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Capturing Success at Autistry Studios: A Qualitative Study

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CAPTURING SUCCESS AT AUTISTRY STUDIOS: A QUALITATIVE STUDY

Capturing Success at Autistry Studios: A Qualitative Study

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December, 2015

CAPTURING SUCCESS AT AUTISTRY STUDIOS: A QUALITATIVE STUDY

This thesis, written under the direction of the candidates' faculty advisor and approved by the chair of the Master's program, has been presented to and accepted by the Faculty of the Occupational Therapy department in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy. The content, project, and research methodologies presented in this work represent the work of the candidates alone.

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Abstract

This qualitative study examined the perceived outcomes of participation at Autistry Studios among young adult students with Autism Spectrum Disorder (ASD). Autistry Studios is a unique program offering services to individuals with ASD similar to that of a pre-vocational training program. The mission of Autistry Studios is to help students with ASD become independent adults by engaging in “project-based therapy.” A setting is provided where individuals with ASD can achieve personal and functional growth with the use of creative resources like art supplies, raw materials, and power tools to pursue and complete a project that is client-centered. The purpose of this study was to examine the relationship between attendance at Autistry Studios and improvement in areas of independent living.

Participants were selected using purposive and convenience sampling methods. The results describe the key themes that emerged from semi-structured interviews of three types of stakeholders (participants with ASD, their workshop mentors, and their primary caregivers). The researchers used framework analysis to reveal consistent themes of improvement in five areas: executive functioning, socialization, self-esteem, independence, and self-regulation. These areas are essential to workplace functioning, suggesting that participation in Autistry Studios leads to a scaffolding of skills required in a modern workplace. Results also suggest the principles and practices of Autistry Studios and “project-based therapy” are consistent with occupational therapy theory and practice due to a focus of hands-on participation in functional tasks as observed by the embedded researchers. The methods utilized at Autistry Studios could help occupational therapists modify treatment programs to better benefit clients with ASD.

Introduction

The number of diagnosed cases of autism has been steadily rising, with recent evidence from the United States Center for Disease Control and Prevention (2014) finding that one in 68 children in the United States is born with autism (www.cdc.gov). The rising incidence of autism is an immediate and long-term concern for society when coupled with the continued vocational difficulties experienced by individuals with ASD. Current estimates suggest that 75% of individuals with ASD are unemployed (Wilczynski, 2013). This limits the independence of these individuals and creates chronic underemployment for this population. This data also suggests that our public education system has been failing students with ASD by leaving them unprepared for an independent, adult life once they leave the education system.

Adolescents with ASD currently face an extraordinary challenge making a successful transition from school to independent living as young adults. Finding and maintaining full-time employment post-high school graduation proves most difficult in this transition. According to the Autism Speaks organization (2012), “roughly 50,000 youths with autism will turn 18 years old this year, yet less than half of them have ever participated in part-time employment” (www.autismspeaks.org). This age group faces an overall decline in availability of social services after they “age out” of the K-12 educational system. In fact, only “26% of young adults with severe disabilities were currently working when contacted up to two years after leaving high school” (Trainor, 2012). This deficit of our education system has created a demographic crisis for society, as we face an increasingly larger wave of adolescents with ASD reaching an employable age but not succeeding in finding and maintaining employment. The purpose of this study is to examine the therapeutic process at Autistry Studios to learn what methods are successful in fostering pre-vocational skills in adolescents with ASD.

Literature Review

Introduction

Vocational education for adolescents and adults with ASD is under-researched. “The majority of research and programmatic efforts have focused on young children with relatively little focus placed on adolescents and adults with ASD” (Hendricks, 2010). Employment is an occupation that is personally rewarding and relevant to the individual with ASD. Research indicates employment is most likely the number one priority of an adolescent youth (Hendricks, 2010). Employment is enabling for all individuals because it allows people to earn the wages necessary to live independent lives and pursue their own personal interests, promotes dignity, and improves quality of life.

Engagement in work related tasks has also been found to improve cognitive performance (Hendricks, 2010), which may hint at some of the improvements witnessed in the population at Autistry Studios. There has been a history of anecdotal success at Autistry Studios, based on testimony and experiences by participants, their primary caregivers, and their mentors. However, the problem is there has been a void of research done and results found with the participants at Autistry Studios to further understand the improvements witnessed.

Autism

Autism has been steadily rising in the United States, yet the etiology of the disorder is still unknown. Many different factors appear to be interacting, such as genetics and environment, yet a specific cause or trigger is not understood. Currently, a boy in the United States is five times more likely to develop autism than a girl (www.cdc.gov). With the recent publication of the Diagnostic and Statistical Manual of Mental Disorders, Fifth edition (DSM-5), the clinical definition of ASD has been adjusted to reflect current knowledge of the disorder

(American Psychiatric Association, 2013). ASD is now diagnosed if an individual is displaying consistent deficits in social interaction and communication in many different contexts, and/or if that individual is displaying restrictive or repetitive patterns of interests, behaviors, or activities. These symptoms must be present in early childhood development, be severe enough to cause significant functional impairment, and not be better explained through a separate diagnosis such as Intellectual Disability or Global Developmental Delay (American Psychiatric Association, 2013).

An individual with ASD commonly has difficulties with nonverbal communication, such as misunderstanding body language, not making eye contact, and not understanding gestures (Hendricks, 2010). These deficits makes reciprocal social interactions difficult for individuals with ASD, who usually struggle with interpreting tone of voice, emotion, and affect, as well as more abstract concepts such as symbolic language or sarcasm (Trainor, 2011). These communication challenges result in difficulty developing, maintaining, and understanding social relationships. Often, people with ASD will fail to properly understand the context of their communications and may act in a manner considered socially inappropriate.

Restricted and repetitive interests, activities, or behaviors manifest themselves in many ways. Individuals with ASD may be highly fixated on normally benign objects such as trains or certain colors (American Psychiatric Association, 2013). In addition, individuals with ASD often insist on consistency, meaning that any change in routine or a transition from one activity to another can be challenging. This behavior is often witnessed in schools, where transitions from one subject or activity to another can cause maladaptive behaviors for an adolescent with ASD.

Individuals with ASD often experience difficulty with sensory modulation (American Psychiatric Association, 2013). This causes individuals with ASD to be hypersensitive to some stimuli, or under-responsive to others. For example, a student with ASD may be aversive to the feeling of a shirt tag on the back of his or her neck, or the elastic of his or her waistband. Similarly, another child with ASD may be too under responsive to sensory stimuli such as temperature, sound, or texture. The uncomfortable sensory experiences of children with ASD can often lead to behavioral disruptions in the classroom, thus decreasing learning outcomes.

Currently, over half of individuals with ASD have been found to have average or above average intelligence (www.cdc.gov). This indicates that many young adults with ASD often have intellectual abilities that could enable them to participate in society the same as a neurotypical individual, given the appropriate education and environmental accommodations.

Employment and Autism

The distinguishing characteristics of autism - impaired social interaction, impaired communication, restricted interests and repetitive behavior - conflict with most job demands. Nearly every job requires some social interaction and communication while expecting employees to be flexible and able to deal with new demands as they arise. These complex behaviors are typically difficult for an individual with autism, and contribute to the low employment rates of individuals with ASD.

The growing population of individuals with ASD has not been met with a parallel increase in their rates of employment. Most studies show that between 20% and 33% of individuals with ASD in the United States is employed (Wilczynski, 2013). Additionally, those who are employed are not as likely to advance in the workplace. For instance, “forty-three

percent of employed young adults [with ASD] were reported to work in jobs where most of the other workers also had a disability” (Carter et al, 2011).

Billstedt, Gillberg, & Gillberg (2005) reported results of a longitudinal study of 120 children diagnosed with autism over a span of 13-22 years. Zero participants had a ‘good outcome’, defined by the researchers as, “(a) being employed or in higher education/vocational training, *and*, (b) if over the age of 23 years, living independently, if 22 years or younger, having two or more friends/a steady relationship” (p. 354). In fact, 57% had a poor outcome, defined as “obvious severe handicap, no independent social progress, some clear verbal or nonverbal communicative skills” (p. 354). The employment outcomes of individuals with ASD continue to be poor into their adult years, with observed deficits in social skills and independent living.

When entering employment, individuals with ASD have few workplace options. The likely settings are competitive employment, supported employment, or a sheltered workshop (Wilczynski, 2013). Competitive employment is defined as: individuals with a disability earn at least minimum wage and are paid at a competitive rate, comparable to a non-disabled individual doing the same task. These jobs are typically in a community-based setting. About 6% to 10% of adults with ASD are competitively employed (Taylor and Seltzer, 2011).

Supported employment is organized to offer individuals with a disability an opportunity to work in the community with supports already in place. These supports could include job development, job coaching, transportation, and/or job retention. Individualized supports may also be offered such as assistive technology (Wilczynski, 2013). Sheltered workshops are the most restrictive environments of the three typical options. These are usually non-profit organizations designed to offer people with disabilities the opportunity to work, but at below minimum wage (Wilczynski, 2013). According to Hendricks (2010), supported employment and

competitive employment offer far better outcomes than sheltered workshops in terms of financial gains, social integration, and worker satisfaction.

The majority of working adolescents and adults with ASD in the United States are employed in the following areas: production, building and grounds cleaning and maintenance, food preparation and serving, office and administrative support, and retail and other sales (Carter et al, 2011). While it may seem encouraging that a quarter of adolescents and adults with ASD are currently employed, it is imperative to note that these employees are typically individuals who are considered to be higher functioning on the autism spectrum. Generally, these individuals have been found to be much more skilled at social skill/communication, self-care, behavior, and self-advocacy (Carter et al, 2011). While these are all skills that are positively correlated to a higher probability of making a successful transition from education to employment, they are not always emphasized in the proper way or emphasized at all in current pre-vocational transition programs.

Workplace advantages and challenges for individuals with ASD

There can be distinct advantages to employers and companies when employing an individual with ASD. For instance, in an employment setting, individuals with autism are known to be trustworthy, reliable, and have low absenteeism (Hagner and Cooney, 2005). Individuals with ASD can also be employer assets for positions that require particular strengths such as intense focus, attention to detail, repetitive tasks, or jobs with social isolation (Smith, Belcher, and Juhrs, 1995). As society advances, many of these traits may become desirable for employees working in the technology sector.

Individuals with ASD, however, do face some challenges in the workplace, primarily due to communication deficits. Interactional difficulties with supervisors and co-workers are a

consistent hindrance in the work environment for individuals with ASD and can often lead to termination of employment (Bolman, 2008). Social nuances that a neurotypical person has mastered such as nonverbal communication and understanding directions can be obstacles for an individual with ASD in the workplace. These individuals typically have difficulty understanding facial expressions, symbolic language, and reciprocal social interactions (Hendricks, 2009).

Education and Disability

Since the passage of Individuals with Disabilities Education Act (IDEA) in 1990, public schools are required to devise a transition plan for individuals with ASD before they leave the education system. Under this statute, school professionals are tasked with designing or collaborating with programs designed to meet the vocational needs of individuals with ASD, preparing them for a life of independence. Despite legal mandates and continual efforts to improve the education of individuals with disabilities in general, the outcome data suggests these programs and schools have not been successful in transitioning adolescents with ASD out of the school system and into the workforce (Carter & Lee, 2012).

Another initiative, the Workforce Investment Act (1998), requires vocational rehabilitation agencies to be involved in the school to work transition process. These agencies are tasked with conducting outreach programs to identify students with disabilities and their associated school systems. Once identified, these stakeholders (public high schools, state and local agencies) must then collaborate together to develop an Individualized Plan for Employment for when the student with a disability leaves the school system (Wilczynski, 2013).

There is growing evidence to suggest that employment outcomes for adolescents with ASD are improved if they are first employed while still in high school (Carter, Austin and Trainor, 2012). A program such as Autistry Studios may serve an important function between

school and work. By participating in an environment that encourages pre-vocational skill building, adolescents with ASD at Autistry Studios may be gaining crucial exposure to the rigors of employment without the pressure of failure inherent in a competitive employment setting.

Pre-vocational training for adolescents and young adults with ASD

Current pre-vocational transition programs for adolescents with ASD can be described as a bridge to nowhere. Despite considerable data and media reports publicizing an increase in ASD incidence, there is currently still very little known about how best to provide support that will result in postsecondary success (Hendricks, 2010). Carter, et al. (2011) reported that while “having a vocational IEP goal, receiving job search instruction, and spending more than one quarter of the day in work-study outside school individually yielded significant odds ratios, they were no longer significant when considered in conjunction with access to paid work experiences.” Carter et al (2011) concludes that it is actual, hands-on work experience, rather than indirect experiences or academic preparatory experiences that produced the best outcome for young people with severe disabilities.

The number of individuals with ASD is increasing, therefore, the number of individuals with ASD requiring pre-vocational training services is also increasing. The limited body of research evaluating employment outcomes of the vocational rehabilitation system suggests that services provided through these programs are less than optimal for individuals with ASD and do not provide sufficient support (Hendricks, 2010). Despite the positive correlation between hands-on work experience and increased likelihood of employment attainment among this population, “access to job shadowing, job skills training, job placement support, job coaching, and internship or apprenticeship experiences during high school are consistently low” for youth with autism (Wagner et. al, 2003) as cited in (Lee & Carter, 2012). While there are a few

identified areas that appear to be associated with the increased likelihood of a successful school-to-work transition, further research is necessary to understand the relationship between employment and pre-vocational skills. The program at Autistry Studios has had early anecdotal success, and does not follow the traditional vocational skills models that have been found to be modestly effective at best. Further research into the effectiveness of the pre-vocational program currently in place at Autistry Studios could shed light on innovative ways to address the employment deficit of individuals with ASD.

Autistry Studios

Project-based learning

Located in San Rafael, California, Autistry Studios is a non-profit organization that supports adolescents and adults with ASD to engage in project-based learning. Students explore a topic that they are interested in, and then create a plan to turn that topic into a hands-on project. All projects are completed in the workshop at Autistry Studios under supervision of staff. The workshop is located in an open warehouse and is fully stocked with an array of equipment. Some focus areas of the workshop include equipment and materials to do projects involving technology, woodworking, and art. Students are free to explore the workshop to inspire their interests and to facilitate choosing a particular project to undertake. The projects usually take students one to two months to complete. During this time, students learn how to plan, initiate, collaborate with Autistry staff, and problem-solve to accomplish goals.

The program at Autistry Studios encourages the scaffolding of skills required to fully function in the adult world. Opportunities to learn and practice specific job skills in a supportive environment, such as teamwork and task planning, are promoted. Students are able to apply and

practice said job skills in simulated work experiences, all while allowing for the development of interpersonal relationship skills through interaction among students and staff.

Social Interconnectedness

At Autistry Studios, each student interacts and works with their peers. Students with similar interests are able to collaborate on projects together. This interaction promotes social skills amongst the students. Students are encouraged to listen, learn, and engage with their peers while working on projects. Social skills that students practice and strengthen include sharing, patience, and respect. To further promote social interaction among students, Autistry Studios incorporates a milieu meal into each of its workshops. Students have a chance to relax, connect with their peers, practice social skills, and engage in conversation. The workshop sessions and opportunities for socialization help to establish a normative and friendly environment where students are more at ease and likely to communicate.

Students are also paired with adult mentors who assist the students during the course of their projects. The mentors help the students identify issues and problem solve throughout the course of the project. Mentors form relationships with the students to help support them emotionally when a project becomes frustrating. Students and mentors are overseen by directors at Autistry Studios. The directors' role is to engage with both the students and mentors as an extra source of support. The directors help make sure the students are staying on task with their goals and projects. They also support the mentors who work one-on-one with the students by providing suggestions and sharing expertise in working with adolescents and adults who have been diagnosed with ASD.

Emphasis on Education

Since the target population of Autistry Studios is adolescents, a tutoring program is offered to help participants with their academics. This program affords students another support and resource to promote success in their academic endeavors. Due to Autistry Studios being focused on student success during and after adolescence, a resource they offer is helping students connect with colleges. This includes researching colleges based on departments and majors, navigating the application process, and scheduling meetings with college advisors. In order to help fund students' post-secondary education, Autistry Studios helps students research available scholarships. They provide students with guidance in navigating websites, completing applications, and connecting with community organizations that offer scholarships.

Relation to Occupational Therapy

Occupational therapy (OT) is a therapeutic process designed to maximize an individual's independence through active participation in desired activities. These activities can be as simple as daily hygiene routines as well as complex occupations such as maintaining employment. The project-based therapy process utilized at Autistry Studios is designed to help individuals with ASD develop vocational skills that will help them acquire and maintain employment. Keeping a consistent job helps these individuals maximize their independence. While Autistry Studios does not have an occupational therapist on staff, the directors have developed a strategic partnership with the Dominican University Occupational Therapy faculty due to common theoretical perspectives on intervention. By promoting hands-on participation in self-directed voluntary projects, Autistry Studios are operating from a client-centered approach, consistent with the occupational therapy perspective.

Summary

Autism incidence rates in the U.S have been rising consistently, leading to societal challenges as an increasing number of individuals with ASD try and fail to enter the workplace. Currently, employment rates of individuals with autism are poor, despite evidence suggesting an equivalency in intelligence compared to neurotypical individuals. Additionally, new evidence suggests some companies or industries may prefer an employee with ASD, yet there has not been a corresponding bump in employment figures.

Current research suggests individuals with ASD experience difficulties in the workplace due to poor communication skills, perceived inappropriate behaviors, and difficulty multi-tasking or transitioning from one task to another. In turn, these maladaptive behaviors could partially result from poor vocational and education programs that are not effectively preparing individuals with ASD for participation in the modern workforce. One reason for the ineffectiveness of these programs is that a paucity of research exists about what interventions are effective to increase the employment rate of individuals with ASD. The unique program in development at Autistry Studios may be effectively targeting these skill deficits for individuals with ASD, yet more research is necessary to understand what components of the program are successful, and why.

By researching the Autistry Studios program, components of successful transitions from school to employment and independent living can be identified. By identifying effective practices, modification of similar pre-vocational training programs for individuals with ASD can be made. Such modifications may reduce the overall costs of vocational support expenditures and other costs related to unemployment among those with disabilities like ASD (Kuangparichat, 2010). Because “young people with severe disabilities often leave high school without the skills, supports, and connections that lead to meaningful employment (Trainor, 2012),” it is imperative

that such components be implemented and reinforced throughout the program process. In addition, programs such as Autistry should be studied to identify what is making them effective. Through both observation and interviews with Autistry Studios students, peer mentors, staff, and caregivers, narratives can be elicited and then analyzed for common themes of improvements in functioning and successful transitions to independent living. By capturing what is successful at Autistry Studios, prevocational programs can be improved resulting in increased employment, independence, and greater quality of life for adolescents and adults with ASD.

Statement of Purpose and Research Question

The mission of Autistry Studios is to help students with ASD become independent adults. By providing a welcoming setting that encourages students to attain personal and functional growth, it serves a valuable purpose in the lives of adolescents and adults with ASD in Marin County. This objective is achieved by using the extensive creative resources available such as power tools, electronics, and art supplies.

This study was a qualitative case study design. It explored the experiences of adolescents and young adults with ASD who currently attend Autistry Studios, through observation and face-to-face interviews with students, their peer mentors, and caregivers. Data was collected through in-depth interviews, and follow-up interviews were conducted through email and telephone conversations to clarify and answer further questions. The specific phenomenon explored in this study was the perceived impact of regular participation in Autistry Studios' pre-vocational program on independence and executive functioning.

The purpose of this research project is to answer the following questions. How is success defined by the participants of Autistry Studios? What are the changes witnessed in the clients that are deemed to be successful? And how are these changes related to the project-based therapy

program design at Autistry Studios? To answer these questions, the team conducted qualitative interviews with a select group of Autistry Studios clients, their caretakers and their project mentors.

Theoretical Framework

The Ecology of Human Performance (EHP) framework is used to guide this research (Dunn, Brown, & McGuigan, 1994). An individual's environment is vital to a person's ability to perform tasks, activities, and occupations. In this framework, the term "context" is used in place of environment. *Context* is how an individual views his or her personal world and includes the physical environment, cultural environment, social environment, and temporal factors. People's contexts are always changing, and as changes occur, a person's behavior also changes. People constantly interact with their context and that continuous interaction influences their behavior (Dunn et al., 1994). The EHP framework examines the interactions between the individual and activity in a certain context in order to be able to achieve a goal (Dunn et al., 1994). This research study examined how the individual students were impacted by the program design environment set up for them at Autistry Studios and what aspects of that environment encouraged further development of independence.

Another major component of this framework is the *task*. According to EHP, people perform tasks within a context, using their own skills and abilities (Dunn et al., 1994). The context is utilized to support performance of these tasks. A range of possibilities for task performance are available within the context and the person chooses specific tasks to perform according to inherent skills and abilities. Roles can determine tasks that the person chooses to perform (Dunn et al., 1994).

A range of possibilities is available to students at Autistry Studios when they first enter the program. When students first arrive at the program, the mentors and directors of Autistry Studios observe the new students explore the warehouse environment and wait until the students choose a particular area in order to customize a program. For instance, one student might be particularly drawn to the painting area while another student might be particularly drawn to the wood shop area. The students are able to explore a wide range of possibilities for task performance and are able to perform said tasks according to their own skills, abilities, and interests.

The final component of EHP is *performance*. Performance is a component that is completely dependent upon the past experiences of the person and the resources available to him/her (Dunn et al., 1994). Limited abilities and skills might limit performance range as much as contextual barriers. Autistry Studios anticipates that resources will have less of an impact on student performance because the program provides a wide array of resources and activities for students to participate in. The EHP framework describes five intervention strategies for occupational therapists to utilize to improve functional performance, which were considered in relation to the Autistry Studios program:

The first intervention strategy is to *establish* or *restore certain skills and abilities* and to restore them within context. At Autistry Studios, mentors and program directors work with the students to help them engage in activities and/or occupations that they are interested in. For some students, mentors and program directors are actually introducing them to activities and occupations that the students might not have been exposed to before, but may prompt new interests. The second intervention strategy is *alteration*. This intervention focuses on selecting a context that enables performance with the person's current skills and abilities. Essentially, it

involves finding a suitable context, rather than changing the present context to meet abilities (Dunn et al., 1994). Another intervention strategy is *adaptation*. This strategy entails manipulating or changing the context and/or task demands. For instance, a mentor at Autistry Studios might make slight modifications to a particular work station to accommodate the needs of a student. Prevention is another strategy. *Prevention* is actually the main focus of intervention under EHP and is done through addressing particular features of the person, task, and context that could lead to the development of maladaptive performance (Dunn et al., 1994). Finally, one can *create circumstances* that promote more adaptable or complex performance within a context. This intervention strategy emphasizes functional performance without the assumption that a disability might interfere with performance.

Methodology

Research Design

A qualitative case study design explored the experiences of adolescents with ASD who currently attend Autistry Studios. Data were collected through in-depth, semi-structured interviews, clinical observation, researcher journaling, and reflection. The specific phenomenon explored in this study was the perceived impact on client functioning of regular participation in Autistry Studios' pre-vocational program.

A qualitative study design allowed the researchers to learn about the program from multiple stakeholder perspectives to answer the research question. This approach took information directly from the student, the caregiver(s), mentors, and the experiences of the researchers themselves. The mentors work directly with the students at Autistry Studios and their input was based on direct observations and daily interactions, allowing mentors to describe the interventions and trajectories of the students involvement with Autistry Studios. The

caregiver(s) provided their observations and interactions with the students at home and in the community to give information about how the interventions at Autistry are generalizing to other life domains. Additionally, the students themselves were able to share their own perceptions and valuable experiences gained through participation in the Autistry Studios program.

Participants

The researchers interviewed three students with ASD at Autistry, one parent/legal guardian per student, and one Autistry mentor per student. Subjects were recruited via purposeful sampling with the help of the program directors at Autistry Studios. The inclusion criteria for the student participants was that they must be diagnosed with ASD and have the verbal skills to engage in one-on-one interviews. The initial research subjects were also selected based on rapport and trust established with the research team.

Participant consent was obtained through written permission. Participants were made fully aware of the purpose, procedure, potential benefits, and potential risks inherent to the study. Participants understood they were free to revoke their consent at any time and terminate their involvement in the study. Each of the three parents/legal guardians were provided the Social Communication Questionnaire (SCQ)--a brief instrument used to assess and evaluate the communication skills and social functioning of individuals who may have ASD. [The questionnaire was completed by each parent/legal guardian and then results were thereby scored by researchers.] Individuals scoring below 15 indicate levels of higher functioning. Individuals scoring 15 or greater are indicative of ASD, and a further comprehensive assessment should be completed. SCQ scores, gender, and age of all three student participants were then organized into Table 1.

Table 1

Demographic Table of Participants

Participant	Age	Gender	SCQ Score
Client 1	22	M	12
Client 2	18	F	12
Client 3	14	M	21

Data Collection Procedures

The data collected was from semi-structured interviews with students, mentors, and caregivers. Graduate occupational therapy students conducted these interviews with students, caregiver(s), and mentors, either at Autistry Studios or a setting where the participants felt most comfortable. The interviews were based on a core research question of how Autistry Studios has impacted the students. This question was followed with a series of sub-questions aimed to elicit further information. Follow up questions targeted the students' interests, positive outcomes, and areas of progress. Questions for the students were more specific and focused as opposed to broad, open-ended questions that were asked of the mentors and caregiver(s). These aimed to help obtain relevant information that the students may have been unable to verbalize or communicate during the interviews. All interviews were organized and displayed in Table 2.

Table 2

Interview Question Bank

For Client

1. Tell me about your experience at Autistry Studios.
2. How has your participation at Autistry Studios benefitted you?
3. How has your overall level of independence changed since attending Autistry Studios?
4. How has your ability to relate with others changed since attending Autistry Studios?
5. How has your ability to organize tasks in your life changed since attending Autistry Studios?
6. How has your school/work performance benefited from your participation at Autistry Studios?
7. What do you think is the most important part of the Autistry Studios experience?
8. How has Autistry Studios affected the way you view your future?

For Client's Mentor

1. What positive changes have you witnessed in your client while at Autistry Studios?
2. How has your client's overall independence level changed?
3. How has your client's social skills changed since joining Autistry Studios?
4. How has your client's executive functioning changed since his or her participation at Autistry Studios?
5. How has Autistry Studios benefitted your client's work/educational performance?
6. What do you think is the most important part of the Autistry Studios experience?
7. How has your client's view about his or her future changed?

Table 2 Continued

For Client's Parent/Caregiver

1. How has participation at Autistry Studios benefitted your child/dependent?
 2. How has Autistry Studios affected your child/dependent's executive functioning?
 3. How has Autistry Studios affected your child/dependent's social skills?
 4. How has your child/dependent's independence level changed?
 5. How has your child/dependent's view about his/her future changed?
 6. How has Autistry Studios benefitted your child/dependent's work/educational performance?
 7. What do you think is the most important part of the Autistry Studios experience?
-

Participants or caregivers also provided basic demographic information such as age and education level. The interviews were recorded for later data analysis. A vertical interview process was used to conduct an in-depth exploration of each client and his or her associated mentors and caregivers. This would allow each researcher the ability to examine the surrounding social context of each client to gather a more complete picture of his or her level of functioning and what progress has been achieved. By clustering the interviews in this manner, we were able to triangulate responses around the client till we reached a point of saturation with our data. Contextual data at Autistry Studios was gathered through observations and a reflective journal kept by each member of the research team. This was accomplished by members of the research team interacting with the students in an active volunteering role. This approach was aimed to minimize anxiety for the students in order to minimize the risks for participants and create an environment where authentic responses were possible. As a prerequisite for the interviews, the

research team spent at least six consecutive weeks at Autistry Studios in the workshop with the students. Each week, the research team members were there at least five hours, leading to roughly a hundred hours of combined observations and client interactions. This allowed for the development of rapport with Autistry students and for the research team members to attain a better understanding of the students' strengths, limitations, personalities, and functional skills. Observing and interacting with the students and the style in which they communicate allowed our team to conduct interviews in a format that resulted in the most relevant information being communicated. In addition, all participants have signed consent forms prior to participating in the study.

Data Analysis Procedures

Client data was analyzed to create case records using a framework analysis as the guiding methodology. According to Smith & Firth (2011), the framework approach to qualitative data analysis is a means of commissioning the research brief, identifying highly focused aims and objectives, and thereby eliciting and managing data through repetitive review of the research. After interviews with participants were transcribed verbatim, all data was read through and organized according to a categorization scheme developed by the researchers. The categorization scheme allowed researchers to begin to organize emergent themes. Creating a classification structure assisted researchers in organizing the data for coding. Data were then coded and recoded for analysis using coding strategies for trustworthiness, such as all data being coded and recoded independently and then revised through comparative consensus. This allowed for triangulation of data sources as all researchers contributed to the coding process. Codes were developed based on information from the literature review and information gathered from face-to-face interviews and observation hours. Consistent themes were noted and data were

re-read multiple times, during which new findings were then compared to original findings.

Within the case studies, thematic quotes and other data patterns have been assigned codes as to whether the source was the parent, student, or students' mentor.

Strategies to control bias in the analysis were employed. Researchers completed reflective journals to document their own personal experiences, and periodic team meetings were held to review analysis procedures for consistency and accuracy. Close collaboration with the program directors of Autistry Studios as well as with the research team thesis adviser ensured proper methodology and validity of data sources.

Ethical Considerations

The AOTA Code of Ethics was followed throughout the duration of this study. Specifically, the research team paid attention to the principles of autonomy, confidentiality, beneficence, and nonmaleficence. Beneficence ensured the safety and well-being of the research participants, while nonmaleficence ensured that no harm would come to any participants of this study. The researchers all have extensive experience working with adolescents with ASD and have completed several psychosocial OT classes at Dominican University. Autonomy and confidentiality ensured that the participants voluntarily participated in the study and that their identities were protected.

An IRB application was submitted and approved by the Dominican University Institutional Review Board for the Protection of Human Subjects (IRBPHS). This ensured no harm would come to the research subjects by consenting to third party oversight of the research methods and procedures. All participants in the study signed letters of consent. This letter stated the purpose, procedure, potential risks, and potential benefits of participating in this study. Each participant was made aware that they are free to withdraw their consent at any time.

Results

Seven distinct themes were determined by the researchers based on the student research participants' experiences at Autistry Studios. Table 3 categorizes and quantifies the emergent themes established upon completion of the data analysis. First, executive functioning categorizes cognitive processes that relate to organization, sequencing, planning, and problem solving. Second, socialization addresses communication abilities, interpersonal interactions, and behavior that is appropriate. Third, self-esteem refers to changes in both behavior and internal thought processes. These include attempting new tasks, engaging in challenging projects, and having an improved sense of self-confidence. Fourth, independence can be classified as decreasing the frequency or removing supports (physical, emotional, social, etc.) that were previously in place for the students. Independence is explained as an improvement and increase in the capacity of self-governance and functioning that is demonstrated by the students. Fifth, self-regulation represents changes in behaviors and capacities of the students in relation to social participation (interrupting, maintaining appropriate personal space, etc.), work (decreasing amount of time distracted while working on projects, independently taking a rest break when becoming frustrated, etc.), and education (being able to independently schedule time for homework and studying, asking for academic support when needed, etc.). Sixth, employment addresses attainment of volunteering, internships, and paid work experiences. Lastly, education refers to improved academic performance, classroom participation, and identification of areas of academic interest.

Table 3

Theme Frequencies

Participants	Executive Functioning	Socialization	Self-Esteem	Independence	Self-Regulation	Employment	Education
Client 1	1	7	2	4	3	1	0
Client 2	4	2	5	4	1	0	2
Client 3	4	5	7	2	2	1	3
Totals*	9	14	14	10	6	2	5
Percentage	15%	23%	23%	17%	10%	3%	8%

Note. *Grand Total = 60

Table 3 indicates that research participants spoke more about the effect on client areas of socialization and self-esteem, followed by independence, executive functioning, and self-regulation. Education and employment were the two least prevalent themes that emerged from the data analysis. Table 4 provides exemplar quotes that were provided by the clients, parents, and a mentor. These quotes are direct and insightful examples that provide a clear sense of the benefits that the Autistry Studios experience yields.

Table 4

Client, Parent, Mentor Direct Quotes

Participant	Executive Functioning	Socialization	Self-Esteem	Independence	Self-Regulation
Client 1	“He’s more of a self-advocate. He’s more willing to take risks.” (parent)	“The social participation exposed him to new activities and occupations.” (parent)	“Using his interests allows him to develop more self-confidence.” (parent)	“Autistry allowed him to become independent with public transportation and commuting.” (parent)	“He can now self-regulate. He knows when to take a break.” (parent)
Client 2	“I figured out what I needed to, my goals for a certain project, and how to achieve it.” (client)	“I met new people, like Janet and Dan. I had to get to know all the other students around here.” (client)	“This has been a place for her to feel safe and accepted. And they get her.” (parent)	“I can easily do independent stuff. I learned how to take care of my own situations and problem solve.” (client)	“Now, I’m more aware of my condition, and I can organize my thoughts and sentences.” (client)
Client 3	“He comes up with ideas, researches, plans, and develops them. It teaches him problem-solving.” (parent)	“I’m talkative to people, and more out there in the world. My social skills improved when working with peers.” (client)	“He views himself in a better way. For the first time, he has a community. It’s built his confidence.” (parent)	“He’s more positive about his future. He sees himself in the world as more of an adult, with the skills needed to be one.” (parent)	“Now he’s responsible about doing work he’s agreed to do, before taking a break.” (mentor)

Tables 5-13 (Appendix C) provide more focused cross comparisons of all the themes that emerged from the interview data. Specific cross comparisons include the client and their mentor, the client and their parent, and the parent and mentor of a client. These tables provide a more clear understanding of the specific areas of benefit Autistry Studios is providing. The

researchers identified and tallied all of the participants' interview responses in these tables. Tallies were counted, summed, and represented with corresponding percentages for each theme identified. Therefore, this provides a focused snapshot of all participant interview responses that allows for comparisons of the prevalence of each emergent theme.

Tables 5-7 represent client 1, their mentor, and parent. Results from table 5 indicate that socialization was the most prevalent theme representing 42% of the interview responses from client 1 and their mentor, followed by self-regulation at 23%. These participants least reported executive functioning and employment, with both themes representing only 4% of responses. Table 6 denotes that socialization and independence were the most reported themes by client 1 and their parent at 33% and 30%, respectively. Executive functioning and employment were least reported by these participants, with both themes representing 3% of responses. Results from table 7 indicate that client 1's mentor and parent reported socialization to be the most prevalent theme at 35% of responses. These participants found self-esteem to be the least prevalent theme reported at 15%.

Tables 8-10 represent client 2, their mentor, and parent. Results from table 8 indicate that self-esteem was the most common theme reported at 25% by client 2 and their mentor, followed by executive functioning and independence at 21% each. Self-regulation was the least prevalent theme, indicated at 7% from these participants. Table 9 denotes that self-esteem and independence were the most reported themes by client 2 and their parent at 32% and 29%, respectively. These participants least reported self-regulation and employment, with both themes representing 4% of responses. Results from table 10 indicate that client 2's mentor and parent reported self-esteem and independence to be the most prevalent at 30% of responses. These

participants found self-regulation, employment, and education to be the least prevalent themes reported at 5% each.

Tables 11-13 represent client 3, their mentor, and parent. Results from table 11 report that socialization and self-esteem was the most common themes indicated at 28% each. Employment was the least prevalent theme, indicated at 3% from these participants. Table 12 denotes that self-esteem and socialization were the most reported themes by client 3 and their parent at 35% and 22%, respectively. Employment was the least reported by these participants, representing 3% of responses. Results from table 13 indicate that client 3's mentor and parent reported self-esteem and socialization to be the most prevalent at 35% and 31%, respectively. These participants found independence, executive functioning, and education to be the least prevalent themes reported at 12% each.

Executive Functions

Reported improvement in the area of executive functioning included: self-advocacy, project development and implementation, problem solving, and initiation of tasks. Autistry Studios clients indicated enjoyment and satisfaction from planning, problem solving, and designing their projects. A client explained a typical day: "At lunch by the end of it we would say to each other what we're working on, what order we need to do it, and organize these tasks to complete our projects. For example, I'm working on a sword from a movie and so what I had to do today was reconfigure some measurements to make sure that they would drill correctly onto a piece of wood and then after that we would have to test that on the machine to see if it would work on the wood and if it didn't we would have to reconfigure it again and we have to order up what we were supposed to do." This client reported improvements in executive functioning at home, noting: "If I had math homework, history homework, and science homework, I would

probably organize it into a system which I can do it in a good amount of time. I would start with my math homework, finish that, do my chores, then start on my history homework, then have dinner, then finish off some science homework and then go to sleep, so yeah I would say the skills here (at Autistry Studios) can be easily used at home.”

The parent of Client 3 echoed these sentiments: “He’s making sure that we’re all ready for Autistry, and when we’re supposed to leave. He’s figuring out problem solving a lot more. I see it around the house, like we’re having some kind of issue and he’s figuring out more how to do it. He has a lot more faith in himself that he can brainstorm ideas and do it.” Client 3 supported this statement, saying: “A big thing at Autistry for me is the mold and modeling. You take a while to think everything through so it doesn’t become a really big thing. Making something also helps me in the real world, especially with my abilities.”

The project-based process at Autistry Studios encourages this development in executive functioning skills. While each project is based on the interests of the client, a general workflow emerged when a client was developing a project. First, they would be tasked with finding images online that depicted the character, object, or item they wished to create. Next, they would brainstorm and sketch possible ways to construct it considering material properties and design. Then, they would create a smaller test piece to problem-solve and figure out how they would implement the design at an accurate scale. Finally, the finished product would be created.

Socialization

Interview participants universally noted improvement in the area of socialization, which was mainly fostered through Autistry Studios’ milieu environment, including the designated mealtime. Improved socialization skills were exhibited through newfound interests in activities and occupations and increased engagement in social activities including text messaging and peer-

to-peer contact. Increased comfort when communicating with others, improved self-efficacy, and increased self-awareness of ASD limitations supported overall improved self-esteem in Autistry students. From a parent: “They have lunch together and it encourages [Client 3] to be socially engaged. [Client 3] isn’t necessarily social on his own but in that environment he’s encouraged to be social. He didn’t want to text before Autistry Studios. And then he came home one day from Autistry and he was texting. So there were definitely some things that his peers at Autistry were doing that got him interested in pursuing those activities too. The milieu and additional social participation exposed him to certain activities and occupations that he may not have ever been prompted to pursue had it not been for Autistry.”

Client socialization was a strong component of the Autistry Studios experience. The environment was set-up in a way to foster comfortable social opportunities that clients were free to engage in. Despite this, socialization was rarely an outright goal for the program, but rather a common thread that weaved its way throughout the program design at Autistry Studios. For example, work spaces are designed to be communal. Clients can reach out to other clients for help in navigating a problem, and often do. There is plenty of space should an individual prefer to work independently.

Independence

Increases in the areas of generalized independence were noted via a variety of behavioral changes including independent use of public transportation, employment-seeking, and household chores. “If there was one specific thing that happened directly from Autistry was getting him to become independent with public transportation and commuting on his own,” responded a mother. Another parent reported: “I think she’s become a little more independent. She’s able to get up on her own now, which just up until a year ago was a real problem.” A client commented:

“My parents like helping me with anything or they would have to remind me about a lot of stuff and then when I came here I could figure out what I needed to do, what my goals are for a certain project and how to achieve it.”

Self-esteem

A theme found consistent in the interview responses and the researcher's reflective journal entries was the contextualization for ASD provided by Autistry Studios. It appears that one of the main benefits for clients at Autistry Studios is to interact with other adolescents with ASD in a setting outside of school in which the clients participate voluntarily. Clients were able to find common ground with each other, share stories about their experiences, and see similar behaviors from a different perspective, which helped them understand their own reality.

“I think that it is kind of an inside to out perspective of being on the spectrum,” a mentor commented. “So it’s not people who are ‘normal’ helping you try and act normal. But it’s a place where the norm is to be quirky, and odd, and geeky. And that it is about how you kind of use your strengths and talents to support the things that are hard for you. And it’s something that everyone is going through so the kids get to see people who are at different stages. I think it is really awesome that the college guys come on Sunday and I know that’s been really powerful for some of our kids.”

Many had been stigmatized over the years and felt like they were an “other” but the inclusive environment at Autistry Studios made them feel like they belonged and were part of an in-group. Here they found other kids with similar interests, ways of being, and patterns of communication which felt natural and normal. “I think she’s at a place now of having it more integrated in her self identity that she is someone that being on the autism spectrum does affect her but it’s not something that she has a lot of shame around, and that’s more of the feeling she

had when she first came here,” a mentor reported. A client supported this thought, saying “I would say I relate better with my parents because it is tough being a parent to a kid and occasionally here I would see through that view of a parent to explain something to a child in the most simplest way you can without confusing them. I can see how it's tough to take care of someone.” It is this experience of contextualization and normalization that appears to be quite powerful, but also difficult to research and pinpoint to specific programmatic efforts at Autistry Studios. A parent closed her interview by saying, “I think the most valuable thing for her is that in the end, this has been a place for her to feel safe and accepted. Again, I think she resisted it at first, but as she became more comfortable with it it’s been very reassuring and supportive. And they get her, which is nice.”

Self-regulation

Finally, self-regulation was a common theme noted as an area of improvement among participants. Interview participants noted positive changes in the areas of self-regulating work breaks and controlling habitual behaviorisms typical with individuals with Autism. “[Client 3] over the last few years has really learned a lot of self-management skills. I think his self-regulation around anxiety has gotten a lot better. That doesn't mean he’s still not anxious--he is. He has a fairly anxious personality, but he has gotten much better at managing that. He used to chew his sleeve. He doesn’t do that anymore. He asks for help now, when he didn’t do that before.” This same parent shared: “My son can now self-regulate. He knows when he needs to take a break. He’s been going to Autistry for years and there is no doubt that Autistry has been pretty instrumental in facilitating him to develop these skills to initiate on his own taking breaks.”

Similarly, a client who used to poorly manage her time has benefitted from the scaffolding at Autistry Studios. From her mentor who witnessed the progress: “Now she’s really responsible about doing the work that she’s agreed to do before taking a break. At first we kind of pulled the devices all the way away and we made the mentors more in charge of the breaks and now it’s gone to a point where she does keep her phone with her, she has her ipad with her, but she knows what’s expected of her around the devices.”

Discussion

Analysis of the qualitative interviews of Autistry Studios client’s, parents, and mentors indicates that Autistry Studios is succeeding in many targeted areas while falling short in others. Themes that emerged around gains made at Autistry Studios were executive functioning, socialization, self-esteem, independence, self-regulation, employment and education. The project-based approach helps motivate the clients to work on their projects and remain energized despite experiencing setbacks and frustrations throughout the course of the project. By tailoring the intervention to be inherently motivating for the client, Autistry Studios is able to leverage the interests of the client to engage in projects that improve pre-vocational skills, such as executive functioning and self-regulation. This approach is consistent with the philosophy of occupational therapy because it is client-centered and focuses on occupations that are internally motivating for the client. This process is explained by a director of Autistry Studios: “It’s very individually oriented, so we challenge the individual. We have a very therapeutic approach to this in that we look at the whole person and their growth. It’s not just a one-size-fits-all approach. We don’t say, ‘let’s teach them how to use a screw driver.’ We take the whole person and their interests help them find what they’re good at and make it stronger” (Janet Lawson, personal communication, February 19, 2105).

The self-directed nature of the program was reflected in the results, with some interview participants focusing on different areas of client functioning. Some parents were appreciative of the socializing and normalizing environment created at Autistry Studios, while others were more focused on the increased executive functioning skills displayed by their children.

There were drawbacks to this approach though, because it also allows a client to only work on projects that are inherently motivating. A client could end up only working on projects that address an area of strength they already possess, leading to an intervention that is less challenging to the client and less targeted to that client's specific needs. This process culminated into an individualized program that was more successful for some of the clients and less successful for others.

Common feedback from parents was a wish for more transitional services into actual employment, internship, or volunteer possibilities. Our data analysis supports this sentiment, as evidenced by education and employment being the least common codes that emerged from interview data. Some clients have been placed into internship positions at the Buck Institute for Aging, while others have gone on to college. Presently, career services are not a major focus of Autistry Studios, though the directors have stated a desire to expand their program into this area.

Some clients entered Autistry Studios with passionate interests that they explored aggressively, while other clients were more passive about the entire process and depended heavily on staff for motivation and direction. By lacking a standardized program, clients have much more freedom to succeed or fail, which works great for some clients but less so for others.

Limitations

There were limitations to this study. This was a qualitative study which was designed to generate initial themes about the process at Autistry Studios and which areas of client

functioning were being successfully targeted. These findings do not necessarily generalize to the larger population. Our sample size was small and from an affluent area of the country, thus is a poor representation of the demographics of individuals with autism in the U.S. A second limitation of the study was the researcher's inability to control for the difference in time that clients were attending Autistry Studios. Some of the participants had been attending for many years, while others were there a shorter length of time. In addition, there were significant differences in the ages of the participants and relative developmental levels. None of these variables were able to be controlled by the researchers, leading to possible effects that appear to relate to participation at Autistry Studios but may in fact not.

Additionally, a large age gap was present between the research subjects. They were all at different stages of development and maturity, possibly leading to confounding variables unrelated to participation at Autistry Studios.

A third and final limitation of the study was the potential bias from research participants. Initially, each of the three researchers was to interview a client at Autistry Studios, the client's parent/legal guardian, and the client's mentor. One of the clients interviewed has been attending Autistry Studios since its opening almost six years ago. When Autistry Studios initially opened, the original staff members, the founders and directors, took on the role of mentoring and providing guidance to participants. Despite the director's bias towards her own organization, she was still chosen to interview as the role of one of the client's mentor due to her familiarity with the client and his progression over the past six years attending the program.

Implications for Occupational Therapy

The findings of this study offer many implications for occupation-based interventions for adolescents with ASD and, more specifically, occupation-based interventions led by a licensed

occupational therapist. The foundation of Autistry Studios is parallel to the philosophy of occupational therapy. For instance, the client-based and intrinsically motivating nature of the Autistry Studios program suggests that there is great value in leveraging the interests of children and adolescents with ASD when participating in therapy sessions.

One implication is that working in an environment that has a component of risk can be beneficial for an adolescent with ASD. While intensely supervised, power tools and heavy machinery are readily available at Autistry Studios to a client that has demonstrated consistent safety practices. The directors of Autistry Studios call this “the dignity of risk”. A consistent theme that emerged from the data was the increased confidence and feelings of self-efficacy associated with completing a project that was inherently dangerous and at times “scary”. All of the participants were proud of the projects they had completed, and understood they had to challenge themselves to get it done. This could inform other programs for individuals with ASD by incorporating challenging or “risky” situations that are client-centered and are guided by the “just right challenge”. The ensuing dignity and appreciation of trust felt by the clients appears to have been a major factor in the successes experienced at Autistry Studios.

Another implication of our findings suggests that the milieu created at Autistry Studios was effective at improving social skills for individuals with ASD. By including a group meal in every session, clients began each session socializing and becoming at ease in the workshop, aiding their transition to a new environment and establishing common points of discussion for the rest of the day. The physical organization of the workshop itself also provided a good balance between group and individual priorities. Large work tables are used that can seat six people, allowing multiple clients and mentors to be working at a table on individualized projects yet engaging in group dynamics if and when they choose. This creates a “low pressure”

atmosphere that does not force socialization, but provides opportunities for it to emerge organically.

Adolescents and young adults with ASD that are practicing prevocational skills by completing projects that are client-centered would benefit from occupational therapy services. At Autistry Studios, guiding principles used in working with clients with ASD include a holistic approach, providing necessary accommodations by adapting the environment, and engagement in meaningful occupations. Occupational therapy shares these principles and uses them to evaluate, assess, and provide treatment to clients. Focus areas of prevocational skills training and project-based therapy programs are to provide opportunities and create an environment in which clients improve their abilities and explore education, work, leisure, and social pursuits. The scope of practice of occupational therapists includes education, work, leisure, and social participation (American Occupational Therapy Association, 2014). Therefore, occupational therapists can bring benefits to prevocational skills training and project-based therapy programs for adolescents and young adults with ASD by designing individualized and group skilled interventions that are client-centered. Occupational therapy services that would strengthen existing and future programs include skilled observations, standardized evaluations and assessments, and building rapport with clients using therapeutic listening to establish short and long-term client goals. Occupational therapists would then be able to instruct, train, and collaborate with clients to implement skilled interventions that are evidence based. To ensure that optimal benefits to clients are achieved, occupational therapists would regularly evaluate their services to verify that functional improvements are occurring.

Conclusions

The purpose of the study was to investigate the experiences of youth at Autistry Studios and perceived improvements in areas of belonging and independence. Results suggest that there was a positive relationship between attendance and participation in Autistry Studios and improving perceived levels of independence and functioning. Several areas were identified that are essential to seeking employment, including: executive functioning, socialization, self-esteem, independence, and self-regulation. Further research is needed to develop and implement standardized documentation practices at Autistry Studios to monitor and track areas of improvement. Results could lead to increased funding and community support for this unique and worthwhile program.

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Appendix A
Autistry Studios Consent Form for Research Participation (Dependents)

Purpose and Background

Ali Ives, Joey Bava, and Vince Colombano, graduate students, and Dr. Julia Wilbarger, Department of Occupational Therapy at Dominican University of California, are doing a study on the effectiveness of the Autistry Studios program in improving independence in adults with Autism, by utilizing project-based learning. Because of the ever-increasing rate of Autism diagnoses and the parallel increase in unemployment and dependence among this population, the researchers are interested in learning whether adults with Autism can increase their roles of independence by attending Autistry Studios program.

My dependent is being asked to participate because s/he has a diagnosis of Autism.

Procedures

If I agree to allow my dependent to be in this study, the following will happen:

1. I will complete The Social Communication Questionnaire (SCQ), which grades the level of severity of Autism.
2. My dependent will participate in a one-on-one open-ended interview with one researcher for approximately 1 hour. In the interview, my dependent will answer questions about their overall level of independence and how Autistry has impacted them. They may choose to discontinue the interview at any time.
3. I will also participate in a separate one-on-one open-ended interview with one researcher for approximately 1 hour. In the interview, I will answer questions about my dependent and how they have improved in areas of occupations since attending Autistry. I may choose to discontinue the interview at any time.

Risks and/or discomforts

1. My dependent may become uncomfortable or upset during the 60 minute interview period. If this happens, the researchers will attempt to comfort my dependent. If my dependent continues to be upset, the researches will discontinue the interview and re-schedule for another time.
2. Study records will be kept as confidential as is possible. No individual identities will be used in any reports or publications resulting from the study. All personal references and identifying information will be eliminated when the data are transcribed, and all participants will be identified by numerical code only, thereby assuring confidentiality regarding the participant's responses. The master list for these codes will be kept by Vince Colombano in a locked file, separate from the transcripts. Only the researcher and her faculty advisors will see coded transcripts. One year after the completion of the research, all written and recorded materials will be destroyed.

Benefits

There will be no direct benefit to me or to my dependent from participating in this study. The anticipated benefit of this study is a better understanding of how Autistry is positively impacting and promoting independence among adults with Autism, so further improvements can be made.

Costs/Financial Considerations

There will be no costs to me or to my dependent as a result of taking part in this study.

Payment/Reimbursement

Neither my dependent nor I will be reimbursed for participation in this study.

Questions

I have talked to either Ali Ives, Joey Bava, or Vince Colombano about this study and have had my questions answered. If I have further questions about the study, I may call Ali Ives (480) 249-6095 or Dr. Wilbarger (415) 257-0125. If I have any questions or comments about participation in this study, I should first talk with the researchers. If for some reason I do not wish to do this, I may contact the Dominican University of California Institutional Review Board for the Protection of Human Participants (IRBPHP), which is concerned with protection of volunteers in research projects. I may reach the IRBPHP Office by calling (415) 482-3547 and leaving a voicemail message, or FAX at (415) 257-0165, or by writing to IRBPHP, Office of Associate Vice President for Academic Affairs, Dominican University of California, 50 Acacia Avenue, San Rafael, CA 94901.

Consent

I have been given a copy of this consent form, signed and dated, to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I am free to decline to have my dependent be in this study, or to withdraw my child from it at any point. My decision as to whether or not to have my dependent participate in this study will have no influence on my dependent's present or future status as a student at Autistry Studios.

My signature below indicates that I agree to allow my dependent to participate in this study.

Signature of Participant's Parent/Guardian

Date

Signature of Person Obtaining Consent

Date

Appendix B
Interactive Review Board (IRB) Acceptance Letter

March 5, 2015

Ali Ives
50 Acacia Ave.
San Rafael, CA 94901

Dear Ali:

I have reviewed your proposal entitled *Capturing Success at Autistry Studios: A Qualitative Study* submitted to the Dominican University Institutional Review Board for the Protection of Human Participants (IRBPHP Application, #10341). I am approving it as having met the requirements for minimizing risk and protecting the rights of the participants in your research.

In your final report or paper please indicate that your project was approved by the IRBPHP and indicate the identification number.

I wish you well in your very interesting research effort.

Sincerely,

Martha Nelson, Ph.D.
Associate Vice President for Academic Affairs
Chair, IRBPHP

cc: Julia Wilbarger

Institutional Review Board for the Protection of Human Subjects

Office of the Associate Vice President for Academic Affairs · 50 Acacia Avenue, San Rafael, California 95901-2298 · 415-257-1310

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Appendix C
Results Tables 5-13

Table 5

Client 1/Client 1's Mentor

	<u>Executive Functioning</u>	<u>Socialization</u>	<u>Self-Esteem</u>	<u>Independence</u>	<u>Self-Regulation</u>	<u>Employment</u>
Client 1	1	7	2	4	3	1
Client 1's Mentor	0	4	1	0	3	0
Totals*	1	11	3	4	6	1
Percentages	4%	42%	12%	15%	23%	4%

Note. *Grand Total = 26

Table 6

Client 1/Client 1's Parent

	<u>Executive Functioning</u>	<u>Socialization</u>	<u>Self-Esteem</u>	<u>Independence</u>	<u>Self-Regulation</u>	<u>Employment</u>
Client 1	1	7	2	4	3	1
Client 1's Parent	0	3	2	5	2	0
Totals*	1	10	4	9	5	1
Percentages	3%	33%	13%	30%	17%	3%

Note. *Grand Total = 30

Table 7

Client 1's Mentor/Client 1's Parent

	<u>Independence</u>	<u>Self-Esteem</u>	<u>Self-Regulation</u>	<u>Socialization</u>
Client 1's Mentor	0	1	3	4
Client 1's Parent	5	2	2	3
Totals*	5	3	5	7
Percentages	25%	15%	25%	35%

Note. *Grand Total = 20

Table 8

Client 2/Client 2's Mentor

	<u>Executive Functioning</u>	<u>Socialization</u>	<u>Self-Esteem</u>	<u>Independence</u>	<u>Self-Regulation</u>	<u>Education</u>
Client 2	4	2	5	4	1	2
Client 2's Mentor	2	2	2	2	1	1
Totals*	6	4	7	6	2	3
Percentages	21%	14%	25%	21%	7%	11%

Note. *Grand Total = 28

Table 9

Client 2/Client 2's Parent

	<u>Executive Function- ing</u>	<u>Socializat- ion</u>	<u>Self- Este- em</u>	<u>Independe- nce</u>	<u>Self- Regulati- on</u>	<u>Employ- ment</u>	<u>Educati- on</u>
Client 2	4	2	5	4	1	0	2
Client 2's Parent	1	0	4	4	0	1	0
Totals*	5	2	9	8	1	1	2
Percenta- ges	18%	7%	32%	29%	4%	4%	7%

Note. *Grand Total = 28

Table 10

Client 2's Mentor/Client 2's Parent

	<u>Executive Functioni- ng</u>	<u>Self- Esteem</u>	<u>Independe- nce</u>	<u>Self- Regulati- on</u>	<u>Employ- ment</u>	<u>Socializat- ion</u>	<u>Educati- on</u>
Client 2's Mentor	2	2	2	1	0	2	1
Client 2's Parent	1	4	4	0	1	0	0
Totals*	3	6	6	1	1	2	1
Percenta- ges	15%	30%	30%	5%	5%	10%	5%

Note. *Grand Total = 20

Table 11

Client 3/Client 3's Mentor

	<u>Executive Function- ing</u>	<u>Socializat -ion</u>	<u>Self- Este- em</u>	<u>Independe- nce</u>	<u>Self- Regulat- ion</u>	<u>Employ- ment</u>	<u>Education</u>
Client 3	4	5	7	2	2	1	3
Client 3's Mentor	0	5	3	2	0	0	2
Totals*	4	10	10	4	2	1	5
Percenta- ges	11%	28%	28%	11%	6%	3%	14%

Note. *Grand Total = 36

Table 12

Client 3/Client 3's Parent

	<u>Executive Functioni- ng</u>	<u>Socializa- tion</u>	<u>Self- Esteem</u>	<u>Independe- nce</u>	<u>Self- Regulat- ion</u>	<u>Employ- ment</u>	<u>Educat- ion</u>
Client 3	4	5	7	2	2	1	3
Client 3's Parent	2	3	6	1	0	0	1
Totals*	6	8	13	3	2	1	4
Percenta- ges	16%	22%	35%	8%	5%	3%	11%

Note. *Grand Total = 37

Table 13

Client 3's Mentor/Client 3's Parent

	<u>Socializati-</u> <u>on</u>	<u>Self-</u> <u>Esteem</u>	<u>Independe-</u> <u>nce</u>	<u>Executive</u> <u>Functioning</u>	<u>Education</u>
Client 3's Mentor	5	3	2	1	2
Client 3's Parent	3	6	1	2	1
Totals*	8	9	3	3	3
Percentages	31%	35%	12%	12%	12%

Note. *Grand Total = 26