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Pawsitive Purpose: The Impact of Autism Assistance Dogs on Levels of Participation and Engagement in Occupations of Children with Autism Spectrum Disorder

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CERTIFICATE OF APPROVAL

This is to certify that the thesis of

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submitted in partial fulfillment of the requirements of the degree of Master of Science in the Department of Occupational Therapy, School of Health Sciences and Human Performance, at Ithaca College has been approved.

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Abstract

Importance: The World Health Organization recognizes that participation is important to an individual's health and wellbeing; yet children with autism spectrum disorder participate in activities less frequently and with less variety compared to neurotypical children.

Objective: To describe the role of autism assistance dogs in promoting participation and engagement in occupations and activities of daily living (ADLs) of children with autism spectrum disorder.

Design: Two semi-structured interviews from a narrative perspective were conducted with each of four participants. Interpretative phenomenology and Creswell's thematic analysis were used to code and analyze qualitative data.

Setting: Interviews were conducted by video interview.

Participants: Four volunteer parents/primary handlers of their child's autism assistance dog participated in the study. Inclusion criteria: Family must have had an autism assistance dog for greater than one year prior to the start of the study.

Outcomes and Measures: Develop codes and theoretical perspectives to better understand the lived experience of autism assistance dog users.

Results: The role of autism assistance dogs is multifactored; these dogs improve children's participation and engagement across all domains of occupation. All the participants reported that the benefits of autism assistance dogs outweigh the challenges associated with owning/using an assistance dog.

Conclusions and Relevance: Autism assistance dogs are a valuable, alternative form of adaptive equipment for children with ASD that can serve a broad purpose in increasing participation in daily life.

What This Article Adds: The four stories provided reveal that advocating for and assisting families in acquiring an autism assistance dog along with helping families to best use the dogs to support participation of their children is an area of practice and is an appropriate location for occupational therapy practitioners to concentrate interventions in when working with families with children with ASD.

Acknowledgments

I would like to sincerely thank the four participants who agreed to participate in this study. I greatly appreciate your willingness to share your time and experiences with me. Your contributions to this study are invaluable.

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I would like to thank my family and friends for supporting me throughout this lengthy process. Your words of encouragement and endless support helped me to pursue this journey, even during the toughest, most daunting times. Without you all, I would not have completed this project or pursued my passion.

Dedication

This research is dedicated to Noah Cervantes and his family. It is because of their support and inspiration to pursue a career involving animal assisted interventions that I completed this study. Thank you for your endless support and words of encouragement. You are an amazing family; my passion for OT and animal assisted intervention only grew while working with your family. An even bigger thank you for supporting my transition from OT student to OT student practitioner to future OTR/L.

This research is also dedicated to Pepper, the puppy that I raised for Guiding Eyes for the Blind during my time at Ithaca College. Pepper, I am so proud of you and of your accomplishments. Thank you for pushing me to combine my passion for OT and dogs into my future career. Without you, I would never have become so interested in animal assisted intervention or training pediatric assistance dogs. I cannot thank you enough for your endless love and support. Thank you for being my "gopher" while incorporating dog assisted interventions in the pediatric OT clinic- your flexibility and passion to help kids will never be forgotten.

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Chapter 1: Introduction

Personal Ties and Inspiration

During my time as an occupational therapy major at Ithaca College, I raised a puppy named Pepper for Guiding Eyes for the Blind. I further had the opportunity to incorporate Pepper into my life as an occupational therapy student; I was an active participant in the on-campus pediatric occupational therapy clinic where I treated a child under the supervision of one of my professors and began incorporating the puppy into some of the sessions. This served a dual purpose by further socializing Pepper with children, familiarizing her with various types of equipment, and exposing her to spontaneous experiences while being a motivator for my client to actively participate in the therapy session. After witnessing the benefits Pepper provided for my client in the clinic, his parents became interested in pursuing an assistance dog for him and the clinic team worked to support them in achieving this goal. I began researching assistance dog agencies and types of pediatric assistance dogs that would fit my client's complex needs. Through my research, I discovered that there were only a small number of organizations that trained pediatric assistance dogs, since it is an emerging phenomenon. Due to the client's medical complexities and rare diagnosis, several agencies were dismissive of the family's requests for services. Eventually, I found an organization that trains autism assistance dogs for children with Autism Spectrum Disorder, which was one of my client's many diagnoses. This organization was willing to work with this family and child. With the support of my faculty supervisor, I collaborated with both the client's family and the organization during the application, matching, and training process to ensure that the dog was trained to meet both the client and his family's unique needs. Once, the family returned home with their autism assistance dog, we helped them incorporate the

dog into their daily roles, routines, and environments to promote the client's optimal occupational performance.

After the completion of that process, I began to wonder, if there is a vast number of benefits via the use of assistance dogs for adults with disabilities, then why is there limited research on the benefits regarding the use of assistance dogs for children with disabilities? I decided to complete an individual thesis and create a study that could begin to fill this gap in evidence.

Background

This qualitative study assesses the role of autism assistance dogs in promoting participation and engagement in occupations and activities of daily living (ADLs) for children with autism spectrum disorder (ASD). The prevalence of ASD has risen nationally; it currently affects approximately 1 in 59 children in the United States (Centers for Disease Control and Prevention, 2019b). Though many diagnostic criteria focus on deficits compared to neurotypical functioning, many people with ASD are uniquely functional and have enhanced abilities in varied areas compared to neurotypical individuals. They may experience challenges with participation related to these differences since much of the social and contextual world is designed for those who fit a neurotypical profile. This research study uses a strengths-based perspective with a focus on neurodiversity regarding ASD (Atherton, Lummis, Day, & Cross, 2019; Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). While acknowledging the movement in the autistic community by self-advocates and allies to shift towards identity-first language such as autistic person or autistic individual, this document is written using person first language at the request of the family members who participated as subjects. All four

parents reported that until their children become older and can self-identify they choose to refer to their children as a "child with ASD" rather than "an autistic child."

Neurodiversity.

Neurodiversity is the idea that humans are not all neurologically identical, but rather neurological differences such as ASD are the result of natural genetic variations in the human genome that diversify our species (Atherton et al., 2019; Schaaf, Benevides, & Zapletal, 2010). The phenotype used for diagnosis assures that children with autism have some specific similarities but within this, there is significant variation. According to the Lurie Center for Autism at MassGen for Children, "each child with autism spectrum disorder is a unique individual; people with ASD differ as much from one another as do all people. Children and adults with ASD may speak or interact with others. They may have good eye contact. They may be verbal or non-verbal. They may be very bright, of average intelligence or have cognitive deficits" (2019, number 20). This powerful quote embodies a foundational perspective in which this study is built, recognizing that individuals with ASD hold unique strengths, weaknesses, and differences just like neurotypical individuals.

Within those differences, children with ASD often experience difficulty participating fully in daily activities that are important to them and their families. They frequently have difficulty interacting with peers due to differences in social skills; this affects their ability to initiate, respond, and maintain social interactions to develop and maintain relationships with peers both inside and outside of the home (Hyman & Levy, 2013). These neurological differences may impede spontaneous development of play with neurotypical peers, especially pretend play, and can cause difficulties establishing

relationships with peers since play is the primary occupation for children and youth (Hyman & Levy, 2013). Many children with ASD also have sensory processing differences including hypersensitivity to auditory, tactile, and olfactory stimuli. Individuals with ASD often demonstrate heightened abilities to perceive detail which may influence a child's responsiveness to sensory stimuli and influence their behavioral and emotional reactions in both positive and negative ways (Atherton et al., 2019; Hyman & Levy, 2013). This can impact ease of transitions between activities, routines, and/or environments which may impede functioning, engagement, and quality of life (QOL). Children may demonstrate unusual responses/behaviors to sensory input such as covering ears, hand/arm flapping, and rocking (Hyman & Levy, 2013). The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-V) diagnostic criteria for ASD includes demonstration of repetitive, perseverated, stereotyped, and restricted behaviors/interests which may develop into rituals. Many children with ASD demonstrate difficulty with changes to their environments, routines, occupations, etc. Completion of daily tasks and routines, establishing/maintaining relationships, self-injurious behaviors, and bolting/wandering from safety are common challenges associated with the intersection between common cultural expectations for children and ASD (American Occupational Therapy Association [AOTA], 2020b; Autism and Developmental Disabilities Monitoring [ADDM] Network, 2020; Solomon & Lawlor, 2013; Tomchek, LaVesser, & Watling, 2015). Unexpected changes may trigger fear or anxiety, and the child may become extremely distressed. An inability to communicate this distress or a mismatch between a child's responses and family or societal expectations can be interpreted as negative and unsafe behaviors. This may manifest as self-injurious

behaviors which can include head banging, arm biting, and scratching. Bolting or wandering from safety is another response that can put a child in danger. Approximately 50% of children with ASD wander or bolt from safety and 90% of deaths of children with ASD 14 years old or younger are caused by drowning after wandering or bolting (Law & Anderson, 2011; Solomon & Lawlor, 2013).

As defined from a neurodiverse perspective, autism is a biological difference among individuals that should be acknowledged as a component of natural human variation in which the associated differences should be honored (Atherton et al., 2019; Lurie Center for Autism, 2019). It is important to note that differences do not necessarily equate to deficits but rather differences may appear as deficits because children with ASD must adapt to a world that is designed to promote optimal functioning for neurotypical individuals (Atherton et al., 2019; Kapp et al., 2013). In the same way that neurotypical individuals demonstrate weaknesses, individuals with ASD also demonstrate weaknesses that may impede upon their functioning while adapting to a neurotypical society. According to Kapp et al. (2013), "neurodiversity advocates promote subjective well-being and adaptive rather than typical functioning," (p. 60). Hence practitioners' and families' focuses should be on promoting the child's subjective well-being. Proponents of the neurodiversity movement urge interventions to be tailored towards the child's specific interests and strengths to foster adaptive skills to positively address challenges that they may be facing (Kapp et al., 2013).

Children with ASD have demonstrated a heightened ability to understand, use, and integrate visual information into their daily lives (Atherton et al., 2019). Many children with ASD have a proclivity toward an astute area of interest and have been noted

to demonstrate heightened imaginary capabilities, enriched perceptual abilities, and enhanced abilities to process detail (Atherton et al., 2019). Children's heightened imaginary capabilities may relate to the increased prevalence of anthropomorphism amongst children with ASD (Atherton et al., 2019).

Anthropomorphism.

Anthropomorphism is the contribution of human characteristics to non-human beings or inanimate objects (Atherton et al., 2019). Individuals with ASD are socially motivated and have a desire for efficacy, but often have difficulty connecting with other human beings. This may cause individuals with ASD to experience high rates of loneliness and a diminished sense of self (Atherton & Cross, 2018; Atherton et al., 2019; Schaaf et al., 2010). Atherton et al., (2019) reported that individuals with ASD may identify more closely with animals than they do to humans when seeking social connection. It has been hypothesized that individuals with ASD have atypical human facial processing due to differences in the brain's limbic system, specifically the amygdala and fusiform gyrus (Schaaf et al., 2010). It has also been hypothesized that individuals with ASD have heightened anthropomorphic facial processing abilities, strengthening their abilities to connect and socialize in animal-focused contexts (Atherton & Cross, 2018; Atherton et al., 2019; O'Haire, McKenzie, Beck, & Slaughter, 2013; Schaaf et al., 2010).

Therapeutic services.

In order to enable utmost participation and success, children with ASD often require more therapy and medical care compared to neurotypical children, significantly increasing medical expenditures for children with ASD. According to Autism Speaks

(2017), “the cost of caring for Americans with autism had reached $268 billion in 2015 and would rise to $461 billion by 2025 in the absence of more-effective interventions and support across the life span,” (p. 30). Occupational therapy is the second most frequently provided service to children with ASD (Tomchek, LaVesser, & Watling, 2015). Occupational therapy practitioners work with children with ASD, their families, schools, organizations, community services, and other healthcare providers to provide children with the services and adaptations to support their ability to fully participate in their lives. Occupational therapy interventions are designed to foster occupational engagement and social participation by working on adaptive behaviors, social engagement, play, flexibility, problem solving, and sensory processing. Individualized, comprehensive, client-centered interventions are integral to promoting increased independence and ability to engage in meaningful occupations and daily routines (Tomchek et al., 2015).

Assistive technology.

Assistive technology (AT) is one type of intervention that occupational therapist practitioners use to, “to improve clients’ performance, enable participation, or maintain their meaningful engagement in occupation,” (Goodrich, Gitlow, Smith, & Kannenberg, 2016, p. 1). AT is used to help clients meet their goals and engage in occupations with a *just right* challenge by creating an optimal fit between the person, environment, and occupation. AT may be used as either a means or an end to improve occupational participation and performance. It is the role of occupational therapist practitioners to identify, recommend, design, create, apply, modify, and train the client in the use of AT to improve access to occupations (Goodrich et al., 2016).

As described in an early article regarding the use of service dogs as an adaptive strategy by Camp (2001), assistance dogs are considered a type of AT, as they provide compensatory function during daily life activities in both the home and community. Hence, the use of assistance dogs as AT to improve functional independence falls into the domain and scope of practice of occupational therapy (Camp, 2001; Fairman & Huebner, 2008). Assistance dogs are widely known for the profound impact that they have on their handlers; assistance dogs provide services for people with disabilities, providing them independence and freedom in their daily lives.

Figure 1 represents the three types of assistance dogs, namely guide dogs, hearing dogs, and service dogs (Rintala, Matamoros, & Seitz, 2008; Stace, 2016). Assistance dogs are specially trained and permanently placed with a person with a disability, who then becomes known as the dog's handler. Guide dogs aid individuals with visual impairments; they help ensure the safety of their handler during functional and community mobility by navigating through crowds and traffic, avoiding obstacles, stopping at steps/curbs, crossing the street, and guiding them to targets such as restaurants, bus stops, etc. (Bremhorst, Mongillo, Howell, & Marinelli, 2018; Fairman & Huebner, 2008; Mudge, Rewi, & Channon, 2017; Yamamoto & Hart, 2019). Hearing dogs alert individuals who are deaf or hard of hearing to sounds such as name calls, doorbells, timers, telephone rings, fire alarms, approaching vehicles, and alarm clocks (Rintala et al., 2008; Winkle, Crowe, & Hendrix, 2012). Service dogs are trained to help individuals with mobility/balance impairments, psychiatric disabilities, medical issues (ex: seizure alert, diabetic low blood sugar alert) and other medical diagnoses such as autism spectrum disorder (Winkle et al., 2012; Yamamoto & Hart, 2019).

Numerous benefits of assistance dogs have been researched and documented. According to Winkle et al. (2012), service dogs for people with physical disabilities provide functional, psychological, and social/participation benefits. Service dogs significantly increase their handler's functional independence by diminishing reliance on others and decreasing the need for caregiving. A study conducted by Allen and Blascovich (2006), determined that mobility dogs decreased the need for both paid and unpaid assistance to complete activities of daily living. These reductions were quite large, accounting for a 68% reduction in paid assistance and a 64% reduction in unpaid assistance in their sample. They extrapolated that these reductions would lead to significant cost savings even when accounting for the initial cost and maintenance fees associated with obtaining and caring for the dog. Additionally, assistance dogs reduce the amount of stress and anxiety for both the handler and the handler's family (Rintala et al., 2008; Stace, 2016).

Assistance dogs can serve both pediatric and adult populations; the appropriate type of assistance dog is determined based upon an individual's disability, medical diagnosis, and eligibility criteria. Types of assistance dogs that are common to both pediatric and adult clients are shown in Figure 1. These include guide dogs, hearing dogs, seizure alert dogs, seizure response dogs, diabetic alert dogs, mobility dogs, and service dogs for individuals with physical disabilities (Rintala et al., 2008; Stace, 2016). According to Stace (2016), in recent years there has been an increase in the use of assistance dogs with pediatric clients and there has been diversification in the types and duties of assistance dogs.

Autism assistance dogs are a relatively new type of pediatric assistance dog that function in a three-point handling system consisting of the dog, the child, and the parent/caregiver (Stace, 2016). Though little research has been done in this area, a study by Viau, Arsenault-Lapierre, Fecteau, Champagne, Walker, & Lupien (2010) showed that autism assistance dogs can help decrease cortisol, a stress hormone, in children with ASD, potentially promoting behavioral benefits in the children. Use of an autism assistance dog helps improve children's ability to handle stressful situations, process sensory input, communicate with others, and reduce undesirable/self-injurious behaviors. Autism assistance dogs are individually trained to help improve engagement, empathy, communication, independence, and QOL for children with ASD (Carlisle, 2015; Good Dog Autism Companions, 2017).

Significance of Problem

With an increase in the prevalence of ASD comes an increase in the number of children with ASD that will need access to treatment, interventions, and therapy to help them to improve their functional engagement and participation in occupations. Research is needed to demonstrate the value of autism assistance dogs as an assistive technology intervention to promote participation and engagement in occupations for children with ASD. This study aims to describe the potential benefits of making this intervention widely accepted, beneficial, and accessible for children with ASD while filling the gaps in the current literature regarding the uses and benefits of pediatric assistance dogs.

Theory

Theory is a combination of principles used to inform occupational therapy practice and research; it helps us describe, rationalize, and predict behavior and relationships (Cole & Tufano, 2008a). Theories may be multidisciplinary; occupational

therapy practitioners may borrow or share compatible theories with other disciplines to gain insight into their client (Cole & Tufano, 2008a). Therapists use theory to understand occupations and to help improve people's occupational performance. Theory is the foundation for occupational therapy evaluations, interventions, and treatment sessions. In research, theory is used to establish assumptions, guide design of methods, and inform data analysis (Cole & Tufano, 2008a).

Narrative theory and interpretive phenomenology were used as the theoretical basis for designing this project. Mattingly and Lawlor (2000) present foundational narrative theory research that demonstrates the importance of eliciting stories during interviews to understand each person's unique perspectives and lived experiences. Narrative theory was selected for this research because of its unique ability to center the individualized stories of and lived experiences of families with children that use autism assistance dogs (Mattingly & Lawlor, 2000). Interpretive phenomenology was selected to allow for the expertise of the researcher developed through participation in occupational therapy education and first-person experience of supporting a family in obtaining an autism assistance dog (Peat, Rodriguez, & Smith, 2019; Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2015). This expertise and experience provide a framework for a rich interpretation of the stories shared by participants about their lived experience. This study further uses the theories of biophilia and occupational adaptation to guide the interpretation of the results.

Narrative theory.

The use of narratives is extremely useful in understanding, interpreting, and valuing individual's personal experiences and perspectives (Crepeau & Cohn, 2014).

Illness and disability influence an individuals' sense of self and personal experience (Crepeau & Cohn, 2014; Mattingly & Lawlor, 2000). Narratives help convey a person's lived experiences via use of thick descriptions and rich depictions of past events (Crepeau & Cohn, 2014; Mattingly & Lawlor, 2000). Narrative interviews are helpful to understand an individual as an occupational being and help attach meaning to an individual's roles, routines, habits, and daily activities (Crepeau & Cohn, 2014). One type of narrative interview is an illness narrative which is, "elicited from family members concerning their experiences caring for their child," (Mattingly & Lawlor, 2000, p. 7). Although the family members providing the illness narrative may not have an illness or disability, the entire familial unit experiences a child's disability when caring for and interacting with the child, as the child plays an integral role in each family member's life and the familial unit as a whole (Mattingly & Lawlor, 2000). Treatment stories are often revealed via illness narratives and describe treatments and interventions offered by family members, healthcare professionals, and education professionals (Mattingly and Lawlor, 2000). These stories help us understand treatment experiences, treatment efficacy, and treatment value that may not be able to be quantitatively depicted (Crepeau & Cohn, 2014; Mattingly & Lawlor, 2000).

Biophilia.

The biophilia hypothesis professes that humans have an innate attraction to nature and to the natural form of living things (Griess, 2010). This concept supports the presence of human-animal interactions and the facilitation of human-animal bonds. Human-animal bonds are mutually beneficial bonds shared between humans and animals, positively impacting the health and well-being of both species (Kirkham & The Organization for

Human-Animal Interaction Research and Education [OHAIRE] Group, 2020). This innate affiliation may promote a positive bond that can also provide an element of healing (Elmacı & Cevizci, 2015). Throughout evolution humans have demonstrated an aversion to aggressive, potentially threatening animals and an affinity towards friendly, calming animals, such as dogs (Carlisle, 2015). Children demonstrate increased curiosity towards animals because of their ability to relate and empathize with an animal's dependence upon older individuals for care and survival (Melson, 2006). Melson (2006) suggests that the introduction of the opportunity for children to interact with dogs may further motivate children to interact with the world and their environment. Hence, incorporation of dogs into children's lives in various ways may help encourage and motivate children to increasingly participate in numerous aspects of their daily lives.

Occupational adaptation (OA).

As described in Cole and Tufano (2008b), occupational Adaptation Model was developed in 1992 by Schkade and Schultz to guide occupational therapy practice. This holistic model is applied across the life span and focuses on the dynamic, interactive process between an individual and their environment to promote function and engagement in occupations (Cole & Tufano, 2008b). Humans are intrinsically motivated to demonstrate mastery of meaningful occupations in their environments; if they are unable to function and/or complete an occupation within a certain environment, the requirements and demands of the occupation may be adapted. Contextual and environmental demands also motivate the person to adapt their behaviors in order to meet the demands and to develop mastery of the task or occupation (Cole & Tufano, 2008b).

One type of adaptation that is often used to adapt the context, environment, or demands of a task is assistive technology. According to Goodrich & Garza (2015), assistive technology "is any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities," (para. 1). According to this definition, assistance animals may be considered an alternative type of assistive technology for individuals with disabilities because service dogs provide services to individuals with disabilities to improve their functional independence and ability to complete tasks of daily living. The roles and duties provided by assistance animals align within the definition of the purpose of assistive technology as stated in the Technology Act (Camp, 2001). It is within the scope of occupational therapy practice to design interventions and adaptations to improve occupational performance, role competence, and participation amongst individual's with ASD (Tomchek et al., 2015). Hence autism assistance dogs could be considered a type of assistive technology as they can "provide compensatory functions both at home and in the community," (Camp, 2001, p. 509).

Rationale

In general, assistance dogs have become a well-known adaptation for adult populations, especially for those with post-traumatic stress disorder (PTSD), vision impairments, hearing impairments, mobility issues, and medical complications (e.g. seizures, diabetes) (Audrestch, Whelan, Grice, Asher, England, & Freeman, 2015; Rintala et al., 2008; Singleton, Picard, & Ferrara, 2019). Pediatric assistance dogs are an emerging phenomenon that are not yet well understood or widely used. More specifically, new types of assistance dogs have been established as the assistance dog field has

advanced. Further research on newer and less common types of assistance dogs, such as autism assistance dogs, is necessary to document the uses, benefits, and impact of these assistance dogs. To further promote the use and integration of autism assistance dogs as an adaptation for children with autism spectrum disorder, research needs to be done to describe the benefits that these dogs provide in improving children's occupational functioning, participation, and independence.

Statement of Purpose

Although increasing research is being done on the use and benefits of assistance dogs, especially in adult populations, there is a significant lack of research describing the benefits, functional implications, and specific activities that pediatric assistance dogs help children participate in. The aim of this thesis study is to describe the role of autism assistance dogs in promoting participation and engagement in occupations and activities of daily living (ADLs) for children with autism spectrum disorder.

Research Questions

1. What occupations do autism assistance dogs help children with autism spectrum disorder engage in?
2. How does an autism assistance dog facilitate greater participation in occupations and daily routines among children with autism spectrum disorder?

Definition of Terms

Although emotional support dogs, therapy dogs, and assistance dogs all fulfill important roles for their handlers, they each serve different purposes and have different legal access rights. Hence, these terms are not interchangeable. Figure 1 depicts the relationship between these terms and taxonomy of dogs in society. The terms used in Figure 1, and additional related terms, are defined below to provide a common

understanding for reference throughout this study. In an effort to deconstruct common misconceptions regarding assistance animals in society, the assistance animal terms will be used in accordance with the definitions set forth by Assistance Dogs International (ADI) (2020). Permission has been granted by the executive director of ADI to reprint the following definitions:

1. Assistance animal: a generic term for a guide, hearing, or service dog specifically trained to do three or more tasks to mitigate the effects of an individual's disability. The presence of a dog for protection, personal defense, or comfort does not qualify that dog as an assistance dog. Assistance dogs are covered under many legislative access laws for public access rights when working with their disabled handler.
2. Guide dog: a dog that guides individuals who are blind or visually impaired. The presence of a dog for protection, personal defense, or comfort does not qualify that dog as a guide dog.
3. Hearing dog: a dog that alerts individuals who are deaf or hard of hearing to specific sounds. The presence of a dog for protection, personal defense, or comfort does not qualify that dog as a hearing dog.
4. Service dog: a dog that works for individuals with disabilities other than blindness or deafness. Service dogs are trained to perform a wide variety of tasks including but not limited to, pulling a wheelchair, bracing, retrieving, alerting to a medical crisis, and providing assistance in a medical crisis.

5. Alert Service Dog: a dog that is trained to alert a person that the onset of a medical condition is imminent. This is a type of service dog. Common types include seizure alert service dogs and diabetic alert service dogs.
6. Response Service Dog: a dog that is trained to provide safety to person who is experiencing or has just experienced a medical episode, such as a seizure. This is a type of service dog.
7. Psychiatric Service Dog: a dog that is trained to mitigate a mental health disability. This is a type of service dog.
8. Emotional support animal (ESA): a companion animal that provides emotional or therapeutic support to an individual with a mental health condition or emotional disorder simply by being present. Emotional support animals do not receive the same training as assistance dogs and therefore, depending upon the country, may have different laws regarding their public access privileges. For example, in the United States of America, Emotional Support Animals do not have the same right to public access as an assistance dog and its handler.
9. Therapy Dog: a pet dog trained to provide affection, comfort, and love to those it interacts with in many different settings. Therapy dog owners may volunteer their time to visit with their animals to facilities in which the team is welcomed or may be practitioners who utilize the dog in a professional setting. Therapy dogs are not covered under the legislative public access laws, and therefore do not have the same public access rights as an assistance dog and its handler.
10. Facility dog: a specially trained dog that that works with a volunteer or professional in a residential or clinic setting. The dog must be trained to do

specific, skilled tasks in a variety of different situations within the facility environment with multiple clients; it must be more than just a presence within the facility. The volunteer or professional handler is trained by a program. In some countries, facility dogs do not have any public access while in other countries public access is permitted only when the dog and trained handler are directly working with a client with a disability.

11. Task: this is a trained behavior that the dog does on cue (or command) to mitigate its partner's disability. The cue can be verbal, a hand signal, something in the environment and/or some behavior exhibited by the partner or another person. Examples of a verbal cue could be "take it" and a hand signal could be pointing at an object to indicate to the dog to retrieve it. A cue in the environment might be a strap on a door, a car in the road, or an alarm clock ringing. The behavior of a person could be falling to the ground, hand shaking, or emitting odor of low blood sugar.
12. Puppy raiser: a person or family appointed by a program to socialize and prepare a young dog to enter formal training. This is generally a volunteer.
13. Animal Assisted Intervention (AAI): various procedures that are goal-directed and targets the specific aspects (developmental, therapeutic, emotional, behavioral…) of individual or groups of people involved in working with trained animals. It is conducted by animal-handler team by meeting the standards of the competent program.

A visual representation of the components of animal assisted intervention and their relationships are depicted in Figure 2.

Delimitations

The researcher used a convenience sample drawn from recruitment from a single organization that specifically trains autism assistance dogs for children with ASD. This parameter was established to maintain consistency with the participants and the autism assistance dogs to better understand the lived experience of families who use autism assistance dogs. This delimitation also ensured that all the primary handlers and autism assistance dogs received similar training and shared similar experiences that may have affected the impact and effectiveness the assistance dog has had upon the child.

The researcher conducted two semi-structured narrative interviews with each participant to improve the validity and depth of data collected from the participants. The interviews were conducted virtually via Zoom for the researcher to establish stronger rapport with the participants and to gather observations regarding the participants' body language and facial expressions. This parameter also allowed for the researcher to virtually meet some of the autism assistance dogs and some of the children with ASD.

Limitations

This study presented some limitations; one limitation was that all the participants were recruited from a single autism assistance dog organization to assess the impact of autism assistance dogs. Although this helped to ensure similar training, matching, and lived experiences, this study did not include other organizations and manners of training.

The lack of diversity of the small sample was also a limitation of the study because it did not capture the full array of families with a child with ASD who have acquired an autism assistance dog; all of the information collected from each participant was unique to the individuals and dogs discussed in the study.

Although the researcher worked under the mentorship and guidance of a committee of experienced and published researchers, the student researcher was a novice researcher. Prior to interviewing participants, interview techniques were practiced to learn skills to minimize bias and the use of leading questions.

Chapter 2: Literature Review

Approximately 1.85% of 8-year-old children are diagnosed with ASD (ADDM Network, 2020). In addition to typical challenges faced by children as they transition from children to adolescence, children with ASD face additional challenges regarding their roles, responsibilities, and opportunities. According to the Centers for Disease Control, "fewer young people with ASD have the same opportunities as their peers without ASD," (2020, para. 1) and many youth, adolescents, and young adults with ASD have "limited opportunity for community or social activities—nearly 40% spend little or no time with friends," (2020, para. 1). Assistive technology is one intervention that has become increasingly popular to help individuals with ASD establish and maintain relationships, communicate, and interact with other people (Centers for Disease Control and Prevention, 2019c). Interventions and treatments for ASD are typically multi-disciplinary, combining multiple approaches to create an individualized treatment plan to fit each unique individual (Centers for Disease Control and Prevention, 2019c). There is minimal evidence regarding the best or most effective intervention method for children with ASD, especially for older children, that are designed to improve functioning during the child's development and transition to adulthood (Centers for Disease Control and Prevention, 2019c; Centers for Disease Control and Protection, 2020).

One type of emerging alternative intervention for children with ASD is autism assistance dogs. Although there is minimal published research regarding the use and effectiveness of autism assistance dogs for children, there are many published personal accounts and narratives. A blog run by an assistance dog training organization, NEADS,

discusses one of their client's stories after receiving a service dog for their child with ASD. The parent reports,

> I didn't expect that having a Service Dog would have such an impact on Parker and for it to be as useful as it is. I didn't foresee how it would make him more responsible. He used to only think about himself, but with Evers, he's now thinking about how he needs to take her out, get her fed, and exercise and play with her… Evers is helping Parker open up to other people, because when we're out in public, people want to meet her and talk about her. It was heartwarming to attend back-to-school night and see Parker talking about his project to strangers. I know part of this is because he's growing up, but I don't think we would have seen so many changes without Evers (NEADS, 2020, para. 4).

There are a lot of misconceptions regarding the role, duties, purpose, and benefits of the use of assistance animals. To better understand the role of assistance dogs for people living with different disabilities, the taxonomy of assistance dogs will be discussed. The current evidence regarding autism spectrum disorder and occupational therapy will then be reviewed to provide a foundation to demonstrate differences that children with ASD live with and how autism assistance dogs may be able to minimize the functional challenges children with ASD face. In order to further support the role that autism assistance dogs may have in facilitating greater independence and participation in specific occupations/activities of daily living for children with ASD, the following general topics will be discussed: assistance dogs, autism spectrum disorder, and occupational therapy.

Initially I will review literature related to assistance dogs, including the different types of dogs and their associated duties. I will also review the benefits of assistance animals that have been documented in the literature thus far. Additionally, since the diagnostic category for the children involved in this study is ASD, I will review common symptoms and treatments associated with ASD. I will also discuss the role of OT in

working with children with ASD and the role of animals in ASD intervention. Thirdly, I will review literature related to OT more generally as well as some theoretical constructions that I have used to guide my research and analysis. The following is an outline of the topics that will be discussed in this chapter.

Assistance Dogs

The possible duties and tasks assistance dogs are trained to aid individuals with provide context to understanding the influence assistance dogs can have on individual and family life. Majority of past and present literature regarding specific job duties of assistance dogs is based upon research with adult populations. This, in large part, is due to easier access and increased awareness regarding the use of assistance dogs for adults with various conditions including PTSD, diabetes, seizure disorders, mobility impairments, vision impairments, and hearing deficits. The most common job duties reported as means of functional assistance provided by assistance dogs, includes retrieving items, carrying of items (in mouth or on back), opening/closing doors, turning on/off lights, barking to alert presence of emergency/activating emergency alert system (gather other person), pushing automatic door buttons, bracing (provision of mobility support/position maintenance/balance/stability), dressing, alerting handler to sounds, and navigating environments/obstacles (Allen & Blascovich, 2006; Audrestch, et al., 2015; Camp, 2001; Fairman & Huebner, 2008; Mackinnon, 2014; Rintala et al., 2008; Stace, 2016).

One of the most common job duties performed by all types of assistance dogs includes retrieving items for their handlers (Audrestch et al., 2015; Fairman & Huebner, 2008). Dogs may be trained to retrieve various items of different shapes, sizes, and

weights for their handler; this may be done on command and/or may also be completed automatically when the handler unknowingly drops an item (Camp, 2001). Common items that assistance dogs are trained to retrieve include telephones, medication bottles, water bottles, and shoes (Camp, 2001; Rintala et al., 2008). Researchers from the Department of Veteran Affairs Medical Center conducted a pre-post, wait list-controlled pilot study to analyze the impact of assistance dogs on the lives of their handlers living with mobility or hearing impairments. The results of the study indicated that 88.9% of handlers in the experimental group reported that item retrieval was the most frequent duty performed by their service dog (Rintala et al., 2008). A study conducted by occupational therapy practitioners, Fairman and Huebner (2008), supports this conclusion, indicating that handlers reported their service dog assisted them with 99% of item retrieval.

Many of the job duties that assistance dogs aid adult handlers with can also benefit the pediatric population to promote improved functioning and engagement in occupations (Berry, Borgi, Francia, Alleva, & Cirulli, 2013; Stace, 2016). Although assistance dogs have been used to improve safety, functioning, and independence in adult populations for centuries, the use of assistance dogs for pediatric clients is a relatively new phenomenon that began within the past thirty years (Burrows, 2007; Burrows, Adams, & Spiers, 2008; Cohen, 2018; Irvin, 2014; Pawsitivity Service Dogs, 2019). Emerging types of assistance dogs being used for pediatric clients include medical alert dogs (diabetic alert dogs, seizure alert and/or response dogs), dogs for children with physical disabilities, hearing dogs, guide/facilitated guide dogs, and autism assistance dogs (Stace, 2016).

Guide dogs.

Guide dogs and facilitated guide dogs help individuals with visual impairments to navigate their environment, avoid obstacles, and locate items/destinations (Assistance Dogs International, 2020; Reightler, 2018; Stace, 2016; Winkle, Herlache-Pretzer, Ni, & Jones, 2020). Guide dogs stop at curbs to help notify their handler of a change in street level and to help them prepare to cross streets safely. Guide dogs must demonstrate selective disobedience to ensure safety of their handler by ignoring their handler's cues in potentially dangerous situations (Audrestch et al., 2015).

A facilitated guide dog differs from a traditional guide dog in that the dog, child, and parent work together as a triad team in which the dog alerts the team to environmental obstacles and safety hazards while the parent acts as the navigator (Stace, 2016). Facilitated guide dogs are often used with younger children while they learn how to work with their guide dog until they transition to a traditional guide dog duo once they become older, more mature, and more independent (Stace, 2016).

Hearing dogs.

Hearing dogs assist in alerting individuals who are deaf or hard of hearing to various noises and sounds including smoke alarms, doorbells, telephones, alarm clocks, school bells, emergency sirens, and of people calling their names (Rintala et al., 2008; Stace, 2016). Hearing dogs are trained to alert their handler by touching them with their paw or nudging them with their nose. After alerting their handler to the noise, the dog will lead their handler to the source of the noise; if the noise is the fire alarm, the dog will lay down or respond in a specialized way to alert the handler of the emergency situation (Audrestch et al., 2015).

Service dogs.

Service dogs are uniquely trained to complete physical and medical tasks that individuals with disabilities may have difficulty completing due to physical and mental impairments (Rodriguez, Bibbo, Verdon, & O'Haire, 2019). These dogs are individually trained and learn tasks tailored to meet the individual's needs. Service dogs trained in multiple assistance roles are considered dual-purpose dogs (Audrestch et al., 2015). Examples of the tasks that service dogs assist individuals with include dressing/undressing, toileting, item retrieval, activating light switches/accessible door switches, opening/closing doors, propelling wheelchairs, acting as a brace during various transfers including bed to chair/sit to stand, and acting as a brace/stable support during bathing and showering (Onsager, 2011; Stace, 2016).

Mobility dogs.

Assistance dogs for individuals with physical disabilities may be trained as mobility dogs to retrieve items for their handler, pull a wheelchair, open/close doors, etc. Mobility dogs are a specific type of service dog that aid individuals with mobility impairments to improve their ambulation and functional mobility, increasing their access and functioning in both their homes and communities (Fairman & Huebner, 2008). Mobility dogs are trained to help individuals maintain their balance and stability during ambulation to improve their handler's independence and safety while decreasing risk of falls. They help their handler maintain positioning to promote improved body mechanics to reduce risk of injury and facilitate mobility (Rintala et al., 2008). Mobility dogs may be trained to perform a task known as bracing; bracing provides assistance to the handler while standing and while completing transfers (Camp, 2001). Mobility dogs may also be

trained to move/propel mobility aids and equipment such as propelling a wheelchair for their handler and/or moving their handler's cane into reach (Rintala et al., 2008).

Alert dogs.

Individuals with medical conditions that demonstrate symptoms prior to onset may use alert dogs to notify them of symptoms to ensure their safety. Often medical alert dogs detect changes in odor that is undetectable to humans (Audrestch et al., 2015). According to Krawczyk (2017), "their presence alone can alleviate stress or fear. There have been instances when the service dog has a skill that medical science cannot provide. At times, the dog can be a better intervention than those provided by medical equipment," (The Role of the Healthcare Professional, para. 3). They are trained to alert their handler to changes in medical conditions so that the handler is able to take necessary steps to ensure their safety during the medical episode and avoid emergency episodes, such as a collapse (Pesterfield, Guest, Brainch, & Swanson, 2015). Diabetic alert dogs are specifically trained to detect changes in blood sugar and alert the individual during hyperglycemic or hypoglycemic episodes. (Gonder-Fredrick, Rice, Warren, Vaida, & Shepard, 2013; Rooney, Morant, & Guest, 2013; Stace, 2016). Seizure alert dogs are specially trained to recognize changes in an individual's scent and then alert the individual of an oncoming seizure. Depending upon their training, these dogs may alert their handler by either licking, vocalizing (whining/barking), jumping on them, or staring them in the eyes (Brown & Goldstein, 2011; Martos Martinez-Caja et al., 2019; Wells, Lawson, & Siriwardena, 2008).

If a medical alert dog works for a child, the dog may notify the child and/or parent of an oncoming medical episode (Audrestch et al., 2015; Stace, 2016). For example,

seizure alert dogs may be trained to bark to alert parents that the child is having a seizure while playing outside or in another room. Seizure alert dogs may also be trained to nudge the child in a specific manner and/or activate a pre-programmed alarm to call for parents and/or medical assistance.

Response dogs.

Seizure response dogs respond to the individual during and after a seizure; they are trained to specifically lie next to a person during a seizure to keep them safe and prevent them from injury (Kiriakopoulos, 2019; Kirton, Winter, Wirell, & Snead, 2008; Stace, 2016). A seizure response dog can be trained to break an individual's fall at the beginning of a seizure by positioning themselves between the individual and the floor to prevent injury. Yet other dogs assist children and their parents by retrieving medication/telephone post seizure, act as a brace to support the child while standing post seizure, and provide comfort to the child (Brown & Goldstein, 2011; Kiriakopoulos, 2019; Kirton et al., 2008; Stace, 2016). Assistance dogs can be dually trained to be both a seizure alert and a seizure response dog.

Psychiatric service dogs.

Psychiatric assistance dogs (PADs) are service dogs that are trained to assist an individual with a diagnosed mental health condition such as post-traumatic stress disorder (PTSD), schizophrenia, bipolar disorder, depression, or anxiety (Lloyd, Johnston, & Lewis, 2019). Despite limited published research regarding the types of dogs and specific services PADs provide, Lloyd and colleagues (2019) found that PADs perform multiple tasks to improve their handlers' mental health and functional participation in their daily lives. These tasks may include providing nudging/pawing to reorient the handler to the

present time from dissociations or hallucinations, interrupting undesirable behavior, providing constant body contact to decrease anxiety, and providing spatial distance by blocking others from coming into close contact with the handler. PADs differ from ESAs in their level of training. ESAs are pets that have not received any specific training to perform a function for their owners; however, their presence has been deemed necessary by a mental health professional to provide emotional support to their owner (Lloyd et al., 2019; Schoenfeld-Tacher, Hellyer, Cheung, & Kogan, 2017; Yamamoto, Lopez, & Hart, 2015).

Autism assistance dogs.

Autism assistance dogs are a relatively novel type of pediatric assistance dog. The first report of the official training and placement of an autism assistance dog was in 1997 (Burrows, Adams, & Millman, 2008). One of the main tasks that autism assistance dogs are trained to do is to prevent a child from bolting (Berry et al., 2013; Burrows et al. 2008; Good Dog Autism Companions, 2017; O'Haire, 2013). Many children with ASD have impaired safety awareness and will wander and escape from their caregivers, especially in public places, posing a serious safety threat (Arky, 2019; Good Dog Autism Companions, 2017; Stace, 2016). Many autism assistance dog teams function in a triad team composed of the dog, child, and parent. The teams often use a dual leash system in which the child is tethered to the dog by a waist leash and the parent holds another leash that is also connected to the dog to decreased bolting (Good Dog Autism Companions, 2017; Stace, 2016). Autism assistance dogs are also trained to help comfort the child in order to improve bedtime routines and sleep hygiene (Berry et al., 2013; Stace, 2016). Autism assistance dogs are often trained to provide sensory input to individuals with

autism and may be trained to interrupt undesirable behaviors (Good Dog Autism Companions, 2017).

Benefits of assistance dogs.

The provision of numerous benefits provided by assistance dogs has been researched and reviewed by multiple disciplines. The most notable benefits, for both adult and pediatric users of assistance dogs, cited throughout the literature amongst majority of the disciplines, includes increased independence, participation, and safety across various contexts (Allen & Blascovich, 2006; Audrestch et al., 2015; Stace, 2016). Assistance dogs improve an individual's independence in completing activities of daily living while simultaneously improving their participation in completion of daily tasks, roles, and routines (Audrestch et al., 2015; Camp, 2001; Fairman & Huebner, 2008; Hall, MacMichael, Turner, & Mills, 2017; Herlache-Pretzer et al., 2017; Mackinnon, 2014; Stace, 2016; Winkle et al., 2012). For example, a service dog may be trained to open doors -manual or accessible- for their handler. In the past, the handler most likely would have had to rely on assistance from others- paid or unpaid- in order to access these opportunities. The service dog improves the handler's functional independence by providing direct access, by opening doors, to activities and services in the community that the handler may not have been able to independently access prior to having their service dog. (Camp, 2001). Increased independence helps promote increased competence, empowering individuals to participate in more activities such as meal preparation, shopping, work, and travelling (Herlache-Pretzer et al., 2017). One of the biggest assets of the use of assistance dogs includes their ability to improve one's functional mobility, improving the individual's ability to access and participate in various activities and

environments. Participation improvements have been demonstrated in both home and community activities as well as in social contexts; one notable area of improvement in community participation includes increased school and employment attendance (Allen & Blascovich, 2006; Mackinnon, 2014).

Assistance dogs also help facilitate improved social participation, allowing individuals to interact with people in the community and to experience a variety of different social experiences and relationships. Individuals that use assistance dogs have reported that their dogs may create a presence of comfort and familiarity, allowing the individual to be more approachable to others in public. This in turn, often elicits conversations and increases social participation in public environments while also serving the dual purpose of educating the general public about the role of assistance dogs in one's daily lives. A qualitative study analyzing the effects of guide dog use on an individual's occupational performance discovered that the dog had a large impact on their handler's social participation,

> socially, participants have started meeting new people in public because their guide served as a conversation starter. Many people stop to talk with them, and some participants reported that they enjoyed this new social interaction because it has allowed them to meet new individuals (Reightler, 2018, p. 48).

Children with ASD typically have difficulty with social communication and other human interaction due to difficulties with understanding/interpreting social cues. Recent studies have demonstrated dogs' ability to aid children with ASD with social participation. In a study analyzing children with ASD's preference for interaction with and responsiveness to either dogs, people, or toys, the children chose to interact with the dog most frequently (Prothmann, Ettrich, & Prothmann, 2009). Data demonstrates that the children interacted with the dog at least twice as often as with the other person and

sixteen times as often as with the toy (Prothmann et al., 2009). Recent literature has indicated dogs may act as a social buffer because children with ASD are better able to comprehend non-human animal communication compared to human communication; children with ASD may find it easier to predict and process the dog's interactions in the manners in which dogs communicate their intentions (Camp, 2001; Prothmann et al., 2009). This ability to understand/communicate with the dog may occur as a result of decreased stress responses experienced by the child while communicating with the dog (Burrows, 2007; O'Haire, 2013; Viau et al., 2010). The decreased stress response may result from the increased consistency in the dog's interactions compared to interactions with other children which often yield unexpected results (O'Haire, 2013; Solomon, 2010; Viau et al., 2010). The environmental, physical, and behavioral consistency of animals may help decrease stress caused by social interactions for children with ASD, providing them more opportunity dedicated towards focus on processing and understanding the social implications and appropriate responses (O'Haire, 2017; Solomon, 2010; Viau et al., 2010; Wilkinson, 2010). The presence of animals, compared to toys, during free play between children with ASD and their typically developing peers promotes an increase in social behaviors and social participation by increasing the initiation of social interactions, prosocial behaviors, positive affect, and appropriate social responses amongst children with ASD (O'Haire, McKenzie, Beck, & Slaughter, 2013). Carlisle (2015) found that children with ASD whose families owned pets demonstrated increased assertive social skills in comparison to children with ASD living without pets. This may be a significant factor contributing to the trend of families with children with ASD towards obtaining a

pet and a potential correlation between the presence of increased social skills amongst children with ASD in dog owning families (Carlisle, 2014; Carlisle, 2015).

Provision of safety is an invaluable benefit of assistance dogs that benefits both physical and psychological health; it aids in improving the user's physical safety during engagement in occupations while decreasing both the user and the caregiver's anxieties regarding potential of physical harm during engagement in occupations. Decreased rates of depression, anxiety, and tension have been associated with the obtainment, use, and integration of assistance dogs into one's daily life. Other psychological benefits have also been reported through both individual and parental reports, including increased confidence, security, self-assertiveness, advocacy, and freedom (Audrestch et al., 2015).

Burrows and colleagues (2008) conducted a qualitative ethnographic study to determine the effect of assistance dogs on safety and well-being for children with ASD. The most impactful service reported by parents of children with ASD was physical safety; the assistance dog ensures the child's physical safety by preventing them from bolting, alerting the parents of attempted wandering, and waking up the parents during the night if the child woke up or was injured. The assistance dog's safety alerts decreased stress levels in both the parents and the child, while enabling the parents to give the child more independence to engage in activities with the assurance that the child was always being closely monitored. This also enabled families to participate in more community outings with the child such as grocery shopping and participation in family leisure activities. Parents also reported increased interaction with community members; they felt that they were more approachable when the dog was present and that it served as an

opportunity to educate individuals about ASD and autism assistance dogs, promoting increased acceptance and understanding in society.

The increase in independence associated with the use of assistance dogs reduces caregiver stress and provides direct financial benefits across the lifespan (Allen & Blascovich, 2006; Fairman & Huebner, 2008). A study conducted by Allen and Blascovich (2006) concluded that the use of assistance dogs significantly decreases both the amount of paid and unpaid assistance required by individuals with physical disabilities and mobility impairments:

> an expected canine service period of 8 years, and $8, $10, and $12 per hour for paid human assistance…actual savings begin to accrue during the second year and increase to $60,000 or more after 8 years as a function of human assistance costs per hour. In addition to dollar savings, the presence of a service dog was also associated with a decrease of approximately 25 (64%) biweekly unpaid assistance hours, thereby diminishing a substantial time and economic burden for family and friends who were caregivers (p. 1004).

Occupational therapy practitioners Fairman and Huebner (2008) examined the effect of assistance dogs on individuals with disabilities through an occupational therapy point of view on 202 assistance dog handlers. Each handler completed a 31-question survey containing both open and closed-ended questions to analyze functional assistance, social functions, and emotional functions of assistance dogs. Results indicated the majority of the dogs provided functional assistance in home and community mobility, obtainment/use of communication devices, shopping, cleaning, and play/leisure activities. Participants reported their assistance dog functionally assists them with 84.2% of community mobility and with 78.2% of house mobility. Majority of handlers indicated their assistance dog provided increased feelings of safety and increased their social interactions in public. Collectively, the vast majority of benefits provided by the use of

and incorporation of assistance dogs drastically improves one's overall well-being and QOL.

Autism Spectrum Disorder (ASD)

Introduction to ASD.

The prevalence of ASD continues to rise in the United States each year. In 2012 approximately 1 in 69 children were living with a diagnosis of ASD (Centers for Disease Control and Prevention, 2019b). As of 2018, ASD affects approximately 1 in 59 children (Centers for Disease Control and Prevention, 2019b). Males are four times more likely to be living with ASD compared to females; 1 in 37 males compared to 1 in 151 females are living with a diagnosis of ASD (Centers for Disease Control and Prevention, 2019b). Neurodiversity is the idea that humans are not all neurologically identical, but rather neurological differences such as ASD are the result of natural genetic variations in the human genome that diversify our species (Atherton et al., 2019; Schaaf et al., 2010). According to Kapp (2013), "neurodiversity advocates promote subjective well-being and adaptive rather than typical functioning, such as reliable, but not necessarily spoken, communication" (p. 60). As defined from a neurodiverse perspective, autism is a biological difference amongst individuals that should be acknowledged as a component of natural human variation in which the associated differences should be honored (Atherton et al., 2019; Lurie Center for Autism, 2019). It is important to note that differences do not necessarily equate to deficits but rather differences may appear as deficits because children with ASD must adapt to a world that is designed to promote optimal functioning for neurotypical individuals (Atherton et al., 2019; Kapp et al., 2013). According to the Lurie Center for Autism at MassGen for Children,

> each child with autism spectrum disorder is a unique individual; people with ASD differ as much from one another as do all people. Children and adults with ASD may speak or interact with others. They may have good eye contact. They may be verbal or non-verbal. They may be very bright, of average intelligence or have cognitive deficits (2019, para. 20).

This powerful quote embodies the foundational perspective in which this study is built, recognizing that individuals with ASD behold unique strengths, weaknesses, and differences just like neurotypical individuals. Hence practitioners' and families' focuses should be on promoting the child's subjective well-being. With that said, proponents of the neurodiversity movement urge interventions to be tailored towards the child's specific interests and strengths in order to foster adaptive skills to positively address challenges that they may be facing (Kapp et al., 2013).

DSM diagnostic criteria.

The DSM-V is a handbook published by the American Psychological Association that is internationally used by healthcare professionals created to establish universal language and reliable diagnoses. The DSM outlines descriptions, symptoms, and diagnostic criterion for mental disorders. The DSM-VDSM and contains significant changes in diagnostic criteria for Autism Spectrum Disorder (American Psychiatric Association, 2013b).

In the DSM-IV, autism was considered one of four pervasive developmental disorders (PPD). The DSM-V outlines more specific and evidenced based criterion for diagnosing autism related disorders; individuals diagnosed with any of the four PDDs from the DSM-IV fit the new criteria for autism spectrum disorder under the new DSM-V criteria (American Psychiatric Association, 2013a). The diagnostic criteria for autism spectrum disorder (ASD) under the DSM-V are as follows:

- "Persistent deficits in social communication and social interaction across multiple contexts," (Centers for Disease Control and Prevention, 2019a, para. 3).
- "Restricted, repetitive patterns of behavior, interests, or activities," (Centers for Disease Control and Prevention, 2019a, para. 7).
- "Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)," (Centers for Disease Control and Prevention, 2019a, para. 12)
- "Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning," (Centers for Disease Control and Prevention, 2019a, para. 13).
- "These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level," (Centers for Disease Control and Prevention, 2019a, para.14).

The DSM also outlines three levels of severity of ASD. Level 1 is categorized as *requiring support*. Individuals with a severity of level 1 have difficulty initiating and responding to social interactions with others. With the use of supports, difficulties are significantly minimized, but without establishment and utilization of supports, deficits cause significant social impairments (American Psychiatric Association, 2013b; American Psychiatric Association, 2013a; Carpenter, 2013). Level 2 is categorized as

requiring substantial support. Individuals with level 2 ASD have significant deficits in communication skills; even with the implementation of supports, impairments are apparent during social interactions (American Psychiatric Association, 2013b, 2013a; Carpenter, 2013). Individuals with ASD of severity level 3 are categorized as *requiring very substantial support* and exhibit severe deficits in social communication which substantially impairs their ability to initiate and respond to social advances (American Psychiatric Association, 2013b, 2013a; Carpenter, 2013).

Common symptoms and behaviors.

There are two main categories of symptoms of ASD, including deficits in social communication and repetitive restrictive patterns of behavior (Centers for Disease Control and Prevention, 2019a). Characteristic symptoms of deficits in social communication include impairments in social-emotional reciprocity, nonverbal communicative behaviors/gestures during social interactions, and the establishment/maintenance/insight of relationships with others (American Psychiatric Association, 2013a; Carpenter, 2013). Restrictive and repetitive patterns of behavior are often exemplified by rigidity/inflexibility in thinking patterns, aversion to change, fixated interests, and hyper or hypo responsivity to sensory input (American Psychiatric Association, 2013b; Carpenter, 2013). Common behaviors exemplified by individuals with ASD include hand flapping, aversion to loud noises, scripting, rocking, echolalia, difficulties with transitions, aversion to certain textures, perseveration, visual fixation on lights/movements, excessive smelling and touching of objects, inappropriate expression of emotion, and lack of observation/response to contextual clues (Carpenter, 2013; Centers for Disease Control and Prevention, 2019a; Hyman & Levy, 2013).

Link between occupational therapy and ASD.

Occupational therapy is the second most frequent service provided to individuals with ASD (Interactive Autism Network, 2011; Tomchek et al., 2015). Individuals with ASD often receive occupational therapy services to address

> difficulties in areas of occupation such as self-care; IADLs; sleep; functional and pretend play; leisure pursuits; social participation; education and work performance; and performance skills, performance patterns, and client factors such as sensory integration and modulation, self-regulation, praxis, and motor imitation (Tomchek et al., 2015, p. 2).

A client-centered approach is used to determine the individual's goals via communication with the individual, family members, caregivers, and educators. Interventions are uniquely designed to help individuals in achieving these goals to improve engagement in meaningful occupations to promote their health, well-being, and participation in daily life (Tomchek et al., 2015).

Common treatments.

Treatments for ASD typically address communication, social, and behavioral difficulties associated with ASD (Kopelman, Lindgren, & Wacker, 2020; Ospina, Seida, Clark, Karkhaneh, Hartling, Tjosvold, Vandermeer, & Smith 2008; Tomchek et al., 2015). Types of treatments include developmental interventions, behavior and communication interventions, dietary approaches, medication, and complementary and alternative medicine (Ospina et al., 2008). Research has demonstrated that early intervention (EI) for children with ASD can significantly improve their learning and communication skills (Centers for Disease Control and Prevention, 2019c; Corsello, 2005; Lurie Center for Autism, 2019; National Institutes of Health, 2017). The human brain is the most malleable at a young age; thus early intervention is imperative in

providing the child with services to promote their learning, progress, and potential throughout the life span (Case-Smith, 2010; Case-Smith & Arbesman, 2008; Nahmias, Pellecchia, Stahmer, & Mandell, 2019; National Institutes of Health, 2017). Early intervention programs are offered to children from birth to three years of age and typically incorporate family training/education, speech therapy, physical therapy, occupational therapy, nutrition services, assistive technology services, psychological services, and audiology services (Center for Parent Information and Resources, 2017; National Institutes of Health, 2017). Early intervention addresses various domains including cognitive, physical, communication, social-emotional, and self-help skills (Case-Smith, 2013; Case-Smith & Arbesman, 2008; Center for Parent Information and Resources, 2017).

Applied Behavioral Analysis (ABA) is one of the most commonly used behavior and communication approaches for treating ASD (Centers for Disease Control and Prevention, 2019b). ABA therapy is based upon the medical model of disability which views ASD as a "disease" that needs to be "cured," (Shyman, 2016). ABA is a controversial method of treatment due to the intensity and the goals of the method (Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Shyman, 2016). The goal of ABA is to increase a child's positive behaviors and independence by teaching typical behaviors associated with the child's chronological age (Shyman, 2016). The four general principles in which ABA is based upon are observable behaviors, analysis and measurement of relations between environments and behaviors, single subject design demonstration of environments and behaviors, and socially relevant behaviors (Kopelman et al., 2020). Many ABA programs emphasize the teaching of new behaviors and

generalizing them across settings to promote socially relevant behaviors and decrease problem behaviors. There is not one specific approach used in ABA therapy but rather, various techniques and approaches are used depending on the child and severity levels of the behaviors (Kopelman et al., 2020). According to a meta-analysis analyzing the effectiveness of behavioral and developmental interventions for ASD, all the studies that were reviewed and that compared discrete trial training to no treatment reported statistically significant results. Some of the studies also indicated that positive motor and functional outcomes resulted from the use of ABA therapy (Ospina et al., 2008).

Many children with ASD also benefit from other therapies including occupational therapy (OT) and speech language pathology (SLP) (Centers for Disease Control and Prevention, 2019c; Kopelman et al., 2020). SLP helps children improve their verbal and non-verbal communication skills (Kopelman et al., 2020). OT helps children learn self-help skills and adaptive techniques to promote increased independence in their activities of daily living (Kopelman et al., 2020). Case-Smith and Arbesman (2008) identified six main categories of evidence based occupational therapy intervention for children with ASD, "(1) sensory integration and sensory-based interventions; (2) relationship-based, interactive interventions; (3) developmental skill-based programs; (4) social cognitive skill training; (5) parent-directed or parent-mediated approaches; and (6) intensive behavioral intervention," (p. 416). Many children with ASD have sensory processing difficulties and receive sensory integration therapy and/or sensory-based interventions. A systematic review of twenty-three studies by Watling and Hauer (2015) discovered moderate evidence that supported the use of Ayres Sensory Integration (ASI) to improve occupational performance and participation in daily activities amongst children with

ASD. The review also found mixed results regarding the effectiveness of the use of sensory-based interventions (SBI's) (Watling & Hauer, 2015). Another systematic review was conducted by Case-Smith, Weaver, and Fristad (2015) to analyze the effectiveness of sensory integration therapy and sensory-based interventions as currently practiced and reflected in the literature. Researchers found minimal positive effects for children receiving SBI's (Case-Smith et al., 2015). The review further revealed randomized control trials using sensory integration therapy generated positive effects, but it is important to note that these studies were small and additional trials using standardized protocols must be done to validate this finding (Case-Smith et al., 2015).

Often social skills training is used during both occupational and speech language therapy to help children with ASD better understand and learn socially appropriate interaction skills. According to a systemic review of 79 treatment studies by Matson, Matson, & Rivet (2007), common methods of social skills intervention can be categorized into five general groupings: modeling and reinforcement, peer-mediated intervention, reinforcement schedules and activities, scripts and stories, and miscellaneous. A meta-analysis of 38 studies conducted by Wang and Spillane (2009) further discovered that additional interventions to address social skills include social stories, video modeling, cognitive behavioral training, theory of mind training, and pivotal response training. In a study conducted by Becker, Rogers, and Burrows (2017), children with ASD that received animal assisted social skills training exhibited less socially inappropriate behaviors and challenges, decreased amounts of repetitive behaviors, and increased amounts of socially appropriate interactions and responses with others.

Dogs and ASD.

Currently, there are three distinct relationships between dogs and children with ASD. The first relationship is pet dog ownership amongst families with children with ASD. The second relationship is the use of therapy dogs in animal assisted activities and/or animal assisted therapy during skilled therapy sessions for children with ASD. The third relationship between dogs and ASD includes autism assistance dogs. The most impactful finding of the relationship between dogs and children with ASD which has been demonstrated as an occurrence in all three types of relationships is the improvement of social skills (Carlisle, 2015; O'Haire, 2013).

Animal Assisted Intervention (AAI)

Grigore and Rusu (2014) conducted a study analyzing the impact of a combination of two treatment interventions for children with ASD, the social story method and animal assisted intervention, on communication and social interactions. The results of the study indicated that the presence of a therapy dog during the social story intervention increased the frequency of social interactions while decreasing the number of social prompts/cues required to elicit appropriate social interactions amongst children with ASD. This may demonstrate the integral role that dogs may have in allowing children with ASD to participate in social interactions with their typically developing peers.

An ethnographic study, conducted by Solomon (2010) , demonstrates a dog's role in supporting children with ASD communication, emotional connections, and participation in daily life activities. Solomon analyzed two case studies based on a pilot study that she was conducting on AAT for children with ASD. One of the children

participated in AAT with therapy dogs while the other child had their own assistance dog. The major themes identified through both children's experiences include increased social interaction and social participation. Interactions with the dogs provided further opportunities to practice social actions, in both linguistic and nonlinguistic manners, and opportunities to coordinate these actions with other individuals. These interactions increased both children’s social competence and confidence. Child two's service dog additionally facilitated increased community engagement, increased participation in daily life activities, and increased familial participation.

Autism Assistance Dogs

The integral term supporting this phenomenon is the human-animal interaction. Overtime, humans have evolved to develop a secure, calming attachment to other social, friendly animals, such as dogs (Carlisle, 2015). This attachment may facilitate a reduction in stress associated with social interactions amongst children with ASD. Autism assistance dogs have been shown to decrease levels of a stress hormone, cortisol, in children with ASD. Researchers from the University of Montreal and from McGill University designed a tri phase exploratory study to measure the effects of service dogs on salivary cortisol secretion in children with ASD. The results of the study proved to be statistically significant and indicated that the presence of an assistance dog decreased cortical awakening response (CAR) by 48%, corresponding to a decrease in disruptive and aversive behaviors (Viau et al., 2010). Parental and child account of personal experiences with their autism assistance dog also report that their assistance dog decreases stress for the child, parents, and entire familial unit, especially during novel experiences, social interactions, new environments, and public outings (Mackinnon,

2014). Additional benefits include increased social reciprocity and ability to form social relationships, increased communication, increased emotional regulation, increased sensory regulation, and increased participation in home and community activities (Mackinnon, 2014).

Occupational Therapy (OT)

Occupational therapy practitioners help individuals across the lifespan participate in the things they need and want to do in their daily lives. Common occupational therapy services include comprehensive evaluations of the client's home and other environments (e.g., workplace, school), recommendations for adaptive equipment and training in its use, and guidance and education for family members and caregivers (American Occupational Therapy Association [AOTA], 2014; AOTA, 2020a; Goodrich & Garza, 2015). Occupational therapy practitioners have a holistic perspective, in which the focus is on adapting the environment to fit the person, and the person is an integral part of the therapy team (AOTA, 2014; AOTA, 2020a). Treatment is client-centered, and therapists collaborate with the client and their families throughout the therapeutic process. Occupational therapy practitioners often work with individuals with ASD to improve participation in the areas of "self-care; IADLs; sleep; functional and pretend play; leisure pursuits; social participation; education and work performance; and performance skills, performance patterns, and client factors such as sensory integration and modulation, self-regulation, praxis, and motor imitation," (Tomchek et al., 2015, p. 2).

Occupations are purposeful, goal-directed activities that provide meaning and value to an individual; they are central to a person's identity and foster a sense of competence (AOTA, 2014). The Occupational Therapy Practice Framework: Domain and

Process, 4th edition (OTPF-4) is an official document that delineates the central concepts/components that ground occupational therapy practice to define its contributions to an individual's health/well-being, define areas of practice/expertise, and to define the profession's theoretical underpinnings (AOTA, 2020b). There are six types of occupational therapy treatment interventions, including occupations and activities, interventions to support occupations, education and training, advocacy, group interventions, and virtual interventions (AOTA, 2020b). Occupations may be used as either a means or an end during treatment sessions. As described in a fundamental article by Gray (1998), using occupations as a means during therapy involves the use of occupations during treatment to produce a therapeutic change to improve an individual's skills and abilities required to participate in another occupation. Feeding a dog during an occupational therapy session to work on an individual's fine motor skills, grip strength, manipulation of containers, etc. is an example of using occupations as a means during therapy to improve the individual's skills required for personal meal preparation and feeding. Utilizing occupations as an end involves the use of the actual occupation that the individual would like to improve their competency in during a therapy session (Gray, 1998). Feeding a dog during an occupational therapy session to improve an individual's competency in pet care is an example of the use of occupation as an end. Preparatory methods are methods that are used during therapy to help prepare an individual for occupational performance and competence (AOTA, 2014). One type of preparatory method is assistive technology and environmental modification (AOTA, 2014).

Participation.

Participation is the foundation of occupational science and is an integral component of occupational therapy. Participation in various aspects of life contributes to individuals' function, independence, and QOL (Baron, Hawrylyshyn, Hunt, & McDougall, 2019). The word "participation" is extremely broad and has many different definitions, even within the field of occupational therapy. As defined in the foundational text about occupational performance and participation in occupations, Law (2002) defines *participation* was derived from a Latin origin- *particeps* and *pars + capere*, meaning part-take and shared-in (Oxford Advanced Learner's Dictionary, 2020). The World Health Organization (WHO), historically defines participation as "involvement in a life situation," (World Health Organization, 2001, p. 10). The Occupational Therapy Practice Framework (OTPF-4) uses the definition from WHO while further delineating that "participation naturally occurs when clients are actively involved in carrying out occupations or daily life activities they find purposeful and meaningful. More specific outcomes of occupational therapy intervention are multidimensional and support the end result of participation,"(AOTA, 2020b, p. 5). Participation is typically active but also may be passive if/when an individual is listening, observing others, or observing the environment (Khetani & Coster, 2014). Active participation is important because the brain is able to experience, learn, understand, and integrate information more efficiently and effectively when an individual is engaged in the task (Parham & Mailloux, 2015). Social participation is extremely important for people throughout the lifespan and the term is often used interchangeable with the term participation. According to Gillen & Schell (2014), social participation is the, "interweaving of occupations to support desired

engagement in community and family activities as well as those involving peers and friends," (p. 607). Participation also occurs in both formal and informal activities that occur throughout one's everyday life (Law, 2002).

Although the term participation may be defined differently in different areas of practice and contexts, the commonality shared by these definitions resides in a set of essential characteristics. Essential characteristics of participation include that the activity in which one partakes is meaningful and goal-oriented while also providing a sense of challenge and a sense of mastery (Law, 2002). A qualitative research study analyzing the lived experience of participation amongst children with disabilities yielded four themes describing/defining the meaning of successful participation: having fun, feeling successful, doing and being with others, and doing things myself (Heah, Case, McGuire, & Law, 2006). The study also found that successful participation amongst children with disabilities is influenced by environmental supports and barriers and personal supports and barriers. Environmental supports and barriers were influenced by community program design, parent values and preferences, parent vigilance, and social and physical support (Heah et al., 2006). It is integral to understand the value and importance of participation in an individual's life to understand how participation or lack of thereof can impact an individual. There are less opportunities for children with disabilities to participate in community programs and social activities, especially outside of school (Chakraborty, Rao, Shenoy, Davda, & Suprabha, 2019; Heah et al., 2006; Jaffe & Cosper, 2015). Furthermore, many children with disabilities interact with adults far more frequently than with their peers (Jaffe & Cosper, 2015). Often many of these adults are either their teachers and classroom aids or family members since there are less

social/community opportunities outside of school that accommodate children with disabilities (Jaffe & Cosper, 2015). With that said, participation is a predominant focus of occupational therapy, especially for children with disabilities.

OT theory.

Theory is used to inform occupational therapy practice and to guide practitioners when creating treatment plans and designing client-based interventions. According to Oberle (2017), "it is imperative to understand theory and frames of references to be able to justify why you are implementing any given treatment strategy," (p.12).

Occupational adaptation.

Occupational Adaptation Model (OAM) views an individual as the performer of occupations, activities that are self-perceived as meaningful, via active participation within one's natural environment (Schultz & Schkade, 1992). There are three basic tenants of this model, including the person, the occupational environment, and the interaction of both components to influence the occupation (Schultz & Schkade, 1992). According to Schultz & Schkade (1992), an individual's desire to participate in an occupation and to demonstrate relative mastery of the occupation creates an occupational response. This occupational response is also influenced by the challenges and performance expectations that the occupational environment poses in conjunction with the role expectations created via the interaction between the person and the environment (Schkade & Schultz, 1992). Schkade and Schultz (1992), explain that in order to meet these demands, the individual must produce an adaptive response to the occupational challenge to increase their mastery of the occupation.

OAM supports the use of assistance dogs for children with ASD. The child is the performer of occupations within their natural environment. Their natural environments may consist of the home, school, community, etc. The interaction between the child and the environments in which the child attempts to participate in occupations influence the child's ability to successfully participate and to master the occupation. The child's desire to participate in the occupation and the interaction between the child and the demands of the environment facilitates an occupational response. Since many environments are designed to meet the needs of neurotypical children, many children with ASD must produce an adaptive response in order to successfully participate in the occupation in the natural environment. The use of an autism assistance dog may be an appropriate adaptive response for children with ASD to increase participation and mastery of occupations while improving the child's ability to meet role expectations.

It is within the domain of occupational therapy practitioners to assist individuals in adapting their roles, environments, and/or occupations to improve their occupational performance, role competence, and mastery of occupations. Occupational therapy practitioners may use a rehabilitative approach to assist individuals in improving their participation, in maximizing their independence, and in increasing their occupational performance (AOTA, 2014; Baum & Law, 1997; Goodrich & Garza, 2015; Gray, 1998). This approach is used to help clients to regain or maintain their prior level of functioning or to compensate for their deficits to improve their occupational performance and functioning. Adaptive equipment is a type of assistive technology that can aide individuals in increasing their participation and independence during occupational performance. According to Goodrich and Garza (2015), an assistive technology device

"is any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities," (Assistive Technology Defined, para. 1). Hence, autism assistance dogs can be considered a form of assistive technology for individuals with ASD (Camp, 2001; Goodrich & Garza, 2015; Goodrich et al., 2016). Occupational therapy practitioners have the skills and knowledge to provide clients with assistive technology services which Goodrich and Garza (2015) defined as, "the evaluation of need, the process of acquiring the device, fitting or customizing the device, coordinating the intervention plan, and providing training and technical support to the user and related support personnel," (Assistive Technology Defined, para. 1). Autism assistance dogs are an alternative form of assistive devices that occupational therapy practitioners should consider exploring with appropriate clients (Camp, 2001).

In a study conducted by Isaacson (2013), occupational therapy students completed a fieldwork rotation at Therapeutics, an organization that trains service dogs for individuals with physical disabilities (Isaacson, 2013). One of the themes that was discovered throughout the fieldwork was the use of service dogs as an adaptive technology,

> service dogs are similar to an adaptive technology, and I don't think a lot of people know about it. I think it's probably one of the best ways to be independent and not have to rely on someone else, and yet, the person also has a companion, (Isaacson, 2013, p. 6).

This finding further supports the use of service dogs as adaptive technology for people with disabilities. Specifically, autism assistance dogs can be considered a piece of assistive technology used to facilitate an adaptive response for children with ASD.

Current use of animals in OT.

Occupational therapy practitioners have become increasingly interested in the integration of AAT into their clinical practices with the increase in emerging evidence regarding the use and benefits of animal assisted therapy. An early master's thesis conducted by Lori Buckley at Florida State University supports the increased use of AAT as occupational therapy practitioners have become increasingly educated in its use. Buckley (1999) discovered that most of the 179 occupational therapy practitioners that completed her survey, expressed their support of AAT as a valid treatment modality and majority of the practitioners expressed interest in learning more about AAT (Buckley, 1999). The two most common animals associated with animal assisted therapy include horses and dogs (Chitic, Rusu, & Szamoskozi, n.d.; Winkle, Case, & Wimer, 2018). Hippotherapy is the goal-directed, therapeutic use of horses by occupational therapists, physical therapists, and/or speech language pathologists to improve client functioning across various domains including, but not limited to, strength, endurance, sensory processing, communication, adaptive responses, mobility, coordination, attention, cognition, and balance. Hippotherapy incorporates the use of a dynamic surface to facilitate improved neuromuscular responses to improve client functioning to meet habilitative and rehabilitative goals (American Hippotherapy Association, 2019; Bender & McKenzie, 2008; Yarborough, Stumbo, Yarborough, Owen-Smith, & Green, 2018).

There are three main methods that OTs use to implement AAI and incorporate the use of dogs into their practice; practitioners may work with volunteer therapy dogs visiting organizations to provide skilled therapeutic services, obtain a trained therapy dog from an accredited assistance dog organization, or self-train a therapy dog (Winkle et al.,

2018). The diverse population of clients and the vast array of settings that AAI can be applied to demonstrates the unique position that occupational therapy practitioners have in implementing the use of AAI in the various health care settings and cliental that they work with. Common clinical conditions that OTs have used AAI with include traumatic brain injuries, spinal cord injuries, dementia, cerebrovascular accident, multiple sclerosis, cerebral palsy, muscular dystrophy, cancer, amputation, Parkinson's disease, developmental disabilities, mental health impairments, schizophrenia, and autism spectrum disorder (Buckley, 1999). According to McCune, Esposito, & Griffin (2017), "today, AAIs are practiced with people at all stages of life, and can be found in every conceivable medical or mental health care setting, as well as in schools, universities, workplaces, community centers, juvenile detention facilities, and prisons," (p. 136).

Common AAI that therapists have clients engage in with the therapy dog include feeding, grooming, petting, communicating, playing, and exercising. Therapists report using the dogs as a preparatory method, a means towards improving underlying skills, and/or as ends towards meeting direct pet care related goals (Velde, Cipriani, & Fisher, 2005; Winkle et al., 2018). For example, one therapist may use the dog in the session as a preparatory method to establish therapeutic rapport and facilitate social responses to prepare a client to practice social responses in a human context. Yet another therapist may have the client practice petting the dog to facilitate finger extension, sensory integration, and improved arm range of motion. And even yet another therapist may practice brushing the dog during a session to address the client's goal of resuming direct care of her dog.

Occupational therapy practitioners use dogs as a modality during intervention/treatment sessions designed to create/promote, establish/restore, maintain, modify, and prevent individualized client outcomes based upon their functional goals (AOTA, 2014; Velde et al., 2005). The use of AAI during therapy allows clients to re-learn their meaningful roles of caretaker and pet owner while creating a dynamic shift in the social and physical environments. Some settings that OTs have used AAI within include hospitals, rehabilitation facilities, outpatient clinics, long term care facilities, skilled nursing facilities, schools, and mental health settings.

Current relationship between OT and assistance animal organizations.

Occupational therapy practitioners and assistance animal training organizations share similar interests and goals to increase functional independence amongst individuals with disabilities. Occupational therapist and professor, Mary Isaacson summarizes the work of Sachs-Ericsson, Hansen, & Fitzgerald (2002) which reveals "the purpose of training and placing service dogs is to minimize the impact of a disability on a person's everyday life and everyday occupations," (Isaacson, 2013, p. 1). She goes on to state that, "these occupations may include ADL, IADL, education, work, play, leisure, or social participation," (Isaacson, 2013, p. 1). Through this perspective, one can consider assistance dogs as a form of assistive technology, as assistance dogs are specifically trained to improve functioning in one's daily life (Camp, 2001; Fairman & Huebner, 2008; Herlache-Pretzer et al., 2017; Rodriguez et al., 2019; Stace, 2016; Vincent, Gagnon, Routhier, Leblond, Boucher, Blanchet, & Martin-Lemoyne, 2015; Winkle et al., 2012). It is within occupational therapy's scope of practice to provide individuals with

disabilities assistive technology to improve their functioning and independence in daily activities.

Isaacson conducted a study to analyze the role of occupational therapy students in training service dogs during their level one fieldwork placement in a non-traditional fieldwork setting at a service dog training agency. Data was collected via in-depth, face-to-face, semi-structured interviews with the Executive Director of the training organization, the organization's certified dog trainer, and two OT students. Results indicated that common themes shared amongst both disciplines included similarities between occupational therapy and service dog training/placement, use of adaptation in dog training and placement, opportunities for advocacy, creative thinking, a people-first approach by the students, professionalism, and the use of PEO theory to guide practice. The findings of this study indicate that OT students on fieldwork had a role in training service dogs and is pertinent because it indicates that OT's can have a role in the training and placement of service animals for their clients. These findings further demonstrate the beneficial, integral roles that OT's may have in the service dog profession as an emerging area of practice.

Conclusion

Though this review encompasses only the relevant literature related to assistance dogs, autism spectrum disorder, and occupational therapy, there is an abundance of literature regarding the integration of a combination of either two or three of the previously listed topics. The vast majority of the literature regarding the benefits of assistance dogs on an individual's participation, engagement, occupational performance, and independence with daily occupations focuses on the adult population. The literature

further heavily focuses upon assistance dogs for individuals with physical disabilities and mental health conditions such as PTSD. There was minimal literature that explicitly discussed specific activities of daily living (ADLs) and occupations or domains of occupations that assistance dogs can aid individuals in.

With that said, animal assisted intervention has become increasingly popular and more research has been done to examine its effectiveness. The increasing amount of literature regarding the benefits of animal assisted intervention for children's participation in daily life builds a foundation for further research regarding the potential benefits of pediatric assistance dogs. However, there is minimal research specifically studying the benefits of autism assistance dogs for individuals, let alone the pediatric population. Participation is an integral part of an individual's QOL. The opportunities and abilities of a child to participate in occupations throughout their childhood and adolescence influences their health and well-being throughout their entire life span. Furthermore, I was unable to find any studies analyzing the benefits and use of autism assistance dogs to improve children's participation in their daily lives.

Chapter 3: Methodology

Design and Procedure

This study used a narrative and an interpretive phenomenological approach to explore the experiences of four families who have obtained an autism assistance dog for their child. Two semi-structured, narratively framed interviews were conducted with each primary handler to elicit stories and experiences regarding the process of obtaining the dog, integration of the dog into the child's daily life, and the role of the dog in the child's life. The study was approved by the Ithaca College Review Board for Human Subjects Research and all participants provided informed consent. Upon completion of the study, each participant received a $20 gift card to thank them for their participation and donation of their time.

Methods of rigor were incorporated throughout the study to ensure trustworthiness of data. According to Lincoln & Guba (1985), there are four components of trustworthiness- credibility, transferability, dependability, and confirmability. Credibility was established via data triangulation, investigator triangulation, prolonged engagement, member checking, and persistent observation (Korstjens & Moser, 2018). Conduction of interviews and collection of field notes established data triangulation. The interviews occurred during different times of the day and during periods of time in which the participants had minimal distractions and disruptions (Korstjens & Moser, 2018). To establish investigator triangulation, two members of the thesis committee reviewed all of the data, the third reviewed part of the data, and all thesis committee members participated in an external audit of the identified themes. The committee members held expertise as both faculty members and occupational therapy practitioners with expertise in pediatrics and animal assisted intervention. This serves to ensure accuracy and

reliability of the data analysis (Creswell & Creswell, 2017). All of the researchers collaborated to make further data coding, analysis, and interpretation conclusions (Korstjens & Moser, 2018). Establishment of prolonged engagement criterion occurred via conduction of two interviews with each participant; this served as a method of rapport building with each participant and provided sufficient time for participants to describe their experiences, supported with specific examples, for the collection of rich data (Korstjens & Moser, 2018).

Member checking, the opportunity for participants to endorse or refute a researcher's interpretation of past data, serves as a measure of credibility and validity for the findings of the study (Creswell & Creswell, 2017). Although none of the participants disagreed with the interpretation of the information from the first interview, opportunities for corrections were presented to the participants. Member checking was conducted by briefly reviewing and summarizing the information, concepts, experiences, and themes that emerged from the first interview at the beginning of each follow-up interview (Creswell & Creswell, 2017; Korstjens & Moser, 2018). Prior to starting the second interview participants were then asked follow-up questions based upon unclear sentiments from the first interview.

Credibility was also established via persistent observation which is defined as, "identifying those characteristics and elements that are most relevant to the problem or issue under study, on which you will focus in detail," (Korstjens & Moser, 2018, p. 121). This was performed via the rereading of the transcripts, coding and recoding the data, analyzing and relabeling the themes numerous times (Korstjens & Moser, 2018).

Thick descriptions of the data were provided to maintain transferability (Korstjens & Moser, 2018). Several pieces of rich data and relevant contextual information are reported to provide meaning to the experiences revealed during the study. Throughout the interview process a journal of field notes documented context and observations made during the conversations with the participants (Creswell & Creswell, 2017; Phillippi & Lauderdale, 2018). The primary researcher also logged her biases and questions throughout the process to ensure continual awareness of her prior knowledge, biases, assumptions, and preconceptions to demonstrate reflexivity throughout the study and to remain as objective as possible when analyzing and discussing the results (Korstjens & Moser, 2018). To establish dependability and confirmability, maintenance of an audit trail provided transparency of the research path (Korstjens & Moser, 2018).

Participants

Participants were recruited via a single autism assistance dog training organization. The president of the organization was contacted via email and asked if she would be willing to post a recruitment statement on the behalf of the primary investigator. The president consented and posted the recruitment statement on a private Facebook group for families that have received an autism assistance dog from the organization. Interested participants were instructed to directly reach out to the primary investigator for more information and to enroll in the study. Four primary handlers contacted the investigator and were asked to complete a prescreening questionnaire to ensure that they met the following inclusion criteria for the study: 18 years or older, the parent or primary caregiver of a child with ASD and the primary handler of the child's autism assistance dog, willing to discuss their experiences regarding the impact of the

autism assistance dog. Participants were excluded from the study if they had the autism assistance dog for less than one year prior to the start of the study (this was to ensure that the participants have had the dog long enough to have surpassed the adjustment phase and have established a bond with the dog).

Data Collection and Measures

Participants were required to complete a brief prescreening questionnaire to determine eligibility for the study and to gather background data prior to the first interview (See Appendix E). Each participant completed two interviews with the researcher via video chat. First interviews were designed to elicit narrative explanations in order to obtain more specific information and experiences from each family to inform follow-up questions asked in the second interviews. The first interview gathered information regarding the processing of obtaining the assistance dog and integrating it into the child/family's daily life (See Appendix F). The second interview was a follow-up interview based upon responses and information from the first interview, designed to elicit information regarding the specific duties of the dog, activities that the dog aids the child in, as well as the benefits and challenges associated with having an autism assistance dog (See Appendix F). The second interview was designed to obtain more data to fill in gaps from the first interview and to serve as a member check to improve the validity of data (Portney & Watkins, 2015). An interview protocol was developed in consultation with the thesis committee members in order to prepare for the interview and to guide the researcher in asking questions to ascertain important information related to the research.

Analysis

Interviews were transcribed via TEMI, an automatic transcription service. After the automatic transcription was completed, the primary investigator edited and perfected the transcript to ensure accuracy of transcribed interview data. The data was then manually analyzed by the researcher using an interpretative phenomenological and narrative theory approach (Creswell & Creswell, 2017; Smith, Flowers, & Larkin, 2009). Each recording was transcribed within 24 hours of the interview and read after completion of the finalized transcript to develop questions for the subsequent interview. After the conclusion of all the interviews, the transcripts were read multiple times by the primary researcher to develop an initial list of codes. During the coding process, the transcripts were broken into chunks based on narrative principles to form explanations and to identify themes from within each interview (Creswell & Creswell, 2017). The themes were then compared within cases and across cases.

Weekly data analysis meetings were held between myself and my thesis advisor. Additionally, the other two committee members and an additional faculty member participated in data analysis and investigator triangulation several times during the semester. During the preliminary round of coding fragmented data may have been labeled with multiple codes. A final, single code was determined based upon the fundamental notion of the fragment during the final round of data analysis (Creswell & Creswell, 2017). The first round of coding yielded 18 initial codes. After consultation with committee members and additional reading of the data, these were narrowed into 10 primary codes. The final codes were then aggregated into the following six themes:

- Multi-factored role of autism assistance dogs

- “They are not robots.” Challenges associated with having autism assistance dog
- “What if he was an oxygen tank?” The dog as an adaptive tool
- “Lay on.” The provision of deep pressure and sensory input to improve self-regulation
- Match made in heaven: Considering not only one, but two personalities
- Going, going, gone: The power of the leash in bolting prevention

For the purposes of this thesis, the first theme, “multi-factored role of autism assistance dogs,” is fully explored. Four subthemes were identified which describe the different roles the dogs played in the lives of the families. These are:

- Occupation facilitator
- Symbols of Awareness: Making the invisible visible
- An age appropriate security blanket
- Generators of Familial Participation and Outings: Making the Impossible Possible.

This theme and the four subthemes are fully explored in the results section of the manuscript in Chapter 4. The study yielded an abundance of rich data, exceeding the scope of the following manuscript, requiring me to delve into one theme in detail. I chose to explore “the multi-factored role of autism assistance dogs” in depth because it summarizes the numerous roles that autism assistance dogs play in both the child's and the families’ lives, providing foundational knowledge and novel perspectives required to further understand the value that these dogs provide for the child and family, as occupational beings. Due to the scope of this project and the limitations on space derived

from the publication requirements of the manuscript, the additional themes are not fully explored but are listed with supporting quotes in Appendix G.

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Chapter 4: Manuscript

Abstract

Importance: The World Health Organization recognizes that participation is important to an individual's health and wellbeing; yet children with autism spectrum disorder participate in activities less frequently and with less variety compared to neurotypical children.

Objective: To describe the role of autism assistance dogs in promoting participation and engagement in occupations and activities of daily living (ADLs) of children with autism spectrum disorder.

Design: Two semi-structured interviews from a narrative perspective were conducted with each of four participants. Interpretative phenomenology and Creswell's thematic analysis were used to code and analyze qualitative data.

Setting: Interviews were conducted by video interview.

Participants: Four volunteer parents/primary handlers of their child's autism assistance dog participated in the study. Inclusion criteria: Family must have had an autism assistance dog for greater than one year prior to the start of the study.

Outcomes and Measures: Develop codes and theoretical perspectives to better understand the lived experience of autism assistance dog users.

Results: The role of autism assistance dogs is multifactored; these dogs improve children's participation and engagement across all domains of occupation. All the participants reported that the benefits of autism assistance dogs outweigh the challenges associated with owning/using an assistance dog.

Conclusions and Relevance: Autism assistance dogs are a valuable, alternative form of adaptive equipment for children with ASD that can serve a broad purpose in increasing participation in daily life.

What This Article Adds: The four stories provided reveal that advocating for and assisting families in acquiring an autism assistance dog along with helping families to best use the dogs to support participation of their children is an area of practice and is an appropriate location for occupational therapy practitioners to concentrate interventions in when working with families with children with ASD.

Introduction

This qualitative study assesses the role of autism assistance dogs in promoting participation and engagement in occupations and activities of daily living (ADLs) for children with autism spectrum disorder (ASD). The prevalence of ASD has risen nationally; it currently affects approximately 1 in 59 children in the United States (Centers for Disease Control and Prevention, 2019). Many people with ASD are uniquely functional and have enhanced abilities in varied areas compared to neurotypical individuals.

ASD is a neurological difference amongst individuals; the associated differences should be honored and acknowledged as a component of natural human variation to further diversify the human species (Atherton, Lummis, Day, & Cross, 2019; Lurie Center for Autism, 2019; Schaaf, Benevides, & Zapletal, 2010). According to Kapp, Gillespie-Lynch, Sherman, & Hutman (2013), "neurodiversity advocates promote subjective well-being and adaptive rather than typical functioning," (p. 60). Helping to promote this adaptive functioning of children and their families can be an important role for occupational therapy practitioners working from a strength based and family centered perspective. Neurological differences that are commonly seen in children with ASD may impede spontaneous development of play and can cause difficulties establishing relationships with peers (Hyman & Levy, 2013). However, many children with ASD have a proclivity toward an astute area of interest and have been noted to demonstrate heightened imaginary capabilities, enriched perceptual abilities, and enhanced abilities to process detail (Atherton et al., 2019).

According to the human-animal interaction (HAI) theory, relationships between humans and animals are dynamic and mutually beneficial (O'Haire, 2013). Many individuals with ASD have unique connections and relationships with animals. Animal relationships may be valuable to children with autism because they offer social facilitation, attentional focus, and nonjudgmental companions (Guérin & The Organization for Human-Animal Interaction Research and Education [OHAIRE] Group, n.d.). Children's heightened imaginary capabilities may relate to the increased prevalence of anthropomorphism, the contribution of human characteristics to non-human beings or inanimate objects, amongst children with ASD (Atherton et al., 2019). While individuals with ASD are socially motivated they experience high rates of loneliness (Atherton & Cross, 2018; Atherton et al., 2019; Schaaf et al., 2010). Atherton and colleagues (2019) described how individuals with ASD may identify more closely with animals than they do to humans when seeking social connection. Individuals with ASD may also have heightened anthropomorphic facial processing abilities, strengthening their abilities to connect and socialize in animal-focused contexts (Atherton & Cross, 2018; Atherton et al., 2019; O'Haire, McKenzie, Beck, & Slaughter, 2013; Schaaf et al., 2010).

Neurological differences among children with ASD may influence their responsiveness to sensory stimuli, impacting their behavioral and emotional reactions in both positive and negative ways (Atherton et al., 2019; Hyman & Levy, 2013). This can affect ease of transitions between activities, routines, and/or environments which may impede functioning, engagement, and quality of life (QOL). Self-injurious behaviors and bolting or wandering from safety are commonly exhibited by children with ASD. Approximately 50% of children with ASD wander or bolt from safety; 90% of deaths of

children with ASD 14 years or younger are caused by drowning after wandering or bolting (Law & Anderson, 2011; Solomon & Lawlor, 2013).

It is important to note that differences do not necessarily equate to deficits but rather differences may appear as deficits because children with ASD must adapt to a world that is designed to promote optimal functioning for neurotypical individuals (Atherton et al., 2019; Kapp et al., 2013). In order to enable utmost participation and success, children with ASD often require more therapy and medical care compared to neurotypical children (Tomchek, LaVesser, & Watling, 2015). Occupational therapy is the second most frequently provided service to children with ASD (Tomchek et al., 2015). Interventions are designed to foster occupational engagement and social participation by working on adaptive behaviors, social engagement, play, flexibility, problem solving, and sensory processing. Individualized, comprehensive, client-centered interventions are integral to promoting increased independence and ability to engage in meaningful occupations and daily routines (Tomchek et al., 2015). Hence, occupational therapy services promote the child's subjective well-being and interventions by tailoring activities towards the child's specific interests and strengths in order to foster adaptive skills to positively address challenges that they may be facing (Kapp et al., 2013). Therapy and adaptive equipment may be required to assist children with ASD in adapting to environments and expectations that are more commonly designed for neurotypical families. One type of adaptive equipment that may be helpful is the provision of an assistance dog specifically trained to help children with ASD (Berry, Borgi, Francia, Alleva, & Cirulli, 2013; Camp, 2001; O'Haire, 2013).

Dogs and ASD.

Three distinct relationships between dogs and children with ASD have been identified: pet dog ownership amongst families with children with ASD, the use of therapy dogs in animal assisted intervention during skilled therapy sessions for children with ASD, and autism assistance dogs. The most impactful finding of the relationship between dogs and children with ASD, which has been demonstrated as an occurrence in all three types of relationships, is the improvement of social skills and social interaction with others (Carlisle, 2015; O'Haire, 2013; O'Haire et al., 2013).

Animal assisted intervention (AAI).

As defined by Assistance Dogs International (2020), animal assisted intervention (AAI) is comprised of "various procedures that are goal-directed and targets the specific aspects (developmental, therapeutic, emotion, behavioral…) of individual or groups of people involved in working with trained animals," (para. 7). Grigore & Rusu (2014) conducted a study analyzing the impact of a combination of two treatment interventions for children with ASD, the social story method and animal assisted intervention, on communication and social interactions. The results of the study indicated that the presence of a therapy dog during the social story intervention increased the frequency of social interactions while decreasing the number of social prompts or cues required to elicit appropriate social interactions amongst children with ASD. This may demonstrate the integral role that dogs may have in promoting social interactions between children and their typically developing peers.

Solomon (2010) further demonstrates dogs' role in supporting children with ASD communication, emotional connections, and participation in daily life activities. Solomon

analyzed two case studies based on a pilot study that she was conducting on AAI for children with ASD. One of the children participated in AAI with therapy dogs while the other child had their own assistance dog. The major themes identified through both children's experiences include increasing social interaction by providing the child the opportunity to practice highly social actions and coordinate them with other individuals, while increasing their social competence and confidence (Solomon, 2010). Additional findings, specific to child two's autism assistance dog, included facilitation of increased community engagement, increased participation in daily life activities, and increased familial participation (Solomon, 2010). This evidence, while limited, supports the idea that the constant presence of an autism assistance dog assists a child across various contexts and environments throughout their daily life compared to the presence of a therapy dog in therapeutic context.

Autism assistance dogs.

The integral theory supporting the assistive and supportive roles that dogs play for children with ASD is the human-animal interaction. Overtime, humans evolved to develop a secure, calming attachment to other social, friendly animals, such as dogs, and this attachment may facilitate a reduction in stress associated with social interactions amongst children with ASD (Carlisle, 2015). Autism assistance dogs decrease levels of cortisol, a stress hormone, in children with ASD. Viau, Arsenault-Lapierre, Fecteau, Champagne, Walker, and Lupien (2010) conducted a study to measure the effects of service dogs on salivary cortisol secretion, a stress hormone, in children with ASD. The results of the study proved to be statistically significant, indicating that the presence of an assistance dog decreased cortical awakening response (CAR) by 48%, corresponding to a

decrease in disruptive and aversive behaviors (Viau et al., 2010). Parental and child accounts of personal experiences with their autism assistance dog also report that the assistance dog decreases stress for the child, the parents and the entire familial unit, especially during novel experiences, social interactions, new environments, and public outings (Mackinnon, 2014). Additional benefits include increased social reciprocity and ability to form social relationships, increased communication, increased emotional regulation, increased sensory regulation, and increased participation in home and community activities (Mackinnon, 2014).

Assistive technology (AT) is one type of intervention, "to improve clients' performance, enable participation, or maintain their meaningful engagement in occupation," (Goodrich, Gitlow, Smith, & Kannenberg, 2016, p. 1). AT helps clients meet their goals and engage in occupations with a "just right" challenge by creating an optimal fit between the person, environment, and occupation. AT may be used as either a means or an end to improve occupational participation and performance. It is the role of occupational therapy practitioners to identify, recommend, design, create, apply, modify, and train the client in the use of AT to improve access to occupations (Goodrich et al., 2016).

Assistance dogs are a type of AT, as they provide compensatory function during daily life activities in both the home and community; hence, the use of assistance dogs as AT to improve functional independence falls into the domain and scope of practice of occupational therapy (Burrows, 2007; Burrows, Adams, & Spiers, 2008; Camp, 2001; Fairman & Huebner, 2008). Assistance dogs are widely known for the profound impact that they have on their handlers; assistance dogs provide services for people with

disabilities, giving them independence and freedom in their daily lives. The most common types of assistance dogs include guide dogs, hearing dogs, and service dogs (Rintala, Matamoros, & Seitz, 2008; Stace, 2016). Assistance dogs are specially trained and permanently placed with a person with a disability, who then becomes known as the dog's handler. Service dogs are trained to help individuals with mobility or balance impairments, psychiatric disabilities, medical issues (e.g. seizure alert, diabetic low blood sugar alert) and other medical diagnoses such as autism spectrum disorder (Winkle, Crowe, & Hendrix, 2012; Yamamoto & Hart, 2019).

Research documents the numerous benefits that assistance dogs provide. According to Winkle et al. (2012), service dogs for people with physical disabilities provide functional, psychological, and social participation benefits. Service dogs significantly increase their handler's functional independence by diminishing reliance on others and decreasing the need for caregiving. Assistance dogs have been proven to reduce the amount of stress and anxiety for both the handler and the handler's family (Rintala et al., 2008; Stace, 2016).

Assistance dogs can serve both pediatric and adult populations; the appropriate type of assistance dog is determined based upon an individual's disability, medical diagnosis, and eligibility criteria. According to Stace (2016), in recent years there has been an increase in the use of assistance dogs with pediatric clients and there has been diversification in the types and duties of assistance dogs. Autism assistance dogs are a relatively new type of pediatric assistance dog that function in a three-point handling system consisting of the dog, the child, and the parent or caregiver (Stace, 2016). Viau et al. (2010) demonstrated that autism assistance dogs decrease the Cortisol Awakening

Response (CAR) in children with ASD, potentially promoting behavioral benefits in the children. Use of an autism assistance dog may help improve children's ability to handle stressful situations, process sensory input, communicate with others, and reduce undesirable and self-injurious behaviors (Viau et al., 2010). Autism assistance dogs are individually trained to help improve engagement, empathy, communication, independence, and QOL for children with ASD (Carlisle, 2015; Good Dog Autism Companions, 2017).

While preliminary evidence alludes to the use of autism assistance dogs to improve children's functional engagement and participation in occupations in children with ASD, there is a gap in research that explicitly demonstrates the use of these dogs as an effective intervention. There is a significant lack of research describing the benefits, functional implications, and specific activities that pediatric assistance dogs help children participate in. The aim of this study is to describe the role and value of autism assistance dogs as an intervention in promoting participation and engagement in occupations and activities of daily living (ADLs) for children with autism spectrum disorder. The following research questions will be addressed: 1. What occupations do autism assistance dogs help children with ASD engage in? 2. How does an autism assistance dog facilitate greater participation in occupations and daily routines among children with ASD?

Methods

Research design.

This study used narrative and interpretive phenomenological approaches to explore the experiences of four families who obtained an autism assistance dog for their child. Participants were recruited via a single autism assistance dog training organization,

where the president of the organization posted the recruitment statement asking interested parties to directly contact the primary investigator on a private Facebook group for families that have received an autism assistance dog from the organization. Four primary handlers contacted the investigator and completed a prescreening questionnaire to ensure that they were 18 years or older, the parent or primary caregiver of a child with ASD, the primary handler of the child's autism assistance dog, and willing to discuss their experiences regarding the impact of the autism assistance dog. Additionally, participants were required to possess their autism assistance dog for at least a year to ensure the handler was beyond the adjustment phase and had an established bond with their dog. Two semi-structured, narratively focused interviews were conducted with each primary handler to elicit stories and experiences regarding the process of obtaining the dog, integration of the dog into the child's daily life, and the role of the dog in the child's life.

Based on Lincoln and Guba (1985) methods of rigor, components of credibility, transferability, dependability, and conformability were incorporated throughout the study to ensure trustworthiness of data. Credibility was established via data triangulation, investigator triangulation, prolonged engagement, member checking, and persistent observation (Korstjens & Moser, 2018). Conducting interviews and collecting field notes established data triangulation. The interviews occurred during different times of the day and during periods of time in which the participants had minimal distractions and disruptions (Korstjens & Moser, 2018). To establish investigator triangulation, two members of the thesis committee reviewed all of the data, the third reviewed part of the data, and all thesis committee members participated in an external audit of the identified themes. The committee members held expertise as both faculty

members and occupational therapy practitioners with expertise in pediatrics and animal assisted intervention. This serves to ensure accuracy and reliability of the data analysis (Creswell & Creswell, 2017). All of the researchers collaborated to make further data coding, analysis, and interpretation conclusions (Korstjens & Moser, 2018). Conducting two interviews with each participant established prolonged engagement criterion and served as a method of rapport building with participants. Two interview sessions provided ample time for participants to describe their experiences, supported with specific examples, for the collection of rich data (Korstjens & Moser, 2018).

Member checking, the opportunity for participants to endorse or refute a researcher's interpretation of past data, serves as a measure of credibility and validity for the findings of the study (Creswell & Creswell, 2017). Member checking was conducted by briefly reviewing and summarizing the information, concepts, experiences, and themes that emerged from the first interview at the beginning of the second interview (Creswell & Creswell, 2017; Korstjens & Moser, 2018). Participants were then asked follow-up questions developed from the content of the first interview to provide clarification and deepen the researcher's understanding of the concepts provided.

Credibility was also established via persistent observation which is defined as, "identifying those characteristics and elements that are most relevant to the problem or issue under study, on which you will focus in detail," (Korstjens & Moser, 2018, p. 121). This was performed via the rereading of the transcripts, coding and recoding the data, and analyzing and relabeling the themes numerous times (Korstjens & Moser, 2018).

Thick descriptions of the data were provided to maintain transferability (Korstjens & Moser, 2018). Several pieces of rich data and relevant contextual information are reported to provide meaning to the experiences revealed during the study. Throughout the interview process, a journal of field notes documented context and observations captured during the conversations with the participants (Creswell & Creswell, 2017; Phillippi & Lauderdale, 2018). The primary researcher also logged her self-identified biases and questions to promote reflexivity throughout the study and to remain as objective as possible when analyzing and discussing the results (Korstjens & Moser, 2018). To establish dependability and confirmability, maintenance of an audit trail provided transparency of the research path (Korstjens & Moser, 2018).

Researcher.

The primary researcher is a master's occupational therapy student and puppy raiser for a guide dog training organization. She has an interest in pursuing a specialty in animal assisted interventions and had the opportunity to incorporate one of the guide dogs in training into her work with a pediatric client. Working with the dog as part of the occupational therapy intervention inspired the client to pursue his own assistance dog. The primary researcher was integral in researching and working with organizations to specially train the dog to meet the client's unique and complex needs. Having prior experience with guide dogs provided the primary researcher with a foundational understanding of the independence and functional engagement that assistance dogs may provide their handlers. Bias was managed by keeping a journal where possible biases were recorded and reflected on as they surfaced throughout the study. Data analysis

occurred in partnership with three occupational therapy faculty members with a variety of clinical and research related experience.

Participants.

Four families volunteered to participate in the study. All four families met the inclusion criteria and were accepted to participate in the study. This produced a sample that was more homogenous in participant characteristics than would be expected with randomized sampling of four participants from a larger pool of volunteers. For example, each family had one child with ASD and one typically developing sibling. The ages of the children with ASD were also very similar as seen in Table 1. Participants owned the autism assistance dogs between two and four years, and all primary handlers were the mothers and all families presented as white and middle class. The lack of diversity in this sample may limit the findings. Pseudonyms are used throughout the article to protect the anonymity of the handler, child, and dog.

Data collection and measures.

Participants were required to complete a brief prescreening questionnaire to determine eligibility for the study and to gather background data prior to the first interview. Each participant completed two interviews with the researcher via video chat. An interview protocol was developed in consultation with content experts in order to prepare for the interview. First interviews were designed to elicit narrative explanations in order to obtain more specific information and experiences from each family and focused on the process of obtaining the assistance dog and integrating it into the child and family's daily life. The second interview questions were created based upon responses and information from the first interview. Additional questions were designed to

elicit more information regarding the specific duties of the dog, activities that the dog aids the child in, as well as the benefits and challenges associated with having an autism assistance dog. The second interview was also used as a member check to improve the validity of data (Portney & Watkins, 2015).

Analysis.

Interviews were transcribed via TEMI, an automatic transcription service within 24 hours of the interview. The primary investigator then cleaned the transcript to ensure accuracy of transcribed interview data. The data was then manually analyzed by the researcher using an interpretative phenomenological and narrative theory approach (Creswell & Creswell, 2017; Smith, Flowers, & Larkin, 2009). First interview transcriptions were initially analyzed in order to develop questions for the subsequent interview. After the conclusion of all the interviews, the transcripts were read multiple times by the primary researcher to develop an initial list of codes. During the coding process, the transcripts were broken into chunks based on narrative principles to form explanations and to identify themes from within each interview (Creswell & Creswell, 2017). The themes were then compared within cases and across cases. Weekly data analysis meetings were held between the primary researcher and her supervising faculty advisor. Additionally, the other two committee members and an additional faculty member read transcripts and participated in data analysis meetings and investigator triangulation occurred several times during the semester to increase validity. During analysis, codes were assigned and consolidated until a primary code remained assigned to each data fragment (Creswell & Creswell, 2017). The final code was determined based upon the fundamental notion of the fragment. The first round of

coding yielded 18 initial codes. After consultation with committee members and additional reading of the data, these were narrowed into 10 primary codes. The final codes were then aggregated into six themes. This article describes a single important theme and its four subthemes that emerged from the data because the "Multi-factored Role of Autism Assistance Dogs" theme holds particular clinical and scientific relevance for occupational therapy practitioners.

Findings/Results

The data collected from the study yielded an abundance of rich, novel information about the broad role that autism assistance dogs can play in childhood occupations and family life. In striving to understand and describe the multifactored role of the service dog, several components were identified and became sub-themes. These were dogs as: occupational facilitators, symbols of awareness, age appropriate security blankets, and generators of familial experiences. Each of these will be further described below.

Occupation facilitator.

Throughout the interviews, participants reported that the assistance dog provided their child and their family with assistance across every area of occupation as outlined in the Occupational Therapy Practice Framework: Domain and Process (OTPF-4) (American Occupational Therapy Association [AOTA], 2020). Sleep, dressing, feeding, and safety were chosen as examples though each area was represented in the full analysis.

Sleep.

Three of the four participants discussed the role that the dogs played in helping the child prepare and participate in sleep. One mother, Bella specifically spoke about how having the dog sleep with her son David each night improved not only David's sleep

hygiene and bedtime routine, but also the family's quality of sleep. Prior to having their dog, Dixon, one of David's parents would have to lay on top of him each night to provide the deep pressure required for him to remain in bed and to fall asleep. Applying deep pressure to David in preparation for sleeping became one of Dixon's jobs and "now [David] goes to sleep right away and obviously we don't have to stay in there with him to help him sleep. So that makes a huge difference. It improves his quality of sleep and [ours]...Especially when my husband was gone, I'd be up all night with him and I'd be exhausted trying to take care of him and his brother the next day." Additionally, Bella described how Dixon helps David sleep through the night, improving his sleep hygiene. Subsequently, Bella noted improvement in her own quality of sleep, quality of time with her husband after the kids went to bed, and her exhaustion level in her day to day life.

Dressing.

One of the specialty commands that David's dog was taught involved dressing. Bella also shared that David had difficulty with transitions in his morning routine, especially getting ready to go to school. In order to ease this transition, Dixon was taught to retrieve David's shoes. "So for David, [the dog] knows how to get his shoes". They use this "on more difficult days, like if he is having a hard time getting ready." Prior to Dixon, Bella disclosed that David would refuse to gather his shoes or other clothing items required to get ready for school because he did not want to leave the house. This resulted in her having to gather David's clothes and get him dressed causing more anxiety and stress for both parties involved. Now, Dixon gathers these essential items and prompts David to get dressed which provides David a sense of calm while decreasing the amount of work that Bella must do for David and increasing his independence.

Feeding.

The majority of the participants discussed the unexpected, yet beneficial role that the dog played during feeding and mealtime. One mother, Helena, described how the dog improved her daughter Diana's participation during mealtime. "Diana will feed [the dog] human food sometimes...So like if she's eating string cheese, she'll peel off a string and give it to Fern…it's bonding and socialization and communication for them." Although feeding dogs from the table is otherwise often frowned upon, in this special case Helena described how it helped her daughter bond with the dog and provided help for her to participate in mealtime. She says:

> *From the training we got [sharing food is] a bonding thing and they advised us not to interfere with that and I don't want to either. Because she'll also sit through her meals and eat more with him. Or try new things. Because it really is a way that they are close together.*

Helena explains that the dog's presence seems to ground Diana and prolongs the amount of time that she remains seated and participates in meals. By eating the foods that Diana provides the dog, the dog models appropriate behavior and willingness to try novel foods at mealtime.

Helena further described that the dog's role during mealtimes was very beneficial outside of the home at restaurants, as restaurants can be overstimulating for Diana. She said that one of the biggest "roadblocks for our family before Fern was going out in public and being embarrassed [and] feeling defeated if we had to leave somewhere, especially restaurants…[because she'd start a] tantrum and we would have to get up and leave." Prior to having a service dog, it was difficult for Helena's family to eat meals at

restaurants. Since having a service dog, Helena reports that Diana does much better at restaurants and will sit through an entire meal. She further explained that she usually has the dog lay on Diana's feet to provide sensory input to help regulate her and keep her calm with all of the noise in the restaurant. She also positioned the dog to lay on the ground under the table at the restaurant to block the exit of the booth to encourage Diana to remain seated during the meal.

Safety.

Children's safety is extremely important, especially for children with ASD since they are more likely to bolt away from parents or caregivers (Solomon & Lawlor, 2013). A third mother, Olivia, discussed the invaluable role that her family's dog, Comet, played in keeping her son from bolting. She explained that her son Xavier "tends to be an eloper and a runner even in...the room if you're just trying to walk him to the door, his little body doesn't cooperate and he may go up to...a different area." The family used a technique called tethering where the child wears a waist leash that is attached to the dog. An adult can also hold a separate leash to assist with dog control. Olivia described how "when he's tethered with Comet...it helps him stay kind of focused and going where he needs to go and less about us pulling on him to keep him close." This gave Xavier more freedom in his environment. Olivia reported that this had significant impact on Xavier's wellbeing. She said "we saw Xavier become just a happier healthier, like a more independent kid. I didn't realize how much we were pulling on him and how probably hard that was for him and his little sensory system." This was very significant to the family. Olivia shared that "I think just being tethered and providing that opportunity for Xavier to be independent was probably the biggest thing, perhaps the biggest win." Prior

to having Comet, Olivia would constantly need to hold Xavier and guide him to appropriate locations to prevent bolting and ensure his safety. Now the dog prevents Xavier from bolting and eliminates the need for Olivia or other family members to constantly be pulling on his hands.

Symbols of awareness: Making the invisible visible.

Each of the participants discussed the role of the dog in visually symbolizing the child's invisible disability. Prior to having the dog, participants disclosed that the child and family often received glares or judgment from others when their child presented atypical behaviors in the community. The participants further explained that this often resulted from individuals assuming that the child was neurotypical since they did not display any physical or visual signs of impairment. The presence of the assistance dog signaled that there was a disability present without the parents having to disclose that their child was not simply misbehaving but had a neurological difference. The fourth mother, Danica, provided one of these examples. She described a time in which her family was flying home from a family vacation and her son Collin was knocking on the screen on the seat in front of him. Before the flight had even taken off the person in the seat turned around to complain. Danica described the scene:

> *He goes, 'Do I need to switch seats?' And I said, 'I'm really sorry, you know,' and so he must have seen Jasper [the dog] right before he was turning back around. And later on in the flight the drink cart came down and I said, 'Sir, you know, can I buy you a drink? For, you know, the inconvenience earlier.' And he looked at me and he said, 'No, I owe you an apology and I'm so sorry.' And it wasn't because of*

anything other than the fact that he saw Jasper and he knew there was something else going on.

The dog's simple presence diminished the family's stress regarding judgments from other people and eliminated the family's need to provide others with an explanation. The explanation was implied by the presence of an assistance dog. Once this man saw it, he knew that the child had a disability and was not simply misbehaving. This evoked a different perspective, provoking him to be more compassionate, accepting, and kind to both the child and his family. Olivia described a similar instance when they first took their son and the assistance dog trick-or-treating. She says “The first Halloween, it was funny, that we took Comet and Xavier. I was like, ‘Y'all know that candy does not cure autism, right?’ Because the people were just so much more understanding and more patient and more willing to help or be kinder and not give the evil glares or the comments or what not.” The dogs’ presence brought more compassion to the child and the family. People were more patient with Xavier and as such he was able to participate more fully in a childhood occupation.

An age appropriate security blanket.

Each participant reported that the simple presence of the dog allowed the child to participate in their occupations. The dogs helped ground the children and provided them a source of comfort. Bella described how the dog served as a surrogate for the comfort she once provided for her son, “the easiest way to relate it is she's like a security blanket. So, I mean, I think that's kind of the role that I played for a really long time. But that's hard when you're- when you get older, you can't always have your mommy around…it's just almost like a reassurance kind of thing to have her there and available.” The dog’s

presence acted as a socially and age appropriate security blanket for the children. They provided the children with comfort during experiences they found stressful. The dogs also helped decrease the child's anxiety during transitions, times of stress, and instances of high stimulation that may have overwhelmed the child. Danica described a high stress situation in which she needed to take Collin to the emergency room. She explained that he has a phobia of going to the doctor and does not let the doctors or nurses take his blood pressure, look in his ears, etc.

> *We had Jasper with us…and I didn't even have her necessarily do a command. I just had her come and sit facing him in between his legs. And I said, 'Why don't you rub her ears?' Cause he loves to rub her ears and he let the doctor look in his ears and all of the people in there were in awe. Because when we came in, as soon as they had the tool…he was like, 'No, no ears, no ears!' And so the people working there, saw his extreme aversion to that. The fact that just focusing on Jasper and… just her presence there and him being able to focus on her…my jaw was on the ground because I never thought that would happen.*

All the participants said that the dogs' presence not only provided comfort for the child, but also for the family, especially during community outings. The dogs' presence further allowed the children and families to participate in a variety of previously difficult or impossible situations due to the children's challenges with change, transitions, and novel stimuli.

Generators of familial participation and outings: Making the impossible possible.

All the participants discussed the significant impact that the awareness and the presence of the dog had on the child's ability to participate in community outings. This allowed all the families to go on family outings that were not otherwise possible prior to having the autism assistance dog. Olivia stated, “Comet has been a game changer for our family. We got to do a lot of things that we never got to do. I mean, even little things like going trick or treating was almost impossible [before].” All of the participants expressed significant gratitude towards the dogs for enabling the child to participate in community outings and easing transitions. This translated to increased occurrence and quality of family activities. It further provided access to many spaces in the community that were not previously attainable such as the movies, the zoo, and school events.

Discussion

This study demonstrates that the role of autism assistance dogs is multi-factored and can be highly complex. The dogs in this study played large roles as occupational facilitators; they assisted the children in participating more safely, successfully, and independently in all occupational domains listed in the OTPF-4 (AOTA, 2020). This unique finding has not been previously featured in the literature. This study also provides a description of some of the ways in which autism assistance dogs specifically assisted the children in participating more fully in their occupations and daily activities. Participation in occupations allows individuals to establish their unique occupational identity. Increased participation in occupations further promotes increased occupational competency amongst the children, as it improves their proficiency initiating and

partaking in their goal directed actions (Kielhofner & Burke, 1980; Cole & Tufano, 2008a). This sense of occupational competency provides a sense of motivation and can improve the child's self-esteem and willingness to participate in daily occupations that may have previously been difficult (Kielhofner & Burke, 1980; Cole & Tufano, 2008a).

The dogs also acted as a means to create and restore occupational roles that both the children and families had difficulty participating in within their homes, schools, and communities. The dogs helped the children fulfill roles such as sibling, son or daughter, friend, student, and peer (AOTA, 2020). The ability of the children to participate in these internalized roles increases the children and families' participation more fully in valued occupations across contexts and environments (AOTA, 2020; Kielhofner & Burke, 1980; Cole & Tufano, 2008b). The dogs' ability to enhance these roles supported the children in developing their own identities and providing them with a sense of purpose (AOTA, 2020; Cole & Tufano, 2008b).

All of the children's autism assistance dogs increased their familial participation. The children's improved ability to participate in their family unit further translated into the families' ability to participate in their roles, routines, and occupations as a unit. It also improved the families' community engagement. Families' ability to participate in occupations together as a familial unit was also restored by incorporation of the autism assistance dog into the families' lives.

Quality of life is a multidimensional, subjective context that includes physical, psychological, and social components such as occupational participation, safety, and well-being (Baron, Hawrylyshyn, Hunt, & McDougall, 2019). This study demonstrates the positive impact that autism assistance dogs have on children and families' QOL.

There is a large difference in QOL throughout the lifespan between individuals with ASD and neurotypical individuals (Baron et al., 2019; Van Heijst & Geurts, 2014). Cultural expectations for behavior and social participation that are mismatched with the abilities of individuals with ASD can lead to a decrease in QOL. By acting as age appropriate security blankets, the dogs in this study decreased the children's stress levels and improved their emotional regulation. This improved their affective experience during social interactions and participation in activities inside and outside of their homes. This increase in comfort and pleasure during activities can be assumed to improve their overall QOL.

By acting as symbols of awareness and making the invisible visible, these autism assistance dogs helped decrease the amount of stress that the children and families experienced as a result of their invisible disability (Viau et al., 2010). The dogs evoked empathy from others which decreased the amount of judgement that the families and children experienced when in public. The dogs symbolized that the child had an invisible disability, eliminating the need to explain or defend their child's actions to other people. In addition, people were less likely to judge the child and family if the child did not act according to social norms because the dog signaled that the child had different needs due to a disability.

Additionally, the autism assistance dogs helped decrease the incidence of bolting and improved the physical safety of the children (Stace, 2016). Knowing that their children were less likely to bolt helped decrease parental stress regarding the children's safety. This allowed the families to participate in community outings that they were not apt to previously engage in due to their concerns about the child's stress levels and safety.

Stress is negatively correlated with mental health, physical health, and QOL (Baron et al., 2019; Chakraborty, Rao, Shenoy, Davda, & Suprabha, 2019). Parents of children with disabilities have significantly higher levels of stress compared to parents with neurotypical children (Chakraborty et al., 2019). The autism assistance dogs reduced the amount of stress that these parents of children with ASD experienced, which improved both the parent's QOL and the family's overall QOL. Despite the overall positive impact that autism assistance dogs had on these children and families' QOL, it is important to note that there were challenges associated with having a service dog such as constant and consistent need for training. Although all of the participants reported that the benefits of autism assistance dogs outweighed the challenges. Constant work and problem-solving was required throughout the course of the relationship of the triad team.

Autism assistance dogs are a relatively novel intervention. This study showed that their use in these four families increased the children's ability to participate in daily occupations while improving QOL for the children and the family as a whole. This research contributes to the foundational understanding of autism assistance dogs as an assistive technology intervention for children and families. It highlights the need for continued research to assess the effects of autism assistance dogs on children and their family's quality of life.

Limitations

The limitations of this study relate to the lack of diversity in the small sample. Since autism assistance dogs are a novel tool, the population from which to recruit was limited. The results of this study are not intended to be generalized to the larger

population, but rather to be used as examples that can inform practice possibilities and inspire future studies.

Implications for Occupational Therapy Practice

Family centered care requires that occupational therapy practitioners advocate for our clients and for their families. Part of this advocacy involves analyzing a child's needs across many domains and helping families to select and to obtain appropriate assistive technology that best facilitates child and family participation in meaningful occupations. This study shows that autism assistance dogs can be the assistive technology application that allows a family to increase their participation and overall QOL. As such, occupational therapy practitioners can help the client and their family advocate for the dog with the child's primary care provider, the training organizations that the family decides to apply with, and their funding sources. Additionally, occupational therapy practitioners' ability to perform task analysis and identify factors that limit a child's participation in daily activities provides a unique role for working with assistance dog training organizations to improve training of assistance dogs to specifically meet a child and family's unique needs. It is important for occupational therapy practitioners to have a foundational understanding of assistance animals and of the process of referring appropriate children and their families to assistance dog training organizations. In addition, some organizations may require a medical referral or letter of medical necessity during the application process to ensure that the dog could meet the child and family's needs. Additionally, occupational therapy practitioners may encounter families that already are using an autism assistance dog. In these cases, it is vital to acknowledge both the child's and the parent's unique roles as members of the triad team. This allows the

occupational therapist to consider the role of the dog in the family's daily life when planning treatment sessions, intervention strategies, and home adaptations.

This study provides four powerful examples of how autism assistance dogs can profoundly impact the lives of the children and families they serve. Future studies are needed to explore the effects on children's daily participation and engagement in occupations and to illuminate potential barriers to families obtaining autism assistance dogs. Additionally, quantitative research may be useful for exploring how many families are referred to assistance dog programs and how many are accepted. QOL measures could be used to quantify improvements for parents and for children after receiving an autism assistance dog. This would provide compelling evidence for the inclusion of advocacy and training for these programs as part of evidence-based autism intervention.

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Figure 1: Taxonomy of Dogs in Society

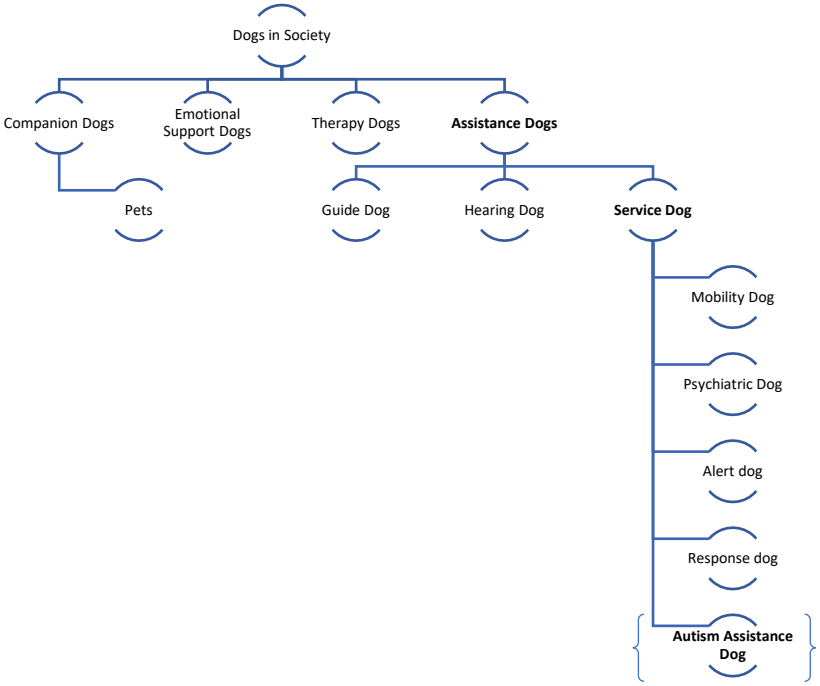

Figure 2: Taxonomy of Animal Assisted Interventions

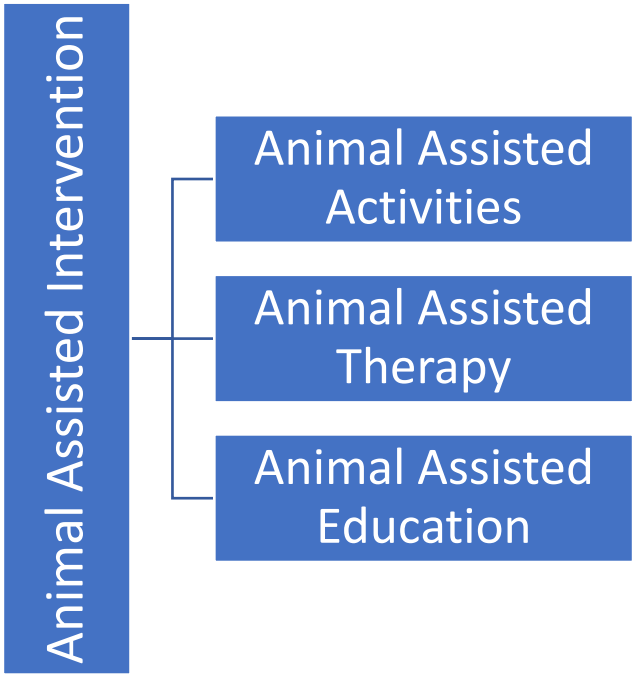

Figure 3: Outline of Literature Review Topics

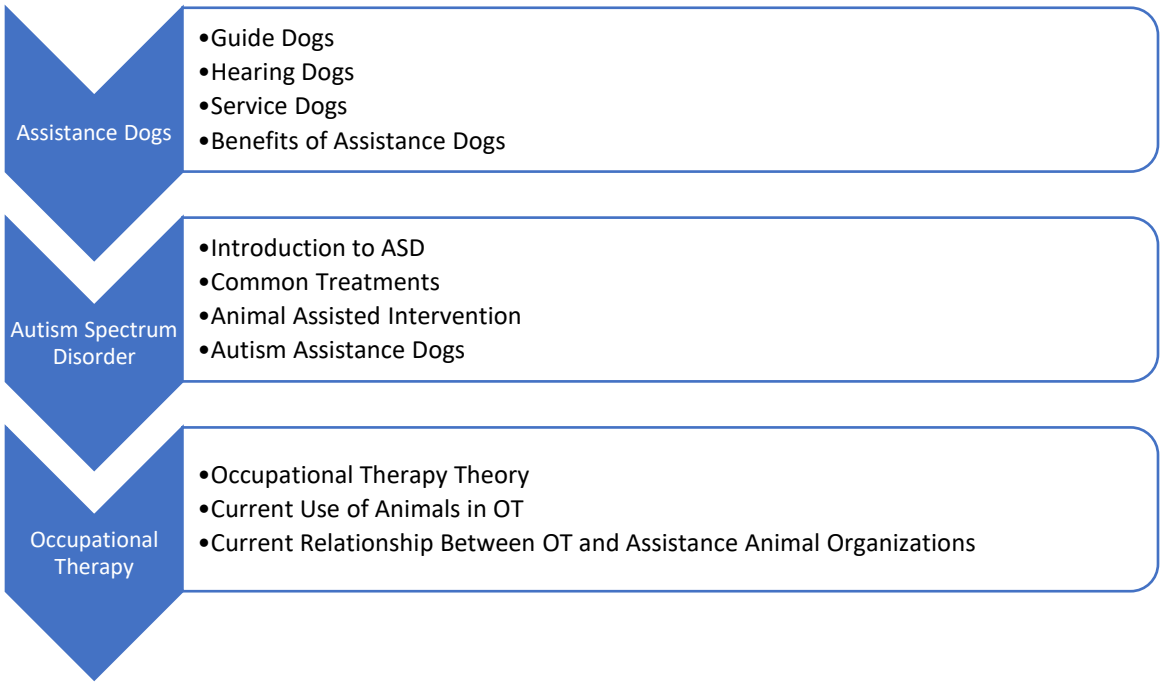

Table 1: Participant Characteristics

Primary Handler	Handler relationship to child	Child	Child Age (years)	Child Sex	Dog	Dog Age (years)	Years Together
Olivia	Mother	Xavier	9	M	Comet	4.5	3
Helena	Mother	Diana	9	F	Fern	3.5	2
Bella	Mother	David	13	M	Dixon	3	2
Danica	Mother	Collin	13	M	Jasper	5	4
*Pseudonyms are used throughout the study to protect the anonymity of the handler, child, and dog							

Table 2: Number of Instances Participant Mentioned Dog Assisting in Specific Occupations

Occupation	Occupation Subcategory	Instances family mentioned
ADLs	Dressing	II
	Feeding	IIIIII
IADLs	Care of pets	IIIIIIIIII
	Community mobility	IIIIIIIIIIIIIIIIIIIIIIIIIIIIIIII
	Health management & maintenance	IIIIIIIIIIIIII
	Safety & emergency maintenance	IIIIIIIII
	Shopping	IIIIIIIIIII
Rest & Sleep	Rest	IIIIIIII
	Sleep Preparation	IIIII
	Sleep Participation	IIIIIIII
Education	Formal Educational Participation	IIIIIII
	Informal personal education participation	IIIIII
Play	Play exploration	IIIIII
	Play participation	IIIIIIIIIII
Leisure	Leisure exploration	IIIIII
	Leisure participation	IIIIIIIIIIIIII
Social Participation	Community	IIIIIIIIIIIIIIIIIIIII
	Family	IIIIIIIIIIII
	Peer, friend	IIIIIIIIIII

Appendix A- Ithaca College IRB Approval Letter

Ithaca College IRB *Approval Notification*

To: Morgan Starkweather
From: Ithaca College IRB
Subject: Protocol #46
Date: 10/04/2019

ITHACA COLLEGE
Sponsored Research

Re: [IRBID] - Pawsitive Purpose: The Impact of Autism Assistance Dogs on Levels of Independence and Engagement in Occupations of Children with Autism Spectrum Disorder

Thank you for submitting your proposal to the Institutional Review Board for Human Subjects Research (IRB). You are authorized to begin your project. This approval is issued under the Ithaca College's OHRP Federal-wide Assurance #00004870 and will remain in effect for a period of one year from the date of authorization.

Please add the IRB approval number IRB [IRBID] to ALL recruitment and consent materials.

After you have finished the project (when data collection is complete and there is no further risk to human subjects), please terminate your protocol in Axiom.

Should you wish to revise the approved project, please submit an amendment through Axiom.

Please note that if there are any adverse events resulting from this research, they must be submitted through Axiom.

Sincerely,

Warren J. Calderone

Warren Calderone
Director of Corporate, Foundation Relations, and Sponsored Research
Institutional Review Board for Human Subjects Research

953 Danby Road, Ithaca, NY 14850, (607) 274-1206
www.ithaca.edu/sponsored-research

ithaca.edu

Appendix B- Informed Consent Form

Title of Study: Pawsitive Purpose: The Impact of Autism Assistance Dogs on Levels of Independence and Engagement in Occupations of Children with Autism Spectrum Disorder

Principal Investigator: Morgan Starkweather, OTS, Ithaca College

Faculty Advisor: Kimberly Wilkinson PhD, OTR/L, Ithaca College

Study Sponsor/Funding Agency: Ithaca College Department of Occupational Therapy

Invitation to Participate in a Research Study

You are invited to participate in a research study. In order to participate, you must be 18 years or older, the primary handler and/or the parents of a child with autism spectrum disorder (ASD) that received an autism assistance dog and have had the dog for at least one year. Taking part in this research study is voluntary. You are not required to participate in this study. You may stop or withdraw your participation from this study at any time.

Important Information about this Research Study

Purpose of the study: to assess the role of autism assistance dogs in promoting independence and engagement in occupations and activities of daily living for children with Autism Spectrum Disorder (ASD).

If you choose to participate, you will be asked to complete a short prescreening questionnaire and two individual, one hour interviews with the researcher via video chat. The total time commitment for participation is approximately 2 hours.

Risks and discomforts associated with this research: There is no anticipated discomfort or risks associated with participating in this study.

Direct benefits to the participants: There are no direct benefits from participating in this study.

You will receive $10 gift card for each interview you complete from your choice of either Target or Amazon.com.

Alternative procedures/treatments: There are no alternative procedures/treatments.

Please read this entire form and ask questions before deciding whether you would like to participate in this research study

1. Purpose of the Study

The purpose of this study is to assess the role of autism assistance dogs in promoting independence and engagement in occupations and activities of daily living for children with Autism Spectrum Disorder (ASD). The study seeks to elicit the training, benefits, challenges, supports, emotions, and suggestions regarding the overall process of obtaining the assistance dog and integrating it into the child's daily life.

2. Benefits of the Study

Researcher- This research is benefitting the researcher by completing a thesis to fulfill requirements for a master's degree in Occupational Therapy.

Participants- Although you may not directly benefit from taking part in this study, you may find it helpful to share your experiences throughout the process. Your participation in this study may help to promote better understanding and social acceptance of the role of autism assistance dogs. Your feedback and participation may also help to improve the application, matching, training, and follow-up process implemented by Good Dog Autism Companions.

Scientific community- This research may help contribute to obtaining concrete data regarding the roles, duties, and impacts of autism assistance dogs on the daily lives of children with ASD. This may help strengthen the literature and knowledge of pediatric providers regarding characteristics of children that may benefit from an autism assistance dog, the process of obtaining a dog, and the influence the dog may have on both the child and their family's lives.

Occupational Therapy community- This research may help educate occupational therapy practitioners regarding their potential role in the referral of a child with ASD for an autism assistance dog. It may also help educate occupational therapy practitioners regarding their potential role in working with assistance dog organizations during the training process to help customize the dog's commands and to adapt the tasks that the dog may perform in order to best suit the child.

3. What You Will You Be Asked to Do

You will be asked to complete a short prescreening questionnaire and to participate in two, one-hour long interviews via video chat. Interview questions will focus on activities that the dog helps your child with, changes in your child's independence since having the dog, your satisfaction, and the overall experience of the process.

The estimated total participation time is approximately two hours.

Criteria that exclude participation in this study include owning the assistance dog for less than one year or not being the parent or caregiver of a child diagnosed with ASD.

You will receive $10 gift card for each interview you complete from your choice of either Target or Amazon.com.

4. Withdrawal from the Study

Your decision to take part in this research study is entirely voluntary. If you feel uncomfortable answering any questions during the interview, you may omit answers to these questions by saying that you would prefer not to answer. You may refuse to take part in or you may withdraw from the study at any time without penalty.

If you withdraw from the study, you will only receive gift card compensation for the interviews you participated in.

If you withdraw from the study, you may choose for the data already collected to be destroyed or you may allow us to use what was already collected.

5. Risks

Although, there are no anticipated risks foreseen by participating in the study, there is a small chance that you may feel uncomfortable answering questions during the study. If you experience this discomfort you may choose not to answer any question at any time.

6. How the Data will be Maintained in Confidence

Your responses will remain confidential, meaning that we will know your identity, but will take measures to protect your identity from discovery by others. The video chat interview will be audiotaped. The audiotapes will be transcribed using a reputable transcription company with a signed non-disclosure agreement. Pseudonyms will be used in written transcripts of your interviews and any identifying details will be removed. A copy of transcribed data and your informed consent form will be kept separately for a minimum of three years upon completion of study in a cabinet in Dr. Wilkinson's office in Smiddy Hall at Ithaca College. Digital copies of de-identified transcripts will be stored on a password-protected computer.

7. Use of information beyond this study

Identifying information may be removed and this de-identified information may be used for future research without additional informed consent from the participant.

8. Clinical Results

Any clinically relevant research results will be disclosed to all research participants via a standard email document informing the participants of the major themes and results identified from the study.

9. Compensation for Injury

Though it is extremely unlikely, if you suffer an injury that requires any treatment or hospitalization as a direct result of this study, the cost for such care will be charged to you. If you have insurance, you may bill your insurance company. You will be responsible to pay all costs not covered by your insurance. Ithaca College will not pay for any care, lost wages, or provide other financial compensation.

10. If You Would Like More Information about the Study

Contact the primary student researcher, Morgan Starkweather, OTS via email: mstarkweather@ithaca.edu or

Contact the faculty advisor, Kimberly Wilkinson, PhD, OTR/L via email: kwilkinson@ithaca.edu or

Contact the IRB via email or phone from the information below:

Ithaca College IRB
Peggy Ryan Williams Center
953 Danby Road
Ithaca, NY 14850
irb@ithaca.edu
(607) 274-3113

I have read the above and I understand its contents. I agree to participate in the study. I acknowledge that I am 18 years of age or older.

_____

Print or Type Name

_____
____

Signature Date

I give my permission to be audiotaped.

_____
_____

Signature Date

Appendix C- Recruitment Post

Recruitment Post (this will be sent as an attachment to an email from the director of Good Dog Autism Companions)

Dear families, my name is Morgan Starkweather and I am an occupational therapy student from Ithaca College. I am writing my master's thesis on the role that autism assistance dogs have in increasing a child's independence. As such, I am looking to interview three to five primary handlers about the process of obtaining the dog, integration of the dog into the child's daily life, and the role of the dog in the child's life.

The study will take approximately two hours of your time. It involves completing a short pre-screening questionnaire and participating in two video chat interviews that will last up to one hour each. They will be audio recorded and transcribed for data analysis. You will receive a $10 gift card to either Target or Amazon for participation in each interview.

I will ensure your privacy by keeping your identity confidential, and using pseudonyms in any written work or presentations about the study.

To sign-up or to request more information please contact me directly at:

Morgan Starkweather
mstarkweather@ithaca.edu
Dept. Occupational Therapy
Ithaca College
Ithaca, NY 14850

Appendix D- Reprint Permissions

Chris Diefenthaler <chris@assistancedogsinternational.org>
Mon 4/13/2020 8:54 AM

Dear Morgan,

Thank you for contacting Assistance Dogs International (ADI).

I am happy to grant you permission to use our terms and definitions in your thesis.

ADI wishes you the best during these challenging times.

Kindest regards,

Chris Diefenthaler
Executive Director

Assistance Dogs International (ADI)
(419) 350-5788

Appendix E- Prescreening Questionnaire

Prescreening Questionnaire (will be online in multiple choice format via Qualtrics)

Primary caregiver name:

Primary caregiver phone number:

Primary caregiver email address:

Best method of contact:

Name & relationship of primary handler to child:

Child's Name:

Child's Age:

Child's Gender:

How many children do you have?

Autism Assistance Dog Name:

Autism Assistance Dog Age:

How many years have you had your Good Dog!? **1-18**

Did you have any pets prior to obtaining your Good Dog? **Yes/No**

Did your child previously have an emotional support animal or an assistance animal? **Yes/No**

How did your family learn about autism assistance dogs? **Doctor/Therapist/Peer group/Social media/Other**

How did your family learn about Good Dog specifically? **(short answer)**

Does your child take their assistance dog to school? **Yes/No**

Appendix F- Interview Protocol

First Interview

"Hi _____. It is nice to finally meet you and to put a name to the face. How are you doing? I want to thank you again for your participation in this project. Before beginning the interview, I have a few things that I want to quickly review:

- As stated in the consent form, your participation in this study is completely voluntary. If there are any questions that you do not want to answer or to discuss please let me know and we will simply move on. With that said, if there is anything that you would like to elaborate upon or other related experiences that you would like to share, please feel free to do so.
- This interview and your identity will be kept confidential. Although this interview is being audio recorded and will be transcribed for data collection, I may be taking some notes just to help me stay on track and to organize my thoughts. At times, this may cause some of my responses to be delayed as I process information.
- If at any point during the interview you need a break please let me know so that we can take a break.
- Feel free to take as long as you need to think about the questions prior to answering- I know that sometimes it is hard to think of specific examples and such on the spot, so please do not worry if you feel as though your answers are delayed.
- I have planned for this interview to last for no longer than 1 hour, if we do not talk for the whole hour, that is okay.

I am very interested and eager to learn more about your experience, your child's experience, and your family's experience about the impact of autism assistance dogs. This first interview will give me a better idea of your child, your dog, the training experience, and activities that the dog helps your child with. Do you have any last minute questions for me before we begin?"

Topic #1: Orientation to child

- First, could you please tell me about your child?
    - What are your daily routines like? (weekday & weekend)

Topic #2: Orientation to obtaining and integrating autism assistance dog

- Can you please tell me the story about how your family got your assistance dog?
    - Prior to having an assistance dog, what behaviors did your child exhibit?
    - How did these behaviors impede their participation in daily life?
    - What made you decide to pursue getting an assistance dog?
    - How did you become aware of autism assistance dogs in general?
    - How did you become aware of Good Dog! Autism Companions specifically?
- Can you please tell me the story about the matching process and the dog coming to live with you?
    - What were your initial expectations of the dog?

    - What was the matching and training process like for you?
    - What kind of support did you have throughout the process?
- Looking back, is there any support or resources that you wish you had that you did not?

Topic #3: Activities that the dog and child participate in together

- What activities does the dog help your child participate in at home?
    - In the community?
    - At school?

"Thank you for participating in this interview. I hope that you found it to be a valuable experience, as I know that I have learned a lot from your experiences. I will be in touch in the next few weeks to schedule the second interview, which will expand upon some of the information that you have shared with me today."

Second Interview

"Hi _____. It is nice to see you again. How are you doing?

Do you have any follow-up questions, comments, or concerns from the first interview?

This second interview, will help me to understand the specialized training that your dog has received to best meet the needs of your child, the impact the dog has on your child's daily life activities and participation, the dog and child's relationship, and a reflection regarding the overall experience of having an autism assistance dog. Do you have any questions for me before we begin?"

Topic 4: Specialized training for task completion and assistance

- What specialized commands, if any, does the dog know?

Topic 5: Engagement in daily life roles/routines/activities

- Tell me about what your child did with his/her dog yesterday?
- Tell me about what your child and his/her dog did this past weekend?

Topic 6: Dog and child relationship

- Can you tell me about a time that the assistance dog and your child worked really well together?
- Can you tell me about a time that the assistance dog did not work as well as expected?
- Can you tell me about a time that having the assistance dog made your life more challenging?
- Can you tell me a story about a time when you realized that your child and the dog had bonded?
    - When did this occur?

Topic 7: Experience of owning an assistance dog

- What has the experience of having an autism assistance dog been like?
    - How has it been different for you (as the handler/parent)?
    - Your child?
    - whole family?
- What are the benefits that you have seen since your child has received their dog?
    - Ask for a specific example
- Tell me about some of the challenges that you and your child have faced since receiving their dog?
    - Ask for a specific example

General closure statements

- Is there anything else that you would like to share?
- We have covered a lot of information and reviewed a lot of different experiences, is there anything significant that you think I may have missed?
- Earlier in the interview you mentioned _____. Could you please go back and tell me a little bit more about this experience?

"I am very appreciative of you taking the time to share your knowledge and experiences with me. I am excited to complete this project to continue to educate people on the impact of autism assistance dogs on children's participation in daily life activities. If you have any other questions or want to follow-up about the results of the study, please feel free to contact me via email anytime. I will be in touch with you in the next few weeks regarding your gift card compensation and general themes that emerged from all of the interviews."

IF EMOTIONS IMPACT INTERVIEW

- Validate and acknowledge emotions
    - I can see that this is difficult…
    - It is not surprising and is normal for you to feel this way….
- Ask if they need a break
- Ask if they would like to move onto the next topic/question
- Give them the option to stop the interview (after they have taken a break)
- I can see that this has been hard for you and emotionally taxing. How are you feeling now?

Appendix G- List of Additional Themes and Supporting Quotes

- "They are not robots." Challenges associated with having autism assistance dog
    - "They're not robots…so we knew that…there was going to be work involved and there's still work involved…I mean she tried to snatch a treat from me about a week ago and it like set off a red flag for me and I had to text the teacher and be like, 'Hey, I just want to make sure that you guys aren't teasing her with her carrot snacks...' And sure enough, David had been making her do tricks at school I guess, and holding the food in front of her, kind of teasing her with it. And…I just had to reiterate it- like, we can't do that the way she's been trained…We don't ever want her to have like an aggressive kind of drive to get food…So it's always a work in progress…because again…they're not robots. They're animals. They're well behaved, well-trained animals, but they're not robots, they're not perfect." [Bella, interview 1]
    - "It's just some continuing work you know? It's like being a parent, you don't just parent for the first 6 months, you're always parenting and teaching and working on things. And with Dixon that's no exception. But it's absolutely worth it- just for what she does for David and for our family." [Bella, interview 1]
    - "I think there's just always that like overlying awareness that he could do something or misbehave, that would give service dogs a bad name or that would…translate into I'm a bad mom or I'm a bad handler. Like if he barks unexpectedly. One thing he does that I've worked on so hard and I just

don't know that I'm ever going to be able to fix it, is if we're in the doctor's office and the door's closed and they knock on the door, he like he barks. And it's only one…but…here you are in…a doctor's office where you're already like tiptoeing around because you're bringing an animal into this super, hygenic place and the first thing he does when the doctor walks in is let out a woof… it's little moments like that where I feel my stress level go up a little…I expect it now and now I don't get flustered…I don't let it deter me from bringing him…it's just part of it…he's still a dog, at the end of the day." [Helena, interview 2]

- "I think that was the biggest 'aha' thing for me is all of the work that it takes to have…a service dog in general…they're still dogs and they're going to still bark sometimes and they're still gonna pick up a piece of food off the ground occasionally. And I think when you have a kiddo with special needs, it's really hard because you're just staying on top of them and then you have this dog [that you also need to stay on top of]… And that was a learning experience. Um, but that was hard cause I didn't want to mess it up… you get this big responsibility of a dog and a very well trained dog at that." [Olivia, interview 2]
- "I'd much rather go into things open and [share to others in public] like, here we are and here's what we do and here's why [the dog's] here instead of just to show up with a service dog… and make them like wonder, 'Like, is that a real service dog? Is he trained? Where did he get his training from, are they just, you know- are they faking?' And you know, it [being

stopped and questioned] happens- it happens a lot here because people do bring their [non-assistance] dogs everywhere…I hate to say it, but there are a lot of people that fake service dogs. I don't want to deal with that. So for me it's almost easier to just act preemptively [and explain the service dog's duties before being questioned. Especially because people many people will ask questions that are not legally asked to allow according to ADA]. Especially you know because, because Diana has autism and…it's invisible, unless she's exhibiting behaviors." [Helena, interview 2]

- What if he was an oxygen tank? The dog as an adaptive tool
    - "I see it [the dog] as…just part of our pack and this is part of Collin's tools, you know, his headphones, his necklace and everything else." [Danica, interview 2]
    - "If we're talking about Fern [the dog] being a tool, I look at it the same way. If [the dog] was a pair of crutches or a wheelchair or…an oxygen tank, are they going to deny that?" [Helena, interview 2]
    - "Those are the times where I have to think of Fern as a tool, and not a dog…so I'll ask myself, well, 'what if he was a wheelchair? Would I wheel him out just to make everyone comfortable or do I keep the tool in here?' So, and I'm very calm and I'm very confident in Fern and his behavior and my ability to control him…I had one mom that was like, 'Oh yeah, my kid's afraid of your dog…' I just said, 'Oh yeah, that's okay.' You know… I do, I feel bad…but at the same time he's under my chair. I make him as unobtrusive as possible…And then I'm proud of myself because it's like I

have to make those decisions on my own…do I cower out and be like okay, we'll go wait in the car or do I keep him available if Diana needs him? That can be tricky because I really do want to be respectful of people and I understand that kids have fears, but Diana has a right to have her dog there as well." [Helena, interview 2]

- "Lay on": The provision of deep pressure and sensory input to improve self-regulation
    - "The first night [the dog] came home, I mean we had her in bed with him doing a lay on…to kind of ease them into like, well now this is what [the dog] does instead of mommy or daddy sitting with you and laying on top of you to help you fall asleep- [the dog] does this." [Bella, interview 1]
    - "We would have had to lay on him- like physically like our whole body lay on top of him to get him calm enough to go to sleep and then it would have taken a long time for him to go to sleep. Now he goes to sleep right away and obviously we don't have to stay in there with him to help him sleep." [Bella, interview 2]
    - "If she's on the ground [having a tantrum], I always use lay on and he instinctively…like usually I don't even finish saying the command and he's already on her because he knows what she needs." [Helena, interview 2]
    - "I'm starting to find that Xavier really seeks Comet out more at home. He'll seek Comet out for pressure. Like he'll grab on Comet and like push Comet onto his like stomach or onto his body." [Olivia, interview 2]

- “One thing I use Comet for a lot in the morning is Xavier doesn't want to get out of bed, so I tell Comet to get up on the bed and then to kiss and he'll get up because you know, the dog's kissing him in the face…a lot of it at home is just kind of like love and playing and that deep pressure.” [Olivia, interview 2]

- Match made in heaven: Considering not only one, but two personalities
  - “I think a lot of times people don't understand how important it is to be matched with an animal that fits your family and your child.” [Bella, interview 1]
  - “Especially with autism dogs…it's not always that the child doesn't get to be the handler, but very often the parent is the handler, so you're not only matching…the parent's style, but you're also having to match it to the child…it's different cause you have to take in two people's styles.” [Danica, interview 1]
  - “When we were at the training, there were four of us and four dogs. It’s amazing how much those dogs personalities really do match the person's. Um our family kind of goes a lot and we…have a lot of energy. And Comet has a lot of energy. Actually, when we were at Disney with Comet, he came in and just crashed on the bed and I took a picture and sent it to the trainer [saying] ‘look, I wore him out’ because they were like, this dog never gets worn out…so that was a pretty cool process.” [Olivia, interview 1]

- “Labradoodles are so pack oriented; they want to love everybody in the family…I mean that's Fern. Like he has his own unique relationship with each one of us in the house…he loves us all, like so much, but he knows that he works for Diana. So he knows when he puts his vest on and when we leave the house- he knows he's on duty and that that's the girl that he works for. Like his eyes are on her. He won't take his eyes off her. He follows her where ever she goes.” [Helena, interview 1}

- Going, going, gone: The power of the leash in bolting prevention
  - “He was never tethered, but like he knows he has his dog and he knows it's his responsibility and how much she helps him, so he knows not to drop the leash. It's given him more patience and also still keeps him from bolting- it's like the bond is an invisible tether.” [Bella, interview 2]
  - “I wanted him to be able to not have to hold my hand out in public, but I needed to keep him with us and that's when she did mention that sometimes they do tethering. And so like we're at Disneyland and he's holding a leash for Jasper and I'm holding a leash for Jasper that helps to keep him with us without having it look inappropriate- that there's a 13 year old boy that's taller than me that's holding my hands. You know, so kind of age appropriateness but keeping him safe at the same time.” [Danica, interview 1]
  - “Maybe four years ago/five years ago, Diana was bolting from me a lot. Like would run from me; like we had to call the police cause she ran off in the mall from me and we couldn't find her- like she was a full on runner

and so I didn't know what it was going to look like. Are we going to have to put like the vest thing around her? Um, but by the time we got Fern, she was a little bit older and I was like, let's start with the least restrictive thing and then just see how that works. And it worked. She grabbed the leash and she doesn't really let it go. And if she does let it go, it's just something kind of- it's not purposeful. It's like oh I want to look at that and she'll kinda like drop the leash, but it's never like drop the leash and runaway. If anything, she's very like, where's Fern? Is he coming? I need to know where he is." [Helena, interview 1]

Appendix H- AJOT Author Guidelines

Authors submitting manuscripts based on qualitative research should refer to the standards developed by the American Psychological Association Publications and Communications Board Working Group on Journal Article Reporting Standards for Qualitative Research (JARS–Qual Working Group). See Levitt, H. M., Bamberg, M., Creswell, J. W., Frost, D. M., Josselson, R., & Suárez-Orozco, C. (2018). Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA Publications and Communications Board task force report. *American Psychologist, 73,* 26 -46. http://psycnet.apa.org/doi/10.1037/amp000015

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Instructions for AJOT Structured Abstracts

(updated March 2020)

AJOT requires structured abstracts for all research articles. Guidelines for abstracts for abstracts for research reporting original data (including qualitative research), meta-analyses, systematic reviews, and meta-syntheses are below.

In addition to these requirements, authors should note the following:

- Abstracts should contain only information that is also provided in the main text of the manuscript while not extensively repeating the findings.
- In adhering to the word count, authors may write parts of the abstract as phrases rather than as complete sentences.
- *AJOT* editorial staff may combine abstract headings, as appropriate.

Each abstract should conclude with "**What This Article Adds,"** one or two sentences that provide a plain-language summary of what the research adds to occupational therapy or how it could benefit occupational therapy clients. This section is **not** included in the abstract word count.

Original Data (Including Qualitative Research)

Abstracts should have no more than 250 words and should use the headings listed below, in the order indicated.

Importance: Provide one or two sentences explaining the importance of the study question.

Objective: Provide the objective or study question (e.g., "To assess the validity of. . . ." "To assess the effectiveness of. . . ."). For studies with multiple objectives, state the main objective and key secondary objectives. State any a priori hypotheses tested.

Design: State the study type (randomized clinical trial, cohort, interview or focus group, etc.) and basic design of the study. Indicate the study length and follow-up intervals as well as any relevant blinding of researchers.

For *qualitative research*, include the sampling and data collection method, the analytical approach taken and its justification in light of the research question, and how the reliability and validity of the data were determined.

Setting: Describe the study setting (e.g., individual clinic, community, health care institution).

Participants: Summarize the clinical issues, inclusion criteria, and sociodemographic features of study participants. Indicate the number of eligible participants and the selection process (random, snowball, volunteer, etc.).

Intervention: If the study involves an intervention, describe its key components, including the method and duration.

Outcomes and Measures: State the study outcome measures planned before data collection began; if the manuscript does not report the planned outcomes, state why. Indicate whether the hypotheses tested were formulated during or after data collection. Be sure to explain any outcomes or measures that would not be familiar to a general occupational therapy readership.

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Results: State the basic demographic information (e.g., sex, age) and final number of study participants. Summarize the main outcomes of the study; if space permits, present key quantitative results (with confidence intervals or other qualifiers, if applicable). In reporting statistics, refer to *AJOT*'s resources on reporting standards and the Guidelines for Contributors.

Conclusions and Relevance: State conclusions that are directly supported by the results, whether the findings support or refute the hypotheses tested. Indicate the implications for clinical practice or health policy (to be elaborated upon in the manuscript's "Implications for Occupational Therapy Practice" section). Indicate whether additional study is required before the results can be applied in clinical settings.

For *qualitative research*, provide sufficient information to support the interpretation of qualitative data. Give equal emphasis to positive and negative findings of equal scientific merit, or deviant cases that do not fit the central interpretation of qualitative findings.

What This Article Adds (not included in abstract word count): Provide one or two sentences that provide a plain-language summary of what the research adds to occupational therapy or how the results could benefit occupational therapy clients.