

The University of Southern Mississippi

DETERMINING CONTENT VALIDITY FOR THE
TRANSITION AWARENESS AND POSSIBILITIES SCALE (TAPS)

by

Melynda Burck Ross

Abstract of a Dissertation
Submitted to the Graduate School
of The University of Southern Mississippi
in Partial Fulfillment of the Requirements
for the Degree of Doctor of Philosophy

December 2011

ABSTRACT

DETERMINING CONTENT VALIDITY FOR THE TRANSITION AWARENESS AND POSSIBILITIES SCALE (TAPS)

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The Transition Awareness & Possibilities Scale (TAPS) was crafted after an extensive review of literature was conducted to find research that examined and described specific aspects of transition programming: inputs, including supports and skill instruction; processes, including parent and support provider perceptions of the transition experience; and outcomes, including quality of life and traditional, quantitatively-measured outcomes. Once developed, the TAPS will allow a teacher or transition coordinator to know what information a family is lacking about transition planning and adult service options for students with disabilities who need extensive or pervasive supports.

In this research, content validity was used as a collective term to describe (a) wording clarity (b) content domain representativeness, and (c) content domain sampling adequacy. To establish content validity for the TAPS, ten experts who had backgrounds in the overall content area of special education and transition, specific niche areas (i.e., subtopics of inputs, processes, or outputs), as well as survey design were consulted. The reviewers were asked to rate the items on the TAPS using a researcher-created instrument. This allowed for the collection of both quantitative data and additional commentary. For each section, reviewers were asked to give standardized ratings for the

representativeness of the content domain and wording clarity for both questions and answer choices. These were rated separately, each on four-point scales, with a rating of “4” indicating that no revisions were necessary, and a rating of “1” indicating that the item was not representative or not clear. From these scores, the average pairwise agreement was then calculated to determine the amount of absolute agreement between reviewers. The average pairwise agreement consistently revealed good agreement between the reviewers in all areas except wording clarity. The reviewers’ comments addressed six concerns: consistency, clarifications, additions, omissions, formatting, and relevancy. It was this qualitative data that provided the most insight to the ratings and made sense of the numbers (i.e., because the end goal is to revise the TAPS, the reviewers’ comments were more useful than statistics that simply indicated the reviewers’ disagreement).

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December 2011

DEDICATION

This work is dedicated to the loves of my life: Chris, Avery, and Presley. We are Team Ross, and together we have earned this degree by various contributions and forfeitures. Soli Deo Gloria!

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My deepest appreciation extends to the reviewers who examined the Transition Awareness & Possibilities Scale. The feedback that Dr. Robert Baer, Dr. Erik Carter, Dr. Sarah Geenen, Dr. Kyeong-Hwa Kim, Dr. Craig Michaels, Dr. Lynn Newman, Dr. Dawn Rowe, Dr. David Test, Dr. Audrey Trainor, and Dr. Michael Wehmeyer provided was thorough and invaluable. Additional thanks to Dr. Jim Gardner for allowing the *Quality Measures 2005*® to be included.

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Dr. Linda McDowell profoundly influenced my understanding of providing supports, facilitating transition, and building families' capacities. I cherish Linda; she became my friend, second mother, and life coach. She knows what really matters and uses her powers for good. Indeed, most of us would do well to have half of her work ethic and humility. Linda once (twice?) told me: "Don't leave the doc program with the desire to impress people, but with the desire to influence people." Done.

I also wish to thank Dr. Elgin Hillman, Dr. Kyna Shelly, and Dr. Phil Wilson for sharing guidance and wisdom over the course of this project. Dr. Hillman's insight significantly influenced the development of the expert review form. Dr.

Shelley patiently refined my understanding of survey design. Dr. Wilson most graciously shared his expertise across state lines, provided fresh perspective, and asked probing, thoughtful questions. This research benefitted from these individuals, along with Drs. Filce and McDowell, understanding my vision for the TAPS and skillfully redirecting me when my methods needed refining.

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Chris, my husband, has held our family together and fed and watered our children these long years. He was at my first graduation, and now my last. He has loved me since high school when I was, indeed, a very different creature. We have traveled a long road together and became best friends along the way. He keeps me grounded without clipping my wings, and lets me aloft when I need to fly. I am grateful for his unwavering selflessness and never-ending gifts of Junior Mints.

LIST OF TABLES

Table

1. Reviewer Ratings of the Wording Clarity for Section A: Demographics	178
2. Ratings of Absolute Agreement by Ten Expert Reviewers	178
3. Ratings of Absolute Agreement by Expert Reviewers for Section B	183
4. Reviewer Ratings of the Wording Clarity for Communication Frequency Interval	184
5. Reviewer Ratings of the Wording Clarity for Purposes of Communication	185
6. Reviewer Ratings of the Wording Clarity for Sources of Curricular Information	188
7. Expert Reviewers Agreement for Section C: Content Area Knowledge and Skills	191
8. Expert Reviewers Agreement for Section D: Adult Services and Supports	194
9. Expert Reviewers Agreement of Content Area Knowledge and Skills Using Multiple Methods for Intraclass Calculation	204
10. Expert Reviewers Agreement of Services and Supports Using Multiple Methods for Intraclass Calculation	205
11. Expert Reviewers Pairwise Agreement for Representativeness by Section/Subsection	207
12. Expert Reviewers Pairwise Agreement for Wording Clarity by Section/Subsection	208
13. Expert Reviewers Suggestions for Improving Sampling Adequacy	209

.LIST OF ILLUSTRATIONS

Figure

1. Quality Measures 2005®	33
2. Reviewer format for Questions 1 and 2 and Question 3 stem	169
3. Reviewer format for Questions 15-86 (Sections C & D)	170
4. Revised Question B that clarifies the relationship of the respondent with the young adult	212

TABLE OF CONTENTS

ABSTRACT	ii
DEDICATION	iii
ACKNOWLEDGMENTS	iv
LIST OF TABLES	vi
LIST OF ILLUSTRATIONS	vii
CHAPTER	
I. INTRODUCTION.....	1
Theoretical Framework	
Statement of the Problem	
Purpose of the Study	
Limitations	
Delimitations	
Assumptions	
Definitions of Key Terms	
Summary	
II. REVIEW OF LITERATURE.....	20
Source Collection and Delimitation	
Shifting Perceptions of Individuals with Disabilities	
Current State of Transition and Adulthood for Individuals with Significant Disabilities	
Community Participation and Self-Determined Housing Options	
The Evolution of Disability Law, Special Education, and Parent Participation	
Evidenced-Based Programming	
Student-Focused Planning	
Student Development Resulting in Successful Adult Outcomes	
Collaborative Service Delivery	
Program Structure and Policies	
Family Involvement, Empowerment, and Training	
Collaboration	
Conclusion of Review of Literature	
Bridging the Knowledge Gap	

III.	RESEARCH DESIGN AND METHODOLOGY.....	155
	Research Questions	
	Organization of the Chapter	
	Description of the Draft Instrument	
	Selection of Transition Content Experts	
	The Expert Review Form	
	Method of Quantitative Analysis	
	Conclusion	
IV.	ANALYSIS OF DATA.....	171
	Research Questions	
	Organization of Data Analysis	
	Findings in Section A: Demographics	
	Findings for Section B: Teacher-Parent Communication	
	Review of Section C: Skills and Knowledge—	
	Sources of Information	
	Representativeness of Section C: Skills and Knowledge—	
	Content Areas and Skills	
	Wording Clarity and Formatting of Section C: Content Areas and Skills	
	Review of Wording Clarity and Formatting for Section D:	
	Adult Services and Supports	
	Review of the Overall Content Coverage and Format of the TAPS	
	Chapter Summary	
V.	FINDINGS, CONCLUSIONS, AND IMPLICATIONS.....	194
	Summary of the Study	
	Findings	
	Conclusions	
	Implications	
	Revisions to Section B: Teacher-Parent Communication	
	Revisions to Transition Programming Section C: Skills and	
	Knowledge—Sources of Information	
	Revisions to Section C: Skills and Knowledge—	
	Content Areas and Skills	
	Revisions to Section D: Adult Services and Supports	
	Formatting Revisions to the Entire Instrument	
	Future Research	
	Summary	
	APPENDIXES	225
	REFERENCES.....	255

Chapter I

Do not ever let anyone or any movement—whether anti–public education zealots, presumed legal eagles, bosses above you who may have grown weary and callous, private school program hustlers, or just all-around naysayers—drive a wedge between you and the parents. Your partnership with the parents is sacred; it is the very heartbeat of the educational enterprise and the very soul of effective special education for yours and their special children. Without your partnership, there is nothing, as the saying goes, “but the sound of one hand clapping.”

(Hulett, 2009, para. 42)

In order to collaborate with teachers, doctors, and social service providers, parents of individuals with disabilities are expected to have initiative, be knowledgeable and competent with regard to their children’s education and healthcare needs, and make decisions in the best interests of the child. According to Trainor (2010), engaging in advocacy efforts on behalf of their children sometimes leads parents to adopt paradoxical roles as both collaborators and combatants with teachers, administrators, and other service providers. For some parents, acquiring information, navigating social services, and collaborating with professionals comes naturally, but other parents struggle to procure supports and services (Bjarnason, 2002; Murray, Christensen, Umbarger, Rade, Aldridge, & Niemeyer, 2007; Stoner, Bock, Thompson, Angell, Heyl, & Crowley, 2005).

Some parents of students with disabilities claim that the special education and adult services processes are difficult to navigate: accessing information is

difficult, available services are unadvertised, and eligibility requirements are confusing and inconsistent (Chambers, Hughes, & Carter, 2004; Hanson, 2003; Kim, Lee, & Morningstar, 2007; Kim & Morningstar, 2005; Stoner & Angell, 2006; Townsley, 2004). This results in the families having a “knowledge gap” that becomes especially significant during the transition from high school to adult services. Many families do not know what options exist in the community for employment, leisure activities, post-secondary education options, or independent living (Goupil, Tassé, Garcin, & Doré, 2002; Heslop, Mallett, Simons, & Ward, 2002; Tarleton & Ward, 2005). Parents are critical to the entire transition process—from the conception of goals to the realization of successful post-secondary outcomes (Blue-Banning, Turnbull, & Pereira, 2002; Ferguson, Ferguson, & Jones, 1988; Geenen, Powers, Lopez-Vasquez, 2001; Kalyanpur & Harry, 1999; Wagner, Newman, Cameto, Garza, & Levine, 2005). Parents have higher expectations for their children than other members of the transition team (Heslop et al., 2002; Morris, 2002; Beresford, 2004), and the influence and tenacity of the family is usually the significant variable leading to successful employment or independent living outcomes (Hendley & Pascal, 2001; Beresford, 2004). Parents are more empowered, motivated, and encouraged about anticipated adult experiences when involved in the planning process, and as the primary decision makers, it is critical that parents are given the opportunity to obtain the necessary knowledge to make sound decisions to fully represent the best interests of the child within the context of their family (Geeter, Poppes, & Vlaskamp, 2002; Hassazi, Gordon & Rowe, 1985, as cited in Zhang, Katsiyannis, & Zhang, 2002; Kim & Turnbull, 2004; Kraemer,

McIntyre, & Blacher, 2003; Kraemer & Blacher, 2001; Neece, Kraemer, & Blacher, 2009).

The Individuals with Disabilities Education Improvement Act (2004) made it clear that parents (or guardians) are to have decision-making power regarding special education. In IDEIA (2004) and in other regulatory documents, families are given the decision-making power and are encouraged to “participate.” In theory, the possible forms of participation are varied—from passive presence to active advocacy, or even adversarial confrontation (Trainor, 2010). The term “participation” is not qualified in any way. This omission naïvely ignores the breadth of diversity abounding in parents’ beliefs and values regarding rights and responsibilities, and assumes much, in that parents will have the knowledge and skills needed to participate appropriately (Kalyanpur, Harry, & Skrtic, 2000); however, all families have different needs and knowledge levels (Goldfarb, et al., 2010). Repeatedly, parents emphasize that one of the greatest needs for the family is simply information (Ankeny, Wilkins, & Spain, 2009; Grigal & Newbert, 2004; Smart, 2004; Tarleton & Ward, 2005; Westling, 1997). Ethical guidelines and best practices suggest that professionals should practice family-centered care by giving family members information and guiding families through any learning processes that must occur (Allen & Petr, 1996; American Nurses Association, 2001; Cooney, 2002; Council for Exceptional Children, 2010; National Association of Social Workers, 1999; Riddell, Wilson, & Baron, 2001). The intention of providing family-centered care is to meet the needs of the individual while concurrently educating and empowering the family. However, further research is needed to determine the factors that result in some

parents developing self-determination and increasing knowledge, while others remain strictly reliant on professionals.

Theoretical Framework

Role expectations in our society run deep. In the American education system, traditional roles have been that teachers teach, students learn, and parents volunteer and support teachers when asked. Although the concept of special education upsets traditional role expectations by involving parents on a deeper level, many of the participants themselves—educators, administrators, and parents—have not yet let go of these traditional role expectations. To deviate from the traditional role of parent requires knowledge of the law and a willingness to take on an advocacy or proactive role, as well as the ability to obtain information and knowledge, and this requires cultural and social capital—knowing what one needs to know, how to find it, and whom to ask. It is parents with social, cultural, and economic capital who have been able to circumvent traditional role expectations to advocate on behalf of their children and secure a quality (special) education (Horvat, Weininger, & Lareau, 2003; Lareau & Horvat, 1999; Trainor, 2010). Therefore, parents dispossessing social or cultural capital are at a significant disadvantage from other parents.

This researcher contends that the combined effects of (cultural and social) capital theory and role theory, may be useful in explaining the ability of some parents to advocate and garner the appropriate knowledge to affect individual services and systems-wide change, as well as the inability of other parents who may be unaware, unempowered, or unable to affect the same influence to improve their children's individual educational experiences. Social

capital is created as relationships and social networks are formed that afford the exchange of information and cultural, economic, and (additional) social capital (Bourdieu, 1986); having more individuals from which to draw expertise or ask questions yields more knowledge (Coleman, 1988). Cultural capital refers to the knowledge, skills, dispositions, or education that an individual has that inform the way a person thinks and acts (Bourdieu, 1986). Possessing cultural capital yields (direct) knowledge, but possessing social capital also yields (indirect) knowledge, in that the individual has family, friends, and acquaintances that contribute both their cultural capital and expert knowledge.

Cornwell and Cornwell (2008) examined access to expertise as a form of social capital. Those who possess highly developed skills or techniques, and can transmit these skills or techniques to others are experts (Gerver & Bensman, 1954, as cited in Cornwell & Cornwell, 2008). Individuals with specialized knowledge are naturally stratified in the top SES of society, as (a) people who are contracted for their expertise are more easily procured by those with economic capital, and (b) experts themselves are generally from a higher status and possess more cultural capital, and so socialize with like people (principle of homophily). Having expert contacts can improve individual outcomes; make knowledge and information available, or comprehensible (as in the case of legal or medical information); or provide political influence or legal options (Cornwell & Cornwell, 2008). Therefore, in the case of special education, it is the parent who has a large social network who is most likely to be aware of special education law, parent advocacy, and student rights.

This application of capital theory is congruent with other research that has shown that students from single-parent families and lower SES have significantly worse academic outcomes than other students (Arroyo, Rhoad, & Drew, 1999; de Boucker & Lavalee, 1998; De Haan & MacDermid, 1998; Knighton & Mirza, 2002; Ryan & Adams, 1999; Walpole, 2003). The correlation between low SES and poor educational outcomes is often attributed to the lack of cultural capital of the students, but recent research suggests that cultural capital is not easily dissected from social capital (Cornwell & Cornwell, 2008; Horvat et al., 2003; Trainor, 2008, 2010). Although single-parent families tend to have much lower incomes than two-parent families, social capital is also less available for single-parent families because there is only one adult establishing a social network; in addition, these families tend to move more often and have to re-establish relationships (McLanahan & Sandefur, 1994, as cited in Portes, 1998).

Trainor (2010) found that parents that had limited access to disability-specific or special education resources were usually eligible for free and reduced lunches. Parents who were in the lower SES strata also often had unsuccessful advocacy efforts that relied heavily on sharing personal knowledge of their individual children. Contrary to this, parents who supplemented intuition and child-specific knowledge with research and became disability experts themselves were likely to be successful advocates (Trainor, 2010). In these instances, both cultural capital (knowledge, attitudes, and skills) and social capital (relationships, group membership, and networks) contributed to the success of the advocacy efforts.

Two elements critical to the understanding of this application of capital theory are field and habitus. Field is the space and time in which interactions occur and the “unspoken social rules” under which people operate. Habitus is the values or dispositions that primarily result from childhood rearing and are reflected in the worldview and paradigms of the individual. These elements parallel with role theory and its applications in parent-teacher interactions. Habitus, like role expectations, are often acting under the radar of the actors, unquestioned and unexamined, but are nonetheless significant (Bourdieu, 1986). For example, even when parents possess large amounts of capital, they are sometimes challenged when advocacy efforts are incongruent with teachers’ worldviews (Horvat et al., 2003; Lareau & Horvat, 1999).

Often, “capital begets capital” (Trainor, 2010, p.158). In other words, the various types of capital—economic capital (money), cultural capital (knowledge and skills), and social capital (relationships)—function together to create more of the same (e.g., “the rich get richer”). According to Bourdieu (1986), different forms of capital can be exchanged for each other, but ultimately because those with the most capital make the rules and control the fields, such as schools, the status quo is maintained in acts of social reproduction. For example, a family who is new to a town will be unfamiliar with the culture of the school (i.e., lacking school-specific cultural capital). If the parent does not know many people in town (i.e., lacks social capital) the student will be, for the most part, on his or her own at school. However, as soon as the parent meets several neighbors or joins a social organization (e.g., country club), the parent has built social capital and now may exchange some of the social capital for school-specific cultural

capital. Contrary to this, the parents of lower SES families are usually too busy working to join any of these types of organizations; these parents are trying to acquire economic capital to make ends meet.

Social capital offers school-specific benefits to families in the areas of conveyance of information, influence and control (over people or decisions), and social solidarity (Horvat, et al., 2003; Lareau & Horvat, 1999; Sandefur & Laumann, 1998, as cited in Goddard, 2003). Families with capital often intervene so their children get assigned to teachers perceived as more effective, address issues perceived as unjust toward students, and receive more quality individualized special education services (Horvat et al., 2003). Legislation and school structures are established with equity of services as the goal, but often this is not achieved because of the human element (Trainor, 2008).

As expected with this amalgam of capital and role theories, the parents who cling tightly to role expectations and lacked significant social capital, did not “rock the boat.” Those parents did not advocate for their child’s rights, cite legal precedents, or follow-up when services were not being delivered (Trainor, 2010). Along the same vein of “capital begets capital,” parents who advocated the most and received better than average healthcare and related services recognized that their economic capital afforded them these “luxuries.” Relief from the burden of additional costs associated with extra supports is often simply a result of invested time required to build the relationships in order to advocate on behalf of a child, in addition to the knowledge of educational systems and special education (Trainor, 2010, p.44).

Statement of the Problem

Overall, young adults with disabilities are graduating less, and then faring much worse than their typical peers in the areas of employment, post-secondary education, and independent living (Benz, Lindstrom, & Yovanoff, 2000; Condon & Callahan, 2008; Hart, Zimbrich, & Ghiloni, 2001; Johnson, Stodden, Emanuel, Luecking, & Mack, 2002; Neubert, Moon, & Grigal, 2004; Newman, Wagner, Cameto, & Knokey, 2009; NOD, 2004; Powers, Gil-Kashiwabara, Powers, Geenen, Balandran, & Palmer, 2005; Rusch & Wolfe, 2009). In testimony before the Pennsylvania House of Representatives' Committee on Transition Issues for Individuals with Autism, McAndrews (2008) asserted that many transition services required by *IDEIA* (2004) are not being implemented because parents do not know to request them at all, or do not follow-up and monitor implementation of the student's program. Several researchers have captured the voices of young adults, parents, and professionals who describe the faulty collaboration between parents and special educators and the resultant gaps in transition services (e.g., Ankeny et al., 2009; Antle, Montgomery, & Stapleford, 2009; Beresford, 2004; Bjarnason, 2002; Cooney, 2002; Michaels & Ferrara, 2005; O'Connor, 2008; Swain & Walker, 2003). Perhaps the dismal postsecondary outcomes common to so many adults with disabilities are simply a logical consequence to poor transition planning and implementation.

Although parent participation and the requisite knowledge is important across exceptionalities, when students have disabilities requiring extensive or pervasive supports it is especially important, as these students will require the most supports and services throughout adulthood (Luckasson et al., 2002).

These students also have significantly poorer transition outcomes; less than 8% of students with significant disabilities leave high school employed, enrolled in a post secondary institution, or living independently (Condon & Callahan, 2008; Harris & Associates, Inc., 2000; NOD, 2004). Ideally, parents and transition team members should collaborate so that students with disabilities are provided an appropriate education based on an individual transition plan that drives the curricula and instruction. When this occurs, successful adult outcomes are more likely to result.

For researchers seeking first-hand accounts of collaboration between parents and special educators and the perceived gaps in services, there are qualitative pieces in the literature that provide rich data (e.g., Ankeny et al., 2009; Antle et al., 2009; Beresford, 2004; Bjarnason, 2002; Cooney, 2002; Michaels & Ferrara, 2005; O'Connor, 2008; Swain & Walker, 2003); however, narratives cannot be compiled, aggregated, or manipulated by a single school district looking for their own trends. Further, it is unlikely that a school district will invest the time for qualitative interviews with every family. What is also uncertain is the degree of trust between teachers and families, and how this would affect the families' ability to give honest answers.

After transition, parents and students will no longer be the school's responsibility; hopefully, the school district will have prepared the family and given them information, explained options for the future, and empowered and educated the family (Johnson, 2004). However, there is no instrument in the literature that allows a teacher or transition coordinator to know what information a family is lacking about transition planning and adult service options. If the

family does not know what to ask, or if the school is not forthcoming with information, there is a strong possibility that the parents and student will miss out on valuable opportunities to build skills, determine eligibility (and get on waiting lists), and prepare for the transition to adult services.

Purpose of the Study

The ultimate goal for the Transition Awareness & Possibilities Scale (TAPS) is to provide a guide for families regarding areas where their transition programming knowledge may be lacking and to assist in identifying priorities for the next parent-teacher conference or IEP/ITP meeting. The TAPS may also be used on a district-wide level for program evaluation. As schools are charged with collaborating with families and educating parents to build their capacity to support their child, collective results from this instrument will indicate to schools how well they are educating family members and/or if teachers and school district personnel are communicating effectively with parents about (a) skill instruction; (b) potential adult needs, and/or (c) adult service options. The TAPS may provide direction for the school to provide better curricula and/or improved instruction of functional skills, improved and/or targeted communication with families, and facilitate interagency collaboration between school districts and adult services. By providing a comprehensive, valid, reliable instrument, schools and families will improve communication and transition planning, as family members' increased knowledge and empowerment will ultimately result in better transition outcomes and quality of life for adults with disabilities.

The Transition Awareness & Possibilities Scale was crafted after an extensive review of literature provided a comprehensive framework for the

survey. In essence, three separate reviews were conducted to find research that examined and described specific aspects of transition programming: inputs, including supports and skill instruction; processes, including parent and support provider perceptions of the transition experience; and outcomes, including quality of life and traditional, quantitatively-measured outcomes. The results were then synthesized to form a comprehensive document that laid the foundation for the TAPS. Because such a vast breadth of research bolstered the TAPS, utmost care needed to be taken to ensure the comprehensiveness of the document was balanced with usability and relevance for families and schools.

Thus, the purpose of this study was to establish the content validity for the Transition Awareness and Possibilities Scale through an extensive review process with experts who had a background in the overall content area, specific niche areas (i.e., subtopics of inputs, processes, or outputs), as well as survey design. A panel of expert reviewers was chosen to rate TAPS items on wording clarity, content domain representativeness, and comment on the overall construction and format of the TAPS. Reviewers were specifically chosen for content expertise; however, expert reviewers can also identify problems with survey construction that, if corrected, will increase the quality of the survey data (Olson, 2010). This was the first step in the process to determine the reliability and validity of the instrument so that schools and families can use the TAPS to determine parents' knowledge of transition programming—including how to procure adult supports and services when necessary. This instrument will also measure parents' satisfaction with communication and collaboration.

Research Questions

1. What is the technical adequacy of the *Transition Awareness & Possibilities Scale* with regard to (a) wording clarity (b) content domain representativeness, and (c) content domain sampling adequacy?

Limitations

DeMaio and Landreth (2003) cited several limitations to expert reviews that apply here (DeMaio & Landreth, 2003, as cited in Olson, 2010):

1. Some expert reviewers spent more time on the review than others.
2. Reviewers may have had different expectations for the task (e.g., helping a graduate student versus contributing to the development of an instrument that will be viable and eventually used in the field).
3. Reviewers may have had different expectations about what constitutes a “good” or “bad” question.
4. Reviewers have different amounts of experience and training in survey methodology and questionnaire construction, thereby resulting in contradictory feedback.
5. Additionally, statistical analysis was somewhat limited due to the small sample size (n=10).

Delimitations

The following delimiters were applied to this research:

1. The primary aim of this research is to establish content validity of the TAPS using a panel of expert reviewers. As such, all reviewers were purposively selected professionals.
2. The items included on the TAPS were limited to areas of transition

programming supported by published research or additions by the expert reviewers.

3. The expert reviewers were given 4 weeks to review the TAPS.
4. The reviewers were not told the identities of the other reviewers.
5. The reviewers did not see other reviewers' feedback.
6. The reviewers did not have additional opportunities to edit or add to their comments after submitting reviews.

Assumptions

For the purpose of this study, two assumptions were made:

1. Respondents answered candidly.
2. Respondents reviewed the TAPS individually.

Definitions of Key Terms

Child with a Disability – is

a child with mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (referred to in this title as “emotional disturbance”), orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and who, by reason thereof, needs special education and related services. (20 U.S.C. 1400 § 602)

Fair Labor Standards Act – is a statute passed in 1938 that created standards for minimum wage and overtime pay, but also included provisions for the 14(c) Special Wage Certificate exception to the minimum wage standard. (29 U.S.C. § 214[c])

Individuals with Disabilities Education Improvement Act of 2004 – is the reauthorization of the Individuals with Disabilities Education Act (IDEA, 2004, PL 108-446). The reauthorized federal law mandated free and appropriate public education for all students; included in the law are specific requirements for transition planning. This law will be referred to in this document as IDEIA.

Individual Education Plan (IEP) – is a written statement required for each child who attends public school and receives special education and/or related services. The IDEIA requires specific information to be included in each child's IEP including present levels of performance, location of special education services, type of services provided, frequency and duration of services, disability (subclassification entitling the student to special education), learning goals, the student's educational placement, and provision of other related services established under IDEIA.

Individual Transition Plan (ITP) – is the section of the IEP that outlines transition planning towards adult outcome goals. Includes instructional goals, programming, and services necessary for the student to reach those goals.

Local education agency (LEA) – is

A public board of education or other public authority legally constituted within a State for either administrative control or direction of, or to perform a service function for, public elementary or secondary schools in a city, county, township, school district, or other political subdivision of a State, or for a combination of school districts or counties as are recognized in a State as an

administrative agency for its public elementary or secondary schools. (20 U.S.C. § 1401[19][A])

Parent – is

A natural, adoptive or foster parent of a child (unless a foster parent is prohibited by State law from serving as a parent); a guardian (but not the State if the child is a ward of the State); an individual acting in the place of a natural or adoptive parent (including a grandparent, stepparent, or other relative) with whom the child lives, or an individual who is legally responsible for the child's welfare, or an individual assigned under law to be a surrogate parent. (20 U.S.C. § 1401)

Plans for Achieving Self Support (PASS) – is a program from Social Security Insurance intended to help individuals with disabilities save part of their income without losing SSI benefits. Eligible individuals set aside money in PASS accounts to pay for items or services needed to achieve a specific work goal.

Postsecondary Education – is school or training beyond high school. This can mean traditional college or university, or dual-enrollment. PSE programs allow young adults with disabilities to build vocational skills, expand social networks, learn academic material, and bolster independence and self-determination in an age-appropriate environment while still receiving IDEIA-funded services (Grigal, Neubert, & Moon, 2002; Griffin, McMillan, Hodapp, 2010; Hart, Grigal, Sax, Martinez, & Will, 2006).

Quality of Life – is comprised of variables that are meaningful to human beings despite age, gender, socioeconomic and cultural differences: availability

of shelter, food, and clothing; desired autonomy; and meaningful relationships with others (Sheppard-Jones, Thompson Prout, & Kleinert, 2005). Several theories are built upon Schalock & Verdugo's (2002) review of literature that described eight quality of life indicators: emotional well-being, interpersonal relations, material well-being, personal development (e.g. pursuing and achieving one's goals), physical well-being, rights, social inclusion in one's community, and possessing self-determination.

Segregated Employment – is any type of work environment that congregates individuals with disabilities apart from the general public. The most common type is the sheltered workshop, also called industries, industrial workshops, affirmative industries, training workshops, vocational workshops, and rehabilitation workshops (Migliore, Mank, Grossi, & Rogan, 2007).

Self-Determination – is a combination of skills, knowledge and beliefs that enables a person to engage in goal-directed self-regulated behavior (Field, Martin, Miller, Ward, & Wehmeyer, 1998), or, “the ability to identify and achieve goals based on a foundation of knowing and valuing oneself” (Field & Hoffman, 1994, p. 164).

Social Capital – is possessing of relationships and networks that afford the exchange of cultural and economic capital, as well as information and additional social capital (Bourdieu, 1986), or the assets (the knowledge and information) resulting from the network.

Special Education – is specially designed instruction, at public expense, in various locations that may include general education classrooms, hospitals, and self-contained locations (IDEIA, 2004).

Supported Employment – is employment that occurs when initial or ongoing supports are provided that facilitates an individual’s success in an integrated, competitive work environment. Individuals who benefit from supported employment are those who would otherwise be unable sustain employment due to the incompatibility of the effects of their disability with the expectations of their chosen occupation.

Transition – is the term used to describe the life events that occur as young adults move from parent or guardian care in school-focused environments to independent adult living with work or post-secondary school as the focus (Halpern, 1994). Beginning no later than age 16 and updated annually thereafter, a child is educated not only for future employment and independent community living, but also with the prospect for continued, lifelong learning that is “results-oriented” delineated in terms that are measurable (20 U.S.C.A. § 601[d][1][A]).

Transition Services – are “[a] coordinated set of activities for a child with a disability;” learning that is results-oriented and improves academic and functional achievement (20 U.S.C.A. § 602[34][d][1][A]).

Conclusion

Young adults who transition from high school often have disappointing outcomes. The reality of adulthood does not match the promises of transition planning. Although parents have decision-making power, school districts control funding, and, despite implications in IDEIA and codes of ethics, professionals also usually have a monopoly on knowledge, as well. The preceding chapter presented the gap in the literature, a statement of the problem, and concluded

by defining terms. Chapter Two will present an overview of relevant literature—specifically, the history of special education and legislation, descriptions of transition programming commonly found in efficient and effective transition programs, and will conclude with parent narratives regarding the knowledge gap and parent perceptions of school-home collaboration. Chapter Three will outline the method for establishing the content validity of the TAPS instrument.

CHAPTER II

REVIEW OF LITERATURE

The overarching goal of educational systems is to prepare individuals to be contributing members of society (Brown, Farrington, Suomi, Ziegler, & Knight, 1999). Although all states mandated compulsory education by 1918, individuals with disabilities were not guaranteed an opportunity to have a free, appropriate public education (such was provided to all other citizens) until 1973. However, even after educational rights were provided, children with disabilities continued to experience poor educational outcomes that yielded similarly poor adult outcomes (Beresford, 2004; Blackorby & Wagner, 1996; Hughes, 2009; Whittenburg, Golden, & Fishman, 2002). Thus, in 1997, the amendments to IDEA included an increased focus on transition planning for students with disabilities. Since that time, there have been many changes in the services provided and how the effectiveness of those services is measured. This chapter presents a comprehensive review of the literature relating to best-practice programming for transition to adult service programs, outcome indicators of successful transition to adulthood for young adults with significant disabilities, the current state of transition outcomes, and parent perceptions of the transition experience. A discussion of shifting perceptions of disability over time is also provided, highlighting the evolution of disability law and mandated special education, and the eventual legislation of parent participation. Valued practices that are found in exemplary transition programs are then described. The review of the literature also examines current outcome trends for young adults with significant disabilities and examines the oft-cited barriers for implementing

“best”-practices and the actual practices that result. Parents’ perceptions and concerns during the transition process are then presented prior to the conclusion of the review.

Source Collection and Delimitation

The reviewed literature is primarily peer-reviewed articles and texts associated with special education, transition from secondary school to adult services, and parent-professional collaboration. The topic is such that multiple perspectives—that of researchers, practitioners, policy-makers, and families—are relevant and, therefore, included. This is an exhaustive review of literature with selective citation (Cooper, 1988). Empirical research reports, state and federal laws, and qualitative interviews with parents regarding transition were examined and comprise the bulk of the review literature. Conference papers and self-published electronic documents have not been included in this review.

It was appropriate and necessary to include secondary sources to develop a broad framework for understanding the evolution of special education and adult services, to explore parent and professional relationships, and to better understand the pragmatic consequences of these interactions. In the rare instance that a trade magazine article was widely circulated among researchers, distributed to pre-service teachers, or otherwise garnered the researcher’s attention, it merited consideration. If the author’s expertise could be confirmed by evaluating other (peer-reviewed) publications, the article was included.

The University of Southern Mississippi’s ANNA catalog was also searched for any texts that may have significant ties to the key descriptors (“disability,” “transition,” “parents,” “teachers,” “adult services,” “knowledge,”

“special education,” “functional skills,” “curriculum,” and “parent knowledge”).

Additional resources also came from graduate coursework and texts, professional conference publications, and private organization publications and marketing materials.

The bulk of the primary and secondary sources included in this review of literature came from peer-reviewed articles, published from 2000-2011 that were retrieved from several databases: EBSCOhost Electronic Journals Service, Education Full Text (Wilson), ERIC (EBSCO version - 1966-Present), Google Scholar, JSTOR, and the Social Sciences Citation Index. Because of the multifaceted nature of this review of literature, there were multiple searches conducted in each database with various combinations of the key words “disability,” “transition,” “parents,” “teachers,” “adult services,” “knowledge,” “special education,” “functional skills,” “curriculum,” and “parent knowledge” in titles and abstracts of articles.

Several delimiters were then used to determine appropriate literature to be included in the review:

1. Works that focused primarily on young adults with mental illness were omitted.
2. Those that focused exclusively on transition to preschool, elementary, middle, or high school were excluded.
3. Works that solely addressed health care transition were also excluded.
4. Literature that focused primarily on students with learning disabilities or other mild disabilities was omitted.

5. Articles that profiled specific individuals were omitted.
6. Works with the primary purpose of profiling academic or behavioral interventions were omitted.
7. Only literature published in English was included.

After these parameters were established and the database searches were exhausted, the author also reviewed the reference lists of the previously selected articles, and retrieved other potentially relevant works that had not appeared in previous searches.

Shifting Perceptions of Individuals with Disabilities

Throughout history, people with disabilities have been perceived with varying degrees of worth: valued by society as entertainers, implicated and condemned as criminals, and thought to have been touched by the hand of God (Adams, 1997; Reiser, 2005). In the Greek city-state Sparta, parents were legally obligated to abandon malformed or sickly infants. Aristotle decreed, "...let there be a law that no deformed child should live" (Aristotle, 350 B.C.E./1984, p. 169). From the Middle Ages to the Renaissance, adults with disabilities were exploited as court jesters, locked up in leper colonies known as Cities of the Damned, and placed in cages to entertain passers-by and limit mobility (Pfeiffer, 1993; Reiser, 2005). Confucius and Zoroaster both proclaimed that people with disabilities were "Children of a Caring God" (The Minnesota Governor's Council on Developmental Disabilities, n.d., para. 2); however, Martin Luther strongly disagreed and proclaimed that individuals who had disabilities were possessed by Satan and should be drowned in the nearest river (Reiser, 2006).

During the 17th and 18th Centuries, influential people began to perceive people with disabilities differently (Beirne-Smith, Patton, & Kim, 2006), and during the Enlightenment, influential thinkers such as John Locke and Jean Jacques Rousseau determined that persons with intellectual disabilities were capable of learning. Philip Pinel's claim that the mentally ill were diseased, rather than sinful or immoral, evolved into the medical model of disability and was the catalyst for the rise of institutions (Pfeiffer, 1993). In the 1840s, the first public institutions were created to train and teach in accord with the medical model belief that people with disabilities needed to be cured or rehabilitated. However, within a generation, institutions originally designed to serve as temporary training facilities began assuming a custodial role--no longer functioning to rehabilitate patients, but to segregate "unteachable idiots" and "retardates" from the rest of society (Beirne-Smith, et al., 2006; Pfeiffer, 1993; Wehmeyer, Bersani, & Gagne, 2000).

The characterization of individuals with disabilities then continued to decline: people with mental retardation were considered menaces and the suspected cause of societal ills including crime, poverty, and promiscuity. Individuals with disabilities were considered immoral, evil, or genetically flawed and treated like sub-human creatures to be feared and avoided (Wehmeyer, et al., 2000). In early twentieth-century America, these perceptions were supported in legislation by sterilization laws (Beirne-Smith et al., 2006; Pfeiffer, 1994) that were upheld as Constitutional by the Supreme Court in *Buck v. Bell* (1927). Many European nations also had sterilization laws, and people with

disabilities were among the first to be executed by the Third Reich during the Holocaust (Reiser, 2006; Pfeiffer 1994).

Deinstitutionalization, Participation, and Community-Inclusion

Americans' attitudes towards individuals with disabilities first began to change after World War I, as soldiers came back from the war as amputees or victims of shell-shock (Pfeiffer, 1993). In 1918, the Smith-Sears Veterans Rehabilitation Act provided for vocational rehabilitation and return to employment of veterans with disabilities; however, civilians later benefited from reauthorizations that made vocational training available to individuals with mental retardation. The Smith-Fess Vocational Rehabilitation Act was reauthorized in 1954, after the Korean War, and in 1965, after the Vietnam War, to reflect new disability paradigms and medical technology.

During the 1940s and 1950s there was a strong national movement, as people began to believe that individuals with intellectual disabilities could be helped (Pfeiffer, 1994), and the resulting advancement of the principle of normalization was an attempt to make "available to all people with disabilities patterns of life and conditions of everyday living which (were) as close as possible to the regular circumstances and ways of life or society," (Perrin and Nirje, 1985, pg. 69).

During this time, the largest group of advocates was parents of children with disabilities who met for social support and shared kinship (Beirne-Smith et al., 2006; Reiser, 2006). These informal parent groups then mobilized and actively pursued civil equality and legislated educational opportunities for their children. Famous Americans such as the Kennedys and Dale Evans spoke

publicly about their children with disabilities, and hometown heroes who returned wounded from war positively contributed to the changing perception of disability (Parent Advocacy Coalition for Educational Rights [PACER] Center, 2004). President Eisenhower spoke about the economic benefits of this paradigm shift in a 1954 message to Congress:

We are spending three times as much in public assistance to care for nonproductive disabled people as it would cost to make them self-sufficient and taxpaying members of their communities. Rehabilitated people as a group pay back in federal income taxes many times the cost of their rehabilitation. (Eisenhower, 1954, para. 31, as cited in Woolley and Peters, n.d.)

Throughout the last half of the 20th Century, institutions and attitudes were again in flux. During the 1960s and 1970s, state institutions returned their focus to rehabilitation and respite, and there were increased opportunities for community service, education, and jobs (Beirne-Smith, et al., 2006; Reiser, 2006). This attitude shift was fueled by increasing activism and self-advocacy: participants in the disability movement modeled their behaviors after the Civil Rights leaders of the 1960s and proposed similar protections and rights for Americans with disabilities. In 1973, Section 504 of the Vocational Rehabilitation Act protected people with disabilities from discrimination in all federal programs (including discrimination by government-funded employers); however, the Department of Health, Education and Welfare only enacted regulations enforcing the legislation in April, 1977, after a ten-city protest by disability-rights activists (Goldman, Lesser, Lincer, Parks, & Salmen, 2003). In the 1980s and

1990s, people with disabilities continued to self-advocate, and in the United States, most states stopped building institutions and a push for community inclusion began (Lakin, 2007).

On the heels of the Olmstead decision, during the first decade of the 21st century many gains were made in the areas of civil rights for individuals with disabilities and disability education. The Developmental Disability Assistance and Bill of Rights Act (DD Act) was reauthorized in 2000 with the stated purpose that individuals with developmental disabilities and their families "...participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs..." (PL 106-402 § 101[b]). In order for these outcomes to happen, the DD Act created state Developmental Disability Councils (DD Councils), Protection and Advocacy Centers (P&As), and University Centers for Excellence (UCEs).

The State Councils on Developmental Disabilities were created to support and engage in individual- and family-directed advocacy, capacity building, and systems-change activities. Thus, DD Councils promote and fund activities that "encourage individuals to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life," (PL 106-402 §121[2]). DD Council-supported efforts prioritize eight areas of emphasis: quality assurance, education and early intervention, child-care, health, employment, housing, transportation, recreation, and quality of life (PL 106-402 § 102[2]). Protection and Advocacy Systems (P&As) were

charged with protecting and advocating the human rights of individuals with disabilities, including the use of legal or administrative actions (PL 106-402 § 143[2][A][i]). The P&As investigate claims of abuse and neglect and, if necessary, proceed with legal action. Especially critical is that P&As act independently from all service-providing agencies; therefore, P&As can advocate, investigate, or pursue legal actions without conflicts of interest. The University Centers for Excellence were specifically created “to provide leadership in, advise Federal, State, and community policymakers about, and promote opportunities for individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life,” (PL 106-402 § 153[a][1]). To that end, The University Centers for Excellence provide interdisciplinary pre-service preparation and continuing education, training and technical assistance for individuals with developmental disabilities and those who support them, and conduct and disseminate research (PL 106-402 § 153[a][2]). Although these sister agencies were each charged with specific tasks, the DD Act also charges each to work together and with other “related councils, committees, and programs” to prevent barriers to services, or enhance systems design or redesign (PL 106-402 § 125[c][5][H]).

In addition to the DD Act in 2000, The Americans with Disabilities Act was reauthorized in 2004 to prohibit different types of disability discrimination, including employment discrimination and telecommunication access restrictions (P.L. 101-336). The Individuals with Disabilities Education Act (IDEA) was also reauthorized in 2004 to more closely align with the No Child Left Behind Act

(NCLB) and increase academic expectations for students with disabilities. The nearly simultaneous passage of these pieces of legislation suggested that the concerns of disability advocates and education reformers had been heard, and the turn of the century had brought forth a more inclusive America.

Theorizing Disability

Currently, no model of disability theory has emerged to be canonized in the literature; advocates, researchers, and other stakeholders continue to have varied experiences, perceptions, and solutions for any number of questions concerning disability issues that may arise. However, there are several commonalities to the multiple models of disability theory that co-exist (Michailakis, 2003; Thomas, 2004; Vehmas, 2004). Theoretically, disability is amorphous—it means different things to different people. The word disability, is now (in American education and social work) synonymous with impairment, and is an acceptable term if used in conjunction with person-first language. Consequently, there are disparate differences between the connotations *having a disability*, as in having a functional impairment of a body system that results in some degree in restricted activity, and *being disabled*, which implies an undesirable state of functioning, or less-than-well-being (Vehmas, 2004). How the concept of disability functions in a society is determined by many complex forces, from archaic traditions and mores to simple numbers—the oft subscribed “majority rule.” Historically, injustices occur when a majority of individuals can identify a subgroup of individuals that do not fit the socially accepted concept of normality. Because social structures—conceptual and tangible—result from the collective assumption of the way the typical members of society function,

disability (as an attitude—not used in lieu of the word impairment) exists within the parameters established by society and operates according to the meanings given to it by the majority (Oliver, 1992; Thomas, 2004; Vehmas, 2004). Silvers (1994) supposed that perhaps it is the minority status, not the disability that is the issue, “they are inferior not because they are too defective, but because they are too few” (as cited in Vehmas, p. 169). To date, the perception of some disability advocates is that despite monumental gains over the past century, the collective attitude of society at large did not adjust as quickly or uncompromisingly as the legislative mandates.

Quality of Life

“...the slipperiest creature in the conceptual zoo,” (Compton, 1997, p. 120, as cited in Lyons, 2010). Much more intrapersonal than the societal response toward disability, but equally amorphous, is the concept of quality of life. Professionals and families agree that education and rehabilitation do influence quality of life; however, there is a lack of consensus of how to operationally define quality of life (Halpern, 1994). Halpern, Nave, Close, & Nelson’s (1986) transition model viewed QOL as a subjective measure for outcomes. Halpern intended QOL to be the natural measure of the success of the transition process and advocated for QOL as a longitudinal measure to quantify outcomes of transition planning and implementation. Halpern et al.’s (1986) model did not become widespread throughout the field, and was seemingly abandoned despite the logic and potential implications.

In 1994, after reviewing the literature, Halpern suggested that quality of life indicators fit into 3 broad domains: physical and material well-being,

performance of adult roles, and personal fulfillment. Since then, more proposed domains have appeared in the literature: interpersonal relations, social inclusion, personal development, physical well-being, self-determination, material well-being, emotional well-being, rights, environment, family, recreation and leisure, and safety and security. According to Schalock (2004), domains are etic (i.e. the same for all people), although emic indicators—personal characteristics and environmental variables—are housed in each domain; as a result, quality of life must be interpreted through a cultural lens.

Measuring Quality of Life. Researchers attempt to objectively measure variables that are meaningful to human beings despite age, gender, socioeconomic, and cultural differences: availability of shelter, food, and clothing; desired autonomy; and meaningful relationships with others (Sheppard-Jones et al., 2005). However, the dichotomy between the objective and subjective indicators that comprise an individual's quality of life, and which category of variables has more influence—both to the individual and to the researcher—is often debated. Some researchers are adamant that quality of life is such an intimate and subjective measure that it has no meaning apart from the experiences of individuals (Taylor & Bogdan, 1990, as cited in McIntyre, Kraemer, Blacher, & Simmerman, 2004). Schalock, Bonham, and Marchand (2000) described six quality of life indicators: having basic needs met, pursuing and achieving one's goals, living a life that is multidimensional and consensually validated, being empowered, social inclusion in one's community, and possessing self-determination. Other models exist in the literature, but often the debate boils down to the weight given to objective (observable) versus

subjective (individually valuable) descriptors (Lyons, 2010; McIntyre et al., 2004).

The Council on Quality and Leadership (CQL) is an international organization with the mission of defining, measuring, and evaluating personal and community-based QOL for people with disabilities and people with mental illness (CQL, 2005). In the 1990s, CQL developed the *Personal Outcome Measures* (POMs) tool to assess the QOL of individuals; these were again refined in 2005. There are 21 POMs, organized in three factors—My Self, My World, and My Dreams (CQL, 2005). While all of the *Quality Measures 2005*® work synchronously, the *Personal Outcome Measures*, *Responsive Services*, and *Community Life* measures are explicitly person-centered and target individuals' emic quality of life variables.

CQL set the standard in measuring QOL, not by striving to comply with regulations and mandates, but rather, by responding to the needs of individuals and families. These needs are assessed and evaluated with a system of synchronized measures known as the *Quality Measures 2005*® (see Figure 1). CQL offers feedback and accreditation to agencies, support groups, and communities that provide support to individuals who have disabilities. An agency or organization wanting to demonstrate the highest effort in promoting QOL for individuals with disabilities can apply for assessment and accreditation in five areas: *Shared Values*, *Basic Assurances*, *Personal Outcome Measures*, *Responsive Services*, and *Community Life*.

<i>Quality Measures 2005SM</i>	
Quality Measures	Factors
SHARED VALUES	<p><i>Shared Values around People</i></p> <ol style="list-style-type: none"> 1. Dignity and Worth 2. Legal and Human Rights 3. Self-Determination and Choice <p><i>Shared Values in the Community</i></p> <ol style="list-style-type: none"> 4. Community Settings 5. Social Capital <p><i>Shared Values of the Organization</i></p> <ol style="list-style-type: none"> 6. Community Partnerships 7. Shared Leadership 8. Continuous Learning 9. Open Communication 10. Continuous Improvement
BASIC ASSURANCESSM	<ol style="list-style-type: none"> 1. Rights Protection and Promotion 2. Dignity and Respect 3. Natural Support Networks 4. Protection from Abuse, Neglect, Mistreatment and Exploitation 5. Best Possible Health 6. Safe Environments 7. Staff Resources and Supports 8. Positive Services and Supports 9. Continuity and Personal Security 10. Basic AssurancesSM System
RESPONSIVE SERVICESSM	<ol style="list-style-type: none"> 1. Person Focus 2. Community Focus 3. Strategic Focus 4. Accountability Focus
PERSONAL OUTCOME MEASURESSM	<ol style="list-style-type: none"> 1. My Self 2. My World 3. My Dreams

Figure 1. Quality Measures 2005®. *Note:* Used with permission by Dr. Jim Gardner. ©The Council on Quality and Leadership (CQL).

The new century signaled CQL's broadening paradigm—from strictly measuring personal outcomes, to focusing on the person in a community context: giving individuals tools to garner social capital, emphasizing formal and informal supports, and, ultimately, using collective resources to build inclusive

communities (CQL, 2005). However, CQL's research showed that agencies continued to have difficulty breaking from conventional paradigms that endorsed site-based social services programs. Beginning in 2010, CQL began field-testing *What Really Matters Initiative*—an intensive protocol for providing technical assistance to organizations that provide services and supports to the elderly, people with mental illness, people with intellectual and developmental disabilities, and people with other chronic illnesses (CQL, 2010). The *What Really Matters Initiative* strives to bridge the gap between philosophy, research, and practice to provide targeted agency-centered planning and technical assistance so that individual agencies and organizations can escape intuitional paradigms and provide person-centered supports within the community.

Parents report using the transition period as a time to reflect on children's strengths, capabilities, and autonomy (Goupil et al., 2002). During this time, families begin to maximize their young adult's independence, prioritize interventions, and devise strategies to better understand and meet the transitioning student's needs (Goupil et al., 2002). In McIntyre et al.'s (2004) research with mothers of children with significant intellectual disabilities, respondents' answers yielded traditional factors that were indicative of a high quality of life: recreation opportunities, employment, self-determined choices, basic needs met, family, and social independence. Throughout the literature, parents' overarching goals for their transitioning children were that the young adults develop a sense of personal fulfillment using their talents and skills, make contributions to their community, and remain safe (Cooney, 2002).

Communication deficits, combined with cognitive disabilities, sometimes make it very difficult to accurately determine the quality of life of individuals with significant disabilities. Most researchers use family members who have intimate knowledge of the individual to act as proxy respondents on survey instruments (Petry & Maes, 2006). Proxy respondents are asked to honestly answer as if they were the individuals with disabilities, even if the answer conflicts with the proxy's own beliefs (Plimley, 2007). However, there are conflicting schools of thought on this method, and some evidence points to little agreement between persons with an intellectual disability and proxies (Cummins, 2002; Heal & Sigelman, 1996). Other studies showed that proxies who were family members had a greater fidelity to the individual's intended answers than unrelated proxy-respondents (McVilly, Burton-Smith & Davidson, 2000). Cummins (2002) theorizes that any responses from caregivers (family or unrelated) are valid only as a reflection of shared life experiences. As the degree of subjectivity of responses increase, there are increasingly lower correlations between self-responses and proxy-responses; therefore, the validity of proxy responses decreases (Cummins, 2002).

Some research has shown that individuals with higher cognitive functioning have higher quality of life (Kraemer, McIntyre, & Blacher, 2003); however, McIntyre et al. (2004) contend that quality of life is likely so subjective in nature that these research findings may be due to how quality of life was measured. Although research is ongoing, the prevailing theory is that presence of a disability does not automatically detract from QOL (Edgerton, 1990, as cited in Lyons, 2010). "Due to the complexity of quality of life, and especially due to

the differences in countenance and experience between the assessors and those being assessed, determining the quality of life for people with profound cognitive disability will probably always rely on very fine judgments and forms of empathy, which are not easily operationalized and put to paper” (Goode & Hogg, 1994, p. 205).

Current State of Transition and Adulthood for Individuals with Significant Disabilities

The preceding section described the complexity that accompanies interpreting quality of life and the variables that comprise it. Semantics aside, what emerges from the literature is that individuals inherently desire a meaningful life that includes pleasurable experiences, satisfying relationships, and contributions to one’s environment (Carruthers & Hood, 2007). Therefore, researchers and transition-focused groups have identified valued outcomes that denote successful transition into adulthood. However, for many valued outcomes, there are few published studies in the literature measuring the impact of the programming and the resulting skill developments or post-secondary outcomes (Test, Fowler, Kohler, & Kortering, 2010). In addition, transition research suggests that transition programs are not implemented with fidelity, nor in the spirit of the law (Certo et al., 2009; Collet-Klingenberg, 1998; Landmark, Zhang, & Montoya, 2007; NCSET, 2004; Repetto, Webb, Garvan, & Washington, 2002). Consequently, large numbers of transition programs do not have the desired or anticipated impact on post-school outcomes (Landmark et al., 2007; NCSET, 2004; 2002, Repetto et al., 2002).

In addition to poor transition planning and execution, there are also a myriad of obstacles the young person must contend with after exiting high school: lingering an indeterminate time on a waiting list once eligibility for services has been established (Davis, 2003); navigating a social services system to try to qualify for services that vary by state, and are awarded on a case by case basis (Hart, Zimbrich, & Whelley, 2002); and a lack of available, affordable, reliable transportation (Darrah, Magill-Evans, & Galambos, 2010; Gill & Renwick, 2007; Hughes, 2009). Contrary to typical peers, once students with disabilities leave school, the lack of opportunities to enjoy meaningful activities, socialize, or further develop skills or abilities dissipates, and this often leads to loneliness (Beresford, 2004).

The post-school outcomes realized by the vast majority are “tragically unacceptable” and a waste of “hopes, dreams, lives, and increasingly scarce tax dollars” (Brown, Shiraga, & Kessler, 2006, p. 93). Young adults with disabilities still have unacceptable rates of school completion, adult employment, post-secondary education, and independent living (Benz et al., 2000; Condon & Callahan, 2008; Graham, 2007; Hart et al., 2001; Johnson et al., 2002; Neubert et al., 2004; 2005; NOD, 2004; Powers, Hogansen, Geenen, Powers, & Gil-Kashiwabara, 2008; Rusch & Wolfe, 2009). In tough economic times, individuals with disabilities are the often first to be laid off, as was the case during the summer of 2009 when the unemployment rate was 9.5% overall, but the unemployment rate for individuals with disabilities was 14.3% (June) and 15.1% (July) (National Council on Disability, 2010). Because of the difficulties in both finding and maintaining employment, adult Americans with

disabilities are more likely to live in poverty and go without healthcare (2004 Harris Survey/National Organization on Disability), and less than 20% of adults with intellectual disabilities live in out-of-home placements (Stancliffe & Lakin, 2004, as cited in Davenport & Eidelman, 2008). While their typical peers are off to college or beginning careers, many students transition from school to segregated workshops and activity centers, or stay at home with family members or paid caregivers (Blackorby & Wagner, 1996; Brown et al., 1999; Brown et al., 2006; Gill & Renwick, 2007; Hunt, 2004; Luecking & Certo, 2002; Murphy & Rogan, 1995; Wehman, Revell, & Kregel, 1998).

The research shows that the post-transition outcomes of young adults with significant disabilities are worse than individuals with milder disabilities, who typically need fewer supports. In the United States, less than 8% of students with significant disabilities leave high school employed, enrolled in a post secondary institution, or living independently (Condon & Callahan, 2008; Harris & Associates, Inc., 2000; NOD, 2004). In addition, adults with significant intellectual disabilities are three times more likely than typical peers to have household incomes of \$15,000 or less (Butterworth & Gilmore, 2000; Harris & Associates, Inc., 2000). For students with significant disabilities, the likelihood of achieving successful transition outcomes depends upon a combination of factors: the quality of the Individualized Transition Plan (ITP), the collaboration of the transition planning team, active use of self determination skills, and degree of parental support (Beresford, 2004; Blacher, 2001; Ferguson et al. 1988; Wehmeyer & Palmer, 2003; Zhang, Katsiyannis, & Zhang, 2002). Important to note, however, is that the transition outcomes typically reported are

easily measurable, typical indicators of post-secondary success for American adults. Typical adults base degrees of success on employment status, wages, and independent living status; however, these traditional indexes of transition success are inappropriate for some students with significant disabilities (Neece et al., 2009). For some individuals with significant disabilities, traditional measures may be less important than safety, health, and general well-being—illusive quality of life factors that are difficult to quantify (thus far, only CQL has published a validated system of measurement for QOL) and are never standardized.

Employment Legislation

For most Americans, employment is a large part of the typical adult experience; however, for many generations, individuals with disabilities were thought incapable of significantly contributing to their communities in any way, much less as a valued employee. Further, employers were often reluctant to hire employees with disabilities because of fear that an employee with disabilities would take longer to train, require expensive equipment modifications, still be incapable and need extra supervision after training, or should the need arise, be impossible to terminate without legal repercussions (Condon & Callahan, 2008; Wehman & Revell, 2005). Several pieces of legislation attempted to remove the barriers to employment created by antiquated mores and misunderstandings or a lack of correct information.

The two pieces of legislation most often cited for the anti-discriminatory language and employment policies contained within are The Vocational Rehabilitation Act (1973) and The Americans with Disabilities Act (1990). In

1973, Section 504 of The Vocational Rehabilitation Act (RA) protected people with disabilities from being discriminated by federal programs (including government-funded employers). The Americans with Disabilities Act (ADA) of 1990 prohibited employment discrimination on the basis of disability (including hiring, evaluating, promoting) and required employers to provide reasonable accommodations if doing so would not cause "undue hardship," (P.L. 101-336 § 101[10][B],(1990). In essence, The ADA extended many of The Rehabilitation Act's provisions into the public sector, instead of being limited to entities that receive federal funds.

Although these pieces of legislation prohibited discriminatory actions, individuals with disabilities continue to have significantly more difficult times securing and retaining employment (Condon & Callahan, 2008; Wehman, 2006). Individuals with disabilities often need a service provider to assist with job coaching and vocational skill development after transitioning from high school. Therefore, it is necessary to have an entity that operates with the purpose of distributing public supports to provide training, equipment, and other services that allow individuals who have disabilities to find and maintain employment.

State-federal vocational rehabilitation services system. In the United States, the state-federal vocational rehabilitation (VR) program is the lead funding agency responsible for providing employment services for individuals with disabilities (NCD, 2010). Each state has a VR program; because some states choose to separate the VR program for individuals who have visual impairments, there are 80 VR programs across the nation, all under the direction of the Rehabilitation Services Administration (RSA) of the U.S. Department of

Education (NCD, 2010). Annually, VR serves more than 600,000 people with disabilities. Of these, 200,000 recipients are working in the community with supports funded by VR (NCD, 2010); the remaining 400,000 receive other ancillary services or are in segregated employment settings. In some states, this includes sheltered workshops directly owned or directed by VR.

The primary goal of VR is to help people become more independent through employment. Thus, VR offers both pre-vocational and employment-centered services and supports such as assessment, career guidance and counseling, funding for academic training, assistive technology, on-the-job training, job coaching, and transportation (NCD, 2010). To be eligible for VR services, an individual must have an emotional, physical, or intellectual disability that creates substantial barriers to finding or maintaining employment (PL 93-112). Priority is given to individuals with the most severe disabilities; however, it is the VR counselor's discretion if he or she believes the applicant "can benefit in terms of an employment outcome from vocational rehabilitation services" (29 U.S.C. § 705[20][A][ii]). In effect, if a VR counselor believes the individual's disability is too severe and prevents the applicant from benefiting from any of VR's services, the applicant will be denied.

The Vocational Rehabilitation system is often criticized for a lack of accountability (NCD, 2010). VR does publish yearly aggregate data on closed cases, but does not track outcomes for specific populations, including transition-aged young adults. Therefore, it is difficult to determine how often VR partners with local school districts, and to what extent existing partnerships result in successful outcomes. It is also unclear how to ameliorate the 66.5% of VR

cases that are closed without a successful employment outcome (Cimera & Oswald, 2009), or how many individuals need VR services but do not complete applications (for any reason). Although a 2008 report by the National Council on Disability concluded that VR was beginning to better prioritize transition-aged youth, NCD was unable to determine how desirable outcomes were achieved for individuals due to "inadequate methodologies." In addition, there are no sanctions in place if VR does not show positive outcomes for an individual, follow-through with an individual plan, or provide family-centered care (NCD, 2010). Because there is no goal-based oversight, there are also no consequences for case managers or individual VR offices that fail to meet goals or support a certain number of applicants (regardless of outcomes documentation).

One-stop workforce centers. In 1998, The Workforce Investment Act overhauled the employment-training system: programs were combined and streamlined, states were given local spending flexibility, and funding was tied to accountability (P.L. 105-220, 29 U.S.C. 2801, et seq.). The most immediate result of The WIA was the creation of the One-Stop workforce centers, often called WIN job centers, as the local hub that all federally-funded job assistance flows through, including unemployment insurance (NCD, 2010). The One-Stop centers were designed to create and support infrastructure within local communities that support economic and employment growth, by providing wrap-around employment services and comprehensive workforce development. The WIA mandated that each One-Stop center be centrally located within the community, and because the One-Stop centers receive federal funds and are

intended to support all citizens, the centers must have specific information and training for people with disabilities and for whom English is a second language.

Each One-Stop center is invested in the community it serves, has interagency partnerships, and prepares applicants by integrating all levels of vocational services (*i.e.* evaluation, placement, planning, and follow up). The WIA mandated that job applicants participate in trial work experiences and have personal control over Individual Plans for Employment (IPE), allowing job-seekers autonomy to make informed decisions after receiving information about all parameters of services offered by the One-Stop center (Wehman, 2006). In an attempt to determine how to best match the needs of local employers with qualified workers, state and local Workforce Investment Boards have representatives from the private sector, public school educators, and non-profit human services (NCD, 2010). In addition, each state's VR agency and Employment Services (usually referred to as unemployment services) are mandated partners.

For job seekers, the wrap-around services of a One-Stop career center are more efficient than seeking employment-related services from multiple offices. In addition, human service delivery is almost always improved when interagency collaboration is present. However, there have been two recent studies that reveal that the implementation of One-Stop centers and the wrap-around concept is still lacking. In 2004, a study commissioned by the Urban Institute found that many WIN job centers were not ADA accessible. In addition, once inside, some job centers did not have computer equipment that was accessible. And, although VR is a partner, the One-Stop centers are required to

first assist individuals with disabilities who request services, and only refer individuals to VR after exhausting the One-Stop center's resources. Instead, what the Urban Institute's research showed was that often individuals with disabilities were immediately referred to VR—perhaps because VR does not rely on the outcome measures of employment, earnings, or credentials for funding (NCD, 2010). Contrary to VR, One-Stop career centers are held accountable for outcomes; to receive federal funds, the One-Stop job coaches must show results.

Ticket to Work Incentive Improvement Act. As the twentieth century drew to a close, several pieces of legislation focused specifically on increasing employment and independent living outcomes for individuals with disabilities. The Workforce Investment Act of 1998 created One-Stop workforce centers to provide information, training, and other employment resources in one location. The Rehabilitation Act Amendments of 1998 mandated federal dollars to be matched by states in order to provide funds for independent living supports and training for independent living skills. Both The Rehabilitation Act (1973) and The Workforce Investment Act (1998) focused on increasing the access to employment for people with disabilities. Although these pieces of legislation may remedy the issues created by hesitant employers or ineffective case managers, these individuals are not single-handedly responsible for the unemployment and underemployment crisis. Individuals with disabilities are themselves sometimes hesitant to get jobs because of the potential to lose social security and/or Medicaid benefits (Migliore, Grossi, Mank, & Rogan, 2008).

To help remedy the conflict between remaining employed and receiving public supports, Congress passed the Ticket to Work Incentive Improvement Act (TWIIA, 1999) to prevent employed recipients from losing their benefits by a series of changes to the system. Under the TWIIA, states could remove or adjust income caps for Medicaid recipients and recipients could continue medical coverage even if their condition improved as a result of the medical coverage. In addition, workers could retain Medicare Part A coverage for 4.5 years and have access to VR and employment services indefinitely.

However, the TWIIA did not meet expectations, and it was revamped in 2008 (NCD, 2010). The new regulations reward successful private sector employment networks (EN) that support individuals with disabilities (in lieu of VR providing the services). The ENs are rewarded for the supports they provide which allow individuals that they support to remain employed for five years or more (NCD, 2010). This program is targeted specifically with the intention of reducing the burden on the social security trust fund (as people are gainfully employed, the amount of SSI or SSDI these individuals would receive decreases), but at this time it is too early to tell if the 2008 legislation has been had an effect on the number of individuals with disabilities who are employed long-term.

Regardless of how an individual comes to be employed or why, there is at first one significant choice that must be made—whether to seek employment in an integrated or segregated environment. This a charged issue, hotly debated by families, advocacy groups, and political entities. Where an individual with disabilities chooses to work affects many things—from an

individual's choice of friends, to expected lifetime earnings potential. Often how the decision is made is simply what is available, or perceived to be available, to the individual and the family.

Segregated Employment

Segregated employment is any type of work environment that congregates individuals with disabilities apart from the general public. By far, the most common method of segregated employment is the sheltered workshop—also called industries, industrial workshops, affirmative industries, training workshops, vocational workshops, and rehabilitation workshops (Migliore et al., 2007). The template for the sheltered workshop as it exists today originated during the 1950s and 1960s when they were designed as safe places for adults with disabilities to go during the day, and were seen by parents as sanctuaries “to give their sons or daughters dignity, self worth, socialization, and most of all respite because parents had peace of mind that their son or daughter was safe, secure, and protected against the risks and demands of the competitive world” (National Disability Rights Network, 2011, p. 6). Today, sheltered workshops still provide generally safe environments and support families in their daily routines (Migliore et al., 2007; Migliore et al., 2008; Singer, 2002; Smyth & McConkey, 2003; Townsley, 2004).

Contrary to other adult service options that require endless paperwork and waiting lists, sheltered workshops are predictable and rarely turn people away (Migliore et al., 2007; Singer, 2002). Although individuals may not be receiving vocational training or individualized services (due to funding constraints or waiting lists), new applicants will usually not be turned down for a

placement. This is because if individuals are physically present, the facility can bill Medicaid for time and services (Migliore et al., 2007). Because of this, states are often reluctant to give up the workshop model or introduce other options. Throughout the last decade, state MR/DD agencies served over 360,000 individuals with significant intellectual disabilities in sheltered or segregated settings and less than 130,000 in community employment—a consistent 3-to-1 margin (Migliore et al., 2008; Rizzolo, Hemp, Braddock, and Pomeranz-Essley, 2004, as cited in Certo et al., 2009).

There are many inconsistencies with the stated purposes of sheltered workshops. Despite the large numbers of people served in the workshop environment, or the readiness model espoused by most sheltered workshops, workshops rarely prepare individuals to work in community settings (Migliore et al., 2007; NDRN, 2011). Sheltered workshops also do not provide standard wages and benefits, and so limit the potential for independence or self-sufficiency of the employees. In addition, in the workshop, the *clients*—the adults with disabilities—are always subordinate to paid staff *employees* (Migliore et al., 2007). In essence, workshop “employees” are in actuality, “attendees.” The whole of the workshop environment is grounded in an archaic philosophy that is out of compliance with the Supreme Court’s holding in the *Olmstead* decision (1999), that endorsed opportunities for individuals with disabilities to have more access to cost-effective community-based services (Johnson, 2004; NDRN, 2011; *Olmstead v. L.C. & E.W.*, 1999).

Sheltered workshops receive a sizable amount of revenue from government subsidies (sometimes 45%) and other public resources (NDRN,

2011). As a result, there is none of the pressure that typical businesses have to keep up with the demand for innovation and competition. Laws such as the Javits-Wagner-O'Day Act of 1971 (commonly referred to as the AbilityOne Program) that mandate that all federal agencies purchase certain services and supplies from industries that employ at least 40% employees with disabilities, ensure that sheltered workshops also do not have the marketing costs associated with typical businesses. However, these savings are not passed on to the employees. The workshops often do not pay comparable wages, or hourly wages, to those individuals employed by the workshop (Migliore et al., 2007; NDRN, 2011). Rogan et al. (2001) compared the earnings and hours worked of 291 individuals who moved out of 40 sheltered workshops across the country. The results showed that the average sheltered workshop employee's net pay was \$175 per month; after the same individuals transitioned to competitive employment, their average net pay increased to \$456 per week. In Hayward and Schmidt-Davis's Second Final Report (2003) of the longitudinal review of Vocational Rehabilitation outcomes for 8,500 individuals from 1994-2000, VR recipients who worked in competitive and supported employment consistently earned significantly higher wages and worked more hours than clients who were placed in sheltered workshops by VR counselors. The sheltered workshop attendees often earned sub-minimum wages.

In 1938, the Fair Labor Standards Act created standards for minimum wage and overtime pay, but because this was an age of assembly lines and factories, an exception to the minimum wage standard gave incentive to employers to hire veterans with disabilities who might have produced less than

quota (29 U.S.C. § 214[c]). According to the National Disability Rights Network (2011), the exclusion—known as 14(c) Special Wage Certificate—once used to encourage employers to hire veterans, now is largely used to pay employees pennies on the dollar for meaningful work. The formula for the allowable piece-rate is based on a ratio commensurate with productivity (based on the ratio of productivity compared to the average performance measure of three typical employees). However, the 14(c) exclusion is not exclusive to segregated work environments. These are simply, by far, the most common entities to take advantage of the legislation: only 24% of the agencies requesting permits employ individuals in integrated settings (NDRN, 2011).

In a 2007 study, 74% (N=202) of adults with intellectual disabilities, when asked, desired employment in the local community instead of the sheltered workshop where the respondents were employed at the time (Migliore et al., 2007). In the same study, only 27% of the participants' families were opposed to integrated, supported employment. Some of the individuals in the workshop could possibly have avoided segregated employment if person-centered transition planning had occurred. Yet, transition coordinators admit to routinely placing students in available positions without attempting to match students to specific jobs based on individual skills and preferences (Hughes & Carter, 2002; Rabren, Dunn, & Chambers 2002; Thoma & Held, 2002; Zhang, Ivester, Chen, & Katsiyannis, 2005). When Migliore et al. (2008) questioned why adults with intellectual disabilities continued to choose to work in sheltered workshops, 46% of adults with intellectual disabilities, 40% of families, and 60% of workshop staff replied that they did not recall anyone encouraging the workshop attendees to

pursue employment outside the sheltered workshop. Only 29% of families reported that VR counselors offered employment options other than the sheltered workshop. Such a large percentage of VR counselors not offering integrated employment options may be unlikely, but the perception that the sheltered workshop was the only option is significant. Perhaps even more significant for students transitioning to adult services is that only 10% of families reported that the school suggested integrated employment for young adults transitioning to adult services (Migliore et al., 2008).

In Eggleton, Robertson, Ryan, & Kober's (1999) study, the quality of life for participants who were attending a sheltered workshop was measured and found to be comparable to those who were unemployed. However, there was a significant increase in the quality of life of participants who left the sheltered workshop and began working in the community. Likewise, in Garcia-Villamisar, Wehman, and Navarro's (2002) international study that followed cohorts of employees in Spain and Germany over a period of four years, the employees that worked in sheltered workshops did not have any change of quality of life. However, the employees that worked (individually) in their communities had a significant increase in quality of life.

Sheltered workshops and segregated programs have been harshly criticized in recent years for drawing excessive costs, showing poor outcomes, and perpetuating the medical model that holds professional status above family decision-making power and imply that people with disabilities are not welcome participants in society (Certo et al., 2009; Kregel, Wehman, Revell, Hill, & Cimera, 2000; Rusch & Wolfe, 2009). One rationale for the perpetuation of

sheltered workshops is that some parents may perceive that their child's disabilities are simply too significant to make employment a possibility (Migliore et al., 2007). Therefore, some families may choose for a young adult to transition to a segregated setting because the parents believe that it is the best fit for the individual's skills, preferences, and needs, but more often than not, this choice is a result of lack of options or lack of information (Chambers et al., 2004; Migliore et al., 2007). It takes supports, services, and an infrastructure built by both public and private human service providers—such as education and vocational programs—in order for individuals and families to have access to multiple employment options and be confident that the option they choose is appropriate—not just a default choice due to lack of other options or realistic long-term supports (NCD, 2010). When information is offered and the spirit of the law is upheld, individuals and their families are most likely to get complete information about services and supports apart from segregated employment.

Integrated Employment

In 1991, the Department of Justice issued guidelines requiring public entities to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities” (42 U.S.C. § 12101[a][8]). Integrated employment pays prevailing market wages and occurs in typical environments where the proportions of workers who have disabilities does not exceed the natural proportions of people with disabilities in the community (Migliore et al., 2007). Advocates for integrated employment often cite the subjective, intangible benefits of an inclusive society and the personal benefits the individual receives from a job in the community; however,

there is also the reality of cost-benefit to taxpayers as a primary reason for advocating for integrated employment. Migliore et al. (2007), point out that some people question if integrated employment can provide the continuity of employment or safe environment that a sheltered workshop can. In addition, transportation issues may be more likely to arise when individuals are working in the community. Integrated employment does require more planning and often additional supports—including natural supports, such as co-workers or friends—who are willing to become invested and involved in the individual's life. Job coaches and transition coordinators who have had great success with integrated employment look at the entire job—potential safety concerns, possible transportation issues, and even demeanor of co-workers—when considering a potential employer.

Supported employment. Supported employment occurs when initial or ongoing supports are provided that allows an individual to be successful in an integrated, competitive work environment. Supported employment is backed by legislation that encourages living and working in integrated settings and is grounded in the philosophy that individuals with disabilities deserve the dignity of employment with equitable wages and benefits (42 U.S.C. § 12101[a][8]). Individuals who benefit from supported employment are those who would otherwise be unable sustain employment due to the incompatibility of the effects of their disability with the expectations of their chosen occupation. Common supports include transportation, assistive technology, job coaching, pre-vocational job training, or supervision for the duration of employment. Supported employment is typically funded by an entity such as VR and is always

offered at no cost to the employer. Employers usually report satisfaction with employees who receive supports and willingness to hire other individuals utilizing employment supports, if necessary (Nietupski, Hamre-Nietupski, Vander-Hart, & Fishback, 1996, as cited in Migliore et al., 2008).

Several longitudinal studies have examined supported employment programs in various states to determine the cost-benefit of supported employment to taxpayers. Although programs and operations are vastly different throughout the country, in every instance supported employment programs have been more cost-efficient per-person than sheltered workshops—even for individuals with severe disabilities—and the cost-benefit increased over time (Cimera, 2007; Cimera, 2008; Cimera & Oswald, 2009; Kregel et al., 2000).

Customized employment. Customized employment is similar to supported employment in that it espouses many of the same values, such as the presumption of the right to work in competitive employment for a commensurate wage (Phillips et al., 2009). However, the hallmark of customized employment is the negotiation of responsibilities between the job seeker and potential employer so that the job candidate's needs, skills, preferences, and choices align with those of the business owner (Inge, 2006; Inge & Targett, 2008; Phillips et al., 2009). It is this departure from the traditional reactions to market forces and the proactive customization of a position where there was none, that is, according to Griffin, Hammis, Geary, and Sullivan (2008), an evolution beyond supported employment. Customized employment is somewhat amorphous in that it can be many things—self-employment, job carving, job creation, job sharing, or any other type of negotiated duties (Citron et al., 2008).

It is somewhat easier to define what does not fall into the realm of customized employment: group placements or enclaves, positions with sub-minimum wages, or entry-level job placements that do not fit with the job seeker's talents, preferences, or choices.

Customized employment begins with the employment specialist creating a profile of the applicant and discovering the individual's preferences, strengths, talents, skills, needs, likes, and dislikes (Inge, 2007; Phillips et al., 2009). With this information, gathered from observations and interviews, the employment specialist can then build a positive profile of the job seeker and determine what contributions the applicant has, and in what environments the individual would be most successful. The job specialist then approaches specifically selected business owners who fit the profile of the individual's potential employers. Armed with a complete, positive profile of the job seeker, a job is negotiated only after it is determined that the business owner has a need the candidate can meet. Because the job specialist is not responding to an advertised position, topics of negotiations will usually include both essential and non-essential job responsibilities—duties, hours, wages, supports, and benefits (Phillips et al., 2009). The result is an individualized position, unique to the employee.

In Luecking, Cuozzo, Leedy, and Seleznow's (2008) study on one One-Stop career center's initial experience with customized employment, 80% of participants were working one year after initial job negotiation and placement. In addition, the average wage of participants was \$3.00 above minimum wage. This is typical for employees who have jobs customized, because when employment is customized, many entry-level tasks that have traditionally been

delegated to individuals with disabilities are by-passed, as these tasks often do not match individuals' preferences, skills, talents, or desires. In Minneapolis, an interagency partnership spearheaded by the local One-Stop center also had successful customized employment outcomes well above the national average for employment outcomes (Rogers, Lavin, Tran, Gantenbein, & Sharpe, 2008). Throughout the five years of the study, 62% of all participants held individualized positions at competitive wages, with 66% of participants working in the negotiated position one-year later.

Despite multiple pieces of legislation that prohibited employment discrimination, established a central location for vocational information, and prevented loss of benefits for employees, approximately 70% of all persons with disabilities in the United States between the ages of 18 and 64 are unemployed or grossly underemployed (Branstad et al., 2002); customized employment may be the solution to the unemployment epidemic. Customized employment can benefit any individual, but is especially valuable for people who have the most difficult time finding or maintaining employment. For some individuals with significant disabilities, there will simply never be an advertised job that will match the individual's skills, talents, and preferences. Parents and the professionals on the transition team may falsely believe that individuals with significant disabilities are simply "too disabled" to work in the community. The premise of customized employment is that if an individual with disabilities has one skill, he or she can do a job; it is just a matter of finding the employer who has the specific needs that the person can fill (Condon & Callahan 2008; Phillips et al., 2009).

When planning for transition to adult services, employment should be an essential goal. There are two primary reasons why: (a) contributing to one's community often results in increased skills, self esteem, social competency, autonomy, and sense of well being (Eggleton et al., 1999), and (b) the resulting income allows individuals to avoid poverty and realize decisions, dreams, and activities that require money. It is the combination of autonomy, skills, relationships, and income that allows individuals to satisfy their needs and attain their life goals, resulting in an increased quality of life (Eggleton et al., 1999). Spending money is the embodiment of self-determination.

Community Participation and Self-Determined Housing Options

Individuals with disabilities, especially significant disabilities, are often not active participants in the local community (White, Lloyd Simpson, Gonda, Ravesloot, & Coble, 2010). Many individuals do not have planned experiences, and, therefore, do not know what the local community has to offer. Some areas of the community may be inaccessible. Without planned outings, young adults with significant disabilities typically do not enjoy meaningful activities, socialize, or further develop skills or abilities; this often leads to loneliness (Beresford, 2004; Schuster, Timmons, & Moloney, 2003). Young adults who do have social networks are still often isolated, as one of the most commonly reported barriers is reliable transportation (Darrah et al., 2010; Gill & Renwick, 2007; Hughes, 2009).

In Grigal and Neubert's (2004) survey, one-third of parents responded that their family was planning for the transitioning young adult to remain at home after high school. Ninety percent of adults with disabilities live with their parents

(Rusch & Wolfe, 2008); historically, families of adults with significant disabilities either chose for their son or daughter to remain living at home, or to live in an institution or group home. However, more individuals and their families are realizing that by planning supports and anticipating funding options, individuals with disabilities can live where and with whom they choose, as indicated by more parents who respond that living independently or in an apartment with a friend would also be a desirable option for their child (Grigal & Neubert, 2004; Westling, 1997).

Centers for Independent Living

Families and transition teams may request information and assistance from one of the Centers for Independent Living (CIL) that are funded by VR. The CILs are charged with maximizing the “leadership, empowerment, independence, and productivity of individuals with disabilities to integrate these individuals into the mainstream of American society” (The Rehabilitation Act of 1973, 29 U.S.C. § 701 et seq.). To that end, CILs offer four core services: peer counseling, independent living skills training, individual and systems advocacy, and information and referral. All CILs are directed by people with disabilities; thus, more than 51% of the board and 51% of the staff are composed of people with disabilities.

A 2003 study commissioned by the Rehabilitation Services Administration (RSA) surveyed all CIL directors and a nationally representative sample of consumers of CIL services (Cherry Engineering Support Services, Inc., 2003). The survey results revealed that over 90% of CILs provided ADA training, group support, personal assistance service or referral, assistance acquiring technology

or adaptive equipment, technical assistance on access, and advocacy training (CESSI, 2003). Ninety-eight percent of CILs provided housing referral and assistance; 85% also provided advice on home modifications. Eighty-two percent of individuals who used the CIL training in independent living reported an increase in quality of life. Seventy-seven percent of those who used personal assistance reported an increased quality of life. The services that CILs provided improved the quality of the respondents' lives. Forty-seven percent of respondents said their lives were "much better," and 29% said their lives were "somewhat better" since receiving services from the CIL (CESSI, 2003).

The four core services that CILs offer can be invaluable for individuals and families. CILs provide information and person-to-person support. However, often, the reality is that without long-term funding sources, individuals who want to live, work, and play in their communities may feel like they face an insurmountable task when it comes to procuring needed supports (Lakin, 2007; McLaughlin et al., 2009).

Funding for Adult Services and Supports

No other citizens are as affected by federal and state laws as individuals with disabilities (Davenport & Eidelman, 2008; Eggleton et al., 2009). Both education and public supports are controlled at the state level. The availability of public support varies widely by state, and has a significant impact on caregiver burden and family quality of life (McLaughlin et al., 2009). Yet, many parents do not know that public benefits—amounts and eligibility requirements—are state-specific (Davenport & Eidelman, 2008). Individuals often lament that "the

system” makes people dependent by design (Cooney, 2002; McLaughlin et al., 2009); however, there are, in fact, at least fifty different “systems.”

HCBS and Section 1915. In 1981, Congress created the HCBS waiver in Section 1915(c) Title XIX of the Social Security Act; this applies to specific populations—primarily individuals with the most significant disabilities—who are most at risk for institutionalization (*i.e.* adults age 65 and older; individuals who have physical disabilities; individuals with intellectual developmental disabilities; people with mental illnesses; and individuals who have had a traumatic brain injury) (Lipson & Williams, 2009; Miller, Ramsland, & Harrington, 1999, as cited in Certo et al., 2009). The Department of Education oversees the RSA; states submit annual plans for providing services for the upcoming year, and thereby secure funds to serve the specific populations the states have chosen to provide supports for via waivers (Certo et al., 2009). States have to turn in specific numbers to be served (based on subpopulation classification) and cannot exceed these estimates. However, how the individuals are served is left up to the state, and can include many different types of services if the outcome is in lieu of institutionalization (Certo et al., 2009). Depending upon the state formula (in the contractual agreement between the state and the federal government), the federal government will pay 50% or more for residential services for an individual with severe disabilities to live in an institution, intermediate care facilities (with ICF MR/DD funds), or residential services (with HCBS waivers). However, contrary to most other supports (*e.g.* day habilitation, supported employment, or hospitalization), most states do not include HCBS waivers as a standard service option for Medicaid recipients to choose from (because new

HCBS participant slots are not annually funded). Therefore, it is not common practice for Medicaid recipients to have access to funding for supports—such as job development, employment supports, and leisure and recreational supports—that allow individuals to live and work in their home communities (Lakin 2004, 2008; Certo et al., 2009).

In 2005, the Deficit Reduction Act (DRA) included several changes to legislation with the intention of reducing expenditures; complying with directives implied by the Supreme Court's Olmstead decision (*Olmstead v. L.C. & E.W.*, 527 U.S. 581; 1999) and President Bush's New Freedom Initiative (Bush, 2001); and expanding and increasing service options for individuals who rely on public supports (Lakin, 2007; Wiener & Anderson, 2009). Two sections, 1915(i) and 1915(j), were added to the Social Security Act. Section 1915(i) gives states the option to provide HBCS services for individuals who are not typically at-risk for institutionalization because of a disability classification, but who use the same types of 1915(c) supports. States cannot classify 1915(i) recipients based on disability, but can establish functional, need-based criteria for individuals to qualify for specific supports; participants must also not have income not exceeding 150% above the federal poverty level. Section 1915(j) authorizes states to make self-directed personal assistance services (PAS) available to 1915(c) waiver recipients, in lieu of agency-directed services, including direct cash payments to participants (a true exercise in *money follows the person*). The U.S. Congress also authorized the Money Follows the Person (MFP) Demonstration Grant Program as part of the DRA. The MFP program provided states the opportunity to receive enhanced matching federal funds from the

Center for Medicare and Medicaid Services (CMS) to support states' pioneering efforts to determine the best ways to significantly reduce the number of people residing in institutions (P.L. 109-171).

Money Follows the Person. Over the past decade, Money Follows the Person (MFP) programs have been endorsed by individuals, families, and disability advocates as an alternative to other CMS programs that have been traditionally agency-controlled, institutionally-biased, limited personal choice, and, on average, cost significantly more than community-based supports (Hertz, 2010; Lipson & Williams, 2009; Watts, 2011). However, the MFP program title is somewhat of a misnomer, as it is inconsistent with the connotation for *money follows the person*, which indicates giving fiscal control to individuals or their families, instead of government agencies or proxies. Rather, individuals who participate in the MFP Demonstration Grant Program are able to receive up to three categories of HCBS: (1) qualified HCBS, (2) demonstration services, and (3) supplemental services (Brown, Irvin, Lipson, Simon, & Wenzlow, 2008). Demonstration services are Medicaid services not already included in the state's HCBS menu of services, or HCBS above what MFP participants would have received with typical Medicaid recipient status (Brown et al., 2008). Supplemental services pay for formerly unfunded supports (e.g. expanded case management; one-time housing expenses, such as security deposits or household furnishings; assistive technology; or transportation supports) for up to twelve months to facilitate a successful transition from an institutional setting to a community-based setting (i.e. home, apartment, or group home with no more than four residents). In addition to providing for individual outcomes, the MFP

Demonstration Grant Program is providing for longevity, as states have to explain during the initial application process how they will use the enhanced federal medical assistance percentage (FMAP) to overhaul and restructure the state's long-term care (LTC) system (known as *rebalancing*) to provide more HCBS and ensure longevity and replication of the project activities after the demonstration project has concluded and the federal funding stream has ended (Hertz, 2010). States must rebalance their LTC systems so the MFP demonstration project does not leave the state in worse financial shape than before (by not transitioning individuals from institutions, replacing them with other individuals currently on waiting lists, and having more individuals to support—in the institutions and community—when the project is over and the enhanced FMAP dissolves).

During the first six years of the MFP program, nearly 13,000 individuals were successfully transitioned out of institutions; however, of these, only approximately 3,200 were individuals who had a developmental disability. According to a report commissioned by the Kaiser Commission on Medicaid and the Uninsured, this is largely due to complex health and expensive LTC needs of individuals with developmental disabilities (Watts, 2011). However, in a 2010 survey, the initial state participants (in addition to Washington D.C.) initially receiving the MFP funds reported that the “most significant challenges facing MFP in the year ahead” (*i.e.* 2011) were lack of affordable housing (47%), lack of qualified DSPs or family caregivers (47%), and weak community infrastructure (33%) (Watts, 2011). Only 23% of states reported that

transitioning complex individuals to community-based services was a significant concern.

A more likely contributor for the disparate numbers of successful transitions between the elderly and individuals with different types of disabilities was one of the initial eligibility requirements. Until 2010, to be eligible to participate in the MFP program, the individual must have been a resident in an institutional setting for at least six months and not on a short-term rehabilitation track (Watts, 2011). This greatly increased the likelihood of a MFP program participant being age 65 or over; in 2004, at least 77% of all individuals who qualified for the MFP program were over 65 (Wenzlow & Lipson, 2009). Individuals who have developmental disabilities and live in institutional settings are not only significantly younger, these individuals tend to enter and exit residences more frequently, and were, therefore, often ineligible for the MFP program when the six-month eligibility requirement was in effect. After the healthcare reform in 2010, the residency requirement changed to 90 days; this is anticipated to increase the number of potential non-senior MFP participants.

Programs like the MFP program are moving individuals with disabilities closer to community-based supports and family-centered care. States are attempting to create single point-of-entry systems that are less bureaucratic and more likely to provide better, self-directed care (Wiener & Anderson, 2009). However, the MFP is still a demonstration project (as of 2011, 37 states and the District of Columbia are in various stages of piloting programs). An enduring understanding that the MFP program is conveying to both families and

professionals is that the need for complete transition programming never ceases—no matter the person’s age, location, or the specific disability.

PASS Plans. Families must know the additional supports that their child may need in order to plan for them – not only to determine providers, but also to establish a plan of action and determine how to procure and pay for these services and supports should the need arise (Caldwell & Heller, 2003). Hewitt et al. (2000) estimated that the average family with a child who has a significant disability spends an additional \$16,058 per year on respite care, specialized or adaptive equipment, environmental and home modifications, transportation, and therapeutic services. These additional expenses are in addition to missed wages from parents’ sick days and personal days that sometimes result from caring for an individual with a significant disability.

One example of the fiscal crisis compounding with the “knowledge gap” families have about transition is the failure of the Social Security Administration’s Plans to Achieve Self-Support (PASS) plans to make any significant difference in more than a fraction of individuals’ lives. The value of a PASS plan is that it allows Supplemental Security Income (SSI) recipients to redirect wages that they earn into a PASS account, earmarked for a specific purpose (Office of Research and Evaluation and Statistics, 2003). The advantages of PASS plans are twofold. First, the redirected wages reduce the monthly countable income and will increase the public SSI support the individual remains eligible for each month (ORES, 2003). Additionally, these redirected funds are kept in a PASS account that allows the individual to save for supports

or services (such as specialized training, equipment, or supports) they need to accomplish their vocational goals.

Despite the undeniable benefits of PASS plans, they are under-utilized almost to the point of non-existence. To qualify for a PASS plan, a student must meet medical requirements and have countable income that reduces his or her SSI payment below the \$623 per month income cap (Condon & Callahan, 2008). Due to parents and professionals not knowing about PASS plans, or being unable to complete the application process, only two-tenths of 1% of individuals who would qualify for the plans are using them (Condon & Callahan, 2008).

Due to the advocacy efforts of many individuals in the last 30 years, institutions are closing; however, the majority of individuals in communities live in residences owned by someone else. With assistance from CILs or other organizations, students can work toward a long-term independent living goal if they choose. When families are informed and have the support of professionals, funding can be more quickly and easily secured to provide supports for the student to live, work, and play in his or her community. Therefore, to best prepare for adulthood, researchers and practitioners advise that the student and family make best use of the resources at hand—beginning with public education, including specially designed instruction, tailored to the student and family's long-term goals.

The preceding sections described the beginning of the historical marginalization of individuals with disabilities and progression to the current state of individuals with disabilities (as a sub-culture), as the United States

grapples with issues of employment, community living, and quality of life. The previous section examined also employment legislation as it applies specifically to adults with disabilities, as well as the differences between segregated and integrated employment. It was only one generation ago that young adults with disabilities were kept out of the classroom and inside the home, or sent to a residential facility (Lakin, 2007). Great strides have been made in special education, but the outcomes speak for themselves. Despite legislation and advocacy efforts, adult outcomes are still inconsistent and especially dismal for individuals with significant disabilities (Landmark et al., 2007; NCSET, 2004; Repetto et al., 2002). The goal, therefore, is still for students to be consistently prepared for the transition to adulthood. The following section will describe the evolution of special education, from simply including students by permitting access into the classroom, until now—the age of accountability.

The Evolution of Disability Law, Special Education, and Parent Participation

By 1918, all states required compulsory education for most children (National Center for Educational Statistics, 2004); however, states still retained the rights to exclude students considered uneducable. Chief Justice Earl Warren in the *Brown vs. Board of Education* decision perhaps unknowingly set a precedent for people with disabilities to be educated in public schools:

In these days, it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education. Such an opportunity, where the state has undertaken to provide it, is a right that must be available to all on equal terms. (Warren, 1954, para. 9)

Over a decade later, the Elementary & Secondary Education Act (1965) made funding available to educate those who were previously deprived of an education. In 1972, two important court rulings, *Pennsylvania Association of Retarded Citizens (PARC) v. Commonwealth of Pennsylvania* and *Mills v. Board of Education of Washington D.C.* mandated that school districts must provide a free and appropriate education (FAPE) to children with disabilities. In addition, placing students with disabilities in special schools or under programs exclusively for students with disabilities was prohibited. These rulings also provided parents with options to pursue if they thought their child was not being provided a FAPE.

After case law precedent was set, Congress prohibited educational discrimination and mandated FAPE. In 1975, the Education for all Handicapped Children Act (EAHCA) not only mandated that public schools offer all children with disabilities a free and appropriate education, but also authorized funding to the states to enforce the law. The EAHCA was reauthorized in 1990 and 1997, and was then known as the Individuals with Disabilities Education Act (IDEA). *The Individuals with Disabilities Education Act of 1997*

The IDEA (1997) extended the concept of access to a FAPE by mandating specific requirements that would “confer some educational benefit” (*Bd. of Educ. v. Rowley*, 458 U.S. 176, 206-07, 102 S.Ct. 3034, 73 L.Ed.2d 690 [1982]). The IDEA (1997) also prescribed specific guidelines for Individualized Education Plans (IEPs). The 1997 Amendments required that students with significant disabilities be included in state-wide assessments and mandated that necessary accommodations be made in order to allow individuals to participate

in state assessments, including the creation of alternate assessments (Agran, Alper, & Wehmeyer, 2002; Dymond & Orelove, 2001). IDEA (1997) also provided guidelines for the many rights and responsibilities for parents: participation in the IEP process, consent for evaluations, right to student records, and due process. The 1997 Amendments to IDEA gave teachers better ways to document progress and also indicated that parents were expected to be active team members and advocate on behalf of their children. The changes in IDEA 1997 were significant because they indicated that lawmakers recognized that presence in the classroom did not guarantee learning, and students with disabilities and their families should not be content with simply being present in the classroom. As such, students were expected to participate in the classroom activities, and for the first time, IDEA (1997) included an expectation of preparation for future adulthood.

Transition requirements. The 1997 reauthorization of the Individuals with Disabilities Education Act was the first legislation that required transition services for school-aged children with disabilities (Sitlington & Clark, 2006; Wehman, 2001). IDEA (1997) described transition planning as a team-facilitated process for developing a “coordinated set of activities for a student, designed within an outcome oriented process, which promotes movement from school to post-school activities ... based upon the individual student’s needs, taking into account student preferences and interests,” (§ 300.18).

IDEA (1997) required that schools provide transition services that are outcome-oriented and also provide students with disabilities necessary planning, instruction, and related services to fully participate in post-school activities

including: (a) community living, (b) competitive and supportive employment, and (c) vocational training (IDEA, 1997, as cited in Frankland, Turnbull, Wehmeyer, & Blackmountain, 2004). A significant result of the explicit transition requirements in the 1997 amendments was the implicit change in purpose of special education that differed from the statutory language found in the 1990 amendments. The 1990 amendments maintained the spirit of the Rowley decision, which held that special education and related services must provide access—a basic “floor of opportunity” for students with disabilities (*Bd. of Educ. Hendrick Hudson Central School Dist. v. Rowley*, 458 US 176 [1982]). In the 1997 amendments, the IDEA changed from a statute focused simply about “access,” to one that is focused on “transition services, . . . an outcome-based process, which promotes movement from school to post- school activities . . . taking into account the student’s preferences and interests” (20 U.S.C. § 1401[30]; 34 C.F.R. § 300.29). This change in semantics was timely in that students with disabilities were not just allowed access to classrooms and instruction, but were also recognized as capable of producing outcomes worthy of long-term planning and preparation.

No Child Left Behind and Special Education

Previous legislation and case law had affirmed that that children have unique needs and circumstances (*Bd. of Educ. Hendrick Hudson Central School Dist. v. Rowley*, 458 US 176, 1982; IDEA, 2004), yet how to best meet these needs and standardize the quality of education outcomes waxed and waned with each political season. In 2001, a bi-partisan group lead by Senator Ted Kennedy co-authored legislation in an effort to improve education outcomes for

all students while closing the achievement gaps for minority students and students with disabilities (Johnson, 2004; Wehman, 2006). Then-President George W. Bush signed the No Child Left Behind Act and was quickly criticized for controversial, unrealistic timelines and lack of funding for states. Under the auspices of increased accountability and flexibility, the NCLB Act (2001) sought to buttress student achievement by offering expanded options for parents, mandating LEA accountability for outcomes, and requiring empirically-based teaching methods by practitioners (Johnson, 2004). NCLB also picked-up where The National Education Goals' benchmark of increasing parent involvement in schools, for both parents of typical children and children with disabilities, left off (Farkus, Johnson, & Duffett, 1999).

Although NCLB is a general education mandate, there are several components that affect special education services, especially the requirement for empirically based teaching practices for students with low-incidence and severe disabilities (Allbritten, Mainzer, & Ziegler, 2004). Empirically based research was defined in NCLB as “research that involves the application of rigorous, systematic, and objective procedures to obtain reliable and valid knowledge relevant to education activities and programs” (NCLB, 20 U.S.C. 7801 & 9101 [37]). Until evidence-based practices were required in the NCLB legislation, little research was conducted to determine the best way to assess and report learning outcomes by students with severe disabilities (Browder & Cooper-Duffy, 2003). The NCLB academic requirements were contrary to typical learning priorities for students with severe disabilities that had historically been focused on life domains, social skills, and embedded functional skills (Agran et

al., 2002). Previously, the individual indicators that learning was occurring were often not objective, measurable, or reportable.

An immediate problem with providing evidence-based academic instruction for students with severe disabilities was the lack of practice—and the resulting lack of research (Browder & Cooper-Duffy, 2003). Instruction had typically focused on functional skills, social skills, and inclusion, but not necessarily academic instruction for students with severe disabilities. Teachers had to figure out how to incorporate practical instruction and family-prioritized transition goals with the new requirements for empirically based academic instruction that could be measured with state-approved assessments.

Researchers suggested that functional reading and math were the most logical places to begin teaching academics and preparing for assessments (Browder & Cooper-Duffy, 2003), but cautioned that there were several unknowns which might hinder NCLB implementation and the calculation of annual yearly progress (AYP): the lack of literature to provide evidence-based practices for teaching students with complex, multiple disabilities; sparse research-based assessment strategies for measuring academic growth; and a lack of research to support extending instruction beyond functional domains. In addition, critics of NCLB charged that standardization does not allow parents and teachers to focus limited time and resources on important learning outcomes that cannot be measured by grade-level testing; in other words, the “Henry Ford” model would not work for special education and students with disabilities for whom progress and achievement must often be atypically measured (Allbritten et al., 2004).

The 2004 Reauthorization of IDEA

The Individuals with Disabilities Education Act was reauthorized in 2004 and was then named The Individuals with Disabilities Education Improvements Act—IDEIA. It is also often referred to as IDEA 2004 (this document will use IDEIA to avoid confusion with previous authorizations of IDEA). “The goal of the IDEA 2004 amendments was to improve educational services to students with disabilities, with the focus on improving student performance. In addition, the reauthorization emphasized the alignment of IDEA with the No Child Left Behind Act...” (Committee on Education And Labor, United States House of Representatives, April, 2007). While both acts work in conjunction with one another regarding students with disabilities, teachers sometimes wrestle with how to mesh the two. The Court has held that because IDEIA was a reauthorization, not a completely new law, NCLB is the most recent legislation and will supersede IDEIA should the laws conflict (*Bd. of Educ. v. Spellings*, 2008).

IDEIA complemented NCLB’s focus on quality and accountability in education for all students by shifting the emphasis from access for students with disabilities to participation and student performance (Apling & Jones, 2005); as a result, there were several modifications in the statutory language and requirements of IDEIA. IDEIA mandated that the Individual Education Plans (IEPs) and transition goals should be based on the “academic, developmental, and functional needs of the child” (IDEIA, 2004), and the IEP must include “a statement of the child's present levels of academic achievement and functional performance, including how the child's disability affects the child's involvement

and progress in the general education curriculum,” (34 CFR § 300.320 [a][1]). School districts were also required to begin transition planning by the time a student is 16 (instead of 14), link transition goals with classroom and community instruction, and document this on the IEP (deFur, 2002; Halpern, Yovanoff, Doren, & Benz, 1995; Sitlington & Clark, 2006; Storms, O’Leary, & Williams, 2000). IDEIA also incorporated more transition-focused language when specifically defining the mission of K-12 education as meeting each child’s unique needs and preparing them “for further education, employment and independent living” (34 CFR 300.1[a]), (20 U.S.C. § 1400[d][1][A]).

This language is significant, as often transition planning often carries the connotation of employment planning, because employment is such a large part of the American adult experience. By including further education and independent living in the statute, the legislation holds school districts liable for preparing young adults for successful outcomes in multiple domains and links funding to preparation in these areas, as well.

Reporting outcomes: State Performance Plans and Annual Performance Reports. The focus on outcomes began with the semantic changes in IDEA 1997 that shifted the focus to outcomes, rather than programming. IDEA 1997 required that the number of children being served by each LEA, the age of the children being served, and the specific settings in which the children received services be published; however, the data was inadequate to determine if state programs were effective (Hebbeler & Barton, 2007). Within the last decade, both the 2004 reauthorization of the Individuals with Disabilities Education Act and the No Child Left Behind Act of 2001 included provisions for measuring

outcomes, not just inputs and population demographics. By December 2005, each state was required to describe the ongoing efforts to provide a FAPE to all children with disabilities in “a performance plan that evaluates the State’s efforts to implement the requirements and purposes of (IDEIA) and describes how the state will improve such implementation” (20 U.S.C. 1400 § 616[b][1][A]). In State Performance Plans (SPP), states are to outline six-year plans to measure twenty (predetermined) indicators and substantiate active efforts to monitor, enforce, and evaluate IDEA Part B and Part C programs. In addition, states are also required to submit Annual Performance Reports (APRs) that document the performance of LEAs on each of the twenty indicators as outlined in Part B of IDEIA.

Five of the twenty indicators from Part B of IDEIA are related to transition outcomes. Indicators one and two are indirectly related to transition: indicator one measures the percent of youth with IEPs graduating from high school with a regular diploma and indicator two measures the percent of youth with IEPs dropping out of high school. While both the number of students who graduate and dropout are concerning to all educators, there are three indicators that are more specifically related to transition outcomes: indicators eight, thirteen, and fourteen. Indicator eight measures the percent of parents with a child receiving special education services who report schools facilitated family involvement (20 U.S.C. § 1416[a][3][B]). Indicator 13 measures the percent of youth ages 16 and above with an IEP that includes coordinated, measurable, annual IEP goals and transition services that will reasonably enable the child to meet the post secondary goals (20 U.S.C. § 1416[a][3][B]). Indicator 14 measures the percent

of youth who had IEPs, are no longer in secondary school and who have been competitively employed, enrolled in some type of postsecondary school, or both, within one year of leaving high school (20 U.S.C. § 1416[a][3][B]).

The Office of Special Education Programs (OSEP) reviews both SPPs and APRs to determine compliance with IDEIA and to assist in the development of a plan for technical assistance to states (20 U.S.C. 1400 § 616[i][2]). Fiscal decisions are made based on these data, and states risk losing funding if unsatisfactory progress is not improved (Apling & Jones, 2005; 20 U.S.C. 1400 § 616). Because states may vary in offered services, provision of services, and assessment strategies, OSEP has given states the freedom to determine state-specific collection and measurement procedures (Hebbeler & Barton, 2007).

While flexibility in the age of accountability is sometimes a refreshing alternative, in this case, it leads to ambiguous and invalid data interpretation. Indeed, Indicator 8 data tells how many families *perceive* that they received information from the school district about transition. Indicator 14 gives a good indication of how many students are working or attending post-secondary education one year after high school, but it does not indicate if that is what that individual wants to be doing, or if he or she was prepared for that environment, or needed more support or training. The least-telling is Indicator 13, which is often self-reported by school districts, and asks states to compile quantitative data for qualitative variables: “*coordinated, measurable, annual IEP goals and transition services that will reasonably enable the child to meet the post secondary goals*” (emphasis added to show qualitative nature of the question) (20 U.S.C. § 1416[a][3][B]).

Transition planning is not a discrete event. It cannot be summed up in a “Statement of Transition Services” on an IEP; therefore, multiple documents, such as assessment data, meeting minutes, and records would need to be examined in order to determine if coordinated goals and services were in place that would reasonably enable the student to meet those postsecondary goals. In addition, there must be evidence that (a) the student was invited to the IEP Team meeting where transition services are to be discussed, and (b) if appropriate, a representative of any participating agency was invited to the IEP meeting with the prior consent of the parent (or student who has reached the age of majority) (20 U.S.C. § 1416[a][3][B]). In the age of empirical research, it seems contradictory to leave “*coordinated...IEP goals and transition services that will reasonably enable the child to meet the post-secondary goals*” to interpretation (20 U.S.C. § 1416[a][3][B]). Nevertheless, it is up to the states to determine the process of documentation that yields valid data for Indicator 13.

Significance of Transition

There are many definitions of transition services and transition outcomes found in legislation, but usually “transition” is used to describe the life events that occur as young adults move from parent or guardian care in school-focused environments to independent adult living with work or post-secondary school as the focus (Halpern, 1994). The Council for Exceptional Children uses a more global definition of transition which does not specifically state that the transitioning young adult be associated with “school” or “work,” but rather that the young person moves from a primary role of “student” to assume an adult role in the community (de Fur, Todd-Allen, & Getzel, 2001). High school

graduation is often not the culminating rite of passage for students with disabilities that it is for typical high school graduates (Hudson, 2003; Micheals & Ferrara, 2005; Townsley, 2004). Because young adults with disabilities, particularly those with more significant disabilities, often lack autonomy and require continued extensive support to become contributing citizens, their adulthood is a “problematic concept, at best imperfectly realized, and for some postponed indefinitely” (May, 2001, p. 76). Thus, transition planning is necessary for students with disabilities to identify goals, expected outcomes, and needed services and supports (Wehman, 2006).

Evidenced-Based Programming

While there have been federal efforts to evaluate special education services—including transition services—through the Annual Performance Reports, guidance for more substantive evaluation of transition-related service inputs and outcomes can be found in the literature. According to Wehman (2006), in order for students to have the best opportunity for successful adult outcomes, schools should teach and provide opportunities for students to develop personal responsibility, self-determination, social competence and vocational competence—including academic skills that students will need to be successful on the job. Schools that successfully prepare students for adulthood do not focus exclusively on academics; instead, these schools focus on preparing students for success in future environments and building skills necessary for independent or supported living, employment, and even post-secondary education. According to Agran, Alper, and Wehmeyer (2002), students must be provided with knowledge and opportunities to develop

competency in exercising choice and making personal decisions and then use this knowledge to take an active role in transition planning. Developing life-long learning skills, identifying interests, and establishing friendships are some of the primary goals of high school (Wehman, 2006). "Schools are time-limited means to ends. They are not ends" (Brown et al., 1999, p.119).

While each individual, their family, dreams, and circumstances are unique, specific service-delivery inputs and characteristics consistently appear in the literature as components of effective and efficient transition programs. In the field of special education, practices are referred to as "empirically-based" or "scientifically-based" practices, "best practices," and "valued practices." These terms are often used interchangeably, but mean very different things. According to The Education Sciences Reform Act of 2002, the term "scientifically based research standards" means research standards that (a) apply rigorous, systematic, and objective methodology to obtain reliable and valid knowledge relevant to education activities and programs, and (b) present findings and make claims that are appropriate to and supported by the methods that have been employed (p. 4). Many of the inputs discussed as exemplars of "best-practice," are simply not supported (at this time) with scientifically-based evidence. For example, Test et al. (2010) searched the literature for scientifically based inputs that resulted in positive transition outcomes. After a thorough search, and applying rigorous methods, no published accounts of interagency collaboration could withstand the scrutiny (Test et al, 2010). However, interagency collaboration is a valued practice to families and transition teams. Individuals can attest that it does yield better outcomes (Beresford, 2004; Crane, Gramlich,

& Peterson, 2004; Epstein & Jansorn, 2004; Grigal, Neubert & Moon, 2001; Harry, 2008; Hart et al., 2001; Luecking & Certo, 2002; Stewart, 2009).

Likewise, there are very few studies documenting the outcomes of self-determination (Wehmeyer & Palmer, 2003). Self-determination, like autonomy or quality of life, is a value, and as such, it is difficult to translate into quantitative outcomes. However, the absence of self-determination and the resulting acquiescence is rather easy to measure. Therefore, possessing self-determination is a valued trait.

The Education Sciences Reform Act of 2002 did not leave room for qualitative data in the definition for “scientifically-based research standards” (P.L. 107-279 § 102[18]). However, in the social science and human services, individuals must often tell stories to convey information and receive services. Some of the best data received from families is qualitative data. However, it also lends itself to a more emotive tone. Therefore, in some of the discussion throughout, when parent interviews are the primary data source, the writing will reflect this in some of the impassioned statements.

The remainder of this review of the literature is organized according to Kohler’s Taxonomy for Transition Programming (1996). Kohler’s Taxonomy organizes education and service inputs into five conceptual areas of service delivery: student-focused planning, student development, interagency collaboration, program structure, and family involvement. The framework aligns with prevailing values-based philosophy that encourages self-determined student participation and family-centered care (Kohler and Field, 2003).

Student-Focused Planning

Successful transition does not happen naturally; the groundwork must be laid. The ancient Greek aphorism “Know thyself” sums-up the intent of student-focused planning. Throughout this preliminary period, essential information is being learned about the student: dreams, wants, needs, talents, skills, dislikes, and interests are being discovered. According to Kohler and Field (2003), it is also in this beginning stage that students and their families should be learning how to make self-determined decisions. It is also during the infancy of the planning process when roles are being clarified. This is when relationships with service providers are formed and team-building occurs. The culmination of this stage is the transition plan—the document that will serve as the student’s roadmap to adulthood. However, to provide the appropriate experiences, instruction, and supports along the journey, it is essential that the transition team have a holistic knowledge of the student.

Transition Assessments

The Division for Career Development and Transition (DCDT) uses “Transition Assessment” as an umbrella term that includes any assessment that occurs during the process of collecting data on the individuals’ needs, preferences, and interests as related to current and future (working, educational, living, personal, and social) environments (Sitlington, Neubert, & Leconte, 1997). Transition assessments may be informal interviews, direct observations, environmental analyses, or curriculum-based assessments (CBAs). Formal assessments include adaptive behavior assessments (e.g. The Vineland Adaptive Behavior Scales), aptitude tests, work-value inventories, intelligence

tests, achievement tests, personality profiles, self-determination assessments (e.g. The Arc's Self-Determination Scale, or Choice Maker Self-Determination Assessment), or transition planning inventories (NSTTAC, nd). During transition planning, assessments should be used to obtain and organize information about the young adult's skills needs and preferences (Allen, 2007; Benz, Yovanoff, & Doren, 1997; Frank & Sitlington, 2000). Therefore, assessments should occur in a variety of natural environments, with the cooperation of a variety of collaborators including family, potential employers, and people in the community (Field & Hoffman, 2007; Sax & Thoma, 2002; Sitlington et al., 1997). Assessments allow transition-planning teams to meet students' needs and plan for the appropriate supports (Green & Kochhar-Bryant, 2003; Thoma, Held, & Saddler, 2002).

In surveys of transition coordinators regarding school district assessment practices, transition coordinators revealed that assessment is rarely a priority (Herbert, Lorenz, & Trusty, 2010; Zhang et al., 2005). In Zhang et al.'s (2005) survey, although half of the respondents reported that transition coordinators were responsible for building relationships with employers and placing students in jobs, less than half reported that giving vocational assessments (e.g. to discover strengths or interests) was the responsibility of a transition coordinator. In addition, 63% of respondents claimed that their school district did not do transition assessment well, and 2% of respondents reported that their school district did not conduct transition assessments at all. In Herbert et al.'s (2010) survey, 53% of transition coordinators were responsible for giving assessments, but 13% of the same respondents thought career assessments and on-the-job

training were “not useful” (p. 21). In Thoma et al.’s (2002) research, special educator respondents revealed that psychometrists were most likely to conduct formal assessments in Arizona and Nevada schools (89%); however, ecological inventories, task analyses, and person-centered planning were the least likely assessments to be facilitated by any school representative, even though the literature reveals that these assessments often provide the most valuable information.

When transition coordinators do not conduct assessments to discover the preferences, strengths, and interests of students, this likely passes to the special education teacher or the parent. However, when transition assessments become solely the family’s responsibility, it is unlikely to translate into desired outcomes (Benz et al., 1997; Zhang et al., 2005).

Assessment data should serve as the “common thread” and the foundation for defining goals and services in the IEP and ITP (Sitlington et al., 1997; Thoma et al., 2002). Assessment data gives transition teams insight into the student’s interests and present levels of performance. Additionally, psychological or developmental data should be collected, compiled, and retained for future eligibility requirements for students who may need adult services and supports from VR, MR/DD, or other providers (Neubert, 2003). Transition plans can only be written after transition teams know (a) what skills and interests the student has at the time the plan is written and, (b) what adult goals the student is working toward.

Complete Transition Plans

School districts with exemplary transition programs create written transition plans that are more comprehensive than the “Statement of Transition Services” required by IDEIA (Greene & Kochhar-Bryant, 2003). Initially this extensive planning might be difficult for parents and students, as it is likely unfamiliar and awkward to conceive of such long-term goals; however, envisioning the future and considering the realities and potentials of everyday life is necessary because backwards-planning from these long-term goals will lead to appropriate curricula and instruction during the high school years (Newman, 2005). Breaking the transition planning process into segments during the final years of high school can reduce stress and allow for quick wins to raise transition team morale (Goupil et al., 2002).

The transition plan is a living document and changes with the young adult’s emerging needs and desires; the team should revisit the plan and make frequent adjustments as necessary (Goupil et al., 2002). The resulting plan should encompass all of the young adult’s environments and provide opportunities for the transitioning student to practice any skills he or she will need to meet his or her ultimate goals (Dymond & Orelove, 2001). Transition teams should be cautious not to omit critical areas of needed support (Beresford, 2004). Historically, transition teams have focused on helping the student learn vocational skills and secure employment (Lake & Billingsley, 2000); however, employment is only one of many facets of adult life and should be recognized as just a component of the plan.

Many parents lack complete understanding of the transition process and do not realize that transition planning at school should cover all aspects of the young person's life, not just employment or further education (Heslop et al. 2002; Kraemer & Blacher, 2001; Tarleton & Ward, 2005). This is not surprising, as *transition* often equates to *employment* in research projects and in practice (Beresford, 2004). In interviews, over one-quarter to one-half of parents reported that they have never seen a transition plan (Kraemer & Blacher, 2001). If this is, in fact, true, the school districts were out of compliance, but more likely there was just a simple "Statement of Transition" on a single page of the IEP that seemed so inconsequential that the parents do not remember signing it.

Everson, Zhang, and Guillory's (2002) study of transition plans in Louisiana revealed that ITPs generally followed the letter of the law and included the elements required by both IDEIA and Louisiana state law (assessment, student and family involvement, multiple agency participation, embedded transition statement, family centered supports, etc.). However, most of the ITPs did not fully uphold the spirit of the law by maximizing the transition team expertise and setting goals for each of Louisiana's "transition planning menu" objectives (e.g. financial needs, domestic needs, recreation, transportation, relationships, or advocacy). The researchers discovered that health and medical, advocacy and legal, and transportation were the least likely of the areas to be addressed (Everson et al., 2002). Only 7% of ITPs addressed health and medical objectives. The researchers concluded that the presence of the transition planning menu was insufficient because its implementation was

not required. Without legislative mandate, or training and technical assistance, implementation is unlikely (Everson et al., 2002).

Parents, with the shared expertise of the transition team, must plan for the immediate and long-term futures when their child is transitioning to adult services. Examinations of empirical research reviews in the literature similarly revealed that transition plans generally included required elements, but left out comprehensive plans for all domains of adult life (Blue-Banning et al., 2002; Goupil et al., 2002; Powers et al., 2008). Powers et al. (2008) reviewed 400 transition plans for completeness. Of these, only 36% included health and medical goals, and only six plans had detailed steps outlining how the goals would be achieved (including the skills that the student needed to learn). Similar analyses of transition plans in other locations revealed omissions in leisure-skill and vocational skill development (Goupil et al., 2002).

In Blue-Banning et al.'s (2002) research interviews, no parent participants mentioned planning for Augmentative and Alternative Communication (AAC) devices or instruction, despite the fact that students with significant disabilities have the potential to significantly benefit from AAC. Gold (1980) believed that "level of functioning is determined by the availability of training technology and the amount of resources society is willing to allocate, and not by significant limitations in biological potential" (Gold, 1980, p. 148). These omissions of AAC (or other assistive technology) in ITPs are significant, both for families' support needs and because of financial repercussions. It is imperative that families try to secure any assistive technologies or therapeutic devices the student might need before the child is released from the responsibility of IDEIA, or the

individual may never be able to procure some devices or receive some services due to lack of funds (Brown et al., 2006; Certo et al., 2009; Stewart, 2009).

Student Participation

Exemplary programs involve students in educational planning and decision making with the goal of training young adults to build informal support systems with natural supports and eventually self-manage person-directed resources (Grigal & Neubert, 2004; Wagner et al., 2005). Although students with significant or low-incidence disabilities often have communication difficulties, and the transition team often relies heavily on the parents' input and expectations, the student should also be included in the transition planning process as much as possible (Goupil et al., 2002; Izzo & Lamb, 2002). When young adults participate in the planning process, they are more committed to the transition efforts and will be more apt to attain their goals (Arndt, Konrad, & Test, 2006; Field & Hoffman, 2002; Izzo & Lamb, 2002; Johnson, 2004; Zhang et al., 2002).

Person-Centered Planning

Person-centered planning (PCP) is a values-based best-practice that transforms the transition process from a generic deficit-oriented program to one of individualized services and supports based on abilities, choice, and self-determination (Everson, 1996; Kohler & Field, 2003). According to Holburn (2002), the specific aims of PCP are to reduce social isolation and segregation by establishing friendships, increase opportunities to engage in preferred activities, develop competence, and promote respect. The foundation of person-centered planning is collaboration, shared decision making, and equality

among all stakeholders (Wehman, 2006; Whitney-Thomas, Shaw, Honey, & Butterworth 1998). Unlike traditional planning and service coordination for people with disabilities that was based on the medical model or relied heavily on social services, PCP does not rely on or support any type of professional hierarchy; therefore, the PCP process mobilizes and empowers students, families, and community members (O'Brien, O'Brien, & Mount, 1997; Micheals & Ferrara, 2003). Consequently, teams that use PCP can often circumvent and overcome the bureaucratic nature of the social service agencies (Holburn, 2002).

Person centered approaches are not deficit-oriented; rather, PCP emphasizes personal empowerment, individual- and family-driven decision making, family and friend involvement, and a focus on preferences, strengths, and goals (Whitney-Thomas et al., 1998). According to Wehman (2006), there are basic steps to implementing person-centered transition planning. First the team must convene—family, friends, Local Education Agency (LEA) representatives, community members, agency representatives and service providers—and clarify roles (Wehman, 2006; Zhang et al., 2005). The team then formulates a transition statement and chooses (or identifies) a transition coordinator. The team reviews the historical assessment data and plans or conducts any needed assessments. Transition assessment results should ensure that the right experts are on the transition team; if not, an additional person may need to be added to the team.

After the assessments are completed, the transition coordinator develops a profile of the student with the information provided by the student, family, and

friends (i.e. important relationships, places, background, preferences, dreams, hopes, and fears). The student and family, with the support of the transition team, develop outcome goals based on the information found in the profile. The student, family, and support providers should then work backwards to ensure that the student has the opportunities, experiences, services, and supports that will provide skills, knowledge, and experiences to attain the goals. The specific knowledge and skills that an IEP (or ITP) team prioritizes is not an arbitrary decision (Rainforth, York, & Macdonald, 1997). Choosing curricula, or individual skills to learn is extremely important, as these will eventually scaffold and acquiesce into the skill-set that the student enters with into adulthood (Ankeny et al., 2009). The culmination of these steps is the production of the Individualized Transition Plan (ITP)—a comprehensive plan explaining plans for future employment, post-secondary education, living arrangements, finances, socialization, transportation, medical and health choices, advocacy and legal options (Wehman, 2006).

Simply planning and writing an ITP does not translate into outcomes; the team must modify the ITP when it needs changing (Blackorby & Wagner, 1996; Wehman, 1992, as cited in Sabbatino & Macrine, 2007). Team members must also facilitate implementation of the ITP, and provide regular monitoring, with an agreed-upon method of accountability (Williams & O'Leary, 2001). In addition, when the student is in the last year of school, the exit meeting should occur. This meeting clarifies which goals were met and which are still in progress; which adult service providers are taking over the services formerly provided by the LEA; and officially wraps up the transition planning process. The student's

information and all accompanying documents are forwarded to responsible agencies at the conclusion of the exit meeting (Williams & O'Leary, 2001).

There are several commercially available person-centered planning curricula available. Some of the most widely used are Planning Alternative Tomorrows with Hope—PATH (Pearpoint, O'Brien, & Forest, 1993), Personal Futures Planning (Mount, 1994), Essential Lifestyle Planning (Smull & Harrison, 1992), McGill Action Planning System—MAPS (Vandercook, York, & Forest, 1989), and Whole Life Planning (Butterworth et al., 1993). Whether a commercially available program is used or not, the steps previously mentioned are the same. Person-centered planning takes more time than other methods of planning (Holburn, 2002), but for PCP to work, fidelity to the process is critical.

Families and professionals report that PCP is rarely as ideal as described in the literature. Parents report that new services are rarely developed if existing supports do not match the transitioning individual's needs or preferences (Cooney, 2002; Lake & Billingsley, 2000; Smart, 2004). Professionals often ask parents to compromise by choosing services that are significantly different from the individualized supports initially determined to be ideal for the transitioning young adult. Some professionals feel that the parents are unreasonable and asking for "Rolls-Royce services" that the LEA is not obliged to provide (Runswick-Cole, 2007, as cited in Hodge & Runswick-Cole, 2008, p. 621). Nevertheless, pre-selected options pressure parents to choose from the best of the worst and add to an already uncomfortable situation (Murray, 2007). Parents have reported that this sometimes led to verbal arguments during planning meetings (Cooney 2002).

The meeting facilitator is the key to successful PCP; this individual must have a unique blend of enthusiasm and patience, be a creative problem-solver, and not fall back to traditional methods of planning when the transition planning gets difficult or seems like it is not progressing fast enough (Holburn, 2002).

The goal of PCP is a customized adulthood—this often takes mobilizing people and resources in a human services system—no small feat. The meeting facilitator must help the team celebrate quick wins and remind team members that by persevering and remaining committed to the individual's development and the PCP philosophy, the transitioning student can live, work, and play as he or she chooses.

Student Development Resulting in Successful Adult Outcomes

Transition programs that best prepare students are those that build skills in multiple areas of students' lives: self-determination, functional skills, academic skills, and employment skills (Kohler & Field, 2003). Learning and teaching should occur in both school and community-based environments for maximum generalization of skills.

Self-Determination Instruction

The Rehabilitation Act of 1973 protected the rights of people with disabilities, and the Rehabilitation Act Amendments of 1992 and 1998 included the strongest and most specific statement about self-determination and people with disabilities of any law to date:

Disability is a natural part of the human experience and in no way diminishes the right of individuals to—live independently; enjoy self-determination; make choices; contribute to society; pursue meaningful

careers; and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society. (29 U.S.C. § 701[a][3])

Self-determination is a combination of skills, knowledge and beliefs that enables a person to engage in goal-directed self-regulated behavior (Field et al., 1998), or, "the ability to identify and achieve goals based on a foundation of knowing and valuing oneself" (Field & Hoffman, 1994, p. 164). The term self-determination is also used to describe the philosophy that all individuals have the right to make decisions regarding her or her life (Johnson, 2004). Self-determined students take an active role in the transition planning process and the selection and use of adult services (Roy & Casper, 2006). As a result, individuals who possess high levels of self-determination are more committed to transition efforts and will be more apt to attain their goals (Arndt et al., 2006; Zhang et al., 2002).

Consistently, the literature shows that successful transition programs teach students to be self-determined using systematic instruction—consistent, individualized opportunities to participate in activities that offer choice and decision-making in various environments (Allen, Smith, Test, Flowers, & Wood, 2001; Arndt et al., 2006; Benz et al., 2000; Green & Kochhar-Bryant, 2003; Morningstar, 1997; Powers, et. al., 2001; Thoma, Rogan & Baker, 2001; Ward, 2005, 2006; Wehmeyer & Schwartz, 1997; Zhang et al., 2002). Despite the push for increased self-determination, young people with disabilities are still not consistently taking the lead when it comes to planning for their future, with

almost one-quarter having essentially no involvement in their transition planning (Heslop et al., 2002). According to Wehmeyer (1996), teachers should focus curricular and instructional efforts on promoting the acquisition of the skills and attitudes associated with the twelve "component elements of self-determined behavior" including: (a) choice-making; (b) decision-making; (c) problem-solving; (d) goal-setting and attainment; (e) independence, risk-taking and safety; (f) self-observation, evaluation and reinforcement; (g) self-instruction; (h) self-advocacy and leadership; (j) internal locus of control; (k) positive attributions of efficacy and outcome expectancy; (l) self-awareness and, (m) self-knowledge. However, throughout the field, it appears that teachers are reluctant to include self-determination objectives in IEPs (Wehmeyer, Agran, & Hughes 2000; Wehmeyer & Schwartz, 1997; Zhang, 2005; Zhang et al., 2002). This may be a result of teachers' lack of confidence, as teachers report feeling ill-prepared to teach self-determination skills (Agran, Snow, & Swaner, 1999; Grigal, Neubert, Moon, & Graham, 2003). There are published self-determination curricula to assist teachers of students of all ages, including some specifically designed for students with significant cognitive disabilities or communication deficits. However, very few of the commercially available self-determination curricula have been empirically validated (Eisenmann, 2001).

The Self-Determination Synthesis Project is a national center that houses a database about self-determination curricula, disseminates research, and offers examples of exemplary special education programs using self-determination instruction. Researchers often describe ideal programs that support self-

determination goals as also incorporating many of the other valued practices mentioned in this review of literature: community-based learning, functional curricula, learning in inclusive environments, and incorporating family references and natural supports (Morningstar et al., 2010; Wehmeyer, Agran, & Hughes, 1998). In addition, when both students and teachers have strong administrative support and mentor programs, students' self-determination can be encouraged and practiced beyond the classroom in a variety of environments (Johnson, 2004; Wehmeyer et al., 1998).

Parental support and family involvement is critical for the development of student self-determination (Grigal & Neubert, 2004; Morningstar et al., 2010; Wehmeyer, 1996; Zhang et al., 2002). However, this may not come naturally for all parents; some parents may wrestle with anxiety as their children become self-determined. For some parents, there may be a fine line between wanting young adults to make their own decisions and have typical experiences, and wanting to protect them (Ankeny et al., 2009).

When given a list of potential instructional areas, 61% of parents with young adults who had significant disabilities ranked self-determination as the first, second, or third priority for secondary instruction (Grigal & Neubert, 2004). Despite the importance of parents supporting the development of self-determination in children and young adults, fewer than half of parents in Zhang, Katsiyannis, and Zhang's (2002) study report participating in self-determination activities. To prevent or lessen this in families of students, Zhang, Wehmeyer, and Chen (2005) suggest that teachers train families how to promote self-determination at home.

Throughout the literature, there is general agreement on the definition of self-determination, but there is departure when self-determined behaviors must be operationalized. Simply attending a meeting is not indicative of self-determination. During transition, a more relevant indicator is that a self-determined individual mobilizes and redirects public funds, using money as a tool to attain individual goals (Turnbull & Turnbull, 2006).

Simply possessing self-determination does not guarantee autonomy or authority. A self-determined student who participates in transition and IEP meetings is not automatically granted decision-making power; the student must still defer to parents and professionals until the age of majority, as the law presumes that until then, the student does not possess the knowledge to make an appropriate judgment (Izzo & Lamb, 2002). Even when students with significant or low-incidence disabilities that include communication difficulties must rely on parents to convey appropriate input and expectations, the team should make efforts to include the student in the planning process as much as possible (Goupil et al., 2002). Surveys of the literature, however, reveal that there is limited participation, if any at all, of students with significant disabilities participating in transition planning (Beresford, 2004; Heslop et al., 2002).

The literature also fails to reveal many studies that report empirical evidence that substantiates self-determination inputs yielding positive transition outcomes for individuals with significant disabilities (Wehmeyer & Palmer, 2003). Wehmeyer and Palmer (2003) examined the relationship between self-determined behaviors and post school outcomes at one and three years post-transition. The data showed that individuals who were very self-determined

(initially and three years later) had significant differences in income, employment status, and well-being. According to Test, Fowler, Kohler, and Kortering (2010), several more studies of this nature (or two large, longitudinal studies) should be conducted in order to provide solid empirical evidence for what is widely held as an irrefutable fact in the field (that is, that self-determined individuals have better adult outcomes).

Functional Life Skills Instruction

Life skills and *functional skills* are often used interchangeably, and are skills that have practical applicability to adulthood (Cronin, 1996). Functional life skills can be grouped in five broad skill domains: self-care and domestic living, recreation and leisure, communication and social skills, vocational skills, and community living skills (Nietupski, Hamre-Nietupski, Curtin, & Shrikanth, 1997). Skills practiced in isolation rarely match students' needs and preferences, nor readily generalize into natural settings (Hart et al., 2002). Thus, the learning environment should be structured and managed to provide opportunities for young adults to learn skills while performing age-appropriate tasks in authentic situations.

Alwell and Cobb (2006) reviewed the literature published in the last twenty years to find and summarize scientifically-based research studies (i.e. studies that meet the criteria established by the Education Sciences Reform Act of 2002) that documented the outcomes (by measuring effect sizes) of life skills interventions, specifically domestic/self-help curricula, community participation curricula, and recreation/leisure curricula, for students aged 12-22. Just fifty studies fit the intervention, outcome, and sampling selection criteria for the

review; and also had methodological features that met minimally acceptable standards of internal and external validity.

Seventeen studies measured the impact of domestic or self-help curricula: five studies related specifically to housekeeping, three to cooking and meal preparation, one to laundry, and one study measured sewing machine use. Three studies measured gains in knowledge of person and self-care, and three measures gained in self-monitoring and reduction of problem behaviors. One additional study measured the effect of applied behavior instruction (ABA).

Some studies simultaneously measured more than one domain or skill, and overwhelmingly, the most instruction was for community participation. Money skills were most commonly taught (budgeting, 5 studies; dollar up strategy, 2 studies; speed counting bills and change, 1 study; purchasing, 8 studies). Three studies addressed general community-based instruction, including recognition of sight words and inclusive behaviors. Three studies were conducted on self-protection, and two others measured the effectiveness on teaching students to safely cross streets. Thirteen studies were related to recreation and leisure (games and activities, 5 studies; exercise/sports, 6 studies; general awareness and perception, 2 studies). According to Chambers et al. (2004), recreation is usually not as much of a priority for instruction, despite the fact that it is a priority for families.

“The essence of life skills acquisition cannot be weighed in terms of degrees, diplomas, or other documents; rather, it is demonstrated in their level of independent living, community adjustment, and enhanced quality of life” (Cronin, 1996, p. 53). This may help explain why there were only fifty

publications within the past twenty years surrounding life skills that met the guidelines for empirical research. Teachers and researchers may have neglected the objective, measurable component because the outcomes of successful life skills instruction may be longitudinal or amorphous as, once again, mastery of these skills are correlated with quality of life.

Academic Skills Instruction

Historically, students with significant disabilities were taught functional life skills curricula with much less attention to functional academics. However, since the mandates of NCLB and IDEIA, public schools teach both functional life skills and academic curricula and commonly include both types of goals on IEPs (Browder et al., 2007; Williams & O'Leary, 2001). Moon and Inge (2000) acknowledge the necessity of NCLB and other education legislation that mandate the inclusion of academic instruction for students with significant intellectual disabilities, but caution that IEP goals and accompanying instruction will look different than the academic content for students with milder disabilities.

Without exception, special education programs that use functional life-skills curricula with community-based instruction to teach students with significant disabilities have consistently better transition outcomes than programs that place more emphasis on functional academics or only allow students to practice newly acquired skills in artificial environments (Green & Kochhar-Bryant, 2003; Lim, Girl, & Quah, 2000). An effective approach for planning academic instruction is to refer to the PCP and/or conduct an ecological inventory of future environments to determine the skills that will be needed during adulthood. An ecological inventory of the student's current

environments will reveal the most appropriate opportunities for instruction and opportunistic learning (Collins, Karl, Riggs, Galloway, & Hager, 2010; Snell & Brown, 2005).

Literacy. Research reveals that children with severe disabilities have only a 30% chance of being able to read and write as well as their peers (Koppenhaver, 1991). According to Light & Kelford-Smith, this is due to the prioritization of the students' needs—literacy is not seen as being as critical for development as medical or other basic care needs (Light & Kelford Smith, 1993). Parents claim that teachers do not hold high enough expectations for their children, and perceive the self-contained classrooms as childcare facilities—where students lounge and “vegetate” all day—rather than learning environments (Kim & Morningstar, 2007; Lim et al., 2000; Spann et al., 2003). Even when students with severe disabilities do participate in literacy instruction, it is likely not the caliber of instruction usually given to their peers; rarely are these students immersed in literature or composing their own texts (Kliewer & Landis, 1999; Koppenhaver & Yoder, 1993).

Research showed that when students with significant disabilities learned to read, there were two common components. The first is that an intimate friend or family member, the person closest to the student, recognized the student's potential and capacity to learn (Erickson & Koppenhaver, 1995; Kliewer & Biklen, 2002). The other critical component is that the student was exposed to models of best practice in literacy instruction—similar to the instruction that typical children receive on a regular basis (Erickson & Koppenhaver, 1995). Students with significant disabilities start learning to read in the same general

way that typical children do; these individuals learn sounds, symbols, and phonemic awareness. However, students with significant disabilities will often not be successful if teachers require the mastery of prerequisite skills before teaching new skills once the student seems to plateau (Erickson & Koppenhaver, 1995; Kliewer & Biklen, 2002).

Kliewer and Biklen (2002) equate normal teaching methods with a ladder. Typically, reading instruction begins on one end of a continuum and progresses step-like through individual sub-skills that become increasingly complex. When a student reaches a step that he or she cannot master, this usually marks the end of the student's progression toward literacy. A more dynamic and valued method for teaching individuals with disabilities is varied interaction with and exposure to printed language and symbols. Consequently, teachers must provide direct instruction, but not in the traditional sequence (Kliewer & Biklen, 2002). Literacy instruction for students with severe disabilities is still in the infant stages, but it is clear that differences in communication do not necessarily equate to differences in capacity for learning.

Numeracy. Numeracy is a relatively obscure term, unused outside of education circles: "to be numerate is to use mathematics effectively to meet the general demands of life at home, in paid work, and for participation in community and civic life" (Australian Association of Mathematics Teachers, 1997, p. 15). Mathematics has five broad content areas: number and operations, algebra, geometry, measurement, and data analysis and interpretation. Many studies report success using systematic instruction to teach specific math skills; however, since many students with significant

disabilities follow routines, Browder and Cooper-Duffy (2003) recommend also embedding mathematics instruction into daily routines for ongoing practice opportunities and a link to functional uses.

Browder, Spooner, Ahlgrim-Dezell, Flowers, and Algozzine (2005) reviewed the literature to discover that 27 of 55 studies involving math skills and students with significant disabilities involved money-management. Students with significant intellectual disabilities are most often taught functional skills and specific math applications related to telling time, managing money, and performing measurements, as these are both functional and usually linked to national and state standards in math (Browder et al., 2006; Browder & Cooper-Duffy, 2003). Very rarely are students with significant disabilities exposed to more than basic math skills. However, teachers should be familiar with the five content areas in math in order to properly choose instruction that will support students' transition goals (Browder, et al., 2006). Mathematic instruction should be sequential to scaffold upon previous knowledge and skills and tied to long-term community, residential, and employment outcomes.

Faragher and Brown (2005) studied the effects that numeracy had on quality of life. Qualitative interviews and observations showed that choice and personal control were affected when adults were not numerate because individuals were forced to rely on others to interpret numbers—which led to financial dependence even when individuals were working and earning wages. On the contrary, the numerate individuals were more empowered and used math skills in areas of self-interest and benefit (e.g. measuring weight loss and saving for travel) (Faragher & Brown, 2005).

Employment Education, Skills Training, and On the Job Practice

The Carl D. Perkins Vocational and Applied Technology Education Act of 1990 provided states with money to fund vocational education, work-study, and post-secondary technical education programs. Effective transition programs capitalize on this resource and include vocational education and supervised work experiences to prepare young adults for post-secondary employment when the intensive educational supports and training will not be as readily available (Allen, 2007; Benz et al. 1997; Frank & Sitlington, 2000; Izzo & Lamb, 2002). This vocational preparation also translates into higher wages for individuals than for those who did not have vocational training (Zhang et al., 2005).

Paid work experiences in natural settings. Students preparing to transition from the secondary setting should be given the opportunity to have paid work experiences in natural, community-based settings (Benz et al. 1997; Benz et al., 2000; Frank & Sitlington, 2000; Greene & Kochhar-Bryant, 2003; NCD, 2010). Work-based learning reinforces basic academic and technical skills and extends these skills into natural environments (Benz et al., 1997; Izzo & Lamb, 2002; Luecking & Gramlich, 2003). According to the NCD (2010), when students have paid work experiences, realistic expectations of themselves and realistic perceptions of careers, job opportunities, and responsibilities develop. Students also learn to use social skills in a real-world context while developing a network of potential job opportunities (Luecking & Gramlich, 2003; Roy & Casper, 2006). Real-life work experiences help young adults develop important career-related skills such as teamwork and time management, and

also give individuals the opportunity to make career decisions while the planning team is available to give any needed assistance (Roy & Casper, 2006).

According to the National Council on Disability (2010), across the United States, students are not being afforded enough work experiences before leaving high school. This has dire consequences for students; besides exploring potential interests and career options, students are missing out on valuable work experiences and the opportunities to develop basic work skills. Employers rely on individuals who have basic, generalizable skills that can transfer between employers during job shortages (such as the one the U.S. is currently experiencing). More importantly, longitudinal research reflects that students who are already employed upon exiting high school are more likely to maintain employment longer, be rehired due to their work experience, require less supports from adult service providers, use natural supports (co-workers) more, and attain a higher quality of life as a result (Condon & Callahan, 2008; Muller, Schuler, Burton, & Yates, 2003, as cited in Allen, 2007; NCD, 2010; Roy & Casper, 2006; Sax & Thoma, 2002).

Several longitudinal studies demonstrated that young adults who were taught job-specific skills and gained knowledge during paid work experiences were then able to maintain employment after graduation (Allen, 2007; Kohler, 1993, as cited in Sabbatino & Macrine, 2007). In Raben, Dunn, and Chamber's (2002) study, 87% of the students who participated in paid work experiences with initial significant supports as part of their transition preparation, were still employed one year after exiting high school. When a student with disabilities has paid work experiences in natural settings before leaving the secondary

environment, the student gets exposure to many different career options while teachers, transition coordinators, and team members can identify and plan for the supports that the individual needs in the workplace (Hughes & Carter, 2000; Luecking & Gramlich, 2003; Roy & Casper, 2006). In Migliore et al.'s (2007) research into the preferences of sheltered workshop attendees, families, and support staff, the individuals who had paid work experiences were most confident in their ability to work in integrated community settings. Ideally, a transitioning student who has had paid work experiences will not transition to a sheltered workshop, as paid work experiences will translate into immediate and permanent employment for every student upon exiting high school, regardless of the severity of their disability (Brown et al. 2006; Condon & Callahan, 2008).

Post-Secondary Education

Approximately 30% of students with disabilities continue to post-secondary education (PSE). However, only 2% of students with significant disabilities continue to PSE (Heath, 2003, as cited in Wittenburg, Fishman, Golden & Allen, 2000). When asked, many parents choose post-secondary education as a transition goal for their children, regardless of the severity of disability—in some instances writing it as a goal while having no knowledge of how to make that dream a reality (Grigal & Neubert, 2004). There are currently over 250 PSE programs in the U.S.; approximately half of these programs are dual-enrollment programs for students aged 18-21 that allow students to continue receiving services under the LEA and fiscal umbrella of IDEIA, but in a more age-appropriate environment with more opportunities than a traditional high school environment (Grigal & Dwyer, 2010; Hart, Grigal, & Weir, 2010).

Although many individuals with disabilities may not be qualified for traditional university admissions, dual-enrollment PSE programs afford young adults with intellectual disabilities the opportunity to build vocational skills, expand social networks, learn academic material, and bolster independence and self-determination in an age-appropriate environment while still receiving IDEIA-funded services (Grigal et al., 2002; Griffin, McMillan, & Hodapp, 2010; Hart et al., 2006). There are three different types of dual-enrollment PSE models: substantially separate, mixed or hybrid, and individualized inclusive (Grigal & Neubert, 2004; Hart et al., 2006).

A substantially separate model is similar to a self-contained class on a high school campus. There is not ongoing or sustained interaction with typical peers (Hart et al., 2004). Students participate in programs with other students who have disabilities. Employment experiences may be embedded into the program, but are usually pre-selected so that students go through a rotation of job experiences. Because of the segregated nature of the experiences, Neubert and Moon (2006) found that substantially separate programs for students 18-21 existed in many locations besides postsecondary institutions—business location, apartments or houses, or non-site-based locations. Many of these programs were created decades ago in response to parent and teacher concerns about the age-appropriateness of high school for students 18-21; however, in light of evolving philosophy, research, and accompanying legislation, separate models are no longer providing innovative services, nor are models of best-practice (Hart et al., 2010; Neubert & Moon, 2006).

In a mixed or hybrid model students participate in inclusive classes and campus activities, while concurrently attending class(es) with other students who have disabilities. Individualized employment experiences are also usually embedded into this model, often with a transition coordinator or job coach's assistance. A strength of this model is the interagency collaboration and cooperation required between the postsecondary institution and the LEA; however, there are also additional challenges, as the LEA may need unique policies and procedures for students and teachers at the college campus who have different schedules and a separate academic calendar (Neubert & Moon, 2006). Faculty and staff who facilitate this model must be comfortable and proficient with problem solving (Sulewski, Gilmore, & Foley, 2006).

Hybrid programs allow students to target individualized goals, while building social networks and learning in inclusive environments. Students in hybrid programs often attend high-interest courses for credit, or functional non-credit courses: health and fitness, the arts, computers, basic literacy, remedial math (Grigal & Dwyer, 2010; Neubert et al., 2004). Neubert et al. (2004) found that a significant number of students (n=100) were not taking any classes at all; however, the instrument did not provide enough information to determine if this aligned with the students' goals.

Students involved in hybrid PSE programs typically participate in inclusive campus-wide activities that result in increased independence, self-determination, larger social networks and better quality of life (Hart, Grigal, & Weir, 2010). Students that do not participate in extra activities cite conflicting work schedules, lack of social support or unreliable transportation that prevent

returning to campus after-hours to participate in campus-wide activities (Neubert et al., 2004). Transportation is a consistent challenge, and a significant amount of LEA funds are funneled to transportation (Hart et al., 2004; Grigal & Dwyer, 2010.)

In an inclusive individual support model, students receive individualized services in college courses, certificate programs, or degree programs. There is not a prescribed program or curriculum; each student's person-centered plan dictates an individualized plan of study with opportunities for skill development and appropriate experiences. This model relies heavily on interagency cooperation and planning (Neubert et al., 2004). To date, there has been little research documenting the transition outcomes of students who participate in PSE programs, but individualized PSE resulted in students with high rates of employment with higher wages than students who remained in traditional high school programs (Grigal & Dwyer, 2010; Zafft, Hart, & Zimbrich, 2004).

According to the National Council on Disability (2010), because of the community college system's focus on career and technical education (CTE), the local community college is often the perfect link to transition students to productive careers. Community college programs are designed with embedded work experiences; therefore, these do not have to be built-in as an adaptation for students with disabilities (NCD, 2010). The CTE programs also often have job-placement as an end-goal and are connected with employers in high-demand jobs. According to VR exit-data, young adults with ID are 26% more likely to attain employment and earn a 73% higher weekly income if the

individual has participated in a PSE program (Migliore, Butterworth, & Hart, 2009).

When PSE was a new concept, a pressing challenge was that students were denied admission because they were not otherwise qualified for admission to the university or community college program, most often due to exiting high school without a diploma. Other times, if admission requirements were waived in lieu of alternate program requirements, sometimes funding was an issue if the student was no longer receiving LEA funds, because students are were not eligible for student loans without a diploma (Hart et al., 2006). Since then, a series of changes to legislation made it more possible for students with disabilities to attend college, beginning with H.R. 609: College Access and Opportunity Act of 2005. This allowed students with intellectual disabilities who are enrolled in PSEs, but are no longer under the fiscal umbrella of IDEIA, access to federal work-study funds (it was later reauthorized by the Senate (2007) and House (2008) under Title VII of the Higher Education Act (HEA)]. In 2008, President George W. Bush signed H.R. 4137, the Higher Education Opportunity Act (HEOA; P.L. 110-315), which also allowed students with intellectual disabilities attending PSEs to be eligible for Pell Grants, Supplemental Educational Opportunity Grants, as well as the Federal Work-Study Grants (Title IV, Part G, § 485). H.R. 4137 also authorized the establishment of a national center for new college programs for students with intellectual disabilities that would provide evaluation; technical assistance and outreach; develop recommendations for model accreditation standards; and

disseminate research findings to postsecondary programs, families, and prospective students (Title VII, Part D, Subpart 4, Sec. 777[b]-778).

In Hart et al.'s (2004) profile of PSE programs, respondents reported that some students faced attitudinal barriers from faculty who feared the college curriculum was losing integrity. Zager and Alpern (2010) point out that all students deserve a presumption of competence; additionally, students who are taking classes for credit do so knowing that the course will have unwavering standards, and are prepared—with the transition team—to provide supports (Zager & Alpern, 2010). Usually very little is needed from the instructor. People with intellectual disabilities may need planning and supports to enjoy a quality of life that promotes independence, self-determination, and participation as productive members of society (PCPID, 2004). However, participation begins with social inclusion: full and equitable access to activities, social roles and relationships in the community (Bates & Davis, 2004). When individuals with disabilities live, work, and play in the community, reciprocal relationships are established, and traditional stereotypes are challenged. Post-secondary programs that offer dual-enrollment are age-appropriate, community-based, and often result in better transition outcomes for students who build social networks during employment and learning experiences.

Direct Instruction in Social Skills and Building Friendships

The ability to communicate with others, including correctly interpreting body language and understanding social mores, is important in every environment. Appropriately reciprocating during social exchanges has a direct impact on both how an individual feels about him or herself, and how he or she

is perceived by others. Because of this, some researchers and practitioners agree that social skill instruction is the most critical component of curricula. Social skill instruction not only facilitates students' participation in secondary settings, but also enables young adults to learn to make and sustain friendships and exhibit socially appropriate behaviors in natural settings within the community (Allen, 2007). However, social skills must be directly taught; co-location does not facilitate friendships or naturally guarantee social participation (Bates & Davis, 2004; Jorgensen, 2007). Students must first be taught how to make friends and then given opportunities for networking and building reciprocal relationships (Bates & Davis, 2004).

Whitehurst (2006) studied six students involved with a drama club for two years to find out how the students with disabilities felt throughout the experience. The participants with significant disabilities reported feelings of anxiety, apprehension, and insecurity similar to typical peers. Although the students with disabilities did not make friends with their peers, the peers treated them fairly. Only one participant had a negative experience.

Students' interactions during school hours set the tone for their interactions outside of school; therefore, inclusion is the preferred environment for teaching social skills because it provides the opportunity for more skill practice, allows students a variety of people to practice with, and increases the likelihood for students to develop friendships (Downing & Peckham-Hardin, 2007; McDonnell, Wilcox, & Hardman, 1991). Like functional and academic skills, role playing, counseling, and social skill instruction and practice should occur with family, classmates, and various people in natural settings throughout

the community, in order for the appropriate behaviors to be transferrable (Allen, 2007; Greene & Kochhar-Bryant, 2003; Wehman, 2006). Teachers must also make sure that they pay attention to trends and what typical peers are saying and doing in order to teach and reinforce age-appropriate behaviors for their students (Jorgensen, 2007).

Collaborative Service Delivery

When planning for the transition to adult services, transition teams must be long-term visionaries, yet practical; existing resources should be identified and experts assembled to meet the student's anticipated adult needs (Goupil et al., 2002). It is unlikely that the school district's transition coordinator has up-to-date knowledge of policy, practices, and trends for the vast range of options available over the different sectors involved with the planning process—social services, health, higher education, leisure, employment, etc. (Goupil et al., 2002; Neece et al., 2009; Rude et al., 2005). Because of this, it is impractical for the LEA staff alone to facilitate an appropriate transition plan (Tarleton & Ward, 2005). For example, in multiple studies, LEA personnel admitted that they lacked knowledge about post-secondary options or familiarity with adult services (Goupil et al., 2002; Rude et al., 2005). And, unlike traditional age 3-21 (IDEIA-funded) education and supports, adults' (with disabilities) goals and interests cannot be effectively supported or funded by one agency (Beresford, 2004). Therefore, interagency collaboration should occur between the LEA, private adult agencies, government agencies, employers, and community organizations (Condon & Callahan, 2008; Greene & Kochhar-Bryant, 2003; Luecking & Certo, 2002, 2003; NCD, 2010; Rude et al., 2005).

The transition process takes time and long-term coordination between families, LEAs, current caregivers, and potential service providers (Goupil et al., 2002). When interagency collaboration occurs, there is increased flexibility, more family directed service choices, and smoother community based delivery of person-centered supports (Baker & Stahl, 2004; Epstein, 2005; Grigal et al., 2005; Weir, 2004; Wittenberg et al., 2002). Students benefit from transdisciplinary and interagency collaboration because team members share expertise to offer support and problem solving, but also because the team views the student holistically and with subject area or agency-specific lenses (Garner & Orelove, 1994). A transition team with multiple agencies collaborating together should be a “synthesis of collaborative dialogue and shared expertise” (Jelly et al., 2000, as cited in O’Connor, 2008).

Despite the need for collaborative expertise, adult service agencies rarely attend IEP or transition planning meetings (Chambers et al., 2004; D.J. Kennedy, 2003; Noyes & Sax, 2004; Shapiro et al., 2004; Timmons, Whitney-Thomas, McIntyre, Butterworth, & Allen, 2004). However, this lack of attendance may, in fact, be partially due to lack of invitation by the LEA or family. Nevertheless, without staff to cultivate collaboration by establishing relationships and networks between agencies, bureaucratic constraints and barriers to understanding such as a lack of cross-agency knowledge, long waiting lists, and limited financial resources will not begin to dissolve, and the transitioning student will not get cohesive, streamlined services (Hart, Zimbrich, & Whelley, 2002). Additionally, future transitioning students will be, once again, starting from the ground-up, as there will not be an established relationship or

procedural base among the providers from which to build. Noonan, Morningstar, and Ericksen (2008) found that expecting others to conform to the school hours of 8-3 is unrealistic, and flexible schedules for LEA staff are often necessary to accommodate family preferences and requirements of many service providers.

Service coordination and collaboration between LEAs and adult service agencies are often less than ideal, and in many places, non-existent (Johnson, 2004). Noonan et al. (2008) found that LEAs who had administrative support for maximizing interagency collaboration were more successful than other districts who relied on LEA resources alone: employing flexible scheduling, seeking external funding, using state-supported technical assistance, and cross-training staff on adult services. The districts with the most successful interagency collaboration also did not keep transition-specific knowledge within the special education department; these districts trained parents, staff throughout the district regardless of age or subject-area, and community members (who may or may not ever come in contact with the LEA's former students).

Interagency collaboration is required in legislation and has been identified as a best-practice. However, there is not a best-model—just valued characteristics of good, effective teams: shared case-management (across agencies); strong relationships between providers, young adults, and their families; and independent advocates available to provide an unbiased stance and another voice on behalf of the transitioning young adult (Benz et al., 2000; Beresford, 2004). The defining characteristic of an effective team is the typical method of communication. Effective collaborators communicate using positive

terms, speak respectfully, and use language that can be understood by all—not jargon, rhetoric, or overly-charged or condescending language (Blue-Banning, Frankland, Nelson, & Beegle, 2004). Above all, each team member must be committed to the child and family (Blue-Banning et al., 2004). When there is shared expertise, all parties benefit. Interagency collaboration helps eliminate service gaps and duplication of services, increases efficient use of limited funds, and relieves caregiver burden as a result of assisting with a myriad of family needs (Beresford, 2004; Crane et al., 2004; Epstein & Jansorn, 2004; Harry, 2008; Hart et al., 2001; Luecking & Certo, 2002, 2003; Stewart, 2009).

Collaborative Framework

IDEIA requires a statement of interagency responsibilities and linkages to ensure a continuity of services after students with disabilities leave school; however, research reveals that young adults and their parents still have difficulty finding, accessing, and relying on service providers (Hetherington et al., 2010; Timmons et al., 2004). There is insufficient school district staff, both in numbers and training, to meet the needs of students during the transition period (Beresford, 2004; Heslop et al, 2002; Morris, 2002; Rude et al., 2005; Smart, 2004). In published interviews, parents told of experiencing frustration due to poorly coordinated services and needing to constantly remind each provider to send copies of documents to other relevant parties (Murray, 2007). Often, parents would often have to follow-up and remind the service provider a second-, or third-time, to send the documents to the other team members (Murray, 2007). Inconsistency in services exacerbated existing tension and unsteady relationships between parents, schools, and service providers.

Parents also expressed anxiety in never knowing what quality of service to expect from year to year or from agency to agency (Smart, 2004; Timmons et al., 2004). Often families had to take on an adversarial role to fight for funding or services, or simply to persist for information that should have been readily available (Hetherington et al., 2010). Parents reported that it was rare for a school or agency to have procedures for communication with families; on the contrary, the quality of services and frequency of communication usually depended solely on the quality of relationships parents had with an individual service provider at the time (Lake & Billingsley, 2000; Timmons et al., 2004). Lack of established communication procedures and unreliable personnel sometimes resulted in missed opportunities as parents “stumbled” on information too late after registration deadlines passed (Blue-Banning et al., 2004, p. 175; Hetherington et al., 2010). If professionals do not follow up on commitments, fail to provide information, or provide otherwise poor services, parents’ feelings of discomfort may increase and prevent the parent from properly asserting his or her child’s right to timely, professional service (Cooney, 2002; Kim & Morningstar, 2005).

Interagency agreements. To increase the likelihood of successful collaboration and hold each individual agency accountable for its expectations, a valued practice is for transition planning teams to request that outside agencies write interagency agreements outlining the roles, responsibilities, and communication expectations for each entity (Benz et al., 2000; Crane et al., 2004; Hasazi, Furney, & DeStefano, 1999; Zhang et al., 2005). Some transition programs separate the members into three designated teams—a community-

based, school-based, and an individual-based team—so that transitioning young adults have designated groups allied by appropriate areas of expertise to efficiently meet every need (Aspel, Bettis, Quinn, Test, & Wood, as cited in Zhang et al., 2005). There are usually not punitive measures outlined in interagency agreements for agencies that fail to provide agreed services or supports; therefore, the strength of an agreement lies in the fidelity to which collaborators follow through on their responsibilities. Therefore, strong collaboration and positive team dynamics are still necessary for good outcomes (Crane et al., 2004).

Case Managers and Transition Coordinators

Exemplary transition programs have measures in place to ensure that with all service providers working together, the parent's role remains that of a parent—not service coordinator (Dymond & Orelove, 1994). The transition coordinator can support parents by giving information and helping families to formulate realistic, high expectations (Beresford, 2004). However, this support does not simply cease upon the student's exit from the LEA, these support staff also establish long-term case management across agencies to take over the family support after the transition process is complete (Beresford, 2004; Rusch & Braddock, 2004). This helps to ensure that the family does not feel abandoned once the young adult transitions from the care of the LEA and the protections and provisions of IDEIA.

Despite the call for long-term family support and case-management, for most students there is not a central repository for information, nor one reliable coordinator to organize and keep up with the multiple agencies and support

providers (National Center for the Study of Postsecondary Educational Supports [NCSPSES], 2000). Parents report being frustrated as they worked to secure funding, find suitable support personnel, and rectify other issues that should be the responsibility of a professional case manager (Hetherington et al., 2010; McLaughlin, Goodley, Clavering, & Fisher, 2009; Murray, 2007). This often requires more than stamina, but also learning new terminology, advocacy, and management skills (Hart et al., 2002). In some cases, the parent is simply not authorized to enforce interagency agreements that require agency oversight to remain effective (Crane et al., 2004). When parents feel obligated to perform time-consuming and emotionally-demanding jobs—acting as the lynchpin or making sure professionals' duties and responsibilities are completed—(McLaughlin et al. 2009; Murray, 2007; Timmons et al., 2004), the added role of case manager will leave parents confused and overwhelmed (NCSPSES, 2000).

Published interviews with case managers and social workers gave an overall indication that service providers had a sincere desire to facilitate a successful transition, but were overwhelmed by the demands of the vocation, the complexity of navigating “the system,” an ever-increasing case load, and constant budget cuts (Cooney, 2002; Downs & Carlon, 2009; Tarleton & Ward, 2005; Wright, Hiebert-Murphy, & Trute, 2010). Case managers and social workers indicated that large case loads result in less time to get to know individuals, and admitted that families might receive lackluster services as a result of the service provider's unfamiliarity with service options and lack of a personal relationship with the young adult and family (Downs & Carlon, 2009; Tarleton & Ward, 2005; Wright et al., 2010). Case managers also expressed

frustration at the difficulty experienced when attempting implement family-centered care while collaborating with agencies subscribing to a traditional professional-hierarchical model (Downs & Carlon, 2009); collaborating with these agencies was considered “difficult at best, and generally impossible” (Wright et al., 2010, p. 122). An overwhelmed case manager explained that he did not shift as many responsibilities to the families as he would like, because the policies and bureaucracy would likely be too difficult for the families to handle (Downs & Carlon, 2009). Due to the overwhelming amount of tasks required of most social workers, it is also unlikely that the assigned case-manager will keep up-to-date with the most innovative supports, trends, or best-practices for serving adults with significant disabilities.

Case managers based at the LEA who do provide follow-up services often report collecting data on transition outcomes, but admit not knowing what to do with it (Noonan, Morningstar, & Ericksen, 2008). This is unfortunate, as data is likely forwarded to state departments of education for SPP reports, but then left to linger—not used to improve local transition efforts as intended. However, case managers and transition coordinators report that families return (on their own accord) to ask for information and linkages when needing new services (Noonan et al., 2008).

Program Structure and Policies

Schools that have exemplary transition programs, not only support families, these districts also have an infrastructure in place to support teachers. Successful outcomes are cultivated on a district level, and the goal of efficient and effective transition-focused education drives planning, policy, resource

development, and evaluation (Kohler & Field, 2003). These school districts have discovered how to support students in inclusive classrooms, how to reach out to culturally and linguistically diverse families, and how to bring multiple agencies together to provide cohesive services for families. Districts that provide the most consistent, transition-focused services, with the outcomes to prove it, are not afraid of change (Hasazi et al., 2003). These districts also have solid leadership and a shared vision (Kohler & Field, 2003). In addition, transition-specific knowledge is shared amongst teachers, families, and community members so that everyone may contribute to transitioning students' success.

Inclusion

The latest version of IDEA—The Individuals with Disabilities Education Improvement Act (IDEIA, 2004)—requires that students with disabilities be educated with “non-disabled” peers in natural, inclusive settings to the “maximum extent appropriate” (§ 300.550). According to IDEIA, education in a segregated setting is only permitted if a school district can justify another placement as a necessary last resort:

Each public agency shall ensure:

1. That to the maximum extent appropriate, children with disabilities, including children in public and private institutions or other care facilities, are educated with children who are non-disabled; and
2. That special classes, separate schooling or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability is such that education in

regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. (34 CFR § 300.114[a][2])

Exemplary transition programs follow the law by utilizing related services and supports to offer inclusive instruction to all children, regardless of disability (Benz et al., 1997, 2000; Greene & Kochhar-Bryant, 2003). Even before transition planning occurs, the student's placement will make a substantial difference in projected outcomes (Downing & Peckham-Hardin, 2007; Hart et al., 2002; Hughes, 2009; Ryndak, Ward, Alper, Montgomery, & Storch, 2010; Smart, 2004; Wehman, 2006). Inclusion fosters better transition simply because there is less of a learning curve for the student when transitioning from school into the community (Smart, 2004; Wehman, 2006). In addition, many parents whose children are included in secondary programs internalize the inclusion philosophy and continue to choose inclusive activities for their adult children throughout their post-secondary transition and into adulthood (Downing & Peckham-Hardin, 2007; Hart et al., 2004; Hart, Zimbrich, & Parker, 2005; Spann et al., 2003). Contrary to this, students who are educated in segregated environments usually need to build new skills to help transition to typical, community-based environments (Ryndak et al., 2010; Smart, 2004). However, it is even more common that students with significant disabilities will transition directly from segregated high school programs into similar adult programs, such as sheltered workshops (Hart et al., 2005).

Despite the requirement in IDEIA for students with disabilities to be educated with peers in natural, inclusive settings to the "maximum extent appropriate" (§ 300.550), most students with significant and low-incidence

disabilities spend most of their school day in segregated settings (Johnson & Emmanuel, 2004). Taylor (1988) predicted this to a certain extent when he challenged those in the fields of special education and disability studies to evaluate the LRE principle in light of justice and inclusive philosophy. Taylor urged leaders and those advocating for systems-change to reconsider how the notion of the least restrictive environment aligned with the concepts of justice, dignity, and equity that underlie the human service model. Specifically, Taylor argued that the “continuum of services” translated into practice as a “continuum of placements” based on a critically flawed assumption that more restrictive environments can provide more intensive supports and services (p. 220). Taylor pointed out that because the severity of disability often dictated the placement of an individual, as long as there was a legitimate avenue for segregating parts of the population, people would continue to be *placed* instead of supported. At publication, Taylor’s article was groundbreaking and substantiated the need for deinstitutionalization and community inclusion.

The LRE concept is based on a readiness model (Taylor, 1988). Historically, people have been placed in more-restrictive environments with the intention that as they developed more skills they would move to less-restrictive environments. Taylor pointed out that not only do human service delivery systems fail to support this premise, the model is conceptually flawed in that it relies upon looking at weaknesses and gaps in achievement and performance for justification of placement. Typically, people are not subject to passing benchmarks before being allowed to participate in their community; readiness models are not grounded in research-based practices and are contrary to the

values of equity and justice that comprise the backbone of the human service system.

Inclusive education is a valued practice; however, general educators often fail to use research-based methods (Browder & Cooper-Duffy, 2003). Parents whose children with severe disabilities are included in their neighborhood school's general education classrooms still have concerns. Most common are complaints about the need for purposive socialization with children who do not have disabilities, a pervasive attitude of low academic expectations for the student, and teachers' lack of training on inclusive education (Ryndak & Downing, 1996; Spann et al., 2003).

There have been exponential increases in self-determination, choice-making, and community-based services since Taylor first exposed the weaknesses of the least restrictive environment concept. Despite this, studies such as Palmer, Fuller, Arora, and Nelson's (2001) demonstrate that the overwhelming assumption is still that more restrictive environments can provide more intensive supports and services. In Palmer et al.'s (2001) qualitative study, parents (n=140) were interviewed to determine specific reasons why their family did or did not support education in an inclusive setting for their child with a significant disability. Parents who chose for their child to remain in mostly segregated settings did so because (a) the child's disability was so severe the parent believed the child would not benefit from any instruction provided in a general education setting, (b) the supports were not in place to assist the teacher in a general education setting, (c) the parent believed that inclusion

would over-burden the teacher or negatively impact classmates, or (d) the parent simply wanted the child with peers who also had disabilities.

Ryndak, Downing, Morrison, and Williams (1996) used qualitative methods to find and report the perceptions of parents of 13 students of various ages; each student had moderate to severe disabilities and was included in his or her neighborhood school's general education curriculum. The parents who participated in the study had children whose ages ranged from 5 to 19 years. Interviews revealed 3 ways the instruction varied: physical location of instruction, instructional content, and service delivery. Two overarching themes emerged from the interview data—the parents' desire to be valued and included when it came to making decisions about their children's education, and the conclusion that inclusive education had positively contributed to their child's educational experience.

Ryndak, Rearden, Benner, and Ward (2007) discovered that for most students with significant disabilities who receive special education in inclusive environments, the placement is a direct result of the parent's persistence and commitment to inclusion for their child. When entire schools adopt inclusion policies, the ultimate predictor of the policy's success hinges on the administrators' attitudes toward students with disabilities and inclusion in the general education classroom (Downing & Peckham-Hardin, 2007; Salisbury, 2006). However, without budget and training constraints, there are very few times when the IEP team should determine that a student's educational and support needs cannot be met with special education and related services in a general education classroom: if the student is medically fragile and would

themselves be in danger in a general education classroom, if the student would not receive any benefit at all, if the student poses a danger to the other children, or if the benefit to the student in a more restricted environment greatly outweighs the benefit in the LRE (*Daniel R.R. v. State Board of Ed.*, 874 F.2d 1036 [5th Cir. 1989]). Based on legislation and case law, in these cases, a more restricted environment is justified.

There are many benefits to inclusive programs. When included, students learn appropriate social skills and how to make and maintain friendships (Downing & Peckham-Hardin, 2007; Hughes, 2009; Ryndak et al., 2010). Students who have been educated in inclusive settings have better self-awareness and are already more active in the community (Downing & Peckham-Hardin, 2007; Ryndak et al., 2010; Wehman, 2006). Parents and support professionals are likely to have collaborated and provided functional supports outside of a classroom (Hart et al., 2005). Fundamentally, inclusive settings foster self-determined students who have a more realistic self-concept and know what their strengths and weaknesses are and are better able to procure supports when necessary (Downing & Peckham-Hardin, 2007; Ryndak et al., 2010; Wehman, 2006). According to Johnson (2000), schools must extend IDEIA's standards to ensure that students with significant disabilities have more than just a presence in the classroom, but also have more inclusive curricula and relevant instruction designed to prepare students for adulthood in the twenty-first century.

Culturally and Linguistically Diverse Families

The ultimate goal of transition planning is to define the role the young adult will have in the family, community, and society, and facilitate the desired social relationships and community interactions that will take place throughout the different environments the individual values (Blue-Banning et al., 2002). These roles and interactions are grounded in cultural values, desires, and expectations about social relationships, community participation and role expectations that extend from the home out to the community. Because the transition process centers on the young adult and their family, professionals may sometimes be asked to consider new, diverse perspectives (Cooney, 2002). To that end, professionals must often think creatively to engage Culturally and Linguistically Diverse (CLD) parents, educate families about the transition process, and provide them with information that will enable them to participate in the best interests of their child (Greene & Kochhar-Bryant, 2003).

Mainstream American culture typically views the time immediately after high school as a “coming of age,” when young adults become more independent and self-sufficient. Dominant American culture views independence as an indicator of success (Hatter, Williford, & Dickens, 2000). Culturally and linguistically diverse families may not share these same values or seek similar outcomes for their children (Ankeny et al., 2009; Kim & Morningstar, 2007). People who are of non-Western European heritage often have a strong sense of familial and group identity (Hatter et al., 2000), and may wish for their children to retain this cultural identity while achieving their transition outcomes (Harrison, Wilson, Pine, Chan, & Burrell, 1995, as cited in Hatter et al., 2000).

CLD families have characterized professionals' reception to minority culture or unfamiliar world-views as "insensitivity, more than racism," and have expressed frustration with feeling misunderstood and unsupported. Some CLD families, particularly those from cultures the mainstream American culture is more unfamiliar with, such as Native American and Asian families, remark that some professionals seem outwardly incredulous, "They just don't get it....They just don't get that we might possibly see the world differently than they do" (Geenen, Powers, Vasquez, & Bersani, 2003, p. 35).

Productive collaboration is almost non-existent between professionals and CLD families, or families of low-SES (Kalyanpur et al., 2000). Typically valued outcomes, such as independent living and autonomy, are grounded in mainstream American cultural values (Ankeny et al., 2009; Kim, Lee, & Morningstar, 2007). When person-centered planning does not occur and a single, standard protocol is in place, CLD families may feel confused, isolated, or resentful, as it is more likely that their cultural values will be unrecognized.

Professionals often plan for the young adult's emerging independence from a nuclear family. This contradicts the desire many CLD families have for their adult children to remain at home that stems from the traditional role these adult children play in the extended family. Having a long-term plan for an adult child to living with family does not automatically equate to depriving the individual of self-determination or quality of life. Many Hispanic parents prefer that their adult children live at home; still, these families often continue to encourage self-determination instruction and autonomy (Ankeny et al., 2009; Blue-Banning et al., 2002). However, some professionals discount the

transition-related tasks and preparation that CLD parents do, because it is significantly more family- and community-based instead of school-based (Ankeny et al., 2009; Geenen et al., 2003).

Professionals sometimes intimidate CLD parents (intentionally or not) to the point of non-participation (Ankeny et al., 2009). Parents may feel that professionals exert power and ignore the value of the intimate knowledge of their child's skills and preferences. In Land, Adam, Zhang, and Montoya's (2007) research, one-third of the parents did not know the meaning of the phrase *transition planning* and often did not understand special education jargon; however, parents provided expert information about the transitioning student and made valuable contributions to the transition planning process (Land, Adam, Zhang, & Montoya, 2007, as cited in Ankeny et al., 2009).

Unfortunately, interviews with parents of culturally diverse backgrounds revealed that parents for whom English was a second language would frequently choose to avoid participating in transition meetings or conferences because they felt intimidated (Kim & Morningstar, 2007). CLD parents admitted to often acquiescing to the professionals when disagreeing, because it was less intimidating or embarrassing (Kalyanpur et al., 2000; Kim & Morningstar, 2007). Families who feel disempowered due to a language barrier will also tend to give up if turned down for services, instead of searching for other programs or appealing the decision (Geenen et al., 2003). This may also be partially due to the values of conformity (instead of personal expression) and respect for authority (versus individual initiative) common to many other cultures (Leake & Cholymay, 2004).

To fulfill the both the requirements of IDEIA and the ethical expectations of the profession, materials—legal mandates, information about possible service options, advocacy materials, and support group publications—should be presented to families in the parents' native language and with the family's values and preferences in mind (Kim & Morningstar, 2007). Transition teams and communities who have the most long-lasting outcomes are those that invest in parents from minority backgrounds and teach them to build social capital—to network and build relationships with people who have resources and information (Holcomb-McCoy & Bryan, 2010).

Families in Poverty

Individuals from families on the lower end of the socio-economic spectrum are especially vulnerable to gaps in services and lack of interagency collaboration (Townsend, 2004). However, poverty, exclusion, or marginalization does not automatically correlate with a lack of knowledge or desire to acquire the best for one's child (McLaughlin et al., 2010). Rather, productive collaboration rarely occurs between professionals and families with low-socioeconomic status, because like CLD families, families from low socioeconomic status (SES) backgrounds will typically defer to the professional (Kalyanpur et al., 2000). Typically when person-centered planning and interagency collaboration does not occur at all, families of higher SES will often have more desirable placements than their lower SES counterparts, simply because to find, visit, and vet service providers takes time and resources (Geenen et al., 2003). Many families of lower SES simply do not have the resources to get the information or seek out services.

Individuals from low-SES families will perhaps never again be as close to needed expertise, connections, or services than when in public school. Families from low-income backgrounds simply often lack a social network consisting of people with information, expertise, and resources; in addition, some individuals from lower SES families may be intimidated or uncomfortable approaching professionals who can make these connections for them (Holcomb-McCoy & Bryan, 2010). As a result, adults with disabilities from lower SES families are more likely to stay home and physically degrade (Geenen et al., 2003).

Policy Barriers to Services

Navigating adult services can be daunting for individuals and their families. Federal and state policies may create fragmented services or financial disincentives to multiple-service implementation (Benz et al., 2000; Darrah et al., 2010). For example, when planning for post-secondary employment for individuals with significant disabilities, Vocational Rehabilitation (VR) will likely be involved; however, VR does not fund long-term (usually over 18 months) supports for individuals with significant disabilities, and the service agency who will be providing funding for the long-term supports must be identified before receiving initial services from the VR system (Certo et al., 2009; Condon & Callahan, 2008). Because there is often no permanent funding stream for supports once a student transitions, it is extremely difficult for adults with significant intellectual disabilities to maintain employment (Butterworth & Gilmore, 2000; Migliore & Butterworth, 2008, as cited in Certo et al., 2009). Without good pre-planning and persistence throughout implementation, students

with significant disabilities are at significant risk for institutionalization or an otherwise unproductive and unfulfilling life.

Many government agencies have uncoordinated agendas and conflicting program requirements. For example, an adult may be dually enrolled in both a program that emphasizes employment outcomes and a program with income caps (Crane et al., 2004; Darrah et al., 2009; Johnson et al., 2002; Wittenberg et al., 2002). One of the largest barriers for students and families is waiting for Home and Community Based Services (HCBS) funds to facilitate independent living or similar residential options (Certo, 2009). However, the 1915(c) legislation (that authorizes HCBS waiver) directly conflicts with valued-practices, IDEIA legislation, and DDA legislation that call for individuals who support people with disabilities (especially significant disabilities) to teach self-determination skills, honor the choices of the individual being served, and address all domains including employment and residential options when planning (Certo, 2009). The prevailing theory behind the legislation is that if a student is employed at the time he or she exits school, the individual is at less risk for institutionalization since he or she is earning some income. The resulting practice, in some states, is that as soon as the individual becomes employed, he or she is moved down the priority list for HCBS waiver services. In states that have these conflicting pieces of legislation, it is not likely that an individual with significant disabilities can be employed and concurrently receive HCBS waiver benefits.

Parents who are unable to find appropriate supports for adult children who have disabilities usually provide full-time care for their children in the home;

these families are also often constrained by the law (Caldwell & Heller, 2003; Gill & Renwick, 2007). Financing extended-family supports, such as childcare or respite, is often blocked by policy and is not permitted by many programs (Caldwell & Heller, 2003; McLaughlin et al., 2009). Person-directed resources based on family needs and preferences are not the norm, even when it is difficult for parents to find supports. Advocates and researchers have both called for comparable wages for typical direct support professionals to be paid to family members (if the relative is providing comparable, professional support services); policies that allow families to retain quality direct support professionals and respite care greatly improves families' quality of life (Gill & Renwick, 2007).

Individuals' transition outcomes can be greatly enhanced or hindered by impersonal institutional policies. Inclusive policies and practices are needed on a school-level, not only because transition programming in inclusive settings yields better adult outcomes, but because an inclusive philosophy underlies the principles of justice, equity, and dignity that are the backbone of our human services system—and our entire country (Taylor, 1988). A truly inclusive society is comprised of a myriad of different types of people. Thus, policies must be in place to extend transition programming to individuals from CLD families and families from poverty, to identify and meet needs while building social capital in a respectful environment that augments individual and family strengths.

Family Involvement, Empowerment, and Training

According to Heller, Miller, and Hsieh (1999), families recognize the responsibility that accompanies increased autonomy and therefore want

comprehensive, accurate information about available resources and adult service options in order to make sound, person-centered decisions. When parents have information, they perceive themselves as more competent and capable, and are therefore empowered (Hetherington et al., 2010; Nachshen, 2005; Rude et al., 2005). According to Kohler (1996), special education and transition planning programs should be designed to educate and empower parents throughout the process. Self-determined parents may seek out information from Parent Training Information centers (PTIs) or other support organizations, but ultimately, it is the LEA's responsibility to educate parents about the anticipated effect the child's disability will have on K-12 education, and all domains of adulthood (20 U.S.C. § 1416[a][3][A]).

Families need professionals' collective expertise and connections to aid in making decisions, solving problems, and educating others on behalf of their children (Mines, Nachshen, & Woodford, 2003, as cited in Nachshen, 2005; Rude et al., 2005). Professionals provide information to guide families through the many decisions that must be made as families consider the life-long implications of those decisions (Bruckman & Blanton, 2003; Murray et al., 2007). Planning for adulthood requires many life areas to be addressed such as health and medical, education, social, leisure and recreation, domestic, and community participation (Murray et al., 2007). Ultimately, the family will determine their level of participation; however, professionals can encourage and empower families to assume a decision-making role by giving them the tools that they will need to do so.

Family-Centered Care

Allen & Petr (1996) reviewed 120 professional articles from various disciplines related to the concept of family-centered care and identified 10 key concepts shared by all, or most, of the other researchers. The researchers then proposed a definition of family centered care that included two primary elements: family choice with respect to all aspects of planning and service delivery, and an emphasis on family strengths and capabilities. In practice, family-centered planning means focusing on the family as the unit of attention, collaborating with family while considering family strengths and addressing family needs. Facilitating family-centered care includes giving family members information needed to make informed choices, assuring families have their voices heard and needs met, and focusing on family strengths in decision making and service-delivery (Allen & Petr, 1996).

Parent values are critical to the entire transition process from conception of goals to the realization of successful post secondary outcomes (Blue-Banning et al., 2002; Ferguson et al., 1988; Geenen et al., 2001; Kalyanpur & Harry, 1999; Wagner et al., 2005). When transition goals are created according to the priorities and perceptions of professionals instead of student and family preferences, it is unlikely that the outcomes will be achieved (Wehman, Moon, Everson, Wood, & Barcus, 1988). Because students with significant intellectual disabilities often have significant communication deficits, both professionals and the researchers who document their transition experiences must often rely on the parents' conveyance of experiences, perspectives, values, and expectations when planning (Chambers et al., 2004; Kraemer & Blacher, 2001; Neece et al.,

2009; Whitney-Thomas & Hanley-Maxwell, 1996). Not only do children usually share parent's values and expectations (Lindstrom, Doren, Metheny, Johnson, & Zane, 2007), parents have usually built-up practical knowledge in recognizing and interpreting the child's individual preferences based on intuition and interpreting behaviors and non-verbal communication (Petry & Maes, 2006) When family information and strengths are incorporated into the assessment and evaluation process, transition plans are more likely to translate into outcomes. The resulting family-centered services are guided by fully informed choices made by the family, individualized for each family and incorporates family strengths and preferences, and structured to ensure accessibility full and effective participation in society with minimal disruption of family integrity and routine (Darrah et al., 2009).

Perceptions of Parent-Professional Communication and Collaboration

Parent participation in general education has been increasingly encouraged in legislation, but for parents of students with disabilities, family-centered planning and decision-making is a requirement (IDEIA, 2004). During the time when the medical model of disability was the norm, professionals were generally considered the experts. Now it is more common for the valued practices of family-centered care, self-determined choices, and shared decision-making between parents and professionals to combine, with families ultimately making the final decision based on an array of informed options (Cobb & Alwell, 2009; deFur et al., 2001; Greene et al., 2003; Grigal & Neubert, 2004; Murray et al., 2007; Townsley, 2004; Turnbull et al., 2006). One of the best predictors of young adults' post-secondary success is parent involvement (Hassazi, Gordon

& Rowe, 1985, as cited in Zhang et al., 2002). Often parents have higher expectations for their children than other members of the team (Dean, 2003, as cited in Beresford, 2004; Heslop et al., 2002; Morris, 2002). Evidence shows that parents are more empowered, encouraged, motivated and positive about their child's adult experiences when involved in the planning process as the primary decision makers (Kim & Turnbull, 2004; Kraemer et al. 2003; Kraemer & Blacher, 2001; Neece et al., 2009). Young people report that it is the influence and tenacity of the family, not social services, that is the primary reason for their positive employment outcomes or successful independent living (Hendley & Pascal, 2001; Hetherington et al., 2010; Morris, 2002, as cited in Beresford, 2004). Some parents participate in the planning process and personally fill-in gaps left by social services, such as assuming the roles of direct support professionals (Bjarnason, 2002; Hetherington et al., 2010). However, without parents' clear understanding of the importance of the transition process, the procedures, and their expected role, most parents will likely fall short of expectations, either becoming uncooperative and hindering the process, or becoming disempowered and acquiescing to the most dominant professional's desires (Hatter et al., 2000).

Some parents claim there is still a monopoly of professional expertise (Hatter et al., 2000). When asked, most professionals recognize the centrality of the family to the transition process and the importance of collaboration; however, qualitative interviews with parents and professionals reveal that there is often a significant gap between what many professionals claim to value and

what actually occurs in practice (Bezdek, Summers, & Turnbull, 2010; Blue-Banning et al., 2004).

Bezdek et al. (2010) uncovered a “Goldilocks Perception” amongst professionals—a specific amount of parent involvement that some professionals believe is appropriate (p. 359). The respondents admitted that too much involvement by parents indicated a lack of trust and was perceived as usurping the professional’s competence or authority (although family-centered philosophy dictates that the professionals do not have authority to be undermined). Many of the professionals perceived too little involvement as an indication of misaligned priorities or simply not caring about the child’s plan of care. There was little room for parents to err when calibrating their involvement without receiving judgment from the professionals providing services to their child (Bezdek et al., 2010). Bezdek et al. (2010) did not interview the parents associated with the professional respondents; it is, therefore, unknown if the parents perceived the professionals’ disapproval when the family was over- or under-involved.

Throughout the literature, parents give many reasons for feeling undervalued or unwelcome by the professionals who support their children. According to parents and young adults, it was not uncommon for professionals to affect disinterest and seem unwelcoming during transition planning meetings (deFur, 2001; Powers et al., 1999; Thoma et. al., 1999). Further research supports parent accounts by revealing that some professionals may actually be combative, intimidating, and exert expert power during family-centered meetings (Ankeny et al., 2009; Geenen, Powers, Vasquez, & Bersani, 2003; Dymond &

Orelove, 1994; Turnbull & Turnbull, 2001). Meetings were not perceived to be child- or family-focused, but were instead professionally-driven, document-focused, time-limited, and fulfilled only the minimal requirements of the law (Thoma et. al., 1999). Placements or services were often perceived to be determined by a social services budget, or by program openings. Parents reported that professionals focused on existing services, but did not consider creating new opportunities based on student needs, skills, or interests if pre-existing services were not a good match. The paradigm shift from finding placements for people, to adapting services to meet people's needs, was present in the literature, but not in practice (Kim, Lee, & Morningstar, 2007; Smart, 2004).

Because transition-planning activities are guided by government policy and regulated by professionals, families may feel a significant loss of empowerment when requested services and supports are not provided (Cooney, 2002). Additionally, parents perceive a lack of urgency and resent long waiting times between the team decisions, actions, or steps toward progress (Smart, 2004). Even when families' requests are granted, student and parent preferences and goals expressed during the transition planning stages rarely translate into the anticipated outcomes as intended by the transition planning team (Smart, 2004; Thompson, Fulk, & Piercy, 2000).

Parents in Stoner and Angell's (2006) study reported that even extremely positive relationships with teachers were grounded in a guarded trust and an awareness that the professionals were contractually obligated to a school district that had concerns—such as budgets, personnel, and limited resources—that

likely took priority over the needs of one family. Not all parents report negative interactions with professionals, however. Some report that insight from the family and child-specific expertise were welcomed during interactions with teachers and service providers (O'Connor, 2008). These parents felt validated, respected, and included in the special education and transition programming and reported that the school successfully kept lines of communication open.

Nationwide, one-half of schools do not communicate weekly or monthly with families (Epstein & Jansorn, 2004). Parents report that teachers rarely initiate communication unless there is a problem (Spann et al., 2003). In Lake and Billingsley's (2000) parent interviews, respondents complained that professionals do not see the child as a holistic individual and that everything mentioned in school communication was negative or deficit-oriented. However, Fonteine, Zijlstra, and Vlaskamp's (2008) study revealed that parents and teachers may simply have different communication priorities. Based on the reviews of communication logs, teachers communicated with parents about health issues only when teachers presented information and wanted suggestions or solutions. On the contrary, parents often informally wrote about the child's health issues or disability, but did not write as much about the child's typical daily experiences. Overall, teachers communicated twice as often as parents did, and wrote significantly more information about daily activities (Fonteine et al., 2008).

Throughout the literature, parents' trust in professionals increased when professionals were child-focused, demonstrated competence, and kept their word (Hodge & Runswick-Cole, 2008; Stoner & Angell, 2006). When this

occurred, parents were more apt to recognize an error in judgment or gap in the professionals' knowledge as a result of a role difference (i.e. the mother should naturally know more about her child) than as a professional deficit (Stoner & Angell, 2006).

Healthy parent-professional collaboration improves outcomes and makes for a more enjoyable transition process for both parents and professionals (Blacher, 2001; Ferguson et al., 1988). In order for the transition planning team to thrive, there must be a willingness to trust and a pervasive mood of respect based in recognition of each team member's individual competence in fulfilling his or her role and using best-practices to achieve the team's collective goals (Blue-Banning et al., 2004). For maximum team cohesiveness, power should be shared—not just decision-making power, but also power in service implementation (Blue-Banning et al., 2004). Because many parents will have never needed to formally advocate for themselves or their child, advocacy will need to be a shared responsibility of all transition team members; this can only be accomplished with loyalty and devotion to the young adult (Harry, 2008). Yet, it takes quality collaboration above and beyond the legislated baseline to maintain effective relationships that result in consistently positive student outcomes. Professionals should forge strong authentic relationships with families in order to ascertain families' worldviews, values, and priorities (King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009). Individual services that will be the most successful will work within the contexts of families' needs, strengths, and schedules.

Parent Participation and Family-Driven Decision Making

Unlike many of the other valued practices profiled in the literature, the expectation of parent participation and discretionary power is also found in education legislation. The Individuals with Disabilities Education Improvement Act (2004) requires direct parent participation in IEP development (Flannigan, 2005; Vaden-Kiernan, 2005). Professionals (including educators) and parents have historically had perceptions of power surrounding the relationship between their respective roles and the unbalance of knowledge, trust, and control each possessed (Farkus et al., 1999; Ferguson, 2008; Swain & Walker, 2003; Woods, Bagley, & Glatter, 1998). This relationship is further complicated when students with disabilities are involved due to the importance of parental involvement and parents' right to make decisions that may sometimes contradict LEA or other professionals' suggestions. Both family-centered care and person-centered planning require a shift in power sharing; professionals must change their paradigm from *expert* to *team member* (Cooney, 2002; Riddell et al., 2001).

Because families all have different needs and knowledge levels, collaboration may be better if professionals take time to understand the families' needs and ask the parents and transitioning young adult how they wish to work with the service providers (Goldfarb et al., 2010). In many studies, parents revealed struggling to procure supports and services since the moment of their child's birth (Bjarnason, 2002; Murray, 2007; Stoner et al., 2005). Navigating and negotiating the social services system continued throughout the child's life, but some periods were more difficult than others. Parents remembered that early transition into special education programs was often traumatic, and

expressed that entering into early childhood services or elementary education was a difficult shift, from interacting with medically-focused professionals to educationally-focused professionals (Stoner et al., 2005). Parents reported feeling that they were blindly expected to trust professionals and hand over control of their children's lives to outsiders (Cooney, 2002). That time of uncertainty and emotional strain left lasting scars that later influenced parents' willingness to collaborate and share in decision-making. Further, parents reported those feelings of uncertainty and vulnerability often returned when confronted with new situations or when feeling outnumbered or unwanted by professionals (Bjarnason, 2002; Stoner et al., 2005).

Other parents reported positive early-transition experiences and expressed regret that their family received markedly less family-centered care during the transition to adult services than when their child was younger (Smart, 2004). In fact, the early intervention model has come the closest to providing whole-family care by providing early respite care, counseling, and parent training (Heller et al., 1999), but there has been no research to determine if a similar model would work for students transitioning from high school and their families.

Sometimes, even as children progressed through the school system and received special education and supports, parents felt as if their participation was inconvenient to the school professionals, and the offerings of choices were formalities because decisions had already been made prior to parents' arrival (Swain & Walker, 2003). Families were not always adequately supported by professionals through the decision-making process (Murray et al., 2007), and

some parents reported feeling intentionally prevented from making decisions by professional gate-keeping and withheld information (O'Connor, 2008; Swain & Walker, 2003). Assertive parents felt as if the quality of care and service provision depended on the sensitivity in which the parent responded to the professionals who had final say over the LEA's budget and distribution of resources (O'Connor, 2008; Swain & Walker, 2003; Trainor, 2010). Learning diplomacy and negotiation was a valuable tool, and parents specifically tried not to be perceived as aggressive (O'Connor, 2008; Stoner & Angell, 2006; Trainor, 2010). However, many professionals embrace parents' eager desire to contribute and admitted that parents often had state-of-the-art knowledge about treatment and prognoses that the professional was unaware of (Downs & Carlon, 2009; McLaughlin, et al., 2009).

It is likely that many times parents and professionals may be reacting to the stress of the environment and anticipated conflict, rather than actual disagreement of agenda or misunderstanding of roles. In Koffey's (1997) survey of parents and teachers of individuals with severe disabilities, parents and professionals agreed on shared teaching responsibilities for 10 different skill areas (no statistically significant differences were seen with regard to differences in the students' ages or support needs). In addition, positive parent-professional relationships developed when professionals listened to parents and showed interest in the child, instead of the diagnosis (Hodge & Runswick-Cole, 2008); for example, mothers were receptive of questionable information (perhaps, even disagreeable or unpleasant information) when teachers were respectful (Ankeny et al., 2009).

What researchers and practitioners can infer from the vast spectrum of parent experiences is that there is no model collaboration experience (Stoner & Angell, 2006; Stoner et al., 2005; O'Connor, 2008; Dymond & Orelove, 1994). Parents appreciated and recognized teachers, specifically, as concerned, compassionate, and fighting for students despite having their own limited resources and supports (Spann et al., 2003). Positive parent perceptions consistently result from exemplary practices of individual teachers and a trusting relationship with competent school district personnel (Ryndak & Downing, 1996; Spann et al., 2003; Trainor, 2010).

When the transition planning team is communicating and working effectively, knowledge, power, and control are evenly distributed amongst the group (Kraemer & Blacher, 2005; Shapiro et al., 2004); parent-professional collaboration is likely to stall if parents perceive unbalance of any of these areas (Woods et al., 1998). Parents feel uncomfortable at meetings where they are outnumbered by those who they might initially perceive as, at worst, adversaries, and at best, strangers (Ankeny et al., 2009; Cooney, 2002; Dymond & Orelove, 1994). Unfamiliar jargon and procedures also contribute to parents' anxiety and feelings of inexperience and inadequacy (Cooney, 2002; deFur et al., 2001; Dymond & Orelove, 1994; Powers et al., 1999; Thoma et al., 2001). Poor communication and inadequate role clarification further contribute to parent anxiety and can become a barrier to smooth transition (Dymond & Orelove, 1994).

When parents' and the transitioning individual's knowledge of strengths, needs, and preferences are incorporated into the service delivery system, the

procedures are more responsive and flexible (Murray, 2007; Dymond & Orellove, 1994). However, even when families are functioning as the primary decision-makers, collaboration, understanding, and collegiality cannot be mandated; this feature of policy is often problematic, as multiple perspectives rarely contribute to understanding in emotionally-charged environments (O'Conner, 2008). In addition, professionals and parents often have the inability to recognize diverse perspectives (Cooney, 2002). These difficulties are often compounded because transition team members do not have the conflict-management skills to mitigate tension when dissension erupts. Some parents will display passive acceptance, to avoid causing conflict (Bjarnason, 2002); however, over-reliance on professionals can lead parents to have limited vision for their child's potential (Tarleton & Ward, 2005). Some parents reported seeking information and services outside of the LEA after there was a complete breakdown of trust or perception of incompetence (P.J. Kennedy, 2004). Other parents simply see team conflict as inevitable and begin to believe that self-reliance and independence from "the system" is the only way to survive and preserve sanity (Bjarnason, 2002).

Even when families and professionals are collaborating and engaging in person-centered planning and family-driven decision making, the transition period can still be emotionally trying for families--especially when discussing the young adult's limitations, or the actions it will take to make the transition plan a reality (Goupil et al., 2002). Parents may hesitate to be involved because of habitually deferring to professionals' expert power, feeling unqualified to make a significant contribution, or the family might just be occupied with the realities of

typical life demands (Farkus et al., 1999). Customarily, parental involvement for typical children, as well as those who receive special education, decreases as the children progress through school (Farkus et al., 1999; Kim & Morningstar, 2005). Some parents may have less desire to be informed, or the parents may be reticent to engage with teachers due to previous negative experiences (Kim & Morningstar, 2005). According to Farkus et al. (1999), parents and professionals who distrust or fear each other will have less purposeful and successful collaboration.

Conclusion of Review of Literature

Transition programming is a relatively new concept, and is still being refined. Evidenced-based components of transition programming that yield successful transition outcomes have been identified (Kohler, 1996; Test et al., 2010); however transition research suggests that most transition programs are not implemented with fidelity, nor in the spirit of the law (Certo et al., 2009; Landmar et al., 2007; Repetto et al., 2002). Consequently, large numbers of transition programs do not have the desired or anticipated impact on post-school outcomes (Landmark et al., 2007; Repetto et al., 2002). In addition, there are often policy barriers that make obtaining needed services and supports difficult (Davis, 2003; Hart et al., 2002).

Young adults with disabilities still have unacceptable rates of school completion, adult employment, post-secondary education, and independent living (Benz et al., 2000; Condon & Callahan, 2008; Graham, 2007; Hart et al., 2001; Johnson et al., 2002; Neubert et al., 2004; NOD, 2004; Powers et al., 2008; Rusch & Wolfe, 2009). Most young adults with significant disabilities

transition from school to segregated workshops and activity centers, or stay at home with family members or paid caregivers (Blackorby & Wagner, 1996; Brown et al., 1999; Brown et al., 2006; Gill & Renwick, 2007; Luecking & Certo, 2002; Murphy & Rogan, 1995; Wehman et al., 1998). For students with significant disabilities, the likelihood of achieving successful transition outcomes depends upon a combination of factors: the quality of the Individualized Transition Plan (ITP), the collaboration of the transition planning team, active use of self determination skills, and degree of parental support (Beresford, 2004; Blacher, 2001; Ferguson et al. 1988; Wehmeyer & Palmer, 2003; Zhang et al., 2002). Parents are naturally invested in their children, but will also have a longer practical commitment to supporting an adult child with a disability through adulthood (Antle et al., 2009). Longitudinal research has shown that the family will be the only consistent source of support for young adults after high school (Ankeny et al., 2009; Turnbull et al., 2006). Professionals, no matter the depth of relationship, or quality of services provided, are only a temporary support. According to Wehman (2001), parents, therefore, have a responsibility to themselves, and their children to exercise legislated rights and use appropriate decision-making power.

Building Capacity within the Family

The limited research that has been conducted about parent knowledge revealed that, typically, parents who are active participants in the school district are the most knowledgeable. However, researchers can not determine if highly involved (but initially, less-knowledgeable) parents know more information as a result of the good relationships established with LEA personnel, or if well-

informed parents choose to become involved in their children's school and establish relationships with LEA personnel (Vaden-Kiernan, 2005). Parents who attend formal trainings or belong to support groups are more likely to exhibit behaviors that support their children's educational development (Newman, 2005). Families who attend OSEP meetings are more likely to be involved and attend IEP meetings; individuals whose families participate in outside activities are also more likely to use external supports (Newman, 2005). More research is needed in this area, but clearly, formal parent training is often the catalyst for increased parent involvement, and parent involvement is correlated to increased knowledge.

Providing values-based family-centered care first begins with offering information. Parents need to know supports that are available in the home and community to mitigate decisions that may result from fear or ignorance (Geeter et al., 2002; Smart, 2004). Individuals with both cultural capital (e.g. knowledge) and economic capital (e.g. money) resources are less likely to perceive unfamiliar situations as stressful, better able to manage stress, and are able to more creatively solve problems (Hobfall, 2002). Despite this, little research has been done about how to best convey information to families (Singer, 2002), or who or where parents currently rely upon for the best and most helpful information regarding transition options (i.e. tracking parents' social capital).

The Knowledge Gap Regarding Transition

Navigating the transition from school to adulthood requires complex knowledge of educational systems, special education-specific knowledge, and social networking (Caldwell & Heller, 2003). According to McAndrews (2008),

unless a parent is knowledgeable enough to demand best practices, the intensive assessments, skill instruction, and transition services required by IDEA rarely occur. In published research, parents emphasized knowing what “transition” was, *per se*, but admitting not knowing that “transition” encompassed all domains, not just the transition from high school to college or work (Beresford, 2004; Heslop et al. 2002; Kraemer & Blacher, 2001; Tarleton & Ward, 2005). Throughout the literature, regardless of the child’s diagnosis, parents uniformly emphasize that one of the greatest needs for the family is simply information (Ankeny et al., 2009; Grigal & Neubert, 2004; Smart, 2004; Westling, 1997). Parents consistently reported not knowing how to access information, what services were available, or how eligibility was determined (Chambers et al., 2004; Hanson, 2003; Kim & Morningstar, 2005; Stoner & Angell, 2006; Townsley, 2004). Some parents felt the need to formally request organizational knowledge, such as basic information about the roles and responsibilities of the professionals who attend planning meetings or explanation of the timelines that influence or regulate services and supports (Heslop et al., 2002). Parents also expressed the desire to be kept abreast of changes in services (Smart, 2004). In Griffin et al.’s (2010) research on post-secondary education (PSE), 56% of parent-respondents who chose to add comments to give advice to other parents about transition specifically commented on the importance of families being self-determined, informed about rights, and proactive in planning. However, 8% of parent-respondents specifically commented on feeling unqualified to answer the question and admitted coveting advice themselves.

Parents advocate for children with disabilities and may, therefore, sometimes disagree with LEA staff that have been formally trained in education law and are more comfortable interpreting rules and regulations (Lake & Billingsley, 2000). In published interviews, many parents revealed a perception that the LEA capitalized on families' naiveté and withheld information to prevent parents from requesting services (Epstein & Jansorn, 2004). In Ryndak and Downing's (1996) interviews with parents of students who were being served in inclusive settings, some parents admitted to initially voluntarily giving up power, believing that the school district was the expert, and, therefore, not questioning their child's placement or instructional plan. All parents were (at the time of the study) involved with an advocacy group, and likely possessed more knowledge of the continuum of services and were more empowered than parents who did not have an affiliation. That these families admitted giving-up decision-making power because of feelings of inadequacy to make decisions on their children's behalfs underscores the need for family education and advocacy training for all parents.

According to Lake and Billingsley (2000), parents do not always have "judgmental knowledge"—enough information to make a good judgment about service delivery (p. 245). When parents who had been involved in a conflict with an LEA were interviewed they often admitted to being oblivious to their ignorance of special education policies and practices and unaware of the inadequacy of their knowledge until a crisis occurred (Lake & Billingsley, 2000). In another study, a recent recognition of a gap in knowledge greatly increased existing stress for the parent (Greeter et al., 2002).

Some mothers and fathers acknowledge their evolution into a “professional parent” because of the day-to-day responsibilities and (pseudo) professional health and social services provided by the family at home (McLaughlin et al., 2009, p. 82; Trainor, 2010). Other parents explained that in order to combat professionals’ expertise and preoccupation with diagnoses and deficiencies, mothers or fathers developed a level of professional knowledge and became an authority on the medical and educational aspects of their child’s disability (Hodge & Runswick-Cole, 2008; Trainor, 2010).

Access to Adult Services and Supports

Throughout the literature, parents declared that adult services were lacking and acknowledged that to receive supports the family might have to fight for services (Tarleton & Ward, 2005; Gill & Renwick, 2007). Most of the time, these declarations were quickly followed-up with an admission of ignorance in not knowing exactly what to fight for (Tarleton & Ward, 2005). Parents expressed extreme gratitude for teachers that provided information on community resources and adult options (Ankeny et al., 2009). Chambers, Hughes, and Carter’s (2004) qualitative study, although small-scale (n=16), provides insight to emotions, choices, and questions that parents and siblings of young adults with significant disabilities often have. Parents of young adults with significant disabilities were asked, “What do you believe is most important to your child when he or she finishes high school?” (Chambers et al., 2004, p. 82). Five of eight parents chose “living arrangements”; two of eight parents chose “employment,” and one chose “post-secondary education” (p. 84). Families were then asked to indicate what choices were important at all to their

child or sibling and what degree of knowledge the family member had about potential options. All respondents reported that employment and developing friendships were “very important” (p. 84). Similarly, all of the parents and siblings reported that leisure and recreation skills were extremely important, but respondents admitted to not knowing much about recreation options for individuals with significant disabilities, nor where to seek out the information (Chambers et al., 2004).

All parent-respondents reported knowing their child valued post-secondary options, but none expected their son or daughter to attend any type of post-secondary program or knew of any options for people with disabilities despite the fact that, at the time, there were over one hundred specialized transition programs and over thirty post-secondary programs on community college and university campuses (Grigal, Dwyre, & Davis, 2006; Grigal et al., 2004). All family members indicated that future employment and independent living were important to them and their family member, but in direct opposition to this, all respondents also anticipated that the transitioning young adult would live at home and work in a segregated setting. This juxtaposition of values and expectations is indicative of many families who simply do not know what options exist in the community for employment, leisure activities, post-secondary education options, or independent living (Goupil et al., 2002; Heslop et al., 2002).

In Gill and Renwick’s (2007) interviews, parents revealed that services were often not available, accessible, or adequate to meet the needs of their adult child, nor provided the parent with needed respite (Gill & Renwick, 2007).

Parents expressed weariness and recognition that others just do not understand the day-to-day responsibilities of caring for an adult who has significant needs (Ankeny et al., 2009). Families want information, choices, and services that support the young adult's needs, preferences, and expectations, but that are also realistic and available locally (Tarleton & Ward, 2005).

Parents stressed that their adult children's future occupations did not matter as long as jobs fit their child's skills and preferences (Blue-Banning et al., 2002). Parents wanted sons and daughters to participate in typical community activities, or similar (adapted) activities, with typical friends and peers (Blue-Banning et al., 2002). Because high parental expectations have been found to be the most significant predictor of positive employment and independent living outcomes (Hendley & Pascal 2002; Lindstrom et al., 2007; Morris, 2002), it is extremely important that parents are given the opportunity to obtain the necessary knowledge to make sound decisions and fully represent the best interests of the child within the context of their family (Geeter et al., 2002).

Long-Term Effects of The Knowledge Gap

A parent's lack of knowledge will likely have life-long consequences for the young adult with significant disabilities. Heller and Factor's (1993) study found that caregivers are increasingly likely to desire an out of home placement when loved one's needs are not being met and the family is experiencing a high degree of stress (Heller & Factor, 1993, as cited in Smart, 2004). In Australia, parents opposed deinstitutionalization, citing fears for the safety of adult children and anticipating negative consequences for the family (Tabatabainia, 2003, as cited in Lemay, 2009). Follow-up investigation and further questioning

determined that the families had no knowledge of the process of deinstitutionalization. The government and social services personnel had simply contacted the families of the institutionalized adults and explained the family member was coming home. The families did not understand the philosophy of deinstitutionalization, the expected benefits, nor that service and supports were available in the community (Tabatabainia, 2003, as cited in Lemay, 2009).

In Heller, Miller, and Hsieh's (1999) study, the researchers gave families money to allow them to choose and purchase services for respite care in the hopes of eliminating caregiver strain. However, several participants were unable to spend their entire allotment, because of insufficient services or lack of knowledge of support providers. Even with cash in hand, parents did not have the knowledge of where to go or who to ask to find support providers (Heller et al., 1999). Because families did not have capacity to problem solve, nor the networking capability, money was not enough; without cultural or social capital, economic capital is naught.

Bridging the Knowledge Gap

In order to collaborate with teachers, doctors, and social service providers, parents of individuals with disabilities are expected to have initiative, be knowledgeable and competent with regard to their children's education and healthcare needs, and make decisions in the best interests of the child. In order to plan comprehensive services and supports, families should know the etiology of their son or daughter's disability, supports offered by community-based providers and facilities, how to negotiate the legalities of the social service system, the limits of personal insurance, and how to classify disability expenses

separately from household expenses for tax purposes (Geeter et al., 2002). For some parents, acquiring information, navigating social services, and collaborating with professionals comes naturally, but other parents struggle to procure supports and services (Bjarnason, 2002; Murray et al., 2007; Stoner et al., 2005). Many practitioners and advocates want to convert the current funding system (regulated by the state and federal government) to a self-directed system. While it is grounded in solid civil rights philosophy, and makes fiscal sense, a self-directed system increases parents' responsibility to have good information and make sound decisions even more significant (Sloper, 1999, as cited in Geeter et al., 2002). Sloper (1999) contends that placing all decision-making power and resource-management under the control of families must happen only after a crucial, significant question has been satisfactorily answered: Are parents ready to take on the role of a knowledgeable administrator, especially with regard to medical issues?

This chapter examined the history of special education, the characteristics of effective and efficient transition programming, and the parent's role from caregiver to decision-maker. The concluding section profiled the comprehensive knowledge needed in many areas—such as policy, medicine, education, and finance—that many parents lack that is so vital during the transition period as the period of entitlement ends and navigating a system of eligibility begins. To deviate from the traditional role of parent requires knowledge of the law and a willingness to take on an advocacy or proactive role, as well as the ability to obtain information and knowledge, and this requires cultural and social capital—knowing what one needs to know, how to find it, and

whom to ask. The combined effects of (cultural and social) capital theory and role theory, may be useful in explaining the ability of some parents to advocate and garner the appropriate knowledge to affect individual services and systems-wide change, as well as the inability of other parents who may be unaware, unempowered, or unable to afford the same influence to improve their children's individual educational experiences (Horvat et al., 2003; Lareau & Horvat, 1999; Trainor, 2010). The intention of providing family-centered care is to meet the needs of the individual while concurrently educating and empowering the family. However, further research is needed to determine the factors that result in some parents developing self-determination and increasing knowledge, while others remain strictly reliant on professionals.

This researcher commonly witnessed parents who desired to provide the best for their children, yet lacked requisite knowledge. These experiences, combined with the knowledge that it is the school district's responsibility to educate parents about transition options, were the impetus for the creation of the TAPS instrument. With it, school districts can very quickly tell on a district-wide level what understandings and knowledge parents are lacking. However, each individual family can also use the results to determine what to learn, plan, and ask at the next transition or IEP meeting. The TAPS instrument will provide quality data that will make lives better.

CHAPTER III

RESEARCH DESIGN AND METHODOLOGY

Quantitative research has consistently shown that across all exceptionalities young adults with disabilities have poorer post-secondary outcomes than their typical peers (Hayward & Schmidt-Davis, 2000; Horn, Berktold, & Bobbitt, 1999; NDRN, 2011; Newman et al., 2009; NOD, 2004). Qualitative researchers have captured multiple perspectives, as young adults, parents, and professionals described less than ideal collaboration, revealed gaps in transition services, and insinuated that poor post-secondary outcomes are a logical consequence stemming from poor transition programming and implementation (Ankey et al., 2009; Antle et al., 2009; Beresford, 2004; Bjarnason, 2002; Cooney, 2002; Michaels & Ferrara, 2006; O'Connor, 2008; Swain & Walker, 2003). Ideally, parents and transition team members should collaborate so that students with disabilities are provided an appropriate education based on an individual transition plan that drives the curricula and instruction. Not only will this provide an appropriate education for the student while he or she is in school, the intention is that as the family and school develop a partnership, the school district will be building the family's capacity while preparing the individual for the future: giving information; explaining post-school education and employment options; and helping to establish linkages with adult service providers (Johnson, 2004).

Person-centered planning methods currently facilitate this exchange of information between families and schools, and there are published instruments to facilitate PCP (e.g., MAPS, PATH, and Personal Futures Planning).

However, families and professionals report that PCP is rarely as ideal as described in the literature; person-centered planning takes more time than other methods of planning, and the PCP facilitator is the key to successful outcomes when PCP is used (Holburn, 2002). Therefore, because there is no singular published instrument that reveals what transition programming information a family is lacking, if the family does not know what to ask, or if the school does not provide correct, complete information, there is a strong possibility that valuable opportunities and deadlines may be missed. Thus, the purpose of this study was establish content validity for the TAPS, a researcher-developed instrument designed to identify the transition programming knowledge of parents who have young adults with significant disabilities.

Research Question

This study sought to answer one primary research question: What is the technical adequacy of the Transition Awareness & Possibilities Scale with regard to (a) wording clarity (b) content domain representativeness, and (c) content domain sampling adequacy?

Organization of the Chapter

This chapter will begin with an overview of the Transition Awareness and Possibilities Survey (TAPS). This will include a description of the initial sections of the TAPS and items included therein. The criteria for choosing experts to review the TAPS will then be described, and a discussion of the creation of the expert review form will follow. The chapter will conclude with a discussion of the method of data analysis.

Description of the Draft Instrument

The Transition Awareness & Possibilities Scale (TAPS) was developed after a comprehensive review of published empirical research as reported in the previous chapter. Thus, the content domain of transition programming was defined by this researcher as *the longitudinal assessment, planning, skill-building, and networking that occurs between young adults, their families, teachers, service providers, and other stakeholders that facilitates the young adult's shift from the role of a student in a secondary environment to an adult in the community*. Parents' perceptions and concerns during the transition process were the driving force behind this research and led to the overall construct of the TAPS: parents' preparation for their child's transition to adult services. Therefore, the survey items were designed to measure parents' knowledge of transition planning procedures, content area knowledge and skill instruction, and planning for potential adult support needs.

The TAPS is organized into four sections (see Appendix B). Section A collects demographics information from the respondents and consists of 16 items; nine of the items refer to the respondent or the respondent's home, and seven items specifically refer to the transition-aged young adult. Section B collects information pertaining to communication between teachers and families and the satisfaction of respondents regarding family-school relations. In this section, there are two questions about the frequency of communication between teachers and respondents and seven questions addressing the purpose of communication (with an optional "other" item for respondents who wish to add additional information). Questions one and two are multiple-choice format with

answer choices listed in a (decreasing) ordinal scale. Questions three through eight are also multiple-choice format, but are organized in a chart form and increase on an ordinal scale. Respondents indicate their level of satisfaction on a six-point Likert scale (with an additional N/A option), so that respondents' choices range from "I am never contacted about this" to "I am contacted about this almost everyday." The last five items in Section B ask the respondents about their satisfaction with the frequency and purposes of communication. The final question, question 12, segues to Section C by asking about the respondents' satisfaction with their personal level of knowledge about transition programming.

Sections C and D of the TAPS have a similar structure and comprise the bulk of the instrument. Section C addresses skills and knowledge relevant to transition programming. Section C begins by asking respondents where they get information about the young adult's curricular options—question 13 asks for all the sources of information (respondents are instructed to choose all that apply), and question 14 asks for the respondents' best source of information (respondents are instructed to "select only one"). Section C then moves to a three-stem grid with three separate Likert scales that assess respondents' knowledge of the young adults' preparation for transition and adulthood based on relationships with content area knowledge and skills. The three stems for Section C are "I have observed my child demonstrating _____ (*skills or knowledge*) at home and in the community," "I think my child still needs instruction in _____," and "As a family, we have the resources or knowledge to practice _____ with my child at home and in the

community.” Prior to expert review, there were 31 items that individually aligned with the three scales. Respondents answer the questions on a six-point Likert scale; the first and third stems also have a N/A option for respondents who do not think that the content area or skill is relevant to the young adults needs, wants, or goals.

Section D pertains to the supports and services that young adults may need after transitioning from high school. This section also has three stems with variables that respondents insert to answer each question: “My child may need or want _____ during his or her adulthood,” “If my child needed or wanted _____, I know who to call or who to ask to provide this,” and “If my child needed or wanted _____, I know how to pay for it.” Prior to expert review, there were 39 items in Section D. Respondents will denote their level of agreement on a six-point Likert scale. Section D concludes with question 87, which asks for all the sources of information about the young adult’s disability and potential adult needs (respondents are instructed to choose all that apply), and question 88 that asks for the respondents’ best source of information about the young adult’s disability and potential adult needs (respondents are instructed to “select only one”).

The TAPS was designed for parents or other primary caregivers to self-report information. Therefore, readability was a significant concern. The readability for the entire instrument was calculated using Microsoft Word’s embedded tool; the Flesch–Kincaid grade level was 6.9.

The TAPS was developed to encompass most areas of transition programming and is supported by a comprehensive review of research.

However, because the population for the TAPS is families of transitioning young adults, the comprehensiveness of the document must be balanced with utility and relevance for families and schools. Thus, an expert panel was selected to rate the content representativeness, content relevance, and wording clarity of the TAPS.

Selection of Transition Content Experts

The selection process for experts was three-fold. First, professionals from different areas of the country were sought, as the TAPS was designed for use throughout the United States with families who possess different types and degrees of social, economic, and cultural capital. Second, a list of the top contributors to teaching and research surrounding transition programming was generated, and these potential reviewers' vitae were then examined. Experts with niche transition expertise (e.g., experts on English-language learners who have disabilities or with involving parents in the transition process), but also comprehensive special education knowledge were sought. This search yielded a list of 14 potential expert reviewers. An emailed letter was sent to each potential reviewer approximately 4 weeks in advance requesting his or her assistance (see Appendix C). Although the final instrument was not sent at this time, the outline of the literature review substantiating the contents of the TAPS was also enclosed. Fourteen requests for participation were emailed. Of those, 11 responded (the 3 who did not respond, also did not respond to a subsequent letter). One respondent could not participate due to other obligations. Of the remaining 10 expert respondents, 7 immediately confirmed their participation, and the remaining 3 stressed their commitment to the field and support of

graduate research, but were unsure if prior commitments would allow them the time to review the TAPS. However, all 3 did review the TAPS, for a total of 10 expert reviewers (see Appendix D).

The first two tiers of the reviewer selection was clearly relevant to the project purposes—a diverse group of experts from around the country with specific expertise was asked to review the TAPS. Each individual was selected for his or her contributions to the field and professional reputation. Overall, this selection method was successful, as all of the expert reviewers make significant contributions to the special education knowledge base—particularly with regard to transition programming—and were chosen for a particular facet of their transition programming knowledge (as evident in their publications and conference presentations). However, the third tier of the process was equally as important, because to secure the commitment of this caliber of professional for an expert reviewer, advance notice was a necessity. In fact, a two-week window was initially given to reviewers to review the TAPS, but as this was going to be quite difficult for some reviewers, the deadline was extended (almost from the outset), and four weeks was given to reviewers to complete the review.

At the beginning of August, 2011, all confirmed expert reviewers were sent another emailed letter that thanked them for their participation and explained the review process in detail. The TAPS was also included with the letter, as was the hard copy of the expert review form; in addition, the second chapter of this dissertation, the review of literature, was included as an email attachment for any reviewer who questioned the necessity of an item on the TAPS. One reviewer also requested the theoretical framework and research

question, which were then emailed. The instructions included a suggested return date of August 15, but a firm deadline of August 30.

The Expert Review Form

Rather than ask reviewers a series of open-ended questions, a form was developed for reviewers to complete. This provided a uniform method for data collection, so that reviewer agreement could be calculated; however, the form was also structured so that reviewers had ample opportunity to insert comments where they thought necessary. The form was provided in both electronic and hard copy formats (see Appendix E).

The purpose of the expert review was to establish content validity; however, the precise denotation of the term *content validity* is debated by researchers and statisticians (Fitzpatrick, 1983); therefore it is necessary to operationally define how to determine content validity. Specifically, determining content validity was a process that included determining if the items on the TAPS had content relevance and representativeness for the content domain of transition programming and if the content on the TAPS was an adequate sampling of the content that should be measured in order to determine in what areas of transition programming parents need more knowledge and/or supports (Nunnally, 1978, as cited in Yagamahle, 2003). Although a few statisticians debate the accuracy of the term content validity, it is still recognized in the field as a procedural measure of these collective indices, and so this term will be used here when referring to all three criteria (content representativeness, content relevance, and sampling adequacy), in combination with clarity of wording (Fitzpatrick, 1983; Beckstead, 2007).

In order to establish the content validity and usability of the instrument, the expert reviewers were charged with several tasks: to determine if the directions, questions, and response choices were clearly worded so that families who took the TAPS would understand them as intended; to decide if any items could be reworded to sound more respectful to families; to suggest any revisions to the formatting of the instrument; and to recommend the modification of items, removal of items, or addition of items to the TAPS.

The review form began with an explanation of this dissertation; an explanation of the TAPS instrument; and a theoretical definition of the transition programming content domain, and the dimensions included within and organized according to Kohler's Taxonomy (1996). For the demographics section, reviewers were asked to rate each question and the accompanying responses on wording clarity and respectfulness, and were given the opportunity to make additional comments. Wording clarity was rated on a four-point scale; a rating of four indicated that the item's wording was clear (see Figure 2).

On page 3 of the TAPS, questions 1-8 address the frequency and purposes of communication between parents and special education teachers. Please review each question or answer choice for clarity. Rate each item on a scale of 1 to 4, placing a check mark in the appropriate box.					
Item	Wording Clarity				Comments
	1= item is not clear	2= item needs major revisions to be clear	3= item needs minor revisions to be clear	4= item is clear	
Typically, how often do you have communication with your child's special education teacher? (phone calls, emails, letters, notebook correspondence, face-to-face conversations, etc.)					
Typically, how many times do you usually meet (face-to-face) with your child's special education teacher?					
How often and for what purposes does your child's special education teacher communicate with you?					

Figure 2. Reviewer format for Questions 1-2 and Question 3 stem.

For the Teacher-Parent Communication and Sources of Information sections, reviewers were also asked to rate wording clarity and comment on the appropriateness of the possible answer choices.

The sections of the review that addressed the Skills and Knowledge and Adult Services and Supports sections of the TAPS both asked the reviewers to rate the clarity of the items, as before. However, these sections also relied heavily on the reviewers' expertise and familiarity with the content domain of transition programming. In these sections, reviewers were asked to rate each item's representativeness of the content domain (transition programming), also on a four-point scale. An item that represented the content domain would receive a rating of four; items that did not represent the domain would receive a rating of one (see Figure 3). Reviewers were also given space to make item-specific comments.

Transition Programming: The longitudinal assessment, planning, skill-building, and networking that occurs between young adults, their families, teachers, service providers, and other stakeholders that facilitates the young adult's shift from the role of a student in a secondary environment to an adult in the community. Dimensions: <i>Student-Focused Planning, Student Development, Family Involvement</i>										
Please indicate how well each item represents the content domain of Transition Programming. Compare EACH item against the definition. Rate each item on a scale of 1 to 4, placing a check mark in the appropriate box. Then, rate the item's clarity, also by placing a check mark in the appropriate box.										
Item	Representative of Content Domain					Wording Clarity				Comments
	1= item is not representative	2= item needs major revisions to be representative	3= item needs minor revisions to be representative	4= item is representative	Remove from TAPS	1= item is not clear	2= item needs major revisions to be clear	3= item needs minor revisions to be clear	4= item is clear	
"I have observed my child demonstrating _____ (skills or knowledge) at home and in the community."										
"I think my child still needs instruction in _____."										
"As a family, we have the resources or knowledge to practice _____ with my child at home and in the community."										

Figure 3. Reviewer format for Questions 15-86 (Sections C and D).

At the end of every section of the review, reviewers were given the opportunity to comment on the overall content coverage, recommend items to

be added, comment on the formatting of the section, and offer any other comments. These same open-ended questions were also at the conclusion of the entire review. The duality of both structured and freeform feedback provided valuable data with clear trends, yet also capitalized on the specialized knowledge of the experts that had initially led to recruiting these particular reviewers.

Method of Quantitative Analysis

Choosing a method to calculate inter-rater reliability or agreement between the reviewers was difficult due to the unique circumstance of this review—the reviewers were purposively chosen (i.e., they were fixed effects) and had a lot in common. The data was ordinal, and likely to have high trait prevalence. The best snapshot of agreement between reviewers was likely to come from a raw agreement index; however, because this does not account for the effects of chance, another statistic would also be necessary to provide additional perspective. However, according to Ubersax (n.d.), raw statistics should not be discounted for simplicity, but instead appreciated, as they can be clinically meaningful and often more preferable and appropriate than more complex statistical methods such as the ICC, and more meaningful than Fleiss' Kappa.

For the purposes of best utilizing the expert review data, it was appropriate to calculate the average pairwise agreement for each section of questions. Pairwise agreement is a more stringent comparison than the Intraclass Correlation Coefficient (ICC), but often produces more accurate results with regard to consistency, especially when reviewers have high

agreement. To calculate average pairwise agreement, each reviewer's rating of every item is (independently) compared with every other reviewer's rating of the same items (this is repeated for all possible pairs of reviewers), and the total percentage of the agreements is summed. Then, this sum is divided by the total number of pairings. This is the pairwise agreement value for the given assessment item. Typically, a pairwise comparison result of 0.7 or higher is considered to reflect good agreement, 0.6 or higher reflects adequate agreement, and 0.5 or less reflects poor agreement.

Pairwise agreement (a measure of raw agreement) is highly criticized by some researchers and must only be used in specific situations, as it can inflate agreement between raters because there is no adjustment for chance. Therefore, the Fleiss' Kappa was calculated and reported for this review, but with several limitations. First, the raters for this review were not randomly assigned, but were chosen specifically for their expertise. As such, it is extremely likely that the reviewers would have very strong agreements because of similarities in level of education and philosophy, or strong disagreements based on differences in niche expertise. Therefore, although typical survey development indicates that a Kappa or other statistic that calculates the effect of the null hypothesis may be used, one that presupposes the random selection of raters and is primarily used to calculate effects of a null hypothesis may be less useful for this review. Secondly, with such a small number of reviewers ($n=10$), the Kappa is unlikely to produce a reliable estimate of the null hypothesis (Sadatsafavi, Najafzadeh, Lynd, & Marra, 2008). Thirdly, multiple Kappa statistics exist because there is no standard agreement among statisticians as

to how to correct for chance agreement; the nonstandard behavior of raters will always affect any statistic designed to compensate for chance.

Often researchers use the Kappa (k) statistic, or a derivative of it, to calculate interrater agreement. However, in many cases this may not be the appropriate statistic to use. The Kappa statistic can verify the agreement of raters exceeds the expected level of agreement that would occur by chance alone, but it is only appropriate for normally distributed data. There is also not a standard Kappa that indicates “good” agreement. In a study that has more than two reviewers, if a Kappa statistic were to be utilized, the Fleiss’ Kappa would be used. Therefore, Fleiss’ Kappa was calculated, but with this researcher’s significant reservations, because the Fleiss’ Kappa would perhaps offer no more meaningful information than the raw agreement calculation (i.e., pairwise agreement). This researcher was less concerned with how many reviewers agreed, than what items the agreements and disagreements were about.

Fleiss’ Kappa is a multi-rater extension of Scott’s π , and ranges from -1 (denoting perfect disagreement) to +1 (denoting perfect agreement). The problem with Fleiss’ Kappa—and all Kappa statistics—is that if there is a large number of similar ratings by reviewers (i.e., high trait prevalence), the calculated Kappa statistic will be unreasonable, meaningless, and illogical. The Kappa equation is based on the null hypothesis which assumes that each participant (in this case, each reviewer) has a fixed probability of making + or – responses (Fienstein & Cicchetti, 1990). However, this was not the case for this review, nor for most other empirical reviews (Gwet, 2010; Fienstein & Cicchetti, 1990). Thus, a null hypothesis for this research could have been, in fact, that the Fleiss’

Kappas would be invalid because the prior literature review and this researcher's background knowledge ameliorated the effects of chance and prejudiced the statistic itself (i.e., if this researcher had crafted the TAPS perfectly, all of the expert reviewers would have agreed to ratings of "4" for all items). When the numbers of agreements are unbalanced (between possibilities—not between reviewers) high trait prevalence occurs, the "Kappa paradox" occurs and invalidates Fleiss' Kappa, yet increasing average pairwise agreement. Thus, the poorer the data and greatest amount of variability between reviewer agreement, the more applicable and logical the Fleiss' Kappa will be (Gwet, 2010).

Probably the most common assessor of rater agreement across all disciplines is the Intraclass Correlation Coefficient (ICC). The ICC assesses rating reliability by comparing the variability of different ratings of the same case (by multiple raters) to the total variation across all ratings and all cases (Ubersax, 2006). In the case of multiple reviewers rating the same cases, the ICC is calculated using a two-way mixed effects ANOVA:

$$ICC(A,K) = \frac{MS_R - MS_E}{MS_R + \frac{MS_C - MS_E}{N}}$$

When the ICC is calculated using the above formula, N is the number of cases, MSR is the mean square for rows (i.e., cases), MSC is the mean square for columns (i.e., raters), and MSE is the mean square error obtained from a two-way ANOVA. The ICC values, in theory, range from 0 (no agreement) to +1 (perfect agreement), but ICC values sometimes will be negative (indicating no agreement) (Lahey et al., 1983, as cited in Olson, 2010). The ICC(3) that

accounts for fixed effects of the reviewers and is not generalizable other populations would normally be applicable to data garnered from this type of review; however, the small number of reviewers was not a sufficient sample size to calculate adequate ICCs without incredibly large confidence interval ranges. Thus, the ICC was invalid for this study.

A common measure of content validity that is frequently used in nursing, psychology, and education survey design is the Content Validity Index (CVI) (Lynn, 1986; Polit & Beck, 2006; Polit, Beck, & Owen, 2007). This researcher chose not to use the CVI to derive a mathematical indicator of content validity for the TAPS due to an inherent, yet widely ignored, flaw in the calculation of the CVI that inflates the interrater agreement (Beckstead, 2009). On a four-point review scale (as was used in this study) that assumes a rating of a “3” indicates an item needs minor modifications, and a rating of “4” indicates the item needs no modifications, the CVI is calculated as the ratio of experts who give a rating of 3 or 4, divided by the number of experts. However, this collapsing of response categories negates valuable reviewer information and reports agreement where there may have been none: if Reviewer A, gives an item a rating of 3, and Reviewer B gives an item a rating of 4, the CVI would consider this 1.0—perfect agreement—obviously not the case. In addition, from the very start, the CVI incorrectly calculates probability statistics and does not calculate interrater agreement correctly (Beckstead, 2009). It is for these reasons that the CVI, though often used by other researchers to calculate content validity, was not used to determine the content validity of the TAPS.

Conclusion

In this chapter, the method for establishing content validity of the TAPS was discussed. The chapter began with a profile of TAPS. Then, the criteria and process for the selection of expert reviewers was explained and the form that the expert reviewers used to give feedback was described. Lastly, the methods of data analysis—average pairwise agreement and Fleiss' Kappa (though of questionable significance) were explained, and the disregard for two methods not chosen—the ICC and CVI—was justified. The final two chapters report the information garnered from the expert reviewers and the forthcoming revisions to the TAPS based upon this information. In Chapter IV, the expert review results are reported and discussed. In Chapter V, conclusions are drawn as to pragmatic effects of the results and the forthcoming revisions to the TAPS.

CHAPTER IV

ANALYSIS OF DATA

The purpose of this study was to determine the content validity for the Transition Awareness and Possibilities Scale. This was the first step in the process to determine reliability and validity of the instrument so that schools and families may use the TAPS to determine the parents' knowledge of transition programming. To achieve the purposes stated above, expert researchers were asked to review the TAPS so that the technical adequacy of the instrument could be determined. The reviewers were asked to rate the items on the TAPS using a researcher-created instrument. This allowed for the collection of both quantitative data and additional commentary. Throughout this chapter, the pairwise agreement for the reviewers will be reported, as well as Fleiss' Kappa. Reviewer commentary will extend the quantitative data offered by reviewers and provide more detailed suggestions for the revision of the TAPS.

Research Questions

This study sought to answer one primary research question: What is the technical adequacy of the Transition Awareness & Possibilities Scale with regard to (a) wording clarity (b) content domain representativeness, and (c) content domain sampling adequacy?

Organization of Data Analysis

This chapter will begin with an explanation and justification for the quantitative method. The bulk of the chapter will be given to the data itself—that is, the responses from the experts. Pairwise agreement among the reviewers will be reported for each Section, and other natural clusters of questions, and

expository comments from the expert reviewers will be noted, as well. Each section will be discussed in entirety, beginning with Section A and concluding with Section D. A discussion of the implications of the data will be reserved for Chapter V.

Findings in Section A: Demographics

Upon expert review, most items in the demographic section of the TAPS were rated as “clear”, or needing minor revisions to be clear (Table 1). Expert reviewers rated the wording of the items on a one to four scale and then offered suggestions to bring more clarity and exactness to Section A, the demographics section, of the TAPS. The reviewers’ comments addressed four main concerns: consistency, clarifications, omissions, and relevancy.

Table 1

Reviewer Ratings of the Wording Clarity for Section A: Demographics

Question	R1	R2	R3	R4	R5	R6	R7	R8	R9	R10
a	4	3	4	4	4	4	3	4	4	3
b	3	4	4	4	4	4	3	4	4	3
c	4	4	4	4	4	---	4	4	4	4
d	4	4	4	4	4	4	4	4	4	4
e	4	4	4	4	4	4	4	4	4	4
f	4	4	4	4	4	4	4	4	4	4
g	4	4	4	4	3	3	4	4	4	4
h	4	4	4	4	3	3	4	4	4	4
i	4	4	4	4	3	3	4	4	4	4
j	4	4	4	4	3	3	4	1	3	3
k	4	4	4	4	3	3	4	4	4	3
l	4	4	3	3	3	3	4	4	4	4
m	4	2	4	4	3	4	4	4	4	4
n	4	3	4	4	3	4	4	4	4	4
o	4	3	4	4	3	4	4	4	4	4
p	4	2	4	4	3	4	4	1	4	3

Note. All Reviewers rated items on a four-point scale: 1= item is not clear, 2= item needs major revisions to be clear, 3= item needs minor revisions to be clear, 4= item is clear.

The average pairwise agreement is calculated by determining the percent agreement for each question for each pair of reviewers and then averaging these percentages (see Chapter III for a complete explanation of analysis). The average pairwise agreement for the reviewers' ratings of wording clarity for items in the demographics section was 64.148%, indicating agreement between reviewers (Table 2). However, it is important to note that sometimes the ratings of individual reviewers can skew the pairwise agreement. Reviewer 5 had 34.825% average pairwise agreement with the other reviewers. Thus, if Reviewer 5 is removed from the calculation, the average pairwise agreement increases to 70.37%.

Table 2

Ratings of Absolute Agreement by Ten Expert Reviewers

TAPS Section	Method/Statistic Used
	Average Pairwise Agreement
Section A: Demographics	
Wording Clarity	64.148%

Note. All Reviewers rated items on a four-point scale, ranging from 1= item is not clear to 4= item is clear. The ten experts examined n=16 questions in Section A.

Several comments addressed wording consistency errors or potential problems with respondents' perceptions that could compromise the validity of the TAPS. First, to make the demographics section more valid, two reviewers specifically said that the statement from Section B that defined transition and directed parents who have more than one child with disabilities to "choose one child answer questions about," needed to be moved to Section A, so that

parents are clearly aware that all of the remaining questions refer to this particular young adult within their household. One expert reviewer cautioned that all respondents may not consider their younger (e.g., 14-year-old) children as “young adults.” Another reviewer noticed that although parents were initially told that the survey items concerned their “young adult” who was “aged 14-22,” the TAPS did not always use the term “young adult” consistently, but sometimes used “child” instead. To remove all traces of inconsistency, a reviewer suggested that because a “young adult” was initially introduced as an individual who is aged 14-22, item M should ask the total number of children under 22—not 21. In an attempt to increase the accuracy and the precision of TAPS, a reviewer suggested that parents be instructed to “select one” or “all that apply” for race/ethnicity.

The second type of reviewer comments identified areas for which the inclusion of more precise language could avert potential confusion for respondents. In several instances, expert reviewers suggested that the TAPS should provide examples to make answer selection for the respondents easier and more accurate. For example, question B asks respondents, “What is your relation to the young adult who is of transition age (14-22)?” A reviewer suggested that examples of different types of family members be given. Another reviewer suggested that the answer choices for this particular question be changed to Parent; Guardian; Family Member; Other, (Specify). One reviewer suggested that question P (regarding exiting high school) needed to be better described and “perhaps illustrated with examples.” Another reviewer asked if the answer choice “exited without documentation” meant “without a

diploma”; this answer choice likely needs clarification from examples, as well. As an aside—a reviewer cautioned that respondents in different states may find that some high school exiting options may be irrelevant, but did not suggest that they be removed.

Comments from two reviewers suggested that the addition of the words “non-sibling” was confusing in question L and suggested that asking for the number of adults in the home would suffice. A reviewer suggested that using the phrase “has/had an IEP” instead of “receives/received special education services” for question I would avoid technicalities and confusion for respondents. Another reviewer suggested changing some of the language in the TAPS “to be more straightforward,” with the reading level of the target audience more clearly in mind.

Regarding question J, three reviewers questioned why certain IDEA subcategories—particularly specific learning disabilities and emotional/behavioral disorders—were omitted. Presumably, the rest of the reviewers attributed this to the stated target population for the TAPS (i.e., families of students who require extensive or pervasive supports), and only a small percentage of students with specific learning disabilities or emotional/behavioral disorders as a primary disability require this degree of support. However, one of the reviewers who commented on the omission qualified his remark by reminding this author that by inviting parents to forward the TAPS survey to other parents who have children with disabilities (as is the case in after question A), it is likely that families of young adults who have all

different types of disabilities may use the TAPS. Consequently, that was why the reviewer suggested that all subcategories be included on the TAPS.

Several reviewers commented on demographic questions that they regarded as potentially irrelevant—specifically, the respondent’s birth year, the location of the school that provided special education services for the young adult, respondent’s income, and the ethnic background of the young adult with disabilities. Some reviewers said these questions were invasive, as well as irrelevant to the purpose of the study. One reviewer simply asked if this author had combed through the questions thoroughly to be sure that all of the demographic questions were necessary, as the expert reviewer often found himself with extra, irrelevant demographic information at the end of his own research studies.

The reviewer comments for Section A suggested that the demographic questions need some revisions to be clear to all respondents. Directives to respondents need to be re-arranged, and confusing language should be clarified prior to pilot testing. In order to validate the first question (inviting potential respondents to pass the survey to others), additions must be made so that all the subcategories of IDEIA are included. Lastly, two reviewers suggested that the researcher consider moving the demographic section to the end of the TAPS, instead of the beginning, so that respondents are less wary of the researcher or the school administering the TAPS and more likely to give complete, accurate answers, as the purpose for such questions may often be clearer.

Findings for Section B: Teacher-Parent Communication

Section B of the TAPS asks respondents about communication between teachers and families and their level of satisfaction regarding family-school relations. Several analyses were run on the reviewers' ratings of clarity and representativeness for both the stems of the questions and the answer choices (Table 3). The average pairwise agreement for the representativeness of the content domain for the three communication question stems was 57.143% and 55.556% for wording clarity. This was due to reviewers who had concerns with (at least part of) the question stems disagreeing with the other reviewers who rated clearly-worded stems as needing no revisions. Reviewer comments discussed later within this section explain the reviewers' concerns. The pairwise agreement for the answer choices increased for both purposes of communication (80.494%) and frequency of communication (80.889%).

For every variable that was rated in this section, the Fleiss' Kappa was negative, indicating a lack of agreement between reviewers due to anything but chance; however, this is clearly not the case (not only does it seem unlikely given the extensive literature review and purposive sampling of experts, the qualitative data supports purposive agreement). The invalidity of the Kappa can be attributed to several possibilities. Due to the large proportion of disagreement it is also not likely that a Kappa paradox caused by high-trait prevalence. More likely, this is an indicator that because of the small number of reviewers ($n=10$), the Kappa is unlikely to produce a reliable estimate of the null hypothesis (Sadatsafavi et al. 2008).

Table 3

Ratings of Absolute Agreement by Expert Reviewers for Section B

TAPS Section	Method/Statistic Used	
	Average Pairwise Agreement	Fleiss' Kappa
Section B: Communication		
Question Stems		
Representativeness	57.143%	-0.143
Wording Clarity	55.556%	-0.093
Section B: Communication		
Answer Choices		
Purposes of Communication		
Wording Clarity	80.494%	-0.084
Frequency Intervals		
Wording Clarity	80.889%	-0.062

Note. All Reviewers rated items on a four-point scale, ranging from 1= item is not clear to 4= item is clear.

For Section B, reviewers were asked to comment on the appropriateness of the intervals listed for two questions that asked respondents about the frequency of communication between teachers and families. One reviewer questioned the response options for respondents whose frequency of communication fell in-between the options given; this reviewer specifically cited

respondents who may need to select an option that denoted their frequency of communication as “every other week” or “less than once per year.” The reviewer who marked that the interval choices for questions 1 and 2 needed “minor revisions to be clear” (see Table 4), suggested adding “at least” before the intervals. In addition, an expert reviewer suggested the elimination of the “I don’t remember or I’m not sure” answer option and, instead, the augmentation of the question instructions with a directive for unsure participants to select their best answer.

Table 4

Reviewer Ratings of the Wording Clarity for Communication Frequency Interval

Frequency	R1	R2	R3	R4	R5	R6	R7	R8	R9	R10
Almost every school day	4	4	4	4	4	4	4	4	4	4
1-2 times per week	4	4	4	4	4	4	4	4	4	3
1-2 times per month	4	4	4	4	4	4	4	4	4	3
3-4 times per school year	4	4	4	4	4	4	4	4	4	3
1-2 times per year	4	4	4	4	3	4	4	4	4	3

Note. All Reviewers rated items on a four-point scale: 1= item is not clear, 2= item needs major revisions to be clear, 3= item needs minor revisions to be clear, 4= item is clear.

Questions 3-8 on the TAPS ask parents about the purpose of communication between themselves and teachers. Five reasons garnered from the literature are listed, and parents are asked to mark how strongly they agree or disagree with each option as a purpose of their personal communications with their child’s teacher. For this review, experts were asked if the choices listed were worded

clearly and representative of the transition programming content, and if any other purposes for communication should be added to the list. Nine of the ten reviewers rated the options that were already on the TAPS as both “worded clearly” and “representative of the transition programming content” (see Table 4 and Table 5).

Table 5

Reviewer Ratings of the Wording Clarity for Purposes of Communication

Purpose	R1	R2	R3	R4	R5	R6	R7	R8	R9	R10
Ask for my opinion or advice	4	4	4	4	4	4	4	4	4	3
To "check-in" with our family	4	4	4	4	4	4	4	4	4	3
Report daily activities	4	4	4	4	4	4	4	4	4	3
Report problem behavior	4	4	4	4	4	4	4	4	4	3
Report progress on skills, objectives, & goals	4	4	4	4	4	4	4	4	4	3

Note. All Reviewers rated items on a four-point scale: 1= item is not clear, 2= item needs major revisions to be clear, 3= item needs minor revisions to be clear, 4= item is clear.

Experts who rated the items as needing revisions offered explanations to clarify what changes would make a clearly worded item. Only one reviewer commented on the items “Ask my opinion or advice” and “To check-in with family”; this reviewer commented “About what?” for each. Most reviewers offered suggestions for formatting and proofreading correction. For the sake of uniformity between items 1 and 2, a reviewer suggested that “school” be added to the “1-2 times per year” answer choice, so it will have the same format as the

“3-4 times per school year” answer choice. The reviewer who marked that items 5-7 needed minor revisions to be clear suggested that “a child’s” be added (e.g., item 5 would read, “report a child’s daily activities”). One reviewer also pointed out that there was some inconsistent capitalization throughout the section.

Reviewers suggested several additions to the list of purposes for communication between teachers and parents. One reviewer suggested the addition of “share upcoming events or activities.” Another reviewer suggested “check-in regarding mental health or emotional well being,” and another reviewer suggested that “report accomplishments” be included. Two reviewers mentioned adding an option that included communication for the purposes of exchanging information about transition assessment. Five expert reviewers specifically suggested including an option that denoted a purpose of communication regarding overall transition programming (e.g., “discuss transition activities,” “follow up with transition planning,” or “to provide information regarding postsecondary agency services”). In addition, two reviewers suggested adding an option that addressed the communication between teachers and parents that occurs to discuss post-secondary goals and options. Lastly, another reviewer noted that she hoped there were questions in a later section that addressed the parent’s role and level of involvement in the IEP and transition planning meetings and the emotions about the IEP meetings themselves, since questions pertaining to those topics were absent in this section.

As indicated in questions 1 and 2, purposeful, ongoing communication is reciprocal; however, questions 3-8 on the TAPS ask specifically about the

teacher's frequency and purpose of initiating communication with the respondent, but not the respondent's frequency and purpose of communication with the teacher. With this in mind, two reviewers also asked this author to consider if the TAPS should include questions that ask about the reciprocity of communication, or, specifically, about the frequency and purpose of parent-initiated communication.

There were two additional issues in this section that reviewers cautioned might cause confusion for respondents. First, one reviewer urged that respondents must be instructed how to choose which teacher to answer questions about, as many students in high school have more than one special education teacher. Secondly, a reviewer cautioned that measuring two concepts (i.e., frequency and purpose of communication) in one item is complex.

Review of Section C: Skills and Knowledge—Sources of Information

This section of the TAPS asks respondents about where they get their information about curriculum. Question 13 asks, "Please indicate ALL the people and places where you get information about your child's curriculum (what he or she could be learning in school)." Question 14 asks parents to narrow down their sources to the best source of information: "Where do you get THE BEST information about your child's curriculum (what he or she could be learning in school). Select only one." Both questions have the same answer choices; therefore, one review question addressed them both. Expert reviewers were asked to rate the wording clarity of the answer choices, determine if any answer choices should be removed or modified, and add any other sources of information the reviewer deemed necessary.

The average pairwise agreement for the rating of wording clarity was 95.299%, indicating that the reviewers had a high amount of absolute agreement (see Table 6). The Fleiss' Kappa was contrary to this and indicated a lack of agreement. For this section, due to the overwhelming agreement by reviewers, a high-trait prevalence caused a Kappa paradox.

Table 6

Reviewer Ratings of the Wording Clarity for Sources of Curricular Information

TAPS Section	Method/Statistic Used	
	Average Pairwise Agreement	Fleiss' Kappa
Section C: Sources of Information (Questions 13 & 14)		
Wording Clarity	95.299%	0.059

Note. All Reviewers rated items on a four-point scale, ranging from 1= item is not clear to 4= item is clear. Nine experts examined n=13 questions for this part of Section C.

The reviewers had several comments regarding wording clarity and offered additional suggestions for sources of information. As in previous sections, reviewers were asked to determine if the wording of questions 13 and 14 were clear and also given the opportunity to make comments and suggestions. One reviewer suggested that the answer choice "Friends or Family" be separated into two answer choices ("Friends" and "Family"). Another reviewer commented that "Friends or Family" should be changed to "Family or Relatives." It was also suggested that "Formal" be dropped from "Formal Support Groups." In addition to reviewing the wording clarity for the answer choices already present, 6

experts suggested 14 additional people or entities that may be a source of information for young adults and families: conference, informal support group (e.g., church, ethnic community group); job coach, vocational rehabilitation person; journal/magazine; mental health counselor; professional organization (e.g., TASH, CEC); relative; school administrator; school district administrator; school guidance counselor; school psychologist; speech therapist; and workshop.

Several reviewer comments addressed elements of Section C that had the potential to compromise TAPS respondents' ability to give true and valid answers. The intended meaning of *curriculum* in the stem of questions 13 and 14 was unclear to one reviewer—that is, did curriculum mean only academics or encompass community-based, life skills curricula? Because of the various connotations of *special education curriculum*, to some respondents, several of the answer choices may not make sense. The reviewer suggested that the stem of the question be modified so respondents understand that, in this case, *special education curriculum* included life skills and other areas beyond academics (the reviewer did think the answer choices inclusive and appropriate). Another reviewer suggested that the answer choices be clarified and organized into three groups: school-based sources of information, community-based sources of information, and informal sources of information and support.

The previous section examined the comments from the expert reviewers that pertained to the people and organizations that provide information to

parents about potential curricula for young adults who are of transition age. Regarding questions 13 and 14, most of the reviewers thought the wording for each source clear (see Table 6); in addition, experts recommended that other sources be added. However, as the overall reviewer comments revealed, there were both clarity and formatting issues that should be addressed prior to pilot testing. Despite these issues, reviewer comments also indicated that, thus far, the TAPS had overall good visual appeal and was easy to read.

Representativeness of Section C: Skills and Knowledge—

Content Areas and Skills

Section C of the TAPS addresses skills and knowledge relevant to transition programming. Expert reviewers were asked to rate each content area and skill on both wording clarity and representativeness for the transition programming content domain. Most reviewers agreed that the areas and skills were very comprehensive and represented the content domain of transition programming (see Table 7). The average pairwise agreement for the rating of representativeness was 90.848%, indicating that the reviewers had a high amount of absolute agreement that the items well-represented the content domain (transition programming); however, the average pairwise agreement for wording clarity was 57.589%. Overwhelmingly, the expert reviewers indicated that the items listed as transition programming topics, specifically under “skills and knowledge” were representative of the domain content for transition programming and recommended the addition of nine more: banking skills or basic personal finance skills; computer skills; decision-making; employment skills (e.g., punctuality, attendance, time management, job completion, following

directions, self-monitoring); how to work with post-secondary institutions to disclose disability and obtain accommodations; interpersonal skills; self-awareness; using email/internet; and using public transportation. There were no recommendations for deletion. However, one reviewer perceived the items as a “little hit or miss” (i.e., why was math listed as an item, but language arts and science were not?). The representativeness of the content domain was rarely questioned throughout the review of this section; however, the poor agreement between reviewers for wording clarity ratings was indicative of the need for clarification of the terms.

Table 7

Reviewers' Agreement for Section C: Content Area Knowledge and Skills

TAPS Section	Method/Statistic Used
	Average Pairwise Agreement
Section C: Skills & Knowledge	
Representativeness	90.848%
Wording Clarity	57.589%

Note. All reviewers rated items on a four-point scale, ranging from 1= *item is not clear/representative of content domain* to 4= *item is clear/representative of content domain*. The experts examined 31 items related to transition programming content area knowledge and skills. For both representativeness and clarity, n=8 reviewers participated.

Wording Clarity and Formatting of Section C: Content Areas and Skills

One reviewer, who marked items as unclear, commented to clarify that those specific terms were used professionally, but not by families; consequently, this reviewer marked five of the thirty-one skills and knowledge terms (AAC, Non-verbal communication, self-advocacy, self-determination, and self-

monitoring) as needing concrete examples to clarify them for respondents. Similarly, another reviewer who marked items as needing revisions, followed-up with a comment to clarify that the specific items needed definitions or examples; this particular reviewer marked 21/31 of the skills and knowledge items as needing revisions. In fact, several reviewers commented on the need for items in both Sections C and D to have definitions and/or examples added to ensure respondents' understanding of the item.

Several reviewers also suggested that the alphabetic grouping of items was problematic and respondents would likely benefit from a more logical grouping of items into categories and subcategories (e.g., Academic Skills, Functional or Independent Living Skills, etc.). One of the reviewers gave the example that self-determination could be a category with the subcategories of choice-making, goal setting, problem-solving.

Another significant issue with Section C was the non-parallel structure of the skill and knowledge items; that is, some items were behaviorally-defined verbs that directly related to transition programming (e.g., completing applications for employment) and others were general nouns (e.g., math). Reviewers recommended that these items be reworded. Not only were some items nonparallel, sometimes the items were awkward and did not fit into the stem [e.g., "I have observed my child demonstrating (sex education) at home and in the community"]. This ill-fit of the noun "sex education" into the first stem caught the attention of more than one reviewer (although only one reviewer uncovered the larger problem of parallel structure between objectively-defined behaviors and general items).

Two reviewers mentioned concerns with the potential for respondents to misunderstand that there are three separate stems and with three scales. One of the reviewers suggested that an example could be added to the directions for clarification. A reviewer was also concerned about the number of items and “the need to go through the list 3 times.” Another reviewer suggested that an “already has skill” answer choice be added.

Similar to the other sections, there was also a recommendation to correct some inconsistent capitalization in Section C. In addition, a reviewer suggested that “my child” be changed to “young adult” in the statements. The non-parallel structure of the items was a concern for reviewers, who also agreed that many of the terms needed to be better defined or have examples to give clarity and meaning to respondents outside of the profession. Lastly, reviewers suggested that the items in the skill list in Section C be grouped in a logical format, in lieu of the alphabetic organization.

Content Representativeness for Section D: Adult Services and Supports

Section D of the TAPS pertains to the supports and services that young adults may need after transitioning from high school. The content in Section D was regarded as “good,” “fine,” “thorough,” by most reviewers; however, more than one reviewer marked to remove some options from TAPS: adult daycare, day-habilitation, home-delivered meals, long-term hospitalization, sheltered workshop, and short-term respite or relief service for the family. The average pairwise agreement for the rating of representativeness was 90.848%; again, the average pairwise agreement for wording clarity significantly decreased to was 57.02% (see Table 8).

Table 8

Reviewers' Agreement for Section D: Adult Services and Supports

TAPS Section	Method/Statistic Used
	Average Pairwise Agreement
Section D: Services & Supports	
Representativeness	90.848%
Wording Clarity	57.02%

Note. All reviewers rated items on a four-point scale, ranging from 1= item is not clear/representative of content domain to 4= item is clear/representative of content domain. The experts examined 31 items related to transition programming content area knowledge and skills. For both categories, n=8.

Review of Wording Clarity and Formatting for

Section D: Adult Services and Supports

Section D's format is akin to Section C and reviewers treated it very similarly when commenting on both the content representativeness and format. As mentioned previously, several reviewers commented on the need for items in Section C and D to have definitions and/or examples added to clarify the intended meaning. For example, "Benefits Planning" was listed in Section D; however, Medicaid and Medicare assistance, which would likely fall under benefits planning, did not. Therefore, one reviewer suggested that Medicaid and Medicare be added as examples under benefits planning.

Again, the alphabetic grouping of items was also mentioned as problematic, and reviewers suggested that a grouping that employed categories

and subcategories would likely be more useful. For instance, one reviewer suggested that “Independent Living Arrangements” was a major category with several subcategories (e.g., Chore Services/ Housekeeping Assistance and Medication Management/Oversight). One reviewer commented that he was unclear how an “Intensive, very structured living arrangement (outside of family home)” differed from a group home. Another reviewer suggested separating the item “Therapeutic, Social and Recreational Program” into three separate items. One reviewer also suggested that the third stem for Section D: Adult Services and Supports could be misconstrued by some respondents as asking if they, personally, would be able to pay for the services (instead of simply knowing how to procure resources). Questions 87 and 88 ask TAPS respondents where they get information about adult services and supports. However, the question and answer choice wording and format are almost identical to questions 13 and 14. Thus, the reviewer ratings were identical. In fact, several reviewers simply said “see previous answer” or drew arrows to questions 13 & 14 instead of rewriting applicable comments.

Review of the Overall Content Coverage and Format of the TAPS

When asked to comment on the overall content coverage of the TAPS, the reviewers were generally positive and encouraging. Most reviewers said “good” or “fine.” One expert reviewer remarked that the content was “thorough and covers a broad range of needed skills and knowledge.” Another said that it was possible to list 100 more (skills), but TAPS “hit the important parts.”

Although previous sections discussed the items that would be added to specific sections, there were also a few questions that reviewers suggested

should be included on the TAPS that would potentially fall outside of the current Sections. One reviewer recommended that the TAPS include questions indicating the percent of time the young adult spent in general education classrooms per day. Another reviewer suggested adding some items that would act as indicators of culturally appropriate planning.

When reviewers were asked to comment on the overall formatting of the TAPS “(visual appeal, spacing, readability, etc.),” some suggested comprehensive changes to the entire survey, such as color-coding, for organization, and a 14-point font for increased readability. However, some comments were more intensive.

A reviewer with extensive surveying expertise cautioned that a previous (large) pilot study (for which the reviewer was lead researcher) had revealed that discriminating between “mild” agreement and (standard) agreement, as well as “mild” disagreement and (standard) disagreement was a difficult task for many respondents--not only was it frustrating, but it also took much more time to complete the survey. The reviewer suggested that due to the length of the TAPS, it might be a good idea to consider offering only four answer choices for the questions involving Likert scales (instead of six).

Two reviewers mentioned writing clearer directions for survey respondents, particularly due to the diverse types of questions on the TAPS. For example, in Section C, the formatting changed from the questions in Section B. Although there were directions for the first questions in Section C (questions 13 and 14), the formatting was slightly inconsistent: the directions did not begin with the word “Directions” as in previous sections.

The two final review questions ask the expert reviewers to review the content and formatting of the entire instrument “with both expediency (for TAPS takers) and the dual purposes of the TAPS in mind.” It is there that nine of the ten reviewers offered comments that revealed their conclusion as to the potential of the TAPS to achieve the two stated purposes. Seven of the ten reviewers’ comments alluded that they anticipated that the final version of TAPS would be a complete, comprehensive instrument that would be useful for both families and schools. However, the reviewers were divided. One dissenting reviewer expressed concern that the TAPS would not be useful for program evaluation at a school or district level, and also remarked that most of the information needed for program evaluation (according to Kohler’s Taxonomy) is unlikely to come from family respondents. Another reviewer thought that the survey would not be useful for families, but (presumably) useful for program evaluation.

Chapter Summary

This chapter presented the results of the expert review of the TAPS by 10 reviewers. The reviewers rated the TAPS for representativeness of content domain and wording clarity. The average pairwise agreement was calculated for each section of the review, but because this does not account for the null hypothesis (chance agreement), Fleiss’ Kappa was also determined for each. However, due to the small, purposive sample of reviewers, and (sometimes) high trait prevalence, this additional statistic was rarely insightful. Overall, the reviewers rated representativeness more favorably than wording clarity, but offered clarification and detailed comments to aid in revision of the TAPS. Each

reviewer also was instructed to add or remove items to aid in the determination of sampling adequacy. The following chapter will discuss the implications and conclusions of the reviewers' ratings and remarks.

CHAPTER V

FINDINGS, CONCLUSIONS, AND IMPLICATIONS

There is currently not a standardized tool to assess parents' transition programming knowledge. In Chapter One, the underlying need for a valid and reliable tool to assess parents' transition programming knowledge was introduced. This need was buttressed by the theory that there are disparate transition outcomes for families with limited access to social, cultural, and economic capital. Chapter One also included a list of the definition of terms important to this study and concluded with an explanation of the limitations and delimitations pertaining to this study.

Chapter Two was a review of the literature review pertinent to the content of the Transition Awareness & Possibilities Scale. Chapter Two began with the review of the marginalization of individuals with disabilities and established a context by revealing the current realities of adulthood for individuals with disabilities, particularly in the areas of employment and independent living. The chapter then moved to the inclusion of transition programming requirements in special education legislation and research-based best practices.

Chapters Three and Four described the research process and findings. Chapter Three described the methodology for this research, including how the expert reviewers were selected; the TAPS was described, as was the expert review sheet used for this research. Chapter Three concluded by describing the methods of analyses. Chapter Four explained the findings of the research. The reviewers rated the wording clarity and representativeness of items on the TAPS, as well as recommended additions, modifications, and deletions of items.

In this chapter, the study is summarized. Then, the implications of the expert reviewers' ratings and comments are discussed by section. For each section, conclusions are drawn regarding the modification and elimination of survey items. The revisions to the Transition Awareness & Possibilities Scale (TAPS) that will result from the review are justified. Lastly, areas for further research are discussed.

Summary of the Study

Parents are more empowered, motivated, and encouraged about anticipated adult experiences when involved in the planning process, and as the primary decision makers, it is critical that parents are given the opportunity to obtain the necessary knowledge to make sound decisions to fully represent the best interests of the child with the context of their family (Geeter et al., 2002; Hassazi et al., 1985, as cited in Zhang et al., 2002; Kim & Turnbull, 2004; Kraemer et al., 2003; Kraemer & Blacher, 2001; Neece et al., 2009). However, for some parents, acquiring information, navigating social services, and collaborating with professionals does not come naturally (Bjarnason, 2002; Murray, et al., 2007; Stoner et al., 2005). These families are likely to develop a *knowledge gap* that becomes especially significant during the transition from high school to adult services, and, as a result, many families do not know what options exist in the community for employment, leisure activities, post-secondary education options, or independent living (Goupil et al., 2002; Heslop et al., 2002; Tarleton & Ward, 2005).

Legislation instructs school districts to prepare students “for further education, employment and independent living” {34 CFR § 300.1[a]} (20 U.S.C.

1400[d][1][A]); however, transition research suggests that transition programs are not implemented with fidelity, nor in the spirit of the law (Certo et al., 2009; Collet-Klingenberg, 1998; Landmark et al., 2007; Repetto et al., 2002).

Consequently, large numbers of transition programs do not have the desired or anticipated impact on post-school outcomes (Landmark et al., 2007; NCSET, 2004; Repetto et al., 2002). Each individual, his or her family, and their dreams and circumstances are unique, yet specific service-delivery inputs and characteristics consistently appear in the literature as components of effective and efficient transition programs. Kohler's Taxonomy organizes these into five conceptual areas of service delivery: student-focused planning, student development, interagency collaboration, program structure, and family involvement (Kohler, 1996). The framework aligns with prevailing values-based philosophy that encourages self-determined student participation and family-centered care (Kohler and Field, 2003). When planning for the transition to adult services, transition teams must be long-term visionaries, yet practical; existing resources should be identified and experts assembled to meet the student's anticipated adult needs (Goupil et al., 2002). The transition process takes time and long-term coordination between families, LEAs, current caregivers, and potential service providers. Navigating the transition from school to adulthood requires complex knowledge of educational systems, special education-specific knowledge, and social networking (Caldwell & Heller, 2003). Throughout the literature, regardless of the child's diagnosis, parents uniformly emphasize that one of the greatest needs for the family is simply information (Ankeny et al., 2009; Grigal & Neubert, 2004; Smart, 2004; Westling,

1996). However, many families do not know what to ask, and many school districts do not know what to tell.

After a comprehensive review of literature, the Transition Awareness & Possibilities Scale was designed to aid both school districts and families with transition programming. The TAPS will be used by school districts for formative program evaluation. This instrument will indicate to schools how well they are educating family members about transition programming and/or if teachers and school district personnel are communicating effectively with parents about (a) skill instruction; (b) potential adult needs; and/or (c) adult service options. The TAPS instrument results will also serve as a self-assessment to guide families by indicating areas of the transition programming content domain in which their knowledge may be lacking and suggesting areas to prioritize for the next IEP or transition planning meeting.

Thus, the purpose of this study was to use a panel of expert reviewers to determine the content validity of the TAPS. Reviewers were specifically chosen for content expertise based on both their comprehensive and niche special education expertise. Reviewers used a standardized scale to rate the representativeness and wording clarity of question and answer items and also gave open-ended comments. The next section of this chapter will address the findings from the analyses of data previously presented in Chapter IV.

Findings

For each section, reviewers were asked to give standardized ratings for the representativeness of the content domain and wording clarity for both questions and answer choices. These were rated separately, each on four-point

scales, with a rating of “4” indicating that no revisions were necessary, and a rating of “1” indicating that the item was not representative or not clear. From these scores, the average pairwise agreement was then calculated to determine the amount of absolute agreement between reviewers (although it does not indicate what the reviewers agreed on).

The average pairwise agreement for the demographics section was 64.148%, and the Fleiss' Kappa was .009, indicating no significant agreement or disagreement between reviewers. The average pairwise agreement for the representativeness of the content domain for the three communication question stems was 57.143%. The average pairwise agreement for wording clarity for the communication question stems was 55.556%. The reviewers were more in agreement with the answer choices, as the pairwise agreement for the wording clarity increased for both purposes of communication (80.494%) and frequency of communication (80.889%).

For Section C, the average pairwise agreement for the rating of wording clarity for sources of curricular information was 95.299%, indicating that the reviewers had a high amount of absolute agreement for these two questions (13 and 14). For the question stems in the content area knowledge and skills subsection of Section C, the average pairwise agreement for the rating of representativeness was 77.778%, indicating good agreement, but the average pairwise agreement for the wording clarity rating was 53.704%, indicating disagreement among the reviewers (see Table 9). For the list of content area skills and knowledge items, the average pairwise agreement for the rating of representativeness was 90.848%, indicating that the reviewers had a high

amount of absolute agreement that the items well- represented the content domain (transition programming); however, the average pairwise agreement for wording clarity was 57.589%.

Table 9

Reviewers' Agreement of Content Area Knowledge and Skills Using Multiple Methods for Intraclass Calculation

TAPS Section	Method/Statistic Used	
	Average Pairwise Agreement	Fleiss' Kappa
Section C: Skills & Knowledge STEM		
Representativeness	77.778%	-0.125
Wording Clarity	53.704%	-0.11
Skills & Content Area Knowledge Items ^a		
Representativeness	90.848%	-0.015
Wording Clarity	57.589%	-0.079

Note. All reviewers rated items on a four-point scale, ranging from 1= item is not clear/representative of content domain to 4= item is clear/representative of content domain. a. The experts examined 31 items related to transition programming content area knowledge and skills. For both representativeness and clarity, only n=8 reviewers participated.

The average pairwise agreement for the rating of representativeness for the question stems in Section D, adult services and supports, was 77.778%, indicating good agreement; however, the average pairwise agreement for the wording clarity rating was 54.815%, indicating disagreement among the reviewers (see Table 10). For the list of content area skills and knowledge items, the average pairwise agreement for the rating of representativeness was

90.848%, indicating that the reviewers had a high amount of absolute agreement that the items well- represented the content domain (transition programming); however, the average pairwise agreement for wording clarity was 57.02%.

Table 10

Reviewers' Agreement of Services and Supports Using Multiple Methods for Intra-class Calculation

TAPS Section	Method/Statistic Used	
	Average Pairwise Agreement	Fleiss' Kappa
Section D: Services & Supports Question Stems		
Representativeness ^a	77.778%	-0.125
Wording Clarity	54.815%	-0.076
Section D: Services & Supports Items ^b		
Representativeness	90.848%	-0.015
Wording Clarity	57.02%	-0.084

Note. All reviewers rated items on a four-point scale, ranging from 1= item is not clear/representative of content domain to 4= item is clear/representative of content domain. a. n=8 reviewers rated representativeness of the question stems. The experts examined 39 items related to adult services and supports.

For every calculation, Fleiss' Kappa proved invalid. For example, Fleiss' Kappa was negative (and only .02 points different) when the average pairwise agreement was both 90.848% and when it was 57.02%. The invalidity of the Kappa can (theoretically) be attributed to several possibilities. For some arrays, there was little variance, and a Kappa paradox was likely caused by high-trait

prevalence. However, this was likely overshadowed by a sampling problem. According to Sadatsafavi et al. (2008), in some cases with small numbers of reviewers, the Kappa is unlikely to produce a reliable estimate of the null hypothesis. (This is the same issue with the ICC and why the ICC was not used in this research.)

The expert reviewers provided both quantified ratings on a standardized scale and qualitative data (open-ended comments). The statistical analysis, though necessary, was not as helpful for this research as the reviewer comments. It was qualitative data that provided the most insight to the ratings and made sense of the numbers (i.e., the end goal is to revise the TAPS, so the reviewers' comments are more useful than statistics that simply indicate the degree to which the reviewers disagreed). The purpose of this research was to determine content validity and the technical adequacy of the *Transition Awareness & Possibilities Scale* with regard to (a) wording clarity (b) content domain representativeness, and (c) content domain sampling adequacy. The next section of this chapter will draw conclusions as to the effectiveness of the review to answer this question.

Conclusions

The purpose of the study was to determine the technical adequacy of the TAPS in the areas of wording clarity, content domain representativeness, and sampling adequacy. This research is the first step in establishing reliability and validity for the TAPS. Although the results are more useable (for future research and revisions to the TAPS) when broken down and analyzed by section, an overall picture of interrater agreement can be better understood if collectively

calculated. Collectively, the average pairwise agreement for the representativeness of the TAPS was 78.879%, indicating very good agreement among the reviewers (see Table 11). The reviewers had good pairwise agreement regarding wording clarity with an average of 69.481% for the entire TAPS (see Table 12).

Table 11

<i>Reviewers' Pairwise Agreement for Representativeness by Section/Subsection</i>	
TAPS Section	Average Pairwise Agreement
Section B: Communication Question Stems	57.143%
Section C: Skills & Knowledge STEM	77.778%
Section C: Skills & Knowledge Content Area Items	90.848%
Section D: Services & Supports Question Stems	77.778%
Section D: Services & Supports Items	90.848%
Content Domain for Transition Programming of the TAPS	78.879%

It is more difficult to report content domain sampling adequacy; however, a table of included, suggested additions, and suggested removals is provided to give an overall summary of the reviewers' recommendations for item additions and deletions (see Table 13).

The researcher established a theoretical definition of the construct (transition programming) that framed the TAPS: *The longitudinal assessment, planning, skill-building, and networking that occurs between young adults, their families, teachers, service providers, and other stakeholders that facilitates the young adult's shift from the role of a student in a secondary environment to an*

adult in the community. The items in the TAPS were based on a review of literature, and some of the suggested additions to the TAPS were known omissions during the initial development of the TAPS. That is, this researcher also agreed that, for many students, these skills were relevant and necessary to address (i.e., plan for and learn) during transition programming; however, without empirical research, the skills could not be included in the first version of the TAPS (e.g., Email/Internet skills).

Table 12

Reviewers' Pairwise Agreement for Wording Clarity by Section/Subsection

TAPS Section	Average Pairwise Agreement
Section A: Demographics	64.148%
Section B: Communication Question Stems	55.556%
Section B: Communication Answer Choices	
Purposes of Communication	80.494%
Frequency Intervals	80.889%
Section C: Sources of Information	95.299%
Section C: Skills & Knowledge Question Stems	53.704%
Section C: Skills & Knowledge Content Area Items	57.589%
Section D: Services & Supports Question Stems	54.815%
Section D: Services & Supports Items	57.02%
Section D: Sources of Information	95.299%
Average Pairwise Agreement for Wording Clarity for the TAPS	69.481%

Table 13

Expert Reviewers Suggestions for Improving Sampling Adequacy

TAPS Section	Number of Items		
	Currently Present	Suggested Additions	Suggested Removals ^a
Section A: Demographics	16	2	4 ^b
Section B: Communication			
Question Stems	3	0	0
Purposes of Communication	5	8	0
Frequency Intervals	5	0	0
Section C: Sources of Information	13	14	0
Section C: Skills & Knowledge			
Question Stems	3	0	0
Content Area Items	31	9	0
Section D: Services & Supports			
Question Stems	3	0	0
Services & Supports Items	39	6	6
Section D: Sources of Information ^c	13	14	0

a. Items that were suggested for removal by more than one reviewer were only denoted once.

b. Reviewers questioned the necessity of 4 of the demographic questions; however, these do not affect the sampling adequacy of the instrument.

c. These are the same suggestions that were given by the reviewers for Section C: Sources of Information.

When asked to comment on the overall content coverage of the TAPS, the most of the reviewers indicated that the sampling was adequate for the content domain. One expert reviewer remarked that the content was “thorough and covers a broad range of needed skills and knowledge.” Another said that TAPS “hit the important parts.” Nonetheless, the suggested additions by the expert reviewers will be welcome additions to the TAPS, further increasing the sampling adequacy and filling in the gaps where there was not yet published research to otherwise justify inclusion of an item.

Implications

Based on the reviewer comments and the review of literature, the validation and establishing TAPS as a viable instrument should continue; however, the TAPS needs many revisions. Most of the revisions will increase the clarity and understanding for the TAPS respondents. Some additions will increase the sampling adequacy, and a few deletions will maximize the precision of the instrument and tighten the construct.

Revisions to Section A: Demographics

The revisions to the Demographics Section of the TAPS will address the reviewers’ four main concerns for this section: consistency, clarifications, omissions, and relevancy. However, first, the statement that defines transition and directs parents who have more than one child with disabilities to “choose one child answer questions about,” will be moved to Section A (rather than Section B), so that parents are clearly aware that all of the remaining questions refer to this particular young adult within their household. Only then will

respondents with multiple young adults with disabilities be clear about how to answer the questions.

Several items in the demographics section will be revised to increase the consistency of the TAPS. Not exclusive to Section A, but beginning in the Demographics section, the TAPS will be revised to use the term “young adult,” “transition-aged young adult,” or similar term consistently, in lieu of “child.” Likewise, the term “parent” will be partnered with other terms, such as “caregiver,” “family member,” or “guardian,” (instead of “parent” that was sometimes used to refer to the respondents in the original version). Item M will be changed to refer to a “young adult” as an individual who is aged 14-22.

The revised TAPS will also include examples, revised language, and clearer instructions to increase understanding for respondents. The revised TAPS will provide examples to make answer selection for the respondents easier and more accurate. For example, question B answer asks respondents, “What is your relation to the young adult who is of transition age (14-22)?” The answer choices are currently (a) parent, (b) family member & guardian, (c) guardian, and (d) other. The revised version of TAPS’ answer choices for question B will be similar, but with examples for clarification (see Figure 4).

<p>ⓑ What is your relation to the young adult who is of transition age (14-22)?</p> <p><input type="checkbox"/> Parent: Natural, adoptive, or step-parent</p> <p><input type="checkbox"/> Family Member & Guardian: Blood relative with legal custody. For example, a grandmother with legal custody.</p> <p><input type="checkbox"/> Guardian: Unrelated adult with legal custody. For example, a foster parent.</p> <p><input type="checkbox"/> Other (Please specify): _____</p>
--

Figure 4. Revised Question B that clarifies the relationship of the respondent with the young adult.

It is likely that the question O will be changed to the more colloquial, “How many years until the young adult *finishes* high school?” Along the same vein, question P will be re-worded so that respondents understand the full intention of the question: “What sort of documentation do you anticipate the young adult having when he or she finishes high school?” (examples will be provided alongside the answer choices). The pilot test of the revised TAPS will reveal if this language is clear and understandable to respondents.

Question L will be modified to ask for the number of adults in the home. Although only two reviewers commented that the addition of the term “non-sibling” was confusing,” upon further reflection, the inclusion of the term “parent” was also an error, as it biased the question against young adults who lived with anyone other than parents. Question I will be modified to take the reviewer’s suggestion who recommended that using the phrase “has/had an IEP” instead of “receives/received special education services” may avoid technicalities and confusion for respondents; however, this question will be taken off of the TAPS and moved to an addendum that will be attached during piloting and larger data collection.

Although the target population for the TAPS is families of students who require extensive or pervasive supports, by inviting parents to forward the TAPS survey to other parents who have children with disabilities (as is the case in after question A), it is likely that families of young adults who have all different types of disabilities may use the TAPS. Consequently, question J will be amended to include all of the IDEA subcategories.

Several reviewers commented on demographic questions that they regarded as potentially irrelevant—the respondent’s birth year and the ethnic background of the young adult with disabilities. Indeed, the respondent’s birth year is irrelevant (this was originally to be used for coding purposes, but is certainly not relevant or desirable at this time). The ethnic background of the young adult was unnecessary (and is now slated for removal), but becomes necessary with the addition of a reviewer-suggestion question to assess if the school is including culturally appropriate planning. However, although “of more than one race or multiracial” is an option for this demographics question, there are not instructions to tell respondents to either to “select one” or “all that apply.” To increase the accuracy and the precision of TAPS, this question will be retained (with revised instructions) to accompany a new question that will ask parents about indicators of culturally appropriate transition programming.

The necessity of two other questions was also disputed: the location of the school that provided special education services for the young adult, and the respondent’s income. These two questions are extremely relevant both for schools to use data gathered from the TAPS and for researchers to use data gathered from (large numbers of) TAPS respondents. The location of the school that provided special education services is relevant for two reasons: it is relevant for research to determine where respondents hail from, and for large school districts with more than one high school, it is necessary to establish where the respondent’s LEA is. If parents want to remain anonymous, it will do little good for a school district to assess families and determine where knowledge (and satisfaction) deficits are if the school is not identifiable. For this reason, the

question will remain, but be changed to be *more* specific with the name of the school, not just the location.

The relationship between forms of capital and the knowledge gap about transition programming was one impetus for this research. Literature reveals disparate outcomes for young adults whose guardians have sparse amounts of social or economic capital. However, there have been few (if any) studies that have measured forms of capital alongside (researcher-measured) knowledge that school districts are responsible for. Although questions about income and finances can be perceived as invasive, asking the respondents' incomes is valid because a future cross-tabulation or multiple regression between income level and other variables may provide insight to the relationship between families' economic capital, social capital, and level of transition programming knowledge. For example, questions 13, 14, 87, and 88 (that ask about sources of information) are equally as important for testing the relationship between capital theory and the knowledge gap. Alone, these questions will provide some meaningful information; however, any hypothesis incorporating both social capital and economic capital will be untestable without the respondents' incomes.

Lastly, two reviewers suggested that the demographic questions be moved to the end of the survey; however, this researcher is concerned that this would be problematic and unnecessary for several reasons. Initially, the first question on the TAPS must clarify that the respondents are the appropriate individuals to complete the survey; this question then naturally progresses to other demographic questions. If respondents are hesitant to answer sensitive

questions (e.g., questions regarding income) at the beginning of the survey, this researcher would rather that specific questions, rather than the entire demographics section, be skipped. It is only for validation and reliability purposes that response rates will be of concern; when the TAPS will be primarily used by families as a (locally promoted and distributed) tool to aid in transition planning, the omission of sensitive questions (e.g., income and education) will likely be less critical, as transition planning teams and individual teachers will be building relationships with families and young adults to know their needs, preferences, talents, and skills.

The revisions to the TAPS will include a reformatted demographics section. This will be a completely separate section, and may be completed before or after the rest of the sections. However, for reliability and validation purposes, the demographics section will remain before the other sections—after the IRB statement and consent to participant in research. If the demographics section was moved to the end of the TAPS, it is this researcher's concern pilot respondents may fall-off and not complete the demographics section (at all) after the rest of the survey is completed. Respondents who complete the TAPS as part of upcoming reliability and validity research will be reminded that respondents are anonymous and can skip any questions they choose.

Revisions to Section B: Teacher-Parent Communication

Section B asked respondents about the frequency and purpose of communication between themselves and the young adult's special education teacher. The revisions to Section B are primarily small edits to add clarification

for respondents; however, there are several additions that must be made, as well.

Respondents will first be instructed that if the young adult has more than one special education teacher (as is common in high schools), the respondent should choose only one of the special education teachers to consistently answer questions about. This section will also be revised TAPS to include several reviewer-suggested additions to the list of purposes for communication between teachers and parents.

One reviewer suggested the deletion of the answer choice “I don’t remember or I’m not sure,” and, instead, the respondents be directed to “Choose the best answer.” However, this researcher believes this could possibly invalidate the other answer choices for some respondents. That is, with the retention of the “I don’t remember or I’m not sure” item, respondents can reliably choose other items with confidence, and default to the “I don’t remember or I’m not sure” item when needed. If this option is removed, another answer choice will likely become a default option for unsure parents. Thus, the validity of the information provided by questions 3-8 will be compromised. Therefore the “I don’t remember or I’m not sure” item will be retained.

Most reviewers offered suggestions regarding formatting and proofreading correction. For the sake of uniformity between items 1 and 2, “school” will be added to the “1-2 times per year” answer choice. Items 5-7 will also be revised; however, instead of adding “a child’s” to the item, “a student’s” will be added (e.g., item 5 would read, “report a student’s daily activities”). An additional revision that will add clarity for respondents is the insertion of “at

least” before the intervals that denote the frequency of communication between teachers and families.

As indicated in questions 1 and 2, purposeful, ongoing communication is reciprocal; however, questions 3-8 on the TAPS ask specifically about the teacher’s frequency and purpose of initiating communication with the respondent, but not the respondent’s frequency and purpose of communication with the teacher. With this in mind, two reviewers asked this author to consider if the TAPS should include questions that ask about the reciprocity of communication, or, specifically, about the frequency and purpose of parent-initiated communication. Similarly, another reviewer noted that she hoped there were questions in a later section that addressed the parent’s role and level of involvement in the IEP and transition planning meetings and the emotions about the IEP meetings themselves, since questions pertaining to those topics were absent in this section. Lastly, measuring two concepts (i.e., frequency and purpose of communication) in one item is complex. Thus, respondents’ answers will need to be carefully examined after the pilot study(s) with families and guardians to determine if the question structure is problematic.

Revisions to Transition Programming

Section C: Skills and Knowledge—Sources of Information

Section C pertains to skills and knowledge associated with transition programming. Questions 13 and 14 ask respondents where they get information about transition-related skills and knowledge. There will be significant revisions to the two questions—both to the stem and to the answer choices.

The stem of the questions will be modified so respondents understand that, in this case, “special education curriculum” includes life skills and other areas beyond academics. Two answer choices will also be revised. The (double-barreled) answer choice “Friends or Family” will be separated into two answer choices (“Friends” and “Family”). At that time, “Family” will be modified to “Family or Relatives.” In addition, “Formal” will be dropped from “Formal Support Groups,” so that the answer choice will simply be “Support Groups.” There will also be additional people and entities added as a result of expert reviewers’ suggestions. Following one reviewer’s recommendation, the answer choices will be organized according to domains (e.g., school or community).

The previous section explained the forthcoming revisions to the TAPS that incorporated the comments from the expert reviewers pertaining to the people and organizations that provide information to parents about potential curricula for young adults who are of transition age. The next section will profile the revisions to the content areas and skills within Section C.

Revisions to Section C: Skills and Knowledge—Content Areas and Skills

Section C asks respondents to answer three different questions for each item. Because there are three separate stems with three scales, there is the potential for confusion. Therefore, the instructions for this section will be revised to include a detailed example of a completed item. Although a reviewer suggested that an “already has skill” answer choice be added, this is unnecessary because the respondent can simply choose “strongly disagree” or “disagree” in response to the second question stem (“I think my child still needs

instruction in _____.”). An example to this effect will be given at the beginning of the section.

The revisions to this section will correct the non-parallel structure of the content area and skill items. Despite the majority of the reviewers who commented that the items were complete and comprehensive representation of the domain of transition programming, one reviewer specifically asked why math was included but language arts and science were omitted. This comment is telling, as the reviewer must not have considered that this section of the TAPS asks respondents about what the skills and knowledge they have observed the transitioning young adult demonstrating at home and in the community i.e., “math” is a skill, but “language arts” is not. However, the components of language arts—reading, writing, etc.—are skills, and were included in Section C. The reviewer’s comment also reiterated the need for three revisions: the necessity for stressing to respondents that curricula includes life skills and is not limited to academic skills (discussed in the previous section), the need to behaviorally define each skill in the list, and the need to drop “knowledge” from the first stem. All of the items that are not currently behaviorally defined verbs that directly relate to transition programming (e.g., completing applications for employment) will be revised. For example, instead of “math” the revised item will likely be “perform basic math calculations: addition, subtraction, multiplication, and division.” Each item will be clarified with a lengthy label (e.g., the revised math item), definition, and/or example to ensure respondents’ understanding of the item.

Similar to other sections, Section C also has formatting revisions that will add to the clarity and consistency of the scale. Revisions will be made to change “my child” to “young adult” in the stems, as this will respect the multiple roles respondents may have and maintain consistency throughout the scale. Section C will also be revised so that it has a better, more intuitive flow for respondents. To that end, the items will be grouped into categories and subcategories. The items will first be classified by domains and then organized by similar skills and sub-skills.

Revisions to Section D: Adult Services and Supports

The revision of both the formatting and wording of items in Section D will add clarification for respondents. Section D will be revised so that items which may be unfamiliar to parents have definitions and/or examples. For example, “Medicaid and Medicare assistance” will accompany the item “Benefits Planning” to add clarity for respondents who may be unfamiliar with the concept of benefits planning, but know what Medicaid or Medicare is. Similarly, “Attendant Care” or “Customized Employment” would likely need to be described for some respondents to understand what makes “customized” employment different than competitive or supported employment which respondents are likely to be more familiar with.

The content in Section D was regarded as “good,” “fine,” “thorough,” by several reviewers; however, more than one reviewer marked to remove some options from TAPS. Several of the marked items were also marked as “representative of the content domain.” This may seem, at first, puzzling, but not when one stops to consider the items themselves. Most of the options

tagged for removal were not marked “Remove from TAPS” because they were not representative of the content domain, but because of philosophical reasons. For instance, two reviewers marked to remove non-inclusive options (e.g., day-hab and sheltered workshops) from the TAPS. One reviewer followed-up with comments that clarified that he had a “strongly held bias” and wanted families to think about inclusive options, but also thought that legislation made non-inclusive options difficult to support.

All biases aside, the TAPS instrument was designed for use across the nation. The reality in some states is that these options are still thriving, despite funding constraints and research that consistently reveals that non-inclusive options are not representative of best-practice because these environments do not produce the best quality of life outcomes for adults with disabilities (Eggleton et. al, 1999; Garcia-Villamisar et. al, 2002; Migliore et. al, 2007; NDRN, 2011). Therefore, in order for the purposes of the TAPS to be fulfilled—families use TAPS to check their transition programming knowledge and plan for IEP/ITP meetings and school districts use TAPS to make sure teachers and transition coordinators are educating parents about all locally available options—the non-inclusive options must remain on the TAPS. However, it is this author’s hope that this limitation of the TAPS is recognized at the local level and the transition team will forge relationships with the young adult and family, use assessments, and engage in person-centered planning to guide the family to choose appropriate post-secondary activities.

Like Section C, the items in Section D will also be grouped into categories and subcategories. The items will first be classified by domains and

then organized by similar skills and sub-skills. The revised TAPS will also include recommended services and supports that were suggested by the expert reviewers. Individual items will also be revised to be more indicative of the researcher's intended meaning. The item "Intensive, very structured living arrangement (outside of family home)" will be changed to "Institutional living arrangement." The (triple-barreled) item "Therapeutic, Social and Recreational Program" will be separated into three separate items "Therapeutic Recreation," "Social Programs," and "Recreational Programs" and will also include examples of each. To avoid any misunderstanding, the third stem for Section D: Adult Services and Supports will be reworded to clearly ask if respondents know how to obtain financial support for the services or supports (rather than imply if the respondents could personally pay for the services or supports should the need arise).

Formatting Revisions to the Entire Instrument

Not all revisions to the TAPS are isolated to one section. Some reviewers suggested comprehensive changes to the entire survey, such as color-coding, for organization, and a 14-point font for increased readability; thus, answer columns for table-formatted questions (e.g., Sections C and D) will be color-coded to aid respondents in marking their intended answer. Because the TAPS is quite lengthy (when printed), (only) the hard copy of the TAPS will likely remain 12-point font (although this will be reconsidered after all revisions and pilot testing is complete). In addition, the directions for each section (and individual questions therein) will be revised if not explicit, particularly those that were mentioned specifically by expert reviewers (e.g., questions 13 and 14).

Comprehensive survey administration instructions will also be crafted and provided as an addendum for schools and families; these will explain how to use collective TAPS results for program evaluation and improvement and how to use individual TAPS results during transition programming for an individual.

Due to the length of the survey, and the extensive survey-design experience of the reviewer who recommended removing the “mildly agree” and “mildly disagree” options, those two answer choices will be removed for the Likert scale options and the TAPS will only offer four answer choices for the questions involving Likert scales (instead of six). However, this is the only revision that was taken to shorten the TAPS. Several times, reviewers mentioned the length of the survey as a side note to accompany other comments; however, only one reviewer directly recommended possibly shortening the survey to increase the response rate. While this is important for the pilot (and a significant concern for this researcher), what is more important in the long run is that families have a complete, comprehensive instrument to guide transition programming. Therefore, while response rate is certainly a valid concern, it is superseded by the primary concern: utility.

As discussed in Chapter Four, this utility was questioned as some of the reviewers were in disagreement as to the likelihood of the TAPS achieving its intended purpose. In retrospect, had complete instructions for implementation been included for expert review, along with the TAPS, it is more likely that all reviewers would have been clear as to what exactly this researcher intended by the term “program evaluation.” Examining a collection of TAPS results will help teachers, schools, and school districts assess needs of families; examining pre-

and post-test data will reflect the impact (effectiveness) of transition programming and family relationship-building. For example, if families of young adults who are 16 take the TAPS (pre-test) and use the results to guide transition programming, but then have no greater measure of knowledge or satisfaction when the young adult is 20 years old (e.g., post-test), this would indicate that there is not only a knowledge gap for the parents, but there is perhaps a transition programming gap or maybe a relationship-building gap within the school district. It is in this sense that the TAPS will be useful for program evaluation.

Future Research

The purpose of this research was to establish content validity for the TAPS, as it is a prerequisite for all other types of validity. In the process, expert reviewers also helped establish face validity, as well. However, this research was just a beginning step in the process of establishing the TAPS as a valid and reliable instrument. The next step in this process will be to send the revised instrument to the expert reviewers. Although this was not a Delphi study, it will be beneficial to send the reviewers the revised TAPS to confirm this author's interpretation of the reviewers' comments, thereby insuring the integrity of the instrument as much as possible. Upon the return of the second round of reviewer comments (for all reviewers who wish to participate), it will be necessary to conduct a small-scale pilot study with the revised TAPS. This will provide an extra measure of face validity and (perhaps) catch any final changes that need to be made before the large-scale deployment of the TAPS. After the small pilot, the TAPS will be deployed on a larger scale to establish internal

consistency and criterion-related validity (using a principle components analysis).

Forthcoming Principal Components Analysis

The literature surrounding best-practices for transition and the current state of transition outcomes provided the foundation for the domains that will later be tested using principal components analyses (PCA). After this research to determine the content validity is complete, and the recommended revisions have been made, a large-scale pilot study will provide data for a principal components analysis (PCA) and possible follow-up statistical tests will be run to extract factors. This will uncover the latent relationships of the questions on the TAPS instrument and determine the final structure of the instrument. The two anticipated domains that will emerge are “knowledge of content areas and skills” and “knowledge of potential adult needs and adult service options.”

Parent knowledge of content areas and skills (curricula and instruction):

This domain will be defined by parents’ self-reported knowledge of skills and knowledge a child has been taught, possesses, or is needing further instruction in. Parents scoring high in this domain will have knowledge of the child’s skillset by virtue of recognizing application and deficits in home and community behaviors. Factors relating to this domain are Section C—in the content area and skills section; at the conclusion of the literature review there were 31 variables.

Parent knowledge of potential adult needs and adult service options:

This domain will be defined by parents’ self-reported knowledge of a child’s potential adult needs as indicated by knowledge of the etiology and progression

of the child's disability and individual preferences, as well as parents' self-reported knowledge of purpose, availability, and funding for common public supports and services commonly utilized by adults with low-incidence disabilities. Factors relating to this domain are in Section D; at the conclusion of the literature review there were 39 variables.

After the PCA, the structure of the instrument will be established and the final number of domains within the TAPS will be confirmed. With large sample population data (such as the pilot data), it will be possible to then explore the theoretical underpinnings of this research: Are there demographic variables (related to capital) that may predict a high score on any of the sub-scales and/or total instrument (indicating knowledge of the curricula, transition process and available adult supports)? Once the reliability and validity of the TAPS is established, the TAPS will be available for use in transition programming. Future research would then be centered on individual families' and school districts' use of the TAPS and transition outcomes.

Summary

The ultimate goal of transition planning is to define the role the young adult will have in the family, community, and society, and facilitate the desired social relationships and community interactions that will take place throughout the different environments the individual values (Blue-Banning et al., 2002). Families want information, choices, and services that support the young adult's needs, preferences, and expectations, but that are also realistic and available locally (Tarleton & Ward, 2005). Because high parental expectations have been found to be the most significant predictor of positive employment and

independent living outcomes (Hendley & Pascal 2002; Lindstrom et al., 2007; Morris, 2002), it is extremely important that parents are given the opportunity to obtain the necessary knowledge to make sound decisions and fully represent the best interests of the child within the context of their family (Geeter et al., 2002). Longitudinal research has shown that the family will be the only consistent source of support for young adults after they exit high school (Ankeny et al., 2009; Murray & Curran, 2001; Turnbull et al., 2006). Therefore, it is crucial that families are informed about all aspects of transition programming; however, young adults, parents, and professionals describe faulty collaboration between parents and special educators and the gaps in transition services that result (Ankey et al., 2009; Antle et al., 2009; Beresford, 2004; Bjarnason, 2002; Cooney, 2002; Michaels & Ferrara, 2006; O'Connor, 2008; Swain & Walker, 2003).

McAndrews (2008) asserted that many transition services required by *IDEIA* (2004) are not being implemented because parents do not know to request them at all, or do not follow-up and monitor implementation of the student's program. Furthermore, it is often parents who possess large amounts of cultural capital (knowledge, attitudes, and skills) and social capital (relationships, group membership, and networks) that circumvent procedural (i.e., equitable) channels and have the best transition programming and outcomes (Trainor, 2010; Horvat et al., 2003).

Clearly, many parents covet transition-programming knowledge. However, there is no standardized instrument to determine the transition programming knowledge of parents. Consequently, this research was begun to

fill a gap, both in practice and in the literature. A standardized instrument was needed that determines a family's level of basic transition programming knowledge and allows a teacher or transition coordinator to know what information a family is lacking about transition programming—including adult service options. Families also need an instrument that will help them prioritize for conferences or IEP/ITP meetings. The (revised) TAPS will fulfill both of these purposes.

Before revisions, the expert review determined that the items on the TAPS were very representative of the content domain of transition programming (78.879% average pairwise agreement, for ratings indicating “representative of content domain”) and had good wording clarity (69.481% average pairwise agreement, for ratings indicating “wording is clear”). In addition, the domain sampling was adequate for most of the sections of the TAPS, but needed significant additions for both Sections B and C, as well as better organization to aid the respondents in survey completion. However, given that this research utilized both quantitative and qualitative methodologies, if further research was conducted to establish content validity on the revised TAPS, the average pairwise agreements would likely be significantly higher, as reviewer comments were invaluable and specified exactly what each reviewer thought necessary to bring the TAPS up to research standards. This study was the first in a series necessary to develop an instrument that is valid and reliable to be used by both schools and families to determine families' knowledge of curricula and instruction, young adults' potential adult support needs, and how to procure adult supports and services. After the development process is complete, the

TAPS will be able to assess families' transition programming knowledge so that the school can educate families and bridge the knowledge gap. Only then will transition outcomes for adults with disabilities cease to fall short of their peers.

APPENDIX A

IRB APPROVAL FOR EXPERT REVIEW


**THE UNIVERSITY OF
SOUTHERN MISSISSIPPI**

INSTITUTIONAL REVIEW BOARD
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NOTICE OF COMMITTEE ACTION

The project has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services (45 CFR Part 46), and university guidelines to ensure adherence to the following criteria:

- The risks to subjects are minimized.
- The risks to subjects are reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered regarding risks to subjects must be reported immediately, but not later than 10 days following the event. This should be reported to the IRB Office via the "Adverse Effect Report Form".
- If approved, the maximum period of approval is limited to twelve months. Projects that exceed this period must submit an application for renewal or continuation.

PROTOCOL NUMBER: **11090506**
 PROJECT TITLE: **Determining Content Representativeness and Content Relevance for the Transition Awareness and Possibilities Scale (TAPS) for Parents of Students Requiring Extensive or Pervasive Supports**
 PROJECT TYPE: **Dissertation**
 RESEARCHER/S: **Melynda Ross**
 COLLEGE/DIVISION: **College of Education & Psychology**
 DEPARTMENT: **Curriculum, Instruction, & Special Education**
 FUNDING AGENCY: **N/A**
 IRB COMMITTEE ACTION: **Exempt Approval**
 PERIOD OF PROJECT APPROVAL: **09/22/2011 to 09/21/2012**

Lawrence A. Hosman
 Lawrence A. Hosman, Ph.D.
 Institutional Review Board Chair

9-23-11
 DATE

APPENDIX B

THE TRANSITION AWARENESS & POSSIBILITIES SCALE

Transition Awareness & Possibilities Survey

This research survey is anonymous. No one, not even the researcher, will be able to associate your responses with your identity. Addresses of participants who return paper surveys will not be retained; envelopes will be shredded upon receipt. Participation is voluntary. You may choose not to take the survey, to stop responding at any time, or to skip any questions that you do not want to answer. You must be at least 18 years of age to participate in this study. **Your completion of the survey serves as your voluntary agreement to participate and your certification that you are 18 or older.**

What is the TAPS?

This is the preliminary version of the *Transition Awareness and Possibilities Survey*. Your responses will be combined with the other respondents' responses to help determine the questions, structure, and layout of the final (official) TAPS.

The *Transition Awareness & Possibilities Survey (TAPS)* instrument will be used by school districts for program evaluation. This instrument will indicate to schools how well they are educating family members and/or if teachers and school district personnel are communicating effectively with parents about (a) skill instruction; (b) potential adult needs, and/or (c) adult service options. The TAPS instrument results will also guide families by revealing areas where their knowledge may be lacking, unfamiliar terminology, and areas to prioritize for the next parent-teacher conference or IEP meeting. The hope is that parents and teachers will use the final version of the TAPS to help guide transition planning and facilitate communication, as family members' increased knowledge and empowerment will ultimately result in better transition outcomes and quality of life for adults with disabilities. This survey was designed by Melynda Ross, a doctoral student at The University of Southern Mississippi. If you have any questions or comments about the survey, she may be reached at Melynda.Ross@usm.edu.

A. Demographic Information

A Do you have a young adult in your household who is aged 14-22 and receives (or received) special education or related services?

- Yes
- No (If No, please do not continue this survey, but consider passing it to a friend who has a child who receives special education services and wouldn't mind sharing their experiences. Thank you!)

B What is your relation to the young adult who is of transition age (14-22)?

- Parent
- Family Member & Guardian
- Guardian
- Other _____

C In what year were you born? _____

D What is your gender: Male Female

E Average Yearly Household Income:

- \$0-\$20,000
- \$20,001-\$40,000
- \$40,001-\$60,000
- \$60,001-\$80,000
- \$80,001-\$100,000
- \$100,001 +
- Rather not say

F Your Educational Background:

- Did not complete high school
- High School Diploma/GED
- Some college or vocational training
- B.A. or B.S. (4 year degree)
- Master's
- Doctorate
- Other
- Rather Not Say

G What is your child's gender? Male Female

Transition Awareness & Possibilities Survey

Ⓜ In what year was your child born? _____

① Where does/did your child receive special education services?

City: _____ State _____

④ What is your child's primary disability? (select only one)

- Autism
- Intellectual Developmental Disability (Mental Retardation)
- Visual Impairment
- Hearing Impairment
- Deaf-blindness
- Traumatic Brain Injury
- Multiple Disabilities
- Other _____

ⓧ What is your child's racial/ethnic background?

- American Indian/Native Alaskan/Pacific Islander
- Asian
- Black/ African American
- Caucasian/White
- Hispanic/ Latino
- Of more than one race or multiracial
- Other
- Rather Not Say

① Number of parents or non-sibling adults living in home.

- 1
- 2
- 3
- 4
- 5 or more

Ⓜ TOTAL number of children under 21 who live in the home or receive primary financial support from the parent(s) even if they live somewhere else.

- 1
- 2
- 3
- 4
- 5 or more

Ⓝ TOTAL number of children in the home who receive special education services.

- 1
- 2
- 3
- 4 or more

Ⓞ How many years until your child exits high school?

- My child already exited school
- This school year—1
- 2-3
- 4-5
- 6+
- I'm not sure

Ⓞ How do you anticipate that your child will exit high school (or, how did he or she exit high school)?

- Exited without any documentation
- Earn Regular/Traditional Diploma
- Earn Occupational/Vocational Diploma
- Earn Certificate of Attendance/Completion
- Earn Functional Skills Certificate
- Earn General Equivalency Diploma (GED)
- I'm not sure
- Other _____

Transition Awareness & Possibilities Survey

B. Communication

The **TRANSITION** time period is when families and their child's teachers are preparing for life after high school. Please answer the following questions about your child who is in the transition period, or who has recently finished high school.

If you have more than one child to whom this applies, choose **one** child answer questions about.

① Typically, how often do you have communication with your child's special education teacher? (phone calls, emails, letters, notebook correspondence, face-to-face conversations, etc.)

- Almost every school day
- 1-2 times per month
- 1-2 times per year
- Other _____
- 1-2 times per week
- 3-4 times per school year
- I'm not sure

② Typically, how many times do you usually meet (face-to-face) with your child's special education teacher?

- Almost every school day
- 1-2 times per month
- 1-2 times per year
- Other _____
- 1-2 times per week
- 3-4 times per school year
- I'm not sure

DIRECTIONS: For each of the topics below, please indicate how often and for what purposes your child's special education teacher communicates with you.	I Don't Remember or I'm Not Sure if I am contacted about this	I am Never contacted about this	I am contacted about this 1-2 times once per year	I am contacted about this 3-4 times per year	I am contacted about this 1-2 times per month	I am contacted about this 1-2 times per week	I am contacted about this Almost every day
③ Ask for my opinion or advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
④ To "check-in" with our family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
⑤ Report daily activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
⑥ Report problem behavior	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
⑦ Report progress on skills, objectives, & goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
⑧ Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Transition Awareness & Possibilities Survey

DIRECTIONS: For each question, please indicate how strongly you agree with each statement:

	N/A	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
9 I am very satisfied with how often my child's special education teacher communicates (or used to communicate) with me.	<input type="checkbox"/>						
10 I am very satisfied with the reasons why my child's special education teacher communicates (or used to communicate) with me.	<input type="checkbox"/>						
11 I am very satisfied with how often I meet (or met) with my child's special education teacher.	<input type="checkbox"/>						
12 I am very satisfied with how much I know about what my child is learning (or learned) in school.	<input type="checkbox"/>						

C. Skills & Knowledge

13 Please indicate ALL the people and places where you get information about your child's curriculum (what he or she could be learning in school).

- Special Education Teacher
- General Education Teacher
- Paraprofessional or educational assistant
- Transition coordinator or Transition specialist
- School psychologist or counselor
- Friends or Family
- Local Employer
- Other Parents
- Formal support groups
- Occupational Therapist (OT) or Physical Therapist (PT)
- College Representative
- Internet or personal research
- Non-profit organizations (e.g.: The Arc, Autism Society, Deaf-blind project)
- Other:

14 Where you get THE BEST information about your child's curriculum (what he or she could be learning in school). (Select only one.)

- Special Education Teacher
- General Education Teacher
- Paraprofessional or educational assistant
- Transition coordinator or Transition specialist
- School psychologist or counselor
- Friends or Family
- Local Employer
- Other Parents
- Formal support groups
- Occupational Therapist (OT) or Physical Therapist (PT)
- College Representative
- Internet or personal research
- Non-profit organizations (e.g.: The Arc, Autism Society, Deaf-blind project)
- Other:

Transition Awareness & Possibilities Survey

Here is a list of content areas and skills. Please indicate how strongly you agree with these statements:

	"I have observed my child demonstrating _____ (skills or knowledge) at home and in the community."					"I think my child still needs instruction in _____."					"As a family, we have the resources or knowledge to practice _____ with my child at home and in the community."									
	Strongly Disagree	Disagree	Mildly Disagree	Agree	Strongly Agree	Strongly Disagree	Disagree	Mildly Disagree	Agree	Strongly Agree	N/A	Strongly Disagree	Disagree	Mildly Disagree	Agree	Strongly Agree				
15. Age-appropriate behaviors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Augmentative and Alternative Communication (AAC)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Choice-making	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Community Safety Skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Completing applications for employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Cooking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Dressing, grooming, and practicing good hygiene	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Finding help from trusted adults	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Finding transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Transition Awareness & Possibilities Survey

	"I have observed my child demonstrating _____ (skills or knowledge) at home and in the community."					"I think my child still needs instruction in _____."					"As a family, we have the resources or knowledge to practice _____ with my child at home and in the community."					
	N/A	Strongly Disagree	Disagree	Mildly Disagree	Agree	Strongly Agree	Strongly Disagree	Disagree	Mildly Disagree	Agree	Strongly Agree	Strongly Disagree	Disagree	Mildly Disagree	Agree	Strongly Agree
24. Goal-setting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Housekeeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Job interviewing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Laundry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Math	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Measurement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Money management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Non-verbal communication skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Preparing a resume	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Problem-solving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Reading	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Recreation and leisure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Self-advocacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Transition Awareness & Possibilities Survey

	"I have observed my child demonstrating _____ (skills or knowledge) at home and in the community."					"I think my child still needs instruction in _____."					"As a family, we have the resources or knowledge to practice _____ with my child at home and in the community."					
	N/A	Strongly Disagree	Disagree	Mildly Disagree	Agree	Strongly Agree	Strongly Disagree	Disagree	Mildly Disagree	Agree	Strongly Agree	Strongly Disagree	Disagree	Mildly Disagree	Agree	Strongly Agree
37. Self-determination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Self-monitoring to reduce problem behaviors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Sex education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Social skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Personal safety around strangers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Telling time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. Using the telephone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. Verbal communication skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Written communication skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Transition Awareness & Possibilities Survey

D. Adult Services & Supports

Here is a list of services and supports. Please indicate how strongly you agree with these statements:

	"My child may need or want _____ during his or her adulthood."					"If my child needed or wanted _____, I know who to call or who to ask to provide this."					"If my child needed or wanted _____, I know how to pay for it."				
	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Strongly Agree	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Strongly Agree	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Strongly Agree
47. Adult Daycare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Assistive Technology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. Attendant Care in Community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. Attendant Care in Home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. Behavior Support/Intervention	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. Benefits Planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. Case Management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
54. Chore Services/Housekeeping Assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
55. Counseling and Guidance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
56. Customized Employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Transition Awareness & Possibilities Survey

	"My child may need or want _____ during his or her adulthood."					"If my child needed or wanted _____, I know who to call or who to ask to provide this."					"If my child needed or wanted _____, I know how to pay for it."				
	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Strongly Agree	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Strongly Agree	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Strongly Agree
57. Day-Habilitation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
58. Diagnostic Testing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
59. Durable goods (for example: adult undergarments, medicines)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
60. Financial Planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
61. Group home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
62. Home Delivered Meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
63. Home or vehicle modifications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
64. Independent living arrangement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
65. Intensive, very structured living arrangement (outside of family home)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66. Interest and Aptitude testing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
67. Interpreter Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Transition Awareness & Possibilities Survey

	"My child may need or want _____ during his or her adulthood."					"If my child needed or wanted _____, I know who to call or who to ask to provide this."					"If my child needed or wanted _____, I know how to pay for it."				
	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Strongly Agree	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Strongly Agree	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Strongly Agree
68. Job related services including job search and placement assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
69. Long-Term Hospitalization	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
70. Medication Management/ Oversight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
71. Occupational Therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
72. Person-Centered Planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
73. Physical Therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
74. Post-secondary education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
75. Prosthetic and Orthotic Devices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
76. Sheltered Workshop	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
77. Short-term respite or relief service for the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Transition Awareness & Possibilities Survey

	"My child may need or want _____ during his or her adulthood."					"If my child needed or wanted _____, I know who to call or who to ask to provide this."					"If my child needed or wanted _____, I know how to pay for it."				
	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Strongly Agree	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Strongly Agree	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Strongly Agree
78. Skilled Nursing Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
79. Specialized Medical Equipment and Supplies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
80. Speech therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
81. Supervised living arrangement in the community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
82. Supported employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
83. Therapeutic, Social and Recreational Program	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
84. Transportation supports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
85. Vocational Counseling and Guidance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
86. Vocational skills training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Transition Awareness & Possibilities Survey

87. Please indicate ALL the people and places where you get information about your child's disability and his or her potential future adult needs.

- Special Education Teacher
- Local Employer
- General Education Teacher
- Other Parents
- Paraprofessional or educational assistant
- Formal support groups
- Transition coordinator or Occupational Therapist (OT)
- or Physical Therapist (PT)
- School psychologist or counselor
- College Representative
- Friends or Family
- Internet or personal research
- Non-profit organizations (e.g.: The Arc, Autism Society, Deaf-blind project)
- Other: _____
- Other: _____

88. Where do you get THE BEST information about your child's disability and his or her potential future adult needs. (Select only one.)

- Special Education Teacher
- Local Employer
- General Education Teacher
- Other Parents
- Paraprofessional or educational assistant
- Formal support groups
- Transition coordinator or Occupational Therapist (OT)
- or Physical Therapist (PT)
- School psychologist or counselor
- College Representative
- Friends or Family
- Internet or personal research
- Non-profit organizations (e.g.: The Arc, Autism Society, Deaf-blind project)
- Other: _____
- Other: _____

This is a pilot survey, which means it is not yet finalized. Do you have any comments or suggestions about specific questions or the survey overall?

This project has been reviewed by the Human Subjects Protection Review Committee, which ensures that research projects involving human subjects follow federal regulations. Any questions or concerns about rights as a research subject should be directed to the chair of the Institutional Review Board, The University of Southern Mississippi, 118 College Drive #5147, Hattiesburg, MS 39406-0001, (601) 266-6820.

APPENDIX C

REQUEST FOR EXPERT PARTICIPATION



THE UNIVERSITY OF
SOUTHERN MISSISSIPPI

118 College Drive #5057 | Hattiesburg, MS 39406-0001
Phone: 228-355-0509 | Fax: 601-266-4691 | melynda.ross@usm.edu | www.usm.edu

July 7, 2011

Dr. _____
TITLE
Department
University/Institution
Address

Dear Dr. _____:

Hello! My name is Melynda Ross, and I am a doctoral candidate at The University of Southern Mississippi. I would like you to review an instrument I have created (for my dissertation) that measures parents' knowledge of transition programming—from planning appropriate curricula and skill instruction to finding adult services and supports.

Of course, I am trying to secure transition experts from different areas of the country to increase the validity of the Transition Awareness and Possibilities Survey (TAPS), but I have asked you specifically because _____. I know you are busy with your own projects, but I do hope you have time to lend your expertise.

I am attaching an outline of the second chapter of my dissertation, so you have an idea of what concepts the survey will address. I have successfully defended my proposal and am now putting the final touches on the TAPS question formatting. This letter is simply to give advance notice and request a commitment for your time in late summer. I anticipate sending you the link to the survey during the last week in July, and, if possible, I would like your feedback by August 15. (I will send you a Word document that you may type comments into. Online, there will also be places for you to offer feedback next to the specific questions. I am using SurveyGizmo for the online surveys.)

I would be so thankful for your assistance with this project. If you have any additional questions about this study, please feel free to contact me at ~~(228) 355-0509~~ or by e-mail at melynda.ross@usm.edu.

Whether or not you can commit to review the TAPS in early August, please reply to this email and let me know so that, if necessary, I may find an alternate reviewer. I truly appreciate you!

Sincerely,

Melynda Ross

Melynda Burdette Ross, Ph.D. Candidate
The University of Southern MS

APPENDIX D

EXPERT REVIEWERS

1. Dr. Robert Baer
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8. Dr. David Test
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9. Dr. Audrey Trainor
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APPENDIX E

HARD COPY OF THE REVIEW SHEET

The electronic version of the review sheet can be found here:

<http://edu.surveymzmo.com/s3/597468/Transition-Awareness-Possibilities-Survey-2-0-for-Expert-Reviewers>

This review sheet must be used in conjunction with the TAPS survey.

1. Please write your name _____

2. Explanation of study

PURPOSE OF STUDY:	
The purpose of this study is to determine the accuracy of the content representativeness and content relevance for the Transition Awareness & Possibilities Survey (TAPS). This study is the first in a series necessary to develop an instrument that is valid and reliable to be used by schools and agencies to determine parents' knowledge of curricula and instruction, their child's potential adult support needs, and how to procure adult supports and services.	
PURPOSE OF INSTRUMENT:	
1. It will be used by school districts for program evaluation. This instrument will indicate to schools how well they are educating family members and/or if teachers and school district personnel are communicating effectively with parents about (a) skill instruction; (b) potential adult needs, and/or (c) adult service options. This instrument will also measure parents' satisfaction with the school- and agency-communication and collaboration.	2. The TAPS instrument results will also guide families by suggesting areas their knowledge may be lacking, unfamiliar terminology, and areas to prioritize for the next parent-teacher conference or IEP meeting.
Ultimately, the value of this instrument will be that it will provide direction for the school to provide better curricula and/or improved instruction of functional skills, improved and/or targeted communication with families, and facilitate interagency collaboration between the school, family, and adult service providers.	
The hope is that parents and teachers will use the final version of the TAPS to help guide transition planning and facilitate communication, as family members' increased knowledge and empowerment will ultimately result in better transition outcomes and quality of life for adults with disabilities.	

3. REVIEW OF DEMOGRAPHICS SECTION A

These are the demographic questions on the first two pages of the TAPS. Please review each question for clarity. Rate each item on a scale of 1 to 4, placing a check mark in the appropriate box. If you think the item could be reworded to be more respectful, place a check mark in the designated box.						
Item	Wording Clarity				Item could be reworded to be more respectful	Comments
	1= item is not clear	2= item needs major revisions to be clear	3= item needs minor revisions to be clear	4= item is clear		
Do you have a young adult in your household who is aged 14-22 and receives (or received) special education or related services?						
What is your relation to the young adult who is of transition age (14-22)?						
In what year were you born?						
What is your gender?						
Average Yearly Household Income:						
Your Educational Background:						
What is your child's gender?						
In what year was your child born?						
What is your child's primary disability?						
What is your child's racial/ethnic background?						
Where does/did your child receive special education services?						
Number of parents or non-sibling adults living in home:						
TOTAL number of children under 21 who live in the home or receive primary financial support from the parent(s) even if they live somewhere else:						
TOTAL number of children in the home who receive special education services:						
How many years until your child exits high school?						
How do you anticipate that your child will exit high school (or, how did he or she exit high school)?						

4. REVIEW OF TEACHER-PARENT COMMUNICATION SECTION B

On page 3 of the TAPS, questions 1-8 address the frequency and purposes of communication between parents and special education teachers. Please review each question or answer choice for clarity. Rate each item on a scale of 1 to 4, placing a check mark in the appropriate box.					
Item	Wording Clarity				Comments
	1= item is not clear	2= item needs major revisions to be clear	3= item needs minor revisions to be clear	4= item is clear	
Typically, how often do you have communication with your child's special education teacher? (phone calls, emails, letters, notebook correspondence, face-to-face conversations, etc.)					
Typically, how many times do you usually meet (face-to-face) with your child's special education teacher?					
How often and for what purposes does your child's special education teacher communicate with you?					
Almost every school day					
1-2 times per week					
1-2 times per month					
3-4 times per school year					
1-2 times per year					
Ask for my opinion or advice					
To "check-in" with our family					
Report daily activities					
Report problem behavior					
Report progress on skills, objectives, & goals					

5. REVIEW OF TRANSITION PROGRAMMING SECTION C: SKILLS AND KNOWLEDGE-Sources of Information

Questions 13 and 14 ask parents to indicate the people and places where they get information about their child's curriculum. Please review each item for clarity. Rate each item on a scale of 1 to 4, placing a check mark in the appropriate box. If you do not think the choice should be in this list, please check the box to suggest that it be removed.						
Item	Wording Clarity				Remove from TAPS	Comments
	1= item is not clear	2= item needs major revisions to be clear	3= item needs minor revisions to be clear	4= item is clear		
Special Education Teacher						
General Education Teacher						
Paraprofessional or educational assistant						
Transition coordinator or Transition specialist						
School psychologist or counselor						
Friends or Family						
Local Employer						
Other Parents						
Formal support groups						
Occupational Therapist (OT) or Physical Therapist (PT)						
College Representative						
Internet or personal research						
Non-profit organizations (e.g.: The Arc, Autism Society, Deaf-blind project)						
In the boxes below, add any other sources of information for parents that you think should be added to the lists.						

8. REVIEW OF TRANSITION PROGRAMMING SECTION D: ADULT SERVICES AND SUPPORTS--Sources of Information

Questions 87 and 88 ask parents to indicate the people and places where they get information information about their child's disability and his or her potential future adult needs. Please review each item for clarity. Rate each item on a scale of 1 to 4, placing a check mark in the appropriate box. If you do not think the choice should be in this list, please check the box to suggest that it be removed.

Item	Wording Clarity				Remove from TAPS	Comments
	1= item is not clear	2= item needs major revisions to be clear	3= item needs minor revisions to be clear	4= item is clear		
Special Education Teacher						
General Education Teacher						
Paraprofessional or educational assistant						
Transition coordinator or Transition specialist						
School psychologist or counselor						
Friends or Family						
Local Employer						
Other Parents						
Formal support groups						
Occupational Therapist (OT) or Physical Therapist (PT)						
College Representative						
Internet or personal research						
Non-profit organizations (e.g.: The Arc, Autism Society, Deaf-blind project)						
In the boxes below, add any other sources of information for parents that you think should be added to the lists.						

9. COMPREHENSIVE SUMMARY

THEORETICAL DEFINITION OF CONSTRUCT		
<p>Transition Programming: The longitudinal assessment, planning, skill-building, and networking that occurs between young adults, their families, teachers, service providers, and other stakeholders that facilitates the young adult's shift from the role of a student in a secondary environment to an adult in the community.</p>		
<p>With both expediency (for TAPS takers) and the dual purposes of the TAPS in mind, please review the entire instrument in the text boxes below. (Attach additional sheets if necessary.)</p>		
Overall Content Coverage	Items That Need to Be Added	Formatting
Any Other Comments		

REFERENCES

- Adams, M. (1997). Pedagogical frameworks for social justice education. In M. Adams, L. A. Bell, & P. Griffin (Eds.), *Teaching for diversity and social justice: A sourcebook for teachers and trainers* (2nd ed) (pp. 30-43). New York, NY: Routledge.
- Agran, M., Alper, S., & Wehmeyer, M. (2002). Access to the general curriculum for students with significant disabilities: What it means to teachers. *Education and Training in Mental Retardation and Developmental Disabilities*, 37(2), 123-133.
- Agran, M., Snow, K., & Swaner, J. (1999). Teacher perceptions of self-determination: Benefits, characteristics, strategies. *Education and Training in Mental Retardation and Developmental Disabilities*, 34(3), 293-301.
- Allbritten, D., Mainzer, R., & Ziegler, D. (2004). Will students with disabilities be scapegoats for school failures? *Educational HORIZONS*, 82, 153-160.
- Allen, E. M. (2007). *Parent perceptions of transition planning services for students with Asperger's syndrome*. Master's thesis, University of Kansas.
- Allen, R. I., & Petr, C. G. (1996). Toward developing standards and measurements for family-centered practice in family support programs. In G. Singer, L. Powers, & A. Olsen (Eds.), *Redefining family support: Innovations in public-private partnerships* (pp. 57-86). Baltimore, MD: Brookes Publishing.

- Allen, S. K., Smith, A. C., Test, D. W., Flowers, C., & Wood, W. M. (2001). The effects of self-directed IEP on student participation in IEP meetings. *Career Development for Exceptional Individuals, 24*(2), 107-120.
- Alwell, M., & Cobb, B. (2006). A systematic review of the effects of curricular interventions on the acquisition of functional life skills by youth with disabilities. *What Works Transition Research Synthesis*. Kalamazoo, MI: National Secondary Transition Technical Assistance Center (NSTTAC).
- American Nurses Association. (2001). Code of ethics for nurses with interpretive statements. Retrieved from <http://www.nursingworld.org/MainMenuCategories/EthicsStandards/CodeofEthicsforNurses/Code-of-Ethics.aspx>
- Americans with Disabilities Act of 1990, codified, as amended, at 42 U.S.C. §§ 12101 *et seq.*
- Ankeny, E.M., Wilkins, J., & Spain., J. (2009). Mothers' experiences of transition planning for their children with disabilities. *TEACHING Exceptional Children, 41*(6), 28-36.
- Antle, B. J., Montgomery, G., & Stapleford, C. (2009). The many layers of social support: Capturing the voices of young people with spina bifida and their parents. *Health & Social Work, 34*(2), 97-106.
- Arndt, S. A., Konrad, M., & Test, D. W. (2006). Effects of the self-directed IEP on student participation in planning meetings. *Remedial and Special Education, 27*(4), 194-207.

- Arroyo, A. A., Rhoad, R., & Drew, P. (1999). Meeting diverse student needs in urban schools: Research-based recommendations for school personnel. *Preventing School Failure, 43*(4), 145-153.
- Aristotle. (2009). *Politics by Aristotle (Written 350 B.C.E.)* (B. Jowett, Trans.). Los Angeles: Indo-European Publishing. (Original work published in 350 B.C.E.)
- Baer, R., Simmons, T., & Flexer, R. (1996). Transition practice and policy compliance in Ohio: A survey of secondary special educators. *Career Development for Exceptional Individuals, 19*(1), 61-72.
- Baer, R. M., Flexer, R. W., Beck, S., Amstutz, N., Hoffman, L., Brothers, J., ... Zechman, C. (2003). A collaborative follow-up study on transition service utilization and post-school outcomes. *Career Development for Exceptional Individuals, 26*(1), 7-25.
- Baker, L., & Stahl. (2004). Case study of interagency coordinating councils: Examining collaboration in services for children with disabilities. *Journal of Disability Policy Studies, 15*(3), 168-177.
- Bates, P., & Davis, F. A. (2004). Social capital, social inclusion and services for people with learning disabilities. *Disability & Society, 19*(3), 195-207.
- Beckstead, J.W. (2009). Content validity is naught. *International Journal of Nursing Studies, 46*, 785-792.
- Beirne-Smith, M., Patton, J. R., & Kim, S. H. (2006). *Mental retardation: An introduction to intellectual disabilities*. New York, NY: Prentice Hall.

- Benz, M. R., Lindstrom, L., & Yovanoff, P. (2000). Improving graduation and employment outcomes of students with disabilities: Predictive factors and student perspectives. *Exceptional Children, 66*(4), 509-529.
- Benz, M. R., Yovanoff, P., & Doren, B. (1997). School-To-Work components that predict postschool success for students with and without disabilities. *Exceptional Children, 63*(2), 151-165.
- Beresford, B. (2004). On the road to nowhere? Young disabled people and transition. *Child: Care, Health and Development, 30*(6), 581-587.
- Bezdek, J., Summers, J. A., & Turnbull, A. (2010). Professionals' attitudes on partnering with families of children and youth with disabilities. *Education and Training in Autism and Developmental Disabilities, 4*(3), 356-365.
- Bjarnason, D. S. (2002). New voices in Iceland. Parents and adult children: Juggling supports and choices in time and space. *Disability & Society, 17*(3), 307-326.
- Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture. *American Journal on Mental Retardation, 106*(2), 173-188.
- Blackorby, J., & Wagner, M. (1996). Longitudinal postschool outcomes of youth with disabilities: Findings from the national longitudinal transition study. *Exceptional Children, 62*(5), 399-413.
- Blue-Banning, M., Summers, J. A., Frankland, H. C., Nelson, L. L., & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional Children, 70*(2), 167-184.

- Blue-Banning, M., Turnbull, A. P., & Pereira, L. (2002). Hispanic youth/young adults with disabilities: Parents' visions for the future. *Research and Practice for Persons with Severe Disabilities*, 27(3), 204-219.
- Board. of Educ. v. Rowley, 458 U.S. 176 (1982).
- Board. of Educ. v. Spellings, 517 F.3d 922 (7th Cir., 2008).
- Bourdieu, P. (1986). The forms of capital. In J. Richardson (Ed.), *Handbook of Theory and Research for the Sociology of Education*, (pp. 241-258), New York, NY: Greenwood.
- Branstad, T., Acosta, A., Bartlett, S., Berdine, W., Butterfield, P., Chambers, J., ... Fletcher, J. (2002). *A new era: Revitalizing special education for children and their families*. Washington, DC: US Department of Education.
- Browder, D., Ahlgrim-Delzell, L., Flowers, C., Karvonen, M., Spooner, F., & Algozzine, R. (2005). How states implement alternate assessments for students with disabilities: Recommendations for national policy. *Journal of Disability Policy Studies*, 15(4), 209-220.
- Browder, D. M., & Cooper-Duffy, K. (2003). Evidence-Based practices for students with severe disabilities and the requirement for accountability in no child left behind. *The Journal of Special Education*, 37(3), 157-163.
- Browder, D. M., Spooner, F., Wakeman, S., Trela, K., & Baker, J. N. (2006). Aligning instruction with academic content standards: Finding the link. *Research and Practice for Persons with Severe Disabilities*, 31(4), 309-321.

- Browder, D. M., Wakeman, S. Y., Flowers, C., Rickelman, R., Pugalee, D., & Karvonen, M. (2007). Creating access to the general curriculum with links to grade-level content for students with significant cognitive disabilities: An explication of the concept . *The Journal of Special Education, 41*(1), 2-16.
- Brown, L., Farrington, K., Suomi, J., Ziegler, M., & Knight, T. (1999). Work-wage relationships and individuals with disabilities. *Journal of Vocational Rehabilitation, 13*(1), 5-13.
- Brown, R., Irwin, C., Lipson, D. Simon, S. & Wenzlow, A. (2008). *Research Design Report for the Evaluation of the Money Follows the Person (MFP) Grant Program*. Washington, DC: Mathematica Policy Research, Inc. Retrieved from http://www.mathematica-mpr.com/publications/PDFs/MFP_designrpt.pdf
- Brown, L., Shiraga, B., & Kessler, K. (2006). The quest for ordinary lives: The integrated post-school vocational functioning of 50 workers with significant disabilities. *Research and Practice for Persons with Severe Disabilities, 31*(2), 93-121.
- Bruckman, M., Blanton, P. W. (2003). Welfare-to-work single mothers' perspectives on parent involvement in Head Start: Implications for parent-teacher collaboration. *Early Childhood Education, 30*, 145-150.
- Buck v. Bell, 274 U.S. 200 (1927).
- Bush, G.W. (2001). *New freedom initiative*. Washington, DC: The White House.
- Butterworth, J., & Gilmore, D. (2000). Are we there yet? Trends in employment opportunities and supports. *TASH Newsletter, 26*, 5-7.

- Caldwell, J., & Heller, T. (2003). Management of respite and personal assistance services in a consumer-directed family support programme. *Journal of Intellectual Disability Research, 47*(5), 352–366.
- Carruthers, C. P., & Hood, C. D. (2007). Building a life of meaning through therapeutic recreation: The leisure and well-being model, part I. *Therapeutic Recreation Journal, 41*(4), 276-297.
- Certo, N. J., Luecking, R. G., Murphy, S., Brown, L., Courey, S., & Belanger, D. (2009). Seamless transition and long-term support for individuals with severe intellectual disabilities. *Research and Practice for Persons with Severe Disabilities, 33*(3), 85-95.
- CESSI (Cherry Engineering Support Services, Inc.). (2003). *Evaluation of the centers for independent living program*. McLean, VA: Author.
- Chambers, C. R., Hughes, C., & Carter, E. W. (2004). Parent and sibling perspectives on the transition to adulthood. *Education and Training in Developmental Disabilities, 39*(2), 79-94.
- Cimera, & Oswald. (2009). An exploration of the costs of services funded by vocational rehabilitation. *Journal of Rehabilitation, 75*(1), 18-26.
- Cimera, R. E. (2009). The outcomes and costs of public vocational rehabilitation consumers with mental illnesses. *Journal of Applied Rehabilitation Counseling, 40*(2), 28-33.
- Cimera, R. E. (2007). The cost-effectiveness of supported employment and sheltered workshops in Wisconsin: FY 2002-2005. *Journal of Vocational Rehabilitation, 26*(3), 153-158.

- Cimera, R. E. (2008). The cost-trends of supported employment versus sheltered employment. *Journal of Vocational Rehabilitation, 28*(1), 15-20.
- Citron, T., Brooks-Lane, N., Crandell, D., Brady, K., Cooper, M., & Revell, G. (2008). A revolution in the employment process of individuals with disabilities: Customized employment as the catalyst for system change. *Journal of Vocational Rehabilitation, 28*(3), 169-179.
- Cobb, R. B., & Alwell, M. (2009). Transition planning/coordinating interventions for youth with disabilities: A systematic review. *Career Development for Exceptional Individuals, 32*(2), 70-81.
- Coleman, J. S. (1988). Social capital in the creation of human capital. *American Journal of Sociology, 94*, 95-120.
- Collet-Klingenberg, L. L. (1998). The reality of best practices in transition: A case study. *Exceptional Children, 65*(1), 67-78.
- Collins, B., Karl, J., Riggs, L., Galloway, C. G., & Hager, K. D. (2010). Teaching core content with real-life applications to secondary students with moderate and severe disabilities. *TEACHING Exceptional Children, 43*, 52-59.
- Condon, E., & Callahan, M. (2008). Individualized career planning for students with significant support needs utilizing the discovery and vocational profile process, cross-agency collaborative funding and social security work incentives. *Journal of Vocational Rehabilitation, 28*(2), 85-96.
- Cooney, B. F. (2002). Exploring perspectives on transition of youth with disabilities: Voices of young adults, parents, and professionals. *Mental Retardation, 40*(6), 425-435.

- Cooper, H. M. (1988). Organizing knowledge synthesis: A taxonomy of literature reviews. *Knowledge in Society, 1*, 104-126.
- Cornwell, E. Y., & Cornwell, B. (2008). Access to expertise as a form of social capital: An examination of race-and class-based disparities in network ties to experts. *Sociological Perspectives, 51*(4), 853-876.
- Council on Quality and Leadership, The. (2005). *Quality Measures 2005*. Towson, MD: The Council on Quality and Leadership.
- Crane, K., Gramlich, M., & Peterson, K. (2004). Putting interagency agreements into action. *Issue brief*. Minneapolis: National Center on Secondary Education and Transition, (NCSET), Institute on Community Integration, University of Minnesota.
- Cronin, M. E. (1996). Life skills curricula for students with learning disabilities. *Journal of Learning Disabilities, 29*(1), 53-69.
- Cummins, R. A. (2002). Proxy responding for subjective well-being: A review. *International Review of Research in Mental Retardation, 25*, 183-207.
- Darrah, J., Magill-Evans, J., & Galambos, N. L. (2010). Community services for young adults with motor disabilities - A paradox. *Disability and Rehabilitation, 32*(3), 223-229.
- Davenport, T. N., & Eidelman, S. M. (2008). Affordability of family care for an individual with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 46*(5), 396-399.
- Davis, M. (2003). Addressing the needs of youth in transition to adulthood. *Administration and Policy in Mental Health and Mental Health Services Research, 30*(6), 495-509.

- de Broucker, P., & Lavalee, L. (1998). Getting ahead in life: Does your parents' education count? *Education Quarterly Review*, 5(1), 22-28.
- de Haan, L. G., & MacDermid, S. (1998). The relationship of individual and family factors to the psychological well-being of junior high school students living in urban poverty. *Adolescence*, 33(129), 73-89.
- Deficit Reduction Act of 2005, P.L. 109-171, codified, as amended, at 42 U.S.C. §§ 1396 *et seq.*
- deFur, S. H. (2002). Education reform, high-stakes assessment, and students with disabilities. *Remedial and Special Education*, 23(4), 203-211.
- deFur, S. H., Todd-Allen, M., & Getzel, E. E. (2001). Parent participation in the transition planning process. *Career Development for Exceptional Children*, 24, 19-36.
- Developmental Disabilities Assistance and Bill of Rights Act (1963), PL 106-442, codified, as amended, at 42 U.S.C. §§ 6000 *et seq.*
- Downing, J. E., & Peckham-Hardin, K. D. (2007). Inclusive education: What makes it a good education for students with moderate to severe disabilities? *Research and Practice for Persons with Severe Disabilities*, 32(1), 16-30.
- Downs, A., & Carlon, D. M. (2009). School-To-Work transition programs within third-party government. *Journal of Disability Policy Studies*, 20(3), 131-141.
- Dymond, S. K., & Orelove, F. P. (2001). What constitutes effective curriculum for students with severe disabilities? *Exceptionality*, 9(3), 109-122.

- Education Sciences Reform Act of 2002, P.L. 107-279. Retrieved from <http://www.ed.gov/policy/rschstat/leg/PL107-279.pdf>
- Eggleton, I., Robertson, S., Ryan, J., & Kober, R. (1999). The impact of employment on the quality of life of people with an intellectual disability. *Journal of Vocational Rehabilitation, 13*(2), 95-107.
- Eisenmann, L. (2001). Conceptualizing the contributions of career-oriented schooling to self-determination. *Career Development for Exceptional Individuals, 24*(1), 3-17.
- Epstein, J. L. (2005). Links in a professional development chain: Preservice and inservice education for effective programs of school, family, and community partnerships. *The New Educator, 1*(2), 125-141.
- Epstein, J. L., & Jansorn, N. R. (2004). School, family and community partnerships link the plan. *Education Digest: Essential Readings Condensed for Quick Review, 69*(6), 19-23.
- Erickson, K. A., & Koppenhaver, D. A. (1995). Developing a literacy program for children with severe disabilities. *Reading Teacher, 48*, 676-684.
- Everson, J. M. (1996). Using person-centered planning concepts to enhance school-to-adult life transition planning. *Journal of Vocational Rehabilitation, 6*(1), 7-13.
- Everson, J. M., Zhang, D., & Guillory, J. D. (2001). A statewide investigation of individualized transition plans in Louisiana. *Career Development for Exceptional Individuals, 24*(1), 37-49.
- Fair Labor Standards Act of 1938, codified, as amended, at 29 U.S.C. §§ 201 *et seq.*

- Faragher, R. & Brown, R. I. (2005). Numeracy for adults with Down syndrome: It's a matter of quality of life. *Journal of Intellectual Disability Research*, 49(10), 761–765.
- Farkus, S., Johnson, J., & Duffett, A. (1999). *Playing their parts: Parents and teachers talk about parental involvement in public schools*. New York, NY: Public Agenda.
- Ferguson, P. M., Ferguson, D. L., & Jones, D. (1988). Generations of hope: Parental perspectives on the transitions of their children with severe retardation from school to adult life. *Journal of the Association for Persons with Severe Handicaps*, 13(3), 177-187.
- Field, S., & Hoffman, A. (1994). Development of a model for self-determination. *Career Development for Exceptional Individuals*, 17(2), 159-69.
- Field, S., & Hoffman, A. (2002). Lessons learned from implementing the steps to self-determination curriculum. *Remedial and Special Education*, 23(2), 90-98.
- Field, S., & Hoffman, A. (2007). Self-determination in secondary transition assessment. *Assessment for Effective Intervention*, 32(3), 181-190.
- Field, S., Martin, J., Miller, R., Ward, M., & Wehmeyer, M. (1998). *A practical guide for teaching self-determination*. Reston, VA: Council for Exceptional Children.
- Feinstein, A.R., & Cicchetti, D.V. (1990). High agreement but low kappa: The problems of two paradoxes. *Journal of Clinical Epidemiology*, 43, 543-549.

- Fish, W. W. (2008). The IEP meeting: Perceptions of parents of students who receive special education services. *Preventing School Failure, 53*(1), 8-14.
- Fitzpatrick, A.M. (1983). The meaning of content validity. *Applied Psychological Measurement, 3*(1), 7-13.
- Fonteine, H., Zijlstra, H. P., & Vlaskamp, C. (2008). Transfer of information between parents and teachers of children with profound intellectual and multiple disabilities at special educational centres. *Journal of Applied Research in Intellectual Disabilities, 21*(5), 477-483.
- Frank, A. R., & Sitlington, P. L. (2000). Young adults with mental disabilities-- Does transition planning make a difference? *Education and Training in Mental Retardation and Developmental Disabilities, 35*(2), 119-34.
- Frankland, H. C., Turnbull, A. P., Wehmeyer, M. L., & Blackmountain, L. (2004). An exploration of the self-determination construct and disability as it relates to the Diné (Navajo) culture. *Education and Training in Developmental Disabilities, 39*(3), 191-205.
- Garcia-Villamisar, D., Wehman, P., & Navarro, M. D. (2002). Changes in the quality of autistic people's life that work in supported and sheltered employment. A 5-year follow-up study. *Journal of Vocational Rehabilitation, 17*(4), 309-312.
- Garner, H. G., & Orelove, F. P. (Eds.). (1994). *Teamwork in human services: Models and applications across the lifespan*. Boston, MA: Butterworth-Heinemann.

- Geenen, S., Powers, L. E., & Lopez-Vasquez, A. (2001). Multicultural aspects of parent involvement in transition planning. *Exceptional Children, 67*(2), 265-283.
- Geenen, S., Powers, L., Vasquez, A. L., & Bersani, H. (2003). Understanding and promoting the transition of minority adolescents. *Career Development for Exceptional Individuals, 26*(1), 27-46.
- Geeter, K. I., Poppes, P., & Vlaskamp, C. (2002). Parents as experts: The position of parents of children with profound multiple disabilities. *Child-Care Health and Development, 28*(6), 443-454.
- Gill, T. L., & Renwick, R. (2007). Family quality of life and service delivery for families with adults who have developmental disabilities. *Journal on Developmental Disabilities, 13*(3), 13-36.
- Goldfarb, F. D., Devine, K. L., Yingling, J. T., Hill, A., Moss, J., Ogburn, E. S., . . . Pariseau, C. (2010). Partnering with professionals: Family-Centered care from the parent perspective. *Journal of Family Social Work, 13*(2), 91-99.
- Goldman, C., Lesser, A., Lincer, M., Parks, S., & Salmen, J. (2003). Design for accessibility: A cultural administrator's handbook. Washington DC: National Endowment for the Arts. Retrieved from <http://arts.endow.gov/resources/Accessibility/DesignAccessibility.html>
- Goode, D., & Hogg, J. (1994). Towards an understanding of holistic quality of life in people with profound intellectual and multiple disabilities. In D. Goode (Ed.), *Quality of Life for Persons with Disabilities: International*

- Perspectives and Issues*, (pp. 197-207). Cambridge, MA: Brookline Books, Inc.
- Goupil, G., Tasse, M. J., Garcin, N., & Dore, C. (2002). Parent and teacher perceptions of individualised transition planning. *British Journal of Special Education*, 29(3), 127-135.
- Greene, G., & Kochhar-Bryant, C. A. (2003). *Pathways to Successful Transition for Youth with Disabilities*. Upper Saddle River, NJ: Merrill Prentice Hall.
- Greene, G., & Nefsky, P. (1999). Transition for culturally and linguistically diverse youth with disabilities: Closing the gaps. *Multiple Voices for Ethnically Diverse Exceptional Learners*, 3(1), 15-24.
- Griffin, C., Hammis, D., Geary, T., & Sullivan, M. (2008). Customized employment: Where we are; where we're headed. *Journal of Vocational Rehabilitation*, 28(3), 135-139.
- Griffin, M.M., McMillan, E.D., & Hodapp, R.M. (2010). Family perspectives on post-secondary education for students with intellectual disabilities. *Education and Training in Developmental Disabilities*, 45(3), 339-346.
- Grigal, M., & Dwyre, A. (2010). Employment activities and outcomes of college-based transition programs for students with intellectual disabilities. *Think College Insight Brief, Issue No. 3*. Boston, MA: Institute for Community Inclusion, University of Massachusetts Boston.
- Grigal, M., & Neubert, D. A. (2004). Parents' in-school values and post-school expectations for transition-aged youth with disabilities. *Career Development for Exceptional Individuals*, 27(1), 65-85.

- Grigal, M., Dwyre, A., & Davis, H. (2006). Transition services for students aged 18-21 with intellectual disabilities in college and community settings: Models and implications of success. *Information Brief*, 5(5). Minneapolis: National Center on Secondary Education and Transition (NCSET), Institute on Community Integration, University of Minnesota. Retrieved from http://www.ncset.org/publications/info/NCSETInfoBrief_5.5.pdf
- Grigal, M., Neubert, D. A., & Moon, M. S. (2001). Public school programs for students with significant disabilities in post-secondary settings. *Education and Training in Mental Retardation and Developmental Disabilities*, 36(3), 244-254.
- Grigal, M., Neubert, D. A., & Moon, M. S. (2002). Postsecondary options for students with significant disabilities. *Teaching Exceptional Children*, 35(2), 68-73.
- Grigal, M., Neubert, D. A., Moon, M. S., & Graham, S. (2003). Self-Determination for students with disabilities: Views of parents and teachers. *Exceptional Children*, 70(1), 97-113.
- Gwet, K. (2010). *Handbook of inter-rater reliability*, (2nd ed). Gaithersburg, MD: Advanced Analytics, LLC.
- Halpern, A. S. (1994). Quality of life for students with disabilities in transition from school to adulthood. *Social Indicators Research*, 33(1), 193-236.
- Halpern, A. S. (1994). The transition of youth with disabilities to adult life: A position statement of the division on career development and transition, the council for exceptional children. *Career Development for Exceptional Individuals*, 17(2), 115-124.

- Halpern, A. S., Nave, G., Close, D. W., & Nelson, D. (1986). An empirical analysis of the dimensions of community adjustment for adults with mental retardation in semi-independent living programs. *Journal of Intellectual & Developmental Disability, 12*(3), 147-157.
- Halpern, A. S., Yovanoff, P., Doren, B., & Benz, M. R. (1995). Predicting participation in postsecondary education for school leavers with disabilities. *Exceptional Children, 62*(2), 151-164.
- Hanson, M. J. (2003). National legislation for early intervention: United States of America. In S. Odom, M. Hanson, J. Blackman, & S. Kaul (Eds.), *Early intervention practices around the world*. (pp. 253-80). Baltimore, MD: Brookes.
- Harry, B. (2008). Collaboration with culturally and linguistically diverse families: Ideal versus reality. *Exceptional Children, 74*(3), 372-388.
- Hart, D., Grigal, M., Sax, C., Martinez, D., & Will, M. (2006). Postsecondary education options for students with intellectual disabilities. *Research to Practice No. 45*. Boston: Institute for Community Inclusion, UMass Boston. Retrieved from <http://www.communityinclusion.org/pdf/rp45.pdf>
- Hart, D., Grigal, M., & Weir, C. (2010). Expanding the paradigm: Postsecondary education options for individuals with autism spectrum disorder and intellectual disabilities. *Focus on Autism and Other Developmental Disabilities, 25*(3), 134-150.
- Hart, D., Mele-McCarthy, J., Pasternack, R. H., Zimbrich, K., & Parker, D. R. (2004). Community college: A pathway to success for youth with learning,

cognitive, and intellectual disabilities in secondary settings. *Education and Training in Developmental Disabilities*, 39(1), 54-66.

Hart, D., Zimbrich, K., & Ghiloni, C. (2001). Interagency partnerships and funding: Individual supports for youth with significant disabilities as they move into postsecondary education and employment options. *Journal of Vocational Rehabilitation*, 16(3), 145-154.

Hart, D., Zimbrich, K. & Parker, D. (2005). Dual enrollment as a postsecondary education option for students with intellectual disabilities. In E. Getzel & P. Wehman (Eds.), *Going to college: Expanding opportunities for people with disabilities*, (pp. 253-266). Baltimore, MD: Brookes.

Hart, D., Zimbrich, K., & Whelley, T. (2002). Challenges in coordinating and managing services and supports in secondary and postsecondary options. *Issue Brief*, 1(6). Minneapolis, MN: National Center on Secondary Education and Transition (NCSET), Institute on Community Integration, University of Minnesota.

Hatter, R. A., Williford, M., & Dickens, K. (2000). Nurturing and working in partnership with parents during transition. In H. B. Clark & M. Davis (Eds.), *Transition to adulthood: A resource for assisting young people with emotional or behavioral difficulties* (pp. 209-228). Baltimore, MD: Brookes.

Hasazi, S., Furney, K., & DeStefano, L. (1999). School and agency implementation of the IDEA transition mandates: Perspectives from nine sites. *Exceptional Children*, 65(4), 555-567.

- Hayward, B. J., & Schmidt-Davis, H. (2003). Longitudinal study of the vocational rehabilitation services program. *Final report 2: VR services and outcomes*. Washington DC: U.S. Department of Education, Office of Special Education and Rehabilitative Services, Rehabilitation Services Administration.
- Heal, L. W., & Sigelman, C. K. (1996). Methodological issues in quality of life measurement. In R. L. Schalock (Ed.), *Quality of life: Volume 1: Conceptualization and measurement* (pp. 91-104). Washington, DC: American Association on Mental Retardation.
- Hebbeler, K., & Barton, L. R. (2007). The need for data on child and family outcomes at the federal and state levels. *Young Exceptional Children Monograph Series, 9*, 1-15.
- Heller, T., Miller, A. B., & Hsieh, K. (1999). Impact of a consumer-directed family support program on adults with developmental disabilities and their family caregivers. *Family Relations, 48*(4), 419-427.
- Hendley, N., & Pascall, G. (2001). *Disability and Transition to Adulthood: Achieving Independent Living*. Brighton/York: Pavilion/Joseph Rowntree Foundation.
- Herbert, J. T., Lorenz, D. C., & Trusty, J. (2010). Career assessment practices for high school students with disabilities and perceived value reported by transition personnel. *Journal of Rehabilitation, 76*(4), 18-26.
- Hertz, K. J. (2010). The money follows the person demonstration: Early program evaluation analysis. *New Voices in Public Policy, 4*. Fairfax: VA: George Mason University.

- Heslop, P., Mallett, R., Simons, K., & Ward, L. (2002). *Bridging the divide at transition: What happens for young people with learning difficulties and their families?* Kidderminster, U.K.: British Institute of Learning Disabilities.
- Hetherington, S.A., Durant-Jones, L., Johnson, K., Nolan, K., Smith, E., Taylor-Brown, S., & Tuttle, J. (2010). The lived experiences of adolescents with disabilities and their parents in transition planning. *Focus on Autism and Other Developmental Disabilities, 25*(3), 163-172.
- Hewitt, A., Larson, S., Lakin, K., Kwak, N., Sauer, J., Jendro, J., & Lightfoot, E. (2000). *An independent evaluation of the quality of services and system performance of Minnesota's Medicaid Home and Community Based Services for persons with mental retardation and related conditions.* Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living.
- Hobfall, S. E. (2002). Social and psychological resources and adaptation. *Review of General Psychology, 6*(4), 307-324.
- Hodge, N., & Runswick-Cole, K. (2008). Problematizing parent—professional partnerships in education. *Disability & Society, 23*(6), 637-647.
- Holburn, S. (2002). How science can evaluate and enhance person-centered planning. *Research and Practice for Persons with Severe Disabilities, 27*(4), 250-260.
- Holcomb-McCoy, C., & Bryan, J. (2010). Advocacy and empowerment in parent consultation: Implications for theory and practice. *Journal of Counseling & Development, 88*(3), 259-268.

- Horn, L., Berkold, J., & Bobbitt, L. (1999). *Students with disabilities in postsecondary education: A profile of preparation, participation, and outcomes*. Washington DC: U.S. Department of Education, National Center for Education Statistics.
- Horvat, E. M. N., Weininger, E. B., & Lareau, A. (2003). From social ties to social capital: Class differences in the relations between schools and parent networks. *American Educational Research Journal*, 40(2), 319-351.
- Hudson, B. (2003). From adolescence to young adulthood: The partnership challenge for learning disability services in England. *Disability & Society*, 18(3), 259-276.
- Hughes, C. (2009). Postsecondary outcomes in the 21st century-A change is gonna come? *Research and Practice for Persons with Severe Disabilities*, 33(3), 100-102.
- Hughes, C., & Carter, E. W. (2002). Informal assessment procedures. In C. L. Sax & C. A. Thoma (Eds.), *Transition Assessment: Wise Practices for Quality Lives*, (pp. 51-69). Baltimore, MD: Brookes.
- Hulett, K. E. (2009). *Legal Aspects of Special Education*. Upper Saddle River, New Jersey: Pearson Education, Inc. Reprinted with permission from Pearson Education, Inc. Retrieved from http://www.idea35.org/future_implications.html
- Individuals with Disabilities Education Act of 1990. P.L. 94-142, codified, as amended, at 42 U.S.C. §§ 12101 *et seq.*

- Individuals with Disabilities Education Improvement Act of 2004, P.L. 108-446, codified, as amended, at 20 U.S.C. §§ 1400 *et seq.* Regulations promulgated at 34 C.F.R. Parts 300 and 301.
- Inge, K. J. (2006). Customized employment: A growing strategy for facilitating inclusive employment. *Journal of Vocational Rehabilitation, 24*(3), 191-193.
- Inge, K. J., & Targett, P. (2008). Customized employment and disclosure. *Journal of Vocational Rehabilitation, 28*(2), 129-132.
- Izzo, M., & Lamb, M. (2002). Self-Determination and career development: Skills for successful transitions to postsecondary education and employment. A *White Paper for the Post-School Outcomes Network of the National Center on Secondary Education and Transition (NCSET) at the University of Hawaii at Manoa*. Retrieved from <http://www.ncset.Hawaii.edu/Publications>
- Javits–Wagner O’Day Act of 1971, P.L. 92-28, codified as amended at 41 U.S.C. §§ 46-48c.
- Johnson, D.R., & Emanuel, E.J. (Eds.) (2000). *Issues influencing the future of transition programs and services in the United States*. Minneapolis, MN: National Transition Network Institute on Community Integration (UAP), University of Minnesota.
- Johnson, D. R. (2004). Current challenges facing the future of secondary education and transition services for youth with disabilities in the United States. *Discussion Paper*. Minneapolis, MN: National Center on

Secondary Education and Transition (NCSET), Institute on Community Integration, University of Minnesota.

- Johnson, D. R., Stodden, R. A., Emanuel, E. J., Luecking, R., & Mack, M. (2002). Current challenges facing secondary education and transition services: What research tells us. *Exceptional Children, 68*(4), 519-531.
- Kalyanpur, M., & Harry, B. (1999). *Culture in special education: Building reciprocal family-professional relationships*. Baltimore, MD: Brookes.
- Kalyanpur, M., Harry, B., & Skrtic, T. (2000). Equity and advocacy expectations of culturally diverse families' participation in special education. *International Journal of Disability, Development and Education, 47*(2), 119-136.
- Kennedy, D. J. (2003). Linking transition best practices to student outcomes for students with mental retardation. Available from ProQuest Dissertations and Theses database. (UMI No.3115890)
- Kennedy, Patricia J. (2004). The use and evaluation of special education parent advocacy groups as reported by public school principals and special education directors in four New Jersey counties: Bergen, Essex, Morris, and Passaic. Available from ProQuest Dissertations and Theses database. (UMI No.3156496)
- Kim, K., & Turnbull, A. (2004). Transition to adulthood for students with severe disabilities: Shifting toward person-family interdependent planning. *Research & Practice for Persons with Severe Disabilities, 29*(1), 53-57.
- Kim, K. H., Lee, Y., & Morningstar, M. E. (2007). An unheard voice: Korean American parents' expectations, hopes, and experiences concerning their

- adolescent child's future. *Research and Practice for Persons with Severe Disabilities*, 32(4), 253-264.
- Kim, K. H., & Morningstar, M. E. (2005). Transition planning involving culturally and linguistically diverse families. *Career Development for Exceptional Individuals*, 28, 92-103.
- King, G., Baxter, D., Rosenbaum, P., Zwaigenbaum, L., & Bates, A. (2009). Belief systems of families of children with autism spectrum disorders or down syndrome. *Focus on Autism and Other Developmental Disabilities*, 24(1), 50-64.
- Kliewer, C., & Biklen, D. (2001). "School's not really a place for reading": A research synthesis of the literate lives of students with severe disabilities. *The Journal of the Association for Persons with Severe Handicaps*, 26(1), 1-12.
- Kliewer, C., & Landis, D. (1999). Individualizing literacy instruction for young children with moderate to severe disabilities. *Exceptional Children*, 66, 85-100.
- Knighton, T., & Mirza, S. (2002). Post-secondary participation: The effects of parents' education and household income. *Education Quarterly Review*, 8(3), 25-32.
- Kohler, P. D. (1996). Preparing youth with disabilities for future challenges: A taxonomy for transition programming. In P.D. Kohler (Ed.), *Taxonomy for Transition Programming: Linking Research and Practice* (pp. 1-62). Champaign, IL: Transition Research Institute.

- Kohler, P. D., & Field, S. (2003). Transition-focused education: Foundation for the future. *The Journal of Special Education, 37*(3), 174-183.
- Koppenhaver, D. A. (1991). A descriptive analysis of classroom literacy instruction provided to children with severe speech and physical impairments. *Doctoral dissertation*, University of North Carolina-Chapel Hill.
- Koppenhaver, D. A., & Yoder, D. E. (1993). Classroom literacy instruction for children with severe speech and physical impairments (SSPI): What is and what might be. *Topics in Language Disorders, 13*(2), 1-15.
- Kraemer, B. R., & Blacher, J. (2001). Transition for young adults with severe mental retardation: School preparation, parent expectations, and family involvement. *Mental Retardation, 39*(6), 423-435.
- Kraemer, B. R., McIntyre, L. L., & Blacher, J. (2003). Quality of life for young adults with mental retardation during transition. *Mental Retardation, 41*(4), 250-262.
- Kregel, J., Wehman, P., Revell, G., Hill, J., & Cimera, R. (2000). Supported employment benefit-cost analysis: Preliminary findings. *Journal of Vocational Rehabilitation, 14*(3), 153-161.
- Lake, J. F., & Billingsley, B. S. (2000). An analysis of factors that contribute to parent school conflict in special education. *Remedial and Special Education, 21*(4), 240-251.
- Lakin, C. (2007). How does Mississippi stack up?: Envisioning and supporting alternative futures for people with disabilities. Association for Persons in Supported Employment (APSE) conference presentation. Natchez, MS.

- Landmark, L. J. O., Zhang, D. D., & Montoya, L. (2007). Culturally diverse parents' experiences in their children's transition: Knowledge and involvement. *Career Development for Exceptional Individuals, 30*(2), 68-79.
- Lareau, A., & Horvat, E. M. N. (1999). Moments of social inclusion and exclusion race, class, and cultural capital in family-school relationships. *Sociology of Education, 72*(1), 37-53.
- Leake, D., & Cholymay, M. (2004). Addressing the needs of culturally and linguistically diverse students with disabilities in postsecondary education. *Information Brief, 3*(1). Minneapolis, MN: National Center on Secondary Education and Transition (NCSET), Institute on Community Integration, University of Minnesota.
- Lemay, R. A. (2009). Deinstitutionalization of people with developmental disabilities: A review of the literature. *Canadian Journal of Community Mental Health (Revue Canadienne De Santé Mentale Communautaire), 28*(1), 181-194.
- Light, J. & Smith, A. K. (1993). Home literacy experiences of preschoolers who use AAC systems and of their nondisabled peers. *Augmentative and Alternative Communication, 9*(1), 10-25.
- Lim, T., Gurl, M., & Quah, L. (2000). Singaporean parents' curriculum priorities for their children with disabilities. *International Journal of Disability Development and Education, 47*(1), 77-87.

- Lindstrom, L., Doren, B., Metheny, J., Johnson, P., & Zane, C. (2007). Transition to employment: Role of the family in career development. *Exceptional Children, 73*(3), 348-366.
- Lipson, D. J., & Williams, S.R. (2009). Implications for state program features for attaining MFP goals. *National Evaluation of the Money Follows the Person (MFP) Demonstration Grant Program: Reports from the Field*. Princeton, NJ: Mathematica Policy Research.
- Luckasson, R., Borthwick-Duffy, S., Buntinx, W. G. E., Coulter, D. L., Craig, E. M., Reeve, A., . . . Spreat, S. (2002). *Mental retardation: Definition, classification, and systems of supports*, (10th Ed). Washington, DC: American Association on Mental Retardation.
- Luecking, R., & Gramlich, M. (2003). Quality work-based learning and postschool employment success. *Issue Brief, 2*(2). Minneapolis, MN: National Center on Secondary Education and Transition (NCSET), Institute on Community Integration, University of Minnesota.
- Luecking, R. G., & Certo, N. J. (2002). Integrating service systems at the point of transition for youth with significant disabilities: A model that works. *Information Brief, 1*(4). Minneapolis, MN: National Center on Secondary Education and Transition (NCSET), Institute on Community Integration, University of Minnesota.
- Luecking, R. G., & Certo, N. J. (2003). Integrating service systems at the point of transition for youth with significant support needs: A model that works. *American Rehabilitation, 27*(1), 2-9.

- Luecking, R. G., Cuzzo, L., Leedy, M. J., & Seleznow, E. (2008). Universal one-stop access: Pipedream or possibility? *Journal of Vocational Rehabilitation, 28*(3), 181-189.
- Lynn, M.R., (1986). Determination and quantification of content validity. *Nursing Research, 35*(6), 382–385.
- Lyons, G. (2010). Quality of life for persons with intellectual disabilities: A review of the literature. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities*, (pp. 73-126). New York, NY: Springer Science+Business Media.
- May, D. (2001). Becoming adult: School leaving, jobs and the transition to adult life. In D. May's (Ed.) *Transition and Change in the Lives of People with Intellectual Disabilities: Research Highlights in Social Work, 38*, 75-96.
- McAndrews, D. (2008). Legal issues relating to transition planning and post-age 21 services for individuals with autism. *Speaker's Journal, 8*(16), 165-179. Office of the Speaker, Pennsylvania House of Representatives.
- McIntyre, L. L., Kraemer, B. R., Blacher, J., & Simmerman, S. (2004). Quality of life for young adults with severe intellectual disability: Mothers' thoughts and reflections. *Journal of Intellectual & Developmental Disability, 29*(2), 131-146.
- McLaughlin, J., Goodley, D., Clavering, E., & Fisher, P. (2010). *Families raising disabled children: Enabling care and social justice*. London, UK: Palgrave Macmillan.
- McVilly, K. R., Burton-Smith, R. M., & Davidson, J. A. (2000). Concurrence between subject and proxy ratings of quality of life for people with and

- without intellectual disabilities. *Journal of Intellectual & Developmental Disability, 25*(1), 19-39.
- Michaels, C. A., & Ferrara, D. L. (2005). Promoting post-school success for all: The role of collaboration in person-centered transition planning. *Journal of Educational and Psychological Consultation, 16*(4), 287-313.
- Michailakis, D. (2003). The systems theory concept of disability: One is not born a disabled person, one is observed to be one. *Disability & Society, 18*(2), 209-229.
- Migliore, A., Grossi, T., Mank, D., & Rogan, P. (2008). Why do adults with intellectual disabilities work in sheltered workshops? *Journal of Vocational Rehabilitation, 28*(1), 29-40.
- Migliore, A., Mank, D., Grossi, T., & Rogan, P. (2007). Integrated employment or sheltered workshops: Preferences of adults with intellectual disabilities, their families, and staff. *Journal of Vocational Rehabilitation, 26*(1), 5-19.
- Minnesota Governor's Council on Developmental Disabilities, The. (n.d.). The Middle Ages, Renaissance, & Reformation 476 A.D.- 1500 A.D. *Parallels in time: A history of developmental disabilities*. Retrieved from <http://www.mnddc.org/parallels/two/1.html>
- Moon, M.S., & Inge, K. (2000). Vocational preparation and transition. In M. Snell & F. Brown (Eds.), *Instruction of students with severe disabilities* (5th ed.). Upper Saddle River, NJ: Merrill/Prentice-Hall, Inc.
- Morningstar, M. E. (1997). Critical issues in career development and employment preparation for adolescents with disabilities. *Remedial and Special Education, 18*(5), 307-320.

- Morningstar, M. E., Frey, B. B., Noonan, P. M., Ng, J., Clavenna-Deane, B., Graves, P., . . . Williams-Diehm, K. (2010). A preliminary investigation of the relationship of transition preparation and self-determination for students with disabilities in postsecondary educational settings. *Career Development for Exceptional Individuals, 33*(2), 80-94.
- Morris, J. (2002). *Moving into adulthood: Young disabled people moving into adulthood*. York, UK: Joseph Rowntree Foundation.
- Murphy, S. T., & Rogan, P. M. (1995). *Closing the shop: Conversion from sheltered to integrated work*. Baltimore, MD: Brookes.
- Murray, M. M., Christensen, K. A., Umbarger, G. T., Rade, K. C., Aldridge, K., & Niemeyer, J. A. (2007). Supporting family choice. *Early Childhood Education Journal, 35*(2), 111-117.
- Murray, M. M., & Curran, E. M. (2008). Learning together with parents of children with disabilities: Bringing parent-professional partnership education to a new level. *Teacher Education and Special Education, 31*(1), 59-63.
- Murray, S. (2007). Families' care work during the transition from school to post-school for children with severe disabilities. *Family Matters, 76*, 24-29.
- Nachshen, J. S. (2005). Empowerment and families: Building bridges between parents and professionals, theory and research. *Journal on Developmental Disabilities, 11*(1), 67-75.
- National Association of Social Workers. (1999). *Code of ethics of the National Association of Social Workers*. Washington, DC: Author.

- National Council on Disability. (2010). *Workforce infrastructure in support of people with disabilities: Matching human resources to service needs*. Washington, DC: National Council on Disability. Retrieved from http://www.ncd.gov/newsroom/publications/2010/NCD_Workforce508.pdf
- National Disability Rights Network. (2011). *Segregated and exploited: The failure of the disability service system to provide quality work*. Washington, DC: National Disability Rights Network.
- Neece, C. L., Kraemer, B. R., & Blacher, J. (2009). Transition satisfaction and family well being among parents of young adults with severe intellectual disability. *Intellectual and Developmental Disabilities, 47*(1), 31-43.
- Neubert, D. A. (2003). The role of assessment in the transition to adult life process for students with disabilities. *Exceptionality, 11*(2), 63-75.
- Neubert, D. A., Moon, M. S., & Grigal, M. (2004). Activities of students with significant disabilities receiving services in postsecondary settings. *Education and Training in Developmental Disabilities, 39*(1), 16-25.
- Newman, L. (2005). Family involvement in the educational development of youth with disabilities. *A Special Topic Report From the National Longitudinal Transition Study-2 (NLTS2)*. Menlo Park, CA: SRI International. Retrieved from www.nlts2.org/reports/2005.../nlts2_report_2005_03_complete.pdf
- Newman, L., Wagner, M., Cameto, R., & Knokey, A. M. (2009). *The post-high school outcomes of youth with disabilities up to 4 years after high school. A report of findings from the national longitudinal transition study-2 (NLTS2)(NCSE 2009-3017)*. Menlo Park, CA: SRI International. Retrieved from <http://ies.ed.gov/ncser/pubs/20103008/>

No Child Left Behind (NCLB) Act of 2001, P.L. 107-110, codified, as amended,
at 20 U.S.C.A. §§ 6301 *et seq.*

Noonan, P. M., Morningstar, M. E., & Erickson, A. (2008). Improving interagency collaboration. *Career Development for Exceptional Individuals, 31*(3), 132-143.

Noyes, D. A., & Sax, C. L. (2004). Changing systems for transition: Students, families, and professionals working together. *Education and Training in Developmental Disabilities, 39*(1), 35-44.

O'Brien, C. L., O'Brien, J., & Mount, B. (1997). Person-centered planning has arrived ... Or has it? *Mental Retardation, 35*(6), 480-484.

O'Connor, U. (2008). Meeting in the middle? A study of parent--professional partnerships. *European Journal of Special Needs Education, 23*(3), 253-268.

Office of Research, Evaluation and Statistics. (2003). Quarterly Report on SSI Disabled Workers and Work Incentive Provisions: March 2003. Washington, DC: Social Security Administration.

Oliver, M. (1992). Changing the social relations of research production? *Disability & Society, 7*(2), 101-114.

Olmstead v. L.C. & E.W., 527 U.S. 581 (1999).

Olson, K. (2010). An examination of questionnaire evaluation by expert reviewers. *Field Methods, 22*(4), 295-318.

Palmer, D. S., Borthwick-Duffy, S. A., Widaman, K., & Best, S. J. (1998). Influences on parent perceptions of inclusive practices for their children

- with mental retardation. *American Journal of Mental Retardation*, 103(3), 272-287.
- Palmer, D. S., Fuller, K., Arora, T., & Nelson, M. (2001). Taking sides. *Exceptional Children*, 67, 467-484.
- Perrin, B., & Nirje, B. (1985). Setting the record straight: A critique of some frequent misconceptions of the normalization principle. *Australia & New Zealand Journal of Developmental Disabilities*, 20, 141-157.
- Petry, K., & Maes, B. (2006). Identifying expressions of pleasure and displeasure by persons with profound and multiple disabilities. *Journal of Intellectual & Developmental Disability*, 31(1), 28-38.
- Petry, K., Maes, B., & Vlaskamp, C. (2009). Psychometric evaluation of a questionnaire to measure the quality of life of people with profound multiple disabilities (QOL-PMD). *Research in Developmental Disabilities*, 30(6), 1326-1336.
- Pfeiffer, D. (1993). Overview of the disability movement: History, legislative record, and political implications. *Policy Studies Journal*, 21(4), 724-734.
- Pfeiffer, D. (1994). Eugenics and disability discrimination. *Disability & Society*, 9(4), 481-499.
- Phillips, W. L., Callahan, M., Shumpert, N., Puckett, K., Petrey, R., Summers, K., & Phillips, L. (2009). Customized transitions: Discovering the best in us. *Journal of Vocational Rehabilitation*, 30(1), 49-55.
- Plimley, L. A. (2007). A review of quality of life issues and people with autism spectrum disorders. *British Journal of Learning Disabilities*, 35(4), 205-213.

- Polit, D.F., Beck, C.T., (2006). The content validity index: are you sure you know what's being reported? Critique and recommendations. *Research in Nursing & Health*, 29, 489–497.
- Polit, D.F., Beck, C.T., Owen, S.V., (2007). Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Research in Nursing & Health*, 30, 459–467.
- Portes, A. (1998). Social capital: Its origins and applications in modern sociology. *Annual Review of Sociology*, 24(1), 1-24.
- Powell, J. (2007). A comparison of learning outcomes for students with disabilities taught in three dissimilar classroom settings: Support services, team/collaborative, and departmental/pullout. Doctoral dissertation, Auburn University.
- Powers, K., Hogansen, J., Geenen, S., Powers, L. E., & Gil-Kashiwabara, E. (2008). Gender matters in transition to adulthood: A survey study of adolescents with disabilities and their families. *Psychology in the Schools*, 45(4), 349-364.
- Powers, K. M., Gil-Kashiwabara, E., Geenen, S. J., Powers, L. E., Balandran, J., & Palmer, C. (2005). Mandates and effective transition planning practices reflected in IEPs. *Career Development for Exceptional Individuals*, 28(1), 47-59.
- Powers, L. E., Turner, A., Westwood, D., Matuszewski, J., Wilson, R., & Phillips, A. (2001). TAKE CHARGE for the future: A controlled field-test of a model to promote student involvement in transition planning. *Career Development for Exceptional Individuals*, 24(1), 89-103.

- President's Committee for People With Intellectual Disabilities. (2004). *A charge we have to keep: A road map to personal and economic freedom for people with intellectual disabilities in the 21st century*. Washington, DC: U.S. Department of Health and Human Services.
- Rabren, K., Dunn, C., & Chambers D. (2002). Predictors of post high school employment among young adults with disabilities. *Journal of Career Development for Exceptional Individuals*, 25(1), 25–40.
- Rainforth, B., York, J., & MacDonald, C. (1997). *Collaborative teams for students with severe disabilities: Integrating therapy and educational services* (2nd ed.). Baltimore, MD: Brookes.
- Reiser, R. (2005). Disability equality: Confronting the oppression of the past. In M. Cole (Ed.) *Education, equality and human rights: Issues of gender, race, sexuality, disability and class*, (pp. 134-256). London, UK: Routledge.
- Repetto, J. B., Webb, K. W., Garvan, C. W., & Washington, T. (2002). Connecting student outcomes with transition practices in Florida. *Career Development for Exceptional Individuals*, 25(2), 123-139.
- Riddell, S., Wilson, A., & Baron, S. (2001). Gender, social capital and lifelong learning for people with learning difficulties. *International Studies in Sociology of Education*, 11(1), 3-24.
- Rogan, P., Grossi, T., Mank, D., Haynes, D., Thomas, F., & Majd, C. (2001). Changes in wage, hour, benefit, and integration outcomes of former sheltered workshop participants who are now in supported employment. *A Report for the President's Task Force on the Employment of Adults*

with Disabilities. Washington DC: The President's Task Force on the Employment of Adults with Disabilities.

Rogers, C., Lavin, D., Tran, T., Gantenbein, T., & Sharpe, M. (2008).

Customized employment: Changing what it means to be qualified in the workforce for transition-aged youth and young adults. *Journal of Vocational Rehabilitation*, 28(3), 191-207.

Ross, M. (2011). *Expert review form for the Transition Awareness & Possibilities Scale*. Unpublished instrument. Retrieved from <http://edu.surveymzmo.com/s3/597468/Transition-Awareness-Possibilities-Survey-2-0-for-Expert-Reviewers>

Ross, M. (2011). *Transition Awareness & Possibilities Scale*. Unpublished instrument.

Roy, S., & Casper, B. (2006). Preparing for employment: On the home front.

Parent brief. Minneapolis, MN: National Center on Secondary Education and Transition (NCSET), Parent Advocacy Coalition for Educational Rights Center (PACER), University of Minnesota.

Rude, H., Jackson, L., Correa, S., Luckner, J., Muir, S., & Ferrell, K. (2005).

Perceived needs of students with low-incidence disabilities in rural areas. *Rural Special Education Quarterly*, 24(3), 3-14.

Rusch, F. R. & Braddock, D. (2004). Adult day programs versus supported

employment (1988-2002): Spending and service practices of mental retardation and developmental disabilities state agencies. *Research and Practice for Persons with Severe Disabilities*, 29(4), 237-242.

- Rusch, F. R., & Wolfe, P. (2009). When will our values finally result in the creation of new pathways for change-change that we can believe in? *Research and Practice for Persons with Severe Disabilities*, 33(3), 96-97.
- Ryan, B. A., & Adams, G. R. (1999). How do families affect children's success in school. *Education Quarterly Review*, 6(1), 30-43.
- Ryndak, D. L., Downing, J. E., Morrison, A. P., & Williams, L. J. (1996). Parents' perceptions of educational settings and services for children with moderate or severe disabilities. *Remedial and Special Education*, 17(2), 106-118.
- Ryndak, D. L., Reardon, R., Benner, S. R., & Ward, T. (2007). Transitioning to and sustaining district-wide inclusive services: A 7-year study of a district's ongoing journey and its accompanying complexities. *Research and Practice for Persons with Severe Disabilities*, 32(4), 228-246.
- Ryndak, D. L., Ward, T., Alper, S., Montgomery, J. W., & Storch, J. F. (2010). Long-Term outcomes of services for two persons with significant disabilities with differing educational experiences: A qualitative consideration of the impact of educational experiences. *Education and Training in Autism and Developmental Disabilities*, 45(3), 323-338.
- Sax, C. L., & Thoma, C. A. (2002). *Transition Assessment: Wise Practices for Quality Lives*. Baltimore, MD: Brookes.
- Sabbatino, E. D., & Macrine, S. L. (2007). Start on success: A model transition program for high school students with disabilities. *Preventing School Failure*, 52(1), 33-39.

- Sadatsafavi, M., Najafzadeh, M., Lynd, L., & Marra, C. (2008). Reliability studies of diagnostic tests are not using enough observers for robust estimation of interobserver agreement: a simulation study. *Journal of Clinical Epidemiology, 61*(7), 722–727.
- Salisbury, C. (2006). Principals' perspectives on inclusive elementary schools. *Research and Practice for Persons with Severe Disabilities, 31*, 70-82.
- Schalock, R. L. (2004). The concept of quality of life: What we know and do not know. *Journal of Intellectual Disability Research, 48*(3), 203-216.
- Schalock, R. L., Bonham, G. S., & Marchand, C. B. (2000). Consumer based quality of life assessment: A path model of perceived satisfaction. *Evaluation and Program Planning, 23*(1), 77-87.
- Schalock R. L. & Verdugo M. (2002). *Handbook on quality of life for human service practitioners*. Washington DC: American Association on Mental Retardation.
- Schuster, J. L., Timmons, J. C., & Moloney, M. (2003). Barriers to successful transition for young adults who receive SSI and their families. *Career Development for Exceptional Individuals, 26*(1), 47-66.
- Section 1915 of Title XIX of the Social Security Act of 1965, codified, as amended at 42 U.S.C. 1396 §§ 1915 *et seq.*
- Section 504 of the Rehabilitation Act of 1973, P.L. 93-112, codified, as amended, at 29 U.S.C. §§ 701 *et seq.*
- Shapiro, J., Monzó, L. D., Rueda, R., Gomez, J. A., & Blacher, J. (2004). Alienated advocacy: Perspectives of Latina mothers of young adults with developmental disabilities on service systems. *Mental Retardation, 42*(1),

37-54.

- Sheppard-Jones, K., Thompson Prout, H., & Kleinert, H. (2005). Quality of life dimensions for adults with developmental disabilities: A comparative study. *Mental Retardation, 43*(4), 281-291.
- Singer, G. H. S. (2002). Suggestions for a pragmatic program of research on families and disability. *The Journal of Special Education, 36*(3), 150-156.
- Sitlington, P. L. (1996). Transition to living: The neglected component of transition programming for individuals with learning disabilities. *Journal of Learning Disabilities, 29*(1), 31-39.
- Sitlington, P. L., & Clark, G. M. (2006). *Transition education and services for students with disabilities* (4th ed.). Boston, MA: Allyn & Bacon.
- Sitlington, P. L., Neubert, D. A., & LeConte, P. J. (1997). Transition assessment: The position of the Division on Career Development and Transition. *Career Development for Exceptional Individuals, 20*(1), 69-79.
- Smart, M. (2004). Transition planning and the needs of young people and their carers: The alumni project. *British Journal of Special Education, 31*(3), 128-137.
- Smyth, M., & McConkey, R. (2003). Future aspirations of students with severe learning disabilities and of their parents on leaving special schooling. *British Journal of Learning Disabilities, 31*(1), 54-59.
- Spann, S. J., Kohler, F. W., & Soenksen, D. (2003). Examining parents' involvement in and perceptions of special education services: An interview with families in a parent support group. *Focus on Autism and Other Developmental Disabilities, 18*(4), 228-237.

- Stewart, D. (2009). Transition to adult services for young people with disabilities: Current evidence to guide future research. *Developmental Medicine & Child Neurology*, 51(4), 169-173.
- Stoner, J. B., & Angell, M. E. (2006). Parent perspectives on role engagement: An investigation of parents of children with ASD and their self-reported roles with education professionals. *Focus on Autism and Other Developmental Disabilities*, 21(3), 177-189.
- Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M. E., Heyl, B. S., & Crowley, E. P. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and education professionals. *Focus on Autism and Other Developmental Disabilities*, 20(1), 39-51.
- Storms, J., O'Leary, E., & Williams, J. (2000). *Transition requirements: A guide for states, districts, schools, universities and families*. Western Regional Resource Center, College of Education, University of Oregon.
- Swain, J., & Walker, C. (2003). Parent-professional power relations: Parent and professional perspectives. *Disability & Society*, 18(5), 547-560.
- Tarleton, B., & Ward, L. (2005). Changes and choices: Finding out what information young people with learning disabilities, their parents and supporters need at transition. *British Journal of Learning Disabilities*, 33(2), 70-76.
- Taylor, S. J. (1988). Caught in the continuum: A critical analysis of the principle of the least restrictive environment. *Journal of The Association for Persons with Severe Handicaps*, 13(1), 41-53.

- Test, D. W., Fowler, C., Kohler, P., & Korterling, L. (2010). Evidence-based practices and predictors in secondary transition: What we know and what we still need to know. Charlotte, NC: National Secondary Transition Technical Assistance Center.
- Thoma, C. A., Held, M. F., & Saddler, S. (2002). Transition assessment practices in Nevada and Arizona. *Focus on Autism and Other Developmental Disabilities, 17*(4), 242-250.
- Thoma, C. A., Rogan, P., & Baker, S. R. (2001). Student involvement in transition planning: Unheard voices. *Education and Training in Mental Retardation and Developmental Disabilities, 36*(1), 16-29.
- Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability & Society, 19*(6), 569-583.
- Thompson, J. R., Fulk, B. M., & Piercy, S. W. (2000). Do individualized transition plans match the postschool projections of students with learning disabilities and their parents? *Career Development for Exceptional Individuals, 23*(1), 3-25.
- Timmons, J. C., Whitney-Thomas, J., McIntyre Jr, J. P., Butterworth, J., & Allen, D. (2004). Managing service delivery systems and the role of parents during their children's transitions. *The Journal of Rehabilitation, 70*(2), 19-27.
- Townsley, R. (2004). *The Road Ahead? Literature Review: What Does the Literature Tell Us About the Information Needs of Young People with Learning Difficulties and Their Families at Transition*. London, UK: Social Care Institute for Excellence. Retrieved from www.scie.org.uk/

publications/tra

- Trainor, A. A. (2008). Using cultural and social capital to improve postsecondary outcomes and expand transition models for youth with disabilities. *The Journal of Special Education, 42*(3), 148-162.
- Trainor, A. A. (2010). Diverse approaches to parent advocacy during special education homeschool interactions. *Remedial and Special Education, 31*(1), 34-47.
- Turnbull, A., & Turnbull, R. (2006). Self-determination: Is a rose by any other name still a rose? *Research and Practice for Persons with Severe Disabilities, 31*(1), 83-88.
- Ubersax, J. (2006). *Interclass correlation and related methods*. Retrieved from <http://www.john-uebersax.com/stat/icc.htm>
- Vaden-Kiernan, N. (2005). Parents' reports of school practices to provide information to families: 1996 and 2003. *Statistics in Brief*. Washington, DC: Institute of Education Sciences, U.S. Department of Education.
- Vehmas, S. (2004). Ethical analysis of the concept of disability. *Mental Retardation, 42*(3), 209-22.
- Wagner, M., Newman, L., Cameto, R., Garza, N., & Levine, P. (2005). After high school: A first look at the postschool experiences of youth with disabilities. A report from the national longitudinal transition study-2 (NLTS2). Menlo Park, CA: SRI international.
- Walpole, M. B. (2003). Socioeconomic status and college: How SES affects college experiences and outcomes. *The Review of Higher Education, 27*(1), 45-73.

- Ward, M. J. (2005). An historical perspective of self-determination in special education: Accomplishments and challenges. *Research and Practice for Persons with Severe Disabilities, 30*(3), 108-112.
- Ward, M. J. (2006). Self-Determination and special education: Lessons learned and challenges to address. *TASH Connections, 32*(5/6). Retrieved from <http://tash.org/express/06mayjun/ward.htm>
- Watts, M. O. (2011). *Money Follows the Person: A 2010 Snapshot*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured. Retrieved from <http://www.kff.org/medicaid/8142.cfm>
- Wehman, P. (2006). Integrated employment: If not now, when? If not us, who? *Research and Practice for Persons with Severe Disabilities, 31*(2), 122-126.
- Wehman, P. (2006). *Life Beyond the Classroom: Transition Strategies for Young People with Disabilities* (4th ed.). Baltimore, MD: Brookes.
- Wehman, P., Moon, M., Everson, J., Wood, W., & Barcus, J. (1988). *Transition from school to work: New challenges for youth with severe disabilities*. Baltimore, MD: Brookes.
- Wehman, P., & Revell, G. (2005). Lessons learned from the provision and funding of employment services for the MR/DD population. *Journal of Disability Policy Studies, 16*(2), 84-101.
- Wehman, P., Revell, G., & Kregel, J. (1998). Supported employment: A decade of rapid growth and impact. *American Rehabilitation, 24*(1), 31-43.

- Wehmeyer, M. L., Agran, M., & Hughes, C. (1998). *Teaching self-determination to students with disabilities: Basic skills for successful transition*. Baltimore, MD: Brookes.
- Wehmeyer, M. L., Agran, M., & Hughes, C. (2000). A national survey of teachers' promotion of self-determination and student-directed learning. *The Journal of Special Education, 34*(2), 58-68.
- Wehmeyer, M., Bersani, H., & Gagne, R. (2000). Riding the third wave: Self-Determination and self-advocacy in the 21st century. *Focus on Autism and Other Developmental Disabilities, 15*(2), 106-115.
- Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three-years after high school: The impact of self-determination. *Education and Training in Developmental Disabilities, 38*(2), 131-144.
- Wehmeyer, M., & Schwartz, M. (1997). Self-Determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. *Exceptional Children, 63*(2), 245-255.
- Weir, C. (2004). Person-centered and collaborative supports for college success. *Education and Training in Developmental Disabilities, 39*(1), 67-73.
- Wenzlow, A.T. & Lipson, D. J. (2009). Transitioning Medicaid enrollees from institutions to the community: Number of people eligible and number of transitions targeted under MFP. *National Evaluation of the Money Follows the Person (MFP) Demonstration Grant Program: Reports from the Field*. Princeton, NJ.: Mathematica Policy Research.

- Westling, D. L. (1997). What parents of young children with mental disabilities want. *Focus on Autism and Other Developmental Disabilities*, 12(2), 67-78.
- White, G. W., Lloyd Simpson, J., Gonda, C., Ravesloot, C., & Coble, Z. (2010). Moving from independence to interdependence: A conceptual model for better understanding community participation of centers for independent living consumers. *Journal of Disability Policy Studies*, 20(4), 233-240.
- Whitney-Thomas, J., & Hanley-Maxwell, C. (1996). Packing the parachute: Parents' experiences as their children prepare to leave high school. *Exceptional Children*, 63, 357-372.
- Whitney-Thomas, J., Shaw, D., Honey, K., & Butterworth, J. (1998). Building a future: A study of student participation in person-centered planning. *The Journal of the Association for Persons with Severe Handicaps*, 23(2), 119-133.
- Wiener, J.M. & Anderson, W.L. (2009). *Follow the money: Financing home and community-based services*. Pittsburgh: Pennsylvania Medicaid Policy Center, University of Pittsburgh. Retrieved from http://www.pamedicaid.pitt.edu/documents/Homecare_rp_09.pdf
- Williams, J. M., & O'Leary, E. D. (2001). What we've learned and where we go from here. *Career Development for Exceptional Individuals*, 24(1), 51-71.
- Wittenburg, D. C., Golden, T., & Fishman, M. (2002). Transition options for youth with disabilities: An overview of the programs and policies that affect the transition from school. *Journal of Vocational Rehabilitation*, 17(3), 195-206.

- Wittenburg, D. C., & Maag, E. (2002). School to where? A literature review on economic outcomes of youth with disabilities. *Journal of Vocational Rehabilitation, 17*(4), 265-280.
- Woods, P.A., Bagley, C. and Glatter, R. (1998). *School choice and competition: Markets in the public interest?* London, UK: Routledge.
- Woolley, J.T. and Peters, G. (n.d.) The American Presidency Project [online]. Santa Barbara, CA. Retrieved from <http://www.presidency.ucsb.edu/ws/?pid=9886>
- Workforce Investment Act of 1998, P.L. 105-220, codified as amended at 29 U.S.C. §§ 2801 *et seq.*
- Wright, A., Hiebert-Murphy, D., & Trute, B. (2010). Professionals' perspectives on organisational factors that support or hinder the successful implementation of family-centered practice. *Journal of Family Social Work, 13*(2), 114-130.
- Yagamahle, F. (2003). Content validity and its estimation. *Journal of Medical Education, 3*(1), 25-27.
- Zhang, D. (2005). Parent practices in facilitating self-determination skills: The influences of culture, socioeconomic status, and children's special education status. *Research and Practice for Persons with Severe Disabilities, 30*(3), 154-162.
- Zhang, D., Ivester, J. G., Chen, L. J., & Katsiyannis, A. (2005). Perspectives on transition practices. *Career Development for Exceptional Individuals, 28*(1), 15-25.

Zhang, D., Katsiyannis, A., & Zhang, J. (2002). Teacher and parent practice on fostering self-determination of high school students with mild disabilities.

Career Development for Exceptional Individuals, 25(2), 157-169.

Zhang, D., Wehmeyer, M. L., & Chen, L. J. (2005). Parent and teacher engagement in fostering the self-determination of students with disabilities. *Remedial and Special Education*, 26(1), 55-64.