A Participatory Evaluation of an Innovative Technology-Based Program for Adolescents With Autism

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Abstract: Autism spectrum disorder (ASD) is defined by sociocommunicative difficulties and restricted, repetitive behaviors and/or focused interests. Focused interests can motivate people with autism to obtain expertise in their interest areas, which are often expressed through a systematic approach to learning and an affinity for computers, mathematics, and science. Created with the goal of bolstering science, technology, engineering, and math (STEM) skills among teens with ASD, Tech Kids Unlimited (TKU) provides previously unavailable opportunities for youth with ASD in New York City to develop authorial computing skills. The current study, an initial evaluation of TKU's summer curriculum for adolescents with autism, highlights program design, students' own goals for the future, and successful instructional techniques to facilitate learning. A curriculum adaptation based on evaluation results is presented.

Introduction

Autism spectrum disorder (ASD) is defined by symptoms that limit functioning in two domains: social communication and restricted, repetitive patterns of behavior and/or focused interests (APA, 2013). As individuals with ASD enter adolescence and adulthood, many struggle with establishing independence, advocating for themselves, and developing social relationships (Kapp, Gantman, & Laugeson, 2011). However, ASD is associated with notable strengths, including heightened attention to detail (Mottron, Dawson, Soulieres, Hubert, & Burack, 2006) and an enhanced ability to recognize and create patterns and systems (Baron-Cohen, 2009).

People with ASD often express their focused interests through a systematic approach to learning and a strong affinity for computers, mathematics, and science (Baron-Cohen, 2009; Jordan & Caldwell-Harris, 2012). This paper presents data from a participatory summerlong study of an informal technology-based educational program designed to help youth with ASD transition into science, technology, engineering, and math (STEM) fields. The primary aim of this study is to use student and parent perspectives to assess and adapt a maker-based technology curriculum. A secondary aim is to explore if connecting to a community of neurodiverse individuals through a shared interest in technology influences self-understanding and perceptions of autism. A curriculum model, informed by results of this summerlong evaluation, is presented as a working example of future program directions.

Background

The specific skills and interests exhibited by many individuals with ASD should make them well suited to meaningful careers in STEM fields. Nevertheless, the employment outcomes of people with ASD often fail to reflect their potential. Data drawn from a nationally representative sample of youth receiving special education services in the United States revealed that 44.9% of youth with ASD had

never obtained any form of paid employment in the six years after college (Shattuck et al., 2012). Young people with ASD remain chronically underemployed (Nord, Stancliffe, Nye-Lengerman, & Hewitt, 2016; Taylor & Seltzer, 2011) despite their heightened interest in computers and in STEM fields (Gillespie-Lynch, Kapp, Sane-Simpson, Smith, & Hutman, 2014; Wei, Jennifer, Shattuck, McCracken, & Blackorby, 2013) and the growing need for professionals who specialize in STEM fields (Bureau of Labor Statistics, 2015; West, 2012). This gap between the potential that people with ASD have to contribute to society and the difficulty they face attaining opportunities to do so is particularly striking given the large number of people affected by ASD. The current prevalence estimates of ASD in the United States range between 1 in 45 and 1 in 68 young people (Christensen, 2016; Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015).

Technology Programs for Students With ASD

Given that increased aptitude and affinity for technology is common in autism (Baron-Cohen, 2009; Wei et al., 2013), technology-focused programs for youth with ASD may help them transition into meaningful careers by increasing their technological skills and providing networking opportunities, including friendships based on common interests. However, evidence-based programs to help youth with autism develop authorial technology skills are not readily available. This leaves a large gap in evidence-based programs to help youth with ASD turn an interest in technology into marketable skills that will help them succeed in higher education and obtain and maintain competitive employment.

As one of the few available programs to help students with disabilities develop *authorial* computing skills, the nonprofit TKU currently provides a supportive environment rich in technological instruction for students with ASD. Adolescents attend one-week summer camp workshops where a specific theme (e.g., website or game design) is explored in a stimulating, project-based environment. This informal education organization is unique in that it uses a maker-based curriculum wherein students create, interact with, and present their own creations after project-focused workshops. While TKU continues to grow and students often return to attend numerous workshops, a formal assessment of successful programmatic elements and potential areas for improvement had not previously been conducted. A primary aim of the present study was to conduct a pilot *participatory* (i.e., autistic adults were involved in study design, assessment, and manuscript development) program evaluation informed by the perspectives of students and parents in order to adapt the curriculum based on student needs and interests.

Technology as a Tool for Community Building

The opportunities to communicate in unconventional ways provided by computer-mediated communication have led to alternative ways of conceptualizing and enacting disability such as the neurodiversity, or autism rights, movement (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). A central tenet of the neurodiversity movement is that people with autism should be included in the development of autism supports. If the research community hopes to build quality supports that are well aligned with the needs and interests of people with autism, involvement of self-advocates in the research process is essential for producing resources with social validity. Therefore, a college student and a college graduate with autism, one of whom is an author of this manuscript, helped conduct this study.

Given evidence that adults with autism often learn about the neurodiversity movement and develop

more positive ways of thinking about autism via the Internet (Kapp et al., 2013), our research team was interested in examining if in-person neurodiverse communities centered around a shared interest in technology could also foster positive viewpoints on autism among adolescents on the spectrum. Understanding one's own neurodiverse identity may be aided by participation in group activities with other neurodiverse individuals, especially when such interactions are enhanced by curricula tailored to specific interests and strengths. A secondary aim of this study was to examine if students' understanding of autism and their own identities improved after participation in TKU. We hypothesized that exposure to a group of neurodiverse individuals might create a community-based learning environment conducive to improved disability identity and self-advocacy skills among TKU students.

Research Methodology

This study design includes open-ended in-person interviews with student participants between the ages of 13 to 20 (N = 20, M_{age} = 15.9*)* at the beginning and end of one-week summer workshops and surveys distributed to parents (online) and instructors (in-person). Interviews assess students' learning goals/ outcomes, current skills and career goals, perceptions of challenges they may encounter entering STEM fields, and helpful elements of the TKU curriculum. A hands-on construction task was introduced to participants to assess collaborative problem-solving techniques in practice. Participants were asked to build a 25-centimeter-long bridge/tower with a confederate with ASD using mini marshmallows and toothpicks.

Parents answered similar questions to those their children answered and filled out the Social Responsiveness Scale-2 to assess autistic symptomatology in their children (Constantino & Gruber, 2002). TKU instructors completed a survey at the end of each week about effective teaching strategies, learning objectives, challenges, and their plans to improve instruction in the future. Observations of classroom instructional techniques and student engagement were conducted to evaluate student engagement and commonly used teaching strategies to inform program design and further curriculum adaptations.

Results

Aim 1: Program Evaluation—Addressing Student Needs and Interests

Student participants had a mean age of 15.9 years, mean parent-reported SRS *t*-score of 65.4, and 15% were female. Three participants completed only a pretest survey due to absences (n = 2) and dropout (n = 1). Students (via in-person interviews) and parents (via online surveys) were asked similar questions to assess the curriculum in relation to students' needs and goals for the future.

Career goals and skill learning. When asked at pretest, "What job would you like to have in the future?" student participants cited technology fields such as game designer or programmer/developer. Overall, 86% of students indicated STEM careers in their response to this question. A STEM career was coded to include job titles such as game designer, computer programmer, animator, and video editor. When asked at pretest how they were preparing to get a job in the future, few students (42%) provided a specific employment-preparation strategy. When asked during pretest interviews what they would *like* to learn at TKU, only 26% of students identified specific job-related skills they hoped to learn while 80%

of students indicated general excitement about working with technology. When asked what job he would like to have and why, one student replied,

> I've always thought about being a computer programmer or developer. I've been fascinated by technology all my life and have a passion for helping others. … I want to maximize the user experience for apps that could make a significant difference in people's lives.

His response shows a clear affinity for technology and a recognition of the impact technology has on others.

When asked what they had learned at the end of one week at TKU, most students (82%) indicated technological skills, and 24% indicated social skills. When asked what they had learned that could help them get a job, 47% of students indicated technological skills and 24% indicated social skills.

Parent and instructor perspectives. Parents of all teens enrolled in TKU summer programs were invited to participate in surveys about their teens' overall outcomes as a result of participating in a one-week TKU workshop. Using Likert scales, 23 parents indicated that students gained skills needed to obtain employment (M = 5.48 out of 7), technological skills (M = 5.45), social-emotional skills (M = 5.14), and friendships (M = 5.21). Instructors, also surveyed at the end of each week, indicated that summer program participants overall (n = 42) developed technological skills (M = 5.59 out of 7) and were engaged with the curriculum (M = 5.49) and other teens (M = 5.05).

These results indicate that both parents and instructors found TKU's program valuable for teen participants across a number of domains important to the TKU model. Instructors indicated that additional time for each workshop would be beneficial to produce a more in-depth technology project. Both of these concerns are addressed in the curriculum adaptation described below.

Teamwork and observed skills. Introduction and reinforcement of collaborative problem solving and teamwork skills are a major goal of TKU curricula. To evaluate possible improvements in these skills associated with participating in a weeklong session at TKU, students were asked the question, "What skills do you need to do teamwork?" at pre- and posttest. At pretest, 95% of students cited at least one teamwork skill such as cooperating (38%), listening (31%), patience (13%), communication (13%), and planning (6%) within their responses. However, when asked at pretest to build a bridge with a partner (an autistic adult confederate who then rated their collaboration skills), only three students were rated as working collaboratively, sharing ideas and asking for input on the design and execution of their bridge. These results represent a disconnect between verbal understanding of the skills needed to be part of a team and demonstrated skills during a collaborative task. At posttest, new words emerged in response to the question about skills needed to do teamwork. Students continued to cite communication (44%) and listening (19%) while collaboration (19%), compromise (13%), and leadership (13%) also emerged within responses. When asked to build a bridge with a partner at posttest, five students were rated as collaborative team members compared to three students at pretest.

Classroom observations. Observations of classroom activities to assess types of teaching strategies used and the proportion of students on or off task were conducted during 10-minute intervals at two time points each day. Overall, results of classroom observations show that providing technical/procedural directions was the most common teaching style employed, followed by supporting engagement with peers. When asked how their instructor made activities interesting for them, 56% of students described hands-on activities and 31% described playful humor/games. While these strategies were employed

occasionally, coding indicates that more traditional teaching techniques, such as lecture-style teaching using slide shows, were used more often than hands-on instruction. This indicates an area for improvement in future curriculum development.

Aim 2: Perceptions of Autism

Self-description. Students were asked to describe themselves and parents were asked to describe their children. Both student and parent descriptions focused on notable strengths such as heightened skills in working with technology, puzzles, transit systems, and mathematics. “Intelligent” and “caring” were frequently cited character traits (n = 8). As expected given prior research (DeNigris et al., 2017), no students or parents mentioned autism when asked to describe themselves or their children. Together, these findings suggest that the benefits that may come with participation in TKU workshops may be further realized when TKU’s adolescent participants are encouraged to explore, through group-based interactions, not only technology projects but also their own present and desired future identities, as self-understanding is essential for success in higher education and the workplace.

Descriptions of autism. When students were asked to define autism at pretest, most teens focused on challenges associated with autism (63%) and many exhibited difficulties defining autism at all (44%). Those who described autism as a challenge focused on its neurological aspects, for example, a “disorder that affects your brain” (24%), or social aspects, for example, a “problem with social interactions” (29%). Very few adolescents chose to link themselves to autism when defining it (24%), which indicates that they were either unaware of their diagnosis or did not wish to self-identify. At posttest, most students continued to define autism in terms of challenges (38%) or reported difficulty defining autism when asked (44%). It is important to note that 25% of students at posttest (compared to 6% at pretest) described autism as an individual difference without a positive or negative valence. This pattern provides preliminary evidence that participation in TKU’s workshops may over time promote improved acceptance of autism and other individual differences.

A follow-up question, “How do you think autism makes someone stronger?,” elicited responses focused on strengths at both pretest and posttest, likely because of the nature of the question. The majority of participants at pretest (82%) cited some strength with the most popular response being perseverance in response to the challenge of having autism (35%). Some participants mentioned systematic thinking/ detail orientation (18%). When asked the same question, one parent stated that “people with autism will be key for furthering innovation and societal advancement in tackling some of the world’s most intractable problems.” These findings indicate that participants are aware of some strengths associated with autism despite their hesitancy to self-identify and their initial focus on challenges when asked to define autism. Together these findings suggest that TKU has a unique opportunity to build community and foster self-acceptance among adolescents who may be new to self-advocacy and the neurodiversity movement. To help students prepare for higher education and the workforce, curriculum during Summer 2018 workshops focused on building self-understanding and acceptance of diversity.

Future Directions: Model Adaptations and New Curriculum Format

Drawing upon data collected from our comprehensive Summer 2017 evaluation, a number of important programmatic areas of improvement have been identified. A sample curriculum model is outlined below that incorporates many of the changes TKU enacted during the summer of 2018 to create an increasingly

participatory and technology-rich environment for adolescent enrollees. Analysis of data from Summer 2018 programming is under way for future publication.

Affinity-Based Program Themes

It is apparent that enrollment at TKU is highest and students are most engaged in technology learning when the workshop theme is centered around an area of particular interest to our teen population. The most in-demand workshop at TKU is a transit-themed partnership with the New York City Transit Museum. In the past, teens have created informational 3D videos to teach others about subway etiquette. In 2017, the transit theme was centered around creating a transit-based video game using graphic programming software to introduce game-design principles. Some less popular workshops are focused on learning an important skill, such as website design, but have a less exciting client focus. During these weeks, teens are tasked with creating a website for a client such as a personal business or nonprofit. While it is an important professional and employment skill to plan and complete these projects regardless of the theme, curriculum that explores affinity-based themes through higher-level technological instruction may yield the most successful learning outcomes. Based on this assessment, our initial adaptation of TKU's curriculum for Summer 2018 used the transit theme as the primary focus to build upon the students' interests and use their excitement to further learning outcomes.

Continued Hands-On and Game-Based Instruction

As reported by TKU teens and observed by evaluators placed in the classroom, hands-on instruction is most enjoyable and most effective for this group. Humorous or game-based techniques are also preferred and allow for technology learning to be embedded within a game setting. Students were much more likely to engage with the technology theme and fellow students when a game was introduced as a mediator and/or focus of the workshop. Instructors at TKU are employed on a workshop-by-workshop basis with much of the instructional format determined by the preferences of each instructor. Moving forward, we believe all instructors should be informed of the effectiveness of gamified instruction for this group of adolescents. Increasing emphasis should also be placed on hands-on instruction and demonstration rather than through a traditional classroom teaching model wherein students sit in rows and watch a blackboard or on-screen presentation to learn new skills. This was a key point emphasized in teacher training for the Summer 2018 workshop curriculum.

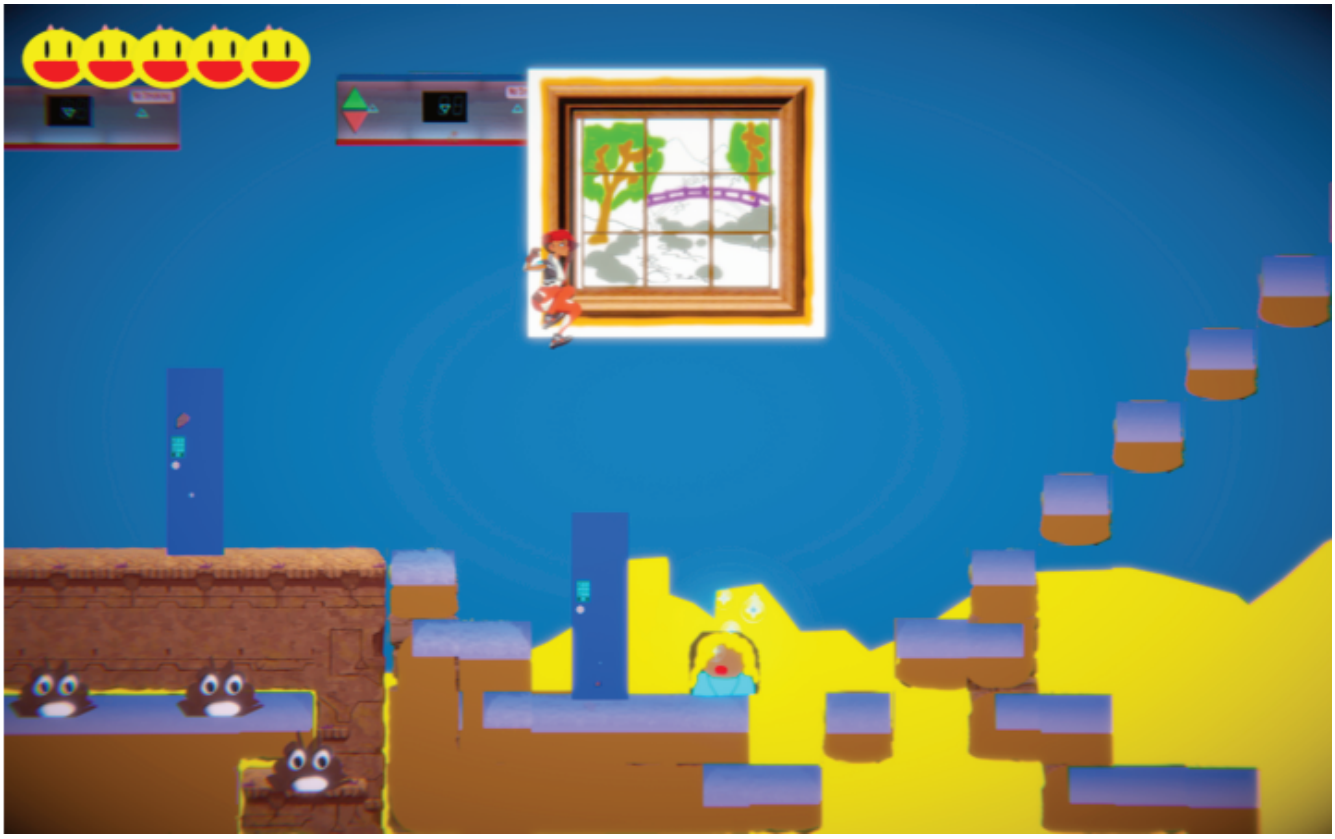
Group-Based Projects to Foster Employment Skills

As demonstrated by student in-person interviews, the vast majority of students are interested in STEM careers but very few can name a specific employment-preparation technique or job-search strategy. Students also have difficulty working with a partner to plan and execute a project cooperatively, as evidenced by the bridge-building task. TKU has the opportunity to build important soft skills, which employers cite are lacking among employees with autism, by introducing primarily group-based technology projects. Workshops vary in their degree of group-based participation but adaptations to the Summer 2018 Transit Game Design workshop focused on group work and participation. This group-based environment included small groups of three to four students working on games from start to finish in addition to a classroom-wide game concept developed by all members. Teams that were created based on student interests and strengths developed either specific game elements or visual assets for the classroom-wide game. This team-based approach furthered the participatory nature of TKU and

encouraged students to introduce and workshop their ideas, present works in progress to the full class, compromise, and iterate their game design based on group feedback.

Adaptations to Workshop Length

TKU workshops traditionally span five days for a total of 25 hours of technology instruction per week. Students are given a free hour at the end of each day to foster free play and spontaneous social interaction. Varying by instructor, 10–15-minute breaks are also given throughout the day to prevent fatigue. Based on classroom observation and student project outcomes, we proposed that future workshops comprise a 10-day session, doubling the number of hours dedicated to each workshop theme. Increasing the time each student is allotted to work on his or her project will allow students to design and test multiple iterations of their project or game. This increase in workshop length also allows for projects with increasing complexity. During posttest interviews in 2017, students reported limited time to engage with the theme and increased stress when attempting to produce an ambitious product during the available five days. The Summer 2018 Transit Game Design workshop was the first 10-day workshop design. Results from this workshop are undergoing analysis for future publication. Examples of student work are presented in Figures 1 and 2.



Figures 1 and 2. Examples of student work coded in Unity to produce a 14-level continuous game. All visual assets were created by students.

Evaluation Significance and Conclusion

Despite increasing need, evidence-based services to help adolescents with ASD transition into the workforce are sorely lacking, particularly for youth who are not intellectually disabled. While the number of youth with ASD seeking vocational rehabilitation services to help them transition into the workforce has grown substantially over the past decade, they continue to earn lower wages than most other disability groups and are also costlier to serve (Burgess & Cimera, 2014; Cimera & Cowan, 2009). The pronounced challenges that young people with ASD face in seeking and maintaining employment often stand in stark contrast to their abilities.

Programs such as TKU are needed to address this gap in services and should be supported by rigorous evidence and evaluation of the program model. Through this initial participatory evaluation and the resultant curricular improvements during Summer 2018, we continue to iteratively develop and adapt teaching strategies to help the growing population of adolescents with autism overcome barriers and succeed in obtaining meaningful jobs through which they can positively impact the world. Data-driven and participatory curricular adaptations are essential for strengthening unique programs such as TKU that teach teens with autism vital technology skills while connecting them to a community of individuals with similar affinities. By building upon the existing affinities of students with autism through hands-on and playful instruction in technology, coupled with structured supports for social interaction, we hope to maximize the potential of new technologies to empower and connect neurodiverse youth.

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