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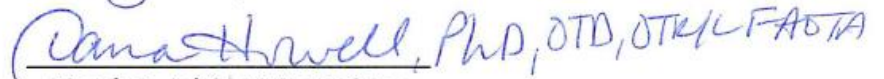
FROM PERCEIVING TO ACHIEVING: EXPERIENCES OF AN ADOLESCENT WITH AUTISM
SPECTRUM DISORDER IN A SUMMER DAY PROGRAM

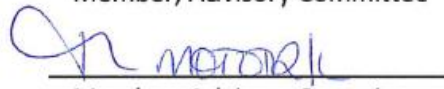
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FROM PERCEIVING TO ACHIEVING: EXPERIENCES OF AN ADOLESCENT WITH AUTISM
SPECTRUM DISORDER IN A SUMMER DAY PROGRAM

BY

SPENCER HAMMOND

Submitted to the Faculty of the Graduate School of
Eastern Kentucky University
in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

2019

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Toby Scott-Cross MOT, OTR/L: Committee member who provided guidance for study development, on site advising during data collection, and suggestions for editing.

Dana Howell PhD, OTD, OTR/L, FAOTA: Committee member who was instrumental in the study's development and provided feedback for editing of the written product.

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Finally the primary author would like to thank his parents and the rest of his family who have supported him throughout his college experience and instilled in him the values and work ethic required to find and follow a plan and a purpose.

ABSTRACT

Literature describing the experiences of adolescents and their families with summer day-programs is scarce. This study sought to reveal such experiences from one individual participating in a summer program, HorseAbility, in which individuals with disabilities interact with each other through planned and self-directed activities, therapeutic riding, and activities associated with taking care of horses. Interviews were conducted with an adolescent diagnosed with Autism Spectrum Disorder, his parent, a staff member of the summer day program, and the therapeutic riding instructor. Observation data and personal journaling was also used for data collection mechanisms. Data sources were triangulated to provide a rich understanding of the case. The interviews were transcribed and coded using an inductive approach. Two major themes were identified including, perception is critical to adolescent experiences and the just right challenge's role for adolescent engagement and memory building. Results suggest reinforcement of typical adolescent developmental challenges and the need for engagement opportunities based upon skill development. Suggestions for future program development are included to support occupational engagement.

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Chapter 1: Introduction

Summer day-camps can be a resource for parents and their children during the summer break between school years. These camps may be considered to provide activities for entertainment, skill building, health promotion, and learning for children while also providing respite care or a daycare-like service for parents. Adolescents often attend summer programs, but many are commonly trusted to care for themselves at home. If an adolescent is unable to care for themselves at home parents may find themselves searching for resources and programs that can provide day care services throughout the summer that their teenager also finds engaging and meaningful. By investigating the perspective of an adolescent in a summer day program and those involved in his care, we can begin to develop an understanding of how a summer program can better serve this population.

Background and Need

According to Baio et al. (2018) it is estimated that one in fifty nine children in the United States are affected by Autism. Autism Spectrum Disorder (ASD) is characterized by challenges with social skills, speech, nonverbal communication, and repetitive behaviors. Other challenges that are often associated with ASD are difficulties with sensory processing and regulation, gastrointestinal disorders, sleep disorders, and seizures (Autism Speaks®, 2018). It can be diagnosed as early as eighteen months (Autism Speaks®, 2018), but it is a lifelong condition with symptoms that often do not improve or reduce in severity as individuals approach adolescence and adulthood (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). It has been found

that services for individuals with ASD often decrease as they move out of childhood (McCarty, 2013). This creates a need for programs that are designed to be inclusive or cater to individuals with ASD so that they can continue to develop skills needed to live as independently as possible and become an engaged, socially contributing member of society.

Adolescence is a time of increased social awareness and influences (Knoll, Magis-Weinberg, Speekenbrink, & Blakemore, 2015) and identity development. It is a time during which an individual is developing a more autonomous identity, yet they are still under the care of their parent or guardian. Therefore, an adolescent should be treated as an individual, but family context and needs should always be considered. Having a child with ASD can restrict a family's ability to engage in meaningful occupations, as the child's needs often are priority (DeGrace, 2004). Individuals with ASD have documented challenges with social skills (American Psychiatric Association (APA), 2013), thus they may struggle during adolescence more than their typically developing peers. However, research suggests that adolescents with ASD can exhibit socially adapted behaviors as a result of being attuned to social contexts (Van Hoorn, Van Dijk, Crone, Stockmann, & Rieffe, 2017) and can learn social skills through interactions with typically developing peers (Jamison & Schuttler, 2017). Summer camps and programs are places that can support an adolescent's development while also fulfilling family needs for daycare or respite care. A crucial element in designing summer programming is ensuring that the target population will be engaged in meaningful occupations. HorseAbility is a nine week summer day camp that serves

families with school aged children with varying disabilities and conditions. Each participant engages in activities with horses, particularly therapeutic riding (TR), led by a certified TR instructor (TRI). Other staff members are trained to provide for unique needs of individuals.

Upon review of the literature on TR, summer programs, and adolescents with ASD, very few studies included qualitative data describing the participants' perceptions. McDaniel Peters and Wood (2017) specifically called for more qualitative studies to be conducted in order to capture the perspectives of participants and parents in regards to TR programs. Exploratory case studies can be used to investigate people's unique experiences (Jones & Hocking, 2015).

Statement of Purpose

This exploratory case study explored an in-depth analysis of the perspectives of an adolescent with ASD, his parent, and select staff members about attendance at a summer day program involving TR through inductive analysis of interviews, observations, and personal journal data.

Grand Question

The grand question that this study sought to answer was: what are the unique experiences of a participant in the HorseAbility program and what do those experiences mean to that participant and those around them?

Literature Review

The purpose of this literature review was to gather, evaluate, and discuss primary and secondary sources regarding Autism Spectrum Disorder (ASD) and

development, adolescents with ASD, engagement of typical adolescents, family experiences/needs, summer day programs for individuals with ASD, and TR. Databases that were used include Academic Search Complete, Agricola, Child Development & Adolescent Studies, CINAHL with Full Text, Education Full Text, Health Source-Consumer Edition, Human Resources Abstracts, Humanities Full Text, MEDLINE, PsycARTICLES, PsycINFO, and SocINDEX with Full Text. Key words included experiences, perceptions, attitudes, views, community program, adolescents, teenagers, teens, young adults, development, identity, therapeutic riding, equine assisted therapy, summer camps, and summer programs. Source mining of articles found was also utilized to acquire primary sources and verify interpretations of findings.

Autism Spectrum Disorder and Development

According to Baio et al. (2018), autism affects an estimated 1 in 59 children in the United States. This is a fifteen percent increase since the estimate from 2012 of 1 in 68 children. They also reported that, although a gender gap still exists between girls and boys being diagnosed with ASD, boys still are diagnosed with ASD more than girls by a ratio of 4:1. Ethnic minorities within the US are beginning to show an increase in diagnosis, possibly due to increased awareness of ASD (Baio et al., 2018). The average age at which children are becoming diagnosed is still after age four although it has been found that individuals can be reliably diagnosed by age two (Baio et al., 2018). As prevalence of ASD increases, advocacy for needed services also increases as individuals may require services across life span from early intervention as an infant to services

well into adulthood. Services must be provided within the context of the physical, cognitive, and social-emotional development of the individual.

Seltzer and colleagues (2004) reported that very few individuals have ASD have symptom improvement or abatement in adolescents and adulthood, yet services for individuals with ASD often decreases as they move out of childhood (McCarty, 2013). Considering the lifelong implications of ASD, it is important that we gain more knowledge about adolescents and adults with ASD so that we can provide age-appropriate services that can assist individuals into their futures. A shift should occur when providing services for adolescents with ASD to a focus on transitioning into adulthood. According to Cimera, Burgess, and Wiley (2013) individuals with ASD may benefit from starting transitional services earlier at age fourteen instead of age sixteen. Benefits found were a higher probability of being employed and earning more wages (Cimera et al., 2013).

Adolescents with ASD

According to an evaluation of evidence-based practices for social skills interventions for individuals with autism by Reichow and Volkmar (2010), only three studies from their review were focused on the adolescent to adult age group. The interventions used in these studies centered on social initiations, social communication, and general social skills and took place in either a community setting or in the home. An understanding of current interventions' foci for this age group and the context in which they are provided can assist in seeking new opportunities and continuing to shape what is known as best practices.

Social skills training has been noted throughout the literature as a significant service for adolescents with ASD (Teitt, Eastman, O'Donnell, & Deitz, 2010). It is essential that the training focus on context specific to them and their social context such as high school (Gutman, Raphael-Greenfield, & Salvant, 2012). It is also beneficial to promote interactions with “typically” developed peers for learning of social skills (Jamison & Schuttler, 2017). Van Hoorn et al. (2017) suggest that socially adaptive behavior is fostered through peer engagement in a social environment. This counters the limited social awareness that is associated with ASD (APA, 2013) and suggests that adolescent males with ASD are aware of and influenced by social context.

Engagement of Typical Adolescents

Adolescence is known as a time of increased awareness of social context and influence (Knoll et al., 2015). Adolescence has been described as “a time of struggle to find a balance between autonomy and connectedness” (Spies Shapiro & Margolin, 2014, p.17). Being connected to others, especially through friendships supports development of identity during adolescence. Jones, Vaterlaus, Jackson, and Morrill (2014) wrote “that along with the increased complexity within friendships, a reciprocal responsibility may exist in the development of identity formation” (p.66) when reporting findings from study on adolescent identity development and friendships. Therefore, adolescents need to be engaged their friendships as a member of a reciprocal relationship. These relationships have expanded beyond immediate family members throughout the past several decades, causing their psychosocial development to be influenced by an expanded social network (Jones et al., 2014). The

internet, new technologies, and expanding social networking have also been found to influence adolescent engagement and identity development. Spies Shapiro and Margolin (2014) completed a systematic review to investigate the link between adolescent identity development and sharing of information on social network sites. A study included in their review found that “self-disclosure, which involves an iterative process of sharing personally relevant information and receiving feedback, is central to identity formation” and that “online self-disclosure to known friends in early adolescent years was associated with greater offline self-disclosure” (p.9). Considering how to foster engagement for the adolescent population requires applying such knowledge regarding the impact of each context, including virtual, on engagement and identity development.

Family Experiences and Needs

When considering working with individuals that are children or adolescents, it is crucial to consider their families as well. According to DeGrace (2004), families that have a child with ASD may experience difficulty engaging in meaningful activities of daily living because of the demands that are placed on their lives to meet specific needs of the child with ASD. It has also been found that over time, families/parents learn and develop different coping strategies and become less dependent on treatment services for their child with ASD (Gray, 2006). Gray (2006) suggested this may be due to children’s challenges becoming less as they develop skills, families and children establish routines, and services not being available for adolescents and adults causing families to seek out other solutions. Within the field of occupational therapy

(OT), the use of family centered care and strategies for coaching parents on strategies to help their child has recently been gaining support and being considered evidence-based practice. A literature review by Simpson (2015) found that preliminary support for the use of contextual coaching interventions to improve occupational performance and participation outcomes in children and adolescents with ASD. Positive effects were found on the “sense of self competence and efficacy” of parents (Simpson, 2015). It is important to consider strategies that support effective for families along the unique needs of families with a child with ASD when developing a program that provides services for such individuals.

Summer Day Programs for Individuals with ASD

Summer programming is a typical experience for adolescents. Research involving summer programs for children, youth, or adolescents is as broad as the list of categories the camps focus on from sports to religion to technology. Therefore, general statements regarding summer programs for individuals with ASD cannot be adequately supported. The American Camp Association (ACA) is “a community of camp professionals who, for over 100 years, have joined together to share our knowledge and experience and to ensure the quality of camp programs” (ACA Inc., 2018a). They provide information regarding camps, programs, and sessions within the United States. Using their website (acacamps.org) a search for camps, sessions, and programs that specifically include and provide services to individuals with ASD produced a list of 57 day camps, 80 programs, and 48 sessions. This resource can be useful for parents searching for summer programming for their child regardless of levels of abilities. Most

literature on summer programs or camps exists in the public domain as promotional materials or covers stories. Liu and Meaney's (2011) cover story does exist in an academic journal, providing preliminary discussion of outcomes of a recreation based summer camp for children with ASD according to parent and camp counselor reports. They concluded that the camp was beneficial for children with ASD and their families (Liu & Meaney, 2011). Kaboski and colleagues (2015) found that during a week-long summer robotics camp during which "highly verbal adolescents with ASD" were paired with typically developing adolescents, adolescents with ASD self-reported reduced social anxiety. They proposed that focusing on strengths of the participants instead of deficits while fostering engagement in an "intrinsic shared interest" negated the need to disclose that individuals had ASD and prevented power imbalances. (Kaboski et al., 2015, p.3867). A limitation noted by Kaboski et al. (2015) was that their results could not be generalized for the ASD population as their study included only individuals with a certain intelligence quotient (IQ) level.

Studies specifically targeting summer day programs for individuals with ASD were difficult to find within the literature and were not generalizable to the ASD population. Most information regarding summer day programs was found within the public domain, serving a more utilitarian purpose for parent resources, but limiting academic review.

Therapeutic Riding

According to the Professional Association of Therapeutic Horsemanship International (PATH Intl., 2018a) TR is defined as "an equine-assisted activity for the

purpose of contributing positively to the cognitive, physical, emotional and social well-being of individuals with special needs". It is one category of many practices that fall under the term, equine-assisted activities (EAA) (PATH Intl., 2018a). During TR sessions, individuals participate in horseback riding with adaptations or supports as needed. The movement of the horse transfers to the rider, facilitating physical input to the rider's muscles along with proprioceptive and vestibular sensory input. Social skills are also targeted as the rider interacts with assistants (horse leader and side walkers), the TR instructor, and even the horse. Therapeutic riding "provides benefits in the areas of health, education, sport and recreation & leisure" (PATH Intl., 2018b). Instructors have knowledge and experience with riding instruction, equine management, teaching methodologies, horsemanship, and disabilities. Through PATH Intl., individuals can receive certification at three levels; registered (basic knowledge), advanced, and master (PATH Intl., 2018c).

Therapeutic riding can lead to improvements in sensory processing (Bass, Duchowny, & Llabre, 2009; Ward, Whalon, Rusnak, Wendell, & Paschall, 2013), a reduction in the severity of autism symptoms (Kern et al., 2011; Ward et al., 2013), decreased negative behaviors (Bass et al., 2009), social motivation (Bass et al., 2009), increased social interactions (Ward et al., 2013), and social functioning (Anderson & Meints, 2016) among children with ASD. Using the Pediatric Quality of Life 4.0 Generic Core Scales (PedsQL) and the Child Health Questionnaire (CHQ), Lanning, Baier, Ivey-Hatz, Krenek, and Tubbs (2014) studied the effects of equine assisted activities on children with ASD. Parent reports suggested an increased quality of life, specifically

among the domains of “social functioning, physical functioning, school functioning, and overall mental health and behaviour” (p.1904). A qualitative study of parents’ perceptions of therapeutic horseback riding (THR) was completed in South Africa by Boyd and le Roux (2017). Parent interviews revealed perceptions that THR had a positive impact on their child physically (posture and core stability), psychologically (self-esteem, confidence, cognitive abilities), and socially (ability to interact with others) (Boyd & le Roux, 2017). Borgi and colleagues (2016) studied the effects of a standardized equine assisted therapy (EAT) program on children with ASD. During the program children completed activities involving horses both on (riding) and off (grooming) the horse. They found that participants showcased improved social functioning and executive functioning (specifically initiating during problem-solving tasks) after the six-month EAT program (Borgi et al., 2016).

McDaniel Peters and Wood (2017) completed a systematic mapping review of peer-reviewed studies involving equine assisted interventions for children and adolescents with ASD from 1980 to 2015. From that time period, they found thirty three articles that met inclusion criteria with 2003 being the year of the oldest study included. Therefore, the authors concluded that scientific review of equine assisted activities began fairly recently. Of the studies included in their review, only one included qualitative measures. McDaniel Peters and Wood (2017) concluded that there is “general proof of concept that equine-assisted interventions can benefit children and adolescents with ASD” (p.3239-3240) and “there is a need for research that privileges the voices and perspectives of people with ASD, their families and

caregivers, regarding whether or how particular equine-assisted interventions benefit them” (p.3240). The one study included in the review that included qualitative measures only incorporated parent reports and no qualitative data from the actual child (McDaniel Peters & Wood, 2017). A gap in the literature exists for qualitative studies aimed at gaining an understanding of participant perceptions of TR.

Summary

Literature was explored to provide an understanding of ASD and development, adolescents with ASD, engagement of typical adolescents, family experiences/needs, summer day programs for individuals with ASD, and TR. Most literature found regarding summer day camps, TR, and family dynamics focusses on the childhood population. A void exists for adolescents. In typical development, adolescents present with many challenges as they negotiate life. The majority of the studies of the effects of TR or EAA are quantitative and do not capture the perception of the participant. Thus a need for this study is presented.

Chapter 2: Journal Article Manuscript

Title

From Perceiving to Achieving: Experiences of an Adolescent with Autism Spectrum Disorder in a Summer Day Program

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Keywords

Adolescents, Summer Day Program, Autism Spectrum Disorder (ASD), Therapeutic Riding (TR), Engagement, Just Right Challenge

Abstract

Literature describing the experiences of adolescents and their families with summer day-programs is scarce. This study sought to reveal such experiences from one individual participating in a summer program, HorseAbility, in which individuals with disabilities interact with each other through planned and self-directed activities, therapeutic riding, and activities associated with taking care of horses. Interviews were conducted with an adolescent diagnosed with Autism Spectrum Disorder, his parent, a staff member of the summer day program, and the therapeutic riding instructor.

Observation data and personal journaling was also used for data collection mechanisms. Data sources were triangulated to provide a rich understanding of the case. The interviews were transcribed and coded using an inductive approach. Two major themes were identified including, perception is critical to adolescent experiences and the just right challenge's role for adolescent engagement and memory building. Results suggest reinforcement of typical adolescent developmental challenges and the need for engagement opportunities based upon skill development. Suggestions for future program development are included to support occupational engagement.

Introduction

According to Baio et al. (2018) it is estimated that one in fifty nine children in the United States are affected by Autism. Autism Spectrum Disorder (ASD) is characterized by challenges with social skills, speech, nonverbal communication, and repetitive behaviors. Other challenges that are often associated with ASD are difficulties with sensory processing and regulation, gastrointestinal disorders, sleep disorders, and seizures (Autism Speaks®, 2018). It can be diagnosed as early as eighteen months (Autism Speaks®, 2018), but it is a lifelong condition with symptoms that often do not improve or reduce in severity as individuals approach adolescence and adulthood (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). It has been found that services for individuals with ASD often decrease as they move out of childhood (McCarty, 2013). This creates a need for programs that are designed to be inclusive or cater to individuals with ASD so that they can continue to develop skills needed to live

as independently as possible and become an engaged, socially contributing member of society.

Adolescence is a time of increased social awareness and influences (Knoll, Magis-Weinberg, Speekenbrink, & Blakemore, 2015) and identity development. It is a time during which an individual is developing a more autonomous identity, yet they are still under the care of their parent or guardian. Therefore, an adolescent should be treated as an individual, but family context and needs should always be considered. Having a child with ASD can restrict a family's ability to engage in meaningful occupations, as the child's needs often are priority (DeGrace, 2004). Individuals with ASD have documented challenges with social skills (American Psychiatric Association (APA), 2013), thus they may struggle during adolescence more than their typically developing peers. However, research suggests that adolescents with ASD can exhibit socially adapted behaviors as a result of being attuned to social contexts (Van Hoorn, Van Dijk, Crone, Stockmann, & Rieffe, 2017) and can learn social skills through interactions with typically developing peers (Jamison & Schuttler, 2017). Summer camps and programs are places that can support an adolescent's development while also fulfilling family needs for daycare or respite care. A crucial element in designing summer programming is ensuring that the target population will be engaged in meaningful occupations. HorseAbility is a nine week summer day camp that serves families with school aged children with varying disabilities and conditions. Each participant engages in activities with horses, particularly therapeutic riding (TR), led by

a certified TR instructor (TRI). Other staff members are trained to provide for unique needs of individuals.

Upon review of the literature on TR, summer programs, and adolescents with ASD, very few studies included qualitative data describing the participants' perceptions. McDaniel Peters and Wood (2017) specifically called for more qualitative studies to be conducted in order to capture the perspectives of participants and parents in regards to TR programs. Exploratory case studies can be used to investigate people's unique experiences (Jones & Hocking, 2015).

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This qualitative exploratory case study explored an in-depth analysis of the perspectives of an adolescent with ASD, his parent, and select staff members about attendance at a summer day program involving TR through inductive analysis of interviews, observations, and personal journal data.

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The grand question this study sought to answer was: what are the unique experiences of a participant in the HorseAbility program and what do those experiences mean to that participant and those around them?

Review of Literature

Literature was explored to provide an understanding of ASD and development, adolescents with ASD, engagement of typical adolescents, family experiences/needs, summer day programs for individuals with ASD, and TR. Most literature found regarding summer day camps, TR, and family dynamics focused on the childhood

population. A void exists for adolescents. In typical development, adolescents present with many challenges as they negotiate life. The majority of the studies of the effects of TR or Equine Assisted Activities (EAA) are quantitative and do not capture the perception of the participant. Thus a need for this study is presented.

Autism Spectrum Disorder and Development

According to Baio et al. (2018), autism affects an estimated 1 in 59 children in the United States. This is a fifteen percent increase since the estimate from 2012 of 1 in 68 children. They also reported that, although a gender gap still exists between girls and boys being diagnosed with ASD, boys still are diagnosed with ASD more than girls by a ratio of 4:1. Ethnic minorities within the US are beginning to show an increase in diagnosis, possibly due to increased awareness of ASD (Baio et al., 2018). The average age at which children are becoming diagnosed is still after age four although it has been found that individuals can be reliably diagnosed by age two (Baio et al., 2018). As prevalence of ASD increases, advocacy for needed services also increases as individuals may require services across life span from early intervention as an infant to services well into adulthood. Services must be provided within the context of the physical, cognitive, and social-emotional development of the individual.

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Family Experiences and Needs

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needs of families with a child with ASD when developing a program that provides services for such individuals.

Summer Day Programs for Individuals with ASD

Summer programming is a typical experience for adolescents. Research involving summer programs for children, youth, or adolescents is as broad as the list of categories the camps focus on from sports to religion to technology. Therefore, general statements regarding summer programs for individuals with ASD cannot be adequately supported. The American Camp Association (ACA) is “a community of camp professionals who, for over 100 years, have joined together to share our knowledge and experience and to ensure the quality of camp programs” (ACA Inc., 2018a). They provide information regarding camps, programs, and sessions within the United States. Using their website (acacamps.org) a search for camps, sessions, and programs that specifically include and provide services to individuals with ASD produced a list of 57 day camps, 80 programs, and 48 sessions. This resource can be useful for parents searching for summer programming for their child regardless of levels of abilities. Most literature on summer programs or camps exists in the public domain as promotional materials or covers stories. Liu and Meaney’s (2011) cover story does exist in an academic journal, providing preliminary discussion of outcomes of a recreation based summer camp for children with ASD according to parent and camp counselor reports. They concluded that the camp was beneficial for children with ASD and their families (Liu & Meaney, 2011). Kaboski and colleagues (2015) found that during a week-long summer robotics camp during which “highly verbal adolescents with ASD” were paired

with typically developing adolescents, adolescents with ASD self-reported reduced social anxiety. They proposed that focusing on strengths of the participants instead of deficits while fostering engagement in an “intrinsic shared interest” negated the need to disclose that individuals had ASD and prevented power imbalances. (Kaboski et al., 2015, p.3867). A limitation noted by Kaboski et al. (2015) was that their results could not be generalized for the ASD population as their study included only individuals with a certain intelligence quotient (IQ) level.

Studies specifically targeting summer day programs for individuals with ASD were difficult to find within the literature and were not generalizable to the ASD population. Most information regarding summer day programs was found within the public domain, serving a more utilitarian purpose for parent resources, but limiting academic review.

Therapeutic Riding

According to the Professional Association of Therapeutic Horsemanship International (PATH Intl., 2018a) TR is defined as “an equine-assisted activity for the purpose of contributing positively to the cognitive, physical, emotional and social well-being of individuals with special needs”. It is one category of many practices that fall under the term, equine-assisted activities (EAA) (PATH Intl., 2018a). During TR sessions, individuals participate in horseback riding with adaptations or supports as needed. The movement of the horse transfers to the rider, facilitating physical input to the rider’s muscles along with proprioceptive and vestibular sensory input. Social skills are also targeted as the rider interacts with assistants (horse leader and side walkers),

the TRI, and even the horse. Therapeutic riding “provides benefits in the areas of health, education, sport and recreation & leisure” (PATH Intl., 2018b). Instructors have knowledge and experience with riding instruction, equine management, teaching methodologies, horsemanship, and disabilities. Through PATH Intl., individuals can receive certification at three levels; registered (basic knowledge), advanced, and master (PATH Intl., 2018c).

Therapeutic riding can lead to improvements in sensory processing (Bass, Duchowny, & Llabre, 2009; Ward, Whalon, Rusnak, Wendell, & Paschall, 2013), a reduction in the severity of autism symptoms (Kern et al., 2011; Ward et al., 2013), decreased negative behaviors (Bass et al., 2009), social motivation (Bass et al., 2009), increased social interactions (Ward et al., 2013), and social functioning (Anderson & Meints, 2016) among children with ASD. Using the Pediatric Quality of Life 4.0 Generic Core Scales (PedsQL) and the Child Health Questionnaire (CHQ), Lanning, Baier, Ivey-Hatz, Krenek, and Tubbs (2014) studied the effects of equine assisted activities on children with ASD. Parent reports suggested an increased quality of life, specifically among the domains of “social functioning, physical functioning, school functioning, and overall mental health and behaviour” (p.1904). A qualitative study of parents’ perceptions of therapeutic horseback riding (THR) was completed in South Africa by Boyd and le Roux (2017). Parent interviews revealed perceptions that THR had a positive impact on their child physically (posture and core stability), psychologically (self-esteem, confidence, cognitive abilities), and socially (ability to interact with others) (Boyd & le Roux, 2017). Borgi and colleagues (2016) studied the effects of a

standardized equine assisted therapy (EAT) program on children with ASD. During the program children completed activities involving horses both on (riding) and off (grooming) the horse. They found that participants showcased improved social functioning and executive functioning (specifically initiating during problem-solving tasks) after the six-month EAT program (Borgi et al., 2016).

McDaniel Peters and Wood (2017) completed a systematic mapping review of peer-reviewed studies involving equine assisted interventions for children and adolescents with ASD from 1980 to 2015. From that time period, they found thirty three articles that met inclusion criteria with 2003 being the year of the oldest study included. Therefore, the authors concluded that scientific review of equine assisted activities began fairly recently. Of the studies included in their review, only one included qualitative measures. McDaniel Peters and Wood (2017) concluded that there is “general proof of concept that equine-assisted interventions can benefit children and adolescents with ASD” (p.3239-3240) and “there is a need for research that privileges the voices and perspectives of people with ASD, their families and caregivers, regarding whether or how particular equine-assisted interventions benefit them” (p.3240). The one study included in the review that included qualitative measures only incorporated parent reports and no qualitative data from the actual child (McDaniel Peters & Wood, 2017). A gap in the literature exists for qualitative studies aimed at gaining an understanding of participant perceptions of TR.

Methods

A qualitative exploratory case study design (Jones & Hocking, 2015) was implemented to explore an in-depth analysis of an adolescent's perspective of attending a summer day program, along with perceptions of his parent and select staff members. Pseudonyms are used throughout reporting of data to maintain confidentiality. For the purpose of this study, the adolescent participant is referred to as "Max". This study was approved by the Eastern Kentucky University (EKU) Institutional Review Board (IRB) to protect the rights of human subjects.

Setting

The camp, HorseAbility, was advertised as a specialized summer program providing children with special needs the opportunity for summer fun. The program focus was to promote enriched learning experiences with horses under the supervision of trained staff that specialize in teaching children with disabilities. The camp was offered at a fully accessible facility located at a horse park in central Kentucky. The camp was offered for 9 weeks, Monday-Friday, 8:00 am-5:00 pm. All participants were required to provide a detailed medical history with a physician's signature for safety purposes. Participants were offered options for varied attendance, with preference given to individuals attending 5 days per week. All participants were expected to provide a brown bag lunch to address modified dietary needs (Easter Seals Cardinal Hill, 2018). During the first several weeks, the age of the participants fluctuated, as did the cognitive abilities of other adolescents. During Week 6, two boys who were similar in age and cognitive abilities to Max began to attend the camp. During Weeks 7-9,

they participated in the camp activities together with the same schedule, as their abilities and interests were better matched. A general schedule was established by the program staff to coordinate meal/snack times, fine and gross motor activities, free time, and TR sessions. Each camp participant's schedule varied as it included a time that they participated in a TR session either individually or in a group. Table 1 is Max's general schedule based upon observation notes.

Table 1 <i>General Schedule of a Typical Day at Camp for Max</i>	
Times	Activity
7:45-8:30am	Arrival, free time and settling in
8:30-11:15am	Fine motor activities
11:15-11:55am	Lunch
12:00-1:30pm	Therapeutic riding lesson
1:40-2:00pm	Gross motor activities and snack
2:00- 4:00pm	Barn chores and activities
4:00-5:00pm	Free time and prepare for pickup

Procedures

Case Selection

The gatekeeper for this program was identified as one of the head staff members of HorseAbility. A convenience sample was obtained based upon gatekeeper recommendations following discussion of the population researcher was primarily interested in studying, adolescents with autism spectrum disorder. Other participants in the summer day program had varied diagnoses and co-morbid conditions.

Data Sources

It is important that researchers utilize multiple data sources to inform a case study (Jones & Hocking, 2015). Data was triangulated between observations, interviews, and journal accounts of the author. All data collection procedures are summarized in Table 2.

	Selection of participants	Observations	Interviews	Journaling
Week 1	X (adolescent participant, parent, and staff member)	X		X
Week 2		X	X	X
Week 3		Researcher absent		X
Week 4		Researcher absent		
Week 5		Student absent		
Week 6		Student absent		X
Week 7		X		X
Week 8	X (therapeutic riding instructor)	X		X
Week 9		X	X	X

Semi-structured in-depth interviews were conducted with one adolescent (Max), the adolescent's parent, the TRI, and one staff member of the HorseAbility program. A total of seven interviews were conducted for this project. The primary author allowed for the participant to become comfortable in the program, thus Week 1 was considered a rapport building time with the expectations of the summer program. Interviews were conducted during the second and ninth week of the nine-

week summer day program. Interviews were conducted during the second week of the summer day program with the adolescent participant, his mother, and a program staff member. Final interviews were repeated with those individuals as well as the program's TRI during the final (ninth) week of the program. The TRI was added as a post interview, based upon researcher observations during the camp and participant engagement. The TRI was selected to add rich description of his engagement during the summer day program. Initial interview questions were created to capture what interviewees' perceptions of HorseAbility and foreseen challenges, outcomes for Max. Final interview questions were formed to encourage reflection on Max's experiences, challenges, and achievements during the summer as well as suggestions for program improvement.

Observation notes were recorded by the primary author over the span of five visits. The researcher was able to complete observations during the first two and final three weeks of HorseAbility. Course work prevented the primary researcher from obtaining observation data during weeks three and four. Max's absence also prevented observations during weeks five and six. A participant observer role was utilized as it promoted more natural integration of the researcher into the context of the program (Jones & Hocking, 2015). Participants of HorseAbility were accustomed to various adults participating in program activities. Observations were written in narrative and listed formats categorized by setting, activity, and time directly after each activity. Notes were written in a separate location than the participants to ensure confidentiality and in order to maintain a participatory role. Staff reports regarding

Max's participation, attitude, and overall engagement over time were also included in observation notes, but were denoted as such to separate them from the researcher's observations. Their reports were brief and not asked or received while Max or other participants were present in order to maintain confidentiality. Observation data provided rich and descriptive examples of Max's behavior so that could be compared to interview data and reports.

The primary author kept a self-reflective journal throughout the process of creating and implementing the project. Journaling continued throughout the transcription and coding processes. Personal thoughts regarding forming and managing the case study along with records of communication with participants, program staff, and the researcher's thesis mentor were recorded for future reference. The self-reflective journal was reviewed to provide insight into decisions made by the primary author to ensure triangulation. Self-reflective journaling also was used to enhance the learning experience of the primary author.

Data Analysis

Interviews were transcribed verbatim and analyzed through an inductive approach along with the observation notes. The primary author methodically read transcripts, observation notes, and personal journal data. While reading, words or phrases were highlighted and/or paraphrased in the margins in order to begin finding similarities and differences among the data. A constant comparative method of coding was used. Throughout this process of initial coding the primary author and committee chair met to discuss codes and emerging themes. A session was held to map out codes

and data. While potential themes were discussed observation notes and transcripts were referred to in order to ensure coding and themes truly reflected the data and therefore the participant's perspectives. Direct quotes were derived from the transcripts that were reflective of the themes that were formed. Codes were collapsed into two major themes, each with their own sub themes.

Results and Discussion

Two major themes were derived from immersion in the qualitative data. They are: perception is critical to adolescent experiences and the just right challenge is needed for adolescent engagement and memory building. Each of the themes are presented as they related to Max's experience. Results included below consist of quotes and observation notes that were derived from the data. The results are discussed in comparison with each other and with literature. Discussion also includes how the author interprets the data within the context of the study.

Perception is Critical to Adolescent Experiences

The first major theme involves the importance of perception when considering the experience of an adolescent with ASD in a summer day program. This was best described through the use of four subthemes: advertising a summer day program, framing activities, attitudes, and social participation and development. These subthemes act as guiding factors for programs that are intended to serve adolescents with ASD.

Advertising a Summer Day Program

The perception of an individual regarding if they will enjoy or want to be engaged in a summer program begins with how the program is presented or advertised to them and the rest of the public. The participant within this study, Max, indicated that he did not want to identify with the special needs population, which was a marketing focus in program design. His mother stated, while discussing some negative attitudes that her son formed during his experience, that “he doesn’t like anybody talking about him having special needs... so it is a huge issue to him that it is a special needs camp”. Negative perspectives of participants can often be mitigated by making the focus of a program an intrinsic shared interest, taking the focus away from any special needs that participants may have (Kaboski et al., 2015). Program development for individuals with special needs must address broad characteristics. Marketing programs such as HorseAbility broadly conveys a safe, yet therapeutic environment for participants. Yet, having too broad of a population focus, such as larger age spans and varying skill levels, as it was noted in observation notes and interviews, may be problematic. In a final interview with a staff member, she stated that the Max “felt like he was too old for the camp” and “he didn’t put himself on the same level.” Programs have to walk a fine line between adequately making known the special needs their program provides services for while also being aware of the identity that their population may have or may be forming (Kaboski et al., 2015). When the target population includes adolescents who are often in a process of forming their identity, this can prove to be a challenge. Adolescence is well known as a time of

changes physically, emotionally, and socially (Knoll et al., 2015). It is a time that individuals are not always sure of who they are and how they should act. Social context becomes more important in adolescence as they become more conscious of other's perceptions and their engagement in activities (Knoll et al., 2015).

Framing Activities

Issues that arise from the struggle between adolescent identity and a program's focus can be mitigated through the way in which activities within the program are framed/ created (Kaboski et al., 2015). Meeting distinctive interests comes to the forefront of the in-depth analysis of this case study. During the initial interview with Max's mother she stated her son's self-esteem had been improved from "learning a new skill that everyone doesn't necessarily know". Horseback riding is a unique opportunity that has appeal to the adolescent population. When asked, during the initial interview, what Max looked forward to he stated "learning to ride outside, just learning to round the horses and stuff". Offering such an experience helps to build skill, character, cognitive problem solving opportunities and understanding of leisure choices and developing occupational competence through interest exploration. Introducing specialized programs such as TR to the special needs population requires consideration of staff training and expertise to properly and safely provide services (PATH Intl., 2018b). This program was advertised as providing such services. Program directors and developers should have a desire to meet the interests of the individuals they serve (ACA, 2018b). Using an ability focus to programming supports inclusive mindsets and reinforces the personal growth and drive for participation needed in the

adolescent population. Therefore, it is crucial for program directors to foresee training needs to properly prepare staff.

Meeting the needs of participants is also an area requiring training to address the range of special physical needs and/or behavioral needs. A staff member of HorseAbility reiterated this when saying “...I think it is important that it is established like this is a camp more for physical disabilities or this is a camp for more behavioral issues or if we are going to do both the counselors are trained in this.” It is important that staff members of the program have the tools, training, and skills to competently and confidently lead participants in activities. Participants and their families possess trust in the staff and their competence, thus shaping their perspective of the camp opportunities.

Attitudes

One word that comes to mind when considering working with adolescents is attitude. This word came up several times throughout this study and deserves to be recognized as a piece of perception. Attitude can be synonymous with outlook or approach as well as defiance or insolence. Max discussed his perceptions of the previous year attending the HorseAbility program. He smiled, sat up a little more straight, and stated “I met a new friend...she helped me go through like horse stuff like tacking, like riding, and all that stuff.” His demeanor completely changed while answering this question revealing his attitude about a part of the camp that had been a significant part of his experience. His outlook on the portion of the camp that challenged him to learn about and interact with horses seemed positive. In his

mother's final interview she stated "it is hard to get a grip on if there is a difference or not with him because he just has attitude out the roof." From her words we could gather that attitude served as a barrier between her knowing and not knowing her son's perception of the program. It is important to recognize that attitude can and will change as perceptions are formed about the program. The key is to recognize this change and adapt accordingly within development of the program.

Social Participation and Development

Navigating the attitudes of participants can be a test of social awareness. Another key element that was found as part of forming perceptions of the program was social participation and development. Although the adolescent within this study has ASD, which is characterized by difficulties with social skills (APA, 2013), he was still very much in tune with his social context. Within the first interview with a staff member, she informed me that "he told the camp counselor from last summer he's over K'NEX. So he moved...to Legos now. So it's like he's too advanced for that." From this quote we get a glimpse of Max attempting to put behind him what he once enjoyed during the fine motor activity time and proclaim that he has moved on to a more challenging activity that is more socially accepted for his stage of development and social context. The typical development of a teenager has a lot of social context intertwined. Spies Shapiro and Margolin (2014) describe adolescence is "a time of struggle to find a balance between autonomy and connectedness" (p.17). Jones and colleagues' (2014) study on adolescent identity development and friendships revealed "that along with the increased complexity within friendships, a reciprocal responsibility

may exist in the development of identity formation” (p.66). They further discussed that adolescent relationships have changed throughout the past several decades, causing their psychosocial development to be influenced by not only their immediate family, but now an expanded social network. The interview data revealed Max establishing and exploring social relationships and friendships throughout the summer.

Part of typical adolescent development can be negotiating the parent-child relationship which can be very dynamic. Within the final parent interview, Max’s mother said “I get attitude at home, but I don’t think that indicates whether he likes coming... It’s teenage nastiness and I’m not going to talk to you, you’re the enemy because you’re the parent.” It is important to recognize that the participants’ perceptions of a program are influenced by their conversations and relationships with their parents. In this study, the parent expressed that, at times, it was difficult for her to communicate with her son. Therefore, she could not assess and then shape his perception of the program.

Another way in which social participation and development was discovered within this study as part of perception development was within the relationships Max formed. A staff member, in her final interview said, “in the beginning we did not have Jack and Bob other friends that are 11 and 13, so even though Max is 16... I think it has completely changed Max’s perspective of the camp and everything.” From this quote we find the role that peer relationships can have in changing the perception of an adolescent. These other two boys, that are considered typically developing, joined half-way through the duration of the program. This allowed Max to now have

relationships with individuals that were more similar to him developmentally than others within the program. This created a shift in attitude and level of engagement allowing for a more positive perception of the camp.

Just Right Challenge

The second theme found within the data was that the just right challenge is needed for engagement and building memories. A process was found as Max worked through the program. This process consisted of fostering engagement, accomplishment and ownership, and eventually recognition through receiving a reward.

Fostering Engagement

Challenges can be provided not only through activities within a program, but also through the social context. It was through social context that Max seemed to be drawn into engagement. The TRI stated;

I noticed a difference in his social skills...Particularly when the two new boys joined about halfway in that were about his age and they started hanging out. [He] had somebody to interact with more and I did see a bigger difference...Talking to people instead of just being quiet...or like one word mumble answers...It's not necessarily peer relationship... but it's actually him being around people that were a little bit more advanced than him in those areas and really pushing him.

For individuals with ASD, socialization can be difficult. The TRI identified Max as having such difficulties when she stated, "I think he needs help more in social skills so that is what we worked on". Max was provided with challenges to his social skills by the introduction of individuals that may be considered more advanced in development of their social skills. From that challenge it was observed that he demonstrated social

skills that were more aligned with the new participants. Before Jack and Bob were introduced into the program, Max was observed to have limited communication with other participants or would make negative statements about others and himself. During an activity that all participants had engaged in numerous times throughout the summer, Max said that he was “stupid” when he was having difficulty with the task. He was capable of completing the task, but when he encountered difficulty, he shut down. Therefore a question arose about whether his aggravation came from the difficulty level of the task, his perception of his abilities, or how the task was presented. Considering the integrated analysis of observations, personal journals and interviews used in this case study, it is proposed that it may be a combination of all three possibilities, but it begins with the level of challenge itself in the task at hand. After the just right social challenge was introduced, he began showcasing a more positive affect, using positive statements, and seemed to be more engaged in activities.

Accomplishment and Ownership

Part of the process of working through the just right challenge can be accomplishment. A sense of accomplishment was evident when Max’s mother reflected on her son’s summer. In her final interview she stated “they posted a video of [Max] and another kid trotting without being on lead...and he was excited about that and talking about that. He is also excited to look at the pictures when they pop up on Facebook of just the other kids at camp and he talks about who they are and what they do...” She also mentioned that “he wants pictures of thing he did” when discussing her son having proof of what he did throughout the summer to share with

others. Spies Shapiro and Margolin (2014) studied the link between adolescent identity development and sharing of information on social network sites through a systematic review. One study revealed “self-disclosure, which involves an iterative process of sharing personally relevant information and receiving feedback, is central to identity formation” and that “online self-disclosure to known friends in early adolescent years was associated with greater offline self-disclosure” (p.9). Max’s desire to have and share photos of him participating in activities that he has engaged in is reflective of how typical adolescents form their identity. Building memories and sharing experiences are typical in adolescent development. These reinforce relationships, interests, and skills.

The initial and final interview with Max produced less data than interviews with others, but this makes what he did say even more important. When asked what he looked forward to during his initial interview he answered, “Learning to ride outside, just learning to round the horses and stuff.” From this statement it can be found that Max wanted to be provided with the challenge of skill development and learning. His mother’s initial interview yielded a similar statement; “It has helped him with self-esteem with learning a new skill that everyone doesn’t necessarily know how to use or whatever with regards to the horses. Not just riding the horses, but grooming them and all the different aspects of it has been very helpful for him.” Learning skills that are not as common within Max’s social and cultural context outside of the summer camp provided him with a sense of ownership. Max’s body language revealed what his preferences and challenges in the camp setting were. When the just right challenge is

carefully structured and provided, adolescents realize the purpose and desire in the opportunities. Without that purpose it may be difficult for them to maintain meaningful engagement.

Recognition Through Reward

The final part within the process of providing the just right challenge was recognition through receiving a reward. Rewards can be something tangible such as an award or certificate that often highlight a specific action or ability than an individual has expressed. They can also be in a less tangible form such as a personal sense of accomplishment. Within this case study the rewards were seen and interpreted as they were both tangible and intangible. The positive affect that Max had developed observed through his body language and actions were evident of a less tangible reward that he felt. He also may have experienced feeling of pride when he was selected as a key assistant during the horse show at the end of camp. This show is a culmination activity attended by family and friends, to display riding skills learned during the camp experience. The level of responsibility was important to Max as it communicated the trust the TRI had in him. A more tangible representation of a reward that Max received was a certificate for being the “Mini Camp Counselor”. Each participant at HorseAbility was given an award created for them specifically. When announcing Max’s award, the staff made it known that he had helped them throughout the summer with the younger participants. While receiving his award Max was smiling and raised his paper up to show other participants, staff, and parents as they clapped. Max received multiple rewards and forms of recognition, reinforcing his

behavior and achievements, enticing ownership of his future engagement and identity, and potentially fostering more engagement in programs in the future to build upon his progress. It is important that achievements invoke some kind of reward to reinforce the adolescent's actions and encourage them to build self-esteem. Reassurance that they achieved something through their experience can help them develop and refine their identity, ensure that they are enjoying the moment, create memories, and possibly entice them to continue to be engaged in various programs.

Limitations

Upon initial contact, the mother of the adolescent participant indicated that she and her son had been previously engaged in other research endeavors. This could have caused answers given during interviews to be rehearsed or less spontaneous than if the participants had not been involved in previous studies. Another limitation to this study is the amount of observation data collected over the nine week period. Observation data was restricted due to participant and/or primary researcher absences from the program. The participant followed a relatively consistent schedule during the five weeks during which observations occurred.

Implications

This exploratory case study reveals that perception is critical to adolescent experiences and explores the role of the just right challenge for adolescent engagement and memory building. These findings are to be considered when working with adolescents with ASD. Program developers and service providers should therefore evaluate their practices to ensure that they are providing activities and tasks that their

participants or clients perceive as engaging. Further, training of staff should include supports for understanding various conditions to support staff confidence levels, using a strengths-based perspective to focus on the abilities of the participants. By including these elements in staff training, participation in such summer activities will help build memories and skills for participants.

Occupational Therapists (OTs) are educated on activity analysis that is essential for program evaluation and development for a variety of populations and conditions including adolescents with ASD. It is critical that programs and interventions designed by OTs also use a strength-based perspective focusing on abilities of clients. This study suggests that the field of OT can benefit from continued qualitative research to derive rich-descriptions of client experiences. Through qualitative data, the power of purposeful engagement in meaningful occupations can be realized.

Conclusion

In-depth analysis of interviews, observation notes, and the primary author's personal journal was conducted in order to gain an understanding of the perspective of one adolescent male with ASD regarding his participation in a summer day camp that included TR. Data was coded using an inductive approach and triangulated to provide a rich understanding of the case. Two major themes emerged from the data; perception is critical to adolescent experiences and the just right challenge's role for adolescent engagement and memory building. Within discussion regarding the participant's perception of his experience in the program four subthemes were discussed; advertising a summer day program, framing activities, attitudes, and social

participation and development. The just right challenge was discussed as a three-part process; fostering engagement, accomplishment and ownership, and eventually recognition through receiving a reward. Suggestions were made for development of programs for adolescents with ASD in order to assist in developing identity, expand occupational opportunities and choices, develop skills for occupational performance, and engage socially to build significant memories. Upon review of the literature, a gap in the research was found for in-depth descriptions of the perceptions of adolescents with ASD participating in summer camps. Specifically this study sought to provide such description of an experience at a summer camp with TR. This case study was meant to begin filling that gap in the literature. These findings cannot be generalized, but may be considered when forming summer programs for adolescents with ASD along with other literature support.

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Appendices

Appendix A: IRB Forms



Institutional Review Board Application for Expedited/Full Review

Instructions:

1. All applications for IRB review must be submitted online by the Principal Investigator.
 2. After completing this application form and all required attachments, access the online submission portal at eku.infoready4.com. Choose Application for Expedited/Full Review from the list of available opportunities and click the Apply button on the right. If needed, you can filter the category column by Institutional Review Board (Human Subjects Research).
 3. If you are a current ECU employee or student, click the option to log in as an ECU user. Your user name and password are the same as what you use to log in to ECU's network. Your user name is not your email address.
 4. Complete the basic information in the online application and upload this application form and all required attachments in their original file formats (i.e., Microsoft Word documents). Please do not save your files as PDFs.
 5. Upon receipt of a new online application, an IRB administrator will review the submission for completeness and return incomplete applications for updates prior to processing.
 6. Once an application is accepted by an IRB administrator, it will be assigned to the faculty advisor (if the principal investigator is a student) and the department chair for approvals prior to being reviewed by the IRB.
 7. If the IRB reviewers have questions or request updates to the application materials, the principal investigator will be notified by email and asked to resubmit the application online.
 8. Once the IRB has approved the application, the principal investigator will be notified by email.
-

1. Title of Project:

A Connection with Animals and Plants: Case Study of an Individual Enrolled in a Summer Program with Horses and Horticulture

2. Principal Investigator:

Principal Investigator Name: Spencer Hammond

Department: Occupational Science and Occupational Therapy

3. Faculty Advisor, Committee Members, and Degree Program (required if PI is an ECU student):

Primary Faculty Advisor: Dr. Shirley O'Brien PhD, OTR/L, FAOTA

Committee Members (required for theses, dissertations, scholarly projects, field experience, or other studies guided by an academic committee):

Dr. Dana Howell PhD, OTD, OTR/L FAOTA

Degree Program: Master of Science in Occupational Therapy

4. Other Investigators: Identify all other investigators assisting in the study. Attach additional pages if needed.

N/A

5. Study Period of Performance: upon IRB approval through November, 30, 2018

Note that research may not begin until IRB approval has been granted.

6. Funding Support: Is the research study funded by an external or internal grant or contract? ☐ Yes ☒ No

Funding Agency: _____

Copy of funding application narrative attached? ☐ Yes (required if study is funded)

7. Risk Category:

- ☒ Not greater than minimal risk. Minimal risk is defined as "the probability and magnitude of physical or psychological harm that is normally encountered in the daily lives, or in the routine medical, dental, or psychological examination of healthy persons."
- ☐ Greater than minimal risk, but of direct benefit to individual participants
- ☐ Greater than minimal risk, no direct benefit to individual participants, but likely to yield generalizable knowledge about the subject's disorder or condition
- ☐ Research not otherwise approvable which presents an opportunity to understand, prevent, or alleviate a serious problem affecting the health or welfare of participants

8. Type of Review: ☒ Expedited Review (complete item #9 below) ☐ Full Review (skip item #9 below)

9. Expedited Review Categories: If the proposed study represents not greater than minimal risk, and all activities fall within one or more of the categories below, the study is eligible for expedited review. Please check all applicable categories of research activities below.

- 1) ☐ Clinical studies of drugs and medical devices only when condition (a) or (b) is met.
 - ☐ (a) Research on drugs for which an investigational new drug application (21 CFR Part 312) is not required. (Note: Research on marketed drugs that significantly increases the risks or decreases the acceptability of the risks associated with the use of the product is not eligible for expedited review.)
 - ☐ (b) Research on medical devices for which (i) an investigational device exemption application (21 CFR Part 812) is not required; or (ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.
- 2) ☐ Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture as follows:
 - ☐ (a) From healthy, nonpregnant adults who weigh at least 110 pounds. For these subjects, the amounts drawn may not exceed 550 ml in an 8 week period and collection may not occur more frequently than 2 times per week; or
 - ☐ (b) From other adults and children considering the age, weight, and health of the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected. For these subjects, the amount drawn may not exceed the lesser of 50 ml or 3 ml per kg in an 8 week period and collection may not occur more frequently than 2 times per week.
- 3) ☐ Prospective collection of biological specimens for research purposes by noninvasive means. Examples: (a) Hair and nail clippings in a nondisfiguring manner; (b) deciduous teeth at time of exfoliation or if routine patient care indicates a need for extraction; (c) permanent teeth if routine patient care indicates a need for extraction; (d) excreta and external secretions (including sweat); (e) uncannulated saliva collected either in an unstimulated fashion or stimulated by chewing gumbase or wax or by applying a dilute citric solution to the tongue; (f) placenta removed at delivery; (g) amniotic fluid obtained at the time of rupture of the membrane prior to or during labor; (h) supra- and subgingival dental plaque and calculus, provided the collection procedure is not more invasive than routine prophylactic scaling of the teeth and the process is

accomplished in accordance with accepted prophylactic techniques; (i) mucosal and skin cells collected by buccal scraping or swab, skin swab, or mouth washings; (j) sputum collected after saline mist nebulization.

- 4) ☐ Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing. (Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications.) Examples: (a) Physical sensors that are applied either to the surface of the body or at a distance and do not involve input of significant amounts of energy into the subject or an invasion of the subject's privacy; (b) weighing or testing sensory acuity; (c) magnetic resonance imaging; (d) electrocardiography, electroencephalography, thermography, detection of naturally occurring radioactivity, electroretinography, ultrasound, diagnostic infrared imaging, doppler blood flow, and echocardiography; (e) moderate exercise, muscular strength testing, body composition assessment, and flexibility testing where appropriate given the age, weight, and health of the individual.
- 5) ☐ Research involving materials (data, documents, records, or specimens) that have been collected or will be collected solely for non-research purposes (such as medical treatment or diagnosis). (Note: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt.)
- 6) ☒ Collection of data from voice, video, digital, or image recordings made for research purposes.
- 7) ☒ Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (Note: Some research in this category may be exempt from the HHS regulations for the protection of human subjects 45 CFR 46.101 (b)(2) and (b)(3). This listing refers only to research that is not exempt.)
- 8) ☐ Continuing review of research previously approved by the convened IRB as follows:
 - (a) ☐ Where (i) the research is permanently closed to the enrollment of new subjects; (ii) all subjects have completed all research-related interventions; and (iii) the research remains active only for long-term follow-up of subjects; or
 - (b) ☐ Where no subjects have been enrolled and no additional risks have been identified; or
 - (c) ☐ Where the remaining research activities are limited to data analysis.
- 9) ☐ Continuing review of research, not conducted under an investigational new drug application or investigational device exemption where categories two (2) through eight (8) do not apply but the IRB has determined and documented at a convened meeting that the research involves no greater than minimal risk and no additional risks have been identified.

10. Background:

- a. **Provide an introduction and background information for the study and provide a discussion of past research findings leading to this study. Cite literature that forms the scientific basis for the research.**

Upon review of the literature, it has been found that many studies conducted on programs involving horticulture based activities and equine-assisted activities do not contain in-depth descriptions of participant's experiences. Studies on gardening and horticulture based programs have been increasing in popularity, but often focus in on the geriatric population and school-based programs. Measurements collected during studies of gardening programs for the pediatric population have been visual-motor skills (Baker, Waliczek, & Zajicek, 2015), self-esteem (Swank & Shin, 2015), self-concept (Beela, Reghunath, & Johnson, 2015; Mei-Lun, Shi-Jer, Wei-Fang, & Chih-Cheng, 2014), and more. In the pediatric population, participation in gardening activities has been found to stimulate creative thinking (Robson & Rowe, 2012). York and Wiseman's (2012) meta-ethnography derived information from four qualitative studies to conclude that occupational therapists can have an impact on health at a community level, broaden their practice, and that there are "fundamental links between gardening and wellbeing" (p.76). These studies regarding gardening and horticulture activities with children did not produce rich and deep description of the participants' experiences. To date, there are few studies that have been completed on programs that incorporate both animals and horticulture activities.

According to O'Haire (2013), through a systematic review for animal assisted interventions for individuals with Autism, only two qualitative studies were found, one of which was a case-study. The qualitative studies incorporated observations and open-ended interviews to evaluate a sense of stress and safety and social interactions. Searches of the literature for studies of programs that involve animals and horticulture activities produced no current studies. Therefore, there is a gap in the literature on programs that utilize both horticulture and animal based activities.

The uniqueness of people means that each and every person's experiences brings to them a certain meaning that shape and mold their lives. It is in those experiences and meanings that we can find the true essence of who we are. This study seeks to reveal such experiences from one individual participating in a summer program in which individuals with disabilities interact with each other through horticulture activities and activities involving horses. The program from which the participant will be selected for this study is a nine week summer day-program for school-aged individuals that have a wide range of disabilities. Ideally, the study will include an adolescent with Autism Spectrum Disorder, but this diagnosis is not a requirement based on the inclusion and exclusion criteria. Although some studies have been completed on programs similar to the one the subject will be participating in, rich description of the experience of a child and their family in such a program is missing from the literature. This study hopes to bring fourth such an experience for others to consider.

References:

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11. Research Objectives:

a. List the research objectives.

The purpose of this case study will be to examine the experiences of one individual participating in a summer program in which individuals with disabilities interact with each other through horticulture activities and activities involving horses.

The grand question is; what are the unique experiences of a participant in the HorseAbility program and what do those experiences mean to that participant and those around them?

Sub-questions include; what specific activities does the participant find value in? How does participation in this program impact the parents or family? What changes could be made to better meet the needs of the participant and his or her family? How is the child supported by program staff and his or her family? What are the social-emotional impacts on the individuals involved with this program? How is a child physically impacted by participation in this program?

12. Subject Population:

a. What criteria will be used to determine the *inclusion* of participants in the study?

The participants in this study will be an adolescent between the ages of 13-18 that is enrolled in the HorseAbility program at Central Kentucky Riding for Hope during the summer of 2018, his or her caregiver/guardian(s), and one staff member of CKRH (employed or volunteer) that has worked with the adolescent.

b. What criteria will be used to determine the *exclusion* of participants in the study?

Exclusion criteria will be if the participant in the HorseAbility program is under age 13 or older than age 18. Participants that do not have expressive communication abilities will not be included in this study.

c. Anticipated Number of Participants (*maximum*): 5

d. Age Range of Participants: 13-75

e. **Gender of Participants:** ☐ Male ☐ Female or ☒ Gender not relevant to study

f. **Ethnicity of Participants:** _____ or ☒ Ethnicity not relevant to study

g. **Health Status of Participants:** _____ or ☒ Health status not relevant to study

h. **Which of the following categories of subject will be included in the study? Please check all that apply.**

1. ☒ Adult Volunteers
2. ☐ College Students age 18 and older
3. ☒ Minors (under age 18) – attach Form M
4. ☐ Pregnant Women (other than by chance)
5. ☐ Fetuses/Neonates
6. ☐ Hospital Patients
7. ☐ Patients at Inpatient Mental Health Facilities
8. ☐ Decisionally-Impaired Individuals – attach Form I
9. ☐ Institutionalized Decisionally-Impaired Individuals – attach Form I
10. ☐ Prisoners – attach Form P
11. ☐ Other – Please Describe: _____

13. Project Location:

a. **Where will the study take place?**

Central Kentucky Riding for Hope in Lexington, KY

b. **If the study will take place at a location other than ECU, attach a letter from an authorized representative of the organization granting permission to use facility for research purposes.**

☐ ECU only ☒ Letter(s) attached

c. **Will any data be collected through organizations other than Eastern Kentucky University?**

☒ No ☐ Yes, complete the following:

- Will personnel of the organization be involved in the data collection process or have access to data after collection? ☐ No ☐ Yes - If yes, list personnel on page 1, include copies of CITI completion reports, and define role here: _____

14. Recruitment of Participants:

a. **How will prospective participants be identified for recruitment into the study?**

Purposeful sampling will be used to identify and recruit participants.

b. **Describe the recruitment procedures to be used with potential participants.**

An announcement will be made by the program director to the parents and program participants during the first week of the program to make them aware of the study. Potential participants will be recruited via verbal communication at the research site (CKRH). This will occur at the end of the first week of the HorseAbility program. Individuals that are interested in participating in the study will be directed to the primary researcher by the program director. Using the verbal recruitment script, the study will be briefly described to interested participants and their parents. One

adolescent and her or his parents will be included in the study. The staff member of the program to be included in the study will also be recruited via verbal communications after the initial adolescent participant and his or her parents have been selected and have agreed to participate in the study. The selection of the staff member will be based on whether or not they were observed to work with the adolescent participant during the program.

- c. Recruitment materials to be used:** Check all that will be used and attach copies:
☐None ☐Advertisement ☐Flyer ☐Telephone Script ☒Verbal Recruitment Script
☐Cover Letter ☐Other:

15. Ensuring Voluntary Participation

a. Who will be responsible for seeking the informed consent of participants?

The primary researcher, Spencer Hammond, will seek informed consent of participants prior to interview and observations.

b. What procedures will be followed to ensure that potential participants are informed about the study and made aware that their decision to participate is voluntary?

Informed consent form will be presented and verbally explained to all participants as well as the purpose of the study. Participants will be asked to voluntarily participate and can choose to stop participation in the study at any time.

c. How will consent be documented?

Signatures for assent, parental permission, and consent will be obtained from all participants prior to participation in the study. They will be provided with a copy to keep for their own records.

d. What consent documents will be used in the study? (Attach copies of all).

- ☒Informed Consent Form ☒Parent/Guardian Permission Form ☒Child/Minor Assent Form ☐Oral Script
☐Other:

16. Research Procedures

a. Describe in detail the research procedures to be followed that pertain to the human participants. Be specific about what you will do and how you will do it. If applicable, differentiate between standard/routine procedures not conducted for research purposes from those that will be performed specifically for this study.

This study will include interviews and observations of participants regarding an adolescent's participation in a summer day-care program involving horses and horticulture activities. The researcher is not responsible or liable for the program itself and is only collecting data regarding one participant and his or her family's experience of the program. The participants will be asked to take part in two interviews lasting about 30 minutes to one hour. The two interviews will be during the second and eighth weeks of the HorseAbility program. The parent/guardian/caregiver of the adolescent participating in this study will be asked multiple questions regarding their child's experience with the program as well as how it has affected their family. A staff member of CKRH that has interacted with the adolescent participating in this study will be asked questions about his or her

interactions with the participant and his or her perspective of the HorseAbility program. A voice recording will be obtained during interviews as well as interview notes, observation notes, and photographs (photographs will be only be taken if given permission and assent). Interviews will be transcribed and coded to derive themes that describe the experiences of the participant and his or her family with regards to the HorseAbility program. Photographs and observation data will be used to triangulate interview data. Observation notes will include but are not limited to information about interactions with other children in the program, how the participant completes tasks, emotions and behaviors that the participant exhibits, and how he or she interact with the horses and materials for gardening activities. Photographs will be taken to capture similar information as observation notes.

17. Potential Risks

a. Describe any potential risks—physical, psychological, social, legal, or other.

There are no potential risks perceived for this study.

b. What procedures will be followed to protect against or minimize any potential risks?

Permission, assent, and informed consent will be obtained. Pseudonyms will be given to participants to ensure confidentiality.

c. How are risks reasonable in relation to the anticipated benefit to participants and in relation to the importance of the knowledge that may reasonably be expected to result?

There are no perceived risks, but the anticipated benefit is to gain a better understanding of the experience of an individual participating in a summer program that involves horses and horticulture activities. Analyzing and understanding this experience can provide insight into how such a program affects the individuals and families it serves.

d. Will alternative choices be made available to participants who choose not to participate?

☒ No ☐ Yes, Describe: _____

18. Incentives and Research Related Costs

a. Will incentives be offered to participants? ☒ No ☐ Yes, complete the following items:

- 1) What incentives will be offered? _____
- 2) If monetary compensation will be offered, indicate how much the participants will be paid and describes the terms of payment. _____
- 3) Describe the method of ensuring that the incentives will not compel individuals to agree to participate in the study. _____
- 4) Describe how the incentives will be funded. _____

b. Will there be any costs to the subjects for participating? ☒ No ☐ Yes: Describe any costs that would be the responsibility of the subjects as a consequence of their participation in the research. _____

19. Research Materials, Records, and Confidentiality

a. What materials will be used for the research process? Include a description of both data collected through the study as well as other data accessed for the study.

An audio recording device will be used to collect voice recordings of the interviews. Photos, if taken, will be taken with a digital camera. Transcription of interviews will be completed by Spencer Hammond with Microsoft Word Processor.

- b. Who will have access to the data?** If anyone outside the research team will have access to the data, provide a justification and include a disclaimer in consent documents.

The primary researcher (Spencer Hammond), faculty advisor (Dr. Shirley O'Brien), and committee chair members (Dr. Dana Howell, and Toby Scott-Cross) will have access to the data.

- c. Describe how and where research records will be stored.** Note that all research-related records must be maintained for a period of three years from the study's completion and are subject to audit. Following the completion of the study and throughout the records retention period, student research records must be maintained by the faculty advisor who signs the application.

Research records will be stored by the faculty advisor in a locked file cabinet located in Dizney 237 on EKU's campus.

- d. How will data be destroyed at the end of the records retention period** (i.e., shredding paper documents, deleting electronic files, physically destroying audio/video recordings)?

Documents will be shredded and electronic files and recordings will be deleted at the end of the records retention period.

- e. Describe procedures for maintaining the confidentiality of human subjects' data.**

All participants will be given pseudonyms to protect confidentiality. All electronic files will be kept on password protected devices and physical materials holding data will be kept locked in a drawer in faculty advisor's office (Dizney 237) when not in use.

20. Application Components (*Check all items that are included*):

A completed application package must include the following:

- ☒ Application Form
- ☒ CITI Training Completion Reports for all investigators, key personnel, and faculty advisors
- ☒ If applicable: Form M: Research Involving Minors/Children
- ☐ If applicable: Form P: Research Involving Prisoners
- ☐ If applicable: Form I: Research Involving Decisionally-Impaired Individuals
- ☐ If applicable: Form W: Research Involving Wards of the State
- ☒ If applicable: recruitment materials (i.e., advertisements, flyers, telephone scripts, verbal recruitment scripts, cover letters, etc.)
- ☒ If applicable: Consent form (required in most all cases), assent form (for subjects who are minors), and parent/guardian permission form (if subjects are minors)
- ☒ If applicable: Instrument(s) to be used for data collection (i.e., questionnaire, interview questions, or assessment scales)
- ☐ If applicable: grant/contract proposal narrative (required if study is funded)
- ☒ If applicable: letter(s) granting permission to use off-campus facility for research.



Institutional Review Board

Form M: Research Involving Minors/Children

This form is a required attachment to applications for projects involving children. In Kentucky, a child is an individual who is less than 18 years of age unless the individual has been legally emancipated. Some federal agencies and other states define children differently. If the study is to be funded by a federal agency, that agency's definition applies; if a study is to be conducted outside Kentucky, that state's definition applies.

1. Investigator Name: Spencer Hammond

2. Research Project Title: A Connection with Animals and Plants: Case Study of an Individual Enrolled in a Summer Program with Horses and Horticulture

3. Risk Level: Minimal risk means that the probability and magnitude of the harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological exams or tests. **Classify the proposed research into one of the following categories (A-C below) and respond to the applicable items that follow.**

- ☒ **A.** The proposed research **does not involve greater than minimal risk** to the subjects.
- Explain why the research is classified in this category.

Interviews and observations will be focused on the minor's involvement in a summer day-care program. This is a voluntary program that individuals have to apply to. The interviews and observations will only concern the participant's experiences in this program.

- Describe procedures for soliciting the assent of the children and the permission of at least one parent/guardian.

Assent and permission will be requested after the purpose of the study is explained. Contact will be made during the time that the child is being picked up from the program.

- ☐ **B.** The proposed research **presents greater than minimal risk and a prospect of direct benefit** to the subjects.

- Explain why the research is classified in this category.
- Justify the risks by explaining the anticipated benefit to the subjects.
- Explain how the relation of the anticipated benefit to the risk is at least as favorable as that presented by available alternative approaches.
- Describe procedures for soliciting the assent of the children and the permission of at least one parent/guardian.

- ☐ **C.** The proposed research **presents greater than minimal risk and no prospect of direct benefit** to the subjects, but is **likely to yield generalizeable knowledge about the subject's disorder or condition**.

- Explain why the research is classified in this category.
- Describe how the risks represent a minor increase over minimal risk.
- Describe how the research procedures present experiences to the subjects that are reasonably commensurate with those inherent in their actual or expected medical, dental, psychological, social, or educational situations.

- iv. Explain why the intervention or procedure is likely to yield generalizeable knowledge about the subjects' disorder or condition which is of vital importance for the understanding or amelioration of the subjects' disorder or condition.
- v. Describe procedures for soliciting the assent of the children and the permission of both parents/guardians (unless only one parent has legal responsibility for the child).

4. Suitability of Subjects: Explain why children are suitable subjects for this research.

This study aims to develop an understanding of an adolescent's perspective of a summer program involving activities that involve animal and horticulture as well as her or his caregiver's perspective of how the program affects their child and family.

5. Previous Research on Adults: Has this research been previously conducted with adults as subjects?

☒ Yes (respond to A below) ☐ No

A. Explain indications that the proposed research will benefit or at least not be harmful to the children.

The proposed research will only seek to gain an understanding of the child's experience in a voluntary program.

6. Number of Children Subjects: Provide a justification for the number of children proposed for enrollment in the project.

It is proposed to enroll one child in this intrinsic case study so that an in-depth understanding of their experiences can be obtained.

7. Understandable Language: Describe what efforts have been made to present information about the study in a language that is understandable to the minor population being recruited (i.e, informational documents, recruitment flyers, assent forms, data collection instruments).

An assent form will be used. This form will be written with a 3rd grade reading level to ensure that the minor population being targeted can understand the form. The purpose of the study will also be discussed verbally with the minor.

Hello Spencer Hammond,

Congratulations! The Institutional Review Board at Eastern Kentucky University has approved your **IRB Application for Expedited Review** for application entitled, "**A Connection with Animals and Plants: Case Study of an Individual Enrolled in a Summer Program with Horses and Horticulture.**" Your approval is effective immediately and will expire on 11/30/18. **You will find your stamped consent forms by accessing your approved application files.**

Principal Investigator Responsibilities: It is the responsibility of the principal investigator to ensure that all investigators and staff associated with this study meet the training requirements for conducting research involving human subjects, follow the approved protocol, use only the approved forms, keep appropriate research records, and comply with applicable University policies and state and federal regulations.

Consent Forms: All subjects must receive a copy of the consent form as approved with the EKU IRB approval stamp. You may access your stamped consent forms by logging into your [InfoReady Review](#) account and selecting your approved application. Copies of the signed consent forms must be kept on file unless a waiver has been granted by the IRB.

Adverse Events: Any adverse or unexpected events that occur in conjunction with this study must be reported to the IRB within ten calendar days of the occurrence.

Research Records: Accurate and detailed research records must be maintained for a minimum of three years following the completion of the research and are subject to audit.

Changes to Approved Research Protocol: If changes to the approved research protocol become necessary, a description of those changes must be submitted for IRB review and approval prior to implementation. Some changes may be approved by expedited review while others may require full IRB review. Changes include, but are not limited to, those involving study personnel, consent forms, subjects, and procedures.

Annual IRB Continuing Review: This approval is valid through the expiration date noted above and is subject to continuing IRB review on an annual basis for as long as the study is active. It is the responsibility of the principal investigator to submit the annual continuing review request and receive approval prior to the anniversary date of the approval. Continuing reviews may be used to continue a project for up to three years from the original approval date, after which time a new application must be filed for IRB review and approval.

Final Report: Within 30 days from the expiration of the project, a final report must be filed with the IRB. A copy of the research results or an abstract from a resulting publication or presentation must be attached. If copies of significant new findings are provided to the research subjects, a copy must be also be provided to the IRB with the final report. Please log in to your [InfoReady Review](#) account, access your approved application, and click the option to submit a final report.

Other Provisions of Approval, if applicable: None

Please contact Sponsored Programs at 859-622-3636 or send email to lisa.royalty@eku.edu with questions about this approval or reporting requirements.

For your reference, we have included feedback on your application that was submitted during the review process.

[View Application](#)

Feedback on Your Application

Faculty Advisor Approval

Reviewer 1

Comments

Response

Reviewer Input: :

I Approve

Keep considering sub questions to delve into program evaluation

Reviewer 2

Comments

Response

Reviewer Input: :

I Approve

Good luck!

Department Chair Approval

Reviewer 1

Comments

Response

Reviewer Input: :

I Approve

Interesting study. Look forward to hearing your results.

IRB Member Review - Round 1

Reviewer 1

Comments

Response

Reviewer Input: :

I Approve

Approved

Appendix B: Recruitment Materials

Appendix B: Recruitment Materials

Verbal Script for Recruitment of Potential Participants

For parent(s) and child:

Hello, my name is Spencer Hammond. I am a master's student in the Occupational Therapy program at ECU. As part of my graduate program, I am completing a master's thesis about the experience of a child and his or her family with a program that provides horticulture activities and activities with animals for children with disabilities. I am only looking for one participant and their family to be involved in this study. If you did take part in this study, I will ask to interview you at your convenience during the second and eighth week of the program here at CKRH. The interviews should only take 30 minutes to 1 hour maximum each time. I would also ask for permission to observe your child here at CKRH in order to gain a little bit more insight into their experience. Would you and your child be interested in participating in this case study?

For staff member:

Hello, my name is Spencer Hammond. I am a master's student in the Occupational Therapy program at ECU. As part of my graduate program, I am completing a master's thesis about the experience of a child and his or her family with a program that provides horticulture activities and activities with animals for children with disabilities. It is my understanding that you work with (Name of Recruited Participant) here at CKRH through the HorseAbility program. Would you be willing to take part in the case study by participating in two interviews regarding your work with the participant? The interviews will be at your convenience here at CKRH during the second and eighth week of the program and should only last about 30 minutes.

Appendix C: Consent Forms

Appendix C: Consent Forms



Consent to Participate in a Research Study

A Connection with Animals and Plants: Case Study of an Individual Enrolled in a Summer Program with Horses and Horticulture

Why am I being asked to participate in this research?

You are being invited to take part in a research study about experiences of an adolescent in a summer program involving animal and horticulture activities. You are being invited to participate in this study because you are the parent/guardian/caregiver of an adolescent in the HorseAbility program at Central Kentucky Riding for Hope (CKRH) or are a staff member that has been identified as someone who works with the adolescent. If you take part in this study, you will be one of about four people to do so.

Who is doing the study?

The person in charge of this study is Spencer Hammond at Eastern Kentucky University. He is being guided in this research by Dr. Shirley O'Brien. There may be other people on the research team assisting at different times during the study.

What is the purpose of the study?

The purpose of this case study will be to examine the experiences of one individual participating in a summer program in which individuals with disabilities interact with each other through horticulture activities and activities involving horses. By doing this study, we hope to gain a better understanding of how the HorseAbility program affects individuals and their family.

Where is the study going to take place and how long will it last?

The research procedures will be conducted at CKRH. You will need to come to CKRH 2 times during the study. Each of those visits will take about 30 minutes to 1 hour. The total amount of time you will be asked to volunteer for this study is 1-2 hours over the next three months.

What will I be asked to do?

You will be asked to take part in two interviews lasting about 30 minutes to one hour. The two interviews will be during the second and eighth weeks of the HorseAbility program. If you are a parent/guardian/caregiver of the adolescent participating in this study, you will be asked multiple questions regarding you or your child's experience with the program as well as how it has affected your family. If you are a staff member of CKRH that has interacted with the adolescent participating in this study, you will be asked questions about your interactions and your perspective of the HorseAbility program.

Are there reasons why I should not take part in this study?

There are no known reasons why you should not take part in this study.

What are the possible risks and discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

Will I benefit from taking part in this study?

You will not get any personal benefit from taking part in this study.

Do I have to take part in this study?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering.

If I don't take part in this study, are there other choices?

If you do not want to be in the study, there are no other choices except to not take part in the study.

What will it cost me to participate?

There are no costs associated with taking part in this study.

Will I receive any payment or rewards for taking part in the study?

You will not receive any payment or reward for taking part in this study.

Who will see the information I give?

Your information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. For example, your name will be kept separate from the information you give, and these two things will be stored in different places under lock and key.

However, there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court or to tell authorities if we believe you have abused a child or are a danger to yourself or someone else. Also, we may be required to show information that identifies you to people who need to be sure we have done the research correctly; these would be people from such organizations as Eastern Kentucky University.

Can my taking part in the study end early?

If you decide to take part in the study, you still have the right to decide at any time that you no longer want to participate. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the agency funding the study decides to stop the study early for a variety of scientific reasons.

What happens if I get hurt or sick during the study?

If you believe you are hurt or if you get sick because of something that is done during the study, you should call Spencer Hammond at 502-220-7411 immediately. It is important for you to understand that Eastern Kentucky University will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. That cost will be your responsibility. Also, Eastern Kentucky University will not pay for any wages you may lose if you are harmed by this study.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to your child's care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer's willingness to pay under these circumstances.

What if I have questions?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Spencer Hammond at 502-220-7411 or spencer_hammond@mymail.ekul.edu. If you have any questions about your rights as a research volunteer, contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636. We will give you a copy of this consent form to take with you.

What else do I need to know?

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in this study.

I have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and agree to participate in this research study.

Signature of person agreeing to take part in the study

Date

Printed name of person taking part in the study

Name of person providing information to subject

EKU
Institutional Review Board
Protocol Number
1580
Approval Valid
5/10/18-11/30/18



Assent Form for Minor's Participation in a Research Project

(for minors between the ages of 13 and 17)

A Connection with Animals and Plants: Case Study of an Individual Enrolled in a Summer Program with Horses and Horticulture

Why am I being asked to participate?

We are conducting research about your experiences with HorseAbility located at Central Kentucky Riding for Hope (CKRH) and would like to ask for your help because we want to know what you think about the program.

What will I be asked to do?

If you decide to participate in this project, you will be asked to answer some questions in two interviews, one at the beginning of the summer and one at the end.

Do I have to participate?

Your parents know that we are asking you if you want to participate, but it is up to you to decide if you want to do this. You should not feel pressured to participate, and you have the right to choose not to participate. You will not lose any rights or benefits you would normally have if you choose not to participate. If you agree to participate now and decide later that you want to stop, all you have to do is tell the researchers, and they will allow you to stop. You will still keep the rights and benefits you had before volunteering.

What will I get for participating?

You will not receive any payment or reward for taking part in this study.

Who will see the information I give?

Your information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. For example, your name will be kept separate from the information you give, and these two things will be stored in different places under lock and key.

Can my taking part in the study end early?

If you decide to take part in the study, you still have the right to decide at any time that you no longer want to participate. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the agency funding the study decides to stop the study early for a variety of scientific reasons.

What if I have questions?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Spencer Hammond, at 502-220-7411. If you have any questions about your rights as a research volunteer, you can

contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636. We will give you a copy of this form to take with you.

I have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and have decided that I would like to participate in this study.

Minor's Name

Minor's Signature

Date

Name of Individual Providing Information to Subject



**Institutional Review Board
Protocol Number**

1580

Approval Valid

5/10/18-11/30/18



Parent/Guardian Permission Form for Minor's Participation in a Research Project

A Connection with Animals and Plants: Case Study of an Individual Enrolled in a Summer Program with Horses and Horticulture

Why is my child being invited to take part in this research?

We would like to invite your child to take part in a research study about his or her experience in the HorseAbility program. This is a single intrinsic case study, so your child will be the only participant.

Who is doing the study?

The person in charge of this study is Spencer Hammond at Eastern Kentucky University. He is being guided in this research by Dr. Shirley O'Brien. There may be other people on the research team assisting at different times during the study.

What is the purpose of the study?

The purpose of this case study will be to examine the experiences of one individual participating in a summer program in which individuals with disabilities interact with each other through horticulture activities and activities involving horses. By doing this study, we hope to gain a better understanding of how the HorseAbility program affects individuals and their family.

Where is the study going to take place and how long will it last?

The research procedures will be conducted at Kentucky Riding for Hope (CKRH). Each session will take about 30 minutes to 1 hour. The total amount of time your child will be asked to volunteer for this study is 1-2 hours over the next three months.

What will my child be asked to do?

Your child will be asked to participate in two interviews; one during week 2 of the HorseAbility program and one during the eighth week of the program. The interviews should not exceed one hour and are expected to last about 30 minutes. These interviews will be coordinated with the program director to ensure that your child does not miss out on any activities that he or she enjoys. The interviews will take place at CKRH in a private space so that your child will be able to express his or her thoughts without distraction. Two people will be present at all times during the interview, the primary researcher and a volunteer staff member of CKRH.

Are there reasons why my child should not take part in this study?

Your child should not take part in this study if he or she cannot communicate their experiences through answering interview questions. Other than this there are no known reasons why your child should not take part in this study.

What are the possible risks and discomforts?

To the best of our knowledge, the things your child will be doing have no more risk of harm than he or she would experience in everyday life.

Will my child benefit from taking part in this study?

Your child will not get any personal benefit from taking part in this study.

Does my child have to take part in the study?

If you decide to allow your child to take part in the study, it should be because your child really wants to volunteer. Your child will not lose any rights he or she would normally have if you choose not to allow him or her to volunteer. If your child participates and either of you change your mind later, your child can stop at any time during the study and still keep the benefits and rights he or she had before volunteering.

If I don't want my child to take part in the study, are there other choices?

If you do not want your child to be in the study, there are no other choices except to not take part in the study.

What will it cost for my child to participate?

There are no costs associated with taking part in this study.

Will my child receive any payment or reward for taking part in the study?

Your child will not receive any payment or reward for taking part in this study.

Who will see the information my child gives?

Your child's information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. Your child will not be identified in these written materials.

We will make every effort to prevent anyone who is not on the research team from knowing that your child gave us information, or what that information is. For example, your child's name will be kept separate from the information he or she gives, and these two things will be stored in different places under lock and key.

However, there are some circumstances in which we may have to show your child's information to other people. For example, the law may require us to show your child's information to a court or to tell authorities if we believe your child have been abused or is a danger to him/herself or someone else. Also, we may be required to show information that identifies your child to people who need to be sure we have done the research correctly; these would be people from such organizations as Eastern Kentucky University.

Can my child's taking part in the study end early?

If your child decides to take part in the study, he or she still has the right to decide at any time that he or she no longer wants to participate. Your child will not be treated differently if he or she decides to stop taking part in the study.

The individuals conducting the study may need to end your child's participation in the study. They may do this if your child is not able to follow the directions they give him or her, if they find that your child's being in the study is more risk than benefit to him or her, or if the agency funding the study decides to stop the study early for a variety of scientific reasons.

What happens if my child gets hurt or sick during the study?

If you believe your child is hurt or if your child gets sick because of something that is done during the study, you should call Spencer Hammond at 502-220-7411 immediately. It is important for you to understand that Eastern Kentucky University will not pay for the cost of any care or treatment that might be necessary because your child gets hurt or sick while taking part in this study. That cost will be your responsibility. Also, Eastern Kentucky University will not pay for any wages that might be lost as a result of this study.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to your child's care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer's willingness to pay under these circumstances.

What if I have questions?

Before you decide whether to accept this invitation for your child to take part in the study, please ask any questions that might come to mind now. Later, if you or your child has questions about the study, you can contact the investigator, Spencer Hammond, at 502-220-7411 or spencer_hammond@mymail.eku.edu. If you have any questions about your child's rights as a research volunteer, contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636. We will give you a copy of this form to take with you.

What else do I need to know?

You will be told if any new information is learned which may affect your child's condition or influence your willingness to continue allowing your child to take part in this study.

I have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and give permission for my child to participate in this research project if he/she chooses to participate.

Parent/Guardian's Name Date

Child's Name Date

Parent/Guardian's Signature Date

Witness Signature Date

EKU
Institutional Review Board
Protocol Number
1580
Approval Valid
5/10/18-11/30/18

Letter of Consent: Central Kentucky Riding for Hope

Institutional Review Board
Eastern Kentucky University
521 Lancaster Avenue
Richmond, Kentucky 40475

Subject: Letter of Authorization to Conduct Research at Central Kentucky Riding for Hope

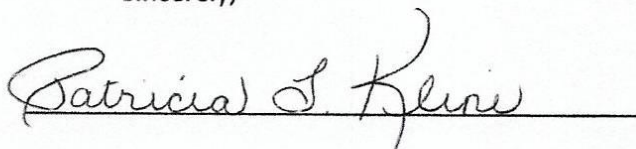
Dear Institutional Review Board:

This letter will serve as authorization for Eastern Kentucky University (EKU) researcher, Spencer Hammond, to conduct the research project entitled, A Connection with Animals and Plants: Case Study of an Individual Enrolled in a Summer Program with Horses and Horticulture, at Central Kentucky Riding for Hope (CKRH) in Lexington, Kentucky.

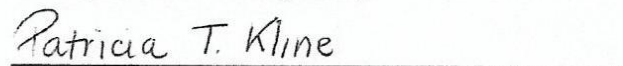
CKRH acknowledges that it has reviewed the protocol presented by the researcher, as well as the associated risks to the Facility and participants. The Facility accepts the protocol and the associated risks to the Facility, and authorizes the research project to proceed. The research project may be implemented at the Facility upon approval from the ECU Institutional Review Board.

If we have any concerns or require additional information, we will contact the researcher and/or Eastern Kentucky University Department of Occupational Science and Occupational Therapy.

Sincerely,



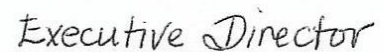
Facility's Authorized Signatory



Printed Name



Date



Title of Authorized Signatory

Appendix D: Interview Questions

Appendix D: Interview Questions

Initial Interview: 2nd week of program

Questions for participant:

1. Have you ever participated in HorseAbility before this year? If so tell me about your previous experiences?
3. What do you look forward to this summer?
4. What are you nervous about or don't think you will like doing this summer?
5. What would you probably be doing if you weren't coming to HorseAbility?

Questions for parents:

1. Has your son/daughter participated in HorseAbility before this year? If so tell me about how the program impacted your child and your family?
2. What led you to signing your child up for this program?
3. What do you hope your child gains from this program?
4. Do you have any apprehensions or foresee any difficulties for your child?
5. How would it affect your family if your child was not enrolled in HorseAbility?

Questions for staff:

1. Have you ever worked with _____ before?
2. Do you have any apprehensions about this summer working with kids at HorseAbility?
3. What do you look forward to about this summer working with kids at HorseAbility?

Exit Interview: 8th week of program

Questions for participant:

1. Tell me about your experiences here at HorseAbility?
2. What is some of your favorite things to do here? What are some things that you don't really like doing at HorseAbility?
 - A) Tell me about working with the horses?
 - B) Tell me about some of the gardening activities?
3. If you couldn't come to this program, what do you think you might be doing?
4. How did your summer compare to your friends or other kids at school?
5. Is there anything that you would change about the program?

Questions for parents:

1. How important is it that your child participates in the HorseAbility program? Why?
2. Have you seen any differences in your child after starting this program? (strengths, challenges)
3. What elements of the program made you select this particular program?
4. How is your child's summer different than other children?
5. Is there anything that you would change about the program?
6. What do you think about your child working with horses? (Riding, brushing, caring for the horse)

7. What do you think about the gardening activities that they do? (digging in the dirt, watching plants grow, being responsible for raising plants)
8. Tell me a story about an exciting time your child had this summer? A time they may have struggled?

Questions for staff:

1. What is your role in this program?
2. Tell me about _____, have you seen a difference in him/her since he started this program?
3. What does your program do for families?
4. What aspects of this program do you think participants get the most out of? Why? What do you think _____ got the most out of? The least?
5. Is there anything you would change about the program?