

THE PUZZLING WORLD OF SOCIAL ENGAGEMENT FOR YOUNG ADULTS
WITH HIGH-FUNCTIONING AUTISM SPECTRUM DISORDER

A thesis submitted to the faculty at Stanbridge University in partial fulfillment of the
requirements for the degree of Master of Science in Occupational Therapy

by

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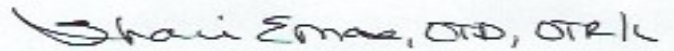
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Certification of Approval

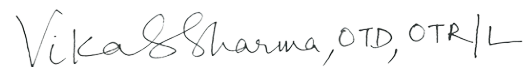
I certify that I have read *The Puzzling World of Social Engagement of Young Adults with High-Functioning Autism Spectrum Disorder* by Randy Kwon, Katherine Monus, Christine Tran, and Hanna Wagner, and in my opinion, this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy at Stanbridge University.



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Dedication

To our families and friends, thank you for supporting us through this challenging and fulfilling journey. We are so grateful for your support and encouragement along the way.

Acknowledgments

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Abstract

The purpose of this project-based thesis was to design a pilot study to evaluate the feasibility of using a social skills game as a social skills intervention with adults diagnosed with high-functioning autism spectrum disorder (HFASD). The game was divided into four themes (employment/education, romantic relationships, emotional regulation, and independent living) to address social interactions in various real-life situations. Five students enrolled in Life College, a transitional program for adults with HFASD, participated in this study. The subjects were divided into two groups, with two student researchers in each group to moderate the game. Data was collected through a short survey which included open-ended and multiple-choice questions. The data revealed that the majority (80%) of the participants enjoyed playing the game and stated that they would play the game again if given the opportunity. This study showed that a social skills game is a feasible and enjoyable intervention for adults with HFASD. Future research should examine long-term outcomes of utilizing this intervention.

Keywords: autism spectrum disorder (ASD), game, employment, education, relationships, emotional regulation, independent living

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The Puzzling World of Social Engagement for Young Adults with High-Functioning Autism Spectrum Disorder

Social skills are the skills people use to interact with one another, both verbally and nonverbally. Social skills include emotional recognition such as understanding tone, the theory of mind, and conversational skills like initiating, maintaining and concluding a conversation (Kandaloft, Didehbani, Krawczyk, Allen, & Chapman, 2013). Social functioning is the way an individual interacts with his or her environment and adapts based on various situations at work, in school, in the home, and the community.

Young adults who have high-functioning autism spectrum disorder (HFASD) may display insufficient social skills and a lack of proper social functioning in daily life (Laugeson, Frankel, & Mogil, 2008). The problem with insufficient social skills and social functioning is that these deficits infiltrate and affect all aspects of life. Studies show that individuals who struggle with typical communication and social skills are often not able to maintain meaningful relationships with peers, family members, or desired romantic partners (Gantman, Kapp, Orenski, & Laugeson, 2011). They are frequently subjected to negative behavior, becoming victims of bullying and even sexual exploitation because they do not understand how to appropriately interact and communicate with those around them (Sullivan & Caterino, 2008; Wadsworth, Nelson, Rossi, & Hill, 2016). This leads to many individuals with HFASD being taken advantage of by others since many people do not understand how individuals with autism function. Members of society regularly interact with these individuals using caution and avoidance because people are unsure how to deal with social awkwardness or the lack of emotion or understanding displayed by these individuals.

As autism rates increase with each passing year, jumping from 1 in 150 children in the year 2000 to 1 in 59 children in the year 2014, interacting with individuals diagnosed with Autism Spectrum Disorder (ASD) is rapidly becoming part of many people's daily life (Centers for Disease Control and Prevention [CDC], 2018). HFASD occurs across all racial, ethnic, and socioeconomic groups, and is four times more common in boys than girls (CDC, 2018). This proves that all individuals have the likely possibility of encountering individuals with HFASD in their social circles, work environments, and even within their own families. It is crucial, therefore, that people do not avoid or socially ostracize individuals with HFASD, as these actions lead to feelings of intense loneliness for the affected individuals (Laugeson, Gantman, Kapp, Orenski, & Ellingsen, 2015). People with HFASD may have difficulty maintaining employment, or participating in occupational, vocational, or recreational activities due to a lack of proper socializing and interacting with others (Laugeson et al., 2015). Learning appropriate social skills is most effective when done concretely, allowing young adults to gain and then utilize the learned skills across multiple situations (McVey et al., 2016). However, it is complicated to create a concrete intervention for young adults with HFASD due to a myriad of factors that cause every social interaction to be slightly different.

Problem Statement

The American Occupational Therapy Association (AOTA) Vision 2025 defines occupational therapy (OT) as an effective solution to promote participation in daily living through health, well-being, and quality of life for all individuals (2017). In the lives of individuals with HFASD, the role of occupational therapists (OTs) is to promote meaningful participation in one's community and to enhance the quality of life for him or

her (AOTA, 2018). This is accomplished through a series of therapeutic and functional tasks and activities. For example, with clients who have ASD, an OT might focus on improving the client's social skills through various role-playing scenarios, practice, and games. The client would be able to better engage in his or her occupations functionally and successfully with the proper assistance in social skills and social functioning.

Working with these clients on social skills can allow them to better adapt to situations in which they find themselves and can improve functional participation in many aspects of their lives. Necessary social skills vary depending on context and situation; therefore, an OT can work with an individual with ASD to promote both professional and casual social skills (AOTA, 2015).

The Occupational Therapy Practice Framework (OTPF) lists a plethora of domains that are of concern to OTs (AOTA, 2014). Individuals with ASD often struggle in many of these domains, due to lack of proper social functioning and social skills. Some domains most relevant to individuals with ASD addressed in this project include Occupations, Client Factors, Performance Skills, and Performance Patterns. Occupations include, but are not limited to, education, employment, leisure, and social participation (AOTA, 2014). Individuals with ASD often struggle to engage in these occupations due to a certain expected level of professionalism and appropriate communication that all individuals involved in these occupations should be able to engage in (Taylor & Seltzer, 2009). Individuals with ASD who lack these skills may have a hard time fitting into society and engaging successfully, thereby isolating themselves from others, and not participating in occupational roles involving others. Client Factors include body functions, temperament, personality, sensory functions, and voice and speech function

(AOTA, 2014). Individuals with ASD frequently have rigid personalities and temperaments, mental rigidity, and are not flexible in most circumstances. Many individuals with ASD may also suffer from Sensory Processing Disorder, meaning they perceive sensory inputs at either an intensely increased or decreased level (Rincon, Sorek, & Yeger, 2017). They often display perseveration, restrictive and repetitive behavior, making it difficult for them to let things or ideas go. For individuals with HFASD, body functions, as well as speech and voice functions, are typical for the most part. Performance Skills include process skills and social interaction skills (AOTA, 2014). Individuals with HFASD often have major deficits in their Performance Skills.

An individual with HFASD does not process things in a typical manner. They often perseverate on things, leading to a stall in the flow conversation or social interaction in which they are engaging. They may have difficulty initiating social interactions with others or adjusting to new situations or people. Performance Patterns include habits, routines, and roles (AOTA, 2014). Individuals with HFASD have many rigid habits and routines due to their perseverating tendencies. Some of these habits and routines are good, such as brushing teeth before bed or showering each morning, but at times, these habits and routines become inhibiting, thereby increasing the likelihood of perseverations. Because of this, it is essential for these individuals to learn regulation. Roles are often affected in individuals with ASD due to a lack of proper social skills and social functioning. This can lead to difficulty for the individual in numerous roles, including spouse, child, parent, friend, co-worker, or peer. By using these various domains from the OTPF, an OT can greatly assist the client in improving the way he or she interacts with others, as well as with the community (AOTA, 2014).

The American Occupational Therapy Foundation (AOTF) states that by the year 2019 the organization is to facilitate a clear understanding of research-based knowledge to enhance participation in occupations and promote quality of life (AOTF, 2016). After conducting an exhaustive literature review, it was evident that social skills deficits seen in children with ASD often continue into, and throughout, adulthood. Through discussion with professionals within the field and an extensive literature search, we were not successful in finding a social skills game specifically focusing on young adults with social skills and social functioning deficits. There are games specific to younger children to increase understanding of emotions and behaviors. However, the young adult population has been left out of numerous studies and interventions, which pointed to a great need. To stay in alignment with the AOTF's objectives, this project aimed to apply evidence-based practice to a specific intervention to meet the needs of an underserved population.

This project attempted to create an intervention game allowing young adults with HFASD to improve their social skills and social interactions, as well as understand how to utilize social skills in social scenarios with others. It was anticipated that the game would lead to greater success in romantic relationships, employment, school, independent living, and community interactions. Interventions such as the Program for Education and Enrichment of Relational Skills (PEERS), which implements role-playing and group discussions, have shown significant improvements in social responsiveness as well as decreased problem behaviors in young adults (McVey et al., 2016). Teenagers with ASD who completed PEERS in conjunction with their families demonstrated improved knowledge of social etiquette relevant to making and keeping friends (Laugeson et al.,

2008). They also hosted more get-togethers, reported having better quality friendships, and parents reported seeing overall improvements in their teen's social skills (Laugeson et al., 2008).

This thesis project, a social skills intervention game, developed a tool to be used in conjunction with a therapist, mentor, or caregiver to increase the client's confidence and success in social engagement. We were hopeful that this would lead to greater life satisfaction for clients who participated in the intervention game. The objective of the game is for individuals with HFASD to show improvement in social skills and social functioning after playing the game several times. The purpose of this project was to provide a tool for therapists and caregivers to implement to improve social skills and social functioning while promoting teamwork between caregiver, therapist, educator, and client.

The priority population for this project was young adults with HFASD. Research among young adults with intellectual disabilities is limited, and the small amount of research that is available primarily involves individuals with ASD and HFASD. This population specifically struggles with social skills and social functioning. Young adults with HFASD often want to engage in social activities, but do not participate due to social barriers such as lack of transportation, attitudes of others, and having no one to engage with during social activities (McCollum, LaVesser, & Berg, 2016). During adolescence, individuals with HFASD become keenly aware that they struggle with peer interactions, which then separates them from many of their peers. Challenges in social skills negatively impact the development of romantic relationships, successful integration in the workplace or school, independent living, and emotional regulation, which in turn further

negatively impacts the autonomy of young adults with ASD. Some specific skills that this population struggles with include verbal and nonverbal communication, eye contact, reciprocal speech, developing community networks, and hosting friends. The importance of social skills and building friendships has been studied, and discoveries found that friendships work as a resiliency factor during stressful life events, whereas having few or no friends has been correlated with depression. Therefore, it is critical to the wellbeing of young adults with ASD to learn proper social functioning and social skills.

Literature Review

The review of literature focused on locating information regarding young adults with HFASD within the broader context of ASD literature and served as the foundation upon which this pilot study was constructed. The following comprehensive review outlines the implications that social functioning and social skills have on occupational performance in young adults with ASD. The literature addressed the importance of social skills and social functioning for this vulnerable population to achieve a high quality of life and overall sense of well-being. A thorough analysis of literature on ASD regarding current interventions for young adults, as well as gaps in literature within autism, illustrated the necessity for this pilot study.

Defining Social Skills within Autism

ASD is a developmental disorder heavily characterized by deficits in an individual's behavior and communication skills. Most individuals diagnosed with ASD display difficulties with social skills and social functioning, as previously discussed. Social interactions are an integral part of many aspects of life. Lacking these functional social interactions can lead to deprivation in stress control, emotional recognition, and

meaningful relationships (Wadsworth et al., 2016; Gantman et al., 2011). This lack of social awareness also often leads to difficulty in daily living and vocational success (Gantman et al., 2011). Difficulty in maintaining meaningful relationships then leads to isolation and feelings of loneliness and psychological distress (Laugeson et al., 2015; Roth & Gillis, 2015). Typically developing individuals are often uncertain of how to successfully interact with individuals diagnosed with ASD, thus widening the gap of social isolation felt by individuals with ASD. As the prevalence of ASD increases across the globe, interactions between typical individuals and individuals with ASD will only continue to grow (Centers for Disease Control and Prevention, 2018). Therefore, it is crucial to the integral and successful functioning of society that typical individuals learn how to understand and interact with individuals with ASD, and that individuals with ASD learn appropriate communication and social skills. Zalewska, Migliore, and Butterworth (2015) confirmed that young adults with ASD scored low on the social skills scale in comparison to peers with other disabilities. While all aspects of life are essential when assessing successful functioning in daily living for individuals with ASD, the four themes that stand out most for needing improvement are romantic relationships, emotional regulation, employment/education, and independent living. These categories encompass the skills necessary for an individual to become a functional part of society.

Romantic Relationships

Relationships are an integral part of every aspect of life, from the workplace, to riding the bus, to living at home with family or a significant other. Maintaining quality interpersonal relationships comes through effective communication, social interactions, and social thinking (Byers, Nichols, & Voyer, 2013). It is human nature to desire

community, intimacy, and relationships. These things come naturally to most typically developed individuals, which is seen through the ability to interact with others using eye-contact, appropriate body language, and empathy. For those with autism, however, these types of social skills are often not present, or are impoverished at best (Roth & Gillis, 2015). Romantic relationships prove particularly difficult for individuals with ASD to engage in successfully, and "...may be more difficult for men with HFA/AS to initiate and thus form a romantic relationship..." (Byers et al., 2013, p. 2624). Impaired social interactions and communications, repetitive negative relational experiences with others, and internalizing stereotypes of society often lead to unfavorable quality of romantic relationships (Byers et al., 2013). Those who experience more intense symptoms of ASD have more difficulty than those who are higher functioning (Byers et al., 2013).

Boundaries can be effortlessly and unintentionally crossed in romantic relationships with others, when an individual with ASD becomes intensely interested in another individual, even to the point of stalking that person due to perseveration tendencies (Roth & Gillis, 2015). Individuals with ASD may find success through online dating, where information about the other person is readily available and they can meet people without stepping into potentially harmful face-to-face interactions initially (Roth & Gillis, 2015). However, many individuals with ASD do not take safety precautions when using online dating, or they use inappropriate safety precautions such as only trusting their 'gut feeling' (Roth & Gillis, 2015). Understanding another person's emotions, otherwise known as the theory of mind, is vital for a healthy relationship to flourish successfully (Mathersul, McDonald & Rushby, 2013). An example of this was seen through the use of a virtual reality social cognition training program facilitating social practice and immediate feedback from a

teacher. Young adults with ASD showed improvements in emotion recognition of faces and voice prosody (Kandalaf et al., 2013).

A more in-depth look into current literature on romantic relationships for individuals with ASD highlighted the need to address sexuality among young adults. The struggle to balance psychosexual development with deficits in social communication and social interaction, not only affects romantic relationships but may also increase behavioral problems regarding sexuality. A longitudinal study of 108 young adults diagnosed with ASD by the age of 10, participated in semi-structured interviews regarding sexual interest, sexual orientation, sexual activity, inappropriate sexual behaviors, and paraphilias. While most participants reported having sexual interests, 32% reported having no sexual interest. More than half of those who reported having sexual interests were heterosexual, while 29% reported having sexual interests towards the same sex or solitary sexual activities (Fernandes et al., 2016). These findings challenge the stereotype that young adults with ASD are uninterested in sex, or are sexually immature, as well as the assumption that sexual orientation leans in favor of homosexual interests.

While problems with interpersonal behavior and communication limit the ability for these individuals to explore sexual drives and romantic relationships, the study also emphasized concern for inappropriate sexual behaviors. Along with caregiver and parental interviews, 29% of participants were found to demonstrate inappropriate sexual behavior, with the most commonly inappropriate sexual behavior being masturbation in public places. Indecent public exposure and inappropriate heterosexual behavior were also reported (Fernandes et al., 2016). The results of this study state that "...intensive social training and sexual education should be imparted at an early age to prevent the

development of problems related to sexuality, rather than implementing interventions after the problems have arisen...” (Fernandes et al., 2016, p. 3162). Increasing awareness about sexuality in individuals with ASD can help eliminate stereotypes and societal pressures. Fernandes et al. (2016) also suggest that addressing the sexual needs of this population will reduce frustration, anxiety, insecurity, and confusion, which, when unaddressed, can lead to problematic and harmful behaviors. The inability of many individuals with ASD to function appropriately in relationships and engage in appropriate sexual encounters reinforced the decision to include romantic relationships as a theme in the pilot study.

Emotional Regulation

Efficient emotional regulation is key to functionally integrating into society as well as into one’s community. Emotional regulation is defined as “...the ability to respond to ongoing demands of experience with the range of emotions in a manner that is socially tolerable and sufficiently flexible to permit spontaneous reactions as well as the ability to delay spontaneous reactions as needed...” (Cole, Michel, & Teti, 1994, p. 76). Young adults must learn to adapt, delay, or adjust reactions regarding situational expectations as well as societal demands, using internal processes such as memory, attention, and intuition (Cole et al., 1994). This requires individuals to be flexible, to conceptualize situations, and to control affective expression. ASD is characterized by symptoms such as discomfort over small changes in the environment, little to no facial expression during communication, and lack of insight into the feelings of others, thus compromising the ability to develop appropriate emotional regulation techniques (Cole et al., 1994). Lack of emotional regulation techniques can

ultimately lead to self-blame, low self-esteem, and low self-worth because it increases the social gap between typical individuals and those diagnosed with ASD. To complicate things further, managing the many emotions that come with stress and anger is difficult for individuals with ASD, due to their trouble with emotion recognition (Wadsworth et al., 2016).

Emotional dysregulation and maladjustment have detrimental effects on all aspects of one's quality of life. Research states that anxiety increases progressively from toddlerhood, into childhood, and continues through older adulthood in the ASD population (Davis et al., 2011). It has also been shown that stress in children with ASD results in patterns of maladaptive behavior, which worsen over time (Lydon et al., 2014). Stress may be a result of the desire for repetition, predictability, and consistency that carry over to into social interactions with others. (Attwood, 2006). Therefore, unfamiliar social circumstances and the component of spontaneity in everyday language and conversation may bring about social anxiety. Children with ASD with high IQs presented with low self-perceived social skills and competence, leading to higher levels of depression (Vickerstaff et al., 2007). It has also been noted that individuals with ASD who had standard intelligence, perceived life events as being more stressful, while also displaying higher blood pressure (systolic and diastolic) and higher heart rates while experiencing stress, compared to typically developing individuals in the community (Bishop-Fitzpatrick, Minshew, Mazefsky, & Eack, 2017). This shows that not only is quality of life influenced negatively but overall health as well for individuals with ASD.

Due to the correlation between depression, anxiety, and social challenges,

Hillier, Fish, Siegel, and Beversdorf (2011) decided to test out an intervention focused on social and vocational skills to address challenges in the lives of young adults with ASD (2011). The intervention was based on the Aspirations Program Model, with forty-nine adults on the autism spectrum participating in eight one-hour weekly meetings. These meetings were conducted in groups of five to seven participants, and the curriculum was discussion-based to improve social and vocational skills. The various topics were specifically chosen to meet the objective needs of the autism community. These topics included: introductions, social communication, relationships, social event, independent living, independence and college, employment, conclusion, and review (Hillier et al., 2011). All sessions were monitored by group facilitators, who supervised discussions and encouraged participation from all group participants. The group sessions allowed members to listen to personal experiences of others and exchange advice while collaborating on problem-solving strategies. Depression, anxiety, and social challenges were measured by questionnaires administered pre- and post-participation in the Aspirations program. Results spanned over a wide variance of scores, showing that 70% of participants reported reduced anxiety, while 77% reported reduced depression. The scores for Peer Relations Index increased as well. However, the results were not significant, as only 58% felt they had improved peer relationships. The overall results of the study showed that social and vocational skills programs focusing on discussion and participation could reduce feelings of anxiety and depression among those on the autism spectrum. The lack of emotional regulation displayed and reported in individuals with ASD, as seen through the literature, affirmed the need to include this as a theme in the pilot

study.

Employment/Education

Being employed and attending school both require practical social skills and social functioning. Postsecondary education is associated with higher rates of employment and income, however, young adults with developmental disabilities, such as ASD, frequently fall behind in admission rates for postsecondary education and struggle to complete their education once admitted (Ross, Marcell, Williams, & Carlson, 2013). Many young adults with ASD have experienced intense social anxiety due to their deficits in social performance, creating a spiral effect preventing them from engaging in social interactions (McVey et al., 2016). Taylor and Seltzer's (2011) longitudinal study on 66 adults from Wisconsin and Massachusetts reported that participants in post-secondary degree programs, or participants who were competitively employed, showed fewer autistic symptoms than young adults who had a supported job or received adult day services.

Furthermore, individuals receiving adult day services had significantly more maladaptive behaviors than individuals who were employed or who were in a post-secondary program (Taylor & Seltzer, 2011). Around 56% of participants spent much of their time in sheltered workshops or day activity centers. However, the study was conducted in a predominantly Caucasian area with high socioeconomic status, limiting generalizability for non-whites and those in low income who were also seeking employment, education, and transportation.

Zalewska et al. (2016) looked at whether personal traits, such as social skills, affected employment. Being proactive in job searching, talking to potential employers,

working successfully with employment services, or answering job ads were highlighted as areas of concern for young adults and their employment status (Zalewska et al., 2016). This study found there were no statistically significant relationships found between social skills and employment, which is inconsistent with previous literature. Because the study used secondary data from the National Longitudinal Transition Study-2 (NLTS2), response items were limited to questions with only three options of “never,” “sometimes,” or “always” (Zalewska et al., 2016). The lack of variability in response items constrained the results of the data. Data collection methods should provide enough options within surveys to gain a precise measurement and perspective of participants. Despite the limitations, development of social skills allowing for appropriate communication and interaction can help with transportation to and from work or school, which in turn reduces the number of barriers to employment and education. Schools reported low rates of supporting young adults with disabilities during the job search with assisting in contacting employers or job placement agencies, thus supporting the need to develop an intervention addressing social skills regarding employment (Zalewska et al., 2016). The literature review regarding employment and education among young adults with ASD illustrated the need to address limitations in social skills to improve and support opportunities within school and work, as well as successful transportation to and from these places. It also reinforced the need to include employment and education as a theme within the pilot study.

Independent Living

Living independently away from one’s parents is a significant step of independence in life, especially for individuals with ASD. Most skills involved in

independent living require certain aspects of social interaction and social functioning.

Self-care skills affect social participation because how a person looks, and how well they care for themselves, influences how others treat them. While self-care skills may seem simple, they are prerequisite skills for participation in work, school, and leisure.

The 2009/2010 National Core Indicator Survey found that 46.2% of adults with an intellectual disability or developmental disabilities lived in specialized institutions or group homes (National Core Indicators, 2009). Transition programs have also been developed to help individuals with ASD learn the necessary skills for independent living (Ross et al., 2013). Most young adults with ASD who graduated from a transition program either lived alone or with roommates, such as spouses or peers, ten years after completion of the program (Ross et al., 2013).

Young adults with ASD also have difficulty with decision-making, which affects financial independence and money management. While the body of literature is extremely limited for young adults with ASD, it was even more minimal when evaluating individual values regarding financial skills and the effects on quality of life and wellbeing (Cheak-Zamora, Teti, Peters, & Maurer-Batjer, 2017). A qualitative study conducted 30-60 minute semi-structured interviews on 27 youths with ASD to explore underlying themes regarding financial management (Cheak-Zamora et al., 2017). This study found that the youths defined being an adult as being able to manage their finances, such as filing taxes and paying bills. Cheak-Zamora et al. (2017) found that youth reported poor financial management and lack of income as obstacles to their independence. Without being able to make or save money, participants stated they could not drive or move out of their current living situations (Cheak-Zamora et al., 2017). Another recurring theme

demonstrated these youth's frustration with inadequate financial education, feeling disappointed that these skills failed to be taught or emphasized while in high school (Cheak-Zamora et al., 2017). These youths did not feel confident in their financial skills, which only worsened when negative experiences in managing their money continued to occur time and time again (Cheak-Zamora et al., 2017). Although the study did not provide generalizable data and offered open-ended questions regarding money, it reiterated the need to advocate for life skills, such as money management, through occupational therapy interventions (Cheak-Zamora et al., 2017).

Many skills are needed for successful transportation such as planning a route, determining the cost of transit, understanding nonverbal road communication, and problem-solving skills in case something goes wrong. Zalewska et al. (2016) reported that "...youth who had a driver's license or used independent transportation means, e.g., biking, public transit, walking, had five times higher odds of being employed" (p. 235). The ability to get to and from work has allowed individuals to accept various jobs while improving overall independence. Results from the NLTS2, using a random sample of 12,000 students with strong generalizability, found that 34% of students with ASD reported transportation assistance as an essential support need, while 55% of participants stated they rode with family or some type of transportation agency, such as a dial-a-van service (Zalewska et al., 2016). While the correlation of these findings was expected, the study further emphasized the need to address transportation as an integral part of the intervention for young adults. The findings of this study focused on the need for more experimental research for young adults and encouraged the theme of independent living in this pilot study. The study recommended that future research should support increasing

awareness of transportation options, how to use transportation independently, and various ways for individuals with ASD to identify alternative methods of transportation (Zalewska et al., 2016).

Residential independence is also an important milestone for young adults. Anderson et al. (2013) studied three living arrangements of young adults with ASD: with parent or guardian, with a roommate, or in a supervised setting. The results of the study, also taken from the NLTS2 database, found that those with ASD were more likely to have lived with a parent or guardian for more extended time periods, and less likely to have ever lived elsewhere or live independently since leaving high school, compared to young adults with other disabilities (Anderson et al., 2013). The study found that "...the first two years immediately following high school differentiate young adults with an ASD from those in other disability categories..." especially in the category of independent living (Anderson et al., 2013, p. 7). These findings rationalized and affirmed the needs assessment of this project by addressing independent living for individuals diagnosed with ASD as a theme within the pilot study. Young adults with ASD struggle with independent living since they are unable to experience residential freedom and financial wisdom, lack functional skills and receive fewer job opportunities.

Statement of Purpose

This study attempted to answer the following question: Do young adults with HFASD perceive benefits to their social skills and social functioning after participating in a social skills based game? The purpose of this project-based pilot study was to conduct a small scale, (convenience sample) preliminary study that evaluated the feasibility, time, cost, and risks of a card-based intervention, designed to improve social skills and social

functioning for young adults with HFASD. It is typically characteristic of individuals with ASD to display impoverished social skills and social functioning, including emotional recognition, the theory of mind, and conversational skills, as was stated in the Introduction (Kandalaft et al., 2013). Adults with ASD enjoy playing games just as much as typically developing individuals. Therefore, a game is a motivating and fun means of intervention (Kandalaft et al., 2013).

A primary focus of occupational therapy is to assist clients in the attainment of personal goals and desires. Occupational therapists can significantly assist individuals with ASD in improving social skills, eventually leading to greater life satisfaction for the client. The student researchers' goal was that clients would be able to eventually engage in meaningful occupations functionally and successfully with proper assistance and education in social skills and social functioning. Working with these clients on social skills, the student researchers hoped to assist them in adapting to various situations and scenarios they find themselves in and improve function in various aspects of their lives.

Theoretical Framework

The Person-Environment-Occupation-Performance (PEOP) model was most applicable to this project because it is a client-centered approach that takes into consideration extrinsic factors, such as the social, spiritual, and cultural experience of a person, as well as their intrinsic factors, including cognition and psychology (Cole & Tufano, 2008). In 1985, the model was developed by Charles Christianson and Carolyn Baum in response to the profession moving away from the medical model (Cole & Tufano, 2008). The PEOP model uses a top-down approach, which allowed for a holistic reflection of the client's occupational performance (Cole & Tufano, 2008). The model

focuses on the importance of occupations (consisting of valued roles, tasks, and activities) and their performance, which in turn influences a person's life roles (Cole & Tufano, 2008). In the PEOP model, the client is an active participator in the intervention and the occupational therapist guides the session (Cole & Tufano, 2008). Participation is influenced by intrinsic motivation, the environment, and the meaning of the occupation (Cole & Tufano, 2008). An OT intervention can assist with a person's ability to adapt when they experience problems in performance (Cole & Tufano, 2008).

In the PEOP model, the client predominantly selects the domain upon which he or she wishes to focus. The domain in the game was already determined (social skills and social functioning). If there was a genre within the social skills domain that the individual wished to focus on, he or she was able to choose to play more rounds in that particular theme. Individuals with autism enjoy and are motivated by playing games, just like typically developing individuals (Kandalaft et al., 2013). A game of this nature is a cost-effective intervention which families, teachers, or therapists can implement with a young adult with autism to negate some of the more expensive options. Knapp et al. (2009) found that the average annual cost of an adult with autism in the United Kingdom was 58,877£ (\$98,571). Therefore, it is crucial to find more cost-effective options for these families. Another extrinsic factor to consider is the individual's natural environment, such as greater difficulty accessing services when living in rural areas. An intervention game that could be played with a teacher or caregiver created an effective intervention option for individuals of lower socioeconomic status, or who live in remote or rural locations.

The Social Cognitive Theory (SCT) examines the relationship between behavior,

personal factors (such as biological or cognitive factors), and the environment. There are four primary constructs within SCT: observational learning, reciprocal learning, view of human functioning, and self-efficacy beliefs and outcome expectancies (Brown, 2011). Observational learning suggested that learning can occur when one watches or listens to other people without receiving any reinforcement for the behavior (Brown, 2011). Reciprocal causation is the way personal factors, environmental factors, and behavior influence one another (Brown, 2011). SCT views human functioning as proactive, self-regulating, and self-reflective (Brown, 2011). This construct states that individuals can reflect upon their thoughts, feelings, and actions and form a response rather than merely reacting to the environment (Brown, 2011). Self-efficacy beliefs and outcome expectancies are the beliefs that a person can set and pursue their goals successfully (Brown, 2011). According to SCT, depending on an individual's behavior, the environment will be a suited fit (Cole & Tufano, 2008). By designing a game to promote social skills and social functioning, this intervention aimed to change the behavior, and therefore promote a better fit between the person, occupation, and environment (Cole & Tufano, 2008). This better fit then promoted occupational performance. Social and life skills groups, similar to this game, can be used as a psychoeducational approach (Cole & Tufano, 2008). Social interactions and appropriate behaviors are learned through problem-solving, collaboration, and generalization (Cole & Tufano, 2008). One benefit of this intervention game was the discussion aspect. Many social interactions have gray areas, so discussing how an interaction might change based on the relationship with any given individual proved essential during gameplay. For example, it is not typical to hug one's doctor. However, it might be appropriate to hug one's doctor if the doctor

performed lifesaving surgery. Providing the ability to discuss the gray area within this example allows for an increase in appropriate behaviors and understanding of social interactions.

Methodology

The goal of this project was to evaluate the feasibility and acceptance of the game by participants in Life College. Also, student researchers wanted to evaluate whether participants perceived improvements and felt more confident in their ability to deal with various social situations within the four themes presented to them.

Participants and Setting

This project targeted young adults from the Life College program who have various disabilities, including HFASD. Life College is a transitional program facilitating learning in the areas of employment and independent living skills for young adults with disabilities through a 2-year program with various courses to prepare them for independence (The TILE Program at Life College, n.d.). The goal of the program is for these individuals to live independently and to be taught transferable job skills so they can choose meaningful careers. Life College offers various courses divided into classroom-based and community-based training. The program consists of classes that teach self-development skills, employment training, and living skills to help individuals transition into independent living. This project's goal of working on social skills fell under the category of courses offered by Life College such as interpersonal relationships, interviewing, transferable job skills, conflict resolution, and independent living skills. Because the students from Life College came to Stanbridge University every week for regularly scheduled classes, we conducted the project in a predetermined classroom on

campus.

The student researchers gathered participants interested in the project after seeking approval from the OT and director of Life College. Participants completed a consent form two weeks before administration of the intervention game on campus at Stanbridge University. An online consent form was also sent out to each parent and was signed for approval. The eligibility requirements include: (a) be a participant in Life College, (b) complete the consent form, and (c) parent must complete the consent form. Anyone who did not complete the consent form, or whose parents did not complete the consent form, were excluded from the pilot study.

Intervention Procedures

Five participants completed the social skills intervention with four graduate students from Stanbridge University's Master of Science in Occupational Therapy program as moderators. The intervention was in the form of a card game and included four different themes: independent living, emotional regulation, employment/education, and romantic relationships. For each round of the game, there was a maximum of three participants from Life College playing with the student researchers. Since there were five participants total, one group had three participants while the other group had two participants. Each group also had two student researchers to moderate the game and facilitate discussion. Each student was provided with three answer cards with various phrases, responses, or behaviors written on them that were used to correspond most appropriately with the topic cards the moderators put face up on the table. The topic cards consisted of various topics for the four categories listed above and were chosen at random in a separate stack from the answer cards (Appendix A). The moderator always picked a

topic from the top of the stack and played the role of judge. When he or she placed a topic card face up on the table, the participants chose which card they believed was the most socially acceptable in their hand and placed it face down on the table (Appendix B). The judge then mixed up the played answer cards to ensure the anonymity of participants, then revealed the answer cards. The judge read each response out loud and selected which card he or she believed to be the most appropriate answer for the topic card (Appendix B). The participant who placed down the winning card collected the topic card after the round. The goal of the game was to be the first person to collect three winning topic cards. After each round, every participant always picked a new answer card from the draw pile to ensure having three answer cards in hand. This allowed participants to have variability in answer cards each round. The participants and student researchers had one full hour to play the game, followed by administration of the post-game survey (Appendix C).

Data Collection

We measured outcomes of feasibility and ease of use by having each participant complete a survey after participating in the game. The survey consisted of multiple choice and free response type questions. Examples of the questions included (a) how did you enjoy playing the game?, (b) did you feel the game was easy to play?, (c) would you play this game again?, (d) who would you play this game with?, and (e) what was your favorite and least favorite part of the game? The results of the first three questions were analyzed quantitatively, showing a percentage of those who responded positively and negatively to the intervention game. The free response questions, as well as any verbal feedback received, were analyzed qualitatively based on appropriate themes. For

confidentiality purposes, student researchers created a master list of numbers coinciding with each participant's name and the information was kept safe in a password protected computer.

Limitations

It is essential to acknowledge the limitations of this project. The study's small sample size characterized the primary limitation of the project, recruited from a convenience sample of young adults enrolled in Life College. Because the pilot study had five participants, the small sample size taken from Life College was not representative of all young adults with HFASD. Future studies should test the card-based intervention on a larger sample size rather than directed at a specific group.

Furthermore, factors such as ethnicity, gender, or socioeconomic status of participants were not taken into consideration for this preliminary study. This may have served as a possible limitation to the findings and would be a vital component to include in future studies for generalizability purposes. Time also influenced the findings of the pilot study. Student researchers spent only one hour with participants to limit the time which participants lost in class. Also, time constraints due to the student researcher's schedules limited the ability to implement the study more than once. The opportunity for more time for the student researchers with the participants could have helped overall findings.

Second, bias functioned as a possible limitation to the study. The reliability of self-reported data through the distribution of a written survey could have been influenced by participant bias, skewing actual experiences of the study. While student researchers informed all participants that there would be no compensation, and honest feedback

regarding their experience was highly encouraged, self-reported responses could have still impacted overall findings. It is also important to note that one of the student researchers was previously employed by Life College and was familiar to some participants within the study, potentially influencing response bias. All efforts to limit bias were made to maintain the integrity of the study.

Third, while the study's population of interest was young adults with HFASD, recruitment procedures found that validating whether a participant had HFASD or simply ASD was limited without access to medical records. Although Life College is inclusive of all adults with disabilities, the primary diagnosis within the program is ASD. HFASD was alluded to through each students' participation in the Life College program. Future research incorporating a more extensive scale study should request proof of diagnosis or administer a standardized assessment to measure individuals with HFASD for inclusion criteria. Additionally, while past studies have shown social skills groups helpful for children and adolescents with HFASD, there was limited research on interventions for young adults with ASD, especially for card-based interventions aimed at promoting social skills and social functioning. While the literature review demonstrated a clear need to address concerns within romantic relationships, emotional regulation, education and employment, and independent living skills, insufficient prior research on interventions specific to young adults with HFASD highlighted the need for additional research to be done before a full-scale research project was conducted. Despite possible limitations of the project which may have slightly affected the findings of the study, this project set the groundwork for potential future comprehensive studies and the need for further research. Additional studies with more substantial and diverse samples studying longitudinal

effects are needed to determine the potential of the study to impact social skills and social functioning over time.

Ethical and Legal Considerations

This study involved working with participants from a vulnerable population who have experienced health disparities as a disability-related cultural group. Ethical and legal considerations were taken by student researchers to ensure that all individuals participating in the project experienced safety and well-being. The American Occupational Therapy Association Occupational Therapy Code of Ethics served as a guide toward maintaining professional and moral practices through its seven core values (AOTA, 2015).

Participants remained the core focus of this study. To maintain beneficence of all participants, a Site Agreement (Appendix F) was provided to the program directors of Life College requesting permission to conduct the pilot study during the program's business hours. A formal letter entitled "Permission to Conduct Pilot Study" (Appendix H) was shared with all program directors of Life College. In the letter, the research team requested permission to recruit students from within the program to participate in the pilot study. All information, including the students in the research team, the purpose of the study, the risks and benefits, as well as time involvement, was included in the letter. The program directors were asked to review the letter, sign it, and return it to the research team or advisor either in person or via the contact email provided. Approval to conduct the pilot study was received and securely stored by the research team.

Student researchers distributed individual recruitment flyers (Appendix I) to students of Life College during a convenient time scheduled by the program directors.

The flyers contained information regarding the purpose of the study and relevant contact information if prospective participants had any questions or concerns. Student researchers explained the study and answered any additional questions that arose from participants.

Once prospective participants had questions and concerns answered via email and expressed an interest in participating in the pilot study, the student researchers then sent them an email with the Consent Form (Appendix J). Participants were all asked to sign and date the form either electronically or physically on a printed hard copy and return it to student researchers one week before the pilot study date. All forms were returned and reviewed by student researchers. An Assent Form (Appendix K), was developed for any potential participants under 17 years of age. However, no minors participated in the study, and the Assent Form was not required. Photos and videos were not taken during the pilot study.

To maintain dignity and exercise the utmost justice with this vulnerable population, all individuals who expressed interest in the study were also asked to provide their parent/legal guardian's email address. The parent or legal guardian was notified that his or her young adult was interested in participating in the study. The parent or legal guardian was asked to sign, date, and return a Parent/Legally Authorized Representative Permission Form (Appendix L). Both forms included a thorough description of the study's purpose, time involvement, risk and benefits, payment, participant rights, and contact information. Stanbridge University's Institutional Review Board reviewed and approved the pilot study (Appendix M).

Although the risks of participating in the pilot intervention game were extremely low, there were potential risks involved. The first potential risk was the chance that

participants may feel uncomfortable conversing with unfamiliar people during the pilot study. To decrease feelings of discomfort while talking with unfamiliar people, such as the student researchers, the investigation team was available before and after the intervention game to answer any questions or concerns from participants or their parents. Also, participants risked the potential of experiencing higher emotions than usual during gameplay. Feeling upset, frustrated, or sad could have resulted. To reduce potential emotional disturbances that might arise as a result of playing the game, participants were informed that they had the choice to opt out at any time during the pilot study without negative consequences.

Another risk taken into consideration was that participants might experience a loss of anonymity. The pilot study was conducted during the Life College hours and students were aware of each other's participation. While participants were aware of each other's participation and anonymity could not be fully ensured, each participant was coded with a pseudonym for publication and presentation of data to maintain confidentiality. The team only discussed matters related to the study in private rooms limited only to investigators, co-investigators, and faculty, as previously mentioned.

Participants were also at risk for missing a portion of Life College's classes on the day of the intervention, since the pilot study was conducted during regular Life College hours. To reduce the risk of missing class content, participants were only included in the study if permission was granted by the program's director. Those who did not meet the program's academic requirements were not invited to participate in limiting the risk of time loss within Life College's regularly scheduled curriculum. Any work missed was not required to be made up, per the director of Life College.

The investigation team also took into consideration the cost to participants as well as compensation. There was no monetary cost to participants. However, they were asked to set aside a maximum of one hour of class time during their regularly scheduled Life College program on the day of the intervention game. This one hour included a brief review of the participant's rights as stated in the signed consent forms, teaching the participants how to play the game, one to two rounds of the game, completion of the follow-up questionnaire, and addressing any questions or concerns the participants had regarding the pilot study. Although the participants lost one hour from the program, the discussion fostered by the topics within the game coincided with similar lessons regarding social skills covered by the program, minimizing the cost to participants. Also, to eliminate potential response bias, participants were notified that reimbursement or compensation would not be provided for time or effort during the pilot study.

To respect participants' rights and anonymity, the confidentiality of data was practiced for all individuals involved in the pilot study. Pseudonyms were assigned to each participant. After receiving consent forms, student researchers coded all identities of participants into pseudonyms and only discussed matters regarding the participants through these assigned pseudonyms. Information (e.g., pseudonyms, real identities, data, results) was stored on private laptops and was password protected and encrypted. All backups of data information were stored on a thumb drive in a manila folder. This folder, as well as all signed consent forms and follow-up questionnaires, were sealed and stored in a locked room in the OT office at Stanbridge University by the faculty thesis advisor. All student researchers understood that data was not to be shared with any outside party. Student researchers also made sure any discussion regarding the pilot study was always

conducted in a private, secure room while speaking at low volume. Records collected from the pilot study will be destroyed precisely one year following the completion of the project by securely deleting all data from personal laptops, thumb drives, and shredding all consent forms and follow-up questionnaires.

Results

Each participant filled out a short survey after the pilot study was completed. All participants (n = 5) were young adults and the group included four male participants and one female participant. Out of the five participants, 80% reported that they enjoyed playing the game and 20% reported that it was okay (Appendix D). When asked if the game was easy to play, 80% reported that it was easy to play and 20% reported that it was slightly challenging to play (Appendix E). When asked if they would play the game again, 80% reported yes and 20% reported no (Appendix F). The participants who reported that they would play the game again reported that they would play with family, friends, or the OT at Life College. When asked what their favorite part of the game was, some responses included “getting to play with others,” and “learning new things.” When asked their least favorite part of the game, some of the responses included “losing,” and “having to choose a card that sounded right but does not fit the word.” Two participants stated that they thought the game would be an excellent way to relieve stress and relax. Another participant reported that he learned new things while playing the game.

Discussion and Application to OT

This study’s purpose was to examine the feasibility of a social skills card game intervention created for young adults with HFASD. Through collected data of multiple choice and free response questions, the study indicated that the game was both feasible

and enjoyable for participants. Data demonstrated that most (80%) of the participants enjoyed playing the game and stated that they would play the game again if given the opportunity. However, when asked verbally, all the participants reported that they liked the game and would like to play it again. A possible explanation for this discrepancy could be that there was a misunderstanding in the wording of the questionnaire, or the participant did not feel comfortable expressing his true feelings verbally to the student researchers. Regardless, the card-based intervention appeared to be fun and well accepted by participants. These findings are significant, as the intervention was designed to be an interactive and fun way to work on social skills for individuals with HFASD. Creation of a game that was fun and interactive for participants seemed to create intrinsic motivation for individuals and led to the self-reported desire for students to play the game again in the future.

Two different groups were involved in playing the card game simultaneously. One group was made up of three participants (group A), while the other group had two participants (group B). In group A, all participants greatly enjoyed the competitive aspect of the game. When choosing responses for a specific topic card, each gave his or her best effort and showed signs of excitement when he or she won a round. Some participants expressed disappointment when they lost a round. However, they never displayed genuine anger or irritability.

An example of this was seen as one participant became disappointed that the moderator did not choose his response, resulting in a loss for that round. However, when he saw the winner's response, he verbally admitted the winning card was a better response than his own. He applauded the winner and continued to do this frequently

when he lost rounds. The competitive environment created by the game not only brought enjoyment but challenged participants in group A to play their best response cards by putting themselves in diverse social situations. Group B participants took part in the game and also appeared to enjoy themselves. Both participants, however, did become easily confused by the wording on several of the topic cards. Therefore, they occasionally played cards they stated they were unsure of in response to the confusing topic card. This confusion fostered meaningful conversations between participants and student researchers. The student researchers were able to explain the meaning of the topic cards in various ways, leading to more successful involvement in the game from participants in group B. This raised productive feedback, as the student researchers were able to consider the fact that more simple language may have been needed on some of the topic cards. Both participants displayed good temperaments, and each round acknowledged the winner's card as the most appropriate, even if it was not their card that was chosen to win the round.

Although the student researchers did not explicitly test whether participants were learning new skills or ideas through gameplay, many participants offered comments stating that they were learning new things as they played the game. Some of the comments on participants' surveys stated: "It could help express your feelings towards certain topics," "I learned new words," and "I think this game would be helpful in a thinking way." This aspect of learning makes this game a good fit for OT interventions because it is helping participants in learning new ways of thinking and expressing themselves, with the end goal of increasing effective social functioning and social skills.

The findings of feasibility and collected data stating participants' enjoyment showed promise because the social skills intervention is a potential tool for working on social skills and improving the overall lives of young adults with HFASD. The intervention game addressed numerous occupations held by young adults including activities of daily living, relationships, education, work, social participation, and more. These fundamental occupations are significant as they enable successful participation within the community, home, school, work, and other settings (AOTA, 2014). Occupational therapists work to assist these individuals in engaging in their occupations successfully. This social skills game provided many "teaching moments" throughout gameplay. Within each of the four themes, many answers or response cards were appropriate, and many that were inappropriate, depending on the topic card in any given round. These various responses provided discussion for participants and gave student researchers many opportunities to listen to participants' thought processes when asked to justify or explain their played response cards. Through this process, student researchers were able to provide guidance and educate participants while using real-world examples.

Conclusion

Summary

This project-based thesis focused on the feasibility of improving social skills and social functioning in young adults diagnosed with HFASD. Since individuals who have been diagnosed with HFASD demonstrate diminished appropriate social skills and social functioning, the goal of this project was to create a card game-based intervention including role play, discussion, and social interaction with the underlying purpose of increasing these skills and functioning in daily life. After piloting our intervention with a

group of Life College students, we believe that with further implementation over time, this intervention has the potential to successfully increase social skills and social functioning for individuals diagnosed with HFASD, thereby increasing their quality of life and ability to engage in successful and meaningful occupations.

Future Implications for Occupational Therapy

This social skills intervention game should be modified for future use by OTs, caregivers, teachers, and parents in order to promote the most optimal results. To measure long term success and effectiveness of the game in improving social skills and interactions in romantic relationships, employment and education, independent living, and emotional regulation, the game will need to be implemented with the same participants regularly. Then results and accurate data will need to be examined in a longitudinal study with a larger sample size than the current pilot study. A pretest-posttest design is ideal, to test the effectiveness of the game on the self-reported improvement of social interaction skills, as well as the reports of families, peers, teachers, and OTs who frequently interact with those participating in the game. As a team, we recognize that a longitudinal study with more participants would show whether this game is effective over time. If this game proves to be unsuccessful or ineffective, then adjustments should be made accordingly in the future, in order to make it more effective in improving social functioning and social skills in individuals with HFASD.

Student researchers implemented this intervention game in a group setting with multiple participants taking part in each game. However, for future use in OT clinics, special education classrooms, or with parents or caregivers, this intervention game could be implemented as a one-on-one activity with just one participant and one moderator. The

moderator will place one topic card on the table. The participant will have all the answer cards in his or her possession and will place on the table all answer cards he or she thinks are a suitable match for the current topic card. The moderator could go through several topic cards for each category, allowing the participant to match answer cards to topic cards as he or she sees fit. After answer cards have been placed down on the table, the moderator should facilitate discussion with the participant to understand why certain cards were placed. This will provide the opportunity for positive feedback to the participant, as well as constructive feedback when needed. The flexibility and universality that this one-on-one option offers could make this game more appealing to those who do not have access to a group setting, or for those participants who are not ready for a group setting but would thrive with the one-on-one implementation of this intervention game.

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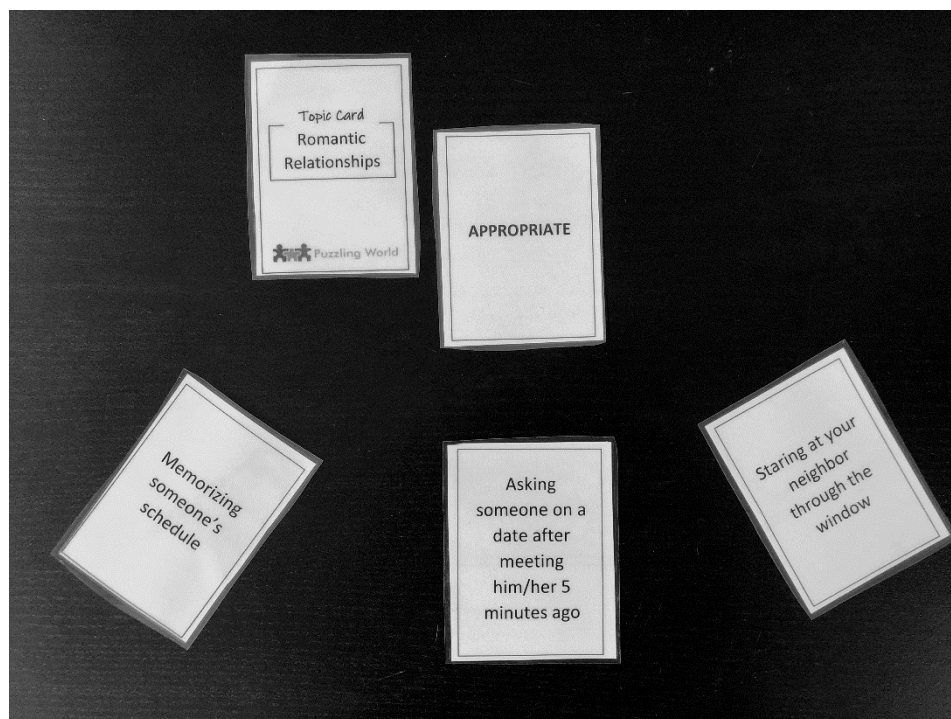
Appendix A

Example of Topic and Answer Cards



Appendix B

Example of Game Play with Topic and Answer Cards



Appendix C

Stanbridge University Research Post-Game Survey

How did you enjoy playing the game?

- A. I liked playing the game
- B. I thought it was ok
- C. I did not enjoy playing the game

Did you feel the game was easy to play?

- A. I thought the game was easy to play.
- B. I thought the game was a little difficult to play.
- C. I thought the game was very difficult to play

Would you play this game again?

- A. Yes, I would play this game again
- B. No, I would not play this game again.

If yes, who would you play this game with?

What was your favorite and least favorite part of the game?

Appendix D

“Did You Enjoy Playing the Game?” Results



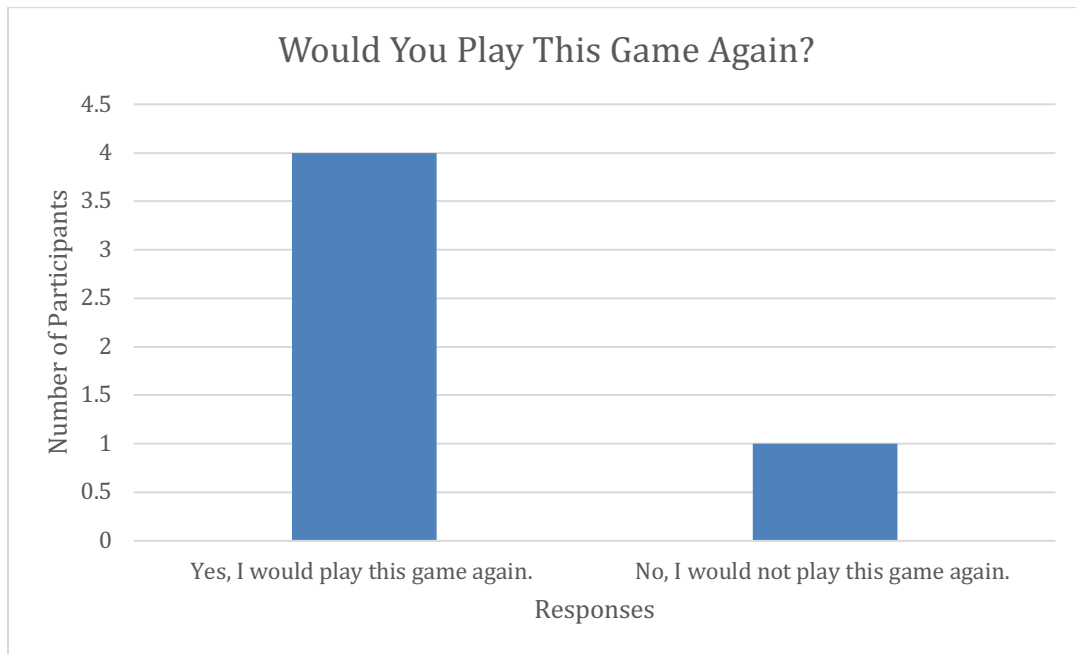
Appendix E

“Did You Feel the Game Was Easy to Play?” Results



Appendix F

“Would You Play This Game Again?” Results



Appendix G

Thesis Site Authorization Form

Stanbridge University

Master of Science in Occupational Therapy Program

Thesis Site Authorization Form

Institution/Program: Stanbridge University - Master of Science in Occupational Therapy**Investigator's Name and Title:** Dr. Shari Emas, OTD, OTR/L**Email of Principal Investigator:** semas@stanbridge.edu**Title of Research:** The Puzzling World of Social Engagement for Young Adults with Autism Spectrum Disorder

Description of Research: Stanbridge University's Master of Science in Occupational Therapy students are creating a card based intervention for young adults who have high functioning Autism Spectrum Disorder. The card activity is designed to address social skills and social engagement in four main areas: relationships, emotional regulation, employment/education, and independent living. The pilot study hopes to recruit potential subjects at this location to participate in a one hour study that will include playing the card game and answering a short questionnaire on their experience. The goal of the game is to facilitate a guided conversation about appropriate responses in various situations.

Researchers will contact and/or recruit participants at this location by: Face-to-face distribution of a flyer during Life College hours containing an email address to contact if interested.


This site has agreed upon the recruitment and data collection methods to be used in this study and will receive information on the outcomes of this study. This research will be completed by: December, 2019.

This investigator has permission to conduct research at:

Facility Name: Life college _____.

Staff Member: Phil Prickett _____.

Position: Program Coordinator _____.

Signature:  _____.

Date: 8/15/2018 10:30:51 AM PDT _____.

Appendix H

Permission to Conduct Pilot Study

STANBRIDGE UNIVERSITY

PERMISSION TO CONDUCT PILOT STUDY

August 2, 2018

Phil Prickett and Greg Brashears
Life College OC
2041 Business Center Drive
Irvine, CA 92612

RE: Permission to Conduct Pilot Study

Dear Mr. Prickett and Mr. Brashears:

We are writing to request permission to conduct a pilot study at Life College OC. We are students in the Master of Science in Occupational Therapy program at Stanbridge University and we are in the process of completing our Master's thesis. The study is entitled "The Puzzling World of Social Engagement for Young Adults with Autism Spectrum Disorder." The purpose of our thesis is to develop a successful social skills and social engagement intervention activity that helps young adults with autism. The intervention consists of an interactive card game that focuses on four main areas necessary for functional independence: relationships, emotional regulation, employment/education, and independent living. Our thesis is to see whether the interactive game can serve as a successful tool for individuals, caregivers, educators, and therapists to work on social skills and improve occupational performance.

Our hope is that Life College OC will allow us to recruit students currently participating within the program. If we are able to receive permission, we would come and pass out flyers to talk about our study. Students interested in participating within the pilot study will be asked to email us and sign a consent form. Potential participants will also be asked to have a parent or legal guardian complete a consent form as well.

Once consent is received, voluntary participants will be asked to play a card game with the researchers of the study. Each participant will be instructed on how to play the card game. Participants will be asked to express their thoughts on decision-making for specific scenarios. Immediately after playing the card game, students will complete a questionnaire. The study should take no more than one hour.

Your approval to allow us to conduct this study at Life College OC will be greatly appreciated. We are happy to answer any questions or concerns you may have regarding our thesis or pilot study. Please feel free to contact us at puzzlingworld7@gmail.com if you have questions or concerns.

If you approve, please sign below which acknowledges your consent and permission for us to conduct this study at your institution.


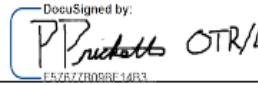
Sincerely,

Stanbridge MSOT Students
Stanbridge University

Enclosures

Cc: Dr. Shari Emas, OTD, OTR/L, Faculty Advisor, Stanbridge University
Hanna Wagner, OTS, Stanbridge University
Randy Kwon, OTS, Stanbridge University
Christine Tran, OTS, Stanbridge University
Katie Monus, OTS, Stanbridge Univesity

Approved by:

Phil Prickett	 F57677B09BF14B3	8/15/2018 10:30:51 AM PDT
Print name	Signature	Date
Phil Prickett	 F57677B09BF14B3	8/15/2018 10:30:51 AM PDT
Print name	Signature	Date

Appendix I

Life College Recruitment Flyer



SIGN UP TO PLAY BY 10/19:
EMAIL TO
PUZZLINGWORLD7@GMAIL.COM

DO YOU LIKE GAMES?

Play a social skills card game with us and give us your thoughts!

WHEN: DURING LIFE COLLEGE CLASS
IN OCTOBER
WHERE: STANBRIDGE

Appendix J

Stanbridge University Research Consent Form

Description: You are invited to play a card game where you can practice your social skills. The game is about living away from home, relationships, emotions, and jobs. Once you finish the game, we will ask you how you felt about it. One of the Stanbridge students will be taking notes while you play. Your thoughts and experiences will be kept private among the Stanbridge students.

Your Time Involvement: The game will take about 1 hour of while at Life College.

Risks and Benefits: We don't expect anything bad to happen to you, but you may feel frustrated or sad when talking about certain topics. While playing this game, you will be able to practice and work on your social skills. Your opinions will help us improve this game.

Payment: It is your choice to play this game; however, you will not be paid or given any rewards.

Participant Rights: After signing this form, you are agreeing to play this game. If you choose to not play or want to stop playing, you will not be punished. You can choose to not answer specific questions. Your name and opinions will not be shared with others outside of the student group to keep your privacy. The results of this study may be presented during professional meetings or published in scientific journals.

Contact Information: If you have any questions, concerns, or complaints about this study you may contact the Faculty Advisor, Dr. Shari Emas at puzzlingworld7@stanbridge.edu.

Independent Contact: If you are in some way dissatisfied with this research and how it is conducted, you may contact Stanbridge University's Vice President of Instruction, Dr. Christine Mallon at Cmallon@stanbridge.edu.

Please keep a copy of this signed and dated consent form for yourself.

Signature of participant

Date

Name of participant

Appendix K

Stanbridge University Research Assent Form (For Ages 17 and Under)

Study Title: The Puzzling World of Social Engagement for Young Adults with High-Functioning Autism Spectrum Disorder

1. What will happen to me in this study?

We are inviting you to participate in a card game. During the game, the student researchers will teach you the rules of the game. You will be asked to make choices and talk about your choices. After the game is over, you will be asked a few questions about what you thought about the game.

2. Can anything bad happen to me?

We do not expect anything bad to happen to you. You may feel overwhelmed, frustrated, or sad at times during the game. If it becomes too much and you want to stop, please tell the researchers.

3. Can anything good happen to me?

Good things can happen to you. You may have fun, you can meet new people, and learn new things about yourself.

4. Do I have any choices during this study?

You have many choices during the game. You can quit anytime you want. You don't have to answer any questions if you don't want to.

5. Will anyone know that I am in this study?

Your name and information will be kept a secret and information about you will only be given to the researchers of this study. Findings of the study will use fake names to protect your identity.

6. What if I get hurt, or don't feel right?

If you get hurt, or you don't feel right, we will stop the game and your parent or legal guardian will decide what you should do next.

7. Who can I talk to about this study?

If you have questions or would like to talk to someone about this study, feel free to contact the research team at puzzlingworld7@stanbridge.edu.

8. What if I have questions about the study but want to talk to someone that is not a part of this study?

If you have questions about the study but want to talk to someone that is not a part of the study, please feel free to contact Stanbridge University's Institutional Review Board at IRB@stanbridge.edu.

9. What if I do not want to do this?

Participation is always up to you. You do not have to play if you don't want to. If you do not want to do this, you can stop at any time without getting in trouble. It is your choice to participate. Just let one of the researchers know as soon as possible.

If you agree to be in this study, please sign here:

Signature of minor

Date

Name of minor

Signature of witness

Date

Appendix L

Stanbridge University Research Parent or Legally Authorized Representative Permission Form (Age 17 or Under or Dependent Adult with Disabilities)

Description: Your child or young adult is invited to participate in pilot study focusing on how to use social skills in daily living. Occupational therapy students at Stanbridge University are creating a card game that addresses social interaction, communication, and behaviors of young adults with HFASD. The purpose of the study is to develop a fun and interactive tool for therapists, caregivers, and clients to use to improve social skills and social functioning. Your child or young adult will be asked to play a card game with other participants and the study's researchers. The game includes topics such as independent living, relationships, and employment, and will ask him/her to share his/her opinions on some of the topics. Once the game is completed, your child or young adult will be asked to complete a questionnaire regarding his or her experience with the game. Observational notes of your child or young adult will be taken for the study's use. All findings of the study will be collected and analyzed, and results of the feasibility of the card game may be presented to students, health care providers, researchers, and faculty and published in scientific journals.

Your Time Involvement: Your child or young adult's participation will take approximately 1 hour in Life College.

Risks and Benefits: While there are no known risks with this study, we believe that the topics discussed could potentially cause your child or young adult to be at greater risk for higher emotional experiences than normal. For example, topics addressed within the card game may cause overwhelming feelings of frustration and/or sadness. While the possibility of this happening is low, we believe you should be aware of the possibility that minimal risk may be encountered. There are no guaranteed benefits from participating within this study, however, if your child or young adult does participate in this study, he/she may receive the following benefits: increased social participation, development of social skills, and awareness of certain behaviors. While there may be no benefits to society at this stage in the study, his/her participation is likely to help us find answers to help young adults with Autism Spectrum Disorder.

Payment: Participation within the study is entirely voluntary. Your child or young adult will not be paid or given any incentives for participating in the research.

Subject Rights: If you have read and signed this form you are allowing your child or young adult to participate in this study. Your child or young adult's participation in this study is voluntary and you have the right to withdraw your child or young adult at any point in time without penalty. Your alternative is to not allow your child or young adult to participate in this study. He or she has the right to refuse to answer specific questions. Your child or young adult's identity will not be disclosed, and confidentiality will be maintained through the use of pseudonyms. The result of this study may be disseminated at professional meetings or published in scientific journals.

Contact Information: If you have any questions, concerns, or complaints about this study you may contact the Faculty Advisor, Dr. Shari Emas (puzzlingworld7@stanbridge.edu).

Independent Contact: If you are in some way dissatisfied with this research and how it is conducted, you may contact Stanbridge University's Vice President of Instruction, Dr. Christine Mallon at Cmallon@stanbridge.edu.

Please keep a copy of this signed and dated consent form for yourself.

Signature of parent or legal guardian

Date

Name of parent or legal guardian

Name of participant

Appendix M

Institutional Review Board Approval



IRB Reviewer Feedback



Reviewer Name: Lakshmi Kodeboyina, PhD
 Student Name(s): Hanna Wagner, Katie Monus, Randy Kwon, Christine Tran
 Advisor Name(s): Dr. Shari Eras
 Study Title: The Puzzling World of Social Engagement for Young Adults with Autism Spectrum Disorder
 Study ID: 080
 Decision: Approve
 Minor Revisions
 Major Revisions

**Reviewer Comments:**

All the comments have been addressed appropriately.

The following comments need prompt attention from the researchers:

- 1) IRB recommends that the research team seek Stanbridge University's approval for this project.
- 2) The recruitment flyer has a private email listed for participant communications. Please propose appropriate measures to keep these communications safe and account handling and closing procedures for this email.

Please reach out to support@stanbridge.edu for further assistance with item 2 listed above.

Please type your name as electronic signature