

A Collaborative Interagency, Interdisciplinary Approach to Transition from Adolescence to Adulthood



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Purpose

This paper was written for and by directors and staff of the networks of University Centers for Excellence in Developmental Disabilities Centers and the Leadership Education in Neurodevelopmental Disabilities programs. It is intended for faculty, staff, trainees, individuals with disabilities, and family members in these two networks as well as policy makers and partners in local and state disability organizations and agencies. The paper aims to promote a dialogue among key stakeholders and to facilitate their engagement in pursuing a more comprehensive, coordinated, supportive, and successful transition process for youth with disabilities from adolescence to young adulthood.

A shorter version, oriented for self-advocates, is being developed.

EXECUTIVE SUMMARY

As youth with intellectual and developmental disabilities (IDD) leave school, they face several transitions including school to work or postsecondary education, family home to community living, and child oriented health care to adult care. Youth should be able to expect self-determined transitions with coordinated support from family, community, professionals, and agencies, but they and their families often experience very little choice, control, or collaboration from the myriad of systems to which they look for support and services for transition.

Multiple barriers stand in the way of a coordinated approach to supporting all aspects of successful transition to adulthood. These barriers include failing to support self-determination as a central element of the person-centered process of transition; insufficient understanding of the role of culture in an individual or family's concept or approach to transition; the tendency for professionals within each transition domain (education, health, community living, employment, others) to use language that is not easily understood by other professionals, youth, families, or other community partners; and neglecting to specifically explore how transition in the different realms could/should be linked for maximizing success.

To that end, this paper promotes four core concepts that are essential to the development and implementation of effective transition plans and process.

1. Self-determination should be the foundation for transition planning.

Promoting the self-determination of adolescents with disabilities has become best practice in secondary education and transition services (Wehmeyer, Agran, Hughes, Martin, Mithaug, & Palmer, 2007). Self-determination status has been linked to the attainment of more positive transition outcomes, including more positive employment and independent living (Martorell, Gutierrez-Rechacha, Pereda, & Ayuso-Mateos, 2008; Wehmeyer, & Palmer, 2003; Wehmeyer & Schwartz, 1997) and recreation and leisure outcomes (McGuire & McDonnell, 2008), and more positive quality of life and life satisfaction (Wehmeyer & Schwartz, 1998; Lachapelle et al., 2005; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Shogren, Lopez, Wehmeyer, Little, & Pressgrove, 2006).

There are numerous curricular and instructional models identified to enable teachers to provide an instructional focus on self-determination (Wehmeyer & Field, 2007). Algozzine, Browder, Karvonen, Test, and Wood (2001) found evidence for the efficacy of instruction to promote component elements of self-determined behavior, including interventions to promote self-advocacy, goal setting and attainment, self-awareness, problem-solving skills, and decision-making skills. These include the *Self-Determined Learning Model of Instruction*, *TAKE CHARGE for the Future*, and other student involvement programs, *The Self-Directed IEP*, and *Whose Future is it Anyway?*. Recent research has provided causal evidence of the importance of

self-determination for students to achieve positive transition outcomes. Shogren, Wehmeyer, Palmer, Rifenbark, and Little (2012) investigated the relationships among self-determination interventions during high school, self-determination status when leaving school, and adult outcomes one and two years after leaving school. Results indicated that self-determination status at the end of high school predicted significantly more positive employment, career goal, and community access outcomes.

2. Transition should be viewed through a cultural lens.

Culture defines the values, beliefs, and practices surrounding when and how youth transition to adulthood. Culture influences the beliefs and practices of families and youth about transition within the contexts of health care, employment, postsecondary education, and independent living. There are several key issues that should be considered.

- *There are significant racial and ethnic disparities in transition services and outcomes.* Hispanic and non-Hispanic Black youth ages 12-17 are significantly less likely than non-Hispanic White youth to have received services needed for transition to adult health care, work, and independence (Child and Adolescent Measurement Initiative, 2006).
- *Transition services and outcomes generally reflect the values of individualism and independence vs. collectivism and interdependence.* Most transition policies, practices, and services may assume that all youth with disabilities or special health care needs and their families value such individual oriented outcomes as self-determination, self-reliance, and independent living. These outcomes may not reflect those of cultural groups, individuals, and families who value collectivism. Individualistic cultures view the process of development for youth as moving from dependence to independence and self-reliance. In contrast, collectivistic cultures see development as moving from dependence to interdependence (Ewalt and Mokuau, 1995).
- *Self-determination is a cultural construct.* The concept of self-determination may be viewed and practiced very differently across cultures (Zhang, 2005). For some youth and families, a goal of individual choice may conflict with cultural values that support group or hierarchical decision-making.

Cultural and linguistic competence must be embedded into all transition services.

3. Interagency collaboration is essential to effective transition.

Interagency coordination and planning is one of the critical elements of transition planning. Noonan, Morningstar, & Erickson (2008) conducted a detailed review and analysis of state and local practices in 29 high performing school districts. Strategies for interagency collaboration were identified that emphasized a complex inter-related system of staffing, support, knowledge building (i.e., training, technical assistance),

relationships, and funding. The strategies identified often required collaboration at both the local and state levels to be successful. Thus, a critical dimension of successful interagency collaboration is the interplay between multiple local and state systems. Typical transition planning teams need to be expanded to include all disciplines and agencies that will impact the life of the person with a disability.

In a comprehensive review of federally funded state programs that support transition, the U.S. Government Accountability Office (2012) found that students with disabilities face systemic barriers as they transition from the entitlement system of special education to the multiple eligibility-driven adult systems. Students and their families may not have sufficient information about the services or options available to them. Consequently, there may be a delay in applying for, and receiving, needed services like job supports, tutoring, or assistive technology. From the agency perspective, the differences in statutory eligibility criteria, lack of common outcomes or common policies for operating across agencies hinders interagency coordination and influences student success at achieving post-school outcomes.

4. Transition planning should include all the perspectives, disciplines, and organizations that will impact the transitioning student.

Perspectives and Issues	Effective Practices
The voice of the transitioning student should be central to the planning process.	Implement a student involvement curriculum (e.g., <i>Self-Directed IEP</i> ; <i>Whose Future is it Anyway?</i>) in preparing students for transition planning.
Self-Determination Students need to increase their ability to self-determine.	Secondary schools should implement of the evidence based self-determination curriculum models (<i>Self-Determined Learning Model of Instruction</i> ; <i>Take Charge for the Future</i>).
Cultural and linguistic competence must be an integral component of all transition services.	Understand the cultural beliefs and practices of the student's family and community. Staff are speaking languages other than English are available to family and youth to discuss their needs and preferences for services.

Perspectives and Issues	Effective Practices
<p>Students and families need accurate information about the range of opportunities and supports available to them.</p> <p>Many families and students report not being prepared for adult life.</p>	<p>Transition planning should begin early and should be person-centered and student-focused.</p> <p>Using navigators helps students and families to understand support systems and service options and to develop specific strategies for implementing transition plans.</p>
<p>Health Care Transition</p> <p>Family members and young adults encounter late preparation for the transition to the adult health care system, have little knowledge about how to navigate the adult health care system, and have difficulty with identifying a new primary care provider and specialists in the adult health care system.</p> <p>Pediatric health care providers face issues such as little time for transition care, lack of reimbursement for transition support, concern that the young adult will not receive the same level of care in the adult health system, lack of adult providers and specialists in the young adult's home community, and little knowledge about community resources that might benefit the young adult and family.</p>	<p>Start the transition process around 12 to 14 years of age; be familiar with eligibility criteria for services, treatments, and equipment in the adult service system; be familiar with health care insurance changes; initiate the identification of a future adult health care provider early; encourage youth to assume an active role in decision making and assume responsibility for interventions.</p> <p>Health care providers should initiate the transition process to adult primary and specialty care around 12 to 14 years of age; develop a transition plan with the youth and his/her family; provide families and youth with health care transition resources; prepare and share a portable medical summary.</p>
<p>Transition Assessments are often limited in scope.</p>	<p>Transition assessment data should include results of self-determination and career assessments, occupational and assistive technology assessments, community-based vocational assessments, adaptive behavior assessments, and family and student interview data.</p>

Perspectives and Issues	Effective Practices
<p>Transition to Employment</p> <p>The number of individuals with disabilities who participate in individual, integrated employment is very low.</p>	<p>Integrate transition assessment activities including career exploration and development into the core curriculum. Promote the expectation that employment is the first option.</p> <p>Provide a variety of volunteer, unpaid, and paid internships (including summer employment) beginning no later than age 14 and continuing until permanent paid employment is obtained.</p> <p>Include in the IEP vocational and career-related goals that result in vocational and career services associated with paid work.</p>
<p>Transition to Postsecondary Education</p> <p>The number of individuals with disabilities who participate in inclusive postsecondary education opportunities is very low, especially for students with intellectual disabilities.</p>	<p>Plan person-centered transition services for high school students as they pursue postsecondary education.</p> <p>Support students with IDD in planning and facilitating their own person-centered meeting.</p> <p>Provide instruction for the educational coaches. Recruit faculty and peers to support students in inclusive college experiences.</p>
<p>Transition to Community Living</p> <p>Young adults need a place to live and work; skills to manage their living environment and navigate their community; self-care skills to ensure safety and personal health; to be included in community activities of their interest; a social network of friends, family members, and allies that support them; and opportunities to participate in leisure/recreation activities.</p>	<p>Youth and adults who receive community living supports have continued needs even when they are receiving supports. Communities and service planners need to anticipate these needs and ensure that the staff providing community living support are trained and equipped with the right competencies to facilitate positive and desired community living outcomes.</p> <p>A comprehensive transition plan should include all of these dimensions and employ effective instructional strategies.</p>

Perspectives and Issues	Effective Practices
<p>Housing</p> <p>Although there are many housing options, people with disabilities are more likely to rent their home than people without disabilities. Most individuals with intellectual disabilities live with family members.</p> <p>There are many barriers to housing, ranging from poverty to racial discrimination.</p> <p>People with disabilities often need basic home modifications to make their homes accessible.</p>	<p>Consider and identify future or current housing options during the IEP and/or person-centered planning process.</p> <p>Examine how public benefits and subsidies impact housing options.</p>
<p>Transportation</p> <p>Difficulty in finding accessible transportation is one of the most common issues experienced by people with disabilities.</p>	<p>Develop a multi-tiered approach to transportation education including (a) orienting students to public transportation, (b) developing customized transportation as needed, and (c) providing individualized travel training.</p>
<p>Technology</p> <p>Technology is a means to increase productivity, communicate, or to simplify a complex task. Assistive technologies (AT) are those that enable individuals to gain, maintain or regain independence.</p>	<p>Seek and use AT as early as possible in a child's development. Ensure access to essential AT. Seek innovative funding arrangements that allow technology to be used in all environments in which the individual interacts.</p> <p>Take advantage of mainstream technology. Get it. Use it. Figure it out.</p>

Policy Implications

This paper outlines many of the beliefs, values, and principles that are commonly shared by policy-makers, professionals, parents, and young people themselves. From a policy perspective, these beliefs, values, and principles are intended to: (a) guide and inform policy-makers as to the importance of inclusion and community integration at all levels and in all facets of community life; (b) lead to federal and state policies that promote positive transition outcomes; (c) ensure that transition-related statutory and policy development is driven by an underlying belief of high expectations for all youth; (d) ensure that policies focused on transition planning and the provision of services are based on self-determination and person-centered approaches; (e) ensure

that policies address the cultural and linguistic diversity of youth with disabilities and their families when designing and implementing transition programs and services; and (f) ensure that federal, state, and local policies are intended to achieve positive transition outcomes and promote interagency coordination and the provision of a unified, flexible array of programs, services, accommodations, and supports.

INTRODUCTION

This paper has been produced by Association of University Centers on Disabilities (AUCD) members who seek to start a conversation about improving interdisciplinary and interagency collaboration in supporting self-determined transition of youth with intellectual and developmental disabilities (IDD) to adulthood and to community life. It is the first step on a path toward improving the transition process for youth in a manner that improves adult outcomes.

Youth with IDD should be able to expect self-determined transitions with coordinated support from family, community, professionals, and agencies. But they and their families often experience very little coordination and collaboration from the myriad of systems to which they look for support and services for transition.

What stands in the way of a coordinated approach to supporting all realms of successful transition to adulthood (school to work or post-secondary education; family home to community living; and child-oriented health care systems to adult systems)? Some of the factors to consider are: failing to support self-determination as a central element of the person-centered process of transition; insufficient understanding of the role of culture in an individual or family's concept or approach to transition; the tendency for professionals within each realm of transition (education, health, community living, employment, others) to use language that is not easily understood by other professionals, youth, families, or community partners; and neglecting to specifically explore how transition

in the different realms could/should be linked for maximizing success.

The separation between the transition “silos” may be especially exaggerated in local services, state agencies, and academic settings where departmental and programmatic barriers, differing regulations, and eligibility criteria are often formidable. University Centers for Excellence in Developmental Disabilities (UCEDDs) and Leadership Education in Neurodevelopmental and Related Disabilities Programs (LENDs), all members of AUCD, are well situated to facilitate communication across agencies, schools, and other providers as they are accustomed to blending resources and have had extensive experience working with interdisciplinary academic departments and community partners. Transition experts from UCEDDs and LENDs across the country are eager to collaborate in breaking down the barriers to collaborative support for transition in response to the well-documented transition needs of youth with IDD. The ongoing process to achieve an interdisciplinary and interagency approach to collaboration will include participation from all involved: youth with IDD, families, professionals from multiple disciplines, community agencies and other community-based partners, and local and state policy makers.

This paper summarizes key evidence and recommendations related to the various transition realms. The transition paradigm described in this paper is based on four concepts:

- Self-determination is the unifying principle that connects all disciplines and agencies involved in the transition process.
- There are multiple perspectives about transition. A comprehensive approach to transition should understand each of these perspectives and integrate them into a holistic paradigm.
- Culture should be considered when designing and implementing transition strategies.
- Interagency collaboration, both at the system level and at the individual level, is the foundation for effective practice.

The sections of this paper are organized around these concepts.

SELF-DETERMINATION AND TRANSITION

Promoting the self-determination of adolescents with disabilities has become best practice in secondary education and transition services (Wehmeyer, Agran, Hughes, Martin, Mithaug, & Palmer, 2007) for several reasons. First, self-determination status has been linked to the attainment of more positive transition outcomes, including more positive employment and independent living (Martorell, Gutierrez-Rechacha, Pereda, & Ayuso-Mateos, 2008; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997) and recreation and leisure outcomes (McGuire & McDonnell, 2008), and more positive quality of life and life satisfaction (Wehmeyer & Schwartz, 1998; Lachapelle et al., 2005; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Shogren, Lopez, Wehmeyer, Little, & Pressgrove, 2006). Second, research across special education disability categories has established the need for intervention to promote self-determination, documenting that students with intellectual disability (Wehmeyer & Metzler, 1995), learning disabilities (Field, Sarver, & Shaw, 2003; Pierson, Carter, Lane, & Glaeser, 2008), emotional and behavioral disorders (Carter, Lane, Pierson, & Glaeser, 2006; Pierson et al., 2008), and autism spectrum disorders (Ward & Meyer, 1999;

Wehmeyer & Shogren, 2008) are less self-determined than their non-disabled peers.

Third, there are numerous curricular and instructional models identified to enable teachers to provide an instructional focus on self-determination (Wehmeyer & Field, 2007). In a meta-analysis of single subject and group subject design studies, Algozzine, Browder, Karvonen, Test, and Wood (2001) found evidence for the efficacy of instruction to promote component elements of self-determined behavior, including interventions to promote self-advocacy, goal setting and attainment, self-awareness, problem-solving skills, and decision-making skills. Cobb, Lehmann, Newman-Gonchar, and Alwell (2009) conducted a narrative metasynthesis—a narrative synthesis of multiple meta-analytic studies—covering seven existing meta-analyses examining self-determination and concluded that there is sufficient evidence to support the promotion of self-determination as effective. Several instructional processes have causal evidence as a function of randomized trial studies of their impact. Shogren, Palmer, Wehmeyer, Williams-Diehm, and Little (in press) and Wehmeyer, Shogren, Palmer, Williams-Diehm, Little, and Boulton (2012) conducted a

randomize-trial study of the efficacy of the *Self-Determined Learning Model of Instruction*, determining that students who received instruction with this model had enhanced self-determination, access to the general education curriculum, and transition and academic goal attainment when compared to their peers who did not receive such instruction. Powers et al. (2012) conducted a longitudinal, randomized study of the efficacy of the *TAKE CHARGE for the Future* intervention with youth in foster care receiving special education services. Students in the treatment group showed higher levels of self-determination, quality of life, and utilization of community transition services. Also, research documents the positive impact of efforts to promote student involvement in educational and transition planning (Martin, Van Dycke, Christensen, Greene, Gardner, & Lovett, 2006; Mason, Field, & Sawilowsky, 2004; Test, Mason, Hughes, Konrad, Neale, & Wood, 2004) on more positive transition and self-determination related outcomes. Two student involvement programs, the *Self-Directed IEP* (Martin et al., 2006) and *Whose Future is it Anyway?* (Palmer, Wehmeyer, Shogren, Williams-Diehm, & Soukup, 2012) have casual evidence of their efficacy to promote self-determination and greater student involvement.

Finally, recent research has provided causal evidence of the importance of self-determination for students to achieve more positive transition outcomes. Wehmeyer, Palmer, Shogren, Williams-Diehm, and Soukup (in press) conducted a randomized trial control group study of the effect of interventions to promote self-determination on the self-determination of high school students receiving special

education services under the categorical areas of intellectual disability and learning disabilities. Students in the treatment group (n=235) received instruction using a variety of instructional methods to promote self-determination and student involvement in educational planning meetings over three years, while students in the control group (n=132) received no such intervention. The self-determination of each student was measured using two instruments across three measurement intervals. Wehmeyer and colleagues found that students with cognitive disabilities who participated in interventions to promote self-determination over a three-year period showed significantly more positive patterns of growth in their self-determination scores than did students not exposed to interventions to promote self-determination.

In a two-year follow-up study of the treatment and control group students in the Wehmeyer et al (in press) study, Shogren, Wehmeyer, Palmer, Rifenbark, & Little (2012) further investigated the relationships among self-determination interventions during high school, self-determination status when leaving school, and adult outcomes one and two years after leaving school. The survey used included questions related to employment, community access, financial independence, independent living, and life satisfaction. Results indicated that self-determination status at measurement time 1 (end of high school) predicted significantly more positive employment, career goal, and community access outcomes, with students who were self-determined scoring significantly higher in all of these areas. In essence, this study provided causal evidence that promoting self-determination results in enhanced

self-determination, and that enhanced self-determination results in more positive

adult outcomes, including employment, career goals, and community access.



PERSPECTIVES ON TRANSITION

Transition occurs across multiple life dimensions; therefore, comprehensive planning must be multidimensional. Planning to support successful transitions must take into account multiple perspectives, the most central of which is that of youth and families. A discussion of the perspective of youth and families is followed by consideration of other essential aspects of transition: healthcare transition, age-appropriate education transition assessment,

transition to employment and to secondary education, transportation as an essential support for transition, and transition to community living. The intent of this section is to describe some of the perspectives that influence the transition process and to identify important considerations and effective practices.

The Perspective of Youth and Families

“I would like to live with my aunt who has provided me with the care that no one else has been able to do. I plan to find a part-time paying job. I would like to spend the rest of my days going to the gym to keep up my health, doing recreational activities in the community, and being part of my social community. I can only do these things if I have wheelchair transportation, a job coach, and a nurse to meet my medical needs.”

Quote from a letter from a youth with IDD to an agency administrator

“When my daughter was transitioning from high school to adult life, I expected assistance in planning ways that my daughter could function with support in various adult roles – work, recreation, continued learning, contributing and engaging in her household and community. I expected that the various entities that were involved with her support (school, in home supports, adult agencies such as VR and DDD) would collaborate together to design supports that would help her reach her unique adult goals. I expected to have good, complete, and understandable information about all support options and that options would be available that would take into consideration her voice (as represented by those who knew her best). I expected that supports would be available in her own community in places of her choosing (work, recreation, home, etc.) and that she would not be required to go to segregated or congregate settings in

order to receive support the support she needs. I had to go digging for much of the information I needed. What I needed most was a guide.”

Quote from a mother whose daughter has recently experienced transition

“All families want information and planning processes that are clear, simple, and individualized. Families and individuals want choice and control – their own voices primary in design of services – rather than decisions made arbitrarily by others. Some families put primacy on safety over expanded experience for their young adults; but by and large, families of individuals with intellectual disabilities want what any family wants for their young adult – health, happiness, ways to engage with their world meaningfully, some chance to socialize and have friends, meaningful relationships. They are looking for the ways and means of supporting these goals for their young adults.”

Quote from a community supports navigator

Youth with IDD have many of the same expectations for the future as do other adolescents. The National Longitudinal Transition Study (Wagner, Newman, Cameto, Levine, & Marder; 2007) documented that 85% of youth definitely expect to graduate from high school with a diploma, but only 52% expect to attend a postsecondary school. 95% definitely expect they will get a paid job, but only 65% expect that they will be financially self-sufficient. 72% definitely expect to live away from home without supervision and 16% expect to live away from home with supervision. Parental expectations are somewhat lower – 60% expect their

family member to graduate from high school with a regular diploma, 29% to attend a postsecondary school, 88% to get a paid job, 47% to be financially self-sufficient, and 54% to live away from home with supervision. Similarly, youth with intellectual disabilities have somewhat lower expectations—74% definitely expect to graduate from high school with a regular diploma, 38% to attend a postsecondary school, 86% to get a paid job, 37% to be financially self-sufficient, and 49% to live away from home with supervision.

Although overall parents have positive expectations about their child's school experience, the level of satisfaction decreases as the student ages. 21% of families are dissatisfied with their child's school experience at the secondary level (NLTS Fact Sheet, 2005). Antosh (2002) interviewed 563 adolescents and young adults (ages 15-23) with disabilities about their school and post school experiences. The sample consisted of youth who graduated high school with a diploma and youth who did not graduate. 48% of youth who graduated reported that their school experience prepared them for employment, 27% for post-secondary education, 39% for living in a residence, 47% to make friends, 39% to get around the community, and 57% to use financial tools. The percentages were lower for youth who did not graduate. 76% of the graduates reported having plans for next year and 68% reported having plans for the future. Graduates who participated actively in IEPs, met with school personnel to prepare for IEPs, and participated in a person-centered planning process reported more positive post school outcomes than those who did not. In a similar set of parent interviews

(Antosh, 2002), more than 90% of families of transition-aged students reported needing information on adult service systems (including housing, employment, post-secondary education, and health) and more than 70% reporting needing information on planning for effective transition, guardianship, and creating a positive vision for their family member's future. The National Core Indicators (NCI) Annual Summary Report for 2010-2011 documents that 47% of respondents in a survey of families/guardians of individuals with intellectual and developmental disabilities reported receiving sufficient information to plan services and 53% reported that the information they received was easy to understand.

Thus, although expectations of youth with disabilities are similar to the expectations of other youth, both youth and families report needing additional information and school experiences that prepare them for adult life. Certain practices have proven effective in helping youth and families to plan meaningful transitions.

- Student focused transition planning has proven effective in improving the transition outcomes of youth with disabilities (Cobb & Alwell, 2009).
- Person-centered planning can strengthen transition by enhancing the quality of assessment and planning, by fostering relationships between parents and professionals, and by providing a process through which multiple agencies can coordinate activities (NCSET Parent Brief, 2004).
- Disability Navigators are defined as “assisting youth in accessing services from various governmental agencies and community-based organizations. The Disability Navigators seek to

fill gaps in existing services by solving system shortcomings and ensuring that the various programs serve participants appropriately when considered from a holistic perspective” (*Colorado Youth Transition Demonstration Project* in Martinez et al, 2008). The use of Family Navigators has proven effective in increasing parent knowledge and future orientation (Kingsnorth, Gall, Beayni, & Rigby, 2011) and in increasing family knowledge of support systems and service options and in developing specific strategies for implementing person-centered plans (Rosenbaum, 2009).

- As cited earlier, increasing self-determination results in more positive adult outcomes, including employment, career goals, and community access.

Healthcare Transition

Background

Healthcare transition is “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (Blum, Garell, Hodgman, Jorissen, Okinow, Orr, & Slap, 1993). Its purpose is to maximize lifelong functioning and potential of the youth/young adult by providing high-quality, developmentally appropriate, and uninterrupted health care services (American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), & American College of Physicians (ACP), 2002). Health care transition needs to be flexible, responsive to the needs of the adolescent and his/her

family, continuous, comprehensive, and coordinated (AAP, AAFP, & ACP, 2002). Often, successful transition happens in environments that provide a medical home to children and youth with special health care needs (McPherson, Arango, & Fox et al., 1998). While there is general consensus that appropriate health care transition planning and preparation will lead to a more successful health care transition into adult health, there are no mandates that require any type of transition preparation in the medical setting. Furthermore, it is not defined whose responsibility it is to prepare youth and their families for this transition. In recent years, health care transition and its successful execution has gained greater attention in the medical field as more than 90% of children with special healthcare needs survive into adulthood (Blum, 1995) and need to transition from their pediatric primary care providers (PCPs) and specialists to adult health care providers. Successful transition is a team process, with pediatric and adult providers playing as much of a role as family members and the young adult him/herself. Despite many available guidelines and tools for successful transition planning, preparation and implementation for health care providers, family members and youth by such entities as the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), American College of Physicians (ACP), and leading researchers in the field, data from the 2009/2010 National Survey of Children with Special Healthcare Needs illustrate that successful healthcare transition is achieved by a mere 40% of all youth between 12 and 17 years of age (National Survey for Children with Special Health Care Needs 2009/2010).

What are the Issues and Barriers?

For families and youth/young adults, the transition from the pediatric to the adult health care system is just one of many transitions in the life of the young adult. Often, health care transitions occur at the same time as many other life-changing transitions, such as the transition from school to postsecondary education or employment and from living at home to living independently (Settersten & Ray, 2010). Coordination of transition planning and efforts is difficult for families in part because many of the systems from which young adults transition are not connected. Health care transition can quickly become overwhelming, especially in light of all the other changes families and their young adult children face. For pediatric health care providers who struggle with low reimbursement rates and little time for care coordination (McManus, Fox, O'Connor, Chapman, & MacKinnon; 2008), health care transition preparation can be difficult to integrate into their practice work flow. Adult health care providers face transitioning adult patients who have congenital and childhood onset medical conditions with which they are not familiar and work within a medical system that make reimbursement for and time commitment to care coordination difficult (Okumura, Heisler, Davis, Cabana, Demonner, & Kerr; 2008; Peter, Forke, Ginsburg, & Schwarz; 2009). While parents and providers are generally overwhelmed, there are also unique barriers that each of them face. Specifically, family members and young adults encounter:

- a. Late preparation for the transition to the adult health care system (National Survey of Children with Special Health Care Needs, 2009/2010 data)

- b. Little knowledge about how to navigate the adult health care system
- c. Little information about the changes regarding eligibility of services, treatments and devices and changes to health care coverage
- d. Difficulty with identifying a new primary care provider and specialists in the adult health care system (Callahan & Cooper, 2006)
- e. Physical and emotional health strain of the caregiver (Murphy, Christian, Caplin, & Young; 2007).

Pediatric health care providers face issues such as (McManus, Fox, O'Connor, Chapman, & MacKinnon; 2008):

- a. Little time for transition care
- b. Lack of reimbursement for transition support to the young adult
- c. Concern that the young adult will not receive the same level of care in the adult health care system as they have provided
- d. Lack of adult providers and specialists in the community to which to transition the young adult
- e. Little knowledge about community resources from which the young adult and family can benefit

Adult health care providers experience such challenges as (Okumura, Heisler, Davis, Cabana, Demonner, & Kerr; 2008; Peter, Forke, Ginsburg, & Schwarz; 2009):

- a. Lack of training in congenital and childhood onset medical conditions
- b. Lack of training in working with patients with disabilities
- c. Lack of communication from pediatric provider
- d. Low reimbursement rates for comprehensive care

Effective Practices—What Needs to Happen?

To improve health care transition for youth/young adults and their family members, a multi-prong approach that includes all partners (providers, youth, family members, etc) is helpful. Many transition resources and tools have been developed for young adults, family members and health care providers (e.g. www.gottransition.org, www.floridahats.org) that can be utilized to improve transition preparation and the transition process. Most recently the AAP, AAFP, and ACP Transitions Clinical Report Authorizing Group published a clinical report that “aims to advance the practice-based implementation of planning, decision-making, and documentation processes for youth who are approaching transition” (American Academy of Pediatrics (AAP), American Accademy of Family Physicians (AAFP), & American College of Physicians (ACP) Transitions Clinical Report Authorizing Group, 2011). The Health Care Transition Planning Algorithm provides the template for an individualized approach to health care transition for all youth/young adults. Quality improvement pilot learning collaboratives of pediatric and adult health care practices are currently underway at various sites for improved health care transition from pediatric to adult health care providers (White, McManus, McAllister, & Cooley; 2012). While these efforts are valuable and promising, broad base implementation of transition policies in medical practices, sharing and utilization of resources and tools with young adults and families, and transition training of health care providers is still lacking. In order to have a successful health care transition experience, it

is recommended that families:

- a. Start the transition process as early as possible, ideally around 12 to 14 years of age of the child (AAP, AAFP, & ACP, 2011).
- b. Familiarize themselves with eligibility criteria for services, treatments, and devices in the adult service system; health care insurance changes; and changes in their role once the child is an adult so they can prepare for those changes.
- c. Involve their child in his/her health care as early and as much as possible and appropriate so the child can move from being the recipient of care to the supervisor of his/her care, following a shared management approach to health care (Gall, Kingsnorth, & Healy; 2006).
- d. Utilize the plethora of transition curricula, checklists, and other tools available online and in print specifically for families.
- e. Initiate the identification of a future adult health care provider for their child while still in the care of the pediatric provider. This allows for a “trial period” and finding the right adult provider before having to leave the pediatric safety net.
- f. Ask their pediatric provider for a portable medical summary that includes essential medical and health information about the youth/young adult that can be shared with a new health care provider.

It is recommended that youth/young adults:

- a. Are active participants in their health care and take responsibility for treatments, medications, scheduling appointments, etc. to the extent possible. For some youth/young adults, this may be as little as handing their insurance card to the medical assistant, for others, this may mean scheduling their appointments, managing their treatments and medications, and communicating with their health care provider.
- b. Utilize health care transition resources and tools specifically geared toward youth/young adults that are available online and in print that can help with self-advocacy skills and health care management.
- c. Are actively engaged in searching and finding an adult health care provider with whom they feel comfortable before they transition out of the pediatric system.

It is recommended that pediatric health care providers (AAP, AAFP, & ACP, 2011):

- a. Establish health care transition policies and processes for their practice.
- b. Initiate the transition process to adult primary and specialty care around 12 to 14 years of age of the youth.
- c. Develop a transition plan with the youth and his/her family around 12 to 14 years of age and update it regularly.
- d. Continuously follow-up with families and youth about their transition preparation and progression.
- e. Provide families and youth with health care transition resources, such as transition checklists and self-advocacy and health management tools.
- f. Prepare and share a portable medical summary with the family and new health care providers that

- encompasses pertinent health information that will allow the new provider to establish appropriate care for the young adult patient.
- g. Be open to communication with the new health care provider until successful transfer of care has occurred.
- h. Utilize Electronic Medical Records (EMR) to establish, progress, and track the health care transition process for improved communication and information exchange.

It is recommended that adult health care providers:

- a. Engage in the transition process with the young adult.
- b. Learn from the young adult and family members.
- c. Be interested in continuously learning about congenital and childhood onset medical conditions.

It is recommended that medical schools and training programs:

- a. Provide more didactic and practical training on working with patients with congenital and childhood onset medical conditions to future adult health care providers.
- b. Provide more didactic and practical training on working with patients with disabilities and their family members.

Health Care Transition is a complex process that requires the interplay of multiple players and systems: the youth/young adult, family members, pediatric health care providers, adult health care providers, and the pediatric and adult health care systems (Bhagat & Richards, 2012). All of these players and systems build the health network in which transition

occurs over multiple years. In addition, this health network needs to take into account additional environmental factors that impact the young adult (Bhagat & Richards, 2012). School, vocational and training programs, transportation, housing, and recreational activities all also play a role in the transition to adult life for the young adult with special health care needs (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). Ideally, transition processes for all of these would be merged to address transition as a whole and not as the sum of its different parts.

Education—Age Appropriate Education Transition Assessments

The Individuals with Disabilities Education Act (IDEA) of 2004 recognizes the pivotal role schools play in shaping transition goals and services of students with disabilities, stating that a primary objective of special education is to “further education, employment, and independent living” (20 U.S.C. § 1400(33)(c)(1)). In accordance with IDEA mandates, the Individual Education Plans (IEPs) of students with disabilities must include measurable postsecondary goals that are annually updated and based upon age-appropriate transition assessments, transition services, and courses of study supporting student postsecondary goals (NSTTAC, 2012a). Transition assessment data may include results of self-determination and career assessments completed by general or special educators, occupational and assistive technology assessments completed by an occupational therapist or assistive technology specialist, community-based assessments

completed by a vocational rehabilitation counselor or adult service provider, and/or adaptive behavior assessments completed by teachers or psychologists. Family and student interview data is also useful when summarizing transition assessment information on the IEP.

Each year the IEP team must develop and review the summary of age-appropriate transition assessments related to postsecondary plans for employment, education or training, and when appropriate independent living. In this multi-year interdisciplinary transition planning process, the team will verify, update, and review the present levels and transition assessment data. Age appropriate transition assessment information will be used by the IEP team to:

- a. Identify, confirm, or update the proposed high school courses of study;
- b. Develop or modify the transition services needed to support the proposed courses of study;
- c. Not later than the IEP for age 16, develop, update, or confirm the appropriate, measurable postsecondary goals in employment, education and training and independent living, if appropriate;
- d. Identify, confirm, or update the transition services to support those goals; and
- e. Identify, confirm, or update the annual IEP goals that support movement to the postsecondary goals.

Transition to Employment

Findings from the National Longitudinal Transition Study-2 (NLTS2) indicate that post-school outcomes for students with IDD are among the poorest outcomes of any disability group (Wagner, Newman, Cameto, Garza, & Levine, 2005).

According to NLTS2 outcomes for transition-age youth, only 17% of youth with IDD and 12% of youth with multiple disabilities were employed one year out of school (Wagner et al., 2005), and approximately 38% of adults with IDD are employed eight years after graduation (Newman et al., 2011). Thus, the need for improved career development and transition planning is well documented.

Generally speaking, employment for persons with and without disabilities is linked to positive societal and individual outcomes, such as labor market contribution, economic independence, and increased self-worth and self-determination (Lehman et al., 2002; Levinson & Palmer 2005; Newman et al., 2011; Rogan, Grossi, & Gajewski 2002). Yet, even with the documented benefits of transition planning, the Bureau of Labor Statistics reported in 2011 that only 17.8% of persons with disabilities were employed opposed to 63.6% of persons without disabilities, and more workers with disabilities (one-third) were employed part-time compared to those without disabilities (one-fifth). In addition, Yelin and Trupin (2003) found that persons with disabilities were more likely to have household incomes below 125 percent of the federal poverty levels than were persons without disabilities. They also found that persons with disabilities across education levels were less likely to be employed than those without disabilities.

The barriers to employment faced by persons with disabilities begin in high school. Studies indicate that youth with disabilities have poorer career decision-making skills, lower career outcomes expectations, and poorer vocational identities than their peers without disabilities (Ochs & Roessler, 2001). This highlights the need for earlier intervention and adoption of curricula with a transition focus in K-12 education. Research has suggested that employability skills can and need to be taught by schools so that students are better prepared for successful employment (Cotton, 2008).

To address employment disparities, integrated employment is a vocational rehabilitation (VR) service option championed by many public policy advocates nationally because it is associated with greater socioeconomic outcomes (Butterworth, Hall, Smith, Migliore, & Winsor, 2009; Cimera, 2009). However, in spite of national policy, there is a lot of variation among states and counties in the types of VR/DD services provided. Some states have moved away from providing integrated employment services in favor of facility-based employment, whereas other states have embraced integrated employment programs across counties (Butterworth et al., 2011). By definition, integrated employment services are provided in a community setting and involve paid employment of the participant. Integrated employment broadly encompasses competitive employment, individual supported employment, group supported employment, and self-employment supports. Whereas integrated (supported) employment focuses on work in community settings with follow-along supports such as job coaching to help

persons with IDD retain their jobs, facility-based employment—often referred to as sheltered workshops or work activity centers—is work that occurs in more self-contained settings where the majority of employees have a disability and require continuous job-related supports and supervision (Butterworth et al., 2011).

There is ample evidence that integrated employment is more cost-effective than facility-based strategies. Using national averages, Cimera (2008) found that integrated employment services cost \$6,618 per year whereas sheltered workshop services cost \$19,388—a statistically significant difference of \$12,770. Corroborating this finding, Rogan and Rinne (2011) found that sheltered employment costs the federal government four times as much as integrated community employment! Additionally, from a tax payer perspective, the ratio of investment to outcome makes integrated employment cost-efficient. That is, for every tax dollar spent toward supporting persons with IDD in integrated employment settings, there is a \$1.22 resulting benefit to taxpayers, which is a decidedly positive return on investment (ROI) (Cimera, 2009).

The evidence in this section provides strong support for early career counseling and early education and support for the process of transition from school to work. Evidence in supporting interdisciplinary strategies to coordinate the transition to employment follows:

- Provide training and support for students on how to self-advocate and become active participants in their IEP, Individualized Plan for Employment (IPE), and ISP meetings to gain services that are
- self-directed and based on age appropriate transition services (Kochaar-Bryant & Izzo, 2006).
- Provide training and support for parents on the positive effects of requiring children with disabilities to complete household chores, having high expectations that their children will become self-supporting in the future (Carter, Austin, & Trainor, 2011), as well as training on how to be an active participant in the IEP, IPE, and ISP to maximize services from education, vocational rehabilitation, and developmental disabilities agencies, respectively.
- Integrate transition assessment activities including career exploration and development into the core curriculum (supported by general educators, special educators, and transition specialists) to assist students in developing self-directed measurable goals for employment, as required by the IDEA of 2004 (Izzo, Yurick, Nagaraja, & Novak, 2010).
- Offer a variety of volunteer, unpaid, and paid internships beginning no later than age 14 and continuing until permanent paid employment is obtained. Carter, Trainor, Swedeen, & Owens (2009) demonstrated the efficacy of combined school and community strategies involving education and VR personnel to increase summer employment through a multi-component intervention to increase summer work experience for students with severe disabilities.
- Advocate for including in the IEP vocational and career-related goals that result in vocational and career services since these services are strongly associated with paid work (Carter, Austin, & Trainor, 2011).

Transition to Postsecondary Education

Postsecondary education (PSE) and training is a factor that impacts successful career outcomes and employment rates. Yulin and Trupin (2003) observed that persons with disabilities experience greater returns from increased levels of education than their non-disabled counterparts. For example, graduates with disabilities who went on to receive some level of post-graduate training were more than two-and-a-half times as likely to be employed, whereas graduates without disabilities who received some level of post-graduate training were only one-and-a-half-times as likely to be employed. Successful transition from secondary school is becoming a chief indicator of the effectiveness of schools in preparing youth for college and career readiness (Baer et al., 2003; Kochhar-Bryant, Bassett, & Webb, 2009) and skills related to choice making, problem solving, decision-making, self-regulation, and self-advocacy and leadership (Wehmeyer & Palmer, 2003). Employment outcomes for individuals who participate in PSE have been shown to be much higher than for those who do not participate in PSE. PSE participation has been linked with better jobs, increased interest to improve one's employment situation, higher wages and better benefits packages, and better quality of life (Clark & Unruh; 2009; Jesien, 2009; Migliore, Butterworth, & Hart, 2009). These outcomes are true of individuals with and without IDD. However, youth with IDD have been shown to participate in PSE at far lower rates than youth without disabilities (Grigal, Hart, & Paiewonsky, 2010; Migliore & Butterworth, 2009; National

Post-School Outcomes Center, 2006).

Youth with IDD who are from low-income backgrounds face more challenges in transitioning to postsecondary education than those who are more advantaged. Wehmeyer (2011) suggests that oppression, segregation, and discrimination—often associated with high poverty environments—inhibit the development of self-determination skills, especially when co-existing with disability. Students from low-income neighborhoods are more likely to attend schools that are racially and ethnically segregated and have limited resources and low graduation rates (Orfield, 2009). These schools are underfunded and understaffed and have the highest drop-out rates reported nationally. Such schools are characterized by limited curricular options and rigor; teacher preparation, experience, and expectations; and parent participation (Washington, Hughes, & Cosgriff, 2012). Findings reveal that a traditionally disenfranchised and underserved population—youth with intellectual disabilities who are primarily African-American and attending a high poverty urban high school—may be missing out on learning and practicing critical self-determination skills and not participating actively in their educational planning. Because self-determination is correlated with academic achievement and positive post-school outcomes for high school youth, incorporating self-determination into school instruction may increase outcomes for low income students with disabilities (Washington, Hughes, & Cosgriff, 2012).

Interdisciplinary strategies to coordinate the transition to postsecondary education follow:

- Plan effective, person-centered transition services for high school students as they pursue postsecondary education (Grigal & Hart, 2010). Involve the college students with IDD in planning and facilitating their own person-centered meeting while they are in college.
- Encourage increasing responsibility for independent living and health matters, including making appointments, refilling prescriptions, and consenting to care (Gilmore, Bloomquist, & Wall, 2011).
- Teach self-advocacy skills and encourage students to advocate for those accommodations that will be acceptable on college campuses. Provide instruction for the educational coaches so they encourage students to become their own self-advocates versus advocating for the student with an IDD.
- Recruit both faculty and students from the university's interdisciplinary programs to support students with IDD in college classes, internships, and recreational activities. Invite faculty and students from the disciplines such as special education, occupational and physical therapy, rehabilitation counseling, social work, and disability studies. Create opportunities for these students to receive course credit for completing practicum assignments with students with IDD.
- Provide a range of universally designed technological supports such as iPads, laptops, and communication devices so students with IDD can maintain their schedules, notes, etc. with age-appropriate supports. Collaborate with faculty and students in occupational

therapy, rehabilitation counseling, and special education to teach students how to use these devices.

Transition to Community Living

There are a number of important components of community living: young adults need a place to live and work; skills to manage their living environment and navigate their community; self-care skills to ensure safety and personal health; to be included in community activities of their interest; have a social network of friends, family members and allies that support them; and they need to participate in leisure/recreation activities. There are a number of types of community and residential services and supports that are designed to support youth and young adults with intellectual and developmental disabilities (IDD) in developing needed skills for community living. Knowledge about how to access these residential services and growing waiting lists for these services certainly are important pieces of information to consider in developing a transition plan. Residential and community services and supports for people with IDD are primarily funded through long term services and supports under Medicaid. Each state offers their own array of residential and community services but there are commonalities.

The *Residential Information Systems Project (RISP)* longitudinal study has identified the types of community living options utilized by people with IDD since 1977. In 2010, 55.9% of people with IDD who received residential services funded by Medicaid received these services in their family home and 12% in a home or

apartment which they owned or leased (Larson et. al., 2012). 26% of people with IDD who receive residential services live in a congregate group setting. The Family and Individual Needs for Disability Supports (FINDS) survey reported in 2010 that more than half of the family caregivers thought the ideal residential setting was somewhere other than the family home, yet 78% of family caregivers live with a family member with IDD. Family caregivers report that 20% of people with IDD had no source of income. 62% have experienced decreases in services and 32% were on a waiting list for services. 40% of family caregivers reported unmet service needs including transportation (45%) and social activities (30%). Family caregivers reported substantial challenges to providing lifelong supports (Anderson, Larson, & Wuorio, 2011). Additionally, new methods for monitoring and supporting more independent community living are emerging through the use of shared living arrangements, including independent living models in which sensor and other home monitoring technology is used that allows for offsite monitoring to ensure safety while simultaneously encouraging greater independence.

It is important to understand the outcomes of long term community and residential services. The National Core Indicators (NCI) provided the *Annual Summary Report for 2010-2011* on measured outcomes of Medicaid funded residential and community supports (ICF/DD and HCBS) for adults with IDD. The NCI documents several important systems trends regarding residential and long term community supports, including:

- Only 58% of adults and 65% of families/guardians report receiving the

services identified in their service plan.

- 41% of adults and 51% of families/guardians report that services change when needs change.
- 23% of adults and 39% of families/guardians report that case management staff connect family members to community supports.
- 71% of adults and 81% of families/guardians report that family members participate in community activities.
- Only 10% of adults have jobs.
- 80-90% have participated in community activities in the past month.
- 50% have exercised or participated in a religious service.
- 40% usually feel lonely.
- Only 30% have ever gone to a self-advocacy meeting.

In another study of residential services (Rafferty & Antosh, 2011), five service provider organizations maintained an activity log for 341 adults who live in a variety of community settings. During a three day period (two week days, one weekend day) an average of 132 minutes was spent participating a community activity, 123 minutes participating in sports, 71 minutes shopping, and 68 minutes participating in a hobby. Only 1% of total time recorded was spent with friends and acquaintances other than those who were employed or supported by the five organizations.

These studies indicate that youth and adults with IDD who receive residential and other community living supports have continued needs even when they are receiving supports. Communities and service planners need to anticipate these needs and ensure that the staff providing community living support are trained and

equipped with the right competencies to facilitate positive and desired community living outcomes. The trends and outcomes identified in the studies described in this section of this paper certainly document the need to incorporate residential living, home living and self-care skills training, community support services, access to community activities, social networks, and participation in recreation and leisure activities into a comprehensive transition plan. The National Secondary Transition Technical Assistance Center (NSTTAC) has documented multiple strategies for developing competence in these areas.

Housing

Critical Needs of Housing for Transition

Housing is critical to people with disabilities transitioning into communities throughout the United States. The *2007 American Housing Survey* revealed an estimated 35.1 million households have one or more individuals with a disability, which represented 32% of the households in the United States in 2007 (Smith, 2009). In addition, the survey revealed that among people below the age of 65, people with disabilities (37%) are more likely than people without disabilities (31%) to rent their home (Smith, 2009). According to the U.S. Census Bureau, 2.17 million people live in nursing homes (1.6 million) or group homes (500,000) (U.S. Census Bureau 1990 and 2000).

Incomes levels are lower for people with disabilities compared to people without disabilities which directly prevents them from obtaining affordable housing rental or homeownership. As a result, an

estimated 14.4 million households with at least one person with a disability cannot afford their housing—this is 41% of all households with disabilities (Affordable Housing Needs 2005, 2007). A recent report, *The Hidden Housing Crisis: Worst Case Housing Needs Among Adults with Disabilities*, estimates that about 2.4 million households with nonelderly people with disabilities, including 1 million families with children, have worst-case housing needs—nearly 40% of all worst-case housing needs in the United States. In addition, another 1.3 million “elderly households” (age 62 years or older) have worst-case housing needs, with many likely also to have a disability. Most are very low income and paying more than half their monthly income for rent (Nelson, 2009). According to *Priced Out in 2008*, a single person in the United States has an income that is five times greater than that of a person receiving SSI assistance, which on average is \$668 a month (Cooper, Korman, O’Hara, & Zovistoski, 2009). The result is that housing choices are limited for people who depend on SSI benefits.

Based on the one-time supplement on disability and housing modifications to the 1995 American Housing Survey, thousands of people with disabilities need basic home modifications to make their homes accessible (Shae, 2004). The greatest need was for grab bars or handrails (an estimated 788,000 households) that, relatively speaking, are not expensive to install. In addition, many people needed basic features that make units “visitable,” including ramps to access the building or home (612,000 households), elevators or lifts to access the unit once in the building (309,000 households), widened doorways and halls

in the unit (297,000 households), and accessible bathrooms (566,000). As might be expected, renters had proportionally greater unmet need for all features when compared to homeowners (Shae, 2004). In addition to modifications to make the physical environment more accessible, there is a need to consider the overall built environment, given the growing number of people affected by environmental exposures—a physical condition that is triggered by the environment (NCEHS, 2009). Current estimates suggest that 11% of the population has some sort of chemical sensitivity (NCEHS, 2009). For people with environmental sensitivities, accessible housing must be free of these environmental triggers. Because housing is not universally designed to accommodate all the different sensitivities, some people have been forced to live in segregated housing that assures control over potential exposures.

Fair Housing has seen hard work and much progress in the past few years, but many of those in the protected classes still face housing discrimination due to their race, color, background, or disability. According to the U.S. Department of Housing and Urban Development (HUD)'s *The State of Fair Housing: FY 2010 Annual Report on Fair Housing* report released in 2011, more than 10,000 fair housing discrimination complaints were filed. Of those 10,000 complaints, discrimination based on a person's disability continued to be the largest category of complaints. In fact, disability was cited as the basis for 4,839 complaints, making up 48% of the total percent of complaints (*HUD's Annual State of Fair Housing Report, 2011*). Statistics show that housing complaints based on disability are a growing trend in the nation. In 2007, disability

complaints accounted for 43% of the complaints, and race made up the base for 37% of complaints. That difference of 6 percentage points has grown to a difference of 14 percentage points (*HUD's Annual State of Fair Housing Report, 2011*). The reason for the growing trend can be attributed to a couple of factors. Many apartment owners directly refuse to make reasonable accommodations or modifications for people with disabilities, while builders, contractors, and architects continue to design and build apartment complexes that violate the clear Accessibility Guidelines. There are more than 54 million people in the United States living with a disability (*National Fair Housing Alliance: Fair Housing Trends Report, 2010*). With this number expected to grow, so will the probability of more housing discrimination complaints filed.

Barriers to Housing

To accomplish the development and maintenance of affordable, accessible, and safe housing for people with disabilities to live in the community, many complex barriers must be addressed with comprehensive strategies. Though these barriers are complex, they can be simply categorized as the following:

- Poverty/Low-income
- Lack of affordable housing stock or units
- Lack of accessible housing (Universal design)
- Housing discrimination
- Lack of community support services or resources
- Lack of public and private housing financing
- Lack of financial education and outreach

- Lack of clearinghouse for housing information

Recommendations

The National Council on Disability issued a report entitled *The State of Housing in America in the 21st Century: A Disability Perspective*, which recommended several important actions on the system and policy level for consideration. The recommendations are as follows:

1. Increase affordable, accessible, and integrated housing for people with disabilities to meet needs and demand.
 2. Increase access to existing units.
 3. Prevent further loss of affordable, accessible housing.
 4. Improve fair housing enforcement of disability rights.
 5. Review HUD and Public Housing Agency (PHA) guidelines for compliance with Section 504 and the Fair Housing Act.
 6. Support and enact new legislation such as the Inclusive Home Design Act or amend the Assets for Independence Act (P.L. 105–285).
 7. Adapt and implement new federal guidance on helping people with disabilities in an emergency.
 8. Develop cross-system coordination and collaboration.
 9. Change systems at the state level.
 10. Provide guidance for housing programs for people with psychiatric disabilities.
 11. Improve the data on people with disabilities and housing needs. (NCD, 2010)
- If young adults and others with disabilities are to transition into the community, this cannot be achieved without accessible, affordable, and safe housing options. However, beyond the policy and system levels, the following are some practical recommendations in preparation for seeking housing that young adults with disabilities and their families should consider as they seek to transition into the community:
1. Consider and identify future or current housing options during the IEP or person-center-planning process.
 2. Seek out opportunities to attend housing financial education events.
 3. If available, attend a homebuyer or rental education workshop.
 4. Personally commit to self-advocacy for system change and independent living.
 5. Establish traditional credit sources in preparation for transition.
 6. Identify comprehensive housing counseling providers in the community.
 7. Examine how current public benefits impact housing options.
 8. If employed, be able to show stable employment history.
 9. If not employed, review options available for employment.
 10. Learn about consumer protection and fairing housing rights.
 11. Seek grant opportunities for down payment, closing cost, and retrofitting assistance in the community.
 12. Seek out subsidized housing options including Section 8 Housing Vouchers and USDA Rural Recapture.
 13. Identified reputable lenders in applying for a mortgage in the community.
 14. Identified reputable realtor and landlords in the community.

Transportation as an Essential Support for Successful Transition

Assuring that students have knowledge and skills around mobility and transportation is an important component of transition planning and requires an interdisciplinary approach. After all, if students are not able to access employment, higher education, or independent living settings because of transportation challenges, they cannot realize post-school goals (Flexer, Baer, Luft, & Simmons, 2013). Transportation education creates a culture, accompanied by a coordinated set of practices, to connect students, families, educators, pupil transporters, and public transportation professionals to create a system by which students have knowledge, access, and choice regarding a transportation continuum as they transition from school to postsecondary education, employment, and independent living settings. Transportation education recognizes the connections across education, pupil transportation, and public transit (Figure 1), and is driven by the needs and interests of students and their families. The result is that students have

choices regarding their transportation preference, and paratransit services are not the only option available to students with disabilities when they leave high school.

Easter Seals Project ACTION developed a multi-tiered framework to help educators think about transportation strategies (Figure 2). A tiered approach enables educators to address transportation topics in a way that integrates transportation content into existing curricular or reforms. For instance, at its foundation and the least intense level, students with and without disabilities are oriented to public transit by participating in opportunities to visit and use public transit, through examples that are embedded in academic materials, and by the collaboration and participation of transportation professionals in school forums. At the second tier, the services become more customized and aligned with the needs of students. At this tier, travel assessment and familiarization may occur, and more focused transportation learning tools may be offered to students, such as mobility checklists (free checklists are available at <http://www.projectaction.org/Initiatives/YouthTransportation.aspx>). At the top tier or the most intense level, travel training, a

Figure 1

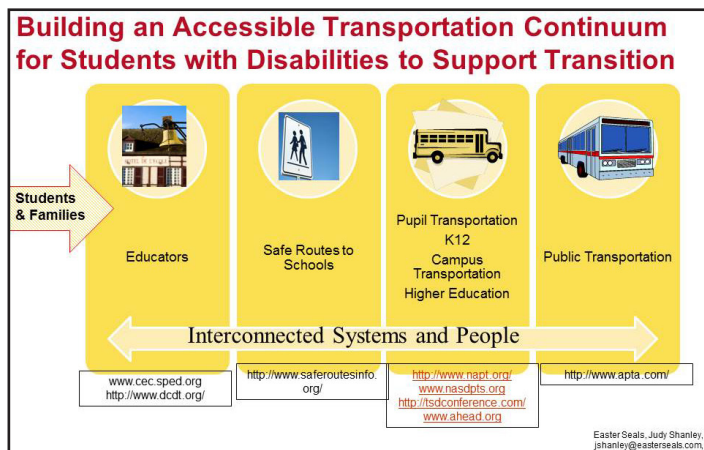
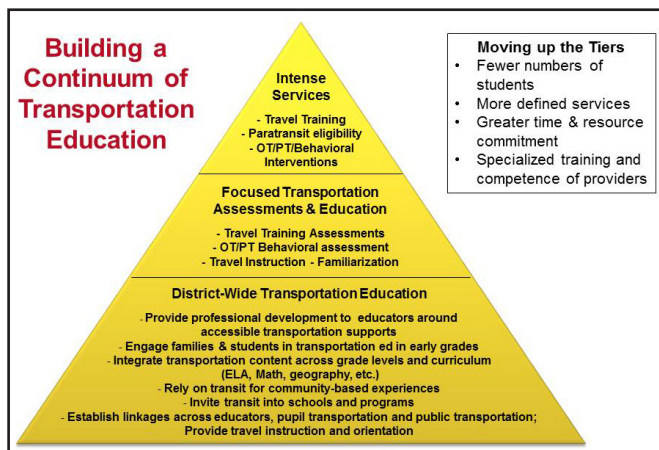


Figure 2



one-to-one service provided to students by trained travel training professionals, is delivered to enable students to navigate on public transportation. Across tiers, it is important to consider the particular assistive technology or supports that can facilitate student engagement in transportation content. For example, students with cognitive disabilities can participate in a travel-buddy program, receive pictorial guides to complement travel training instruction, or use smartphone technology that can help alert them to stops along their travel route.

A transportation education framework embeds transportation content into curriculum and learning so that during transition planning, a focus on the student's transportation needs is routinely part of discussions and services. Assessment information and the experiences that students have had as part of this transportation education framework can inform student transition goals, especially those goals that focus on transportation. Students leave the high school setting equipped with the knowledge and skills to make decisions about their mode of travel that can facilitate their access to employment, higher education, and independent living. An interdisciplinary framework, as depicted in Figure 1, and involving students, families, educators, safe routes to schools, professionals, pupil transporters, and public transporters represents this cross-perspective approach to assure that students have the knowledge and skills to independently access transportation supports.

Technology and Transition

Background

For most, technology is a means to increase productivity, communicate, or to simplify a complex task (Blair, 2004; Mariger, 2012). For those who identify themselves as having a disability, technology is often that, and much more. It is sometimes a means of mobility. Yet others require the daily use of technology to sustain life and to communicate (Scherer & Galvin, 1996).

Technology in the disability context can be understood in at least two ways. First, assistive technologies (AT) are those that enable individuals to gain, maintain, or regain independence. AT includes mobility devices such as wheelchairs, portable ventilators that enable individuals to leave homes or hospitals, and a variety of communication devices and computer adaptations that provide alternative methods to communicate (Alper & Raharinirina, 2006). AT is much more than that, however. In the medical research literature, the term “rehabilitation technology” is pervasive and defines a variety of low and high tech solutions that enable increased independence and community integration for those who have lost functioning due to disease or injury. Technology applications and outcomes experienced in this research domain have clear benefits for people with IDD.

Second, in the mainstream sense, technology refers to devices such as cell phones, smartphones, tablets, desktop or laptop computers, wireless “hot spots,” information kiosks, and so on, to which the general population has access. For example, recent research

(Smith, 2012) indicates that approximately 88% of U.S. adults own some type of cell phone and that 77% of teens age 12-17 own a cell phone (Lenhart, 2012). Technology is useful and available, if not necessary, in interactions with the world around us. One might say it is ubiquitous. Debate focused on supporting increased independence and self-determination for young adults requires careful attention to the increasingly blurred separation between assistive and mainstream technology across the multiple domains in which people interact (Blair, Goldmann, & Relton, 2004; Mann, 2008). In addition to enhanced interactions, technology sometimes represents the voice, the hands, the feet, the ears, or the eyes of individuals who use it.

Individuals and Families

Simply stated, assistive technology is used to help individuals with disabilities interact, communicate, and achieve positive results (Edyburn, 2008; Wehmeyer, Palmer, Williams-Diehm, Shogren, Davies, & Stock, 2011). The technology recommendations listed below are based on a growing research foundation and fit into two overlapping categories: assistive technology and mainstream technology.

Assistive Technology

- Seek and use AT as early as possible in a child's development. To be most effective with children and youth, this generally requires the involvement of families and close care providers in understanding how the technology can be used (Blair, 2004; Alper & Raharinirina, 2006).
- Ensure access to essential AT (e.g.,

communication and/or mobility devices) across life domains. If use of a device is critical in school it is likely necessary at a job site (Burgstahler, 2003).

- Seek funding arrangements that allow technology to be used in all environments in which the individual interacts (e.g., school, home, work, community). This is an important consideration when assistive devices are purchased using public funds and relied on as a primary means of functioning (e.g., augmentative and alternative communication, or AAC) (Hess & Gutierrez, no date).
- Pursue innovative funding to maximize flexibility in how and where technology is used. Individual Development Accounts (IDA), federally-funded state financial programs, AT loan programs, and public/private insurance funding are good possibilities (search "assistive technology funding" online for state-specific resources).
- Ensure that school assignments are accessible to all students, including those who use AT. Teachers increasingly rely on the use of technology to educate children (Edyburn, 2008; Izzo, Murray, & O'Hanlon, 2005). Ensuring that those who use AT can access the same technology (e.g., computers, websites, and so on) as those who don't use AT is critical to student success (Blair, 2006; Rose & Gravel, 2012) during and following school.

Mainstream Technology

- Get it. Use it. Figure it out. Youth who use tablet computers, smart phones, or cell phones are more like their

peers. For example, voice commands, voice typing, and increasingly accurate word prediction applications on most mainstream communication devices help all users. Basic operating systems come with screen magnification, high contrast, and other settings to benefit those with tactile, visual, or other sensory limitations. Use of mainstream technology has an equalizing effect (Scherer, 1996).

- Learn how to use information search

tools such as Google Search. Use of technology has the potential to improve self-determination across most, if not all, domains in which individuals interact. Information and knowledge are power. Enabling access to information and providing learning supports through technology are an essential foundation to self-determination (Lee, Wehmeyer, Palmer, Williams-Diehm, Davies, & Stock, 2011).

TRANSITION THROUGH A CULTURAL LENS

Culture defines the values, beliefs, and practices surrounding when and how youth transition to adulthood. The United States, its territories, and tribal communities embrace myriad rituals that prepare and celebrate the pathway from adolescence to adulthood. Some of these rituals are legally defined, such as when one can vote, enter military service, or get married. Some are religiously or spiritually defined, such as a Bat Mitzvah, Bar Mitzvah, and Confirmation which mark the onset of religious acceptance and responsibility. Some have roots in other culture-specific traditions such as Rites of Passage celebrated by some African American families and communities to mark the journey toward adulthood; and Quinceanera, a 15th birthday symbolic of budding womanhood celebrated by many people of Mexican ancestry, including those who reside in the United States. Culture also defines the beliefs and practices surrounding transition for youth with disabilities and special health care needs. Culture influences the beliefs and practices of families and youth about transition within the contexts of health care, employment, postsecondary

education, and independent living. The following provides a summary of key issues and the evidence about transition through the lens of culture.

There are significant racial and ethnic disparities in transition services and outcomes

Hispanic and non-Hispanic Black youth ages 12-17 are significantly less likely than non-Hispanic White youth to have received services needed for transition to adult health care, work, and independence. While 46.5% of non-Hispanic White youth with special health care needs ages 12-17 were reported to have received these services, only 26.3% of Hispanic and 28.7% of non-Hispanic Black youth achieved this outcome. For Hispanic youth for whom Spanish was reported as their household language, the disparity is even more dramatic—only 11.6% of these youth had families who reported receiving these services (Child and Adolescent Measurement Initiative, 2006). Moreover, racial and ethnic disparities in employment within the

U.S. population mirror the employment status of people with disabilities from racial and ethnic groups other than non-Hispanic White. The unemployment rates in 2009 for those with a disability were higher among Blacks (22.1%) and Hispanics (19%) than among Whites (13.3%) and Asians (11.6%) (Bureau of Labor Statistics, 2010).

The literature indicates that there has been an overall increase in the participation of youth and young adults with intellectual disabilities in postsecondary preparation and education programs from 1970 through the present. Students from families with low incomes and those from racial and ethnic groups other than non-Hispanic White have neither equal preparation, access, nor participation in these postsecondary education programs (Goode & Brady, 2012).

Transition services and outcomes generally reflect the values of individualism and independence vs. collectivism and interdependence

Most transition policies, practices, and services assume that all youth with disabilities or special health care needs and their families value such individual oriented outcomes as self-determination, self-reliance, and independent living. These outcomes may not reflect the perspective of cultural groups, individuals, and families who value collectivism. Individualistic cultures view the process of development for youth as moving from dependence to independence and self-reliance. In contrast, collectivistic cultures see development as moving from dependence to interdependence

(Ewalt and Mokuau, 1995). A collectivistic world view may value contributing to the family through wages and housework over postsecondary education. Residing with family and kin groups may be valued over living on one's own. For example, Rueda et al (2005) found that Latina mothers believed the concept of independent living after high school was completely inappropriate, because marriage marked the transition from youth to adult independence and moving out of the family home. The mothers in the study indicated that employment was not considered particularly relevant, but self-sufficiency in terms of meeting personal needs was. Some African American, Asian, and Hispanic families resist out of home placement and permanency planning based on a philosophy of family interdependence (Harry, et al., 1999). Even the process of transition reflects cultural values. For some families, creating a transition plan is meaningful if it involves a close personal relationship among youth, family, and professionals rather than creating a written plan (Leake, et al, 2004).

Self-determination is a cultural construct

The concept of self-determination may be viewed and practiced very differently across cultures (Zhang, 2005). For some youth and families, a goal of individual choice may conflict with cultural values that support group or hierarchical decision-making. In some cultures decisions for individuals are made taking into consideration the interests of the larger group (extended family or community) as well as the individual. Simultaneously, each—the larger group and the individual—has

mutual responsibilities and provides support to one another. If a culture values a family-centered rather than an individual-centered model of decision making, then expecting a person to make such decisions on his or her own will not feel empowering, but instead, runs the risk of making the person feel isolated and burdened (Goode & Maloof, 2010; Wehmeyer, et al, 2011).

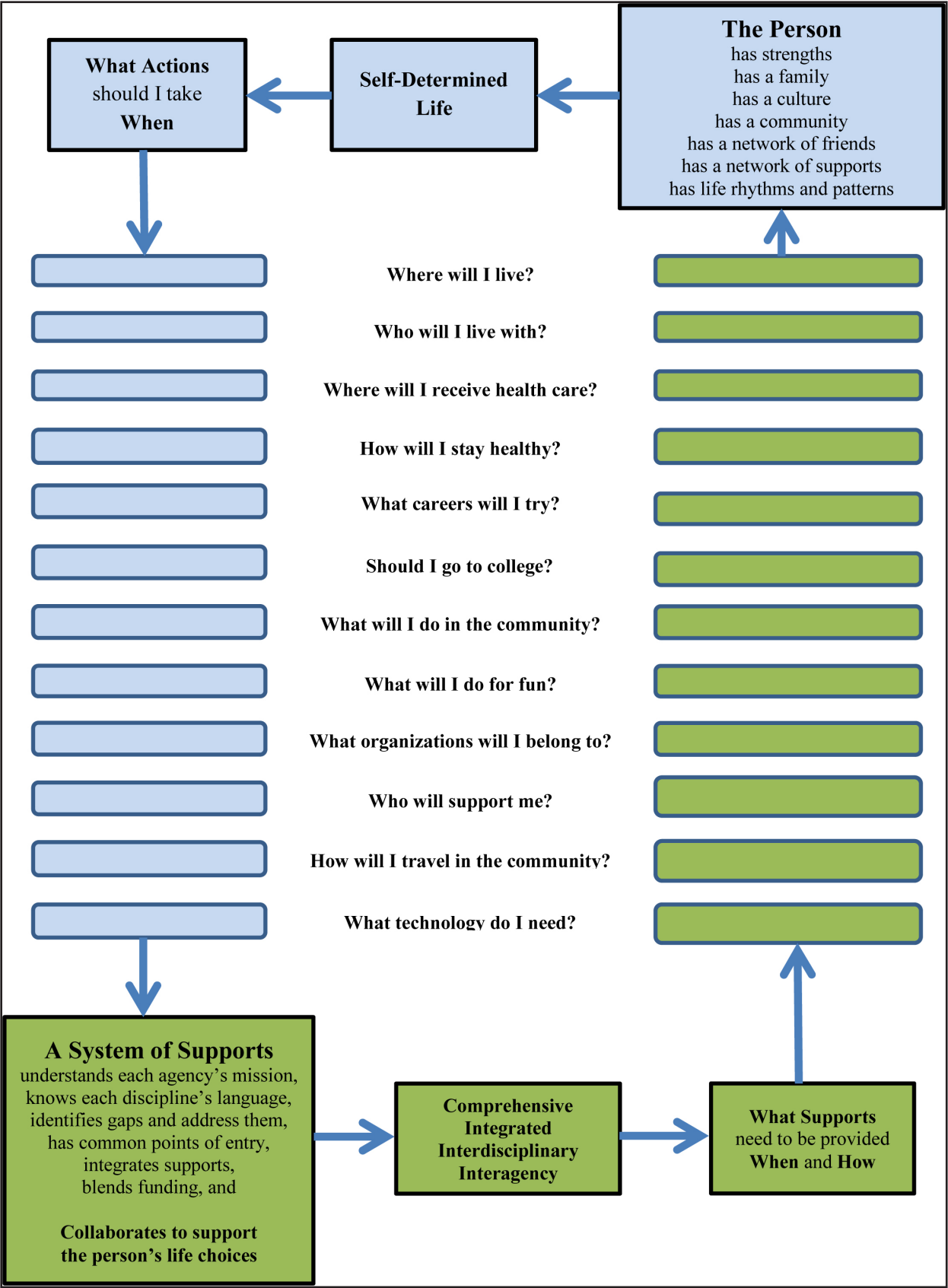
Based on this evidence, cultural and linguistic competence must be an integral component of all transition services. The following practices are suggested for those responsible for transition policy, practice, and evaluation.

- Acquire knowledge about the beliefs and practices related to transition from youth to adulthood for the diverse

cultural groups in the geographic area served by an organization or program.

- Recognize that self-determination is viewed and practiced differently across different cultural groups and must be taken into consideration in the provision of transition services.
- Incorporate cultural values about independence vs. interdependence and collective vs. communal perspectives in planning and provision of transition services.
- Address family and youth needs and preferences for services in languages other than English.
- Engage in cultural and linguistic competence self-assessment (at both the organizational and individual level). Use results to strengthen cultural adaptations to transition services and supports.

The following figure visualizes the integration of the multiple dimensions of comprehensive transition, individual preferences and community supports. It is a guide for adolescents and families as they think about transition.



THE IMPORTANCE OF INTERAGENCY COLLABORATION

Interagency coordination and planning is one of the critical elements of transition planning. The Individuals with Disabilities Education Improvement Act 2004 (IDEIA) mandates the “development and implementation of transition programs, including coordination of services with agencies involved in supporting the transition of students with disabilities to postsecondary activities” (20 U.S.C. 1411[d] § 300.704). Transition services are to be designed within a results-oriented process and include an array of activities including vocational and postsecondary education, integrated employment, continuing and adult education, adult services, independent living, and community participation. The range of possible post-school activities and supports required for successful transition reach beyond what schools alone can provide and require collaboration and support from many adult serving agencies and systems.

Interagency Collaboration

As identified by *Kohler’s Taxonomy for Transition Programming*, interagency collaboration is a primary component of “best practices” in secondary transition to promote positive post-school outcomes for students with disabilities (Kohler, 1993; Kohler, 1996). It is a process whereby various agencies come together with the desired end to provide more comprehensive and appropriate services (California Department of Education 2007). To accomplish this aim often requires high levels of collaboration and

coordination in order to assist students with disabilities to find and sustain employment, live independently, and attain postsecondary education and training. While interagency collaboration is widely endorsed and considered a key variable in what happens to students with disabilities after high school, there is limited research on the interagency process between schools, communities, and adult service agencies or student outcomes (Landmark, Ju, & Zhang, 2010; Luecking & Certo, 2003; Test, Mazzotti, Mustian, Fowler, Kortering, & Kohler, 2009; Test, Fowler, Kohler, & Kortering, 2010). Most of the literature describes essential elements, strategies, or functions of successful interagency teams.

Interagency collaboration is a deceptively simple idea with wide-ranging implications for the transition of youth from school to post-school activities. According to Chrislip & Larson (1994), collaboration is defined as “a mutually beneficial relationship between two or more parties who work toward common goals by sharing responsibility, authority, and accountability for achieving results.” Some collaborative relationships are simple to develop, others are more complex depending on such factors as mutual respect and understanding, communication, funding, the history of the collaboration, and whether the member sees the collaboration as in their self-interest (Matteisch & Monsey, 1992).

Interagency teams are the bringing together of a variety of stakeholders for the purposes of strengthening

the transition process by improving policies, services, and practices; coordinating funding; creating greater access to programs; clarifying roles and responsibilities; and improving outcomes. Examples of potential interagency team members include individuals, families, and representatives from adult service provider agencies, including local education, workforce development, special education, Social Security Administration, state departments of education, vocational rehabilitation, employment and health, human services, and postsecondary institutions (Lawson, 2004; Certo, Luecking, Murphy, Brown, Courey, & Belanger 2008; Stodden, Brown, Galloway, Mrazek, & Noy, 2004).

The level of collaboration, its primary functions, and group membership vary by whether an interagency team's primary focus is at the individual, local/community, or state level. At the individual level, the IEP team brings together a committee to help a single student. Local or community teams create partnerships to influence the coordination, enhancement, and provision of secondary and adult service programs. Their activities may involve resource mapping and direct engagement of local employers. State teams address systems level issues to enhance collaboration, coordination, and integration across systems. When state systems are not coordinated, students with disabilities face significant challenges in the transition from high school (Blalock, 1996; Stodden et al., 2004)

To identify key comprehensive strategies for interagency collaboration, Noonan, Morningstar, & Erickson (2008) conducted a detailed review and analysis of state and local practices in 29 high performing

districts in 5 states. Eleven strategies were identified that emphasized a complex inter-related system of staffing, support, knowledge building (i.e., training, technical assistance), relationships, and funding. The strategies identified often required collaboration at both the local and state levels to be successful. Thus, a critical dimension of successful interagency collaboration is the interplay between multiple local and state systems.

In a comprehensive review of federally funded state programs that support transition, the US Government Accountability Office (2012) found that students with disabilities face systemic barriers as they transition from the entitlement system of special education to the multiple eligibility-driven adult systems. Once students with disabilities leave high school, there is no single government-wide strategy or coordinating entity for transition planning or service delivery. Navigating and establishing eligibility as an adult in multiple agencies may be complex and difficult. Students and their families may not have sufficient information about the services or options available to them. Consequently, there may be a delay in applying for and receiving needed services like job supports, tutoring, or assistive technology. From the agency perspective, the differences in statutory eligibility criteria, lack of common outcomes, or common policies for operating across agencies hinders interagency coordination and influences student success at achieving post-school outcomes.

Effective Practices

- Expand the typical transition planning team to include adult education,

job services agencies (Department of Labor), One-Stop program representatives (Workforce Investment Act), community leaders, community recreation centers, and employers and others (NICHCY, 2010).

- Strengthen the linkages with higher education in transition planning to address postsecondary transition goals and services in order to increase the likelihood of postsecondary success (Gil, 2007; Grigal & Hart, 2010).
- Involve parents and families. Parental expectations are a strong predictor of paid employment post-high school. There was a five-fold increase in post-school employment by young adults whose parents expected that their youth would be self-supporting (Carter, Austin, and Trainor, 2012).
- Prepare for and implement elements of effective interagency teams.

Essential Tools: Interagency Transition Team Development and Facilitation (Stodden, et al., 2004)

provides tools for recruitment, establishing good teaming practices and process, and monitoring and evaluating team progress.

- Address interagency collaboration at the local and state level. State and local communities need to address interagency collaboration within and across each of their levels, including service coordination, training, funding, and information sharing (Noonan, et al, 2008).
- Establish comprehensive transition legislation at the state and federal level that strengthens the coordination, services, and blended funding needed by youth with developmental disabilities to achieve successful post-school outcomes (National Council on Disability, 2008).

RECOMMENDATIONS AND POLICY IMPLICATIONS

For more than 25 years, federal legislation has played a major role in supporting the participation of youth with disabilities in secondary and postsecondary education programs, employment, and other aspects of community living. While an important policy framework has been advanced and strides have been made in achieving the goals and intent of this federal legislation, much more remains to be accomplished on behalf of youth and young adults with disabilities as they transition from school to adult life. Achieving improved and more effective transition services must begin with a coherent policy framework that incorporates greater

consistency across public programs in philosophical values, goals, standards, and practices (Johnson, 2012).

This paper has outlined a number of interagency and interdisciplinary approaches envisioned to support youth with disabilities in their transition from adolescence to adulthood. Future policies that are intended to actualize these approaches can only be accomplished by: (a) developing consistent policy goals at all levels, (b) acknowledging self-determination as a unifying principle that connects all disciplines and agencies involved in the transition

process, (c) viewing the transition period as a shared responsibility among and between schools and community service agencies, and (d) maintaining a clear focus and commitment to post-school outcomes and recognizing the need to engage in continuous and sustained evaluations of these outcomes to guide and inform the policy-making process.

Shared Beliefs, Values, and Guiding Principles

The first and perhaps the most essential step in achieving improved transition services for youth with disabilities is through renewed and explicit articulation of clearly stated and consistent values, beliefs, and principles to guide public policies. Currently, the post-school outcomes students achieve must be accomplished through the interdisciplinary and interagency approaches of multiple federal, state, and local agencies.

Transition services are engulfed by a myriad of federal and state laws and procedural requirements that typically must be patched together to meet the school and post-school needs of youth and young adults with disabilities. Given this complex array of public policies influencing the provision of transition services, shared beliefs, values, and guiding principles provide an important mechanism for adding a sense of coherence on what is “most” essential to achieve through federal, state, and local policy development.

This paper has carefully outlined many of these beliefs, values, and principles that are commonly shared by policy-makers, professionals, parents, and young people themselves. From a policy perspective,

these beliefs, values, and principles are intended to: (a) guide and inform policy-makers as to the importance of inclusion and community integration at all levels and in all facets of community life; (b) lead to federal and state policies that promote positive transition outcomes; (c) ensure that transition-related statutory and policy development is driven by an underlying belief of high expectations for all youth; (d) ensure that policies focused on transition planning and the provision of services are based on self-determination and person-centered approaches; (e) ensure that policies address the cultural and linguistic diversity of youth with disabilities and their families when designing and implementing transition programs and services; and (f) ensure that federal, state, and local policies intended to achieve positive transition outcomes should promote interagency coordination and the provision of a unified, flexible array of programs, services, accommodations, and supports.

The realization is, however, that these values and guiding principles are treated in a piecemeal fashion with federal and state laws governing education, postsecondary education, employment, health-care, community living, transportation, and the like functioning as separate, independent programs and sets of services. Substantial and sustained policy advocacy will be necessary for the integration of these “ideals” as common elements of statutory law and procedural requirements, to ensure that young people with disabilities achieve positive outcomes.

Self-Determination, A Unifying Principle

The current consensus among professionals and parents is that we need to actively promote student self-determination, self-advocacy, and student-centered planning. Federal special education policy has supported students' participation in transition services, acknowledging that in order for this planning to be successful, students have to attend meetings and have the skills and opportunities necessary to advocate effectively for themselves. Starting with the 1990 Re-Authorization of the Individuals with Disabilities Education Act (IDEA), transition services were required to be based on students' needs and take into account students' interests and preferences. The IDEA 1997 and 2004 Amendments further supported student participation in transition planning by requiring that they be invited to their IEP meeting when transition goals were discussed.

Recent studies have also shown that having students acquire and exercise self-determination skills leads to more positive educational and employment outcomes (Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, in press; Wehmeyer & Schwartz, 1997). Izzo and Lamb (2002) suggested that schools seeking to encourage self-determination and positive school outcomes for students with disabilities should: (a) empower parents as partners in promoting self-determination and career development skills, (b) facilitate student-centered IEP planning meetings and self-directed learning models, (c) increase student awareness of their disability and needed accommodations,

(d) offer for credit classes in self-determination and career exploration, (e) teach and reinforce students' internal locus of control, (f) develop self-advocacy skills and support student application of these skills, (g) infuse self-determination and career development skills in the general education curriculum, and (h) develop and implement work-based learning for all students.

Although the need for and value of promoting the self-determination of youth and young adults with disabilities in all aspects of their lives is clear, many important questions related to self-determination, self-advocacy, and student-centered planning remain. These questions include the following: (a) how do self-determination and self-advocacy skills develop over the lifespan?, (b) what school characteristics and practices are associated with more effective student self-determination and self-advocacy?, (c) what role can federal special education policy assume in expanding the value and importance of self-determination in achieving positive post-school outcomes?, and (d) what features of families (e.g., cultural values, beliefs and expectations, socio-economic conditions, English language proficiency, family interactions) affect the development of self-determination skills? These and many other questions need to be addressed in order to ensure that self-determination is acknowledged as the unifying principle that connects all disciplines and agencies involved in the transition process.

Interagency Collaboration and Shared Responsibility

Efforts to achieve greater coordination of services to address the lifelong needs of individuals with disabilities have been a longstanding preoccupation of public policy in education and human services. For almost three decades, interagency collaboration has been viewed as the primary mechanism through which students with disabilities achieve positive post-school outcomes in all areas of adult life, including postsecondary education, employment, community living, and other aspects of community life. The realization is, however, that federal legislation in special education and similarly in vocational education, postsecondary education, health and human services, labor, and other service delivery systems cannot compel another agency to participate in the development of transition plans or commit another agency to pay for services, unless that agency agrees to do so. It is unlikely that Congress will dramatically change this situation on behalf of transition-aged youth with disabilities, thus directing professionals and policymakers to establish other mechanisms to improve the coordination and delivery of services.

Since the mid-1970s, this emphasis on the need for improved coordination of services has been urged upon states in the form of federal legislative mandates to establish interagency agreements at both the state and local levels. Because of conflicting policy goals, eligibility criteria, funding patterns, and other factors that differ across agencies and states, many of these interagency agreements carry little force or are difficult to implement with the flexibility

needed to provide appropriate services for youth and young adults with disabilities. Other barriers such as lack of professional knowledge on collaborative approaches, inability of agencies to share information about students across agency boundaries, lack of outside agency participation in students' IEP transition planning meetings, and other barriers have limited effective levels of interagency collaboration. Several policy-related implications should be considered: (a) using written interagency agreements that clarify agency responsibilities for providing and paying for specific types of transition services; (b) establishing key positions funded jointly by schools and adult agencies to deliver and direct services to students; (c) developing and delivering interagency and cross-agency training of professionals; (d) using interagency planning teams to foster and monitor capacity-building efforts in transition; (e) developing more effective strategies for formally engaging students and families in interagency planning discussions; and (f) undertaking evaluations of the effectiveness of local interagency processes in achieving positive adult life outcomes for transition-aged youth with disabilities.

Maintaining the Commitment to Student Outcomes

The first reference to transition services for students with disabilities was included in the Education for All Handicapped Children Act Amendments (EHA) of 1983. Section 626 of the 1983 Amendments, entitled *Secondary Education and Transitional Services for Handicapped Youth*, authorized funding to support a series of discretionary grant programs

intended to strengthen and coordinate education, training, and related services to assist youth with disabilities in the transition process from school to employment, independent adult living, and/or a postsecondary education. From its earlier inception into federal legislation, the intent has been to support youth with disabilities in developing the knowledge and skills necessary for them to achieve positive post-school outcomes. Policymakers, professionals, and families must continue to sustain this focus on achieving positive transition outcomes for youth with disabilities. IDEA 2004 specifically required states to gather information on a minimum set of post-school outcomes focused on employment and access to postsecondary education. This requirement has helped to establish a minimum baseline of knowledge regarding the post-school experiences of young people with

disabilities. A particular need persists, however, to continue to go beyond present approaches. We need improved information on: (a) the longitudinal nature of post-school adjustment into adulthood; (b) studies that document not only access to postsecondary education, but also rates of successful completion and entry into gainful employment; (c) post-school evaluation of students with disabilities who fail to complete their public education programs and are trying to “make it” in our communities; and (d) studies on the financial and emotional impact of the critical transition years on families. Such information must, in turn, be systematically used to inform federal, state, and local policymakers of the continued commitments and investments that must be made to improve the post-school opportunities outcomes for young people with disabilities.

SUMMARY

Achieving improvements in transition services nationally must build upon comprehensive interagency and interdisciplinary approaches. Greater consistency across public programs in philosophical values, goals, standards, and practices to guide the ongoing management of educational and community services to young adults with disabilities is critically needed. Federal and state legislation has served as a primary impetus for addressing the critical transition period and will continue to do so into the future. How we move forward and with what sense of priority concerning the preferences and needs that must be met for individuals with disabilities is a significant question. Addressing

the many challenges associated with transition will require that we engage a much larger audience in our discussions on how best to proceed. This process should include young people with disabilities, parents, professionals, and policymakers that are representative of the diverse populations that reside in the United States, its territories, and tribal communities. Achievement of needed improvements in transition services will require a broad-based commitment to educating all stakeholders and promoting meaningful collaboration at all levels.

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UCEDD/LEND INTERDISCIPLINARY & INTERAGENCY TRANSITION ACTIVITIES, PROGRAMS, OR PROJECTS

Information by State

Center contact information and select program information can be found on the AUCD website and network directory at www.aucd.org/directory.

State & Center	Contact(s)	Programs/Projects
California <i>USC UCEDD at the Children's Hospital Los Angeles at the University of Southern California</i>	Cecily Betz, Co-Chair of Health Care Transition Research Consortium (cbetz@chla.usc.edu)	<ul style="list-style-type: none"> • Nurse-led self-sustaining transition program • Annual Research symposium
California <i>Tarjan Center at the University of California Los Angeles</i>	Olivia Raynor, Director (oraynor@mednet.ucla.edu) Wilbert Francis, Director of Open the Doors to College (wfrancis@mednet.ucla.edu)	<ul style="list-style-type: none"> • California Consortium on Postsecondary Education for People with Developmental Disabilities (www.semel.ucla.edu/opendoors/about/ccpopd) • California Employment Consortium for Youth and Young Adults with ID/DD (CECY) (http://partnershipsinemployment.com/?page_id=20) • Open the Doors to College (http://www.semel.ucla.edu/opendoors)

State & Center	Contact(s)	Programs/Projects
Delaware <i>Center for Disabilities Studies at the University of Delaware</i>	<p>Ilka Riddle, Associate UCEDD Director at University of Ohio, Cincinnati (formerly of the University of Delaware) (ilka.riddle@cchmc.org)</p> <p>Eileen Mary Sparling, Project Director (sparling@udel.edu)</p> <p>Brian Freedman, Director, TEEM Unit (brianf@udel.edu)</p>	<ul style="list-style-type: none"> • Healthy Transition Workshop Series (http://www.udel.edu/cds/health-wellness.html) • Healthcare Transition Initiative/Clinics • State-wide healthcare transition taskforce • Related Publications (http://www.udel.edu/cds/brochures.html) • Transition Education and Employment Unit (http://www.udel.edu/cds/teem.html) <ul style="list-style-type: none"> • Pathways for Life • Junior Partners in Policymaking • Employment Services • Career and Life Studies Certificate • TEEM Projects
Hawaii <i>Center on Disability Studies at the University of Hawaii at Manoa</i>	<p>Robert Stodden, Principal Investigator (stodden@hawaii.edu)</p> <p>Eric Folk, Project Coordinator</p>	<ul style="list-style-type: none"> • Dual Enrollment with Individualized Supports Project (http://www.cds.hawaii.edu/deis/)
Indiana <i>Indiana University School of Medicine, Center for Youth & Adults with Conditions of Childhood</i>	<p>Erin Gladstone, Program Manager (ebgladst@iupui.edu)</p> <p>Mary Ciccarelli, Medical Director</p>	<ul style="list-style-type: none"> • Indiana Transition Book: A Book for Me and My Friends! (http://www.wishard.edu/transitionworkbook) • Transition Interdisciplinary Clinic (http://www.wishard.edu/cyacc) • Be Your Own Boss Chronic Disease Self-Management Program for youth and young adults
Iowa <i>Center for Disabilities and Development at the University of Iowa</i>	<p>Bob Bacon, Director (robert-bacon@uiowa.edu)</p> <p>Judy Warth, Career Connections Program Liaison (judith-warth@uiowa.edu)</p>	<ul style="list-style-type: none"> • Career Connections (http://www.aea10.k12.ia.us/divlearn/careerconnections/index.html) • Success Stories (http://www.aea10.k12.ia.us/divlearn/careerconnections/studentstories.html)

State & Center	Contact(s)	Programs/Projects
Kansas <i>Lifespan Institute at the University of Kansas</i>	Wendy Parent-Johnson, Director of South Dakota UCEDD (formerly of the Kansas UCEDD)	<ul style="list-style-type: none"> Girls at Work (http://www.girlsatwork.ku.edu/) Systems in Sync Health Care Transition Model (http://www.systemsinsync.org/)
Louisiana <i>LSUHSC-Human Development Center</i>	Phil Wilson, UCEDD Director and Project Co-PI (pwilso2@lsuhsc.edu) Richard Hall, Project Coordinator	<ul style="list-style-type: none"> Postsecondary Education for All Collaborative – a TPSID Dual Enrollment with Individualized Supports Model Project (http://www.hdc.lsuhs.edu/peac/index.html)
Montana <i>The University of Montana Rural Institute</i>	Ellen Condon, Transition Projects (condon@ruralinstitute.umt.edu)	<ul style="list-style-type: none"> Partnerships for Transition (http://ruralinstitute.umt.edu/transition/completed_projects.asp) Youth Corps Project Graduate to Work Transition Toolbox (https://sites.google.com/a/pluk.org/transition-toolbox/) Emerging Leader Stories (http://ruralinstitute.umt.edu/transition/EL_stories.asp)
Minnesota <i>Institute on Community Integration at the University of Minnesota</i>	Jean Ness, Technical Assistance (nessx008@umn.edu)	<ul style="list-style-type: none"> Community Integration Transition Committees (125A.22 of MN Statute) E-Connect Mentoring Program, a school based mentoring program (http://ici.umn.edu/e-connect/) Connecting Through Services Project (student engagement intervention) (http://ici.umn.edu/index.php?projects/view/125) Expanding the Circle Curriculum (http://etc.umn.edu/)

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<i>New Hampshire</i> <i>Institute on Disability at the University of New Hampshire</i>	JoAnne Malloy, RENEW Project Director (joanne.malloy@unh.edu) David Hagner, FCTP Project Director (david.hagner@unh.edu)	<ul style="list-style-type: none"> • RENEW (Transition for students with emotional or behavioral disabilities) (http://www.iod.unh.edu/Projects/renew/renew_main.aspx) • Family-Centered Transition Planning for students with Autism Spectrum Disorders (http://iod.unh.edu/Projects/fctp/project_description.aspx)
<i>New Jersey</i> <i>Elizabeth Boggs Center on Developmental Disabilities at the University of Medicine & Dentistry of New Jersey</i>	Deborah Spitalnik, Director (deborah.spitalnik@umdnj.edu)	<ul style="list-style-type: none"> • Interagency Transition Group is facilitated by the Center • Pathways to Adult Life (http://www.state.nj.us/humanservices/ddd/programs/pathways/)
<i>New Mexico</i> <i>Center for Development and Disability at the University of New Mexico</i>	Tanya Baker-McCue, Division Director (tbaker-mccue@salud.unm.edu) Anthony Cahill, Division Director (acahill@salud.unm.edu)	<ul style="list-style-type: none"> • New Mexico Medical Home Portal • New Mexico Youth in Transition Peer and Family Support Program • New Mexico Alliance for Postsecondary Education for Students with Intellectual Disabilities • New Mexico Postsecondary Education Peer Mentor Training Curriculum (http://hsc-moodle.health.unm.edu) • New Mexico Disability Youth Leaders Project • Summary Report: An assessment of opportunities for, and barriers to, postsecondary education in New Mexico for students with intellectual disabilities • Southwest Conference on Disability: A Special Emphasis Strand: “Transition from Adolescence to Adulthood”

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New York <i>Westchester Institute for Human Development at New York Medical College</i>	John Maltby, Community Services (jmaltby@wihd.org) Naomi Brickel, Project Coordinator, Project SEARCH & Think College (nbrickel@wihd.org)	<ul style="list-style-type: none"> • Project SEARCH: Employment (http://www.wihd.org/page.aspx?pid=762) • Think College: Postsecondary Education (http://www.wihd.org/page.aspx?pid=762) • Housing Resources for people with I/DD (http://www.wihd.org/document.doc?id=381) • Individualized supports and Services: Service Coordination, Person-Centered Planning, Benefits Navigation, Guardianship Guidance (http://www.wihd.org/page.aspx?pid=762) • “My Health, My Choice, My Responsibility” curriculum and app (http://www.wihd.org/page.aspx?pid=810)
Nevada <i>Nevada Center for Excellence in Disabilities at the University of Nevada-Reno</i>	Stephen Rock, Director (rock@unr.edu) Scott Harrington, Vocational Rehabilitation/ Employment (sharring@unr.edu)	<ul style="list-style-type: none"> • Community Based Employment Initiatives – Regional forums (http://www.communityinclusion.org/article.php?article_id=317) • Customized Employment Success Project (nced.info/eps2010/2012/08/31/customized-employment-success/) • Career Exploration Summer Camps
North Carolina <i>Carolina Institute for Developmental Disabilities at the University of North Carolina at Chapel Hill</i>	Deborah Zuver, Director, Project STIRS (deborah.zuver@cidd.unc.edu) Donna Yerby, Adult Clinic Coordinator (donna.yerby@cidd.unc.edu)	<ul style="list-style-type: none"> • NC Postsecondary Education Alliance (http://www.cidd.unc.edu/psea/) • NC Postsecondary Education Capacity-Building Summit (http://www.northcarolina.edu/aa_outreach/NC_CACG - Access Granted - MAY 2012.pdf) • Presentations from co-facilitators at state conferences

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North Dakota <i>Center for Persons with Disabilities at Minot State University</i>	Brent Askvig, Director (brent.askvig@minotstateu.edu) Janet Green, A-STEP Project Director (1-800-233-1737)	<ul style="list-style-type: none"> • A-Step (TPSID) (http://www.thinkcollege.net/tpsid-project-abstracts) • Personal Stories: Contact Janet Green
Ohio <i>Nisonger Center at The Ohio State University</i>	Margo Izzo, Associate UCEDD Director (izzo.1@osu.edu)	<ul style="list-style-type: none"> • Project SEARCH (http://www.cincinnatichildrens.org/service/p/project-search/default/) • Summer residential learning communities delivered by OSU + Ohio State School for the Blind • Transition specialist program (indicator 14 data showed positive outcomes)
Oklahoma <i>Center for Interdisciplinary Learning and Leadership at the University of Oklahoma Health Science Center</i>	Valerie Williams, Director (valerie-williams@ouhsc.edu)	<ul style="list-style-type: none"> • Core Competencies for Interpersonal Collaborative Practice (http://www.ouhsc.edu/facdev/interdisciplinary_programs.aspx)
Oregon <i>Institute on Development & Disability at the Oregon Health & Science University</i>	Don Lollar, Director (lollar@ohsu.edu) Charles Davis, Community Liaison (davichar@ohsu.edu)	<ul style="list-style-type: none"> • Self-Determination Academies • Youth-led Transition Programs: Emerging Leaders (mentoring & theater company) (http://www.emergingleadersnw.org/) • Lollar, DJ (ed). Launching into Adulthood: An Integrated Response to Support Transition of Youth with Chronic Health Conditions and Disabilities. Brookes Publishing: Baltimore. 2010. Contributors: George Jesien, David Johnson, Sue Swenson, and Bonnie Strickland

State & Center	Contact(s)	Programs/Projects
<i>Pennsylvania</i> <i>Institute on Disabilities at Temple University</i>	<p>Celia Feinstein, Co-Executive Director (shoes100@temple.edu)</p> <p>Amy Goldman, Co-Executive Director (amy.goldman@temple.edu)</p> <p>Kathy Miller, Director of Supports and Services (millerk@temple.edu)</p>	<ul style="list-style-type: none"> Academy for Adult Learning (www.disabilities.temple.edu/programs/inclusive/aal.shtml) Augmentative Communication and Empowerment Supports (www.disabilities.temple.edu/aces) Empowered Voices: Transitioning Youth and Families Discovering Authentic Lives
<i>Rhode Island</i> <i>Paul V. Sherlock Center at Rhode Island College</i>	<p>Claire Rosenbaum, Community Supports Navigator Project (crosenbaum@ric.edu)</p> <p>Mark Gunning, Master Teacher/Transition (mgunning@ric.edu)</p>	<ul style="list-style-type: none"> Self-Directed Supports (www.sdsri.net) Community Supports Navigator Project (http://www.ric.edu/sherlockcenter/csn.html) Transition Folder (http://www.ric.edu/sherlockcenter/publications/TranFolder.pdf)
<i>South Dakota</i> <i>Center for Disabilities at the University of South Dakota</i>	<p>Wendy Parent-Johnson, Director</p>	<ul style="list-style-type: none"> Plan It Live It Self-Directed Futures Heartland Individual Health Plan and Transition Project

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<p>Utah</p> <p><i>Center for Persons with Disabilities at Utah State University</i></p>	<p>Jeff Sheen, Transition Project Coordinator (jeff.sheen@usu.edu)</p> <p>Robert Morgan, Director, Utah Transition Action Team (bob.morgan@usu.edu)</p>	<ul style="list-style-type: none"> • Utah Transition Action Team (http://www.cpdusu.org/projects/utat/) • Project PEER (http://www.cpdusu.org/projects/peer/) • Interagency Outreach Training Initiative: Supported Education for Young Adults with Psychiatric Disabilities (contact Scott at scott.kupferman@usu.edu) • M.S./M. Ed. Transition Concentration (www.transitionspecialist.org) • New Community Opportunities Training and Technical Assistance subcontract with Independent Living Research Utilization (ILRU) (http://www.cpdusu.org/projects/nco/) • Utah Statewide Independent Living Council – Youth Leadership Committee (http://usilc.org/council/youth-committee)
<p>Vermont</p> <p><i>VT Interdisciplinary Leadership Education for Health Professionals at the University of Vermont</i></p>	<p>Stephen Contompasis, Vermont LEND Director</p> <p>Nathan Blum, Philadelphia CHOP LEND Director</p>	<ul style="list-style-type: none"> • Collaboration with Children’s Hospital of Philadelphia (CHOP) on Transition Planning and IEP <ul style="list-style-type: none"> • http://aapnews.aappublications.org/content/34/1/15.1.full • http://www2.aap.org/sections/dbpeds/resources.asp • Transition Checklist (http://www.uvm.edu/~cdci/tripscy/?Page=TransPlanRes.html&SM=TnsSubmenu.html) • Postsecondary Collaboration – Vermont Family Network (http://www.vermontfamilynetwork.org/wp-content/uploads/2010/09/FT3-GoingtoWorkCollege.pdf)

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<p><i>Wisconsin</i></p> <p><i>Waisman Center at the University of Wisconsin-Madison</i></p>	<p>Daniel Bier, Associate Director (bier@waisman.wisc.edu)</p>	<ul style="list-style-type: none"> • Healthy and Ready to Work (http://www.waisman.wisc.edu/hrtw/publications.html) • Survey of paraprofessionals caring for individuals with disabilities • Transitioning Health Care Checklist (http://www.emergingleadersnw.org/) • Person-Centered, Asset-Based Approach Report (http://www.waisman.wisc.edu/cedd/pdfs/products/health/Statewide.pdf) • Transition Fact Sheets (http://www.waisman.wisc.edu/hrtw/YFS.pdf) • 3-part training guide (http://www.waisman.wisc.edu/cedd/pdfs/products/health/TAHC_2.pdf) • Guidelines for Employers (http://www.waisman.wisc.edu/cedd/pdfs/products/community/10_things_employer.pdf) • Self-Determination Guide Prepared by Paraprofessionals (http://www.waisman.wisc.edu/cedd/pdfs/products/family/Self-Determination.pdf) • Real Life Stories (http://www.waisman.wisc.edu/cedd/pdfs/products/family/WLIIAnyway.pdf), (http://www.waisman.wisc.edu/naturalsupports/pdfs/YS.pdf)

Health Care Transition Resources

- Got Transition? National Health Care Transition Center (www.gottransition.org)
- Florida Health and Transition Services (HATS) (<http://www.floridahats.org/>)

Transportation Resources

<http://www.projectaction.org/Initiatives/YouthTransportation.aspx>

- Mobility Options in Your Community
- Building a Transportation Education Continuum
- Building Awareness in Accessible Transportation: Transit Assessment Guide for Students, Families and Educators (<http://www.projectaction.org/ResourcesPublications/BrowseOurResourceLibrary/ResourceSearchResults.aspx?org=a2GSpnDbrul=&query=Building%20Awareness%20in%20Accessible%20Transportation>)

Self-Determination Resources

www.ngsd.org/everyone/resource-guide

- Zarrow Center for Learning Enrichment, University of Oklahoma (<http://www.ou.edu/content/education/centers-and-partnerships/zarrow.html>)
- Beach Center on Disability, University of Kansas (http://www.beachcenter.org/education_and_training/self-determination/default.aspx?JScript=1)

**A Collaborative Interagency,
Interdisciplinary Approach
to Transition from Adolescence
to Adulthood**

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Several youth and family members
offered input and comments