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## Parent Priorities and Knowledge Regarding Transition to Adulthood for Middle School Students with Significant Disabilities

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PARENT PRIORITIES AND KNOWLEDGE REGARDING TRANSITION  
TO ADULTHOOD FOR MIDDLE SCHOOL STUDENTS  
WITH SIGNIFICANT DISABILITIES

By

Laura A. Hackwell

A creative project submitted in partial fulfillment  
of the requirements for the degree  
of  
MASTER OF EDUCATION  
in  
Special Education

Approved:

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UTAH STATE UNIVERSITY

Logan, Utah

2018

ABSTRACT

Parent Priorities and Knowledge Regarding Transition  
to Adulthood for Middle School Students  
with Significant Disabilities

by

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Utah State University 2018

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Department: Special Education and Rehabilitation

The Individuals with Disabilities Education Act of 2004 requires transition planning to begin at age 16 years, but many states require transition planning to begin even earlier. In Utah, the amended age for starting transition planning is 14 years. Early implementation of transition planning requires collaboration between middle school teachers, parents, and adult service agencies. Parents of middle school students with significant disabilities completed an online survey to identify postsecondary transition related priorities and knowledge. Participants identified top priorities within seven transition outcomes, as well as the information needed to understand and support their student within each specific transition area. Results showed that middle school parents prioritized the development of social relationships and daily living/functional skills. The highest frequencies included having relationships and seeing friends within organized groups, relationships with family, and living at home. Results from this study will guide

transition teachers and service providers in developing training sessions for parents of middle school students.

## INTRODUCTION

The transition to adulthood can be a stressful time for students with disabilities and their parents because it signals the end of the school routine and the beginning of competition, wait lists for services, and high expectations (Henninger & Taylor, 2014). The 2004 reauthorization of the Individuals with Disabilities Education Act (IDEA) stated that, as part of the individualized education program (IEP), transition goals must be identified and services implemented by the age of 16 years but planning can (and should) begin earlier. As of June 2016, the state of Utah changed its age requirement for transition planning to begin at 14 years. Due to the change of age requirement, services need to be implemented earlier in a student's school career, and therefore, collaboration between middle school and high school teachers becomes essential (Weidenthal & Kochhar-Bryant, 2007).

According to data collected from the National Longitudinal Transition Survey-2 (NLTS-2: Newman et. al, 2011), students with intellectual or developmental disabilities (IDD) were less likely than their typically developing peers to be employed, to enroll in postsecondary education, and to live independently after high school. Specifically, 60% of young adults with disabilities were employed, compared to 66% of young adults without disabilities, 60.1% of young adults with disabilities had enrolled in post-secondary education since leaving high school, compared to 67.4% of the general population, and 45% of young adults with disabilities reported that they were living independently, compared to 59% of young adults without disabilities (Newman et. al.).

What defines a successful transition from school to adulthood? According to the NLTS-2 (Newman et. al, 2011), a successful transition includes participation in

postsecondary education, employment, independent living, and social relationships.

However, these indicators may appear unobtainable for students with severe disabilities because of the additional challenges that they may face, including cognitive and adaptive impairments.

In IDEA (2004), transition services were defined as a “coordinated set of activities for a student with a disability designed to be a within a results-oriented process that is focused on improving the student’s academic and functional achievement to facilitate the movement from school to post-school activities” (34 CFR 300.43, IDEA, 2004). These services must be designed to lead toward postsecondary education, integrated employment, and independent living or community participation. In addition, transition services must be based on the student’s individual needs, strengths, preferences and interests.

According to Kohler (1996), successful transition planning includes family involvement. Partnerships between families and transition service providers not only improve transition services and outcomes for youth with disabilities, but are also essential for families to develop the knowledge and skills that will be needed to continue in an appropriate support role for their adult son or daughter with a disability (DeFur, 2012). Family involvement includes preparation and training. Because transition services now begin in middle school at age 14, transition service providers must begin to work with families in middle school to involve them in the entire transition planning process. The rationale for changing the age to 16 from 14 years was to implement relevant transition services early to better prepare students with disabilities (Nielsen, 2013). Additional research is needed to identify transition training needs of families of children at the

middle school level. The proposed study will focus on the priorities and training needs of parents of middle school students with severe disabilities.

### **Literature Review**

I used ERIC via EbscoHost and Google Scholar and found no results when I combined the search terms *transition practices*, *middle school youth*, and *severe disabilities*. However, I found 46 articles using search terms *transition to adulthood* and *parent perspectives*, 126 articles using search terms *transition planning* and *severe disabilities*, and 33 articles using search terms *transition practices* and *middle school youth*. Because I am interested in transition practices specific to middle school youth with severe disabilities, I selected articles that targeted either parents of middle school students or students with severe disabilities, narrowing my literature review to three articles.

Cimera, Burgess, and Bedesem (2014) examined the impact of early transition services on the vocational outcomes achieved by young adults with intellectual disability (ID). Because of the poor employment outcomes for students with disabilities, policy makers began to address and mandate better transition services. Cimera et. al sought to determine whether beginning transition practices earlier, at age 14 years, improved employment outcomes. Previous research determined that, for students with autism spectrum disorder (ASD), providing transition services early not only significantly increased employment outcomes, but also decreased the cost of services that these individuals require (Cimera, Burgess, & Wiley, 2013).

Cimera et al. (2014) examined two groups: one from states that required transition planning at age 16 years and one from states that required transition planning at age 14. From a total of 24 states, 7,520 young adults with intellectual disability from each group

participated in the study as matched pairs. The researchers examined data provided by the Rehabilitation Services Administration from 2006 to 2009 to determine whether (a) early transition services led to higher rates of employment, (b) early transition services reduced the cost of services, and (c) individuals from early transition states achieved better vocational outcomes. Participants from each group were paired together based on exact matches across seven variables (i.e., age, gender, ethnicity, level of education, severity of disability, and primary and secondary disabilities).

The researchers' data suggested that throughout all 4 years examined, individuals who received early transition services at age 14 years were significantly more likely to be employed than those receiving services at age 16 years. For unknown reasons, the researchers were unable to determine if early transition services reduced the cost of services required to become employed. Overall, 58.8% of individuals receiving transition services starting at the age 14 years were employed compared to 45.6% at age 16 years. According to the results of this study, providing transition services by age 14 years, instead of the required age of 16 years, increased the number of individuals with both ASD and ID who gained employment. The previous research demonstrated improved outcomes for beginning transition at an earlier age. However, more research is needed to determine which aspects of transition planning to focus on at the earlier age.

Henninger and Taylor (2014) conducted a survey to gather information about parents' definitions of a successful transition. These researchers identified criteria for success in adulthood based on open-ended responses from parents of students with intellectual disabilities (ID). Next, they analyzed the differences across parents of children in three groups: pre-high school, high school, and post-high school. Participants



were mostly Caucasian mothers of individuals with ID. Approximately 30% of participants were parents of students who had not yet entered high school, 25% were parents of students in high school, and 42% were parents of students who had exited high school.

Researchers used an open-ended, exploratory questions. Henninger and Taylor (2014) analyzed the responses using qualitative content analysis. They determined a total of 13 codes by identifying responses with similar phrases. Approximately 17% of responses contained more than one theme. Frequencies of themes were identified, then sorted by age group. Identified themes by age group are listed in Table 1.

Table 1

*Identified Transition Themes from Parent Respondents*

Theme	Pre-high school	In high school	Post high school
Having an occupation or functional role in society	70.5%	75.5%	54.8%
Moving out of the home, apart from parent or caregiver	52.5%	41.5%	40.5%
Relationships with peers	31.1%	24.5%	23.8%
Skills required for successful daily functioning	19.7%	28.3%	26.2%
Continuing academic or intellectual pursuits	31.1%	26.4%	13.1%
Independence/ independence with support	18.0%	20.8%	21.4%
Constructive relationship with community	18.0%	30.2%	15.5%
Accessibility and transportation	13.1%	15.1%	16.7%
Psychological well-being	14.8%	11.3%	9.5%

Romantic relationships and/or starting a family	13.1%	7.5%	7.1%
Physical health or safety	11.5%	13.2%	4.8%

A recurrent theme was the idea of a balance between individual needs and environmental supports, which should be reflected throughout transition planning as well as in adult outcome research. When comparing the responses by age group, Henninger and Taylor (2014) indicated that parent perspectives on transition success were somewhat different for those whose son and daughter had already exited the school system. Specifically, parents of children in school were less concerned with postsecondary education and employment and more concerned with independent living, relationships with peers, and functional skills.

While the research conducted by Henninger and Taylor (2014) helped prioritize parent perspectives and concerns, the “pre-high school” group consisted of parents with children of a wide age range, from not yet school age through middle school. The proposed study will prioritize concerns of parents of middle school students specifically, which will assist teachers in developing meaningful transition planning and goals.

Weidenthal and Kochhar-Bryant (2007) investigated common transition practices of eighth and ninth grade special education teachers based on the requirements of the Individuals with Disabilities Act (IDEA). The purpose of this study was to understand how educators can assist 14-15-year-old students with learning disabilities in addressing transition planning needs. Researchers administered a study to middle and high school special educators and department chairs in a large, suburban school district. All participants were involved in the instruction and IEP development of 14-15 year-old students with learning disabilities. The researchers used an open-ended interview/ survey

format, designed to address these questions: (a) To what extent do students attend IEP meetings if the purpose is to consider the student's transition service needs? (b) To what extent are students' strengths considered when developing IEPs and what strategies are used? and (c) To what extent do IEPs include statements of transition service needs that focus on a course of study? The survey was adapted from the National Longitudinal Transition Survey (Johnson et al., 1997) and included statements regarding specific transition provisions of IDEA regulations. Respondents were asked to rate the following using a 4-point rating scale: (a) implementation of transition service needs, (b) strategies to facilitated implementation of each service, and (c) barriers that impeded implementation.

The study discussed and reviewed how eighth and ninth grade special educators incorporated transition practices into IEPs, as required by IDEA. First, although 14-year-old students with learning disabilities attend their IEP meetings, they need to be taught to become more actively engaged. Although IDEA does not specify that students must accept the invitation or participate in the meeting, student preferences and interests need to be considered regardless. Results from the NLTS-2 (Newman et al., 2011) indicated that students who took responsibility for planning their transition and engaged in self-determination activities assumed greater responsibility for their lives after school. Students also become more involved in the planning when discussion began prior to the meeting. Weidenhal and Kochlar-Bryant (2007) stated that self-determination training can be embedded in the curriculum and students can be taught to recognize their strengths and weaknesses.

Survey respondents indicated that obtaining suggestions from the student, family or other knowledgeable person was an effective strategy to determine a student's needs and strengths. Other options included the use of interest inventories or other informal assessments. Sending home a transition questionnaire prior to the meeting also encouraged discussion at the meeting from the student's family members. Finally, survey respondents indicated that transition needs that focused on a course of study was included in the IEP frequently. Middle school teachers should focus on developing ways to ensure success in current coursework and documenting efforts of transition planning throughout middle and high school.

There is a need for further research regarding early and ongoing transition planning. The results of Weidenthal and Kochhar-Bryant (2007) emphasized the significance of self-determination training, identification of student strengths, and long term planning beginning no later than middle school. There are many opportunities related to transition planning available for students at age 14 years, including job exploration and interest. Including students and their families in the transition planning process early will help increase participation, self-advocacy and self-knowledge, and assist students in becoming active participants in their future.

Henninger and Taylor (2014) and the NLTS-2 (Newman et. al, 2011) identified post school outcomes that defined a successful transition. NLTS-2 outcome variables include postsecondary education participation, employment after high school, leisure activities, and social involvement. Outcome areas used in this study were determined based on the NLTS-2 outcomes and those described by Henninger and Tayler (2014).

### **Purpose Statement and Research Questions**

While prior research helped identify parent perspectives and concerns, more research is needed to determine concerns of parents of middle school students specifically because the formal transition process begins at age 14 years in many states. The purpose of this study is to gather information about parent knowledge and priorities regarding postsecondary transition outcomes. The study will include parents/guardians of middle school students with severe disabilities. The information gathered will assist educators in developing a training outline and training priorities for the families of their middle school students. Furthermore, the information gathered would be beneficial to smooth the transition process and assist teachers to engage parents early by understanding their priorities. My research questions are as follows:

Given a survey of parents/guardians of middle school students with severe disabilities,

1. When provided with a list of subcategories within postsecondary transition outcomes, which subcategories will parents/guardians identify as top priorities as measured by percent of total responses?
2. When provided with a list of subcategories within postsecondary transition outcomes, which subcategories will parents/guardians identify as information needed as measured by percent of total responses?

### **Method**

#### **Participants**

Participants of this study were 17 parents or guardians of students ages 11 to 14 years with a severe disability as described by the Utah State Board of Education.

Demographic information on participants is provided in the Results section of this paper. The participants were selected based on the following criteria: (a) participants must have a student who receives special education services, (b) participants must have a student diagnosed with a disability according to Utah state regulations, (c) participants must currently have a student between the ages of 11 and 14 years, and (d) participants must be natural or adoptive parents of the student. In the event that the participant had more than one student that fits within the criteria, they were directed to respond to the survey in regards to the older child. Participants were excluded if they did not meet the above criteria, or if they did not offer informed consent for participation. All participants signed a consent form approved by the university institutional review board agreeing to participate in this research.

### **Survey Design**

This study was conducted via an electronic survey designed through Qualtrics. The survey link was emailed to participants in three school districts across the state of Utah. Following the initial distribution of the survey, a follow up reminder email was sent out. The researcher did not collect any identifying information about participants. All data remained anonymous and confidential.

### **Survey Instrument**

The survey consisted of four parts, Part 1: Demographics, Part 2: Priorities, Part 3: Information needed, and Part 4: Open ended questions. In Part 1, participants responded to a checklist to report on their age, gender, socioeconomic status, and ethnic and cultural background. They also selected their child's special education classification from a list and were able to type their child's specific disability diagnosis, allowing

multiple diagnoses to be recorded. Participants reported on the amount of time that the student spent in the special education classroom and related services (i.e. speech and language, physical therapy, assistive technology) received.

Part 2 of the survey required the parent/guardian to select priorities (i.e., “top concerns”) for their son/daughter within postsecondary transition outcomes. Transition outcomes, determined based on previous research and the NLTS-2 (Newman et al., 2011), consisted of (a) postsecondary education, (b) gaining employment, (c) independent living, (d) social relationships, (e) community involvement or engagement, (e) daily living and functional skills, and (f) health and safety. Each of these areas were prioritized based on their appearance in other related surveys, such as the NLTS-2 (Newman et al., 2011) and the Parent Transition Survey (Fournier, L.L., Revised 2014).

The transition areas in the survey were briefly defined and consisted of a list of five to 10 outcomes. Participants were asked to select no more than three of the listed items as their top concerns but did not rank their top items. Postsecondary education was defined as “Any formal learning activity after high school, including college, vocational training or community classes.” Employment was defined as “Paid work, either part time or full time.” Independent living was defined as “Future living arrangements.” Social relationships were defined as “Social interactions between people.” Community involvement was defined as “Meaningful engagement and participation within the community.” Daily living and functional skills were defined as “Caring for self and functioning independently.” Finally, health and safety were defined as “Physical and emotional well-being.”

Part 3 of the survey instrument asked participants questions about the information they felt they needed to help their child with a successful transition to adulthood. Participants were asked if they would participate in training, if available, in the first three transition areas, postsecondary education, employment, and independent living. Next, participants were asked to identify information needed to assist with their child's transition to adulthood. Under each of the seven previously determined transition areas, four to six components were listed. These components were identified through previous research and surveys, such as the NLTS-2 (Newman et al., 2011) and the Parent Transition Survey (Fournier, L.L., Revised 2014).

Part 4 consisted of two open-ended questions relating to future aspirations, "What are your family's long-term goals for your son/daughter?" and "What concerns you most about your son/daughter's future?". Participant responses were compared to identify similar themes and were summarized narratively.

### **Initial Review of Survey Quality**

The researcher contacted masters committee members to review survey questions prior to the administration of the survey. The group reviewed questions for clarity and quality and provided feedback to the researcher. Feedback was used to revise survey questions, add or subtract content, and confirm the existing content.

## **Results**

A total of 17 parents and guardians responded to the online survey, a response rate that was much lower than anticipated. Although I did not have access to names or numbers of respondents within the districts that participated, I can estimate an



approximate response rate of 10-15%. Of the 17 participants, 16 were the student's biological parent and one was an adoptive parent. Overall, 88.24% of participants were female. The majority of participants (nine) were between 45 and 54 years old and had a bachelor's degree (29.41%). Of the 17 total participants, eight had a 14-year old-child, four had a 13-year-old, three had a 12-year-old child, and one had an 11-year-old child. The majority of respondents (eight) anticipated that their child would exit public school at the age of 22 and indicated that they spent the majority of the day in a life skills/self-contained classroom (76.47%). Special education classifications represented include Autism, Traumatic Brain Injury, Intellectual Disability, Other Health Impairment, Multiple Disabilities, and Speech or Language Impairment.

As shown in Table 2, when asked to select their top three priority outcome areas, participants identified social relationships (22.22%), daily living skills (20.00%), and independent living (17.78%). Open ended responses about long term goals included related to living with family, with assistance or independently, obtaining a job, and being happy, safe and healthy. Open ended responses about future concerns included money for care, limited interactions with others and lack of skills, and ability to live independently. Postsecondary education and community involvement were the lowest priority areas selected by participants (6.67% and 4.44%). Overall, 16.67% of participants indicated that postsecondary education was not a concern, however, none of the participants indicated that community involvement was not a priority or concern.

Table 3 shows the percentage of responses who identified priorities for postsecondary education. As anticipated, postsecondary education was a low priority area and the only area in which "not a priority or concern" was one of the most frequent

responses (see Table 3). Within the postsecondary education theme, participants most frequently selected responses were (a) complete courses on independent living (25%), (b) postsecondary education is not a priority or concern (16.67%), and (c) complete vocational training (13.89%). Participants indicated that they needed more information on postsecondary program options and availability for students with severe disabilities, as well as the availability and cost of community classes. Postsecondary education was not mentioned in any of the open-ended responses.

As shown in Table 4, participants most frequently selected responses within the transition area of employment were (a) supported employment (31.43%), (b) part time competitive employment (20.00%), and (c) adult day program/services (17.14%). Overall, 68.75% of participants indicated that they would participate in training related to employment if it were available. When asked to identify information related to employment needed to assist in their child's transition, the majority of participants selected teaching employment and social skills and reasonable accommodations in the workplace. About one in six participants (17.39%) were also concerned about finding job support, such as a job coach and job training.

Table 5 shows independent living priorities of respondents. Participants most frequently selected responses were (a) living at home (36.11%), (b) living with a family member other than parents (19.44%), and (c) living in a group/residential home with adults with special needs (19.44%). When asked to identify information related to independent living needed to assist in their child's transition, the largest percentage of participants selected funding options and paying for housing (25.71%) and information about assisted living programs (22.86%).

As shown in Table 6, when asked about social relationships, participants prioritized their child's relationships with family members (34.09%) and having friendships within organized groups and activities (36.36%). Participants were least concerned about their child's romantic relationships and starting a family (see Table 6). About one-third of participants (32.43%) stated that they needed more information regarding social outings and groups within their child's community and school. About one-quarter of participants (27.03%) responded that they needed more information to teach their child social skills.

Within the community involvement theme (see Table 7) defined as meaningful engagement and participation within the community, survey participants prioritized independent hobbies outside of the home (26.19%). About one-quarter of participants (23.64%) needed more information finding community programs and groups for individuals with disabilities in their communities. Participants also responded that they needed more information and assistance with exploring their child's interests and hobbies and teaching their children to interact with community members (18.18%). None of the participants indicated that participation within organized sports was a priority.

In the daily living and functional skills theme (see Table 8), participants prioritized their child's ability to prepare food and meals (37.50%), which was also the highest percentage across all seven themes. Independently managing some aspects of finances was the second highest priority within the daily living skills theme (25%) followed by using public transportation to navigate the community (18.75%). Participants responded that they needed more information and assistance to increase their child's

communication skills and to teach their child home living skills (both 23.26%), such as cooking, cleaning, laundry, shopping, and yard work.

Finally, survey participants responded that their child's ability to remain safe from danger or harm was the top priority (31.58%) within the health and safety theme (see Table 9). Managing their own physical health (15.79%) and problem-solving ability (13.16%) were also high priorities within this theme. Participants responded that they needed information regarding how to plan for adult health insurance or Medicaid and how to teach self-advocacy (22.22%).

A total of ten of the 17 participants responded to the open-ended questions. The first question asked, "What are your family's long-term goals for your son/daughter?" Common long term goals were related to holding a job and being able to live independently. Regarding long term goals, one of the participants stated "I want my son to be the best functioning person in society that he can be. I want him to have the supports that he needs to accomplish, but I also need the support as a parent to help him. I feel very alone and undereducated on helping him through transitioning stages."

The second question asked, "What concerns you most about your son/daughter's future?" Participants common concerns about their child's future were related to lack of skills and services and funding availability. One of the participant's stated that a major concern was "that he will be homebound and not receive stimulation from interacting with others." Another stated, "If something were to happen to us (her parents), would she be "taken care of" financially and otherwise, while not putting a huge burden on the siblings to take care of her."

## Discussion

The results of this study demonstrated that parents of middle school students sought explicit training and information on transition-related themes. The results had implications for teachers and service providers working with middle school students and their families. Middle school teachers could use the results of the study to learn about the priorities of the families with whom they work and in turn, target transition planning for students to include high priority areas. Transition service providers, such as independent living centers and community rehabilitation providers, could use the results of this study to plan training sessions and transition fairs. This information can assist students and families begin thinking about and planning transition at a younger age.

The results of this study identified social relationships, daily living skills, and independent living as priorities for parents of middle school students. Middle school teachers can use these identified priority areas to guide their curriculum and align IEP and transition plan goals with parent concerns. All three topics (social relationships, daily living/functional skills, and independent living) are ideal areas to address in the middle school classroom. Teachers can use general education settings and peers to teach social skills. Functional skills, such as food preparation, money management, and community navigation can be aligned with academic instruction and standards and generalized through community-based instruction when possible. These topics are frequently addressed by Centers for Independent Living, community-based centers funded by the Rehabilitation Act offering free services to individuals with disabilities. In addition, teachers should provide training or information for parents to address functional and independent living skills at home and in the community.

Parents of children with severe disabilities provided responses within the employment area illustrating that the majority desired supported employment and/or assistance of a job coach for their child. Teachers and service providers may want to educate parents on the U.S. Department of Labor's Employment First movement and the systems change efforts that have resulted in increased community-based, integrated employment opportunities for all individuals.

Community involvement was rated as the lowest overall priority by participants. However, none of the participants answered that community involvement was not a priority or concern in Part Two of the survey. Within this area, 26% of participants responded that engagement in independent hobbies or interests outside of the home is a priority, implying that community involvement is important to many participants. The discrepancy in this area may be due to an unclear definition or perhaps the possible selections did not accurately represent parent priorities.

This study was specific to selected districts in one state, thus limiting the generalizability of the results. The researcher contacted over 12 school districts throughout the state of Utah, however, many districts refused to participate. Several districts were unwilling to contact parents on behalf of the researcher, therefore, their participation would have risked confidentiality. Only three districts participated in the study. An additional limitation was that all 17 participants answered that they were White. Future researchers may want to identify parents in different geographic locations with various ethnic and cultural characteristics to improve generalization. Researchers may also want to investigate cultural and ethnic differences of transition priorities.

The results of this study provide a glimpse of middle school parents priorities. The data answer many questions, however, they also raise important new ones. For example, why did parents prioritize supported employment over competitive employment? Is this perhaps a lack of knowledge and training and an area that teachers or service providers can address? Future researchers could target the effect of providing specific training sessions related to transition themes on parent priorities and knowledge. Teachers and service providers could develop specific training sessions for middle school parents in order to prepare for their student's transition to adulthood. Conducting training sessions would assist schools in getting families to begin transition planning at a young age.

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Table 1

*Identified Priorities within Transition Themes from Parent Respondents*

Theme	Highest Frequency	Lowest Frequency
Postsecondary education	Complete courses on independent living (25%)	Attending a 2-year college (2.78%)
Gaining employment	Supported employment (31.43%)	Military service (0%)
Independent living	Living at home (36.11%)	Living in an apartment or home (8.33%)
Social relationships	Having friendships within organized groups/ activities (36.36%)	Starting a family (0%)
Community involvement	Engage in independent hobbies outside of the home (26.19%)	Participate in organized sports (0%)
Daily living	Prepare food and meals (37.5%)	Independently manage own finances (0%)
Health and safety	Remain safe from danger or harm (31.58%)	Manage own mental health (5.26%)

Table 2

*Percentages of Total Participants Identifying Prioritized Transition Outcomes*

<b>Transition outcome</b>	<b>Percent of respondents</b>
Social relationships	22.22%
Daily living skills	20.00%
Independent living	17.78%
Employment	15.56%
Health and safety	13.33%
Postsecondary education	6.67%
Community involvement	4.44%

Table 3

*Percentages of Total Participants Identifying Postsecondary Education Priorities*

<b>Priorities</b>	<b>Percent of respondents</b>
Complete courses on independent living	25.00%
Postsecondary education is not a priority or concern	16.67%
Complete vocational training	13.89%
Complete an internship or apprenticeship	11.11%
Complete a service mission	8.33%
Attend an applied technology college	8.33%
Enroll in community classes	5.56%
Attend a 4-year college/university	5.56%
Attend a 2-year college	2.78%
Other (Develop more communication)	2.78%

Table 4

*Percentages of Total Participants Identifying Employment Priorities*

<b>Priorities</b>	<b>Percent of respondents</b>
Supported employment	31.43%
Part time competitive employment	20.00%
Adult day program/services	17.14%
Full time competitive employment	14.29%
Employment is not a priority or concern	11.43%
Self-employment	2.86%
Other (Doing activities)	2.86%
Military service	0.00%

Table 5

*Percentages of Total Participants Identifying Independent Living Priorities*

<b>Priorities</b>	<b>Percent of respondents</b>
Living at home	36.11%
Living with a family member other than parents	19.44%
Living in a group/residential home for adults with special needs	19.44%
Living with roommates	13.89%
Living alone in an apartment or home	8.33%
Independent living is not a priority or concern	2.78%
Other (No response)	0.00%

Table 6

*Percentages of Total Participants Identifying Social Relationship Priorities*

<b>Priorities</b>	<b>Percent of respondents</b>
Having friendships within organized group/activities	36.36%
Relationships with family	34.09%
Having friendships outside of organized activities	25.00%
Romantic relationships	4.55%
Starting a family	0.00%
Other (No response)	0.00%
Social Relationships are not a priority or concern	0.00%



Table 7

*Percentages of Total Participants Identifying Community Involvement Priorities*

<b>Priorities</b>	<b>Percent of respondents</b>
Engage in independent hobbies or interests outside of the home	26.19%
Engage in independent hobbies or interests within the home	21.43%
Demonstrate social responsibility and be law abiding	19.50%
Participate in organized school or community groups	14.29%
Attend church/ church activities	11.90%
Volunteer work/ community service	7.14%
Participate in organized sports	0.00%
Other (No response)	0.00%
Community involvement is not a priority or concern	0.00%

Table 8

*Percentages of Total Participants Identifying Daily Living and Functional Skill Priorities*

<b>Priorities</b>	<b>Percent of respondents</b>
Prepare food and meals	37.50%
Independently manage aspects of own finances	25.00%
Use public transportation to navigate the community	18.75%
Obtain driver's license	6.25%
Other (Self-hygiene, being able to participate)	6.25%
Daily Living and functional skills are not a priority or concern	6.25%
Independently manage own finances	0.00%

Table 9

*Percentages of Total Participants Identifying Health and Safety Priorities*

<b>Priorities</b>	<b>Percent of respondents</b>
Remain safe from danger or harm	31.58%
Manage own physical health	15.79%
Ability to solve problems	13.16%
Have assistance with health and medical choices and decisions	10.53%
Make healthy choices	10.53%
Build self confidence	7.89%
Manage own mental health, including medication management	5.26%
Other (Being cared for)	2.63%
Health and safety is not a priority or concern	2.63%

## **Appendix A**

### **Survey Instrument**

#### **Parent Priorities and Knowledge Regarding Transition**

#### **To Adulthood for Middle School Students**

#### **With Significant Disabilities**

#### **Welcome to the research study!**

We are interested in understanding parent priorities and knowledge regarding transition to adulthood for middle school students with significant disabilities. There are 4 parts to this survey. For part 1, you will be asked to identify basic demographic information about yourself and your child. For part 2, you will be presented with information relevant to postsecondary transition outcomes and asked to identify your family's top three priorities for your child within each transition outcome area. For Part 3, you will be asked to identify the information you need to assist in your child's transition to adulthood within each transition outcome area. Finally, in part 4, you will be presented with two open ended questions regarding your hopes and concerns for your child's future.

Please be assured that your responses will be kept completely confidential.

The study should take you around ten minutes to complete. Your participation in this research is voluntary. You have the right to withdraw at any point during the study, for any reason, and without any prejudice. If you would like to contact the Principal

Investigator in the study to discuss this research, please e-mail bob.morgan@usu.edu.

By clicking the button below, you acknowledge that your participation in the study is voluntary, you are 18 years of age, and that you are aware that you may choose to terminate your participation in the study at any time and for any reason.

Please note that this survey will be best displayed on a laptop or desktop computer. Some features may be less compatible for use on a mobile device.

- I consent, begin the study.
- I do not consent; I do not wish to participate.

### **Part 1: Demographics**

#### **Parent Demographics:**

1. What is your relationship to the student?
  - Biological parent
  - Adoptive parent
  - Foster parent
  - Legal guardian
  - I prefer not to answer
2. What is your gender?

- Male
  - Female
  - I prefer not to answer
3. What is your age?
- 18 to 24 years
  - 25 to 24 years
  - 35 to 44 years
  - 45 to 54 years
  - 55 to 64 years
  - Age 65 or older
  - I prefer not to answer
4. Choose one or more races that you consider yourself to be:
- White
  - Black or African American
  - American Indian or Alaska Native
  - Asian
  - Native Hawaiian or Pacific Islander
  - Other \_\_\_\_\_
  - I prefer not to answer
5. What is the highest level of school you have completed or the highest degree you received?
- Less than high school degree
  - High school graduate (diploma or equivalent including ged)

- Some college but no degree
- Associate degree
- Bachelor's degree
- Master's degree
- Doctoral degree
- Professional degree (JD, MD)

6. What was your total household income in 2016 before taxes?

- Less than \$25,000
- \$25,000 to \$34,999
- \$35,000 to \$49,999
- \$50,000 to \$74,999
- \$75,000 to \$99,999
- \$100,000 to \$149,999
- \$150 or more

**Student Demographics:**

7. How old is your son/daughter now?

- 11
- 12
- 13
- 14

8. Choose one or more races that you consider your son/daughter to be.

- White
- Black or African American

- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Other \_\_\_\_\_
- I prefer not to answer

9. At what age do you anticipate or plan for your son/daughter to exit public school?

- 17
- 18
- 19
- 20
- 21
- 22

10. What disability qualifies your son/daughter for special education?

- Autism/ Autism Spectrum Disorder
- Traumatic Brain Injury
- Specific Learning Disability
- Intellectual Disability
- Emotional Disturbance
- Deaf-Blind
- Blind/Visually Impaired
- Other Health Impairment
- Deaf/Hearing Impairment
- Multiple Disabilities



- Speech or Language Impairment
- Orthopedic Impairment
- Other \_\_\_\_\_

11. Does your son/daughter have a specific medical diagnosis?

- Yes \_\_\_\_\_
- No

12. In which type of classroom does your son/daughter spend the majority of his/her day?

- General education classroom
- Resource classroom
- Self-contained/ Life Skills classroom

13. What related services does your son/daughter receive as part of his/her IEP?

Check all that apply.

- Speech and Language
- Occupational Therapy
- Physical Therapy
- Audiology
- Vision
- Interpreting
- Psychological
- Orientation and Mobility
- Health/Nursing
- Recreation

## Part 2: Parent Priorities

### 1. Postsecondary Education

**Definition:** Any formal learning activity after high school, including college, vocational training or community classes.

Please select **no more than 3** of your family's top priorities for your child.

- Attend a 4-year college/university
- Attend a 2-year college
- Attend an applied technology college
- Complete vocational training
- Complete an internship or apprenticeship
- Enroll in community education class(es)
- Complete a service mission
- Complete courses on independent living
- Other \_\_\_\_\_
- Postsecondary education is not a priority or concern

### 2. Employment

**Definition:** Paid work, either part time or full time.

Please select **no more than 3** of your family's top priorities for your child.

- Full time competitive employment (in an integrated setting, earning at least minimum wage or higher)
- Part time competitive employment

- Supported employment (assistance with obtaining and maintaining employment)
- Military service
- Adult day program/services
- Self-employment
- Other\_\_\_\_\_
- Employment is not a priority or concern

### 3. Independent Living

**Definition:** Future living arrangements

Please select **no more than 3** of your family's top priorities for your child.

- Living at home
- Living with a family member, other than parents (siblings, spouse, etc.)
- Living with roommates in an apartment or home
- Living alone in an apartment or home
- Living in a group/residential home for adults with special needs
- Other\_\_\_\_\_
- Independent living is not a priority or concern

### 4. Social Relationships

**Definition:** Social interactions between people

Please select **no more than 3** of your family's top priorities for your child.

- Relationships with family
- Having friendships and seeing friends within organized groups/activities

- Having friendships and seeing friends outside of organized groups/activities
- Romantic relationships
- Starting a family
- Other\_\_\_\_\_
- Social relationships are not a priority or concern

**5. Community Involvement**

**Definition:** Meaningful engagement and participation within the community.

Please select **no more than 3** of your family’s top priorities for your child.

- Demonstrate social responsibility and be law abiding
- Engage in independent hobbies or interests within the home
- Engage in independent hobbies or interests outside of the home
- Volunteer work/community service
- Participate in organized school or community groups
- Participate in organized sports
- Attend church/ church activities
- Other\_\_\_\_\_
- Community involvement is not a priority or concern

**6. Daily Living & Functional Skills**

**Definition:** Caring for self and functioning independently

Please select **no more than 3** of your family’s top priorities for your child.

- Independently manage own finances

- Independently manage aspects of own finances, i.e. paying bills or budgeting
- Use public transportation to navigate community
- Obtain driver's license
- Prepare food and meals
- Other\_\_\_\_\_
- Daily living and functional skills are not a priority or concern

## 7. Health & Safety

**Definition:** Physical and emotional well-being.

Please select **no more than 3** of your family's top priorities for your child.

- Manage own physical health, including medication management
- Manage own mental health, including medication management
- Have assistance with health and medical choices and decisions
- Ability to solve problems
- Remain safe from danger or harm
- Build self confidence
- Make healthy choices
- Other\_\_\_\_\_
- Health and safety is not a priority or concern

## 8. Please select your top 3 priority outcome areas for your child.

- Postsecondary Education
- Employment
- Independent Living

- Social Relationships
- Community Involvement
- Daily Living and Functional Skills
- Health and Safety

### **Part 3: Information Needed**

**9.** If training were available to help your child transition to postsecondary education, would you participate?

- Yes
- Maybe
- No

**10.** What information relating to **postsecondary education** do you need to assist in your child's transition to adulthood? Select all that apply.

- Registering and choosing high school courses
- Helping my child with the admissions process and testing requirements
- Graduation and understanding the difference between a certificate of completion and high school diploma
- Postsecondary program options and availability for students with severe disabilities
- Availability and cost of community classes
- Paying for college, tuition or course expenses, how to apply for financial aid
- Other \_\_\_\_\_

- I don't know

**11.** If training were available to help your child transition to employment, would you participate?

- Yes
- Maybe
- No

**12.** What information relating to **employment** do you need to assist in your child's transition to adulthood? Select all that apply.

- Finding a job
- Job support (job coach or assistance, job training)
- Teaching employment and social skills
- Information about different employment types (competitive or supported employment, or sheltered workshops)
- Reasonable accommodations in the workplace
- Identifying job preferences, needs and interests
- Other \_\_\_\_\_
- I don't know

**13.** If training were available to help your child transition to independent living, would you participate?

- Yes
- Maybe
- No

**14.** What information relating to **independent living** do you need to assist in your child's transition to adulthood? Select all that apply.

- Assisted living programs
- Finding accessible housing
- Funding options and paying for housing
- Finding a roommate or caregiver
- Teaching money management, bill paying and budgeting
- Other \_\_\_\_\_
- I don't know

**15.** What information relating to **social relationships** do you need to assist in your child's transition to adulthood? Select all that apply.

- Teaching my child social skills
- Teaching my child about sex education
- Maintaining healthy and safe relationships
- Learning about social outings and groups within my child's community/  
school
- Other \_\_\_\_\_
- I don't know

**16.** What information relating to **community involvement** do you need to assist in your child's transition to adulthood? Select all that apply.

- Teaching my child leisure and recreational skills
- Exploring hobbies and interests with my child
- Interacting with community members



- Availability of community programs, groups, or sports for individuals with disabilities
- Teaching my child community navigation and how to locate specific buildings
- Managing time between leisure activities and responsibilities
- Other \_\_\_\_\_
- I don't know

**17.** What information relating to **daily living & functional skills** do you need to assist in your child's transition to adulthood? Select all that apply.

- Increasing my child's communication skills
- Teaching my child time management skills
- Teaching my child home living skills (cooking, cleaning, laundry, shopping, yard work)
- Teaching my child personal hygiene/grooming
- Teaching my child self-determination skills, such as problem solving, planning and goal setting, and self-awareness
- Teaching my child to use public transportation systems
- Other \_\_\_\_\_
- I don't know

**18.** What information relating to **health & safety** do you need to assist in your child's transition to adulthood? Select all that apply.

- My child's rights & responsibilities as a person with a disability
- Teaching my child to recognize and handle an emergency situation

- Disability awareness & disclosure
- Planning for adult health insurance or Medicaid
- Teaching self-advocacy and how to ask for help
- Other \_\_\_\_\_
- I don't know

#### **Part 4: Open Ended Questions**

- 19.** What are your family's long-term goals for your son/daughter?
- 20.** What concerns you most about your son/daughter's future?