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Timothy J. Pead
Utah State University

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PARENT-TO-PARENT INTERACTIVE TRANSITION INFORMATION SESSION: SHARING INFORMATION ON TRANSITION SERVICES FROM HIGH SCHOOL TO POST-SECONDARY EXPERIENCES

by

Timothy J. Pead

A creative project submitted in partial fulfillment
Of the requirements for the degree

of

MASTER OF EDUCATION

in

Special Education

Approved:

Robert Morgan, Ph.D. Major Professor	Charles L. Salzberg, Ph.D. Committee Member
Sarah Rule, Ph.D. Committee Member	Mark McLellan, Ph.D. Dean of Graduate Studies

UTAH STATE UNIVERSITY
Logan, Utah

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Abstract

Parents of high school aged children with moderate to severe intellectual disabilities sometimes experience fear and anxiety associated with transition of children to post-secondary programs. Most information is disseminated to these parents from local education agency staff, including: special education teachers, transition specialists and administrators. This project examined the effects of a parent-to-parent interactive session on knowledge and perspectives of parents in transition. Parents of youth (ages 14-20) who are diagnosed as having moderate to severe intellectual disabilities who live in the school boundaries of the high school within which the researcher teaches were part of this study. A group of four parents who have recently experienced the transition process (post-transition group) shared information on transition and post-secondary programs to a group of 16 parents who will soon be going through the transition process (pre-transition group). The pre-transition parent group served as the participants in this study. The knowledge of the participants was measured using a survey given before and after the parent-to-parent interactive transition information session. Results showed that all of the participants recorded an increase in knowledge gained on transition items and a clearer understanding of specific programs and transition information based on analysis of post-test responses. The results of this study showcased a potentially effective way to share post-secondary transition information from the parent perspective.

Introduction

The Individuals with Disabilities Education Improvement Act of 2004 (IDEIA) outlines requirements for each student eligible for special education services under IDEIA to have a transition plan that is implemented by the individual's 16th birthday. These transition plans are part of each student's individualized education program (IEP) and are put into place to help the student in his/her transition process from high school to post-secondary education programs, employment, and independent living. This transition information includes: postsecondary education, vocational education, integrated employment (including supported employment); continuing and adult education, adult services, independent living, or community participation. The goal for all students with disabilities is to receive post-secondary training that will help them gain employment, access adult services and participate in the community.

An important component in transition from high school to adulthood is family involvement (McNair & Rusch, 1990). Families who remain involved and serve as advocates for their son/daughter, in most cases, enable successful transition. McNair and Rusch (1990) conducted research on parents' perspective regarding their involvement and willingness to take on responsibilities in the transition process of their children. Research was conducted by sending out surveys to 200 families living in the United States who had a son or daughter with disabilities between the ages of 14 and 25. These families were contacted through the Coalitions for Handicapped Awareness and Information Network (CHAIN). The survey was made up of 37 questions that requested demographic information,

addressed the parents plans, questions, involvement and what type of contact they received from school with regards to transition. Of those 200 surveys sent out, the researchers received a response from 108 parents, but only 85 of those were completed correctly (42.5% response rate). The results of the study identified that parents wanted more information on transition. McNair and Rusch found that parents who were involved in the transition program were more likely than parents who were not involved in the transition program to create plans for programs after high school and show more interest in the future of their children. This research begins to make a case for the importance of parent involvement in post-secondary transition and has been verified by findings from other studies (Defur, Todd-Allen, & Getzel, 2001; Morningstar, Turnbull, & Turnbull, 1995; Neece, Kraemer, & Blacher, 2009).

Literature Review

I searched multiple sources for articles relating to parent involvement for secondary transition in special education. These sources included EBSCO Host database (ERIC and Academic Search Premier), Google Scholar, articles recommended by committee members, reference sections from relevant articles, and research on parent networks in transition. Based on these searches, I found approximately 70 articles related to transitioning from high school to adulthood. However, of this total, I found only four articles that dealt with (a) transition from high school to adulthood, (b) students with severe mental retardation or intellectual disabilities, and (c) research conducted on the parent's perspective with regards to transition. I limited my search to these four articles (Defur, Todd-Allen, & Getzel,

2001; McNair & Rusch, 1990; Morningstar, Turnbull, & Turnbull, 1995; Neece, Kraemer, & Blacher, 2009).

Neece et al. (2009) conducted research primarily with mothers ranging from 34-73 years old. Data were gathered from the parents of 128 young adults with severe intellectual disabilities. Letters were mailed out to participants who had registered their young adult with intellectual disabilities at the Southern California Regional Center. Similar to Defur et al. (2001), participants were given an honorarium for their participation in the study. Questionnaires were mailed to participants and in-home interviews were conducted. Data were gathered from 2-3 hr interviews and the completed questionnaires. Narrative, descriptive notes were written down by the interviewer directly after the in-home interview. Similar to the findings of McNair and Rusch (1990), data showed that the satisfaction of parents with regards to transition from high school to adulthood related with their involvement in the transition planning of their young adult with intellectual disabilities. Neece et al. (2009) found that if parents were more involved and informed on transition information, they were more likely to take an active role in the transition process.

Defur et al. (2001) conducted a study with parents who had teenagers with disabilities. Researchers gathered feedback from 28 parents in Virginia. The researchers sought to gather information on the families' experiences in transition, the relationship with school professionals, and the means by which the transition process could be enhanced with the families' participation. Participants were recommended through secondary school transition coordinators from four

geographic regions that represented urban, rural and suburban communities. The participants were divided into four focus groups ranging from six to 10 participants. All participants who participated received a $25 stipend at the completion of the study. Of the 28 participants, one youth represented had multiple disabilities and six had mental retardation. When looking at the participants' ethnicity 75% were African American, around 18% were Caucasian and 7% were Asian. The major findings of the study emphasized the barriers to parental participation in the transition plan including the attitudes of teachers and administrators, the diversity of their students and the stigma of special education. Parent frustrations included: (a) they felt alone and not trusted in the transition process, (b) the school focused on their son or daughter's weaknesses/disability, (c) they were judged by their ethnicity, and (d) they were treated as if they lacked knowledge on transition. The study addressed that professionals can make a difference through better communication, collaboration, connection, caring, and celebrating. A theme that emerged in this study was the inability of the professionals to relate to the parents and their transition needs. This study also contained parent feedback with the use of focus groups and gave another example for the benefit of conducting focus groups with parents presenting information to other parents who can relate and be more receptive to the receiving of parents needs.

Morningstar et al. (1995) researched student impressions of family involvement. Participants were gathered into four focus groups containing transition-aged students from Kansas. These students were recruited personally or through phone calls. Help was also enlisted from administrators and teachers.

These students either had learning disabilities, emotional or behavioral disorder or mild mental retardation. The researchers used a qualitative approach to gathering information during four focus groups. Each focus group lasted for 2 hr. Data were gathered by recording devices and by the researcher who took notes of items discussed. The other leader acted as a moderator asking questions and clarifying comments. The notes and information recorded were then analyzed. The results were divided into student's vision of the future, participation of students in family in transition and the facilitation of self-determination. The student's vision identified occupational goals and future living arrangements. The researchers also identified the influence that families had on the development of how students see themselves in the future. Similar to the findings of McNarr and Rusch (1990) and Defur et al. (2001), researchers made an additional case on how important the role family members play as avid partners with students. Additionally, researchers found that professional educators played an equally important role when helping the student plan for future post-secondary experiences and adulthood.

Parents who are well-informed play an important role in the transition of their youth from high school to post-secondary experiences. Those parents who have experienced the transition process with their son or daughter could provide a useful perspective to those parents who are beginning the transition process. No research was found in my literature review on the effects of parent-to-parent sessions on information regarding transition. This project will contribute to existing literature by determining whether parents who have gone through the

transition process can provide useful information to parents who are beginning the transition process with their son or daughter.

Purpose Statement

In this study, parents of youth who were almost of transition age (i.e., 14-16) and parents of youth who were of transition age (i.e., 17-20) comprised a group referred to as the *Pre-Transition Parents*. Parents of young adults who had experienced transition from high school to adulthood (ages 19-30) comprised a group referred to as the *Post-Transition Parents*. The purpose of this research was to examine whether pre-transition parents gain information and to describe what information was gained based on interaction with post-transition parents.

Research Question

The questions addressed by this project were as follows: (a) Given a parent-to-parent interactive information session, to what extent did input from parents who have gone through the transition process improve the knowledge base of parents in transition as measured by differences in pre-group and post-group survey data? (b) What types of qualitative data on transition issues were provided by pre-transition and post-transition parents?

Method

Participants

In this study, invitations were sent out to 26 households of pre-transition parents of youth (ages 14-20) who were diagnosed as having moderate to severe intellectual disabilities. All participants had children who currently attended or planned to attend high school, where the researcher teaches. Of those parents who were invited, pre-transition parents of 12 households responded that they would

like to participate. There were parents from two households that cancelled the day of the study. Sixteen pre-transition parents attended the meeting. These participants included four adult males and 12 adult females between the ages of 40 and 54. Among the group of pre-transition parents, four participants had received his or her high school diploma or equivalent, five participants had received his or her associates degree or equivalent, six participants had received his or her bachelors degree or equivalent, one participant had received his or her masters degree or equivalent and one participant has received his or her doctorate degree or equivalent.

The participants of the post-transition group represented youth from moderate to severe intellectual disabilities who had attended transition programs at the district's main transition program. Of the youth represented by the post-transition group, one had a part time job; one was self employed and lived in a basement apartment; and three were participating in the district led transition programs. These Post-Transition participants were selected by matching different characteristics of his or her youth such as disability, gender, ethnicity, and health issues compared to the pre-transition participants. Additionally, the researcher screened Post-Transition Group Participants to ensure there were no tight friendships or close associations with participants in the pre-transition group to avoid inflation of pre-survey and post-survey data. The post-transition group conveyed information on transition to the pre-transition group. All participants in the pre-transition group had youth who were currently enrolled or soon to be enrolled in a high school in Utah. The youth of the Pre-Transition Group had all

attended classes in the Life Skills classroom taught by the researcher. Members of the Pre-Transition Group and Post-Transition Group were recruited through personal contact, e-mails and letters from the researcher. The researcher contacted participants with whom the researcher had worked. The researcher contacted principals in the feeder schools of the high school, received permission to contact teachers in those schools who identified students who will be attending the high school in the Life Skills Classroom. The feeder school's teachers invited those participants, via the forwarded e-mail from the researcher and with an invitation letter given them by the researcher.

Setting

Research was conducted in a conference room at the local high school. The Post-Transition Group was seated on a table in a straight line facing the Pre-Transition Group who was seated in a semi circle facing the Post-Transition Group. The researcher and researcher assistant were seated to the side of the Post-Transition Group closest to the door to the conference room. A recording device was placed directly in the front of the room behind the Post-Transition Group to record interactions between the Pre-Transition Group and Post-Transition Group. The participants were then provided with an acceptance letter and consent form including permission to be recorded prior to the interactive sessions. Additional copies of the consent form were also available and handed out to any participant who neglected to bring the form. All participants signed consent forms that were collected before the start of the interactive session.

Dependent Variable and Response Measurement

The research question for this project was to examine the extent to which input from a Post-Transition Group who had experienced the transition process improved the knowledge base of a Pre-Transition Group. Data on the participants' knowledge of transition were collected through a qualitative measurement system. This system was used to gather data in the form of a pre-survey and post-survey (See Appendix A) created by the researcher using a similar table where the participants rated his or her understanding of certain transition processes, procedures, and organizations as referenced in Section VII: Adult Services from the *Parent Transition Survey* created by Morningstar, Crawford, Scarff, and Blue-Banning (n.d.). The researcher was the primary data collector and facilitated the group discussion.

Pre-survey. The pre-survey (Appendix A) was distributed to the pre-transition parent group prior to the start of the interactive session. Individual pre-transition participants completed the survey. The pre-survey asked for the participant's age, gender, level of education attained, and the age of youth with special needs. The pre-survey then asked the participants to rate 10 transition items that are presented to the participants on a yearly basis from the district's transition checklist and transition page of the IEP. These transition items include:

- Graduation options (high school diploma vs. certificate of completion)
- Transition programs available through district lead transition center
- Other post-secondary education options
- Accessibility services for post-secondary education and training
- Future career choices and opportunities

- Housing preferences (where will your child live?)
- Division of Services for People With Disabilities (DSPD)
- Age of majority
- Vocational Rehabilitation (Voc Rehab)
- Supplemental Security Income (SSI) and Medicaid

Pre-transition participants rated his or her understanding and how preparation using a five point scale:

1. I have no knowledge of the transition item
2. I have heard of the transition item
3. I have some basic information on the transition Item
4. I have some advanced knowledge on this transition item
5. I am fully aware and feel prepared for this transition item.

Parents were given time to fill out this pre-survey before the interactive transition information session had begun.

Post-survey. The post-survey was distributed to the Pre-Transition Parent Group at the conclusion of the interactive session. The post-survey was located on a separate sheet of paper from the pre-survey. At the end of the interactive session, participants again scored their understanding and preparation on the same 10 transition items using the same five-point scale. The 10 items were shifted to appear in a different location on the post-survey. In closing, Pre-Transition Parents were asked to fill out their closing thoughts and answer three final questions:

1. What are your overall impressions of the parent-to-parent interactive transition information session?

A. I feel MORE PREPARED for my son or daughter's post-secondary transition.

B. I feel THE SAME about my son or daughter's post-secondary transition

C. I feel MORE UNPREPARED for my son or daughter's post-secondary transition.

2. What specific information did you find most useful?
3. What information are you still unclear on?

These final questions allowed Pre-Transition Parents to provide anecdotal feedback on his or her impressions of the parent-to-parent transition information session. The post-survey was collected from all Pre-Transition Parents except two. One parent had to leave half way through the interactive session and did not fill out a post-survey. The pre-survey and post-survey results for this participant were not included in the final results. Another parent stayed the whole time, but had to run home to take care of a sick child. She took her post-survey home, filled it out, and sent the survey back to school two days later.

Procedures

Procedures consisted of both e-mailing and sending home hard copy invitations and consent forms before the interactive transition session began to the Pre- and Post-transition Groups. A pre-survey for Post-Transition Group, orientation meeting with the Post-Transition Group followed by an interactive transition information session with the Post-Transition Group discussing issues with the Pre-Transition Group. The pre-survey document was administered to the Pre-

Transition Group before the interactive session began. Post-surveys were administered to the Pre-Transition and Post-Transition Group at the end of the interactive transition information session.

Post-transition group pre-survey. The Post-Transition Group filled out a pre-survey rating their knowledge and understanding of the 10 transition topics discussed during the interactive information session. They also answered the following questions: (a) What additional topics do you want to include in this transition interactive information session? (b) What topics can you address and provide knowledge about and/or personal experiences to the Pre-Transition parents?

Post-transition group orientation meeting. An orientation meeting was held 1 hr before the interactive transition session with the Post-Transition Group. Post-Transition Group participants turned in their pre-survey and consent form before participating in the orientation meeting. During this orientation meeting, the researcher explained how to convey information on appropriate topics during the interactive transition information sessions, giving examples of appropriate and inappropriate discussion topics. Appropriate discussion items include:

- Positive experiences in transition programs
- Potential options for transition
- Individualized experiences and approaches to transition from high school to post-secondary transition programs

Inappropriate discussion items include:

- Speaking negatively of specific transition personnel

    - Directors
    - Teachers
    - Post-secondary coordinators
- Speaking negatively of transition programs
    - School
    - District
    - Community programs
    - State/Federal implemented programs

The Post-Transition Group was encouraged to speak frankly and openly with the Pre-Transition Group, but warned that discussion of problems must be accompanied by discussion of solutions.

Interactive transition information session. The interactive transition information session was held in the evening and lasted less than 2 hr. As the Pre-Transition Group entered the high school, direction markers showed them the way to the conference room. Participants turned in consent forms sent home with the acceptance letter. Participants who did not have consent forms were given new forms that were signed and turned in to the researcher prior to the start of the session. Participants were also given an agenda, pre-survey and those without pens were provided one. The agenda outlined the plan for discussion between the Post-Transition Group and the Pre-Transition Group and a space was provided for note taking so participants could record helpful information that could be utilized with their youth (See Appendix B). Light refreshments were provided before the interactive transition information session to give participants an opportunity to

relax and mingle with other participants. During that time, participants were also encouraged to fill out the pre-survey including the demographic information and three pre-survey questions. After approximately 10 min, the researcher took 2 min to explain the purpose of this session. The researcher provided the following description:

> Now we will get started. The purpose of this meeting as disclosed in your invitation and on your agendas is to get together a group of parents and have them talk about transition. I selected these incredible parents over here that I've had the privilege of working with and their children and asked them to come and share their experiences with transition. For you guys to know, transition in my opinion is one of the scariest topics that I have to explain and probably one of the hardest parts of my job. I love my job. I love working with students and it's not fun for me as their teacher to watch them get older anymore than it is for you as their parent. In fact on a yearly basis I find myself in tears quite often to see them moving on and becoming adults and seeing them out in the community reduces me to tears too, I'm just an emotional wreck most of the time. I just want to tell you all thank you so much for coming and for being apart of this. I hope that it will be meaningful and beneficial. I'm just going to quickly introduce my panel of parents and I'll let them disclose as much information as they feel comfortable about their youth. I'm going to turn the time over to them. The purpose of this meeting is to not be overly critical of any transition programs or activities, but just to give you the opportunity to hear of their experiences and ask questions as

we're going through. We're going to try to follow the agenda as much as possible and have them tell you of their experiences of these transition items. Please take notes of any clues of helpful hints that they provide you and keep track of it. This is something we'll address each year at your student's IEP at least.

The researcher then turned the time over to the Post-Transition Group to share their experiences. The researcher and assistant served as narrator to (a) ensure that comments were brief and solution-oriented, (b) ensure that pre-transition participant questions were answered, (c) distribute discussion so that all of the 10 survey topics were addressed, and (d) added content and clarification (but only when necessary) so that comprehensive information was conveyed. For example, in regards to adding content and clarification, when the post-transition parents asked about what other post-secondary education options meant, the researcher and researcher's assistant told them about the disability services centers at local colleges and universities in the area. Also, when a pre-transition parent asked about retention processes in the district, the researcher mentioned that it was done on an individualized basis and the researcher assistant mentioned that decisions were only made when based on data. When it was 15 min before the 2 hr time limit expired and the researcher noticed that a few pre-transition parents were packing up and needing to go, the researcher stood and thanked the Post-Transition Group for sharing their experiences. The researcher thanked the Pre-Transition Group for taking the time to come and participate, passed out the post-survey and asked the Pre-Transition Group to fill out the survey and turn the survey in to the

researcher before exiting the room. The researcher also reminded the Pre-Transition Group that the Post-Transition Group volunteered to provide his or her contact information so the Pre-Transition Group could contact them with any further questions or clarification needed on the transition topics mentioned during the interactive session. That contact information was sent out a few days after the interactive session concluded.

Observation and Data Collection on Topic Emphasis

Two data collectors independently collected data on the extent to which the post-transition group addressed topics in the survey. The second data collector was also a graduate student from the same university as the primary researcher, a special education teacher, and had taught some of the youth of the post-transition participants. The two data collectors used the same list of transition items in the survey instrument. However, they used a survey instrument with definitions on each transition topic. Researchers also used a different scoring rubric from that used by parents. Using the transition list as a *topic emphasis survey*, data collectors scored each item as follows.

1. The topic was addressed or mentioned but not addressed in any detail.
2. The topic was addressed by providing a name instead of an abbreviation, a one- or two-sentence description, or a name of a person to contact but no additional information.
3. The topic was addressed by providing not only information in “2” but additional, comprehensive information about purpose, function, or rationale.

Each of the 10 transition items was scored “1” through “3” by each of two raters. Data collectors were trained to use the topic emphasis survey prior to the interactive session. Inter-observer agreement was calculated by comparing the two scores on each transition item as “same ” (e.g., both score “2”) or “different” (e.g., one observer scores “2” and the other observer scores “3”).

Data Analysis

The researcher compared pre-survey ratings on the 10 transition items using the five-point scale to post-survey responses. If the ratings from the pre-survey were equal to or less than scores of the post-survey, then presumably the researcher would have concluded that no new knowledge was gained from the session. If participant ratings had increased, then presumably the researcher would conclude that knowledge was gained. Anecdotal data from researcher notes and the digital recording device were gathered and is reported in a table format below. This information was distributed to both groups of participants and other parents who were not able to attend the interactive transition information session (Appendix G).

Results

There were two data collectors who rated the extent that the Post-Transition Group discussed each of the 10 transition items. There was 100% inter-rater agreement between the two data collectors. Both data collectors rated seven transition items as a “3”: Division of Services for People with Disabilities, age of majority, Supplemental Security Income and Medicaid, future careers and opportunities, housing preferences, graduation options, and district lead transition centers. The final three transition topics (Vocational Rehabilitation, accessibility

services for post-secondary education and training, and other post-secondary education options) were mentioned by name, abbreviation, and given a brief description, but the Post-Transition Group had little to no personal experiences on these three topics. Both data collectors rated these three transition topics as a "2." Related to the post-survey results from the Pre-Transition Group, both accessibility services and post-secondary education options were the two lowest rated transition topics (See Figure 1).

Pre-Survey Results

Results showed that most of the participants in the Pre-Transition Group rated the 10 transition items in the pre-survey in the 1-to-3 range, suggesting that the participants had limited knowledge of transition (See Figure 1 & Table 1). The mean score on the pre-survey from the Pre-Transition Parent Group was 2.09. Data showed that the four transition items that were scored the lowest were in the areas of accessibility services for post-secondary education and training, age of majority, other post-secondary education options, and Vocational Rehabilitation.

Data showed that most of the Post-Transition Parent group rated the 10 transition items in the pre-survey in the 3-to-5 range, indicating they had basic to advanced knowledge of most of the transition items. The mean score on the pre-survey for the Post-Transition Parent Group was 3.48. From the four Post-Transition Parents selected, there was at least one participant who indicated some advanced to full awareness on each of the 10 transition items.

Post-Survey Results

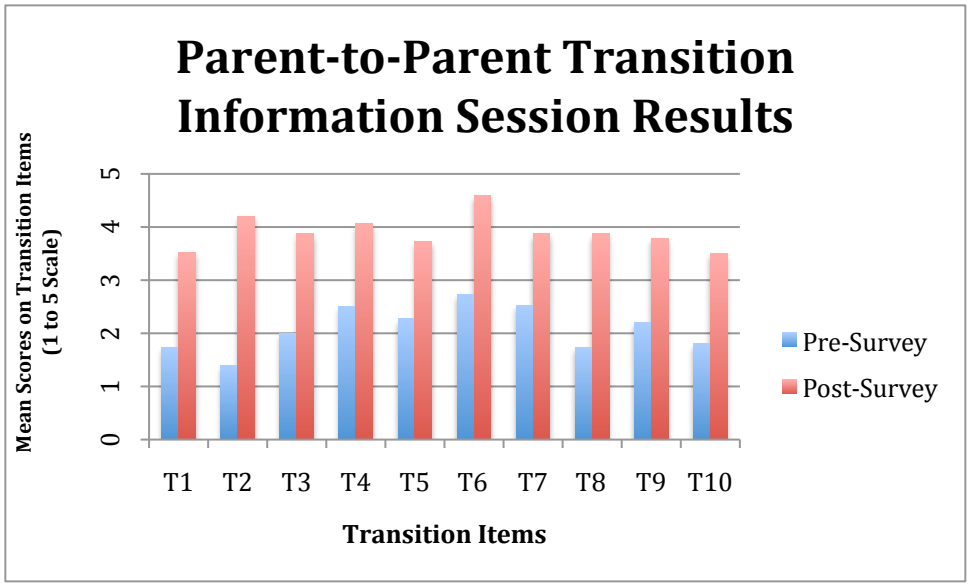
The data collected show that the majority of the participants in the Pre-Transition Group increased their ratings of all of the 10 transition items. Scores fell between the 3-to-5 ranges, meaning the participants felt that they now had some basic information; some advanced knowledge, and some reported feeling fully aware and prepared for this transition item (See Figure 1 & Table 1). In addition to the high range of post-survey results, each participant was asked to give his or her overall impressions of the parent-to-parent interactive transition information session using the following three-point scale:

1. I feel MORE PREPARED for my son or daughter's post-secondary transition
2. I feel THE SAME about my son or daughter's post-secondary transition
3. I feel MORE UNPREPARED for my son or daughter's post-secondary transition

Of the 15 Pre-Transition parent participants who filled out the post survey, 14 of those parents marked that they felt 'MORE PREPARED' for their son or daughter's post-secondary transition, while one participant marked that he or she felt 'THE SAME'.

The data collected in the post-survey showed that all of the participants in the Post-Transition Group thought the process was worthwhile. They thought that parent-to-parent sharing was the best way to communicate transition information. All participants said that they would like to see this event be an ongoing opportunity and they would be willing to participate. Most participants could not think of any way this process could be improved, although one participant felt that one-on-one

Figure 1. Pre-Transition Parent pre and post mean data on 10 transition items*.



*Transition Items: T1= Accessibility services for post-secondary education and training, T2= Age of majority, T3= Transition programs available through district lead transition center, T4= Division of Services for People With Disabilities (DSPD), T5= Future career choices and opportunities, T6= Graduation options (high school diploma vs certificate of completion), T7= Housing preferences (Where will your child live?), T8= Other post-secondary education options, T9= Supplemental Security Income (SSI) and Medicaid, T10= Vocational Rehabilitation.
Figure 1. Pre to post survey results on 10 transition items.

Table 1

**Transition topics pre-transition group participants' post-survey results*

TRANSITION TOPICS PRE-TRANSITION GROUP PARTICIPANTS' KNOWLEDGE ***Out of 15 Participants					
*TRANSITION TOPIC	I HAVE HEARD OF THE TRANSITION ITEM	I HAVE BASIC INFORMATION	I HAVE ADVANCED KNOWLEDGE	I AM FULLY AWARE AND PREPARED	NO RESPONSE
T1	1	7	5	2	0
T2	0	3	6	6	0
T3	0	4	9	2	0
T4	0	4	6	5	0
T5	0	6	7	2	0
T6	0	1	4	10	0
T7	1	3	8	3	0

T8	1	3	8	3	0
T9	1	3	8	2	1
T10	1	7	4	2	1

meetings may also be beneficial and another participant felt that a social media group might be beneficial.

Discussion

The findings of this research show an increase from the pre-survey to the post-survey in terms of ratings of knowledge on transition topics for Pre-Transition Parents. These results showed that a parent-to-parent group session could improve the knowledge base of parents in transition.

Given these results, I would conclude that the parent-to-parent session was effective. Results demonstrated that the session was an effective way for transition information to be transmitted to parents. The session served as a useful approach to educate parents about transition from high school to adulthood and increased parent's awareness of transition opportunities.

One strength of this study was that it allowed transition information to be presented and understood from the perspective of the parent. Also, the environment and population of participants was conducive to helping them feel at ease and able to personalize the information for his or her individual child.

The scope of this project was limited by numbers of participants, length of interactive session, and breadth and depth of topics discussed. There were only 15 Pre-Transition parents who participated and completed the pre- and post-survey in this study. The participants of the study only included parents who have lived and

educated their children at the local high school in Utah. Most parents were middle class in socioeconomic status. The number of post-secondary ideas and transition information presented were limited to the experiences and advice of the post-secondary parent group.

The study was also limited by the metric: self ratings of knowledge. Self-ratings are known to be unreliable and unrepresentative of actual knowledge gain (Schneider & Schimmack, 2009). The researcher cannot conclude that knowledge actually increased as a function of discussion with the Post-Transition Group or if ratings increased due to expectation or bias. Only an actual pre and post-test of information covered in the session would have corroborated knowledge gain. On a related note, rating gains may have been a function of relationships developed and shared experiences among session participants. Pre-Transition Parents found that they had many of the same fears, anxieties, and confusions that Post-Transition Parents initially experienced. Ratings may have changed because they felt more at ease with the transition experience.

Nevertheless, the results of this study showcased one potentially effective way to share post-secondary transition information from the parent perspective. Future research could examine a larger sample size (multiple high schools, districts, county, or state), conduct parent-to-parent meetings regarding children of specific disabilities (including, but not limited to individuals with autism, cerebral palsy, down syndrome, specific learning disabilities, multiple disabilities, as well as others), and examine the effectiveness of holding these interactive transition information sessions with parents of youth in different environments (junior

high/middle school, high school, and post-secondary programs). Data gathered and analyzed from larger groups, groups of different disabilities, and groups in different environments may provide replication of the results of this study.

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Appendices

Appendix A: Pre-survey for post-transition group

Demographic Information:

(Please check the line that best represents your demographic information)

Your age: ___ 35-39 ____ 40-44 ____ 45-49 ____ 50-54 ____ 55 or above

Your gender: ____ Male ____Female

Your Highest Level of Education attained:

____ High School Diploma or Equivalent
____ Associates Degree or Equivalent
____ Bachelors Degree or Equivalent
____ Masters Degree or Equivalent
____ Doctorate Degree or Equivalent

Age of child with special needs: ____ 16 or less ____ 17-18 ____ 19-20 ____ 21 ____ 22 or more

PRE- SURVEY #: (01-04)

Use the following 1-5 scale:
1=I have no knowledge of the transition item
2=I have heard of the Transition Item
3=I have some basic information on the Transition Item
4=I have some advanced knowledge on this Transition Item
5=I am fully aware and feel prepared to share information and/or personal experiences about this Transition Item

***Check (√) one box (either 1, 2, 3, 4, or 5) for each row below. Please fill out the following table based on your understanding and how prepared you feel in the transition process regarding your son and daughter for the following transition items:

Transition Item	1	2	3	4	5
Graduation options (High School Diploma vs Certificate of Completion)					
Transition programs available through district lead transition center					
Other Post-Secondary Education Options					
Accessibility Services for post-secondary education and training					
Future career choices and opportunities					
Housing Preferences (Where will your child live?)					
Division of Services for People With Disabilities (DSPD)					
Age of Majority					
Vocational Rehabilitation (Voc Rehab)					
Supplemental Security Income (SSI) and Medicaid					

***Continued on other side

What additional topics do you want to include in this transition interactive information session?

What topics can you address and provide knowledge about and/or personal experiences to the pre-transition parents?

Appendix B: Interactive transition information session pre-survey for pre-transition group

Demographic Information:

(Please check the line that best represents your demographic information)

Your age: ___ 35-39 ____ 40-44 ____ 45-49 ____ 50-54 ____ 55 or above

Your gender: ____ Male ____Female

Your Highest Level of Education attained:

____ High School Diploma or Equivalent
____ Associates Degree or Equivalent
____ Bachelors Degree or Equivalent
____ Masters Degree or Equivalent
____ Doctorate Degree or Equivalent

Age of child with special needs: ____ 16 or less ____ 17-18 ____ 19-20 ____ 21 ____ 22 or more

Parent-to-Parent Interactive Transition Information Session
PRE- SURVEY #: (01-16)

Use the following 1-5 scale:
1=I have no knowledge of the transition item
2=I have heard of the Transition Item
3=I have some basic information on the Transition Item
4=I have some advanced knowledge on this Transition Item
5=I am fully aware and feel prepared for this Transition Item
***Check (√) one box (either 1, 2, 3, 4, or 5) for each row below. Please fill out the following table based on your understanding and how prepared you feel in the transition process regarding your son and daughter for the following transition items:
**** Star (*) the 5 transition items that you feel are most important for you and your child.

Transition Item	1	2	3	4	5
Graduation options (High School Diploma vs Certificate of Completion)					
Transition programs available through district lead transition center					
Other Post-Secondary Education Options					
Accessibility Services for post-secondary education and training					
Future career choices and opportunities					
Housing Preferences (Where will your child live?)					
Division of Services for People With Disabilities (DSPD)					
Age of Majority					
Vocational Rehabilitation (Voc Rehab)					
Supplemental Security Income (SSI) and Medicaid					

Appendix C: Interactive transition information session post-survey for pre-transition group

Parent-to-Parent Interactive Transition Information Session
POST-SURVEY FORM A #: (01-15)

Use the following 1-5 scale:
1=I have no knowledge of the transition item
2=I have heard of the Transition Item
3=I have some basic information on the Transition Item
4=I have some advanced knowledge on this Transition Item
5=I am fully aware and feel prepared for this Transition Item
***Check (√) one box (either 1, 2, 3, 4, or 5) for each row below. Please fill out the following table based on your understanding and how prepared you feel in the transition process regarding your son and daughter for the following transition items:
**** Star (*) the 5 transition items that you feel are most important for you and your child.

Transition Item	1	2	3	4	5
Division of Services for People With Disabilities (DSPD)					
Age of Majority					
Vocational Rehabilitation (Voc Rehab)					
Supplemental Security Income (SSI) and Medicaid					
Accessibility Services for post-secondary education and training					
Future career choices and opportunities					
Housing Preferences (Where will your child live?)					
Graduation options (High School Diploma vs Certificate of Completion)					
Transition programs available through district lead transition center					
Other Post-Secondary Education Options					

CLOSING THOUGHTS

What are your overall impressions of the Parent-to-Parent Interactive Transition Information Session?

_____ I feel MORE PREPARED for my son or daughter's post-secondary transition
_____ I feel THE SAME about my son or daughter's post-secondary transition
_____ I feel MORE UNPREPARED for my son or daughter's post-secondary transition

What specific information did you find most useful?

What information are you still unclear on?

Appendix D: Interactive transition information session post-survey for post-transition group

Parent-to-Parent Interactive Transition Information Session POST-SURVEY FORM B #: (01-04)
CLOSING THOUGHTS
Do you think this process is a good idea? If so, what was most valuable to communicate to the pre-transition parents? Is there a better way to communicate this information? If you had the opportunity to do this again would you participate? Why or why not? Was there anything that you didn't like? What topics were not brought up that should have been? What would you do differently the next time? Would you like to see this event create an ongoing opportunity to meet with each other to talk about transition? If an ongoing opportunity were created would you participate? What might that process look like (i.e. blog, facebook, in-person conference or another type of venue)?

Appendix E: Parent-to-Parent Interactive Transition Information Session Agenda

Parent-to-Parent Transition Meeting AGENDA	
1. Fill out and/or turn in Letter of Consent 2. Light Refreshments and complete anonymous survey on current knowledge/comfort level with transition from high school to post-secondary activities 3. Purpose of the meeting 4. Introductions 5. Transition Information Sharing Questions and Answers: a. Division of Services for People with Disabilities b. Age of Majority c. Supplemental Security Income and Medicaid d. Graduation Options e. Transition Programs available through district f. Other post-secondary education options g. Accessibility Services for Post-Secondary education and training h. Vocational Rehabilitation i. Future career choices and opportunities j. Housing Preferences 6. Closing/Last Minute Thoughts 7. Fill out transition post-survey	NOTES:

Appendix F: Data Collection Survey Instrument

DATA COLLECTION SURVEY INSTRUMENT			
Use the following 1-3 scale: 1. The topic was addressed or mentioned but not addressed in any detail. 2. The topic was addressed by providing a name instead of an abbreviation, a one- or two-sentence description, or a name of a person to contact but no additional information. 3. The topic was addressed by providing not only information in "2" but additional, comprehensive information about purpose, function, or rationale. ***X all discussed subtopics			
TRANSITION TOPICS			
Division of Services for People With Disabilities (DSPD)	1	2	3
◊ Mentioned by name ◊ Also known as DSPD ◊ Provides Respite Care ◊ Provides an array of home supports ◊ Other: ◊ Other:			
Age of Majority	1	2	3
◊ Mentioned by name ◊ Guardianship ◊ Guardian Associates Available ◊ Occurs when youth reaches the age of 18 ◊ Other: ◊ Other:			
Vocational Rehabilitation (Voc Rehab)	1	2	3
◊ Mentioned by name ◊ Known as Voc Rehab ◊ Takes over after Age 22 ◊ Provides Job Coaching, Counseling, Assistance Finding Work ◊ Other: ◊ Other:			
Supplemental Security Income (SSI) and Medicaid	1	2	3
◊ Mentioned by name ◊ Provides Monthly Support ◊ Provides Medicaid Insurance ◊ Requires Application Process ◊ Based off of Youth's Income not household income ◊ Other: ◊ Other:			

Accessibility Services for post-secondary education and training	1	2	3
◊ Mentioned by name ◊ Local College Accessibility Service Center ◊ Local University Accessibility Service Center ◊ Bring in most current IEP paperwork to view accommodations needed ◊ Other: ◊ Other:			
Future career choices and opportunities	1	2	3
◊ Mentioned by name ◊ Interest Indicator/aptitude assessments ◊ Local job opportunities ◊ Disability friendly work places ◊ Other: ◊ Other:			
Housing Preferences (Where will your child live?)	1	2	3
◊ Mentioned by name ◊ Live at Home ◊ Basement Apartment ◊ Apartment/Roomate ◊ Residential Facilities ◊ Other: ◊ Other:			
Graduation options (High School Diploma vs Certificate of Completion)	1	2	3
◊ Mentioned by name ◊ Basic High School Diploma ◊ Certificate of Completion ◊ Certificate of Progress ◊ Other: ◊ Other:			
Transition programs available through district lead transition center	1	2	3
◊ Mentioned by name ◊ District offered transition programs ◊ Community based work sites ◊ Continuum of Services ◊ Other: ◊ Other:			
Other Post-Secondary Education Options	1	2	3
◊ Mentioned by name ◊ Local Colleges ◊ Local Universities ◊ Other: ◊ Other:			

Appendix G: Parent-to-Parent Transition Meeting Post-Meeting Notes

PARENT-TO-PARENT TRANSITION MEETING
****Post-Meeting Notes****

Accessibility Services for Post-Secondary education and training

- Not a lot of experience with it, it will be something that parents may need to look into and advocate for on an individualized basis.
- Every local college and university has a disability services center. If that is a goal for your student you can look into those options.
- Services may not be as intense as the services you can receive at the high school or other transition programs at the district but they do have services available.
- Services at one university through a 504 plan included a scholarship and peer tutors to take notes.
- You just need to find the right people to talk to at each institution.

Age of Majority

- Also known as Guardianship
- When your child turns 18 you are no longer in charge unless you have guardianship.
- Teachers are no longer required to have you at IEPs
- You have 'No say' in Medical treatment
    - In the Emergency room if your child does not want to have his or her blood drawn or stitches, they're over 18, you don't have guardianship and they say no, they won't do it. If they can't even speak for themselves they will probably be given a case worker and that case worker will start making the decisions and you as the parent won't have a say in those medical procedures.
    - They won't even give you their medical records if you don't have guardianship.
- It is a legal process that you have to go in front of a judge, it does take time, but it's not overwhelming
- Your child must be 18 before going before the judge, technically up until that point you are their guardian. You can begin the process and get all of your paperwork (including letter from your doctor) together before hand so you can get on the list and are prepared to go before the judge. Our judge couldn't have been kinder and more gracious to us.
- You are usually stated as limited guardianship, but it lists over habitation, medical, financial, and some others a total of 5 areas that will be all you need to assist and help your child.
- There are costs involved and Community Organizations are available to help
    - Guardianship Associates of Utah, that provides you with all of the paperwork and references to attorneys that do guardianship. The packet of legal materials purchased here including training was around $250, we priced it out with an attorney and it would have cost us several thousands of dollars.
    - Utah parent Center offers a class and materials for $800, but there may be options to skips the class and just buy the materials.
- You can go "Pro Se" and act as your own attorney
- If you have older children you may want to think about whom you want to take over for you in case of an emergency and put all of them on the document with you. You can put multiple guardians on the form, but they

must all be 18 years old at the time you do it.
- The last stage will involve going before a judge who will ask some very specific questions to the representing attorney of the child. At the end you will receive some documentation that states that you are now their guardian.
- Pay for extra copies at the courthouse, because you are going to need them and use them.

Division of Services for People with Disabilities

- Also known as DSPD
- State run program that helps families or individuals with disabilities
- Money/Services provided for:
  - Respite services
    - People come into your home and sit with your youth while you go grocery shopping
    - Provides interactions, growing experiences, and friends for our children who may not have any friends
    - Provides opportunities for others including college students to have experiences with non-typical peers
    - Even if you don't have respite services through DSPD, you need to find some type of respite whether it's through family members or friends, you need that break
  - Housing: years ago, money was granted to put up a fence around home
  - Money for Voc Rehab/job coaches
  - Parent led summer school (leasing of place and hiring of teachers)
  - Other types of things
- Get on the waiting list: Very few qualify anymore it is not a mandated service, but still get on the list if anything to show our legislatures that there are that many people out there who could use the support and help.
- Qualification is based on the disability and the need. The greater the need in the family the higher up that will place you on the list. Your circumstances may place you on the top 10% of the list, or your circumstances may be so good, that you may never make it up.
- Recently heard that 150 additional cases had been funded this year, which is a huge movement that we haven't seen in quite a while.
- Be honest to get the help that you need
- They have a website that you can go do for additional information

Future career choices and opportunities

- This comes along after your student is 22, when they're going to graduate out of whatever program that they're in.
- Job coaches are available at ATEC and Dan Peterson to practice job skills out in the community and build up your student's resume to use in applying for future jobs
  - Local Hospital (2 sites)
  - Local Department Store
  - Local Foodbank
  - Local Grocery Store
  - Local Small Business
  - Local Publishing Company. Can work on packaging and shipping
- You can also use funds/services through DSPD or SSI to help with this.

- One student works at a fast food joint. Parent was horrified and against having his or her student who has so much potential and do so many job skills working at a fast food joint, but he loves it and doesn't want to work anywhere else. He likes working there, has camaraderie there, they treat him well, he loves their food, and he has self-worth and that's what it's all about. It doesn't matter what we think they should be doing, it's what they're doing. We as parents are use to making all of their decisions for them, we have guardianship over them and feel like we have a little bit of control over them, but they still want to accomplish things and do what they want to do.
- Make sure you know what the individual's skills and abilities are and pair them with a job that they can do, don't feel pigeonholed into a job, but at the same time allow them to choose a job they'll enjoy.
- They can have their own company, working and selling their own products. For more information contact the Post-Transition Parent.

Graduation Options

- An individual decision for all students
- There are two separate things. There is receiving a diploma and participating in commencement.
    - All Students can walk, wear a cap and gown, and participate in all senior activities including commencement where they can walk with their peers.
- As far as the diploma there are two options for the piece of paper received at graduation: Diploma and Certificate of Completion:
    - Diploma:
        - According to federal law if you earn a diploma your services end in the school system
        - If your child can earn a diploma they are probably ready to go out in the real world
        - You would have to be able to do all of the course work (science, history, world languages, math, etc.) and receive credits to earn the diploma
    - Certificate of Completion:
        - Services in the district can continue until age 22.

Housing Preferences

- Individualized decision for you and your child.
- There are options:
    - Could choose to live in apartment
    - Could buy a house with other individuals/caregiver
    - Basement apartment with a caregiver
    - Could live in a group home
    - Could choose to live at home with parents
- You need to dream and let your kids dream. Often times we are so use to taking care of our children that we just assume they'll be with us for the rest of our lives, but we need to stop and realize that they have dreams too even if they can't talk.
- Give children the opportunities to grow and give you the opportunity to be released a little. You'll always have responsibility for them, but you need to stop and allow them to express their desires, allow it to be a seed in your mind, and allow some experimenting. You and your child might not what

they're capable of until you try it.

Other post-secondary education options

- See Accessibility Services for Post-Secondary Education and Training
- There are groups and programs in the community including ones created by parents.
    - They provide services mostly for individuals with disabilities.
    - Talk to parents and find the different options that are available.

Supplemental Security Income and Medicaid

- Also known as SSI
- You can apply for Medicaid along with SSI so that some finances and insurance are taken care of.
- If you have DSPD, you can have Medicaid, but you don't receive Supplemental Security
- Starts again when your child is 18. You can once again have all your paperwork and things ready to go for when your child turns 18.
- Takes a lot of paperwork that looks a little daunting at first, but it's not as bad as it looks
- Just go on-line and fill out an application and you'll receive an email.
- You'll always be denied the first time when you apply and that is the form you fill out that says you have a disability due to a job accident and your collecting money from the times you've contributed through your work. Your child will be denied, because they haven't worked and haven't contributed. That form is SSDI, but you want to fill out the form on SSI
- It is based on the parents' income before the child is 18, but based on their income afterwards and because most of our children don't work, they're on a poverty level and qualify for SSI.
- Charge your child rent:
    - There is a certain monthly amount that you will receive and once your child is 18 you're not financially responsible for them. The maximum amount they receive right now per month is $698. SSI is for people who can afford to take care of themselves that are what we pay our taxes for. If you do not charge them rent they're considering that they have an income and do not need that piece of the monthly allotment. Charge your child around $500 in rent and $150 in food otherwise you may only get a portion of the maximum monthly allotment. If you have a house payment of $2,000 and 4 of you in the house than that is an accurate description of how much your child would pay in rent. If you don't charge enough in rent, they will require you to keep receipts for clothing, food, medication, etc. to qualify for the maximum amount
- You are required to account for the money monthly and fill out a new form each year to re-qualify. You have to show their beginning balance at the beginning of the year, where the money has gone for rent, miscellaneous, & medicine and then show where the account is at now. Your child cannot have more than $2,000 in any type of assets (checking, savings, etc.).
- If you have too much money or forget to fill out the form, they will actually come back and cut off the services. Be looking for those forms in the mail; fill it out and send it in. That's not the difficult part, the difficult part is getting filed and getting the forms in to begin with.
- You need this so you have funding that is not coming out of your pocket

continually to do the things you need to do, maybe to provide them with additional training/schooling, housing, or other things that your child may need.

- Taxes with regards to SSI are not on your taxes they are on your child who is now over the age of 18.
- If they work they can still receive the full allotment, but it can be a little more complicated. There are programs called Ticket-to-Work or a PASS program. They can make x amount of dollars and there is an equation to figure out the amount, but the base amount is there whether they're making a little and getting the remaining balance at SSI or they don't have a job and they're getting the full amount from SSI.
- If you have additional questions just call SSI directly. They can be very helpful walking you through this process.

Transition Programs available through district

- We know what the old transition programs look like. We have been there and were probably some of the ones spreading the bad news, but things have really changed and are getting better. Don't close your doors and your hearts until you have really seen the options that are out there.
- Transition is hard. We need to prepare our students and ourselves for what the next chapter in our lives.
- To help relieve anxiety of students and parents, high school teachers are willing to discuss all options, set up tours of the different facilities, and walk you through the transition process one step at a time.
- The district's guidelines are that after the student has experienced his or her senior year in high school that they would move on to a post-secondary transition program.
- Post-Secondary transition decisions are data based decisions made on an individualized basis and require a retention process to stay in high school after the senior year.
    - Even after you choose one transition program you can always move and you're not pigeonholed into one place until your student is 22. Students can move along the continuum in either program.
- The individual needs of the students will continue to be addressed at the district led transition programs.
    - DISTRICT LED TRANSITION PROGRAM #1
        - In the last two years it has turned over completely we have participated in both programs and the first one was a joke, but now during this whole transition and being involved in school community council.
        - It's treated like a secondary high school
            - It's an extension to high school, back in the day the option of transition program and high school was not a good one and most parents chose to stay in the high school.
            - It's like going to a junior college. They've graduated, left high school, participating in age appropriate things at their skill level.
            - There is a functioning school community council and parent teacher associations (PTA) with parents who are actively involved in what's the best for the school
        - There will be in one of four different classrooms working on

individual needs from their IEP that fit them.
    - There are students riding the bus and going down to the local university to take classes, they have individual job placements, and continue to work on skills and academics in the classroom.
  - The district and director over special education has invested a lot into the transition program and have stood behind the new young and energetic Principal who has really done a great job.
  - Adult program has been taken out and moved
  - They have more job opportunities
- DISTRICT LED TRANSITION PROGRAM #2
  - The tour was an eye opening experience of all of the changes they have made there.
  - They have recently opened a new wing devoted to these kids who are in between going out into the working world and needing 24-hour care. This helps them to be able to continue to learn and continue to be stimulated, but they may not be ready to go out into the work force and hold down a steady job.
  - The school district has made a major investment over there in creating this new sensory room where students can make some great growth with technology advancements including Smart boards, IPods, using sewing machines and other things.

Vocational Rehabilitation

- Also known as Voc Rehab
- Outside the school system
- It's another government program outside the school system that can help if students are able to hold a job and keep a job.
- District Transition Programs have been having Voc Rehab come to the students' last two IEPs to transition students into that program.
- They also have open houses at ATEC.
- You have a long time to worry about that, haven't had a ton of experiences or good experiences
- It is a resource available; don't discount it because some may not have had a good experience with it. Some have good experiences, some have bad, so just try it out and see if it works for you.

Other Ideas Shared Outside the 10 Transition Topics Mentioned Above:

- On-going Clinical Studies at Universities and Medical Institutions in the state and across the nation
  - Provided Brain Mapping
  - Participated in Medication Studies
  - A 3rd of the studies have had an impact on child
  - There was No Cost to us, just questionnaires and having our blood drawn
- Special Needs trusts: Find attorneys who do lots of them and find out all of the information before deciding if you want to do them.