of the role of occupational therapy practitioners in addressing puberty-related changes and challenges with children and adolescents ages 8-16 with autism spectrum disorder.

Will it Cost me Anything to Be in this Study?

You will not have any costs for being in this research study.

Will I Be Paid for Participating?

You will not be paid for being in this research study.

Who is Funding the Study?

The University of North Dakota and the research team are receiving no payments from other agencies, organizations, or companies to conduct this research study.

Confidentiality

The records of this study will be kept private to the extent permitted by law. In any report about this study that might be published, you will not be identified. Your study record may be reviewed by government agencies and the University of North Dakota Institutional Review Board. Your personal information will not be collected or retained at any point during the completion of this survey for the research study. Data will be kept in a file on a private computer in order to safeguard data during storage and analysis. If we write a report or article about this study, we will describe the study results in a summarized manner so that you cannot be identified.

Is this Study Voluntary?

Your participation is voluntary. You may choose not to participate or you may discontinue your participation at any time without penalty. You may choose to skip any questions you prefer not to answer or end the survey at any point. Your decision whether or not to participate will not affect your current or future relations with the University of North Dakota.

Contacts and Questions?

The researchers conducting this survey are **Sydney Larson** and **Kelsey Hemberger**, Masters of Occupational Therapy Students at the University of North Dakota. You may ask any questions you have now. If you later have questions, concerns, or complaints about the research, please contact Sydney Larson at (701) 880-8489 or Kelsey Hemberger at (218) 784-8408. You may also speak with the student advisor, **Sarah Nielsen**, PhD., OTR/L at (701) 777-2208.

If you have any questions regarding your rights as a research subject, you may contact The University of North Dakota Institutional Review Board at **(701) 777-4279** or **UND.irb@research.UND.edu**.

- You may also call this number about any problems, complaints, or concerns you have about this research study.
- You may also call this number if you cannot reach research staff, or you wish to talk with someone who is independent of the research team.
- General information about being a research subject can be found by clicking "Information for Research Participants" on the website: <http://und.edu/research/resources/human-subjects/research-participants.cfm>

By continuing with this survey, you are consenting to participate in the research study.

Do you work with children and adolescents ages 8-16 who have autism spectrum disorders?

- Yes
- No

**A 'Yes' response results in continuing with the survey.*

**A 'No' response results in end of survey.*

Demographics

What is your gender?

- Male
- Female

Please enter your age: _____

Please choose one or more races that you identify with.

- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Other: _____

Are you an occupational therapist or an occupational therapy assistant?

- Occupational therapist
- Occupational therapy assistant

What state do you currently practice in?

Drop down tab for respondent to select appropriate choice.

How many years of experience do you have working as an occupational therapy practitioner?

How many years have you worked with pediatric clients as an occupational therapy practitioner?

What percentage of your typical caseload is comprised of children ages 8-16 with autism spectrum disorder?

- 0-25%
- 26-50%
- 51-75%
- 76-100%

Which of the following severity levels of autism spectrum disorder have your clients experienced? Select all that apply.

- **Severity Level 1 – “Requiring support”**
Social Communication: *“Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.”* (APA, 2013)
Restricted, Repetitive Behaviors: *“Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.”* (APA, 2013)
- **Severity Level 2 – “Requiring substantial support”**
Social Communication: *“Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.”* (APA, 2013)
Restricted, Repetitive Behaviors: *“Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.”* (APA, 2013)
- **Severity Level 3 – “Requiring very substantial support”**
Social Communication: *“Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs and only responds to only very direct social approaches.”* (APA, 2013)
Restricted, Repetitive Behaviors: *“Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.”* (APA, 2013)

In what contexts do you work with children and adolescents ages 8-16 who have autism spectrum disorder? Select all that apply.

- Outpatient clinic
- Outpatient hospital
- Inpatient hospital
- Group home
- Home health
- School
- Community

How much training or continuing education have you had in regards to autism spectrum disorders within the last 10 years? Select all that apply.

- None
- Self-study courses. If so, how many? _____
- In-person trainings/seminars. If so, how many? _____

How much training or continuing education have you had in regards to autism spectrum disorders **and** puberty-related changes and challenges within the last 10 years? Select all that apply.

- None
- Self-Study courses. If so, how many? _____
- In-person trainings/seminars. If so, how many? _____

Which interventions and strategies for children and adolescents ages 8-16 have you been trained or educated on within the last 10 years? Select all that apply.

- Behavioral Strategies** (reinforcement, positive behavioral supports, picture prompts, visual supports and aids, activity schedule)
- Behavioral Skills Training** (Applied Behavioral Analysis, shaping, chaining, graduated guidance)
- Cognitive Strategies** (CO-OP: goal-plan-do-check, joint attention training)
- Social Learning Approaches** (social stories, modeling, peer mediation, social skills training)
- Technology-Based** (iPhone, iPad, iPod, self-prompting personal device assistant, computer-based interventions)
- Ayres Sensory Integration Treatment Approach**
- Sensory Processing Integration**
- Exercise** (yoga, water exercise)
- Parent Training Approaches**
- Equine Assisted/Hippotherapy**
- Specifically Designed Curriculum for Puberty and Sexual Education**
- Other** (please describe): _____

Which of the following assessments have you used with children and adolescents ages 8-16 with autism spectrum disorder? Select all that apply.

- Sensory Processing Measure
- Sensory Profile 2
- Adolescent/Adult Sensory History
- Social Responsiveness Scale, 2nd ed.
- School Function Assessment
- The Goal Oriented Assessment of Lifeskills
- Kohlman Evaluation of Living Skills
- Pediatric Evaluation of Disability Inventory
- Adaptive Behavior Assessment System (ADAS-3)
- The Vineland Adaptive Behavior Scales, 2nd ed.
- Vocational Fit Assessment
- Bruininks-Oseretsky Test of Motor Proficiency (BOT-2)
- Autism Treatment Evaluation Checklist (ATEC)
- Assessment for Mothers of Children with Autism (AMCA)
- Tool to Measure Parenting Self-Efficacy
- The Motivation Assessment Scale (MAS)
- Other (please list): _____

Challenges and Interventions

Considering children and adolescents ages 8-16 with autism spectrum disorder, what specific challenges have you addressed in regards to **copng with puberty-related changes**? Select all that apply.

- None
- Sex-specific maturation
- Physical changes
- Sexual changes
- Social expectations
- Sexuality
- Parent concerns
- Other (please describe): _____

**For all items in this section, if 'None' response is selected, respondent skips intervention question and list.*

Which of the following intervention strategies have you used to address **copng with puberty-related changes**? Check all that apply.

- Behavioral Strategies** (reinforcement, positive behavioral supports, picture prompts, visual supports and aids, activity schedule)
- Behavioral Skills Training** (Applied Behavioral Analysis, shaping, chaining, graduated guidance)
- Cognitive Strategies** (CO-OP: goal-plan-do-check, joint attention training)
- Social Learning Approaches** (social stories, modeling, peer mediation, social skills training)
- Technology-Based** (iPhone, iPad, iPod, self-prompting personal device assistant, computer-based interventions)
- Ayres Sensory Integration Treatment Approach**
- Sensory Processing Integration**
- Exercise** (yoga, water exercise)
- Parent Training Approaches**
- Equine Assisted/Hippotherapy**
- Specifically Designed Curriculums for Puberty and Sexual Education**
- Other** (please describe): _____

**Intervention question is repeated following each challenge question as long as 'None' response is not selected.*

Considering children and adolescents ages 8-16 with autism spectrum disorder, what specific challenges have you addressed in regards to **menstruation**? Select all that apply.

- None
- Feminine hygiene products
- Birth control
- Hygiene management
- Tracking menstrual cycle
- Other (please describe): _____

Which of the following intervention strategies have you used to address **menstruation**? Check all that apply.

List of intervention strategies

Considering children and adolescents ages 8-16 with autism spectrum disorder, what specific challenges have you addressed in regards to **masturbation**? Select all that apply.

- None
- Engagement in the presence of others
- Incorrect technique
- Hyper-masturbation
- Touching genitals in public
- Other (please describe): _____

Which of the following intervention strategies have you used to address **masturbation**? Check all that apply.

List of intervention strategies

Considering children and adolescents ages 8-16 with autism spectrum disorder, what specific challenges have you addressed in regards to **personal hygiene and self-care**? Select all that apply.

- None
- Bathing
- Shaving
- Dressing
- Washing face, acne treatment
- Hair grooming
- Genital cleansing
- Deodorant
- Other (please describe): _____

Which of the following intervention strategies have you used to address **personal hygiene and self-care**? Check all that apply.

List of intervention strategies

Considering children and adolescents ages 8-16 with autism spectrum disorder, what specific challenges have you addressed in regards to **family routines**? Select all that apply.

- None
- Hygiene routines
- Behavioral management
- Privacy and modesty
- Transitioning from dependence to independence
- Other (please describe): _____

Which of the following intervention strategies have you used to address **family routines**? Check all that apply.

List of intervention strategies

Considering children and adolescents ages 8-16 with autism spectrum disorder, what specific challenges have you addressed in regards to **safety**? Select all that apply.

- None
- Sexual abuse prevention
- Avoiding vulnerable situations
- Sexual harassment and bullying
- Healthy relationships
- Other (please describe): _____

Which of the following intervention strategies have you used to address **safety**? Check all that apply.

List of intervention strategies

Considering children and adolescents ages 8-16 with autism spectrum disorder, what specific challenges have you addressed in regards to **emotion regulation**? Select all that apply.

- None
- Anger
- Aggression
- Anxiety
- Unpredictability
- Moodiness
- Other (please describe): _____

Which of the following intervention strategies have you used to address **emotion regulation**? Check all that apply.

List of intervention strategies

Considering children and adolescents ages 8-16 with autism spectrum disorder, what specific challenges have you addressed in regards to **behavior management**? Select all that apply.

- None
- Appropriate vs. inappropriate behaviors
- Self-stimming behaviors
- Obscene gesture
- Obsessive and compulsive behaviors
- Sexual behavior
- Exhibitionism
- Other (please describe): _____

Which of the following intervention strategies have you used to address **behavior management**? Check all that apply.

List of intervention strategies

Considering children and adolescents ages 8-16 with autism spectrum disorder, what specific challenges have you addressed in regards to **social participation**? Select all that apply.

- None
- Social norms
- Awareness of boundaries
- Sexual comments
- Excessive discussion of sexual topics
- Interaction with opposite sex
- Intimate relationships
- Developing/maintaining relationships
- Nonverbal communication
- Other (please describe): _____

Which of the following intervention strategies have you used to address **social participation**? Check all that apply.

List of intervention strategies

Comfort

How comfortable are you discussing puberty changes and challenges with the following individuals?

	0 – not at all comfortable	1 – not so comfortable	2 – somewhat comfortable	3 – very comfortable	4 – extremely comfortable
Children/Adolescents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Who most often initiates discussion about puberty-related concerns regarding children and adolescents ages 8-16 with autism spectrum disorder?

- I do
- Parent(s)
- Child/Adolescent
- Third-Party: teacher, counselor, physician
- Other: _____

How often to children and adolescents ages 8-16 with autism spectrum disorder and/or parents identify goals related to puberty changes and challenges?

Never	Seldom	Often	Mostly	Always
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What type of assistance do parents and adolescents ages 8-16 with autism spectrum disorder most often request? Select all that apply.

- Direct intervention/treatment with the child
- Strategies to implement in the home
- Educational materials
- Other (please describe): _____

Comfort

In regards to children and adolescents ages 8-16 with autism spectrum disorder, select the two areas you feel the most comfortable addressing and the two areas you feel the least comfortable addressing.

Items	Most Comfortable	Least Comfortable
Coping with puberty-related changes		
Menstruation		
Masturbation		
Personal hygiene and self-care		
Family routines		
Safety		
Emotional regulation		
Behavioral management		
Social participation		

In regards to addressing puberty-related challenges with children and adolescents ages 8-16 with autism spectrum disorder, select the two interventions you feel the most confident in implementing and the two interventions you feel the least confident in implementing.

Items	Most Comfortable	Least Comfortable
Behavioral Strategies (reinforcement, positive behavioral supports, picture prompts, visual supports and aids, activity schedule)		
Behavioral Skills Training (Applied Behavioral Analysis, shaping, chaining, graduated guidance)		
Cognitive Strategies (CO-OP: goal-plan-do-check, joint attention training)		
Social Learning Approaches (social stories, modeling, peer mediation, social skills training)		
Technology-Based (iPhone, iPad, iPod, self-prompting personal device assistant, computer-based interventions)		
Ayres Sensory Integration Treatment Approach		
Sensory Processing Integration		
Exercise (yoga, water exercise)		
Parent Training Approaches		
Equine Assisted/Hippotherapy		
Specifically Designed Curriculums for Puberty and Sexual Education		

Conclusion

If there is additional information you would like to share about your experiences working with children and adolescents with autism spectrum disorder or in regards to puberty-related changes and challenges, please use the space provided.

Thank you for taking the time to complete our survey. We appreciate your support for our research. Thank you for helping us benefit the OT profession and ASD population.

Appendix C

Postcard Format

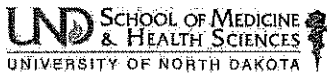
**SYDNEY LARSON &
KELSEY HEMBERGER**



SYDNEY.K.LARSON@UND.EDU



701-880-8489



UNIVERSITY OF NORTH DAKOTA
MASTERS OF OCCUAPTIONAL THERAPY

INVITATION TO PEDIATRIC AUTISM RESEARCH

- Currently there is a limited amount of resources to determine occupational therapy practice trends for addressing puberty and sexuality-related challenges within the ASD population
- Your participation will help inform about occupational therapy's role in addressing changes and challenges during puberty for children and adolescents ages 8-16 with ASD
- Approximately 15 minutes to complete
- Please complete before **November 15, 2017**
- Link to survey: UND.edu/OT/ASDsurvey
Or use QR code:



Thank you for helping us benefit the OT profession and ASD population.

Sincerely,

Sydney Larson, MOTS & Kelsey Hemberger, MOTS

Advised by Dr. Sarah Nielsen

Sydney Larson, OTS & Kelsey Hemberger, OTS
Occupational Therapy Department
School of Medicine and Health Sciences
Suite E321
1301 N. Columbia Rd. Stop 9037
Grand Forks, ND 58202-9037

Mailing Address

Appendix D

Format for Post on OT Connections

The following will be posted on AOTA's OT Connections forums (<http://otconnections.aota.org/>) to inform occupational therapy practitioners of our study and invite participation.

Invitation for Pediatric Autism Research - OT's Role in Addressing Puberty

My partner and I are Master's of Occupational Therapy Students at the University of North Dakota and are conducting a research study. We would like to invite you to complete our survey to help inform about occupational therapy's role in addressing changes and challenges during puberty for children and adolescents ages 8-16 with autism spectrum disorder. The survey will take approximately 15 minutes to complete and your participation would be greatly appreciated.

You can find the survey at the following link through **November 30, 2017**:
UND.edu/OT/ASDsurvey

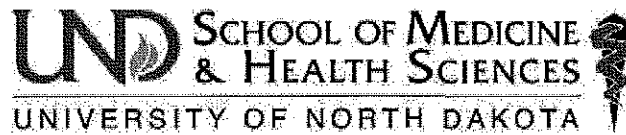
If you have any questions or concerns you can reach us at sydney.k.larson@und.edu or 701-880-8489.

Appendix E

Email Format

Mass email sent out to UND OT Fieldwork Site database on Tuesday, January 9, 2018.

Subject Heading: Invitation to Pediatric Autism Research – OT’s Role in Addressing Puberty



Greetings Occupational Therapy Enthusiasts,

My partner and I are Masters of Occupational Therapy Students at the University of North Dakota and are conducting a study on the role of occupational therapy when addressing puberty within the ASD population.

Currently there is a limited amount of resources to determine occupational therapy practice trends for addressing puberty and sexuality-related challenges within the ASD population. Your participation in our study will help to inform about occupational therapy’s role in addressing changes and challenges during puberty for children and adolescents ages 8-16 with ASD.

The survey will take approximately 15 minutes to complete and your participation would be greatly appreciated. You can find the survey at the following link through

Wednesday, January 24, 2018: UND.edu/OT/ASDsurvey

Please forward this survey to all OTs and OTAs at your site who work with children and adolescents ages 8-16 with ASD.

Thank you for helping us benefit the occupational therapy profession and ASD population.

If you have any questions or concerns, you can reach us at sydney.k.larson@UND.edu or 701-880-8489.

Sincerely,

Sydney Larson, MOTS & Kelsey Hemberger, MOTS

Advised by Dr. Sarah Nielsen

Occupational Therapy Department
School of Medicine and Health Sciences
Suite E321
1301 N. Columbia Rd. Stop 9037
Grand Forks, ND 58202-9037

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