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Parent Perceptions of Post-Secondary Programming Completed by Their Adult Children with Autism Spectrum Disorder

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Abstract

Texas Tech University's Burkhart Center for Autism Education and Research works with communities & families in the greater West Texas area to provide supports and services to individuals with Autism Spectrum Disorder (ASD) with a primary focus on building independent living and vocational skills in a post-secondary environment. In this study, parents of individuals with ASD who had completed the Burkhart Center's Transition Academy completed an online survey. Parents identified areas in which they were satisfied with their child's post-secondary experience as well as dissatisfaction, and of additional need. The findings of this current study may provide critical information to post-secondary programs who work with students with ASD.

Keywords: autism, special education, post-secondary, independent living

Parent Perceptions of Post-Secondary Programming Completed by Their Adult Children with Autism Spectrum Disorder

The Center for Disease Control and Prevention (CDC) estimates that 5,437,988 (2.21%) adults are diagnosed with Autism Spectrum Disorder (ASD), as of 2017 (CDC, 2020). As the number of individuals diagnosed with ASD increases, there is a greater need for helping these individuals better transition from adolescence to adulthood. Young adults with ASD face special challenges and typically have fewer social or vocational opportunities than their peers without ASD (Leonard, 2019).

Postsecondary Outcomes for Students with ASD

Transitioning from high school to postsecondary education or employment is a challenging experience for many students. The process of establishing oneself in a new environment with new norms and expectations is a life task where even typically developing young people struggle. Students with ASD, however, experience drastically lower rates of success in this transition than their typically developing peers (Eaves & Ho, 2007; Hendricks & Wheman, 2009). Each year approximately 50,000 individuals with ASD reach the age where they are eligible, if not socially expected, to become employable members of their community, yet it is estimated that 50-75% of adults with ASD are unemployed (Hendricks, 2010; Rast et al., 2020). Unfortunately, due to marked deficits in verbal, social, cognitive, and behavioral functioning, few adults with ASD have the support needed to successfully participate in postsecondary education programs, employment opportunities, or independent life after leaving high school (Howlin et al., 2004; Nasamran et al., 2017; Rast et al., 2020). Further, research targeted at uncovering interventions to aid in postsecondary transitions for adolescents and adults with ASD is a relatively new area of study, as most research in this area focuses on current

transition outcomes and educational interventions for school-age children (Eaves & Ho, 2007; Hendricks & Wheman, 2009; Howlin et al., 2004).

Despite a limited body of research on specific interventions to aid in postsecondary transition, existing studies point out a need to provide vocational and social skill-building resources for people with ASD moving into adulthood (Hendricks, 2010). A national survey study by Shattuck et al. (2012) examined the prevalence of postsecondary education and employment among young adults with ASD in the US and found that only 55% of individuals sampled had paid employment during the first 6 years after high school. Additionally, Shattuck et al. (2012) found that more than 50% of young adults with ASD had no participation in employment or education in the previous two years before the survey was given. Eaves and Ho (2008) conducted a similar study of postsecondary transition outcomes of young adults (mean age of 24 years old) with ASD and found that only 56% of their sample had ever been employed and most employment was not competitive (e.g., volunteer, part-time). Of the 48 people surveyed for the study only four were living independently with most participants living in group homes or with parents (Eves & Ho, 2007).

Transitioning from high school to the real world can often be difficult for both the student and the parent. It is recommended that a coordinated approach involving multiple facets of daily living, such as vocational education, employment opportunities, and related services, should be utilized during the transition process (IDEA, 2004). Hetherington et. al. (2010) found that studied autistic individuals' knowledge and engagement in their future planning was limited, even after expressing a desire to being included. This same article stated that educational transition and vocational training is important and still requires extensive research. It

recommended family involvement in the earlier stages of transition planning for improved and successful outcomes for their child (Hetherington, et. al., 2010).

Previous research studies show that postsecondary programs can help with successful employment outcomes for young adults with ASD transitioning out of high school. Whittenburg et al. (2019) compared the employment rates and outcomes for young adults with ASD with different levels of education (i.e., no high school diploma, high school special education certificate, high school diploma, high school diploma with some postsecondary educational experience) who received vocational rehabilitation (VR) services. This study also examined the cost-effectiveness and cost-efficiency of these services. After analyzing 4,249 transition-aged youth with ASD, the results demonstrated that those with postsecondary experience had higher rates of employment, earned greater weekly wages, and worked more hours weekly than those with less education. Additionally, the VR services provided to the youth with ASD were also more cost-effective when cost-per-dollar earned was calculated and least cost-effective when cost-per-hours worked was calculated. This study indicates that participation in postsecondary programs can lead to successful employment outcomes (Whittenburg et al., 2019).

Burkhart Center Transition Academy

With approximately 5.4 million adults in the United States having a diagnosis of ASD, it is imperative that states and other entities identify opportunities and resources to support improved outcomes for this population (Dietz et al., 2020). Texas Tech University's Burkhart Center for Autism Education and Research has a program known as the Transition Academy to do just this. The Transition Academy was founded in 2005 and is a weekday, year-round, non-residential program for up to sixteen individuals at a time and is located on the Texas Tech University campus in Lubbock, Texas. While Lubbock, Texas has a population of approximately

254,000, most of the participants who are a part of the Transition Academy program also come from some of the many rural communities that surround Lubbock County (Bureau, n.d.). Young adults aged 18 to 30 years old with a diagnosis of ASD and/or an intellectual disability are eligible to participate in this full-day programming for a maximum of 36 months or until the students' socio-vocational goals have been met. Students apply to the program and are admitted each semester based on the number of spots available each semester, with a range of 3 to 5 students completing the program each semester. Participation in the program is typically funded through state resources contingent on the program providing training in the areas of vocational and independent living. When families reach out with questions in regard to services and costs, if they do not already have a case manager through Texas Workforce Commission, in order to secure funding for this program, we provide the information to them in order to start the process. The information provided does not just provide resources for the family to access the Transition Academy program, but a variety of options for resources and supports available from the surrounding area. Occasionally there are families who would prefer not to go through state resources and choose to pay privately but these numbers are very limited (i.e., an estimate of one individual in the program every 18 months). The staff included the director of the program, the employment specialists, and undergraduate students attending the university who were hired as student workers and were working towards a degree in subjects such education, special education, psychology, or similar fields of study. The staff-to-student ratio averaged around 1 to 3. The goal of Transition Academy was to help each individual participant achieve independence through competitive, paid employment by the time the participants graduated from the program.

Participants were asked to attend classes daily, participate in community internships, trainings, and other activities in order to fulfill independence. Some training topics that were

included in the courses are vocational skills, social skills, life skills: independence through employment, retail arts: production training, workplace endurance, sexual health and safety, music therapy, and community engagement skills training. These training courses were provided by the Transition Academy Learning Specialists and provided in both classroom and onsite training. Some internship and job placement career fields that were offered by the academy include but are not limited to hospitality and tourism, customer service, office professional/clerical, custodial, landscaping, retail, and library sciences. The internship sites partnered with the Transition Academy to provide training to the students with the goal in mind to secure a part-time or full-time job after the internships are completed. Internship sites ranged in location from on-campus programs/facilities or off-campus around the local community.

Research Questions

The purpose of the current study was to review the outcomes of a pilot program emphasizing independent living and vocational skills in young autistic adults. This study sought to determine the successes and challenges parents felt they and their child experienced as part of a post-secondary program addressing independent living and vocational training. Specifically, we sought to identify the lived experiences of parents and caregivers of individuals with ASD who have completed a transition program post-secondary to determine parent satisfaction, dissatisfaction, and areas of need the parents felt would improve on the success of the current transition program offered.

Methods

Participants

Participants were identified via a records review of previously enrolled individuals who successfully completed the Transition Academy from the year of 2013 to 2020. After these

individuals were identified, initial contact was made via telephone to re-establish a connection, update contact information as needed, and provide an initial overview of the study. During the initial phone call, families were asked if they were willing to complete a survey to help address the quality of the program. If parents verbally agreed, the link was sent to each family giving access to both the online consent form and the survey. Subsequently, the individuals contacted were supplied with an anonymous survey link through Qualtrics via email. Participants included parents and/or guardians of individuals who graduated from the Transition Academy. The parents/guardians were asked to complete the survey regarding their perception of the program as it pertained to their child and experiences.

Twenty-four families were listed for initial contact based on current and up to date contact information of former students and families. Of the 24 families who were identified, five were unable to be contacted due to outdated contact information. Nineteen families conveyed interest and were sent the survey. Thirteen (54.17%; n = 13) families completed the survey. The remaining six families did not submit responses. Of the families that responded, 15% lived in rural areas.

Research Design

A descriptive research design in the form of a survey was implemented in the current study. Prior to conducting this study, approval through the researchers' university Institutional Review Board (IRB) was gained. Additionally, a review of similar research projects was conducted to determine the reporting of survey research related to perceptions of secondary programs for individuals with ASD. Areas of need were identified by the research team to determine the focus of the survey instrument. Questions were divided into three sections as follows: (1) questions specific to perceptions of high school transition experiences, (2) questions

specific to the Transition Academy, and (3) questions specific to life after the student was no longer attending the Transition Academy. Once questions were identified, the survey was sent to stakeholders (i.e., graduate students, staff, and parents) within the university's Transition Academy for pretesting in order to get feedback and reliability checks by asking pretest participants to identify ambiguous questions, any unclear terminology, or other problems with the survey instrument prior to dissemination. Items identified through this process were then addressed to ensure results would meet the needs of the current study. The survey was then distributed and utilized to identify parent perceptions of the Transition Academy.

Measure

The current study employed a single, primarily Likert-type survey distributed via Qualtrics. The survey consisted of questions concerning the perceptions and outcomes of the Transition Academy as perceived by the student's parent/guardian(s). Some questions were rated on a satisfaction scale (e.g., extremely satisfied – extremely dissatisfied; extremely prepared – not prepared at all); other questions were multiple-select to identify which goals parents had for their child. There were also two open-ended questions for families to expand on their views, concerns, or thoughts without restriction.

Data Analysis

Descriptive statistics were conducted on the survey outcomes. Percentage of responding was reported to identify parental responding across all domains. The mean and standard deviation are presented for specific Likert items with questions ordered from lowest to highest mean in Table 4.

Results

Lived Experiences

High School

Parents were initially asked questions regarding the lived experiences of their child's transition process from high school. Parents responded with a range of experiences; 69% (n = 9) of parents reported that there were still several skills their child needed to work on to maximize their independence, 23% (n = 3) responded that their child was extremely prepared and had met all their transition goals and were ready for life as the family had planned, and 8% (n = 1) responded that their child was completely unprepared as if the system did not prepare the parent or child to maximize their independence. Further, parents were asked to identify the weight of their opinions and statements during high school transition Individual Education Program (IEP) meetings. Seventy-seven percent (n = 10) of parents responded that their opinions and statements were taken heavily into consideration when making decisions, 8% (n = 1) of parents felt decisions that were made did not consider parent or student involvement, 8% (n = 1) of parents felt their child's opinions and statements were taken heavily into consideration when making decisions, and one family (8%) identified that "[They] made all decisions on [their] own. The school was aware [the school] did not know enough to help in the preparation but supported [the student] the best [the school] could".

Transition Academy

Parents were asked questions regarding their lived experience while receiving services from the Transition Academy, including identifying whether the Transition Academy met the parent's expectations of transition, and 61.5% (n = 8) of parents identified that the Transition Academy either exceeded or far exceeded expectations (both categories had four parents select

the category, or 30.7%, for both exceeded expectations and far exceeded expectations). Thirty percent (n = 4) of parents identified the Transition Academy as having met expectations (e.g., "Equals expectations"), and 8% (n = 1) identified the Transition Academy as having fallen short of expectations.

Parents were then asked to identify which initial goals they had for their child while their child received services from the Transition Academy. These goals along with the percentage of parents who identified each goal for their child are outlined in Table 1. Sixty-nine percent (n = 9) of parents identified that they were "extremely satisfied" with the meeting of their identified goals, 23% (n = 3) were "somewhat satisfied", and 8% (n = 1) were "neither satisfied nor dissatisfied" with the meeting of the identified goals. Further, parents were asked to identify what their child's plans for education or work were after concluding their services at the Transition Academy. These plans along with the percentage of parents who identified each specific plan are outlined in Table 2.

As part of the lived experience of the Transition Academy, parents were asked to identify which components the transition program consisted of for their child. The components and the percentage of parents who identified the component as part of their child's plan is outlined in Table 3.

Overall, 100% (n = 13) of parents/guardians identified that the Transition Academy was effective in preparing their child for life after beyond the Transition Academy (i.e., 23.1% (n = 3) of parents selected "extremely effective", 46.2% (n = 6) selected "very effective", and 30.7% (n = 4) selected "moderately effective").

Parent Satisfaction

Parent/guardian levels of satisfaction for each Transition Academy programmatic component (i.e., internships and work experience, vocational training, art, etc.) were evaluated using a Likert-type scale using the following metrics: extremely satisfied, somewhat satisfied, neither satisfied nor dissatisfied, somewhat dissatisfied, extremely dissatisfied. The percentage of responding for each program component is outlined in Figure 1. According to Figure 1, parents responded with overall satisfaction (i.e., parents selected either 'extremely satisfied' or 'somewhat satisfied') for the following components: internships and work experience (92.2%; n = 12), vocational training (91.6%; n = 11), art (70%; n = 9), social skills (92.2%; n = 12), and community engagement (90.8%; n = 10).

Parent Dissatisfaction

Parent/guardian levels of dissatisfaction for each Transition Academy programmatic component (i.e., internships and work experience, vocational training, art, etc.) were also evaluated using the same Likert-type scale. The percentage of responding for each program component is outlined in Figure 1. According to Figure 1, parents responded with an overall neutral or dissatisfied response (i.e., parents selected either 'extremely dissatisfied', 'somewhat dissatisfied', or 'neither satisfied nor dissatisfied) for the following components: independent living (54.5%; n = 7), physical fitness (63.5%; n = 8), and sexual health and safety training (63.5%; n = 8). It should be noted that no parents (n = 0) selected "extremely dissatisfied" for any of the program components and the three aforementioned program components parents reported as feeling "somewhat dissatisfied".

Parent/guardian anecdotal reporting identified that communication between the

Transition Academy staff and the parents would be an improvement for the families. Examples

included student progress updates, better organization of communication, and better communication regarding understanding parental concerns.

Additional Identified Resources

Parents were provided an open-ended question in the survey to identify what aspects, resources, or additional training they would have liked to see provided to their child while enrolled at the Transition Academy. Independent living skills were identified as the primary additional training requested by parents. The independent living skills requested included driving and money management. Further, one parent identified a need for more employment skills to maintain employment.

Discussion and Future Research

The participants of the current study provided data regarding their perceptions of the Transition Academy, particularly in the success, or lack thereof, of the Transition Academy in meeting their respective goals for their children. Overall, parents were extremely satisfied with the Transition Academy's ability to meet their identified goals, illustrating the Transition Academy as a viable and successful programmatic option for families looking for post-secondary supports for their adult children with autism.

Limitations

One limitation of the study involved differential responding from parent/guardian participants. The survey asked that respondents identify which Transition Academy components were present in their child's programming (e.g., Art, Physical Fitness, Vocational, etc.). The survey then followed up and asked that respondents identify their level of satisfaction with each component their child participated in (i.e., if the respondent identified their child participated in Art, they were asked to rank their level of satisfaction with Art). However, there were

discrepancies in the responding, likely due to the presentation of all components to rank level of satisfaction regardless of whether the parent/guardian noted that component as part of their child's programming. For example, nine parents identified Vocational Skills as part of their child's Transition Academy program, but twelve parents ranked their level of satisfaction with the Vocational Skills component. This created challenges with data analysis of specific satisfaction of parents on specific Transition Academy program components.

A second limitation includes the participant selection in that only parents/guardians of students who successfully completed the Transition Academy were contacted to participate in the survey. By limiting perceptions to families who successfully completed the program, several families who chose to, or were asked to leave the program early, were not surveyed. Not including these potential participants may mean the data is not representative of an unknown number of participants.

A third limitation to highlight is the variance of the autistic adults who were enrolled in and completed the Transition Academy program. Although they all had a diagnosis of ASD, they all displayed a wide range of ASD symptomology and traits, putting them on different ranges of the spectrum from one another. Some required more levels of support or additional time in the program than others. Due to this reason, it can potentially influence the parents' perceptions of current skill levels and goals for service delivery for their child and the level of satisfaction of the program upon completion. The level and degree of ASD symptomology that the adult presents, should be considered, as more levels of support may be needed based on individual needs and ability.

Additional limitations were the lack of up-to-date contact information for former students and their families which limited the number of potential participants for this study. Future work

to provide a more robust number of participants and information would include ways to ensure up to date contact information is kept on file in order to have accurate information that may help Transition Academy improve upon services provided to families.

From the perspective of the participants, there appears to be room for improvement in increased student and parent involvement. As stated earlier, the best practices literature outlines active student and parent engagement as critical to successful transitions (Hetherington et al., 2010). In the future, the Transition Academy should apply this feedback regarding communicative challenges respondents faced while their child was enrolled in the program in order to align further with the defined best practices, and future research should consider looking at programs that have high levels of parental involvement and their perceptions and children's outcomes in post-secondary programs.

Independent Living

According to respondent reporting in the current study, post- Transition Academy life for the majority (92%; n=12) of students involve living at home with a parent, with one student living entirely independently (8%). This indicates that further programming should be considered to increase the likelihood of independent living after completion of the Transition Academy program.

Vocational

According to a recent study, adults with ASD encounter one of the least productive outcomes for community-based employment in their communities with an estimated 14% holding a job in their community (Rast, Roux, & Shattuck, 2019). The Transition Academy has accomplished a 93% successful employment rate in the program and in the current study, 92% (n = 12) of the respondents reported that their child has a job. Underemployment after high school

is problematic for young adults with ASD. Having successful employment outcomes not only benefits the families and the community but can also decrease the reliance and dependence on government funds and public benefits (Rast, Roux, & Shattuck, 2019).

Overall Satisfaction

The overall satisfaction as demonstrated by the respondents, with 100% (n = 13) of respondents identifying that the Transition Academy was effective in meeting their goals, lends credence to the Transition Academy as a positive support for families of students with autism and the students themselves. The variety of programmatic components offered to students in the Transition Academy align with the research that identifies a systematically designed and coordinated set of activities that target student transition from the school setting into the adult world as imperative to the transition process (Hetherington et al., 2010). Furthermore, the levels of willingness to recommend the Transition Academy to other families of students with autism, as reported by respondents (mean = 9.15; range = 6-10) supports the need and usefulness of programs like the Transition Academy for families.

Areas of Need

Under the Individuals with Disabilities Education Act (2004), the transition plan from high school to post-secondary education should include (a) present levels of performance, (b) instruction, (c) related services, (d) community experiences, and (e) employment and other adult daily living objectives that align with the student's personal goals and expectations. The Transition Academy adopts many of these best practices but would benefit from structuring and augmenting a systematic communication process to ensure families are being effectively represented during the post-secondary process. Respondent anecdotal reporting regarding communication practices included the following:

"The communication from the staff was a bit disorganized."

"Although we, as parents, were informed about our [child's] placements and the activities that [they were] a part of, we received little feedback about how things were going. Specifically, we would like to have been informed about what goals were being addressed within different job settings, and whether those goals were truly being met in that specific job setting..."

The literature informs us that familial involvement is beneficial to student outcomes (Heatherington et al., 2010). By structuring communication within the Transition Academy to account for the collaborative spirit, families would be invited in and the impact on student success could be extended. Further, identifying and outlining related services that would benefit the students, particularly those services that are available post-Transition Academy is an additional area of need. More transition programs that provide rigorous and robust programming opportunities for individuals with autism are needed to provide the supports and resources necessary for successful transition, and policy and policy makers should strive to ensure that programs following best practices are available to families of individuals with autism.

Based on the findings and limitations referenced above, future research should endeavor to include participants of both successful students and students who either discontinued the program or were requested to leave the program prior to the full completion. Information gained from families and individuals who chose not to complete the program fully could lead to additional findings in relation to satisfaction or dissatisfaction and what the Transition Academy team could potentially do in order to decrease attrition rate from the program.

Additionally, building this survey into the processes of the Transition Academy by sending this information at scheduled times upon completion (both successful and unsuccessful)

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could provide additional information about perceived success as well as information relative to

employment and living situations immediately after completion, six months later, one year, and

five years after completion of the program; thereby increasing the continued growth and progress

of the program.

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Appendix A

 Table 1

 Goal Category and Percentage of Parents Who Identified Each Goal for Their Child.

Item	%(n)
Find/maintain employment	84.6%(11)
Develop/maintain skills to maintain social connections	84.6%(11)
Develop/maintain skills to live independently	53.8%(7)
Develop/maintain skills to access the community (transportation, shopping,	53.8%(7)
out to events, etc.)	
Other	7.6%(1)

Appendix B

Table 2

Student plan for education/work after the Transition Academy and percentage of parents who identified this student plan.

Find/maintain employment	92.3%(12)
Develop/maintain skills to maintain social connections	76.9%(10)
Develop/maintain skills to live independently	61.5%(8)
Develop/maintain skills to access the community (transportation, shopping, etc.)	53.8%(7)
Other	7.6%(1)

Appendix C

Table 3Transition program component and percentage of parents who identified this component as part of their child's transition program.

Internships and Work Experience	100%(13)
Vocational Training	69.2%(9)
Art	84.6%(11)
Community Engagement	84.6%(11)
Social Skills	92.3%(12)
Independent Living	53.8%(7)
Physical Fitness	53.8%(7)
Sexual Health and Safety Training	30.7%(4)
Other	7.6%(1)

Appendix D

 Table 4

 Items that represent satisfaction across queried domains

Question	Mean	(SD)
Previously, you answered a question about goals your child would work on	3.69	(0.85)
during his/her time in the Transition Academy. How prepared do you feel		
your child was for life after Transition Academy?		
Did the Transition Academy meet your expectations of transition for your	3.92	(1.04)
child?		
How effective do you think the transition program was in preparing your	3.92	(0.76)
child for life beyond school?		
How satisfied were you with the 'meeting' of these goals?	4.16	(0.65)

Note. Likert scoring represented for each item represented 5 (far exceeds/extremely) to 1 (did not meet/not at all).