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**TRANSITION AND TECHNOLOGY RELIANCE:
EXPERIENCES OF YOUTH EXITING HIGH SCHOOL**

Brian J. Dudgeon

A dissertation submitted in partial fulfillment of the
requirements for the degree of

Doctor of Philosophy

University of Washington

2000

Program Authorized to Offer Degree: College of Education

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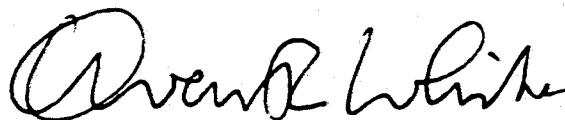
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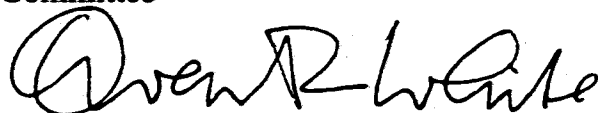
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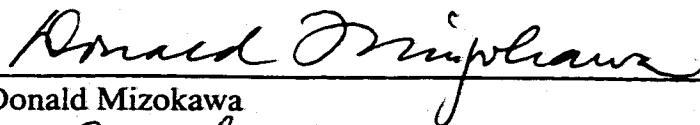


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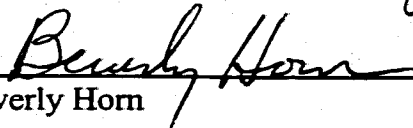
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Abstract

**TRANSITION AND TECHNOLOGY RELIANCE:
EXPERIENCES OF YOUTH EXITING HIGH SCHOOL**

Brian J. Dudgeon

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Objective: For students with special needs, the end of this century brings a long history of education-for-all practices, enthusiasm for uses of technology, and a focus on student's outcomes after graduation. However, disappointing results are observed with some students and particular experiences of those that rely on assistive technology (AT) are just starting to be considered. This study explored AT users' experiences with transition from high school to young adult life.

Method: Eight students or recent graduates participated who had a reliance on AT to enhance mobility and communication. Transition experiences and perspectives were studied with a phenomenological approach wherein interviews, observations, and school records were used in thematic analysis.

Findings: Participants were transitioning toward unclear or tentative outcomes regarding post-secondary education, employment, and independent living. The school's role in transition was acknowledged but not seen as pivotal to outcomes. Participants valued membership in school, but a sense of being a pioneer with disability in the school environment was exhausting and sometimes disappointing. Demands for self-advocacy seemed to generalize as a desire to support others with disability in school and community. Accommodations required deliberate planning, but authority and specificity about alterations were often unclear. Disability and reliance on AT created dilemmas because needs for human assistance continued and was broadened to require technical experts as part of a support network. A recurrent cycle of technology evaluation, selection, acquisition, training, and use inevitably lead to getting stranded because of changing needs, device failure, or new options and features of technology that necessitated re-training. Participants' had few expectations for technology, but were hoping to find greater access and acceptance in the community.

Discussion: Person-centered planning and use of role models with disability are encouraged with transition practices. These suggestions will challenge students' advocacy skills and require them to have a better awareness of what to expect within other community settings. Planning and using accommodations that include technology reliance may be understood better by considering outcomes relative to participation, performance, and productivity. In schools, participation is emphasized, but performance and productivity appear to be critical to young adult life in the community.

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Deep appreciation is extended to the study participants who communicated about experiences with growing up and moving on in life. Not often easy was the sharing of ideas and insights about life with disability and experiences with others at school and in the community. Participant's honesty and reflection about the past, present and future was critical to this research project and the ideas shared and presented for others to gain understanding.

TRANSITION AND TECHNOLOGY RELIANCE: EXPERIENCES OF YOUTH EXITING HIGH SCHOOL

Introduction

Our centenary time brings a state of affairs posing novel opportunity and intimidation for youth with disability. Today's high school students with special needs are among the first to have been continuous recipients of schooling in the *education for all* era. Disabilities have been experiences for a long time, but now uses of technology have become a daily life issue in managing both health and functional performance. Like all youth, those with disability can and must also use information and communication technologies to effectively engage in education and employment. Consequently, expectations for youth that are disabled have perhaps never been greater. Access to education, awareness and growing acceptance of accommodations, and hopes for performance with developing technology lead to potentially bright prospects for youth with disability who are transitioning from school to adult life.

But, what happens during this period? Are these transitions chaotic, or are they ordered, systematic and effective? Chaos arises when the uncertainty of initial conditions leads to unpredictable outcomes. Order exists when conditions are established that lead to reasonably accurate estimates of outcomes. For youth with disability, a number of factors associated with transition create difficulty in sorting out order from chaos. Predicting success is difficult, but forecasting failure is more assured because many adults with reliance on technology are often found to be unemployed or under-employed, live with a dependence on entitlement programs, and may be hidden and uninvolved in community life.

Transition plans and experiences of youth that rely on technology and other accommodations can be systematically studied to sort out important factors influencing their moves into young adult life. This dissertation explores youth that are reliant on the uses of technology in daily living and their experiences with transition from schooling

into young adult life. First, particular challenges that face students who rely on medical, assistive, and/or information technologies are described and discussed. Examined next is the modern emphasis on transition as an outcome issue within education. This review pays particular attention to ways that policy and practices of transition have been promoted and implemented and the outcomes experienced by students who are technology reliant. Next, a method of study is proposed, implemented, and results reported that sought to give voice to students who are technology reliant. Shared are experiences, hopes, and expectations about themselves and transition outcomes that they have sought.

Educators and related services personnel must have a better understanding of the types of issues being faced by these students. Such awareness may help them to more effectively influence goals set by students and families related to transition, and to guide the actions taken to meet desired outcomes. By appraising the experiences of transition, along with the moves toward outcomes being sought, a view of the interactive nature of this period and stage of life is provided. The nature of this inquiry addresses how the personal experience of disability confronts these youth to reconcile the need for reasonable accommodation with the desire to be seen as competent and typical in their activities and pursuit of goals. The process of transitioning from adolescence leads these individuals toward a social identity and experience with disability that challenge the dominant non-disabled culture each time he or she publicly engage in day-to-day activities and events.

The following investigation explores transition experiences by posing the following questions for youth that are technology reliant:

1. What conceptualizations or aspirations are expressed about the preparation and process of transition from school to adult life?
2. What activities and collaborations are experienced or perceived as part of the preparation and process of transition from public education?

3. What initial transition outcomes are expected and how are these transitions understood?
4. How are issues of disability and uses of technology regarded as part of transition planning and outcomes? and,
5. What notions of success in education, employment, independent living, and community participation do participants and their support network express?

Chapter 1: Challenges of transition for youth exiting school

Adolescence, by itself, stirs debate about key factors or experiences that prepare and place youth at the threshold of being adults. Facing youth are quests for identity, autonomy, and intimacy outside the family, independent living, and economic self-sufficiency (Elliott & Feldman, 1990). For youth that experience disability, expectations are that they will have even greater challenges with transition (McAnarney, 1985; Blum, 1992; Blomquist, Brown, Peersen, & Presler, 1998). Chronic illness and disability during adolescence are cast as major threats to mastery of psychosocial skills. These limitations could have "grave, potentially lifelong consequences, both for the individual and for society" (Davis, Anderson, Linkowski, Berger & Feinstein, 1985, p.70). Blum (1995) contended that today's youth with disability are "pioneers on a journey into the future without a road map." Why such worry about children who are disabled? Modern society proposes solutions: schools have special education and social services foster health care, independent living, and work. In America we now promote development and use of assistive technologies that enable school and work performance, and our environments are being altered for better access to all parts of the community. Why should we continue to worry and why should we not have high hopes?

In part, worries about transition outcomes emerge from examining the lifestyle and experiences of young adults who became disabled as children. Despite the presence of special education, "the majority of [its] graduates have not made a successful transition from school to life as an adult in the community" (Schloss, Alper, & Jayne, 1994, p. 215). Case studies of recent graduates with disability document the individual crisis of disability. The everyday drama of young adults with disability is shown to have patterns of drift, moving from one job to the next, no clear or realistic goals, cycles of dependency, sporadic enrollment in post-secondary programs, and a search for support systems or services (Zetlin & Hosseini, 1989). Unlike most of their typically developing peers, the pattern for youth with disability is one of episodic successes and recurrent failures.

Nevertheless, there are also reasons to hope. Some disabled youths are described as “resilient,” (Resnick & Hutton, 1987, p. 796) others are “defiers of negative prediction” (Freeman, Richards, & Groenveld, 1991, p. 365) and some are “an unexpected success story” (Gortmaker, Perrin, Weitzman, Homer, & Sobol, 1993, p. 17). Children and youth with sensory and/or physical disability are among those for whom great expectations are raised (Seelman & Sweeney, 1997; Dorman, 1998). Particular issues for such youth include their dealings with personal (i.e., human) helpers and their use of assistive technologies (West, Mast, Cosel, & Cosel, 1996). Uses of medical technologies (i.e., for health maintenance) and assistive technologies (i.e., for functional mobility, communication, or environmental control) promote a student’s ability to participate in regular education classrooms and other school programs.

The growing number, proportion, and diversity of children with special health care needs has spurred new definitions to acknowledge diagnostic, disability and service needs they represent. “Children with special health care needs are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally” (MacPherson, Arrango, Fox, Lauver, McManus, Newacheck, Perrin, Shonkoff, & Strickland, 1998. P.138). Part of this new definition and discussion brings attention to these children’s needs for medical supplies and equipment, daily living aids, and other technologies that are acknowledged as important parts of accommodations in school. Still, students who rely on technology pose new and unusual challenges related to integration of technology into education and transition to adult life.

The modern idea that higher expectations should be raised for technology-using students may be flawed. Despite an influx of technology options for individuals with disability, and a doubling of assistive technology use in the past 20 years (Scherer & Lane, 1997), no particular improvements in independent living, completion of school, or employment have been observed over a similar period of time (www.nod.org/presssurvey.html#survey). As a result of participatory action research with individuals who used assistive technology to enhance function, Scherer (1993) concluded

that "technology alone is rarely the answer to a person's enhanced quality of life. Assistive technologies can help a person access more opportunities and exercise more options, but they require support services and training, attention to the person's personality, preferences, and capabilities, and the characteristics of the milieu in which the device will be used" (p. 155). Appropriate applications and uses of technology are often complex. A technology's long-term utility, as well as concern for effectiveness, durability, portability, intrusiveness, and dignity needs to be questioned (Williams, 1991). These challenges are intertwined with the array of difficulties for youth that are transitioning from school to adult life. For those with chronic health, sensory or physical disorders who are relying on technology, these and other issues are beginning to be considered. Some of these youth appear to succeed, but more often, their experiences are difficult or unsatisfying (Peraino, 1992).

Why some succeed while others do not challenges those concerned for the welfare of youth. Searching for characteristics or circumstances that coincide with success, and identifying those traits or trials that may correspond with failure has spurred questions among social scientists. With schools having formal and informal mandates to prepare youth for adult years and community needs, educators are among those most interested in researching effective uses of technology in education and impacts on these students' transition experiences and outcomes. Youth that exit high school today are uniquely influenced by the advent of technology and a focus on transition processes and outcomes. These topics are explored next to focus attention on particular issues facing individuals who are technology reliant and to understand how the transition emphasis has come to influence expectations of others and those they have developed for themselves.

The Advent of Technology

One of the reasons for optimism on behalf of students with special needs is the advent of technology (Wehmeyer, 1998; Larsen, 1995; Dorman, 1998; Brodin, 1998). In relation to these students, technology changes impact function in three distinctive ways. *Medical* technology supports health, *assistive* technology enables function, and

information technology enhances learning. Technology change in the late 20th century creates new opportunities and threats for children relying on these devices and systems. Lots of possibility exists (Brodin, 1998); but the advent of technology brings change and requires that new strategies be developed and explored to effectively address students' needs in school and in preparation for adult life.

Medical Technology

Medical devices and aids are used to either avert death or avoid further compromise in health and function. This diverse population includes youth that use ventilators for respiration, parenteral nutrition, intravenous drug use, chemotherapy, renal dialysis, or other device-based techniques to support respiration, nutrition, or excretory function (Ahmann & Bond, 1992). In a 1987 congressional study (U.S. Congress, Office of Technology Assessment, 1987), technology-dependent or technology-assisted children were defined as those who needed both a medical device to compensate for the loss of vital body function along with regular care by a nurse or another trained and skilled individual. At that time from 12,000 to 85,000 such children were thought to require either complex or simple supports, and with changes in health and medical care practices, increasing numbers of technology-dependent children were expected to enter public schools. Various data sources suggest that 30% of children have chronic physical impairments, 7% have limitation in activity, and .2% have severity of limitation needing personal assistance or special equipment to manage activities of daily living (Newacheck, Strickland, Shonkoff, Perrin, McPherson, McManus, Lauver, & Fox, 1998). Also recognized are that these special needs often end up resulting in a 2 to 3 times increase over other students in school absences due to illness.

Management of school placements and performance of children using medical technology, as well as others who are viewed as chronically ill, has received attention both generally as well as with regard to special education. Walker and Jacobs (1984) reviewed historic and modern approaches taken by educators to meet the needs of chronically ill children. Potential problems that may threaten scholastic achievement

include absenteeism, limited alertness and stamina, psychological difficulty, as well as problems with daily management of school scheduling, looking different, and teacher attitudes. In their study, needs such as modifications in curriculum, scheduling, or classroom procedures were often idiosyncratic, episodic, and limited to a few discrete activities. While students with chronic illness have specific needs that are quite diverse, and the numbers of these children are small relative to other populations served in special education. They concluded that attention to these needs could lead to success in sustaining good school performance in regular education classrooms.

Placement of technology-dependent children in general education classrooms is favored based on themes of inclusion and program cost savings (Walker, 1991). In a review of public policy regarding technology-assisted children, Walker notes that support for integration of such children remains problematic and controversial for reasons of liability, expense of technical support, and attitudes of users, fellow students, and teachers. Effective integration of these students is thought to require not just technological strategies, but attitudinal change as well. In a recent study of educational placements, Jones, Clatterbuck, Marquis, Turnbull and Moberly (1996) found that children using ventilator assistance had most often been placed in general classrooms, and when this occurred, families were more satisfied in contrast to children's placement in special education classroom programs. Parents credited the schools with meeting student's needs in academics, health-care, socialization, and psychological-emotional needs.

In special education, children using medical technology and others with chronic illnesses are often assigned to orthopedically impaired (OI) and other health impaired (OHI) categories of disability. The few numbers of medical technology users and the lack of consensus about placement of these children in disability categories makes interpretation of needs and services difficult. Few systematically collected data are available to show how services are being provided to these children, how they are performing in school, and how their transition to young adult life is being addressed.

Assistive Technology

Development and growth of assistive technologies have improved options for individuals who have sensory or physical impairments. Particularly effective has been the development of devices and device systems that enhance function in mobility, communication, and manipulation or other means of environmental control (Johnson, Dudgeon, & Amtmann, 1997). Assistive technology became formally defined in federal legislation, as part of the Technology-Related Assistance for Individuals with Disabilities Act of 1988 (PL 100-407, reauthorized in 1994 and again in 1998), also known as the Tech Act. Assistive technology is defined as:

Any item, piece of equipment, or product system, whether acquired commercially, off-the-shelf, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities

Assistive technology services are defined as:

Any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device.

In 1990, reauthorization of *education for all* legislation, (i.e., Individuals with Disability Education Act (IDEA), PL 101-476), adopted the definition of assistive technology and services and called for provision of these to enable students to benefit from education. Support for assistive technology came forth as students with disabilities were shown to have learned to communicate more effectively, control their environments, and achieve greater mobility (Carey & Sale, 1994; Fein, 1996). Schools thus began to function as advocates for assistive technology to optimize the participation of students in education. Particular attention to uses of assistive technology in special education (Part G IDEA) and transition services (Part C IDEA) are described in legislation and subsequent reauthorization (Galvin & Scherer, 1996). For children who require medical or assistive technologies to benefit from schooling and have no other way to obtain technologies, the schools in effect become the payer of last resort (Martin, Martin, & Terman, 1996).

While high hopes for assistive technology exist among users, families, service providers, and product developers, effective uses of technology to overcome disability are often not realized. Enthusiastic endorsement of different types of assistive technology has given way to cautious optimism when technology is appropriately matched to the right user who has realistic goals (Scherer & Galvin, 1996). High rates of device abandonment and users' dissatisfaction with assistive technology service provision lead to an emphasis on consumer education and active participation in both device selection and product development.

In public schools, assistive technologies are seen as both useful and problematic. Derer, Polsgrove, and Rieth (1996) surveyed several hundred special educators and some related service providers in three States regarding assistive technology use in school settings. Computers, academic software, tape recorders, and video were most commonly cited. Less frequently identified were devices or systems such as books on tape, closed circuit television, alternative computer input software, speech synthesizers, or wheelchairs. Assistive technologies that were least common included adapted calculators, communication boards, alternative computer keyboards, positioning devices, large type books, and hearing aids. Perceived benefits of assistive technology use were cited as being important to environmental factors and instructional factors, as well as to student's personal development and visions of the future. Teachers reported that technology aided the inclusion of students and that this opened doors for them to better participate in instruction within classrooms. Student's who were perceived by teachers as having greater levels of independence because of assistive technology, were also thought to have better self-concepts and have greater visions of their personal futures. Authors of this study regarded that later view as "abstract and idealistic" given the discrepancy between perceived benefits and reporting of existing barriers. Derer et al. (1996) hope that as a knowledge base grows regarding the documentation of change linked to assistive technology, unrealistic expectations about outcomes may diminish.

Others have also cited limitations with the new wave of assistive technology uses in schools. Fein (1996) points out that educators have not effectively determined how

technology can be integrated into the full range of school-related activities and outcomes. After surveying families of students with disability, Parette and VanBiervliet (1990) suggested that more information about assistive technology needs to be provided to school systems and that delivery and use of assistive technology for educational benefits needs greater attention. Wehmeyer (1998) noted that "people with mental retardation and their families are unaware of potential benefit they could derive from assistive technology and, if aware, are not informed about the types of devices available, how to fund them, and where to obtain adequate assessment and training" (p.50).

User's experience with technology in school settings has started to be examined. Todis and Walker (1993) explored the daily uses of technology by 13 students with disability over 12 months. A general finding was that "technology complicates as well as simplifies their lives" (p. 2). They determined that although student training in the use of devices typically occurred at school, preparation of classroom teachers was often lacking. Uses of technology to meet educational objectives were also seen as ineffective or avoided. Staff were viewed as prioritizing their own needs for convenience, cost-savings, and keeping on schedule over their student's needs for self-direction, social customs, self-image, and independence. More effective integration of assistive technology was hoped for if users, families and professionals worked together to identify student goals and values, tie the use of technology to academic, social and personal goals and reevaluate needs and performance frequently.

Hutinger, Johanson, and Stoneburner (1996) addressed, through a case study approach, uses of assistive technology among students classified as multiply handicapped. Each student participant had been served in special programs designed to augment uses of assistive technology, with follow-up study techniques consisting of interviews, observations, and record reviews. Both teachers and parents agreed that the greatest benefit in use of assistive technology was in children's social and emotional behaviors (i.e., self-concept, independence, social interaction, cooperation and exploratory play), but parents tended to report greater levels of improvement by their children than did school staff. Although positive feedback was found among participants,

observations and records were conflicting. Technology was often seen as being used as an alternate way to develop isolated academic skills rather than as a means to integrate or include the student in daily activities. Reciprocal communication was often not among educational objectives, and uses of computers were for drill and practice tasks with no interactive features. It was also pointed out that many technologies used in one classroom or school rarely transition with the student, causing *steps backward* with changes in programs or schools. A general lack of collaboration was observed in accessing and using assistive technologies, with little to no planning for improving uses of assistive technologies found in individualized education plans (IEP).

In a direct survey of teachers who had been involved in accommodating students who used assistive technology, McGregor and Pachuski (1996) found that most teachers were not satisfied with the ability to integrate this technology with their teaching. Equipment complexity and technical support needs, fiscal resource constraints, and need for additional training were identified as barriers to effective use of assistive technology in the classroom environment.

Recent literature on uses of technology in schools continues to be disappointing. Dudgeon, Massagli, and Ross (1997) appraised the school function and performance of students with spinal cord injury, a diagnosis characterized by reliance on medical and assistive technology. They found a high percentage of students having less than optimal success with medical device routines, such as for toileting and respiration. Students were also found to have had routine needs for human assistance when using assistive technologies such as wheelchairs, and adaptive written communication technology. Suggested was that while schools have a long tradition of accommodation, the nature of approaches seem to have sought participation by students rather than performance. A lack of emphasis on competitive performance in the classroom was proposed as a factor that perhaps limits students' perceived success and abilities to perform in the workplace.

For youth with sensory as well as physical disability that rely on assistive technology, further study of their experiences is needed. To date, transition research and

programs have not addressed the new phenomena and circumstances that youth face as they transition with technology from schools to community life.

Information Technology

Another type of technological change impacting students with special needs is occurring in classroom instruction and access to information systems. Educational technology, besides that used in mathematics and science curriculum, has moved quickly into everyday communication. Computer based technology approaches for information acquisition and interactions have grown briskly. Now the Internet world of information retrieval and sharing brings new challenges. Now recognized are demands for technology competency in higher education, and reasonable accommodation to include computer access (Lance, 1996). For some time, workplaces in America have been developing needs for skilled use of technology in production as well as information processing. This brings stress to the need for new workers (i.e., high school graduates) to have higher skills in uses of technology (Braden, 1988).

Teachers' perceive effects of computer use in classrooms as having many benefits relating to students' enthusiasm and providing special opportunities for both the gifted and special needs student (U.S. Congress, Office of Technology Assessment, 1988). Applications of technology in education are seen in computer assisted instruction, mathematics and science, multimedia programs, database management, word processing, language arts, and electronic networks. Computers offer opportunities for interaction, precision, and consistency as well as providing dynamic representations of concepts, phenomena, or relationships.

Linking students with special needs to educational technology has become a particular concern. Given their history with access challenges, Vanderheiden (1987) warned that computers . . . have the potential for becoming the greatest new handicap disabled persons will face. But despite this caution, optimism and high hopes for computer access are evident. Lewis (1993), in her book on special education technology, reports that amazing changes are taking place in lives of people with disabilities because

of new technologies and that one change is to make learning easier. She contends that technology is an important part of the special education experience for students with disabilities, and one that cannot be ignored if we are to prepare students for their future roles as active, participating members of our communities.

Capacity and fluency with use of information technologies is a concern for all youth, but can be an even greater barrier to individuals with disability. For example, poor access to the Internet and other modern sources of information is akin to the barriers designed into tall buildings that had steps and stairs with no ramps or elevators. As greater amounts of daily business moves toward information technology, access by those using different means of control are likely to be greatly challenged by web-page designs only for visitors with vision, hearing, and skilled computer mouse control.

The advent of technology and infusion of devices across home, school and other community environments requires new solutions to assist students in preparation for adult life. Those who are technology reliant are of low incidence, but present highly complex needs. In terms of special education designations, technology has the clearest demonstrated benefits and greatest uses among those with sensory impairments, and physical dysfunction due to orthopedic and/or other health impairments. Technology reliance brings with it new performance demands that challenges students themselves, their families, and the communities in which they live. Immersion in technology comes at a time of new emphasis on transition and adult outcomes for youth with disability.

The Transition Initiative

More than two decades have passed since public policy and law coalesced to mandate that all children, regardless of capacity, is provided with a free and appropriate public education in a least restrictive environment (PL 94-142, 1976). Since that time the nature of this educational mandate and scope of programs have evolved. What began as special schools and dedicated classrooms for qualified students with special needs shifted toward mainstreaming of these children within general school programs. Education has now moved toward inclusive schools and classrooms in which all students participate and receive necessary services. Linkages among school programs and other public services

have also led to early entry for some children to educational resources (i.e., birth to age 6) and later school programming to assist near graduates in transitioning to adult life (i.e., age 16 through graduation or through age 21).

The evolution of school based programs for a child with special needs was largely a consequence of outcome appraisals. Existing procedures and assessment of immediate outcomes has often inspired educators to challenge current policies and practices and make new suggestions for better approaches to meet students' needs. In relation to outcomes such as completion of school, success in employment, independent living, and other aspects of community life as adults, the news about youth with special needs has been discouraging. After the first decade of special education and related services under PL 94-142, Madeline Will (1985), described the results as "disappointing and embarrassing" (p. 80). Representing the Office of Special Education and Rehabilitation, Will pressed for the transition initiative that re-focused education toward employment. The initial priority of transition related to rights to vocation and supports for working life. Halpern (1985) elaborated on the concern for transition as a bridge to the adult years. He re-focused attention on employment, as well as residential living, social as well as interpersonal networks, and other features of community living. These concerns became expressed in the Individuals with Disabilities Education Act (1990) [PL 101-476] in which transition services are described as:

a coordinated set of activities for a student, designed with an outcome-oriented process, which promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, and community participation.

[Such services are]. . . based on the individual student's needs, taking into account the student's preferences and interests, and shall include instruction, community experiences, the development of employment and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation (PL 101-476).

Simplified, the transition mandate calls for a process that envisions the needs of students in the adult world and prepares him or her for that reality. Services relating to transition assistance often include: 1) notification of parents regarding IEP meetings and transition planning, 2) participation in meetings of students and representatives of other agencies that are likely to be responsible for providing or paying for transition services, 3) IEP content addressing instruction, community experiences, and development of employment and other post-school adult living objectives, and 4) designation of agency responsibility for linkage and financial responsibilities associated with provision of services (Dunn, 1996).

Although the concept of *best practices* emerges in education and is applied to practices like transition, research specifying and verifying practices often lags behind. After nearly a decade of transition mandates, a persistent impression about students with special needs is that many do not fare much better today than they did before. Fault may be attributed to both schools' practices and an unwelcoming community to which youth transition. Among special education recipients who even stay in school, the overall report is that 1) few go on to graduate from post-secondary education, 2) few are competitively employed at wages and with benefits that meet their basic needs, and 3) many are described as having chaotic lives with continued dependence on entitlement programs (Blackorby, Edgar, & Korterling, 1991). College bound students with disabilities may also not be faring well. A recent survey showed that few college bound disabled had engaged in career exploration activities like job shadowing, employment, or volunteering (Hitchings Luzzo, Retish, Horvath & Ristow, 1998). "Most of the students with disability cited little or no knowledge of the skills required in the careers in which they expressed an interest" (p.27). Barriers to successful transition by young people with disabilities continue to be observed and attributed to low expectations by parents and other significant people in the community, lack of knowledge of existing career and vocational education services, and lack of self-advocacy skills (Blomquist et al., 1998).

Opinions about the effectiveness of transition practices and outcomes stem largely from research by educators and other social scientists. Phelps (1992) contended that as the quality improvement movement sweeps America, transition practitioners would need

to systematically collect and evaluate information. They will particularly need to appraise the efficacy of existing school-to-work transition programs from perspectives of students and families, employers, and others in the community. He further suggests that a research-based practice in educational settings must develop, that best practices are subject to rules of evidence, and practitioners should gauge practice decisions based on evidence.

Best Practices and Transition Evidence

Transition outcome research began soon after the start of the transition initiative. Hasazi, Gordon and Roe (1985) were among the first to report on longitudinal outcomes of students who had been special education enrollees. Their sample was comprised of 462 students who had received special education in Vermont and had exited school between 1979 -1983. Specific reviews of school records and structured interviews with 301 available students, parents or other knowledgeable informants were carried out. Findings from this cohort of special education students were regarded as startling and spurred debate and commentary about both the effectiveness of special education and appraisal of outcomes. Their findings, reconfirmed in later samples of 133 youth with and without disability (Hasazi, et al., 1989), were that when compared to students in regular education: 1) dropping out of school was more common for special education students; 2) students with disability who found work did so commonly through a self-family-friend network, but were unlikely to have paid work experience during high school; 3) students with disabilities were not as likely to be employed after leaving secondary schools; and 4) if employed students with disabilities worked fewer hours at lower wages.

Edgar (1987) reviewed outcomes of special education students from Washington State who left school by dropping out, aging out, or graduating. In this series, he reported two disappointing trends. The first related to deficient work experience and levels of salary, as only 18% earned more than minimum wage and only 5% of graduates, other than those with mild disabilities, earned a minimum wage. A second finding was that the special education population was transient, with high numbers of students who drop out and disappear from secondary schools. Considering these findings and other indications,

Edgar posed questions about the justification for special education and challenged its mission and methods.

As one of the most frequently cited articles on secondary outcomes, Edgar's challenge was taken up by special educators and has been reflected in a plethora of articles suggesting standards for how to best address transition of students with special needs. Throughout special education, consensus opinion of expert educators who describe state of the art practice is characterized by the label *best practices*. Westling and Fox (1995, p. 42) portrayed "best practices" as a changing landscape impacted by the interaction of social values, legal mandates, professional consensus, and empirical research. They contended that the final basis for arguing that a particular practice is "best" is if research has been conducted to demonstrate its effectiveness, with the goal of research to improve practices that are socially valued.

Wehman (1990) was the first to propose a set of standards that he felt reflected best practices for transition. He stressed the importance of individual student choice with family input, use of local community based factors with the sharing of resources, and the planned collaboration with adult service systems as well as school to business.

Specifically, he proposed the following best practices for transition:

1. Use of individualized transition planning as part of the IEP planning process,
2. Community based instruction,
3. Integrated schools and classes,
4. Direct involvement of family and friends, and
5. Job placement

These suggestions subsequently were incorporated in reauthorization of special education (e.g., IDEA, 1990) and were elaborated on by a variety of authors in special education and related services (Peraino, 1992; Steere, Rose, & Gregory, 1996). Many elements of transition are expressed in a teaching model proposed by Severson, Hoover, and Wheeler (1994) (see Figure 1). The model reflects an ecological approach and highlights a number of components impacting transition. These ideas include parental/student input, interagency collaboration, and school programs that are integrated,

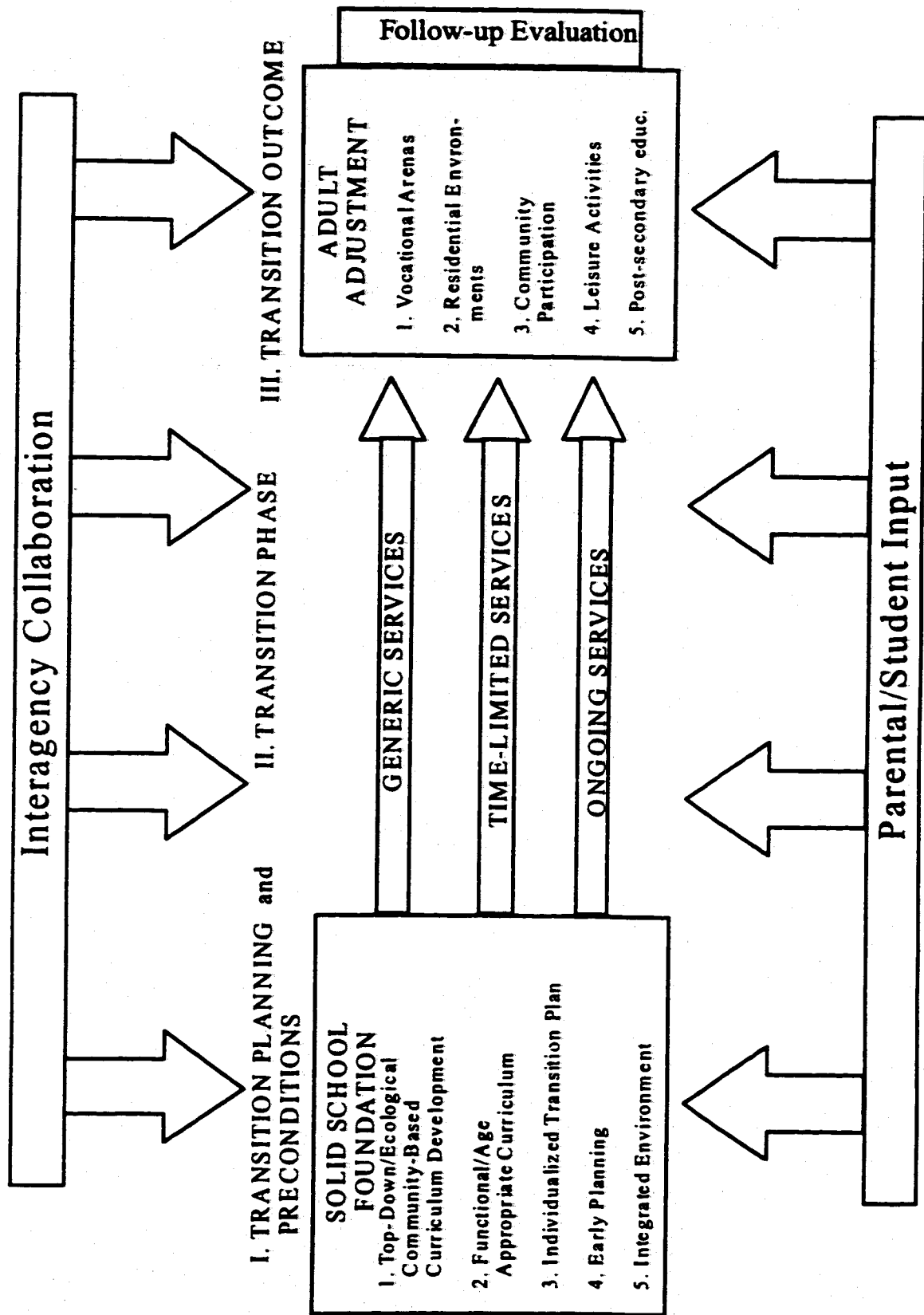


Figure 1: Integrated Transition Model: from Severson, Hoover, and Wheeler (1994)

community based, and individually tailored. Active bridging of services is suggested to meet outcomes in employment and post-secondary advancement, independent living, community participation, and social satisfaction.

With the transition initiative and subsequent education mandates, schools have sought to organize approaches and systems to address transition. Kohler, DeStefano, Wermuth, Grayson, and McGinty (1994) proposed a consensus model for effective and exemplary transition programs and then appraised reports for key elements to be replicated in newly developing programs. They suggested that the most commonly cited characteristics of transition programs were parent involvement, community based instruction, community-referenced curriculum, interagency coordination in service provision, students participation in integrated or least restrictive settings, interdisciplinary transition planning, and vocational assessment with use of employment services. Their findings reflected what has been adopted as "best practices," yet they continued to note that strong empirical evidence in support of these practices is not found. They expressed some pessimism, noting that until we see better transition outcomes being experienced by youth with disability, it will be difficult to guide service programs.

Although the suggestion of best practices, conceptual models, and program descriptions are abundant, research that confirms these beliefs has been sparse. Literature regarding the study of transition has taken different forms, but the general consensus is that transition research is "soft" and more rigorous testing of variables, including practices, is necessary (Greene & Albright, 1995). Follow-up and follow-along studies have been conducted, as well as other inquiries regarding procedures and outcomes of transition. This literature has subsequently been subject to comprehensive review. Kohler (1993) contended that outcomes of youth with disabilities exiting public schools had not improved significantly during the last decade. She sought empirically supported evidence pertaining to best practices. Noting the scarcity of research data she reviewed 49 documents reflecting 46 studies using either follow-up methods (n=18), pseudo or quasi-experimental design (n=20), or theory/opinion pieces (n=11) appearing between 1985-1991. Findings were rated as *substantiated* if data linking results or outcomes with

specific practices were provided, and *implied* if authors suggested a link but showed no specific data-link between practices and outcomes. Substantiated vs. implied practices are presented in Table 1. Kohler argued that these transition practices have been socially validated to some degree, but now must be subjected to empirical validation. With a rather lenient criterion for "substantiation," she acknowledged that there exists "no hard scientific evidence, obtained through rigorously controlled experiments" (p.116). Kohler recommended that, as we become aware of the lack of empirical support for transition-related best practices, we must seek to better define variables, as well as transition practices, and become even more outcome oriented.

Johnson and Rusch (1993) also reviewed research articles and professional literature since 1984 to appraise the transition initiative. They focused on follow-up and outcome tracking, identification and analysis of best practices, policy research, and analyses of model demonstration projects. Outcomes reflecting employment, social-interpersonal status, and residential living were most commonly reported, with some attention to community access and utilization, personal independence, and post-secondary education and training. They too concluded that these outcomes had not changed appreciably from data reported prior to the transition initiative, and that best practices research offers sparse empirical evidence to only support uses of vocational training, parent involvement, paid work experiences, and social skills training as part of transition services. Although these reviews report a similar lack of evidence for most best practices themes for transition, mandates for specific transition service components continue to be declared (Dunn, 1996).

Recent research has sought to observe uses and benefits of best practices in transition. Grigal, Test, Beattie, and Wood (1997) studied IEPs for evidence of transition strategies and services that were being used. Findings were again disappointing. For example, although Grigal et al. asserted that learning self-advocacy skills is essential for successful transition planning, goals involving choice, self-determination, and decision-making skills were not mentioned in transition plans. Their impression was that while documents meet transition obligations, goals were written in broad, general terms;

Table 1: Breakdown of Best-Practices Evidence (From Kohler, 1993)**Substantiated Practices (based on follow-up or quasi-experimental studies)****Vocational training****Parent involvement****Social skills training****Paid work experiences****Follow-up employment services****Employer input****Integration (LREI) mainstreaming****Daily (life) skills training****Employability skills training****Other factors implied by literature but not substantiated by research:****Interagency collaboration/service delivery****Individual plans/planning****Interdisciplinary transition teams****Community based instruction****Vocational assessment****Community referenced curriculum****IEP reflecting transition****Career education curriculum****Formal interagency agreements****Early transition planning****Academic skill training**

timelines were imprecise, follow-up was scarce; and there was minimal collaboration with adult service agencies. A lack of comprehensive transition planning indicated to them a need for improved collaboration, and better preparation of practitioners for work in collaborative service models. In contrast, Collet-Klingenberg (1998) explored for the use of transition best practices and found that participants with learning disability were satisfied with vocation-related activities (e.g., work experiences). Also observed was that instruction in self-determination was an integral part of the transition program, but that this feature was undocumented and apparent only to a trained observer. Emphasized in this study was the importance of designated school transition planning teams and the supports received from community agencies. Research regarding transition practices and outcomes continues and the following section explores trends in recent literature.

Trends within Transition Research

Preparing young people for adult life is a responsibility shared by families, schools as a part of the community, and the young people themselves. This perspective takes shape in accounting for research about transition for youth with disability. Three sorts of inquiry have developed: personal traits of students, the family systems in which children function, and the design and use of schools and other community resources.

Personal traits and transition.

Children with disability are the focal point of transition research, and specific attention to these students' personality traits and styles has developed. The challenging circumstances facing youth with disability fuels concern for these individuals' senses of self. As an example, King, Shultz, Steel, Gilpin and Cathers (1993) compared and contrasted the self-evaluation and self-concepts of male and female adolescents with physical disabilities encompassing diagnostic categories of cerebral palsy, myelodysplasia, or cleft lip/palate. Data analysis compared and contrasted subject data with age and gender matched normative samples from standardized assessments of self-esteem, self-concept, self-acceptance, self-efficacy and values. Social self-efficacy was the only factor to account for a meaningful amount of the variance in independence and

variance in persistence. Findings were consistent with Bandura's (1982) concept of self-efficacy and one's tendency to act in a more persistent manner. These adolescents' abilities to express their opinions and resist pressure from others to conform, and their higher task and goal persistence, call for further analysis of self-efficacy as a strong contributor to life success. Strauser, Waldrop, and Jenkins (1998) cited the need to address Bandura's self-efficacy concept relating to student's beliefs (efficacy expectations) about their capacity to perform, particularly in relation to school to work programs. Noted were Bandura's four means that one obtains efficacy information: performance accomplishments (mastery experiences), vicarious experiences (role models), verbal persuasion (encouragement), and emotional arousal (dampening of anxiety and fear associated with activities).

Within special education, persistence and perseverance have been termed *self-determination* (Wehmeyer, 1992). This trait has been proposed as a salient characteristic associated with positive transition outcomes and an important feature of instructional practices such as in creation of opportunities in choice making, problem solving, goal setting, and self-observation. Self-determination refers to an individual's attitudes toward and ability to act as a primary causal agent in one's life, and to make choices free from undue external influences. This characteristic within students draws attention to specific kinds of experiences they have, what they witness similar people doing, and the expectations placed on them by others. Wehmeyer suggests that self-determination is reflected in four essential characteristics: autonomy, self-regulation, psychological empowerment, and self-realization. Developing and using the *Arcs Self-determination Scale* for use with youth who are cognitively impaired, Wehmeyer & Schwartz (1997) demonstrated that, self-determined students were more likely to achieve positive adult outcomes, including being employed at a higher rate and earning more per hour. However, no special influence was observed between self-determination and other measured transition outcomes (e.g., residential status, higher education or training, or community engagement).

Schloss, et al., (1994) suggested that self-determination is a key variable in training and measurement of performance and that assessment of this construct is best handled through unstructured interviews and observation, recommending such methods for appraising post-school outcomes in relation to self-determination. Speckman, Goldberg, and Herman (1992) did use such qualitative analysis to learn that students with learning disability experience ongoing learning problems, additional life stresses, and tend to be late-bloomers. Successful learning disabled students had realistic adaptation to life events (i.e., they are self-aware, proactive, show perseverance, and emotional stability), demonstrated appropriate goal setting and goal directedness, and used effective support systems. A mullet-element program approach that included inclusive education and community skills training as been advocated and used with adolescent students who have multiple disabilities to enhance their social and classroom participation and their self-determination (Sowers & Powers, 1995). Similar programs have been developed to enhance self-determination with students who have other types of disability (Durlak, Rose, & Bursuck, 1994; Field, 1996).

Wehmeyer (1996) developed a set of recommendations to educators designed to enhance self-determination, yet research on the effectiveness of such interventions has been negligible (Wehmeyer & Lawrence, 1995) and application of this construct to students who are assistive technology reliant has not been reported. An emphasis on empowerment of student's self-determination and family's ability to promote such skill continues to be proposed as a goal of transition services (Szymanski, 1994). However, Merchant and Gajar (1997) point out those self-advocacy skills are often not taught at the high school or post-secondary level. "For years students with disabilities have been dependent on teachers, support staff and parents to make decisions, evaluate performance and serve as their advocates" (p. 224). They propose that this must change because individuals need to be able to self-advocate for services and accommodations. An individual's ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs and rights need not wait for the adult years. The burden involves "making informed decisions and taking responsibility for those decisions" (VanReusen, et al., 1994 pg. 1).

Family systems and transition.

A second theme to develop in transition research has been to focus on influences that families have on transition planning as well as post-school outcomes. Some describe the ending of high-school as "the second shock" for families who have a child with disability; whose first shock was starting school in the first place (Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995, p.3). Families of children who are disabled face inevitable change with transition, characterized as a dilemma about letting go, but needing to advocate more given the shift from entitlement programs for children to eligibility criteria within adult services. Although all family systems face changes with transition, Whitney-Thomas and Hanley-Maxwell (1996) pointed out that the strain on families that include children with disability is more intense. Parents who had children with disability showed greater discomfort with the transition process, and had less optimistic visions about their child's future than did parents of children without disability. Greatest discrepancies were seen with issues of moving out, economic self-sufficiency, expanding social networks, marriage, needs for assistance, range of vocational and residential options, decision making and responsibility. Thorin, Yavanoff, and Irvin (1996) pointed out that "although cultural norms include less active parental involvement in the daily life of the young adult child, day-to-day reality may suggest a need for even greater parental advocacy and oversight . . ." (p. 117).

Family roles in transition planning have started to be formally addressed. Morningstar, Turnbull, and Turnbull (1996) appraised how students felt about their family's contributions in transition planning. Input received from family was important to participants, but unclear was a family's specific involvement in formal transition planning with schools or other agencies. Specific impacts that families had on nurturing self-determination were also unclear. In an extensive review of family involvement with transition, Nisbet, Covert, and Schuh (1992) discussed the mixed point of views and confusion over families' rights and responsibilities in the transition process. They promote a shift in service delivery system toward individualized supports and family

leadership, away from traditional models based primarily on leadership from disciplines such as special educators and related services personnel.

Methods such as personal futures planning (Wehman, 1996) and other means to promote circles of support have been recommended (Whitney-Thomas & Hanley-Maxwell, 1996), and demonstrated in case reporting (Salembier & Furney, 1995). Person-centered planning, by various names has the following goals (Hagner, Helm, & Butterworth, 1996):

- a) primary direction from the individual in shaping the planning process and formulating plans,
- b) involvement of family members and friends the planning process and reliance on personal social relationships as the primary source of support to the individual.
- c) focus on capacities and assets of the individual rather than on limitations and deficiencies.
- d) an emphasis on settings, services, support, and routines available in the community at large rather than those designed for people with disabilities; and
- e) an approach to the planning process that tolerates uncertainty, setbacks, false starts, and disagreements.

Subsequent study of person centered planning methods reveals some positive and negative findings. Hagner, Helm, and Butterworth (1996) followed the process of planning used with 6 individuals who used person-centered planning facilitated by trained professionals. They found that facilitators' had a tendency to behave according to prior roles and training, and that transition outcomes were attributed some to the planning process, but also evident were a number of "unplanned positive outcomes." The process used continued to result in "constraints on equal participation," "difficulty keeping it positive, and excessive control on planning. Authors used the expression "this is your meeting" to remind participants about the focus the process should have. Despite these procedural limits, they concluded that "whole-life planning . . . seemed to mobilize the ability of individuals and their support networks to take advantage of opportunities, provided and increased sense of community, shared responsibility and clearer focus generated by the process " (p. 168). A key element with these approaches is attending to

the preferences of the students or individual of focus. Reid, Everson, and Green (1999) reported that although person centered planning may identify some accurate preferences for people with profound multiple disabilities, the approach should be used cautiously and be supplemented with systematic preference assessments to assure accuracy and relevancy with the individual of focus. They found, with participants who had physical disability and mental retardation, that item and activity preferences identified in person-centered meetings were not found to be preferred later on when individuals were given a choice to participate.

Aside from transition planning procedures, parents' desires for their children's outcome have also been assessed. Hanley-Maxwell, Whitney-Thomas, and Pogoloff (1995) reported about parental desire to have their children develop friendships, fill free time, and find residential alternatives. These parents of children with mental retardation expressed faith in transition processes being proposed by schools. McNair and Rusch (1991) surveyed mothers of 14-25 year old youth with mental retardation about transition. These parents had expectations that their children would not live at home, but would work in the community, and earn a wage greater than or equal to the minimum. They found, however, that a significant number of mothers were unaware of any transition program for their offspring, even though virtually all desired involvement with school in planning.

Families of children with disability face dilemmas. Dilemmas occur when decisions present conflicting choices with equally problematic outcomes for the family. Among families with children who have cognitive and behavioral impairments, six dilemmas are most common (Thorin, et al., 1996):

- 1: Wanting to create opportunities for independence for the young adult versus wanting to ensure that health and safety needs are met.

- 2: Wanting a life separate from the young adult versus wanting to do whatever is necessary to assure a good life for him or her.

- 3: Wanting to provide stability and predictability in the family life versus wanting to meet the changing needs of the young adult and family.

4: Wanting to help create a successful social life for the young adult versus wanting to have less involvement in his or her life.

5: Wanting to avoid burnout versus wanting to do everything possible for the young adult

6: Wanting to maximize the young adult's growth and potential versus wanting to accept the young adult as he or she is.

The burden on a family's hopes and resources may be substantial. Addressing the stress that family may experience with transition, Mellon, Wilgosh, McDonald and Baine (1993) found that parent's concerns were most evident with the lack of choices and options, needs for advocacy, and questioning of their child's maturity and individual vulnerability. In evaluating the roles of family, Brotherson, Berdine, and Sartini (1993) acknowledged burnout among families. They suggested that parents develop expectations for their children to have a community life and that they needed to recognize the importance of their own contributions to these outcomes.

Communities within which transition occurs for youth with disability may also present barriers. For example, employment problems facing young adults are not unique to people with disabilities. Nearly 20% of Americans aged 16-19 live in families with incomes below the poverty line, and nearly 30% live in poor or near-poor families (Sum, Harrington, & Goedicke, 1987). This is a particular concern given the disproportionately high number of special education students who come from families that have low incomes and single parenting (Hodapp & Krasner, 1995). "Children from disadvantaged families are disproportionately represented in the population of children with existing special health care needs" (Newacheck, et al., 1998 p.119). Overall, the greater proportion of children with disability are school aged (vs. toddlers), boys, African American, have household incomes below federal poverty level, are from less educated households, and are more likely to be from single parent families.

Sum et al. (1987) contended that employment is now being sought in a rapidly changing workforce, where some kinds of jobs that were common in the past have

become uncommon or ceased to exist. Modern transition services will likely need to redevelop relationships with the business community so as to prepare youth for contemporary work environments (Kochhar & West, 1995). Presently, entry-level jobs for unskilled workers often pay poverty level wages and offer no benefits or advancement opportunities. The employment situations of many young people are strongly correlated with family income. For instance, only 26% of teens from families with incomes at or below the poverty level are employed, while 48% of teens from families substantially above the poverty level are employed. Teens from poor families are worse off than teens from more affluent families, and they will likely continue the cycle of poverty.

The ongoing challenge facing families of children with disability and communities within which they Thorin and Irvin (1992) highlight transition. They point out that as "increasing numbers of young adults with severe developmental disabilities are ending their years of entitlement to an education and embarking on the road to unfamiliar and uncertain futures as adults. . . [it will be] important to understand and address related concerns of the families whom these young adults depend on for support" (p. 38).

School systems and transition.

Schools have traditionally been looked to for optimizing the success of our nation's youth (McWhirter, McWhirter, McWhirter, & McWhirter, 1993; Pallas, 1993). Public concern about the plight of children and youth that are disabled has in part been directed toward schools to ensure these students' rights of equal access and opportunities within education. "Students are termed 'disabled' because they have real, persistent, and substantial individual differences and educational needs that regular education has been unable to accommodate" (Terman, Lerner, Stevenson, & Behrman, 1996, p. 5). From 8% to 11% of public school children are identified for special education services. Heterogeneity among such children means that some have highly specialized educational needs, such as those using technology, while others have more routinely addressed issues. Common instructional needs within special education include: greater than normal

consistency and intensity of instruction, greater individualization of both academic content and pacing, and greater emphasis on behavior management.

A concern facing schools and special education approaches is that while approximately 12% of students enrolled in schools are officially designated as having disability (Kaye, 1997), 1% to 12% of special education students over the age of 14 are declassified each year. Regular education has had great difficulty accommodating students with special learning needs (Terman, et al., 1996). Declassification, coupled with moves toward inclusion, brings new challenges to regular educators in altering instruction to meet all students' needs. This impacts classrooms and in preparation of students for life as adults in the community. A current emphasis on school-to-work outcomes for all students brings attention to our nation's values and expectations. Schools are to provide academic skills as well as career knowledge and exploration skills leading to work experiences and competency (Benz, Yavanoff, & Doren, 1997). As previously described, how students fare in school, and how they subsequently transition to young adult life is of great concern based on past and current outcome data.

Addressing new transition mandates

Our perspective on the success that youth with disability experience has been shaped in recent years by examining the criteria used to judge the effectiveness of newly created outcome-based transition services. DeStefano and Wagner (1993) described a focus on *outcomes* as being a concern for the individual's achievement, status, and behavior. After exiting schools, outcomes thought to best portray successful adult status have been grouped as those related to employment, post-secondary education and training, social-interpersonal skills, residential status, community access and utilization, and personal independence. However, the specific study of youth with disability who are most likely to be technology reliant has probed only for outcomes regarding engagement in employment or post-secondary education, and residential status (Peraino, 1992; Griffin & Wehman, 1996).

Transition outcomes and youth with technology reliance

The bulk of outcome research has focused on all special education enrollees. This pattern places emphasis on outcomes of students with learning disability, the largest category of services. Specific analyses of post-school outcomes of disabled youth have been conducted based on 'categorical' as well as 'non-categorical' approaches. Lavigne and Faier-Routman (1992, 1993) cite the 'non-categorical' approach as being more ecological, and preferred because it places an emphasis on the likeness of disability experiences. Unfortunately the non-categorical approach is also likely to miss particular experiences of youth with quite different impairments (Dunn, 1996). Those with persistent cognitive impairment have much different needs for accommodation than those with behavior, sensory, or physical impairments as primary causes of disablement.

Attention to students with disabilities resulting in reliance on technology demonstrates that they too experience relatively poor outcomes (Peraino, 1992). However, specific or unique outcomes of youth with health, sensory or physical impairments have generally not been reported, or have been obscured by grouping these students with others. Within schools, students like these account for less than 3% of those served by special education and related services (Kaye, 1997). In landmark follow-up studies (Hasazi, Gordon, & Roe, 1985; Hasazi, Johnson, Hasazi, Gordon, & Hull, 1989) categories of disability are not indicated, or the small numbers of those with technology reliance are either blended or re-combined with other categories (Edgar, 1987; Fairweather & Shaver, 1991). Mithaug, Horiuchi, and Fanning (1985), doing follow-up on 234 students in Colorado who graduated in 1978 and 1979, defined physically disabled as those with vision, hearing, and orthopedic disabilities. They did not isolate independent outcomes in follow-up and commented that students with physical disability were over-represented in their sample (n=19%). Scuccimarra and Speece (1990) included two students with physical disability in their sample of 65 students with mild handicaps, but did not isolate findings in their 2-year follow-up of students graduating from self-contained special education classrooms in 1983-84.

Regardless of grouping within studies, specific outcomes that include physically disabled youth report a high incidence of unemployment, underemployment and financial

insecurity (Gortmaker, et al., 1993), and concerns with achievement of autonomy, independent living, and social maturation (Resnick & Hutton, 1997; Blum, Resnick, Nelson, & St. Germaine, 1991; Kokkonen, Saukkonen, Timonen, Serlo, & Kinnunen, 1991). West, Mast, Cosel and Cosel (1996) interpreted transition outcome studies as showing that few students with OI or OHI were involved in school or community-based work experiences, vocational training, or other career development and job placement experience. Such students were also not connected with adult service agencies. In general their impression was that a student with physical disability fares no better when compared to students with other types of impairment. Griffin and Wehman (1996) drew similar conclusions in reviewing needs of children with sensory impairment. For students with these kinds of disabilities, uses of best practices were lagging behind and not being used.

National Longitudinal Transition Study (NLTS).

One of the most recent and comprehensive data sources for assessing outcomes of students with various kinds of disability is the National Longitudinal Transition Study (NLTS). The US Congress mandated the study in 1983. A research program was funded with data collection beginning in Spring 1987 with follow-along of some participants through 1993. The NLTS was a prospective longitudinal analysis of outcomes seen among a nationally representative sample of youth with disability. The NLTS sampled 8,000 youth that were 13 to 21 years of age and in special education in secondary school in 1985. At various points in follow-up and follow-along, contacts with approximately 600 students with OI and 400 with OHI have been made. In follow-along data, the second wave 3-5 years after exiting secondary schools, assessments were completed on 173 with OI and 92 with OHI. This weighted sample drawn from 30 school districts across the United States allowed generalization as a whole and separately for each of the 11 special education disability categories that were in use in 1985. The two-wave follow-along reassessed students in 1987 and in 1990. For a contrast group, typically developing youth from the National Longitudinal Survey of Youth who were assessed from 1979-1983 was used. Outcome reports continue to reflect a similar trend in major themes of employment, post-secondary enrollment and residential status.

In 1992, Wagner, D'Amico, Marder, Newman, and Blackorby reported that considerable ambiguity existed in classification of youth as OI or OHI. They subsequently concluded that these categorical labels would not be very useful in distinguishing youth with these kinds of physical impairments and their post-school experiences. Most data within these groups were the same, with a few exceptions. Those with OI had patterns of poorer employment outcomes when compared to OHI (e.g., currently competitively employed: OI=22%, OHI= 40%). To reserve a larger number of subjects for exploratory data analysis the OI and OHI categories were blended in subsequent reports. They concluded that youth in either category did not approach the levels of employment of youth with disabilities as a whole. These graduates were even farther from employment levels of youth in the general population. Gains in employment over time were also not large, and residential independence was difficult to achieve (e.g., 72% with OHI living with family 3-5 years after secondary school). In 1993, Wagner, Blackorby, Cameto, and Newman reported that youth with physical disability had among the poorest post-school outcomes of any disability group. In comparison to students with other kinds of disability, they were the least likely to be competitively employed or be fully participating in their communities and earned less money.

NLTS researchers (Wagner et al., 1993; Blackorby & Wagner, 1996) further discussed that this group demonstrated puzzling findings, perhaps owing to a wide diversity of disabilities that would necessitate different approaches of study. For example, those with higher self-care skills were less likely to go on to post-secondary vocational training, to find jobs or to participate fully in communities. Higher functional mental skills were not related to one's likelihood of living independently. They suggested that self-care skills did not appear to be critical to academic post-secondary endeavors, but may have deterred vocational training. Likewise, overcoming physical care needs that precluded independent living could not necessarily be met by higher mental skills alone.

Youth in the physical disability cluster were also found to be those most strongly influenced by parental expectations. If parents expected them to go to college, youth with physical disability were 37% more likely to do so than if parents did not hold this

expectation. If parents expected participation in the community, these youth also showed a 70% greater likelihood to be involved.

Most youth with physical disability had spent a majority of time in regular education. Full-time regular education enrollees were 43% more likely to be competitively employed, 41% more likely to participate in community, and the taking of college preparatory classes resulted in a 26% greater likelihood of college attendance. This finding was not true for all special education students, for whom course failure was common (e.g., 64%) and linked with dropping out. In terms of transition outcomes, "no benefit to regular education placements occurred for youths whose disabilities involved explicit learning problems or cognitive deficits" (Wagner & Blackorby, 1996, p. 117).

Vocational education appeared to demonstrate few benefits to those with physical impairments. Concentrating in a vocational area in high school was associated with a 27% lower likelihood of attending post-secondary academic education, and did not increase the probability of competitive employment. However, work experience was correlated with future vocational success. Those with "real world" jobs as high school students were 33% more likely to have employment 3-5 years after secondary school and be earning \$4,000/year more than those who did not work have work experience in high school. However, a disappointing finding was that although 46 to 60% of students with sensory and physical impairments were likely to attend post-secondary school, only 22 to 44% were employed 3-5 years out of high school. In comparison, 57% of other special education students and 69% of youth in the general population were employed 3-5 years after high school.

Among the conclusions from the NLTS was that post-school success of students with disabilities is perhaps most influenced by these students' in-school successes, regardless of the placement of their courses. "As the inclusion movement gains momentum, great care must be paid to issues of quality and support. Placement in regular education offers little post-school benefits to students who cannot succeed in those courses" (Wagner & Blackorby, 1996, p. 118).

New research directions for transition

Research based practice in education and transition programming is a challenge. Best practices research findings have been sparse and disappointing. Outcome analyses to date have generally painted a rather bleak picture of school effectiveness for youth with technology reliance, as well as other types of disability. Part of this negative portrayal may relate to the research approaches that have been used.

The ecological nature of transition and the multiple factors that may affect lifestyles of children and youth with disability brings attention to the complexity of outcome research and analysis of program effectiveness. This challenge has not gone unnoticed. Halpern (1990) reviewed methods being used to appraise the outcomes of students in special education. His critiques of 25 such studies led him to conclude that it is presently difficult to combine and translate the findings from these studies into a larger body of knowledge. Citing deficits with existing work, he made several recommendations to the field. Among suggestions were that researchers develop and use explanatory and confirmatory factor analysis models, path analysis, time series, and other longitudinal analysis models. He proposed a follow-along research model and suggested uses of factor analytic software to help appraise the integrity of domains of concern, with specified variables, and identified constructs. At the time Halpern was publishing these suggestions the previously cited NLTS was underway and following many of the guidelines Halpern had suggested for study design, data collection, and data analysis.

In contrast to Halpern's suggestions, Blackorby and Edgar's (1992) review of longitudinal research methods being used to appraise transition outcomes led them to caution that we might simply be asking too much of the data that have been collected. They noted that transition is by nature a longitudinal process requiring the use of research methods appropriate for the span of time and scope of factors that might affect the process. Citing the weaknesses inherent in current research and difficult problems to overcome, Blackorby and Edgar made two related suggestions to explore outcomes and variables not readily grasped by traditional performance measures. The first suggestion was to sample for planned comparison, and the second idea was to collect data through quantitative as well as qualitative means. They suggested that one could sample from a

pool of cohorts and match successful and unsuccessful participants as dyads. This use of planned comparison would draw upon quantitative data from school records, follow-along interview surveys, and data from qualitative methods using observation, and open-field interviews. With this approach they contended that one could uncover factors that make some and not others arrive at a "combination of tangibles and intangibles that brings them satisfaction and meets the usual criteria for success" (p. 381).

Suggestions from Halpern (1990) and those made by Blackorby and Edgar (1992) highlight the contrast between traditions of quantitative and qualitative research designs. An effective analogy to compare approaches is to suggest that quantitative methods based on group statistical design are focused on a population whereas qualitative methods tend to focus on the individual. Population based techniques rely on the quantitative tradition in which a sampling of students is carried out in hopes of representing a defined group. Pre-determined techniques for collecting information are scheduled. Most often these employ a survey, planned document review or structured interview to appraise outcomes in employment, residential status and other markers of community function. These data are used in descriptive, correlation and factor analytic analyses to reflect typical outcomes and variables impacting the population under study. Findings may reflect expected outcomes and challenges anticipated for individuals within the population who are transitioning. Individual based techniques rely on the qualitative tradition in which participants are purposely selected to inform the researcher about their perceptions and experiences with transition processes and outcomes. Data emerge from site based interviews and observations, record reviews, and other sources of information to express issues or themes that demonstrate the phenomenon of transition and generate explanations about related experiences and activities.

Quantitative methods, generally through surveys (e.g., NLTS), have been the traditional means that data are collected and appraised to assess school outcomes. However, categorical grouping of participants, segmenting of outcome levels, and the non-continuous nature of appraisal applied to declining pools of subjects have provided little direct evidence of key factors leading to best outcomes. Qualitative methods,

generally through interview and observation are beginning to emerge (e.g., Gallivan-Fenlon, 1994). However, a general lack of familiarity with these methods makes application of findings to policy and practice problematic. DeStefano and Wagner (1993) suggested that any findings about outcomes can have dramatic influence on transition policy and practice. Different stakeholders (e.g., educators, rehabilitation personnel, and policy-makers), however, may view such data in different ways, resulting in interpretations that are likened to "opening Pandora's box" (p. 154). They contended that use of research evidence, or lack of the same, may result in advocacy for additional or more intensive services or the dismantling of transition practices that are still developing to meet the goals of legislation and best practices.

Current understanding of transition indicates that multiple factors influence the process of transition and its various outcomes; particularly in employment, independent living, and community participation. While factor analytic approaches are attractive, few studies have been able to account for meaningful variances in outcomes. Given the complexity of characteristics, systems and resources, as well as the longitudinal nature of transition, it is not surprising that any single variable or factor cannot account for a significant part of the variance in outcome. Like the use of a multifactorial perspective, transition can be viewed as an ecological phenomenon. Interpretive approaches, such as those used in qualitative research, are designed for such analysis and applications of these techniques have proven helpful to understanding the phenomenon of transition and subsequent lifestyles of adults with developmental disabilities.

A careful review of literature addressing transition demonstrates that specific factors or service provisions relating to transition have had negligible impact on outcomes being experienced by youth with disability and their families. Chadsey-Rusch, Rusch and O'Reilly (1991) contend that while it is still not clear which variables impact positively on desired outcomes, those that are positive should be appreciated as a dynamic interaction between youth and their environment. Qualitative research approaches are suggested as the best means to gain an understanding of issues impacting human choice and meaning (Erickson, 1986). Qualitative data-collection methods have

been especially useful in investigating phenomenon where the interpretations or meanings attributed by participants are of interest and where complex interactive social processes in natural contexts are involved (Ferguson, Ferguson & Taylor, 1992).

Conclusions regarding challenges with transition

Good intentions and high hopes continue to be expressed for transition of youth with disability to adult living. The ecological nature of transition points toward developing attitudes as well as facilitating skills and actions involving the students, their families, their schooling and the communities in which they live. Students themselves need active engagement with goal setting habits and actions, showing their capacity to succeed and direct themselves toward desired outcomes. Families need to be active participates in setting goals as well as identifying and using resources within the family, school, and community. Schools need to provide opportunities for participation and feedback about performance that challenges students to adapt and succeed at a level realistic to student's goals. All participants in transition should seek links for students to community services as needed, and enable them to seek employment, post-secondary education, independent living, and taking on of community roles. For students who are technology reliant, the advent and advancement of technology will influence and perpetuate change during and after transition. Novel and unpredictable consequences may be experienced as part of transition with technology. Here too lie high hopes for success, but little evidence that particular experiences or services ensures such outcomes. Uses of technology for health, function, and learning seems also to necessitate responsibility from users, their support systems, and the social and physical environments in which they function.

Chapter 2: A phenomenological approach to understanding experiences of youth who are technology reliant

Given the many factors that appear to influence transition, as well as the dynamic and interactive nature of technology reliance and other accommodations, a focused look at issues was undertaken to make known the experiences of today's students. The novel, complex and dynamic nature of users' experiences with technology and accommodations as part of schooling, independent living, employment, and citizenship leads to the study of these issues using qualitative methods. The approach is linked to the qualitative tradition termed phenomenology, characterized by gaining the individual's experiences and perspectives through analysis of story telling and reflection shared through interactive dialogues. Advocated for use with youth in special education programs, phenomenology allows "an attentiveness, an attitude of intense interest in trying to understand how children construct their reality" (Heshusius, 1986; p. 30). The use of qualitative research methods has been suggested to explore transition processes and outcomes not readily grasped by traditional performance measures (Blackorby & Edgar, 1992). Peck and Furman (1990) cited a long history of these methods being used in special education research.

Students who are using technologies and having related encounters with personal helpers, adapted environments, and other kinds of accommodation are few in number but their circumstances are high in complexity and novelty as they transition out of school. Qualitative methods are valuable for capturing the viewpoints and experiences of participants and for analyzing factors that are not pre-established but rather emerge from systematically collected narrative and observational data. This technique of study makes possible the identification of issues left out of initial thinking, permits the collection of data portraying factors considered to be important, and allows for re-analysis of participant data regarding evidence of particular results or beliefs.

Renewed interest in qualitative methods is seen because of changing beliefs about scientific knowledge and a need for more holistic approaches to human services. Bernard (1994) likened phenomenology to knowledge gained by emphasizing direct observation

of a phenomenon. Observed reality in this tradition is acquired as an expression of consciousness and perception, or the feeling of others who experience the phenomenon. "In phenomenological study, the researcher tries to see reality through the informant's eyes" (p. 15). Bernard suggested that there is no substitute for a good story, when trying to make people understand how the people you have studied think and feel about their lives. Thorne (1997) contended that conventional empirical approaches have proved to be of limited service "in answering some of the most challenging and pressing clinical questions, especially where human subjectivity and interpretation are involved" (p. 287). "A well-crafted narrative may have considerably more 'truth-value' to the clinician than does a well-controlled and effectively orchestrated clinical trial" (p. 288).

Moves toward use of qualitative methods to gain an understanding of transition and uses of technology are emerging (Speckman, Goldberg, & Herman, 1992; Gallivan-Fenlon, 1994; Hutinger, Johanson, & Stoneburner, 1996). Given new circumstances facing youth that use technology to manage disability and enhance performance in education, new and innovative appraisal of the challenges facing these youth as they are in transition is needed.

The basis of a qualitative approach and use of phenomenology

In the study of populations with disability, the individual's perspective has often been left out or avoided. Now being recognized is a dearth of research on the experiences of people with disabilities and a modern need to study their perspectives (Miller, 1997; Celesia, 1996). Traditionally, research methods developed and used in physical and biological sciences have been applied to concerns about personal qualities and adjustment to disability. Results have generally been conceptualized and retold by "outsiders" who are far removed from the real experiences or viewpoints of "insiders" or those with disability themselves. Expressed experiences of "insiders" constitute an important source of data. Researchers now recognize that the effective study of the experience of disablement from the individual's perspective requires the uses of qualitative research approaches, such as phenomenology (Spencer, 1993; Toombs, 1993; Fuhrer, 1994; Peters, 1994; Whiteneck, 1994).

One significant block to studying human experience is a view that such experience is subjective, cannot be objectified, and therefore cannot be studied in a systematic way. Those who use qualitative research address this challenge by re-conceptualizing the research subject as a source of understanding rather than an object to be studied (Peters, 1994). This fundamental shift transforms the *research subject* into an *expert informant*. This move allows for an analysis of the meaning informants' associate with the events and objects of their experiential world, and the grounding of hypothesis development and testing in the experienced life of the group of interest.

An approach to appropriately engage the insider's experience and perspective is that offered by the discipline of phenomenology originally described by Immanuel Kant in 1764 as a method to study 'phenomena' or 'things' (Jasper, 1994). In the early 20th century, Edmund Husserl characterized phenomenology as a method one uses to capture and reflect the "lived experience." A student of Husserl, Martin Heidegger extended the view of phenomenology as the study of "being." Heidegger, and his pupil Hans-Georg Gadamer, brought attention to the transactional nature of human experience and proposed phenomenology as the study of "being in the world" (Annells, 1996). Phenomenological theory views human experience as the unique blending of an ongoing stream of sensations, thoughts, emotions, and memories that emerge through an individual's relationships with objects and events. Each new volley of information builds upon the last, making the human experience an iterative, ongoing process (Peters, 1994).

The goal of a research method based on phenomenological theory is to make the lived experience and reflection about one's world more explicit and understandable to others (Giorgi, 1985). Initial access to such understanding is through individually constructed interviews that capture stories regarding experiences. The primary data gathering tools used by the qualitative researcher are interview and observation. A hallmark of high caliber qualitative research is that primary data from interview and observation are used to further refine and focus the research process itself. The process itself is then interpretive, cyclical and inductive, consisting of an initial theory or preliminary hypothesis that is subsequently shaped and refined. Repeated returns to

collect data for re-analysis are the rule with additional data gathered as needed. The number of interviews, extent of observations, and number of informants in qualitative research are estimated, but not preset. This research process takes shape in the form of a collective narrative data set, organized into elements and structured to reflect the person's experience of the phenomenon through a process of thematic analysis. When viewed in the contexts of personal history, current experience and beliefs, a description of the person's reality as he or she experiences it comes into focus. When applied to groups of individuals who have experienced a similar phenomenon, a general overarching thematic structure emerges through comparison of individual narratives across members of the study group. This procedure also allows for detailed analysis of individual differences within the study group.

Phenomenological research methods have been used in education (Tesch, 1990), nursing (Woods & Catanzaro, 1988), medicine (Baron, 1985; Toombs, 1987), and anthropology (Kaufman, 1988). The continued development and refinement of phenomenological methods are an active focus of research (Giorgi, 1985). A phenomenological approach was the primary qualitative research tactic used in the following investigation.

Phenomenology as science

Phenomenology, as a technique of inquiry, has evolved and taken different pathways since its inception. Such differences are briefly reviewed to address implications for methods later proposed in this inquiry (i.e., to organize data collection and interpretation and to present findings with sound scientific reason and justification).

Husserl's original conception of phenomenology emerged in the Cartesian tradition of seeking sound explanations for truth (Walters, 1995). In this view, rigorous science leads to absolute knowledge, and in Husserl's phenomenology a clear understanding of "essence," then regarded as universal, eternally unchanging over time, and absolute. In contrast, Heidegger and Gadamer regarded phenomenology within an existential perspective. In this view, an understanding of the person must occur as part of the individual's perceived world. They propose that "being" is understood as the studies

of ordinary everyday existence of people doing their everyday activities and the process people use in making sense of their everyday world. In this approach, interpretation of experience is represented as an ongoing transaction between the individual and the situation. Given the ongoing nature of this process, Gadamer contended that interpretation is always on the way, making definitive interpretation not a possibility. In terms of assumptions about science and knowledge, Husserl's perspective is objectivist, linked with positivism. By contrast, Heidegger and Gadamer's approach is primarily subjectivist, in the post-modern (i.e., post-positivism) goals of seeking understanding rather than theory (Annals, 1996).

The distinct foundations underlying phenomenology are important to note in terms of research technique. In all tactics of inquiry are concerns for quality of measurement, procedures of assessment and intervention, and scope of comparison and generalization of findings to others within and outside the population or persons being studied. In quantitative traditions of research, various issues of reliability and validity are discussed to make apparent the relative strengths and weaknesses of an investigation. In qualitative research, following the actions of interpretation, related concerns have been expressed through different terms. Lincoln and Guba (1985), often cited for their perspectives on qualitative methods, suggested that issues of reliability and validity in qualitative inquiry are best described as truth-value, applicability, consistency, and neutrality. *Truth-value* refers to the informant or participant's confidence in the "truth" of the findings about them. *Applicability* relates to how one set of findings is applied to another context or with other informants. *Consistency* is expressed by how the procedures and the findings withstand replication in similar settings and with similar participants. Finally, *neutrality* is a quality found when findings reflect the informant or insider's view, rather than the bias or motivation of the inquirer.

Various treatments of rigor in qualitative research typically take one of two priorities based on the phenomenological foundation being applied. The essence of confirmation of findings and interpretation of findings takes place at two levels: that by colleagues or peer reviewers who function as outsiders and by the informants themselves

or insiders (Beck, 1994). Described in different ways, these dimensions of scientific rigor may be termed *auditability* and *credibility*. *Auditability* is the primary concern for how data collection and interpretation are viewed by the audience, or those peer researchers and readers who will be replicating research or extending findings to practice (i.e., Lincoln and Guba's issues of consistency and neutrality). *Credibility* is the primary concern for how the interpretation of data fits or is agreed to by the participants who have been the source of data (i.e., Lincoln and Guba's issues of truth-value and applicability).

Priorities for scientific rigor reflect different foundations within phenomenology. Following the Cartesian framework of Husserl, issues of confirmation of findings emphasize the audience's perspective with explicit mapping of data matrixes and theme development. In this perspective, the rigor of science is expressed by auditability. This consists of documentation of the investigator's decision trail from informant selection to data collection and analysis, including justifications used in thematic analysis (Stuifbergen & Rogers, 1997). The existential orientation of Heidegger and Gadamer's view of phenomenology emphasizes the participant's reflection and reaction to the interpretive work of the researcher. Participant confirmation through deep reflection and careful disclosure of underlying assumptions of the investigator-interpreter are hallmarks of credibility, or the corroboration of emergent categories, processes, and themes by participants and other informants. Walters (1995) contends that as a product of distinct foundations, Husserlian phenomenology results in a more detached standpoint, whereas Heideggerian phenomenology necessitates a closer involvement.

Scientific rigor and phenomenology

Techniques that augment the scientific rigor of phenomenology can be considered to address both needs of the audience and needs of the participants. A variety of suggestions for rigor has appeared, particularly in reference to research in allied health (Burns, 1988; Munhall, 1994). Three specific strategies guided selection of techniques in this investigation.

Bracketing.

One of the primary concerns in interpretive research like phenomenology is the bias of the investigator. Miles and Huberman (1994) address this topic by noting two possible sources of bias, 1) the effects of the researcher on the case, and 2) the effects of the case on the researcher (p. 265). In phenomenology, one explicit move to avoid researcher bias is termed *bracketing*. To acknowledge an awareness of the researcher's consciousness, bracketing involves a researcher exposing his or her presuppositions about the phenomenon under study. The deliberate examination of one's own beliefs about the phenomenon takes place, so that these may be set aside and leave one's self open for natural spontaneity (Jasper, 1994). This technique favors an openness to the data, permitting astonishment with new observances and interpretation by the informant, inquirer and reviewer. Beck (1994) proposes that the researcher develop the habit of identifying and exposing his or her own biases by putting beliefs and notions out on the table. In reference to youth with technology reliance, and their transition needs and experiences, I have previously discussed my assumptions about challenges likely to be faced by students who rely on technology and outcome dilemmas common to adolescents exiting public school systems. As pointed out by Gallivan-Fenlon (1994) the "transition rhetoric" may not translate into reality for students with disability. Likewise, Dudgeon, et al's (1997) contention that use of technology for participation may not support demands for performance and productivity needs to be *bracketed* in order to remain open to non-supportive data expressed by participants who share his or her view. Bracketing enables new ideas to emerge that may contrast or modify existing thoughts.

Triangulating.

Another inherent weakness identified in phenomenology is a concern for bias in the data provided by the participant. While the very nature of phenomenology is to be open to whatever individual's express, some corroboration of their stories is often necessary. Triangulation is the strategy used to demonstrate that independent measures of the phenomena agree with or at least do not contradict findings (Miles & Huberman, 1994). The term itself comes from triangulate, a technique used in surveying to pinpoint a

location by reflecting three views. In qualitative work, triangulating refers to any strategy that leads to pattern matching using several data sources. Differences can be reflected in sources (e.g., participants, other informants), methods (e.g., interview, observation), researcher (e.g., multiple investigators), or data type (e.g., transcripts, written records and documents). The issues of transition and uses of technology are inherently complex. Therefore, a systematic approach to viewing the experience of students will necessitate direct interview and observation with participants, as well as exposure to beliefs of family and service providers. Given the longitudinal nature of transition, and procedural mandates by law, documentation of school programming and planning also serves as sources of data to corroborate or contrast with participants' accounts of transition.

Thematic Analysis.

Explicit collection and handling of qualitative data and recurring interpretation necessitate a systematic approach. Thematic analysis is used here to include procedures that organize, execute, and conclude a phenomenological investigation. A variety of phenomenological approaches have been proposed and used in allied health (Munhall, 1994). A good fit for exploring and reporting on transition experiences of youth with technology reliance is that conceptualized by Colaizzi, as described in Munhall, and used by Ryan (1996):

Steps proposed by Colaizzi to generate thematic analysis include the following:

- All informants' oral or written descriptions are read in order to gain a feel for the whole.
- Significant statements and phrases that pertain to the experience under investigation are coded.
- Meanings are formulated from these significant statements and phrases.
- Meanings and their links to statements are organized and clustered into themes.
- Themes are used to provide a full description of the experience.
- Investigator returns with the resulting description to original sources for confirmation, reflection and incorporation of new information.

These thematic analysis procedures help to ensure that issues of scientific rigor are addressed. Explicit selection of participants, review of interview and observation methods, as well as coding and linking of statements to themes helps to address the Husserlian concern for auditability. Full description of findings, with confirmation and reflection by participants and other informants, helps to ensure the Heideggerian issue of credibility. Thematic analysis is a repeating and evolving practice of interpretation. Auditability necessitates a need for carefully documenting interviews by audiotaping and transcribing, as well as by recording and reviewing observations and reflections by the investigator through memo writing. Credibility necessitates a return to participants on a periodic or as needed basis to involve the insiders in further explanation and clarification of their expressed experiences and beliefs.

Qualitative methods allow a focused look at the variables that emerge and characterize individuals with technology reliance and their experiences with transition. Specifically, this investigation develops eight stories of participants who have been recruited from school and community settings. Through use of semi-structured interviews and observations with participants as well as family, and service providers, narratives have been analyzed for themes relating to function and participation, transition goal setting, and other beliefs about current and future outcomes during young adult years.

The following study focuses on youth who are reliant on use of assistive technology, and who have been served by special education while participating in regular education or inclusive classrooms. The purpose of this study is to document transition expectations and experiences of youth that are technology reliant and to identify person-specific and sample themes that characterize transition from high school to young adult life. The experiences of eight participants are explored.

Method

Research Design

The study of transition, as it relates to a variety of adult lifestyle outcomes, naturally falls to methods of longitudinal analysis. Traditional to this approach is to both

recruit and study a cross-sectional sample, or to perform serial appraisal of individuals over a period of time as in follow-up or follow-along designs. The following study is based on a cross-sectional strategy and sought follow along data from participants through use of reflection and story telling about their past, present, and future experiences and expectations with transition. This investigation provides a compilation of and reflection about life-stories and subsequent contrasts within and across selected participants and other informants.

Recruitment

Participants were recruited through Assistive Technology Clinic Programs at local hospitals and/or through local school district therapists. Advertisement for self-referral was also arranged through the Washington Assistive Technology Alliance (WATA) Homepage and the Disabilities Opportunities Internetworking Technology (DO-IT) program. Participants referred the investigator to specific family or service provider informants. Participants or parents signed for release of school records that sought to include courses that had been taken, grades, attendance, and IEPs.

Participants

A purposive sample of technology users was selected. Particular efforts for recruiting participants were followed to capture those using assistive technology for purposes of mobility, communication, or environmental control, and who may also use different types of medical technology. All participants are currently or have been enrolled full-time in school programs. Four participants were enrolled in their junior or senior year in high school, or were in school-based transition programs. A second set of four participants had recently graduated from K-12 schooling. Two informants from each participant were recruited to represent family (i.e., parent or guardian), and service providers (i.e., from either medical, educational, or adult services). Views from informants did address issues within family and service support networks and served to confirm and clarify transition experiences of participants. In this study, students or graduates in transition are called *participants* and others who were interviewed from

family or service system are called *informants*. (See Tables 2A Student Participants and 2B Graduate Participants.)

Procedures

Participants and informants engaged in interviews that were semi-structured. Responses were sought on experiences with school, family and community agencies, prescription and training with use of technologies and one's future planning. Research questions comprise the content areas for questions that were posed to participants and informants. The use of semi-structured interviews in phenomenology, and other kinds of qualitative research, is designed to pose a leading question and then guide the respondent toward greater elaboration and clarification of issues and ideas being expressed. (See Appendix A for sample interview questions.)

Field-based interviews were done in mutually agreed upon locations. The participant's home or usual environment of function (e.g., school setting) were preferred and used most often. The use of such naturalistic settings is thought to enhance validity (Erickson, 1986). Interviews with participants took place for approximately 45 to 60 minutes, and often on two occasions depending on availability of participants or informants and interview content needs. Spacing of interviews permitted a period of reflection by both participant and interviewer, and enabled additional probes of the participants in response to issues that emerged from preceding interviews.

Interviews revolved around questions of each person's perception of transition planning, transition activities, and expected or experienced transition outcomes. Further probing in interviews explored for opinions, beliefs and attitudes towards impacts of disability and technology reliance on participant's transition status. Participants and informants were also asked to reflect on their orientation toward success in education, employment, independent living, and community participation. Typical of qualitative research, interviews changed or intensified on particular factors that seemed to distinguish individuals' experiences. Follow-up interviews were conducted for elaboration, or participants were present and participated in interviews with referred

TABLE 2A: Student Participants

| Name | Age/ Gender | Grade or Transition status | Diagnosis, Spec. Ed. | Family and residential status | Hope/Plan for outcomes | Medical Tech. & Self Medication | Assistive Tech. | Information Tech. |
|--------|--------------------|---|---|---|--|--|---|----------------------|
| Barb | 16 y.o., female | Entering 11th grade, regular classrooms | Spinal Cord Injury, Other Health Impaired | With parents and siblings, older sisters and younger brothers and sister | Graduate from HS and go to community and/or community college to become vet. | Clean intermittent cath., Bowel program | Power WC mobility, ADL devices, Van with no lift | Laptop computer |
| Trisha | 17 y.o., female | 11 th , special education program | Cerebral Palsy- spastic quadriplegia, Multi-handicap | With grandmother (guardian) and grandfather- home mods planned | A place to live, freedom with mobility, love, work with people | Bowel & Bladder program schedule | Power WC mobility; electronic AAC device, Van with lift | Adapted computer |
| Tom | 18 y.o., male | Entering 12th grade, special education classroom | Cerebral Palsy-Spastic diplegia, Multi-handicap | With parents and older sister in home with ramped access | Complete high-school, not extended, job, supervised living | none | Power WC mobility, ADL devices, Truck with no lift | Computer |
| Wes | 19 y.o., male | Community- based, Transition program | Cerebral Palsy-spastic diplegia, Multi-Handicap | Entire life with grandparents in adult family home setting | Assisted living, meaningful job that is compatible with benefits/needs | none | Power WC mobility, ADL devices, Van with lift | Computer |

TABLE 2B: Graduate Participants

| Name | Age/ Gender | Grade or Transition status | Diagnosis, Spec. Ed. | Family and residential status | Hope/Plan for outcomes | Medical Tech. & Self Medication | Assistive Tech. | Information Tech. |
|----------|--------------------|---|--|---|---|---------------------------------------|---|--|
| Charlene | 19 y.o., female | Comm. College, Freshman | Cerebral Palsy-spastic diplegia, Orthopedic Handicap | Lives with mother and foster father in adapted home setting, (years) | College graduate, pursue special education, living on own, marriage and parenting | none | Power & manual WC mobility, ADL devices, Van with lift and hand controls | Computer |
| Vanessa | 21 y.o., female | 1998, exited Special Education, Community based transition program | Cerebral Palsy- spastic quadriplegia, Multi-Handicap | Lives with foster mother and father, other residents - others want assisted living | Community participation and enjoyment | Bladder and Bowel program | Power WC mobility, electronic AAC device, ADL devices, Van with lift | Computer with adaptive input |
| Paul | 22 y.o., male | 1994 High School Graduate | Muscular Dystrophy, Orthopedic Handicap | Parents and college age sister in specially designed home | Work in sports broadcasting | Bladder and Bowel program | Power WC mobility, ADL devices, Van with lift | Computer with voice input |
| Jacob | 26 y.o., male | 1993 High School Graduate, now in CC | Cerebral Palsy- spastic quadriplegia Orthopedic Handicap | Lives with parents in family home, adapted (years) | Schooling, work as advocate for disabled | Bowel and bladder program | Power WC mobility, ADL devices, van with lift | Computer with adaptive input and output |

informants.

Participants identified informants who were selected based on the providing information about specific family, school or other community experiences. Single-session interviews with informants were also field-based. Characteristics of informants did not match across participants, although views from informants representing family and social service providers were typically obtained. All interviews with participants and informants were audiotaped and transcribed verbatim for data analysis purposes. A researcher's journal captured field notes consisting of initial impressions about interviews, interpretation of meanings as memos or methodological notes, and contrasts in findings were noted and used in planning successive interviews with participants and informants. Field-notes from interviews were used along with the transcripts to generate participant descriptions.

Data Reduction and Analysis: Classifying and Categorizing Data

Data from this inquiry are comprised of narrative responses and observations gathered from participants and other informants through a series of semi-structured interviews. Participant interview data are considered primary sources, with informant interviews and school records serving to corroborate, clarify or enrich narrative findings. (See Figure 2 for diagram of data planning.)

Concurrent with completion of interviews and transcriptions, reduction of data was handled through a process that involved text coding and summaries being written in a matrix of issues explored within-case and across-case among participants. The matrix approach emerged from Miles and Huberman's (1994) suggestions that non-ordered categories be descriptive for single cases and comparative categories used across cases. Such a matrix is designed to enhance single-case completion, assure coverage of topics within and across interviews, and enable cross-case analysis. For audit purposes, matrix summaries with page and line indexing are available within participant notebook files. Selected participants and informants also responded to code and thematic findings to confirm and elaborate on interpretations to ensure credibility. Use of computer software

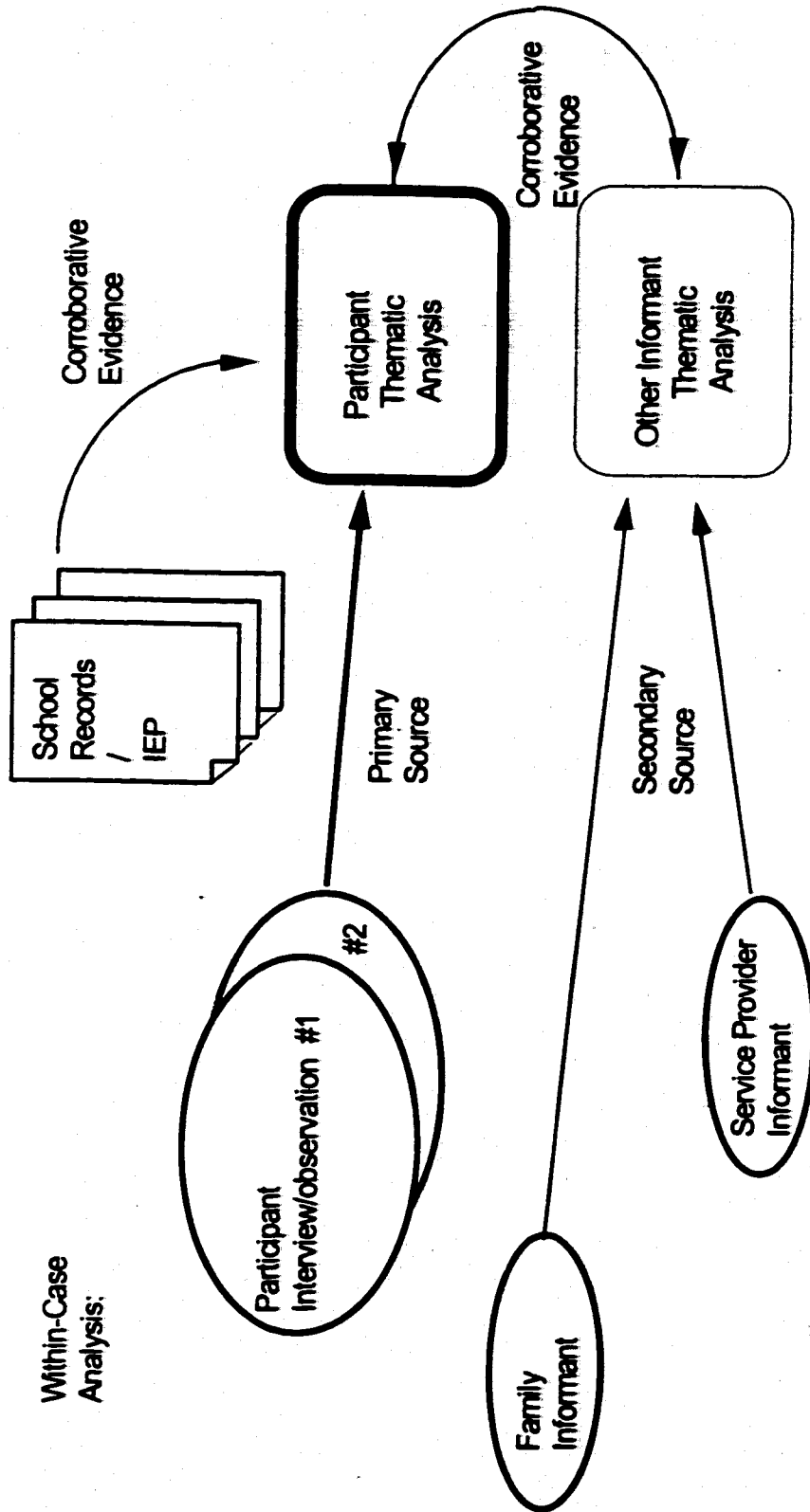


Figure 2: Within case data collection plan

Ethnograph 5.0 enhanced systematic analysis of transcribed interviews and other documents.

Individual participant stories with descriptions and explanations of factors that appear to have influenced transition status represents the first phase of interpretation. Within case analysis proceed then to a second phase, that involves the contrasting of cases through data organized by matrix comparisons and themes that emerge through contemplative dwelling (Parse, Coyne, & Smith, 1985) and by discussions among research associates and participants. (See Figure 3: Conceptual diagram of thematic analysis).

Analysis of interviews and other text materials from participants and informants resulted in the development and use of 18 codes. These are listed and described in Appendix B. The number occasions each code was used within transcripts is also provided. In all 1,825 transcript segments were identified by use of one or more codes.

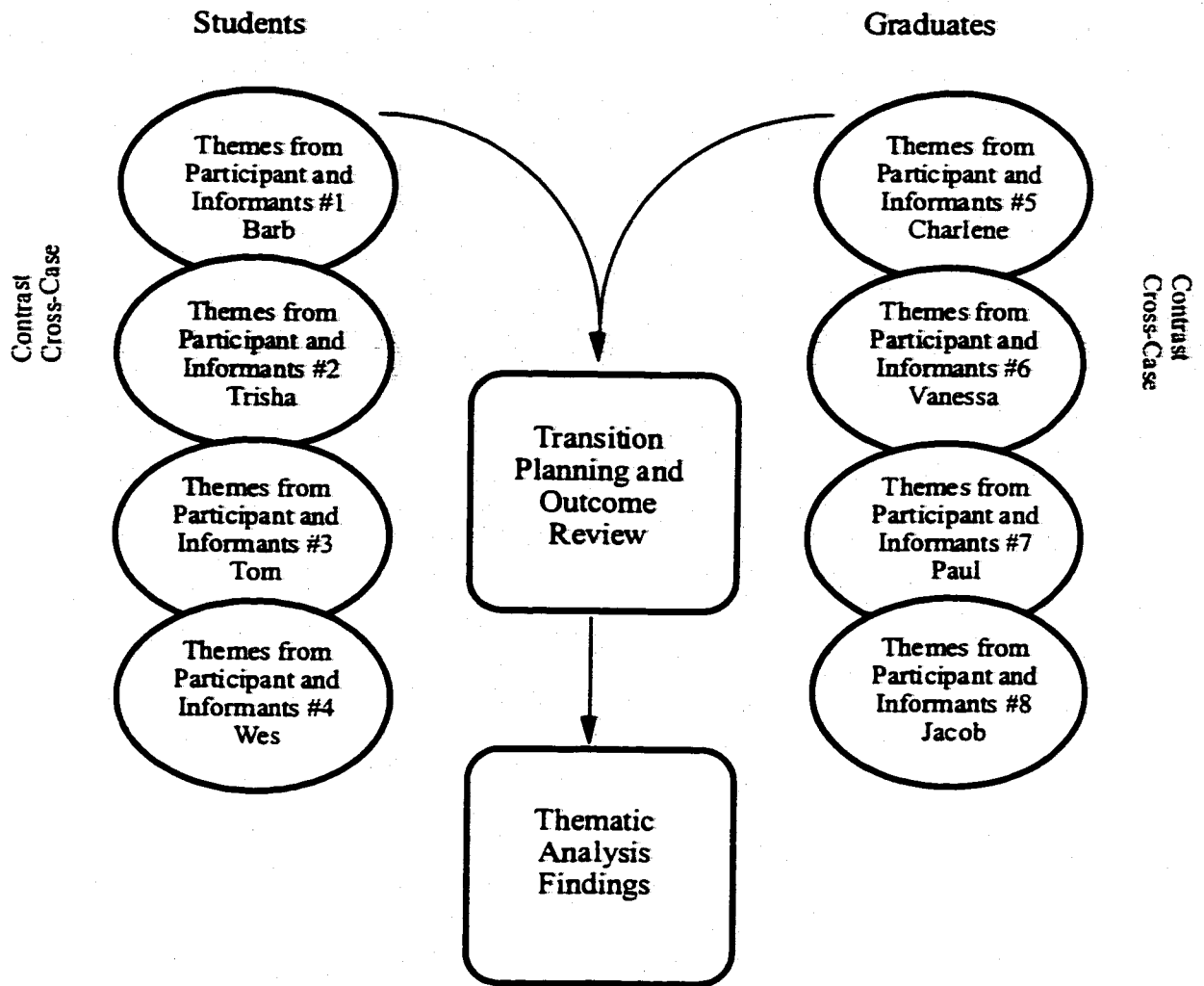


Figure 3: Thematic Analysis Strategy

Chapter 3: Results

Introduction

Participant's transition experiences and thematic findings are presented in three sections. The first is a primarily descriptive summary of the transition story as told by each participant and their selected informants. Participant's current uses of technology are reviewed along with his or her plans for or experiences with transition planning and outcomes. These views are abridged to indicate major issues impacting expectations and experiences with transition being expressed by youth, family, as well as school records and service provider outlooks. The next section provides an overall summary across participants of the transition planning process and outcomes planned or found with schooling, work or vocation, residential status, and citizenship activities. The final section represents a thematic analysis that arises from descriptive overviews and is shaped by recurring ideas shared by participants and other informants. This section identifies and elaborates on three thematic issues that emerged from across participants: membership, accommodation, and dilemmas with technology reliance.

Participant Summaries

In the following section, each participant is introduced relative to his or her transition status, diagnosis and uses of technology. Outcomes being hoped for or experienced are then described and include perspectives of each participant, his or her family, and/or school planning and service provider expectations. Shared are ideas about outcomes that include schooling, employment, community participation and development of personal networks. Names and situations have been changed to protect confidentiality of participants, other informants and service organizations.

Student Participants

Barb

Barb is a 16-year-old girl entering her junior year in high school. She is interested in learning about requirements for both high school graduation and courses that will enable her to get Head Start credits for college. She would like to become a veterinarian

and thinks that she'd enjoy working with cats. Barb has an incomplete cervical spinal cord injury from birth. With tetraplegia, Barb has always used a wheelchair for mobility and requires careful attention to seating and cushioning due to sensory loss below the shoulder level. She has both a power wheelchair with joystick control for mobility at school, and typically uses a manual wheelchair at home and some outings into the community. Her parents do not have a lift with their van, making it impossible for them to transport Barb and her power wheelchair. Presently her mother transfers her and lifts her manual wheelchair in and out of the family minivan. Either parent takes her to and from school where she uses her power wheelchair. For trips to health care providers and other activities, they usually transport her with her manual wheelchair that she self propels and is sometimes pushed. In the summer both wheelchairs are at home. She and her father take responsibility to maintain them, including regular charging of batteries with her power wheelchair. A few years ago Barb received a sports chair from another girl with a disability and she participates in wheelchair racing, an activity advocated and led by Karin, a nurse she has known since early childhood.

In addition to wheelchair use, Barb has impaired hand function that requires the use of hand splints to assist her in holding a pen or pencil for handwriting. She has a computer at home for most written schoolwork but no arrangements have been made at school for Barb to have access to a computer. Barb's mom indicates that she is able to assist other children with questions they have about computer operation. Impaired finger use makes typing slow and Barb has been shown systems like word prediction and speech to text software to speed-up her writing. She hasn't liked what has been shown to her and prefers to use the standard keyboard, often by holding a pencil with an eraser in one of her hands to press keys. Her parents have been involved in exploring augmentation systems for the computer with Barb, but have not felt as though they were worth purchasing.

Because of her mobility impairments Barb has a variety of needs for special commode (toilet) chairs, shower chairs and a number of home modifications enabling access and function. Barb's family has sought out disability design ideas and remodeled their home with ramp entrances, wider hallways, wheel-in shower, and a kitchen island

with special handles to enable food preparation. With her level of spinal cord injury, Barb has bowel and bladder dysfunction requiring special routines. Recently she had a surgical procedure that should enable her to perform independent clean self-catheterization to manage her bladder. With tetraplegia, Barb needs assistance with a variety of personal care tasks including transfers in and out of her wheelchair, performing her bowel program, and having some help with dressing, using cosmetics and hair care. She indicates growing independence in personal care, but expects that she will need some part-time assistance throughout her life to manage personal and household care. Presently, her parents meet all of her needs for assistance.

Starting her junior year in high school Barb is interested in making sure that she takes the right classes to enable graduation and improve upon her chances of getting into college. She recognizes the long (nearly 12 years) of schooling necessary for veterinarian medicine and acknowledges that she wouldn't be able to do a lot of the tasks that a veterinarian may perform. She has volunteered in her community and recently has done some work with a respite-care center program for disabled children. Her pediatrician has inspired this community building and program project. He has also offered her a job working in his office when she finishes school. If not a veterinarian, being a secretary is also considered by Barb as something she could do. Being successful in school and having a job are important to Barb in her future. Other hopes include her having her own place to live, and maybe getting married and having children.

Barb is somewhat shy and speaks sparingly. She initiated volunteering for this study, writing a letter to express her interest and then telling her mother. Regarding other activities, Barb does not express a lot of information. For example, she has participated in wheelchair racing sports in recent years, but declined to comment about this. According to Karin, the nurse referred by Barb for the study, Barb has traveled to and won several national sporting competitions racing a special sports wheelchair. In this activity, Barb is reported to be socially active and independent. Both her mother and Karin note that Barb is goal directed and are confident that she can set and accomplish goals. Karin says, "once [Barb] has a goal and kind of recognizes that, she is very determined as far as doing everything she can to reach that goal." Barb is currently unsure about going directly to a

four-year university and what that might entail in terms of planning for her assistance needs.

Barb's mother Susan "wants the best for her, and whatever it takes [she'll] follow that direction, that road." Barb lives with her parents, and is a middle child with several older and younger siblings. They reside on a large acreage in a small town outside of the metropolitan area. Keeping up with her sisters and brothers (i.e., having a garden spot and participating in sports) are cited by mother and Karin as positive influences on Barb. Going to college is another example, yet Susan admits that she would be happy if Barb stayed close by and didn't leave, and took the office job offered by their Pediatrician (Susan says, "I will get you all the kittens you want"). Although she questions how realistic Barb is about being a veterinarian, Susan is supportive and creative in suggesting how that might work out. She does expect that Barb will graduate from high school and be able to take advantage of a program that allows her to earn credits toward college. Of most concern to Susan, is Barb's lack of experience and apparent vulnerability in dealing with businesses and others in the community who she will likely need to rely on. Susan has advocated within school IEP planning that Barb gets this kind of instruction and experience. Another hope of Susan's relates to "cure" of spinal cord injury. She looks forward to some neurological regeneration and describes having a recent article about this on their refrigerator at home. While she is unsure if this would apply to Barb, she holds some hope for improvement in physical status or benefit from new medical technology.

Currently an incoming junior in high school, Barb has a cumulative grade point average of 2.7 during her 9th and 10th grade years while taking a regular classroom curriculum. Barb qualifies for Special Education under the category of other health impairment. She receives direct service from occupational and physical therapy and also takes a special education study skills class designed to assist her with her learning activities. Physical therapy focuses on exercises and stretching and occupational therapy is working with her on community and job skills. Barb says, "I think we're going to work on finding a job and stuff." Susan describes some disappointment with the hurdles they had to overcome to become informed about the special education and IEP process. Barb's parents perceive the value of specific services, and actively solicit these by doing what is

required, such as getting physician prescriptions. They have also seen a need to carefully review school environments and seek changes when needed. Barb has been a student in five different school buildings. She needs private bathroom space for performing self-catheterization, and they seek full access for her to all parts of the school. A current concern for Susan is Barb's access to the stage for high school graduation.

Barb and her mother referred Karin, a rehabilitation nurse, for the study because of their long history with her and because "she has a lot of zest." Karin was eager to discuss Barb's transition, but admitted that she hasn't been very involved with transition issues with her or other children with disabilities. Karin works at a children's hospital rehabilitation program about 100 miles away from Barb's family home. Barb receives most of her special medical care at the hospital where she is seen every few months and is hospitalized periodically for special procedures or rehabilitation needs. Karin also hopes that Barb will "go to the University level, and participate both academically and perhaps in athletics, graduate and get a career that she would really thrive in." Although reluctant to fully endorse her plan of becoming a veterinarian, Karin encourages her "dreams." According to Karin, Barb is "a millionaire" due to her medical liability claim from her injury at birth. Nevertheless, Karin envisions that Barb will become a "taxpaying, you and me sort of person." She believes that Barb has no limits, and will likely marry and perhaps have children. Aside from the dream of being a veterinarian, Karin envisions recruiting Barb to speak about her disability experiences and encourage a community role where she might be an "advisor to the school." Karin also has hopes that existing and new assistive technology will open up opportunities for Barb, citing examples of other youth she knows who have used computers and other means to become employable.

Barb earns some money from her parents for babysitting her younger brother and sister. She also has performed volunteer work in an office. Her dream of becoming a veterinarian is related to her love of kittens. Barb says, "they are fun to play with and cuddle with and stuff." She describes having this idea "for a long time . . . since I was a little kid." Her interest has facilitated planning at school to include caring for animals as a job simulation activity as part of occupational therapy. Neither Barb nor her mother

reports on Barb's financial status. Rather, they discuss desires for her advanced education and employment and concern for obtaining health insurance.

Due to the level of Barb's paralysis, Karin, Susan and Barb herself expect that she will not live independently. Barb would like to move out and they acknowledge that this would require careful selection and perhaps modifications to a dwelling, along with the hiring or arranging of personal care attendants. No particular ideas were shared about future residence, although Barb has a preference for a smaller town and both she and her mother mention needs for improvements in community accessibility.

Barb has lived her whole life in the same community and with several siblings has been connected to schools and sport programs, church, and a variety of other community activities. Community participation appears to be endorsed and modeled by family. Barb envisions working and doing other community activities that "help people." She cites examples of being in a "key club" at school that helped to "decorate the downtown with Christmas decorations" and work with her church and family on the respite care center program. In terms of her personal network, Barb hopes for a relationship that could lead to marriage and having a family. Neither Barb nor her mother shared any information about friendships that Barb had outside of the family.

Trisha

Trisha is a 17-year-old female who is in 11th grade. She attends a high school program involving self-contained classroom and community-based experiences. She would like to be able to get a "place of my own" someday, and have a "job helping children." Trisha has spastic quadriplegic cerebral palsy and seizure disorder. She uses a power wheelchair for mobility and an augmentative communication device and other adapted methods for communication. A variety of adaptive devices and environmental supports are also used to enable assisted personal care in dressing, bathing, toileting, and most other daily living skills. Trisha uses a Liberator, an electronic voice output device, activated by a custom-programmed touch screen. This device replaced her Touch-Talker communication device a few months ago. Her communication methods include her Liberator and a computer for writing, some handwriting, and some vocal expression for

initiating communication and a few words to confirm or direct conversation. A few gestures and a communication board are also used for specific communication needs. School records suggest that she have access to a typewriter/computer at all times during school. Trisha's joystick controlled power wheelchair is her second, and the chair has a specialized seating apparatus as well as a stand-up feature allowing her height change that assists her with reaching. Trisha crawls with difficulty and needs assistance with transfers in and out of her wheelchair and to other positions such as a toilet, bathtub bench, bed, and couch. A few years ago Trisha's grandmother and guardian acquired a van with a wheelchair lift that has made community mobility much easier and more frequent. This device and Trisha's learning the use of community buses with lifts for transportation has allowed her more independence and greater participation in school and community activities.

Trisha lives with her grandmother and her grandmother's male partner in a two-story home in a major urban area. Several years ago Trisha's mother "gave up" custody to the State. Arlene, her paternal grandmother, went through training and assumed responsibility of Trisha as her legal guardian. Trisha's father (Arlene's son) died of a drug overdose recently. Arlene reports a great commitment to Trisha and if she is unable to continue she would like the State to resume care for her rather than any other family member. Arlene reports having had no other experience with "handicapped kids." She claims to have "learned a lot" and gained a good understanding and admiration of what Trisha faces as someone with "physical struggles." Arlene keeps in touch with doctors, nurses, therapists, and teachers to learn about what is available and how she might best help her.

Still in school, transition hopes for Trisha are still developing, and differ some based on whose ideas are being heard. Trisha indicates that she enjoys school and her friends. She expects to finish high school and would like to go to college, perhaps learning how to take care of children. In terms of work Trisha describes several activities, including a job she helped develop at a local store, school programs involving work and the idea of working with children. She would like to live on her own and to have a boyfriend. Others, such as Arlene say "I don't know," but she too has hopes or dreams for

Trisha. She doesn't expect Trisha to be seriously employed to make a living, but hopes that she has their home to live in and manage, perhaps more schooling, and maybe have a love relationship in her future. Arlene emphasizes community connections with Trisha and continued contact with health care and other support services. Trisha's school teacher and advocate, Carol, puts priority on Trisha having freedom with mobility, group home assisted living, and some kind of work with people. Carol has worked with many individuals like Trisha and notes that many "find their niche" in the community.

For Trisha, the transition planning process is not specific or formal. Perhaps limited by communication methods, she indicates a few hopes, but is unclear or not specific about making progress toward goals. Trisha says that she likes school, but that "I work too hard, a lot of demands." With her Liberator device she writes: "I like to do choir," "go out to work," and "happy with friends, teachers." Her boyfriend's name is "Sam." About her future, Trisha says "I want to go to college," it will "help me get a job," "I will love to do some baby-sitting . . . some of my friends do that." When asked specifically about transition planning with either school or family, Trisha did not respond with her communication device or other methods, looking away and making no comment.

Arlene describes her strategy for the future as being tied to keeping in touch with experts in health care, school, and other social services. Her keeping connected was a factor in Trisha being recruited for participation in this study. Discussion of transition with Arlene involved three issues: dependent care, housing, and planning with the school. Arlene describes plans for continued support of Trisha should something happen to her. Arlene is a survivor of breast cancer and acknowledges that she doesn't know how long her health will permit her to care for Trisha. She is thankful for the experience of having her and describes her personal growth from experiencing day to day life with Trisha. Arlene is enthusiastic about discussing plans for home remodeling that will enable greater independence for Trisha. The home will become Trisha's and Arlene wants to explore options that would enable the house to retain its value. Currently, they are exploring a number of ideas to improve accessibility within the home with remodeling plans to allow Trisha independent access/egress from the first floor. Arlene would like for this house to

become Trisha's, where she could live and have a roommate or assistant hired to help her with daily living.

Although Arlene is reluctant to predict paid employment, she is thankful for the job Trisha negotiated and commends the community for their willingness to work with her. Arlene has sought a regular connection with community organizations. Participation in an annual camping program for children with disability and more recently with Young Life has provided Trisha friendships and travel. She would like Trisha to pursue college, something Arlene never did, but sees little connection with employment. Arlene acknowledges regular contact with a particular teacher at school regarding programming and plans. Although enrolled in a special program, no decisions about extending to age 21 or program emphasis for that period of time are indicated. Arlene sees value in Trisha's writing activities, community work experiences, and training with community bus travel.

Trisha transferred into her local school district after being in a preschool program for children with developmental disabilities. She has progressed through school as a special education student, eligible in the Orthopedic Impaired category. She has been assigned to self-contained classrooms and has received direct related services from physical or occupational therapy and speech language pathology. She attends a high school program out of her neighborhood because of programming needs and because her local school is not accessible with her wheelchair. A "low incidence assessment" was used to develop her current school programming and transition planning. Trisha receives small group and specialized academic training, vocational and job readiness skills training through the community based training program, social skills and self-safety training. Physical therapy includes a swimming program with stretching to maintain movement, and speech therapy working with her new communication device for vocabulary selection and interactive use. Her community-based high school program consists of "functional academics" emphasizing writing and math as well as a modified family life and sexual health curriculum. Community experiences include training in use of community buses, work experiences in a hospital (magazine delivery) and in a nursing home performing cafeteria clean up. After her senior year she may become enrolled in a

full-time vocational training program, but this is uncertain due to her continued dependence in toileting. Her teacher also makes an "I don't know" response regarding Trisha's transition. As a teacher she has brought in successful older students with disability that "children might relate to as they dream and plan" for the future. Continued enrollment through age 21 is being recommended because no other services are available until that age. Responsibility for referral to the Division of Developmental Disabilities (DDD) and Division of Vocational Rehabilitation (DVR) are acknowledged by Carol, however, those agencies seem to "not want involvement" until the student's "last year."

Trisha felt a need to have a job and solicited a local dry-cleaning storeowner to pay her for being a greeter and alerting owners that customers are entering the premises. This activity occurs most Saturday mornings with Arlene transporting her and being on-call in case she needs help with toileting. The man she negotiated the job with has since died, but the opportunity is maintained through other store employees. Arlene and teacher Carol commend this work activity, although Trisha says little about it now. In terms of vocational programs through school, Trisha received training to be a courier of magazines within a hospital, and has been working at a retirement home doing work in the cafeteria. In both these jobs two impairments are viewed as obstacles. Trisha's lack of independent toileting and her drooling are seen as barriers to being in a practical work setting and being socially acceptable. Various efforts to hide drooling and protect materials she handles are being developed. Carol described her as a "hard worker who doesn't shy away from challenges."

Arlene's plan to remodel and use their home is consistent with Carol's suggestion about Trisha's need for assisted living in perhaps a group home with her peers. Trisha indicates a desire for a place of her own but declined to describe specific plans. Arlene acknowledges the problem for Trisha regarding privacy. She has "none" due to her needs for help in bathing and toileting, as well as dressing and nearly all parts of personal care. Arlene's goals for Trisha are "to have her freedom" being able to come and go from the house by herself, managing doors and ramps, and to have easy access to a bathroom and bedroom on the first floor of the home.

Arlene is the familiar care provider, but makes no comment about Trisha's skills in directing others to assist her in personal care tasks. Carol did discuss a need for Trisha to make better use of her communication in initiating and directing others. Carol admits to anticipating and helping so much that Trisha doesn't have opportunities to plan and take responsibility for communicating with others.

Friends and adults she knows at school are important to Trisha. In addition, Arlene has emphasized participation in community groups and Carol indicates a need Trisha will have for working with people. Regular involvement with a summer camp program, attending and being assisted by others in Young-Life and having a job in the community are all cited as valued activities by Arlene. Trisha has little support from family members, except for her Grandmother Arlene who describes a hope that a responsible care provider could be hired or may develop for Trisha. She says that a love relationship for Trisha is "possible" although not likely. But that, "Trisha could be lucky enough to just fall in and find some wonderful guy . . . a guy who says, 'yeah, I love this girl . . . I want her with me . . . such as like me.'"

Tom

Tom is a nearly 18 year old male who will be entering his senior year in high school next year. He looks forward to finishing, but his mother believes he should continue because of a lack of services or programs being available until he is age 21. Tom has a lot of ideas about work, but no plans for further schooling. Tom has spastic diplegic cerebral palsy and mild mental retardation. In addition to motor and cognitive impairments, Tom has vision and hearing problems as well. He walks around his home, but is pushed by family in a manual wheelchair when going outside or into the community. This past year, school district therapists facilitated the purchase of a power wheelchair. Funded through medical insurance, his power wheelchair is housed at school where he uses it regularly and on outings from school. Tom's family does not have a vehicle with a lift to transport the power wheelchair, so it is only used at home in his neighborhood during the summer. Tom's speech is dysarthric, but with knowledge of content and some repetition he is fully intelligible. This was not always true, and as a

child he started to be trained to use sign language. Once he began talking at age 5, he meets most of his communication needs verbally. Hand coordination problems limits Tom's use of handwriting. Sight word reading is still being worked on at school and Tom and his mother find that use of a computer and word processing software greatly enhances his written work. Tom lives with both parents and an older sister. Home modifications are in place for Tom and include a ramp at the front entrance, grab bars and shower chair. They live in a small town that is growing rapidly, but is some distance from the metropolitan area.

Tom is looking forward to finishing school and "getting out of there." He has some dislike of teachers and other authority figures that are always telling him what to do. He acknowledges the option for continuing through age 21, but is clear about wanting to leave. This past year he has had several vocational work experiences through school and he says that he would get a job after graduating. Tom has a number of diverse jobs he would see himself doing. He jokes somewhat about wanting to be a teacher who could tell kids what to do, but be a hero because he wouldn't give any homework. He'd be a nanny and be able to play with kids and watch television all day. Tom also indicates interest in working with automobiles, being an electrician, or carpenter. Most of his interests are tied to people he knows who perform those jobs and who might be able to help him get a start. In school he has had a number of rather unsuccessful job trials in automobile detailing and cafeteria work. Currently he spends a few hours a week working at a local grocery store, cleaning and stocking. This job has been more successful in the eyes of his mother and school, but Tom is not interested in the work long term. Important to Tom is being able to go out and be with friends. He would like to learn to drive a car, but has no persistent demand that this occur. He expects to live with his parents well beyond high school with unclear visions of himself changing, just doing "more of the same."

Debbie is Tom's mother and she also envisions that he will live with them for years to come. She admits to not having planned that far ahead, but feels he is welcome to stay with them and that he will always need some type of assistance. She has stressed with the school that they attend more to vocational training with Tom, and decrease the

time and effort being put in academic subjects. During his senior year she would like the bulk of time and energy to be put into jobs in the community. She appreciates the efforts and resources put toward children like her son, but has developed a number of attitudes and approaches for dealing with "specialists." Mostly she sees herself needing to remain being a mother and attending to Tom's "emotional and spiritual needs." She has listened to and been advised by a number of therapists, teachers and others with strong opinions but who often don't agree with each other. She has also seen them "come and go" and change ideas about as often. Debbie does not see herself as an expert, but as an experienced parent who should rely on her instincts and priorities. She dislikes the IEP meetings because they often make her feel she has failed. Tom's behaviors have been problematic the last few years, particularly in job settings where he demeans authorities, and in social settings where his manners are viewed as problematic. Debbie and her husband feel they have "made some mistakes" but are doing the "best [they] can." She points out that Tom is not in trouble, is socially active and happy, and is loved by family and many friends. Feedback in IEP meetings often makes her cry and feel badly, but she sees herself as being able to assert himself and collaborate with school personnel to benefit Tom.

School IEP records address transition planning with Tom. Debbie and Tom referred Steve, their school case manager, who forwarded school records but declined to respond to requests for an interview. Tom receives special education under the category of multiple disabilities. He is assigned to special education classes with a 40-79% integration into regular general education and receives special services that include consultative speech language, occupational therapy and physical therapy. Transition planning needs are organized around new instruction, vocational education and training, community experiences, employment objectives, and daily living skills. Referral of Tom and his family to DDD and SSI are indicated in school records. Vocational assessment results described in records also reflect a very diverse and somewhat impractical set of preferences Tom has for employment. Transition outcomes are directed at semi-assisted living, and competitive supported employment. Although Tom is cited as having a

positive work attitude and a variety of skills, his work behavior, on-task time and task sequencing problems are seen as barriers to employment.

In classroom work and job training, accommodations for Tom include use and transportation with his power wheelchair, utilization of a functional speech checklist, notes to be taken by a peer or teacher, tests read to him and extra time for study with modified learning objectives. An adapted PE program emphasizes Tom's peer participation in sports, and selection of activities to increase hand/eye coordination, cardiovascular, strength and agility skills. Physical therapy also has goals to have Tom be more controlled in wheelchair transfers, while occupational therapy goals emphasize his completion of fine motor tasks in regular classroom assignments. The school's placement of Tom in an auto shop was amended last year and he was sent to train in cafeteria work. This too ended because of poor performance, and subsequent placement with a local small grocery store was implemented. Tom's mother is hoping that the store owner will continue to involve Tom for a few hours each week during the summer break between junior and senior years. Tom has never qualified for extended school year status, not receiving related or other services during summer months.

While Tom has a general interest and commitment to having a job, he talks about a wide range of pursuits, many of which he has not explored seriously. Limitations with job trials include both mobility and hand use difficulty, but more consistent difficulties relate to task sequencing problems, attention to detail, and work behaviors (e.g., conflict with supervisors who represent authority). Competitive but supported employment are goals agreed to by school and family, although Tom's mother hopes for a greater emphasis on work. He and his mother are aware of SSI benefits and look forward to obtaining those starting in a few months time. Debbie views the importance of work for Tom, wanting him to learn about getting paid for a job well done. However, economic self-sufficiency is not an outcome she has thought much about or planned for with Tom.

Tom envisions staying at home and does not express an interest in being out on his own or living with other friends. He has had little interest in home living skills that school promotes, and relies on his mother and father to manage the home, food and laundry. Debbie is thankful for microwave ovens that Tom has been able to use safely,

permitting him some freedom to prepare snacks on his own. Neither Tom nor his mother has set goals for him moving out and having a residence of his own.

Important to Debbie has been his activity with their immediate and extended family, and a number of family friends. She feels that Tom has a lot of support from others that provide him a routine of going out in the community. He is also an active church youth group member, and participates in Special Olympics. Friendships are important to Tom and he likes the authority over younger children in his church youth group. Debbie sees Tom as very social and accepted among a diverse group of students and adults whom he has worked with and been around his whole lifetime. Ongoing participation with family, church and other activities are an important part of his future according to both Tom and his mother. Tom declares no plans for intimacy or marriage in his future. Although he describes "chasing girlfriends" while using his power wheelchair, no plans or hopes for girlfriends or future partnership are expressed. Although sexual behavior may be a part of Tom's difficulties with social behavior, Debbie declines to discuss this part of Tom's behavior.

Wes

Wes is a 19-year-old male who completed his senior year in high school but his family declined taking his diploma and he subsequently enrolled in the school district's community transition program. He has participated in this program all of this past year and will continue for two more years through age 21. He would like to work using computers and hopes for some greater independence and marriage in his future. Wes has spastic quadriplegic cerebral palsy and learning disability. He uses a power wheelchair driven with a center mounted joystick, is pushed in a manual wheelchair when taken into the community by friends and sometimes by family, and uses a walker or crawls on the floor at home. Wes uses foot-ankle orthotics, and other positioning devices to maintain range of motion. He has a variety of adaptive exercises and recreational mobility devices that include a stationary bicycle, three-wheel tricycle, and gas powered quad runner. Wes's handwriting is slow and of poor quality, so he usually makes use of a computer to write and explore resources found on the Internet. Family currently uses a mini-van that

is equipped with a wheelchair lift. They have also created a number of home modifications such as ramps to enter, exit, and overcome indoor steps. They have modified the home to create widened doorways, grab bars in bathrooms and concrete walkways around the home exterior for wheelchair access. An above ground heated swimming pool with ramp access to the pool deck also exists.

Wes lives with his paternal grandparents who have cared for him since he was 8 months of age. His mother could not "handle" his premature birth and health complications. His father was in the military and asked his parents to help. They have raised Wes in their home his entire life and Wes often calls them mom and dad. Other family members come in and out of Wes's life through the years, but he has regular contact with his father and step-siblings. During the past 12 years Wes's grandparents have operated their home as an adult family home for the developmentally disabled. They currently have two older women as residents.

Wes is an avid football fan and has been an aide for his high school football team the past four years. He is a Seahawks fan and has met several players in the past. His dream is to work for the Seahawk organization making use of office computer skills. Wes currently participates in a transition program that involves computer training and he hopes to be able to develop and use that skill in some kind of employment. His goals now are to establish some job skills and to develop better community access through use of public transportation or driving. He envisions staying in his current home. Functioning in a job is a goal for Wes and one of his expected outcomes from transition. However, he acknowledges not knowing what is ahead and that his dream of working for the Seahawks may have to wait so he get "his feet under him."

Doris, Wes's grandmother, hopes that Wes fully benefits from the transition program and that he be able to engage in employment that he enjoys. She does not have high hopes for him earning wages that will support him, but sees the importance of him having work and responsibility that comes with a job. Grandfather Howard recognizes economic dilemmas with employment and feels that Wes would need to have a high income with benefits to sustain himself due to his special needs. Indications from Doris and Howard are that Wes is welcome to stay with them, and in fact they might wish that

he develop skills to continue managing their group home. Wes serves as his own guardian and no other family members have been designated to substitute for grandparents should they no longer be able to provide care.

During high school, Wes experienced program conflicts that resulted in him being placed out of his neighborhood in a city high school. He was in a self-contained classroom program with students who could not communicate and were more learning impaired than he was. For a number of reasons he and his Grandparents petitioned to permit his full-time return to his familiar school for the remaining six months of his senior year. At school Wes participated in some regular courses and a number of special education classes. He completed school with a 2.98 GPA. Before receiving his diploma, family decided to have Wes enter the community transition program. Goals for transition programming include supported employment and supported community living. He has received 1 to 1 instruction with computers and performed a number of data entry job simulations. Community based employment doing computer data work was planned for the summer, but the family declined to have him participate due to transportation costs to them and conflict with SSI benefits. This next year, job developers will work to create a job for Wes while he continues to perform in training positions to develop improved independence in job performance. Program emphasis is also placed on independence in community access and uses of public transportation services. Debbie, the transition program director, has a goal for job developers to work with the Seahawks to create a job for Wes with them. Wes currently serves as a consumer advisor about disability access regarding new stadium construction. In addition to job goals and community transportation, a concern for school transition planners is Wes's dependence on his grandparents for emotional support as well as reliance on them for supervision of medical needs and other adult services. Wes is described as a "very social person" by both his grandparents and transition teacher. He recognizes this about himself as well. This style appears to be an asset to community activities such as church, football team involvement, and friendships, but is described as a challenge within job training. Wes is viewed by transition trainers as overly dependent on feedback and praise, and often spends his time in social conversation rather than work tasks to be completed.

Computer use in an office setting is a commonly identified job skill that Wes might make use of in future employment. He uses no special adaptations to the computer, but has been instructed in use of some adapted keyboard and mouse use software. He feels that these are not useful and types with his right hand, using his left hand on the shift key. Data entry has been Wes's primary job simulation, using the computer to compile address boards or enter inventory into a spreadsheet file. His inability to write messages is cited as a problem that would limit his function as a telephone or front office receptionist. Attendance is also cited as problematic. While in high school Wes was often absent, although attendance at transition this past year was good and only a few days were missed when he was assigned to community work sites. The concern for grandparents relates to the limited amount of money that Wes can earn before sacrificing some of his monthly SSI support. Howard calculated that Wes could earn only \$60 dollars in the summer job planned for him, before giving up SSI funds and that only his transportation costs would be paid by his income. The family believes that Boeing has jobs for those with disability that pays well and includes health benefits. They calculate that this would be the only kind of job that would make it possible for him to give up SSI benefits. Costs for transportation and residential support would require a substantial income.

Wes has no plans or ideas about moving away from his current home. His grandparents assist him with bathing and some grooming activities. He also depends on their management of the home, including shopping, meal preparation, cleaning and laundry. Goals for the transition program include development of greater community independence and independent living. Wes is seen as avoiding participation in food preparation activities at the transition center and family was reluctant to set goals for independent living tasks at home. Wes acknowledges that he cannot help around the house as much as he would like, but indicates that his grandparents know he would if he could. Grandmother commends Wes's good work ethic and commitment of concern for others.

Wes often cites friendships and being included in his senior year activities was important to him. He cherished the last times with his class and looks forward to reunions

in a few years. Wes has also been involved with his Church, in youth group and in helping with audio equipment operation during church services. He places a lot of emphasis on his faith, belief in God and comfort in things working out "the way God intends." Wes would like to advocate for the disabled. He notes that better access should be designed for those who cannot use computers and community transportation and parking could be changed so that the disabled have better access. Wes notes that he was one of the first to encounter barriers in school and sought to create changes for accessibility. He views this is an ongoing need in the community and would like to be useful in giving advice for the new stadium being built for the Seahawks.

Family contact is very important to Wes and his grandparents. Siblings from his father's remarriage are now in contact with Wes giving him an "awesome" feeling. Wes also notes that he is just one of a few in his extended family that have completed high school. Wes would like to marry sometime in his future, but describes just one experience inviting a teacher's assistant to go with him to his senior year high school homecoming dance.

Graduate Participants

Charlene

Charlene, or Char, is a 19-year-old female who is currently attending community college in her hometown. Participating in regular education, she graduated high school in 1998 and wants to become a special educator. Char has spastic diplegic cerebral palsy. She uses a power wheelchair for the bulk of her community mobility, but also uses a manual wheelchair at times to enable transportation with friends or family out into the community. She is able to use a wheeled walker for moving forward and sometimes makes use of this device around her home, or for special occasions such as receiving her diploma at high school graduation. Char utilizes a computer for the majority of her writing, because she feels her handwriting skills are slow with marginal quality. She avoids bubble sheet test forms and requests extended time for completion of tasks that involve hand skills. Char speaks well and is independent in the majority of her personal care needs when using assistive devices and environmental changes to compensate for balance and reach limitations as part of mobility, dressing and bathing. She is currently

focusing on learning to drive her family's van that has a wheelchair lift and hand-controls for gas and brake. She plans to take the licensing test later this year.

Char lives with her mother and stepfather in a home they have been in for over 10 years. Her mother is an elementary school teacher and her stepfather is an engineer with a major company. Char's mother and father divorced when she was very young and she has limited contact with him. Char credits her mother and stepfather as being major advocates for her throughout her schooling and she sees them and the rest of her extended family as role models for seeking a college education.

Char thinks that her goal of becoming an educator is due to her mother's experiences and because of teacher-assistant work she has done in high school with students who have special needs. Although she applied and thought she was accepted to a private college, her admission was postponed and she has entered a community college to pursue an Associate Arts degree in preparation for later transfer to a 4-year institution. Char plans to live on-campus or with a roommate in another dwelling while at a University. Long-term hopes also include marriage and family.

In planning for and transitioning to an after high school lifestyle, Char largely cites herself and family as being the main advocates within the school system. She views her mother and stepfather as having fought most of the battles, until high school years where her own skills at self-advocacy and negotiation were nurtured by her parents and therapists she worked with. Char views herself as a unique individual who has "fought battles" and can now educate others by advocating for disability accommodations that may make it better or easier for those who will follow. Char acknowledges that she has some peers with disability, and a few who serve as role models. Nevertheless, she was often the first wheelchair user in a school and learned to negotiate for changes in access and transportation systems, often to a point of reasonable compromise rather than complete accommodation. Char views herself as smart and articulate about her accommodation needs, but continues to be disappointed when she encounters situations where she again needs to speak up and remind others about her circumstances and special needs. Now outside of her high school, Char is finding that disability accommodations at

the community college are much easier since there are already systems in place to ask for accommodations (e.g., disability office, counselors).

Char referred Mary, her mother, for the parental interview but she did not respond to requests for a meeting. Char communicated that Mary was busy and committed to assisting her mother and husband with health related concerns. For that reason, an interview was not pressed for and a high degree of consistency was found with Char's accounts of transition experiences, her school service providers' impressions, and special education (i.e., IEP) records signed for by Char herself. Char also referred Doris, a physical therapist she worked with several years ago who has become a friend and someone she seeks advice from.

Char has a long history of pre-school and school related services. She describes being bused to a local children's hospital for therapy, but that later in her elementary years the school district hired it's own therapists. She was first placed in a self-contained classroom with many other children in wheelchairs, but through parent's advocacy she entered her local elementary school in second grade. She continued in regular progression into junior and then senior high school. In her high school years she was eligible for special education in the orthopedically impaired category. She was assigned to a general education program with related services. Those services included indirect OT and PT services where therapists monitored and provided ongoing consultation to Char and teachers or other school personnel as needed. A focus of therapy was often determining how Char could fully participate in general education with "adaptations as needed." She graduated with a 3.1 GPA. Records indicate specific planning for use of a laptop computer and being allowed extra time or shortening of assignments as necessary. Mobility accommodation needs were noted and specifically addressed was participation in a weight training program and swim program. In these activities, special equipment was needed for transfers and assistance from others who were trained by Char with guidance from therapists. Secondary transition services included a "functional vocational evaluation" that explored Char's interests, aptitudes and opportunities. Records designate anticipated post school outcomes being "college program," "competitive employment," and "independent community living with adaptations as needed." Referral of the family

to pursue SSI for financial support, and DVR for transition assistance are also indicated in school records.

Char's current interest is college and graduate school for credentials to be a special educator and work in a self-contained classroom for kids with severe learning needs. She previously thought about becoming a lawyer, according to her former therapist and friend Doris who shared that, Char tends to pursue that which she "feels affirmed or validated in" through feedback from adults with whom she works.

Char "loves" her home and expects her parents to always keep it, although they may lease it out and move to the metropolitan area to be closer to other family members. She's nervous about being out on her own, but expects she could do it with some help from a roommate or another person to help with things like cleaning. Nevertheless she is anxious to move elsewhere and to have her own place, be it at college or another setting. At one point in high school, Doris described that she explored going out of state to college in Arizona where a friend who uses a wheelchair was attending, but Char was reluctant to be far away from "those who (I) can rely on."

Char views herself as active in her community and perhaps an advocate or voice for others who are disabled. Others, see her this way like Doris, who also describes her as broadening her circle of friends, with continued bonds with significant friends from high school. Char had no date for the Senior Prom, nor did she mention any current or former boyfriends, but she admits to having a desire for marriage and perhaps parenting. This idea gives her pause, because Char thinks about the issues her children might face with having a mother with a disability.

Vanessa

Vanessa is a 22-year-old woman who completed a community-based transition program. After finishing high school in 1996 she entered the school district's transition services program for students age 18-21 with developmental disabilities. Since completion, Vanessa has enrolled in special courses at a local community college that she attends with assistance. To date she has taken an anger management class and is currently

enrolled in both art and history courses through a program involving video self-study as well as some classroom attendance. She communicates few ideas about her future, but values social activities. Vanessa has mixed spastic athetoid cerebral palsy. She uses wheelchairs and augmentative communication systems and has a variety of other assistive device and environmental accommodations in place. Physical assistance is needed in all personal care activities and household management. Vanessa operates a joystick controlled power wheelchair for much of her community mobility, but is commonly pushed in a manual wheelchair because of limitations in van transportation options and space limitations in her residence. Mary, Vanessa's foster mother, reports infrequent use of a walker in the home and Vanessa's need for assistance in all transfers from her wheelchair. They have a van equipped with a lift in which Vanessa and other foster children, some using wheelchairs, are transported. Vanessa vocalizes, points and uses eye gaze as her primary means of communication. Her speech intelligibility is rated at less than 30% with unfamiliar communication partners. Vanessa also has a Dynavox II, an electronic augmentative communication system that has both voice output, text display and infrared linkage to a computer serving as an alternative input device. The Dynavox II has a plastic key-guard and is positioned in a protected lap-tray that can be attached to either her power or manual wheelchair.

For more than 14 years, Vanessa has lived with Mary and Bill along with other foster care children in a rambler style home with a ramped entrance. At birth Vanessa was premature and experienced significant respiratory and general health challenges through the first five years of live, in addition to quadriplegic cerebral palsy with mental retardation. Her mother gave her up to foster care at age 6 and she has lived with Mary and Bill since that time. Vanessa stays in contact with her natural mother and other siblings, visiting with them on a monthly basis. Mary and Bill have adult children and grandchildren of their own whom Vanessa feels connected, and she maintains relationships with other foster care children who have lived with them. Presently, Mary and Bill have both Vanessa and Brad with them in their home. Brad is 4 years older than Vanessa and is soon to be placed in a different assisted living setting. He too has cerebral palsy, using both a power wheelchair and augmentative communication system. School

personnel express concern about the status of Vanessa's foster home and the age of Mary and Bill. School representatives hope that Vanessa moves to another assisted living setting with peers of her own age and like capacity. Mary and Bill express sadness over the imminent departure of Brad and do not agree with views about having Vanessa move elsewhere.

Discussion with Vanessa was significantly limited because of her communication impairment. In two face to face interviews with Vanessa she used her Dynavox II device only five times with prompting. The majority of feedback to questions was by vocalization, facial expression and gesture. Through interviews Vanessa expresses that she has "no plans." She previously worked as a volunteer doing delivery of paperwork in a hospital and said, "I liked that." She would now like to "help a doctor . . . deliver for them . . . would like babies." Vanessa describes attending school and "likes to go" to museums, malls, shopping and movies. Affirming suggestions by Mary, Vanessa also likes going to theater musicals, attending dances and listening to music, and going to parties. Although reluctant to use her communication device in interviews, Vanessa is attentive and engaging. She is consistently described as being "very social" (i.e., by Mary, by Dorothy her speech-language pathologist from school, and in school records). Although Vanessa had limited hopes of her future articulated in interviews, school IEP transition records have a large set of transition objectives. These goals and plans were apparently negotiated with Vanessa and her foster parents, although tensions exist between the school and family. IEP transition goals confirm some of the activities described by Vanessa, with several more explicit extensions of those goals. As part of vocational and educational outcomes, "having a paid job working with people," making deliveries for a "food court" or "hospital" are cited. Gardening and volunteer work are also described. Post-high school goals relating to residential status include living with foster parents, roommates, friends; ability to budget and shop independently; and to develop assertiveness and learn to direct her care providers. Transportation goals include use of community buses while using her power wheelchair and going independently to the doctor and leisure activities that she plans. Income support goals address managing

money and developing awareness of SSI, Plan to Achieve Self Sufficiency (PASS) account and foster care or assisted living expenses.

For Mary and Bill, their goals with Vanessa are to have her remain with them and for her to continue enjoying a lifestyle that includes a range of community activities and support of her in any schooling she wishes to pursue. Overall, Mary was disappointed with the community-based transition program because of the "nonspecific training" involved with the program. While Vanessa enjoyed the social activities with people, Mary felt they could have provided the same kinds of experiences. Specifically, a conflict over inappropriate behavior by a driver with community buses caused Mary to cancel Vanessa's use and training of the bus system for a period of time. Delivery job simulations in a local hospital also became disappointing to Mary and Bill because Vanessa really wasn't being independent. Attitudes about the transition program may be in response to the school's known desire to have Vanessa move elsewhere. The status of Mary and Bill is unclear in school records where they are indicated at times as "guardians," and at other places that they serve as "care providers" in their foster role with Vanessa's mother remaining as her guardian. Review of school records and discussion with the school representative that Vanessa referred indicate that a change in foster care status may be forthcoming.

Vanessa was determined eligible for special education, being categorized under multihandicapped status (i.e., mental retardation and health impairment). She was assigned to self-contained special education classrooms throughout her schooling, with integrated non-academic activities such as field trips, sports and clubs. Enrollment through age 21 in the community based transition program focused on vocational transition, functional academics and life skills, as well as speech and language. The overall goal with Vanessa was for "supported employment." Her interests in "deliveries," "work with disabled children," and "classes at community college" are noted in records. IEP transition plan outcome reports that documented particular progress toward post high school goals were not made available. Many of Vanessa's IEP goals were tied to her increased use and developing function with her Dynavox II communication system. The significance of efforts toward communication may be reflected in Vanessa's referral of

Dorothy to be included in the study as a representative of a service provider. As a speech language pathologist, Dorothy worked with Vanessa throughout her secondary education, including the transition program. Dorothy described a long and determined plan to develop a communication system with Vanessa. Dorothy sees the overall benefit to Vanessa of communication technology and believes that Vanessa would have had a different personality were it not for communication technology. Dorothy says, "She was quite retiring . . . now she's thought of as a very social person, and demanding your attention and wanting to go do something else!" Vanessa's sparse spontaneous or voluntary use of the Dynavox may be attributed to a variety of factors according to Dorothy. She notes, Vanessa's needs for environmental supports to make use of the Dynavox and that neither Mary nor Bill is comfortable with re-programming communication content. They also rely on verbal and gesture communication with Vanessa, and owing to their familiarity and time with her they appear to manage. Another conflict to overcome with the device, according to Dorothy, is to not only coax her active use, but make the system more mobile so that it can be used outside of her wheelchair and actively with the computer. Although set up by technical support people from school at their home, the infrared connection to operate the computer and e-mail through the Dynavox is not functioning. Dorothy discussed the hope of school personnel that Vanessa changes residences into "assisted living with other capable learning adults." Technology, environmental planning and human supports are cited as necessary for Vanessa to be able to stay connected with friends in the community, develop volunteer or work activities, and to plan self-initiated activities.

Although school made a referral to DVR, family has initiated no contact. Volunteer work trial experiences as part of transition programming appear to have helped Vanessa develop some desire and vision of herself in a work capacity, however, no formal or informal support for that outcome are described. The likelihood that Vanessa will develop paid employment is somewhat marginal due to lack of independence with community mobility, limited functional communication with unfamiliar communication partners, and questionable incentives based on SSI benefits and personal choices for

activity. Continuation of participation in special community college programs does not appear to be tied to any particular vocational outcome.

Vanessa's current care and future care with Mary and representatives from school are questioning Bill. Although no longer enrolled, the school program has apparently communicated this concern to Vanessa's DDD caseworker. Older foster care residents with Mary and Bill are being placed elsewhere. Vanessa expressed nothing about having a desire to move elsewhere or make a change in who lived with her.

Hopes expressed by Vanessa, Mary and Bill, and school personnel indicate that her social needs and desires are well understood. Everyone nurtures opportunities for community participation through community college, church, entertainment and community contacts. School input places a priority on Vanessa taking more of a self-directed role in initiating and planning her activities, as well as having greater contacts with peers and new friends outside of her family. They hope for a move into a peer setting where she could potentially develop and use more self-initiated and directed care routines. Mary and Bill view Vanessa's needs being supported by their efforts to involve her in several regular community programs and by continued membership in their extended family. Because of her disability and dependence, Vanessa will remain in need of residential living support throughout her life. No new ideas were generated by her or foster parents about her personal relationships outside of biological or foster families.

Paul

Paul is a 22-year-old male who graduated from high school 3 and a half years ago. He has taken a few courses at a community college and with help from family and friends has been pursuing leads to be involved with sports broadcasting. Paul has Duchenne Muscular Dystrophy, a progressive and fatal neuromuscular condition that is characterized by progressive weakness beginning in early childhood and leading to immobility and respiratory failure, usually in the third decade of life. Since middle school, Paul has been using a power wheelchair operated by joystick control. He has special seating needs due to sitting and posture challenges and will soon be receiving a new power wheelchair that has tilt back and elevation change. These features will enable

him to relieve pressure and reposition himself up and down in height. In high school Paul did some manual handwriting, sometimes used a standard computer, and often had other students or school aides take notes for him, or assist in operating a tape recorder. As a teenager, Paul developed use of a service dog named Willie that attended school with him and was under his command to assist as needed. Late in high school Willie functioned in more of a companion role, but was euthanized for health reasons soon after Paul's high school graduation. Also since leaving school Paul recognized the advancement of resources available through computers and sought a new system to use at home. He investigated control options and obtained a new personal computer with voice navigation software. Paul has Internet and e-mail connections he now uses to communicate with friends and explore issues and resources relating to his interest in sports. Paul has had some challenges setting up the microphone he uses with the voice activation on his computer. He is no longer able to write and is having some difficulty reaching and operating his wheelchair joystick. For telephone communication Paul uses a headset and cellular phone. Mobility impairments involve dependence in all transfers and needs for toilet commode chair, electric bed, and wheel in shower chair facilities. About 15 years ago Paul's parents build their home with wheelchair access features. They own a mini-van with a lift for transporting Paul. Paul continues to live with his parents and older sister who is away at college.

Paul's interest and hope since high school has been to enter into and work in sports radio broadcasting. He sought out volunteer experiences while in high school, took special courses in high school and at a community college. He also recruited experiences as an "intern" with several television and radio broadcast groups since leaving school. Paul was anxious to graduate and leave high school with the same students he schooled with for most of his life. Although offered a plan of extending to age 21 he was unsure what value it might have and decided with his parents to exit the school system. He had a transition plan in place, but believes that neither the school nor he and his family put much into it to make it really happen. Paul's plan was to go immediately into what he hoped to do, bypassing the "traditional college and job routine." Paul's mother and former service provider who is a friend describe that Paul's rush to work in broadcasting

relates to his expectedly shortened life span. Paul did not speak of this directly, but on several occasions notes that people working for him through school, adult service agencies and others did not understand his situation. Currently, Paul feels as successful as he can be given his circumstances and faults several of the service providers and systems that let a lot "fall through the cracks." Both his mother and service provider friends also apply fault to school systems and other agencies for not providing the right kind of guidance or assistance. Although not employed and not moving toward that goal, Paul's interest in local sports is active and he enjoys attending many professional sporting events with family and friends. He has been active in soliciting support for new local stadiums, voted on these issues, and has sought to be involved in advising them about accommodations for wheelchair users.

Paul's mother, Erica serves as his primary care provider. She is concerned about Paul's quality of life and acknowledges his desire to avoid college and pursue his interests more directly. As he grows more dependent and vulnerable, she sees herself having more difficulty assisting him and they as a family having to acknowledge the dilemma and tradeoffs of pursuing work experiences as well as community outings. She assists him with all personal care and transportation needs. Many efforts with schooling, DVR counselors, hospital programs, service agencies and durable medical equipment suppliers have been discouraging to them. She has expected better advice and guidance for both Paul and herself, yet continues to experience individuals and systems that do "incomplete work" or have "misguided goals." She credits Paul with initiating a lot of specific actions that lead him toward addressing his own technology needs and opportunities to pursue his dreams. She sees herself being a strong advocate, "sometimes angry and outspoken," but clear and direct in dealing with community agencies.

Paul attended his local school district program since 5th grade. At that time he was beginning wheelchair use and his needs for accommodation grew from that point toward him needing assistance with toileting, exercises to maintain his range of motion, other systems for handling learning materials and managing writing. From the outset of school, Paul was made eligible for Special Education in the category of other health impairment. In high school he received occupational therapy and para-professional services with PE to

maintain mobility. He also attended a special education study hall where he was assisted with school classroom studies. School staff assisted him with transportation and access barriers at school. Paul and his mother acknowledge a transition planning process, but appeared to have incomplete information and few options made available to them. Paul believed that some transportation and therapy assistance could have been provided a year or so after high school, but he chose to be finished with school. Erica notes that she had a strained relationship with the school district's then special education director and felt unsure about what services they might provide. She opted to reinforce Paul's desire to complete high school with his peers.

Paul referred an occupational therapist at school to represent service providers he had worked with. Nancy functioned as Paul's therapist in high school and their friendship developed and extended beyond his graduation. Nancy also felt that the school's transition planning with Paul was not adequate and Paul was not functioning as successfully as he could or should be. She relates that options at the time, based on the special education director's priority, was to assist students toward a college bound outcome, or to have them extend to age 21. In this small suburban school district, many students with major special need transfer to a larger district program with more options for transition planning. Paul was viewed as rather unique, being a wheelchair user in regular education classrooms yet not college bound. Nancy believes that the transition services have improved since Paul's graduation, but still acknowledges that few meaningful employment options exist for non-college students. She notes that the district has eliminated home economics and wood working classes and has few options for linkages with vocational programs. Nancy believes that the school and herself may have failed Paul, but sees some growth in him being more responsible and taking initiative for his own opportunities.

Paul and his family have solicited help in arranging internships with local television and radio. In one of his first experiences with a public television station, Paul regarded the time as positive because of how nice the people were to work with and the depth of involvement he had with writing and advising about film footage. This experience was funded in part through a donation made by a man his father knew. Paul

earned \$6.00 per hour. After a few weeks the experience came to an end and no referral to other opportunities or return to the station were offered. Another positive experience did develop with the sports director of a local radio station. Paul also felt this man was kind, listened to his ideas, and afforded him the opportunity to do some telephone interviewing of high school coaches, scheduling, and other research using the Internet. Paul and his mother regarded several other volunteer internships more negatively. They often felt that stations were just giving him a chance just to get him "off their back." Paul has also experienced a great many false leads or ideas that did not seem to materialize once his family or himself initiates contact.

Paul acknowledges that the sports broadcasting business is a difficult one to enter, given a great deal of competition for the few jobs that are available. He also cites natural limits to "volunteering" and some "red-tape" that restricted the length of the few opportunities he has had. Currently Paul hopes to follow-up on another lead with a friend who works for a software company. They are exploring ways that Paul might try out and give advice to voice technologies that this company is developing. He hopes for some type of meaningful interaction, but is uncertain anything will come of the effort.

While Erica is supportive of Paul's initiative, she acknowledges his disappointment with outcomes and dissatisfaction with those who have served him as advisors. Like Paul she faults school and agency counselors who she thinks should have persuaded him to be more realistic and broaden his interests. Currently she also acknowledges the impracticality of Paul being employed given his needs for assistance and reliance on her for transportation and personal care.

Nancy believes that a job would be a good personal growth experience for Paul, giving him a sense of responsibility and better understanding about meeting demands made by others. She also sees his narrow focus on sports broadcasting as a limitation, and one that has probably restricted any chance of gainful employment. While work outcomes have been disappointing, she believes that Paul has demonstrated success by now taking more self-initiative in developing and following up on leads.

Due to Paul's deteriorating physical condition it is unrealistic to him, mother or therapist that he would or should seek a change of residence. His family explored

programs and Erica is paid as a care provider, a qualification she received by going through training. Other friends provide periodic assistance when she needs time away, but no respite care plan has developed. The latter is an idea suggested by Nancy and recognized by Erica herself to ease the growing dependence Paul has and strain on her "failing back."

According to his mother, Paul does not like to draw attention to himself. He has been reluctant to affiliate with other boys who have Duchenne Dystrophy and needed to be actively recruited by Nancy to come talk with younger children about his service dog. Despite this pattern, Paul feels a commitment to local sports and has been active in both recruiting community support for new stadiums and working with groups to assure that wheelchair access needs are addressed in stadium design.

Paul is likely to remain with his parents until his death. Recognizing Paul's need for privacy and contact with male friends, Erica acknowledges that she "doesn't need to know all that's going on." Freedom to "surf the web" and be involved in chat rooms is afforded to Paul. Paul would like to have more freedom, but given his situation says, "what can be done?"

Jacob

Jacob is a 26-year-old male who finished his public school's transition program in June of 1993 at the age of 21. He has since negotiated and acquired new assistive technology through DVR as part of his plan to enroll in a community college. For the past two years he has been involved in an English as a second language (ESL) program at the college that is designed to prepare him for a regular college curriculum. He would like to do work that helps others who have disability. Jacob has spastic athetoid cerebral palsy that necessitates his use of power mobility and augmentative communication. In addition, he has a moderate hearing loss and is legally blind, necessitating enlarged print and high contrast print materials. Use of corrective lenses has been problematic and hearing loss does not appear to be helped by amplification. Jacob emigrated from Indonesia with his family who does not speak English. He has been in bilingual programs that have been a challenge in development of augmentative communication systems. Jacob's movements

allow him to use knee motion to control his power wheelchair. His current wheelchair has a variety of special seating apparatus and a tilt in space feature to allow him to relieve pressure. He drives with a scanning device and engages direction by activating a plate switch with his knee. He uses a foot switch to activate a change from wheelchair control to operation of an augmentative communication device, a Liberator. As a somewhat new user of this system, Jacob has many preprogrammed expressions and uses Morse Code spelling for some communications. He also makes regular use of a computer with adapted switch input and word processing software with word prediction. Jacob is a regular Internet user with this system. He communicates with local care providers and friends, as well as having several international contacts. Jacob has developed a homepage for communications about disability.

Jacob is independent in operation of his wheelchair and is assisted with set-up for use of Liberator and computer. He is also assisted in all other personal care, including eating and drinking, toileting, hygiene, bathing, transfers and academic work. While in school he had a personal assistant with him and this continues to be true at the community college. Jacob has been denied independent use of special access bus transportation, so he is privately transported and this individual assures that all wheelchair and communication device features are operating when Jacob is left alone at school. There a teaching assistant assists him for two hours during each of the two days he is at school each week.

Jacob lives with both parents in a home that is modified to enable wheelchair entrance and exit from the upper level. Parents and extended family members provide all personal care using durable medical equipment with bathing, toileting and transfers. His family does not have a wheelchair lift for their vehicle, but take Jacob out on occasion using his manual wheelchair. They transfer Jacob and then lift the wheelchair into their minivan. Jacob is unable to propel the manual wheelchair, so it pushed by family members on outings.

Jacob has been attending an ESL class at the same local community college he participated in while in his high school transition program. This has been a source of

frustration because it has taken him a very long time to make progress. He communicates, "I spent five years to study English." Jacob faults high school to some extent because it was not demanding enough. Language skills were also seen as problematic. Jacob describes that he has three languages, Cantonese, Minspeak and English. Minspeak is the programmed language used in his previous augmentative communication device.

Jacob indicates that his goals have not changed a lot since leaving high school. "My specific plans were getting a new computer and a right ESL class for me. DVR helped me a lot. I would like to have my own business in ten years from now. But the money is a problem for me." Both in high school transition, and now Jacob expresses an interest in helping others with communication technology and use of electronic networks. Jacob has represented himself in national and international meetings to bring attention to communication technology for the disabled. In Indonesia, he wrote and electronically voiced a speech. He describes his move to America, his learning of technology access with scanning, Morse Code and Minspeak and lower extremity movement. "I can control my left leg, a little bit of my mouth and my left foot. I can write with my left knee." He goes on to describe further effects from cerebral palsy and speaks of needs for better understanding. "How many people now have some disabled friends? I want to know how many of you are scared of me now? I might look scary to all of you outside of me, but I am still a kid inside of my heart. You might like me if you got to know me better. It is easy to make some disabled friends on the modem network. You never know, you might learn something from them."

Jacob's parents do not speak English, therefore a direct interview with them was not possible. Instead, he referred Gina for participation. She is his former speech-language pathologist and close friend whom he calls "mom" and writes that "she is my godmother." Gina has known Jacob since his enrollment in school at age 11. She has worked with him as he entered an English speaking classroom setting and acquired his first assistive technologies for mobility and communication. As a therapist, she has advocated for him and solicited his participation in demonstrating the uses and challenges of special communication technology. While she has involved Jacob in a variety of local, national and international activities, she acknowledges and is concerned about Jacob's

family's lack of involvement with him in the community. The family frequently "leaves him at home," perhaps due to a cultural belief about being seen in public, not wanting he or they "to be pitied." At home, Jacob receives full-time help from his mother and other family members assist. Although school transition plans indicate exploration of intensive tenant support by the state or a private foundation, Jacob and family appear to want to maintain his care status in their home. Aside from providing a residence, they are not advocating for specific schooling or other work plans. Although school initiated DVR funding for technology and support through the community college, these funds have been exhausted and further assistance would need to be re-negotiated. For Jacob his ideas for community participation and perhaps employment come via the world-wide-web (WWW). Disability advocacy and communication, as well as Internet sales have been suggested.

Extensive school and special education records were made available and Jacob referred Amy for an interview. Amy has worked with Jacob since his entry at the community college that began during his last year as part of the transition program. In public school Jacob received special education from his entry in the 5th grade level after his immigration. The orthopedic impairment category was designated. Due to physical, sensory and bilingual status, uses of standardized tests were not deemed appropriate. Cognitive skills were felt to be at grade level and Jacob was assigned to specialized self-contained services during his high school and transition programs. In transition he attended two mainstream classes each semester and was integrated in non-academic activities like lunch, assemblies, clubs, and fieldtrips. Related services received during high school and transition included consultative physical or occupational therapy to maintain range of motion, monitor equipment needs and consult with classroom teachers. Speech language services were also received to assist with development and use of augmentative communication devices and computer access. Computer programming was felt to be an appropriate vocational avenue, so he attended both regular classes and received specialized training with this subject. Overall goals in the program were for Jacob's transition to the community college. He attended the college two days each week for courses and had other academic goals to improve computer, math, and spelling skills.

At the time of ending his transition program, records indicate that Jacob will continue to need work on his English skills "in order to benefit from and perform in college classes." The earning of a degree was seen as "not desirable right now" and "part-time work more realistic than full-time [work]." Notes from transition teachers describe Jacob's challenges with college: "He is auditing a class that focuses on world issues. They read a lot of books and have classroom discussions. This has been a challenge as Jacob can not read the books fast enough or keep up with the class. Participation in classroom discussion is also limited as it takes him a long time to input sentences. Generating papers or any kind of written work is also a challenge." Currently, Jacob is in an ESL class with other students and is expected to complete all work. He has accommodation needs due to vision impairment and handwriting. His assistant Amy is with him each day at school to provide help with enlarging class materials or translating them to computer or communication systems. Homework assignments are often e-mailed home for him to complete. Discussions with students in class are limited, they not having time to wait for Jacob to compose messages, and he not fully understanding them due to their accents. Advancement after completion of ESL is uncertain at this time. According to Amy, Jacob has lost his DVR support and would need to pay out of pocket for any future college courses.

Jacob has sought greater acceptance in the community. In his invited speech to a group in Indonesia about technology and disability, he communicates that he's had difficulty making friends in school because people are often "scared" of him. He sees the computer modem connection as being the answer to bring people with and without disabilities together for better communication and understanding. He initiated a list-serve of those with disability for discussion of issues, but this site has not been maintained after he entered the ESL community college program.

Jacob sees himself making good use of computers and the Internet, as do others. Gina hopes for some opportunity to connect and advocate through technology, and Amy has a similar hope for Jacob. They see him as having skills and talents to draw community attention to those with special needs. While likely not a moneymaking

pathway, each views the WWW as Jacob's link to the community and means to influence community understanding and acceptance of those who are disabled.

Neither Jacob nor his godmother brought up that he had any companionship outside of family. Although he enjoys people and going out to classes, a lack of participation by Jacob in the community with his family is a dilemma for those working with him. He appears happy to stay with his parents and although they have' in the past' acknowledged the inevitable need for an alternative for Jacob, his mother and father do not appear to have a long term plan for him should their health fail them.

Summary of group

As individuals and as a group, the review of transition processes and outcomes appears disappointing relative to hopes and expectations for most other students who are completing high school. Summarized next, based on participant's accounts, are trends seen in planning and organizing transition, as well as outcomes observed in schooling, work, residence and citizenship.

Planning Transition

Participants and families typically saw themselves, rather than schools, as being responsible for developing hopes and exploring options for transition. Most had tentative, indefinite, or even disappointing relationships with agencies, but were managing to find a way to make the most of the after high school years. The transition planning process was not clearly collaborative and student's view of preparation for after high school demands was questioned. All participants acknowledged the IEP process and specific attention to transition, but students and families viewed such procedures as obligatory or a necessary formality. The process enabled them access to immediate school services or programs, but little else. Entitlement to some form of therapy service, vocational experiences, and community integration opportunities were often sought from special education programs. For families the transition planning process poses another round of dilemmas for them regarding their roles as parent versus provider versus advocate. Tom's mother described particularly well the dilemma faced by parents about meeting their children's needs. Throughout his time in school, Tom's mother notes a need to have distinct roles between

school and family life. She says, "he's had so much therapy in his life, just so much and I don't know, I feel like my mind is going back because high school just hasn't been [as involved.] I remember everybody who worked with him as a young person, has such emphasis on what they were doing with him. Teachers seemed to want him 24 hours a day to be learning his ABC's, with therapists it seemed like all day in school and after school and into bed time, I felt like I needed to be doing therapy. And, I felt like I needed to be mom to him. So I remember those frustrations through the years. They needed to take care of their part and I needed to take care of his spiritual and emotional well being that was my job. But, then I feel like looking back, they feel that I haven't been as supportive as I should have been." She recalls, "I remember the hardest thing in dealing with him when he was small was facing tomorrow, facing the future, because it was always so bleak. I learned really early on with him, and it kept me together a lot of times, to take one day at a time."

The future orientation that is part of transition creates decision-making challenges for families as well as students. For those in school and recent graduates, decisions often hinged on choosing a pathway well before graduation. Family and student tensions about academic content versus functional skill development were often expressed. Although college bound status seemed to be easily accommodated, those not seeking post-secondary enrollment were given a choice between shifting into dedicated transition programs through age 21 or exiting school on one's own. This decision was a dilemma for many because extending schooling appeared to have unclear outcomes aside from being a scheduled activity. After his high school graduation ceremony, Wes's grandparents went into the district office and extended his schooling by entering the district transition program. Wes states that the program "didn't get talked about until after, maybe two months before I was out of school." The program director talked to him and Wes indicated that she told him, "well, just coming out of high school you really won't do anything, and then she told me two weeks ago that next year they're going to try and find me a job that I can do." Wes goes on to say that he "and my grandparent's felt I should do this. 'Cuz it will make me more knowledgeable and that kind of stuff. So I can basically be on my own. So after I got there I got to do some things." Vanessa said that

she went to the transition program and “did nothing.” Her foster mom says that the “transition program finished a year or more ago, [it involved] going out a lot, a waste of time.”

Other students also faced decisions about extending school programs. Paul discussed his option of staying in school but says that he “graduated when I was supposed to graduate. . . . They said I could stay at school a little bit longer . . . I think another year or something . . . and they could help me out that way, but I decided it was best for me to just not do it anymore and just be done [and] we didn’t know what we were going to do.” Paul says he didn’t “know the exact specifics of how long [he] was going to stay” if he’d decided to extend. He thought school might help with therapy and transportation. His mother was also unclear about what the school might have done with him extending. She said, “The one thing I remember is going around in circles . . . the school district [special education director] said the district ‘doesn’t have to do this because Paul qualifies for DDD services’ . . . and I finally gave up because I didn’t think we’d get anywhere with the school system.” She goes on to say, “I don’t think [the school] helped us in any way whatsoever! And it might have . . . I think it’s everybody’s fault . . . we just kind of gave up and fizzled out about it.” Paul concluded about his decision to graduate on time that “you want to move on and make it as normal as you can.” Tom is aware of the option to extend beyond his Senior year but is clear about saying “I don’t want to . . . ’cuz I have more interesting things to do, I got better things to do.” His mother identifies that, “the DDD takes over a lot of his things when he turns 21, so if he doesn’t stay a part of the school system, there is just dead time, he won’t really be helped.” She says, I have mixed feelings, because I really would like him to continue, because they’re isn’t really anything for him to do in the interim . . . I just wouldn’t want him sitting home and being bored with nothing to do. However, he’s really tired of school and if they do not put any emphasis on vocational things . . . I don’t see it being productive probably for either them or him, so I guess I’m really anxious . . . to see what their plans for him are.”

The college bound students, also faced uncertainty about appropriateness of choices and their preparation as part of schooling. Jacob, in reflecting about high school, said, “At first I thought it was great, but I found out it was horrible . . . I couldn’t pass

[English] to go on to the computer class.” He said that in high school “[work] was too low” and although he “learned a lot of computer stuff and math, the classes were too boring.” He goes on to comment that in high school “the teachers talked to me funny and like a baby. They taught the class so slow. Now (in community college) I have a great teacher to help and the class is the right speed for me.” A teaching support individual at community college adds that, “[Jacob] was still pretty used to having people organize things and work individually with him. He wasn’t asked to do a lot of homework, doing a level of homework that was not so great, so he tended to not take [college classes] as seriously at first.” Regarding high school and his extended time through age 21, his assistant says, “I think that he needed more practice in doing some of the self assertion, going and getting what he wanted, getting somebody to meet his needs instead of waiting for someone like me to come along. . . [at this point] I’m still doing what you might call ‘training to get him geared up’.” Char admitted that leaving high school was “scary in a lot of ways because the security I’ve known for 18 years is going to change . . . and I think it’s scary for everybody, but for me, it’s more complicated because of the disability.” In anticipating college, Char comments that “my high school was a breeze. Three-quarters of my classes still let us turn our assignments in a week late! And gave us credit for them. I mean, come on, they don’t let you do that in college.” In describing some of her current experiences, Char says, “I took my first college English class and rewrote a paper six times . . . in high school I could very easily write something the night before . . . and get an ‘A.’ Now [in college] if you want anything above a ‘C’ you’re working on four or five rewrites easily.”

Transition Outcomes

In addition to development of student’s skills, another mandate for model transition programs is to facilitate connections between families and adult services in the community. For many of these students, the referrals were often made to DDD, but this agency was reported to be primarily interested in residential support only and would not be active until these individuals reached age 21. Referral and links with other programs like DVR were often informal or unclear. Although most families had initiated SSI benefit procedures, in no cases were school systems or the IEP transition process viewed

as helpful or pivotal in assisting with this connection. In review of traditional transition outcomes, the eight participants in this study fared as follows. See Table 3 regarding current status and transition outcomes.

TABLE 3: Current status related to transition outcomes

| Name | Residence | Post-Secondary Education | Employment | Community Citizenship |
|----------|-------------|---------------------------------------|--|---------------------------------------|
| Barb | Family Home | Planning CC or 4-year College | None | Volunteer, church |
| Trisha | Family Home | No plans | Token, self-initiated | Young Life |
| Tom | Family Home | No plans | None | Church, Youth Group |
| Wes | Family Home | No plans | None | Church, Football, Advocacy for Sports |
| Charlene | Family Home | Attending CC, planning 4-year College | Summer camp counselor for children with disability | E-mail network, volunteer |
| Vanessa | Foster Home | Some classes at CC | None | Disability Social Group |
| Paul | Family Home | Some classes at CC | None | Voting, Advocacy for Sports |
| Jacob | Family Home | Some classes at CC | None | WWW based communication network |

CC= Community College

Advancing to post-secondary education was planned for or experienced by many participants, but for different purposes. At present none of the participants had enrolled in a 4-year university. Only Lisa and Char anticipated this move with ambitions for professional careers. Lisa sought Head Start college credits and might begin post-secondary education at a community college or university. Char anticipated starting at a 4-year private college but opted to begin at community college to get an associate degree and then transfer. Paul, Jacob and Vanessa have or are utilizing community college to

address interests (e.g., Broadcasting for Paul), enable skill development (e.g., ESL for Jacob) or to provide activity (e.g., Art History for Vanessa). Although they have or are attending classes, none is seeking completion of a degree. Paul has sought non-credit and non-paying intern-training experiences with broadcasting, but none have been continued. Trisha, Tom, and Wes have no plans for schooling beyond high school or dedicated transition programs. None of those in school programs had formal relationships with the DVR. Paul and Jacob had received assessments through DVR and some funding or guidance related to assistive technology needs. Both Lisa and Char were anticipating seeking such assistance, but had not initiated contact to begin exploring options and procedures. Regarding DVR, Char said, "My friends suggested I check it out. My therapist was also aware of it and recommended that I look into it. I don't know if I would be as lucky as my friend Janet and get everything covered, but any amount of help would be well worth it."

Employment experiences and outcomes have also been minimal. With few exceptions, none of the participants have experienced paid employment while in high school or years following graduation. Annie developed a token job on Saturdays, but does not receive a regular wage. Char has been paid as a summer camp counselor for children with disability for the last couple of years. Paul has developed unpaid internships. A family friend had funded one of these, but he has not otherwise sought a job or received a wage. None of the other participants have any work history or receipt of wages, beyond supervised work experiences as part of dedicated transition programs (e.g., Annie, Vanessa, Tom, Wes), or guest speaker payment (e.g., Jacob).

Family's expectations for employment were often limited or unexplored. Trisha's grandmother "wants to find out where Trisha can go to finish her schooling, take all the tests with her machine (i.e., Liberator), finding her a way to make some money." She is unclear "what the plans are . . . nothing [has] really been settled." She admits some uncertainty because she "has never had a handicapped child before." In relation to employment outcome, she says, "most people know that really and truly if you can't do the job, you can't have the job." About her job with the dry cleaners, she says "I don't take it as a real job, it is just helpful to her and the lady is saving Trisha." Her

grandmother has few hopes of real employment, but offers that maybe Trisha could “make her business out of computers, some kind of business that she could do for some home person . . . do her writing and everything . . . I don’t know, that’s the only thing I can think of.” Tom’s mother is uncertain about employment expectations. She says, “I guess I believe in an honest days work for an honest day’s pay and I don’t have a real solid idea, that if he was this as opposed to that he’d be more successful. I think just having a job and being diligent and doing well at whatever he ends up doing, that would make him successful . . . I don’t know. I guess my expectations aren’t very high, I’d love for him to be out there to make enough money to do all the things that would make him happy. I want him to make a living in some fashion, comfortable, whatever that entails, help from the State, whatever. I guess I don’t see him totally independent in that manner.” Wes’s grandmother has a goal for him to “have a job,” but not for economic reasons. She relates, “If he can find a job that he’s happy at, and even if it’s not a great paying job, I want to see him out in the world.” She says, “I am really thrilled with the work ethic that he’s got . . . [but] I think that what he’s going to need to do, is have better computer skills.” Wes’s transition program director estimates that “given the amount of money it would take to support him, I would say it’d be 50/50. He could probably get a job that would help pay about half of his living expenses.” She goes on to conclude that given his living expenses and work skill level, “assisted living is expensive, I expect the State to take over.” Although Paul desires some work activity, his mother describes that “we just have to solve some of his daily life problems. If he had a job, I could take him to do the job if we have a plan, but we don’t have a plan now, I don’t know.”

For these students and graduates, actual work experiences were absent or artificial, and future employment was uncertain. Although ideas for kinds of work activities were voiced, most were continuing to dream, or were resigned to benefit programs and family support. Along with their own limitations with work, and uncertain futures regarding employment, no participant cited a role model with disability that was employed. And, although Lisa and Char described the problems they may anticipate with work and disability, few others had explored particular employment issues. Sometimes work expectations were at odds with social and medical benefit programs. Six of the eight

had regular or soon expected receipt of SSI and dilemmas about how much could be earned while retaining monthly income and health insurance were questioned. When Wes was offered a summer job if his grandparents would transport him to and from the site some 15 miles from their home, they declined. Wes's grandfather explained, "I called Los Angeles and talked to their headquarters yesterday. He goes out and takes a job he can make \$65 a month, after that they take half of what he makes away from SSI. I am not going to allow him to go and work and gain nothing from it." Given the costs of transportation the family concluded and grandpa said, "it's not financially feasible at this time for him to take a job . . . he's going to lose from it. So, I'd rather see him volunteer and get the experience of being there on time, doing the job, this sort of thing. We're not going to let him volunteer to do a job that is going to make money. If he's going to volunteer it's going to be something like a food bank."

None of the participants had experienced a change of residence, all being with their family or long-standing foster care arrangement. Although Lisa and Char anticipated a change of residence as part of college years ahead, a good deal of uncertainty existed about how feasible it would be for them to manage with a roommate or partner, or how they might go about hiring an assistant. All other participants were inclined to continue living with family, and they and families had just begun to address issues of needing other care providers within the home to provide assistance. Vanessa faced the greatest uncertainty about her residential future with her foster family, and others like Trisha needed creation of a more accessible place to live and nurturing of a long-term care provider system beyond family. All other participants and families anticipated continued residential support by immediate or extended family.

Community participation and citizenship is another transition outcome to summarize. Although none of the participants felt, or were described as being, "hidden in the community," participant's level of involvement was typically tied to family initiated and directed activity. Among those in school, Wes participated in extra-curricular activities that included football, and Lisa had activities through clubs. All of those in school were involved with community churches or other youth activities. Among graduates, church and routine social activities were also closely linked to family. Some

independent development of community outreach had developed for a few. Char broadens her personal network through e-mailing and volunteering to represent those with disability in educational programs. Paul has supported new sports stadium development by telephone solicitation and by registering to vote and voting. He too sought to represent interests of those with disability in stadium design. Jacob seeks a connection through e-mail networks and envisions that medium as his way of connecting with others and easing discomfort that may exist about those with disability. Vanessa utilized participation in this study to re-connect with former school personnel who she views as being a part of her personal network.

Thematic Analysis

The taking in of personal stories about transition and a review of particular outcomes brings attention to several themes that characterize this period of time for individuals who rely on technology and human assistance. Contrasts and comparison give rise to three broad issues that bring awareness to what those with technology reliance face as part of transition from public school to young adult life. Major themes relate to 1) membership, 2) accommodations, as well as 3) dilemmas regarding needs for human assistance, going through cycles with technology, and seeking enhanced access and acceptance within the community. Each theme is presented next relative to all participants, wherein similarities and contrasts in views are revealed (See Figure 4).

Membership

When discussing school experiences, participants communicated that membership in a group and a feeling of comfort and belonging in a school system was important. Students and graduates acknowledged the feeling of being a part of a student body and although they recognized their novel or unique status, each seemed to be comfortable with how they were acknowledged and had experienced membership. Trisha says about school that she is most “happy [about] friends and teachers.” Tom’s mother admits that she was “petrified, and [now] was just amazed at the kids, how they’ve treated him. They’ve been great, I’m sure he’s had his trials, he’s just able to let a lot of it roll off his

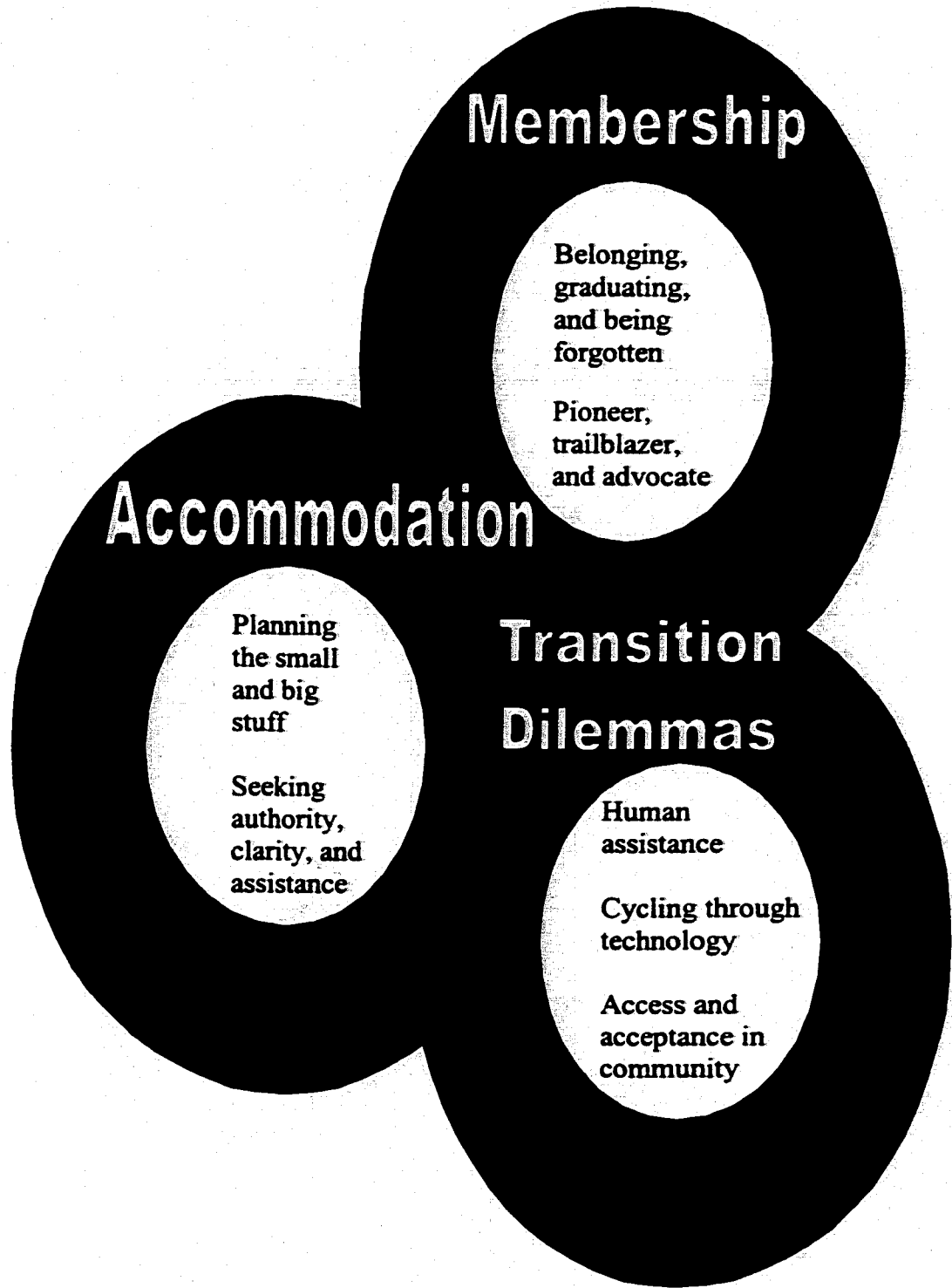


Figure 4: Assistive Technology Transition Themes

back. There are a lot of kids that get involved with him.” Regarding Paul’s experience in high school, his mother stated that “75% of our experiences were positive.” His therapist indicated that although Paul is not a “real outgoing, gregarious type of person, he was well liked . . . and it was very important to Paul to graduate with his class, the kids he had progressed with.” Char related that she’s “been in this school system for 10 years and so you get kind of used to people being the way they are and things being the way they are . . . it’s really weird to leave behind a lot of friends I’ve known for 8 or 10 years . . . I have a really unique group of friends, everyone has different interests, some of them can’t stand each other, but they’re all my friends and they’ve all helped me to become a great part of who I am.” Her speech therapist relates that Vanessa is missed in the transition program and that “they’re hoping that [she] comes back and visits them sometime . . . visit some of your old friends . . . and a few new ones.” In a prepared speech, Jacob said, “I always wanted to make friends my age at school. But I was shy and nobody would talk inside or outside of class. The student’s were scared of me. . . I’m not shy and mad anymore because I know what to do now and I have the power to talk with all of you.” In high school, Jacob liked to help fellow students with their technology. His educational support specialist says he “liked the one-to-one, being a model and a support for that.” For Wes, he struggled to be released from a district special education program to return to his neighborhood and familiar high school group. He described, “I’m going back home, I wanted to be with everybody, but this time I wanted it in my own back yard. I went back to [my school] and I was happy ever since, and I was in my surroundings where I was more comfortable . . . and I was with my friends, I knew the guys.” He was also sentimental about high school friends, about finishing he says, “I felt like this is it, can we just stop time and wait just a little while longer . . . I knew this was it, but I can always count on them being there if I need something.”

Evidence of membership applied to the school as a whole, and was also reflected in participant’s friendship networks that were sometimes small, yet important. Char comments about graduation and life after, she says, “the last time that group will ever be together in the entirety of that group. I still keep in touch with 4-5 people from that group, but I graduated from a class of over 300 people. I still run into people and you see them

on break and stuff, but it's the last time that the group was together." Jacob had trouble making friends in school, but now he describes that "I have many friends that aren't disabled. I met them through the modem and at camp. Mostly they are older than me." Continuation of these networks in post-high school years was often seen as important, yet difficult to maintain. Wes described, "I was concerned, I have maintained contact with my friends, not all of my classmates. I do have all their phone numbers . . . I don't like calling them during school now because they're doing their college stuff." Paul was tentative about some friendships, him "not having real reliable friends in terms of getting around." He goes on to say, "I do the best I can and try to stay in touch with people and stay on it and get people to take me out, but I have a main friend . . . I keep in touch with him a little bit, another friend went away to college . . . so I don't have a lot of real consistent friends. I have people to go out and do stuff with, but just not on a regular basis, what I'd like it to be." Vanessa was feeling somewhat detached from friends, and her therapist described "hoping that she would have the opportunity for living with individuals about her age, in a home setting, that would give them opportunities for a greater independence than what I see." Tom's mother anticipates problems after high school, she says, "He doesn't have a problem relating to people and he does have a network of friends and I know he doesn't understand the implications of the change that will be made after school is out, 'cuz that is his circle of friends now. But, what his social life will be like after school I just have no idea, none."

A major capstone for acknowledging membership and accomplishment as part of high school was participation in graduation. Graduates and families made note of particular hopes and told stories about specific moments and feelings associated with graduation events. Paul's mother describes, "the class gave Paul a standing ovation when he graduated. And they gave Willie [his service dog] a diploma, and Willie took it in his mouth and so it was a neat experience. And then several of his friends went to the party with him, it's an all night party and he had a good time. He's had throughout several friends that have kind of stuck by him. One actually got him a date for the prom, and they doubled." About her graduation, Char describes, "I walked across that stage to accept my diploma with a friend walking behind me to hold on to me, because my balance was just

all over the place, it didn't exist. The longest 25-30 yard walk of my life! But as I shook hands and accepted my diploma, the whole entire class stood up and gave me a standing ovation! Every single one of them stood up! So, that to me was ten years, I've done it! I've earned this!" About his graduation Wes described, "the day of graduation, I planned it from January 'til June to walk to my graduation. I got pneumonia two weeks before graduation, so I couldn't, but I walked to the senior breakfast." He goes on to say, "I would not exchange my diploma from [high school] for nothing. 'Cuz the night of the ceremony, when I went up there, I was pretty proud, I was happy, the big accomplishment was earlier in the day when I walked to the breakfast to show off. I went up there, four of the popular kids were in front, and I was friends with them and I'd talk with them . . . they yelled and screamed and I was like 'this works,' 'this is cool' and I wouldn't trade it for nothing." Other students had experiences like Vanessa, who as a senior was awarded the "Miss Congeniality" award and also the "Miss Teen of Dream On" voted on by her peers.

Highly valued and acknowledged, these ceremonies, past or future, also became a source of conflict due to different needs these students would have. Planning ahead, Barb's mother comments, "I want to see her graduating with the rest of the kids, I want her acknowledged . . . not swept under the rug, she worked very hard to get where she's at. You know, different things in her life were like music, the rest of the kids were on the stage and they put her down on the floor, separated from them, that wasn't acceptable to me. And that's the same way with her graduation, I want her up there, if they have to build a ramp for her to get up there and get her diploma, they're going to do that for her."

For those feeling appreciation for membership and acknowledgment in graduation, issues of accommodation sometimes interfered and lessened the feeling of acceptance. Wes became dismayed about being left out of the school picture during his senior year because he had been assigned to a special education program at another school and no one had told him. He said, "A big group picture was taken on the football field, they do a '97, and I wasn't notified. Well, I come home steamed." Char was looking forward to her Senior Party, but when planning ahead to assure accommodations on the boat found that it wasn't accessible for using the bathroom or reaching the main

party room with her wheelchair. So she said, "I'm not going . . . so I called one of the parents on the planning committee, who was also my girl-scout leader in 3rd and 4th and 5th grade, and I said "Mary, I'm sure you guys meant for this to be accessible, but, it's not." Special arrangements were then made for Char to have someone along to assist her free of charge, but she was disappointed that they had forgotten about her. Paul's mom notes the struggle Paul and she have about circumstances with people. She says, they "ignore you like you don't even exist. Or they'll go out of their way to either be rude . . . [or demeaning]." Despite being well known, Paul's mom says, "I had to constantly ask, I mean for high school graduation, "Did you get a bus for Paul to bus him to graduation?" and of course they didn't . . . no one had thought about a bus for Paul to bus him to the senior party either, and that was quite expensive and I was told that I would have to figure out how to get him there and stuff. The school district said 'no the school had to,' but I had to initiate it and I was made to feel guilty . . . so we got 'Oh, it's extra money,' and 'oh, I forgot!' and it's like they're saying 'It's your problem'."

"Being forgotten" again was a disappointment to students and their families and draws attention to the inevitable challenge of being a novel or unique individual in a large system. Responses to this status may be expressed by frustration with misunderstandings, resistance in negotiating accommodations, or encountering programmatic solutions that did not meet needs of these individuals. Sometimes however, frustrations and dilemmas became a source of involvement that seemed to inspire some toward the taking on of a role as advocate and leader. Many spoke about their feelings of being a pioneer or first of their kind to encounter these school systems and environments. About being a student with disability and seeking accommodations, Wes says, "It's happened since I was in 1st grade, so . . . That didn't bother me. You know, so I just feel that I'm just doing a service that needed to be done. Sometimes we have to fight the district. On the other hand, they get it done one way or another." He goes on to express, "See I'm the front-runner. And then when my other friend that's in a wheelchair, he'd come right behind me, after he got out of middle school and everything was set up for him too, because I was there first." Wes's grandmother talked about him being a spokesperson about disability, "We have two notebooks that are about this thick (+1 inch) letters from all the kids at [the city high

school] before he went down there, he had gone down there and went to different classes and gave talks about what it was like to be in a wheelchair, because they hadn't had somebody who was like him. They were either more involved and couldn't express themselves, or they were walking and didn't express themselves very well." His grandmother concludes, "he's always looking out for the other guy. And I'm really happy that he is." Jacob views himself as contributing to other people's understanding of disability and comfort with those who are different. He writes, "I [was] so mad, I decided to write a speech about CP. I'll go to schools [in my area] and talk to all of the students about CP. Hopefully, this might help disabled persons to make some friends with somebody."

In looking back at her recent graduation, Char comments, "it feels great that I've made it this far. Because I was the first student, physically disabled to the point of using a wheelchair anyway, in the district . . . they didn't have a clue . . . we had to [teach them about adaptations] so they would have a clue. We've literally started from ground zero and build our way up. So it feels great to me that I've fought my way through this district and made it as far as I have." Char goes on to say that they also had to "breakdown barriers socially [because] parents hadn't seen anyone like me, kids hadn't seen anyone like me, teachers didn't know how to handle me." She says, "it wasn't something they could understand, and also physically the schools aren't designed, well now they are because we fought for them to be, but they weren't when I started at them. They are designed now for students coming up behind me, so they don't have to fight." Paul's mom says, "He had physical problems, but he was one of the few students who could academically go into the regular classroom." His therapists acknowledges Paul's unique status by acknowledging that "at the time Paul was in high school, we had two in wheelchairs, so we just don't have lots of those kids here." She describes, "Paul did, at sometime in his high school career, came down and did a talk to one of the special education classes here, 4th and 5th graders in the resource center, about canine companions and service dogs. . . since then Paul and Willie (his service dog) came to our school one week and he gave a little talk to the kids, that was a little outreach."

With membership and attempts to accommodate, the novelty of experiences is also recognized. Barb's mother felt that "it's fairly new for the school system to have children in wheelchairs . . . the schools are into mainstreaming them, they've been really good. They have been working with us, but I don't know a lot of the details until they hit you. Its like problem solving every year, you find something new that you have to figure out with them, but we work pretty well together." She goes on to describe that, "Just the whole school process, she deserves everything everybody else is getting, from her driving to PE classes, through sports even. So, they've never done it before, so we'll give them a little bit of breathing room, but we'll learn together." Regarding Jacob, his therapist notes, "I've had him work with kids who are beginning to use augmentative communication and who need a mentor, a role model. He actually did some spelling tutoring with one of our students, using his augmentative device. He is very intuitive about when to prompt and when not to, and always prepared when he comes in. But, even that takes an enormous amount of organizing to make it work! She goes on to describe, "He is an organizer. He is a person who pulls other people with disabilities together. He's very resourceful. And although he may not feel successful, I think given his disabilities, he's the most successful person I know, given everything that he has against him." She adds, "Jacob, when he was in high school, did this little list serve thing, World Friends of the Disabled, he brought something out so he could communicate with disabled people all over the world."

Accommodation

Belonging at school or with friends, and being acknowledged was a positive feeling for participants and their family. Nevertheless, a special or unique status also brought a sense of disappointment at times due to specific hassles with accommodations and special arrangements.

For these participants, experiences in school using assistive technology and needing human assistance brought a need to have explicit accommodations in place. As evident in each participant's transition story, accommodations were used to improve upon participation in school environments (e.g., architectural changes). Accommodations were also employed to enable involvement in activities (e.g., scheduling and transportation). Barb is tired in the afternoon, her mother notes, "She gets fatigued easily and her studies

suffer for that reason. I like to see that her main critical classes are in the beginning of the day when she's fresher and she has more of her reserves, than at the end of the day when she's tired or she's sick and has to go into the doctor more often."

Related to classroom education, alterations and accommodations were often used in receiving and performing classroom learning activities (e.g., special education resources, learning material adaptations, and computer use), and demonstrating learning performance (e.g., assignment changes, testing modifications,). Discussion about accommodations brings out that one needed to, as Char said, "plan the small stuff and the big stuff." Considerable detail was given in stories about participation in classroom and school activities.

How participants went about managing classroom accommodations often involved arrangements for assistance, uses of technology, and special services. Accommodations in and around school were also critical to student's participation, and sometimes had to be customized in terms of space and schedules. Her mom says that for Barb, "the criteria to [be sure about] is that she is accessible in the bathroom. All that is part of just going into the [particular] school. Every year we have to, especially if she goes into a new school, we have to make sure . . . I'm concerned about the fire safety, what if there are earthquakes, what are they doing . . . and that the bathrooms are accessible to her. She has to have a private room because of her catheterization and her bowel problems. And, there always has to be an aide available to her, so . . . They have worked out a system where she is monitored, so she knows how to get help right away if she needs it." Trisha, Wes, Paul, Jacob and Vanessa also described needs for special access to facilities and use of helpers to manage toileting and other personal care tasks while at school.

Use of computers as assistive technology to augment classroom performance was often attempted. Char recalls that "the basic physical things" she had to rally for, but, "classroom adaptations my therapists have always been willing to take care of, because they understand the necessity for that. I've used computers, I learned to type in 1st grade, and without being able to type things, I wouldn't do anything in school." In later years, Char describes "I've had access to a laptop computer provided by the school district since

I started junior high in 8th grade . . . when I took the advanced placement in psychology exam and there was an essay portion of that exam. I had to file with my high school guidance counselors a special request to use my laptop to type the essay. And, I didn't have a time constraint for the test. Everybody else had a time constraint, but for me it had been removed. I was allowed to type the essay so that my hand didn't limit what I can put into the essay."

Paul negotiated to work his therapy into time with an aide for his physical education credit. He also went on occasion to a special education resource room "mainly just in terms of advocating for me and having a place I could do the work and people could help me. I don't really understand the reason for it, what it was in place of. Everything else was the same as it was for everybody." Paul also received some technology. He described, "They made available a little laptop that I used a little bit, but for the most part they didn't . . . computers weren't a real emphasis basically. I really didn't get to utilize the computer in terms of doing reports or typing papers." Computer technology was also an issue for Tom who likes using his family's older computer at home. At school he says, "we write when we absolutely have to." He'd prefer using a computer for writing and does, "when I can find one. We have two or three thousand kids in our school, ain't got no room for the kids to use the computers."

Wes described a number of accessibility accommodations, but also felt accomplished by developing strategies to complete homework and schoolwork. He said, "Grandma helped me with my homework, and I'd dictate to her and she'd write it out. Now, when I was in high school, and we'd like have health class, they'd have us [make] a magazine and stuff. So sometimes I used the computer at school. I would do my homework on the computer and would come home and do whatever I wanted." Trisha's grandmother describes some of her schoolwork. "She gets five words to use and we make a story, and her friend would write it on paper. But then if there was something that she could change, we would take her computer, her laptop computer and she would write it there and she could write it off herself and put it with the lesson, to let the teacher know that she did it on her own, but she did it through the computer."

Jacob immigrated to America and entered schools as a teen. His therapist described that, "he didn't have any funding for assistive technology until a couple years after [he arrived]. So he was like 13 before ever getting an augmentative communication device [for writing and speaking]. The only computer he had was an [Apple LC], which belonged to the school. He didn't have one of his own. And so, I don't know how well we should publicize this, I basically snuck it out! We just determined that it was a necessary accommodation for him to do school work. He needed to be able to do it at home too."

At the community college now, Jacob requires careful planning for accommodations. His teaching assistant describes a detailed number of steps that must be followed in order for Jacob to participate. "I go in to the classroom and Brad, who is Jacob's driver, drops him off with his wheelchair. Then supposedly Brad checks to make sure things are right. And, this was a problem in the old days when sometimes the cord would come loose, or there was something that didn't work right, and then the light talker (i.e., communication device) wouldn't work, and I would get two days of that sometimes! So, he would arrive. We've had a system where if he's had homework, I have a tickler folder, it's a blue manila envelope, and at the end of class I'd write down what the assignment is, provide materials that are appropriate, that are accessible to him in the folder. I also send assignments via e-mail that I've scanned. But, you know...the first thing you do is take the folder out, get out whatever work he's done so that it's ready for work in class for handing out. So then, as class comes, it may be a combination of individual presentation by the teacher, there's very heavy grammar, I'll take down notes...and I have to write large, because in many ways, I think in class, it's the visual not the communication, that is the most difficult. It's hard for him to see things in class. The teacher has to write on the board, and this is a very good teacher who will work hard. Not all the teachers are so attuned to the special student problems, I think. So, I will write down the things that need to be done."

Accommodation needs typically called upon participants and families to develop skills in seeking and negotiating changes. This process necessitated that they find out who had authority in the school system and what parties needed to be involved in problem solving and agreeing to accommodations. Barb's mother discussed

accommodation planning and finding resources. She says, "Once I know how to work them, they are great. They will help you. They are really good about it; it's just finding them. The thing is, there are a lot of those resources out there, but I don't know what they are. If they had a list of them for parents, where I could say, 'I need this help' and 'I should look up this resource so that this person could direct me to this avenue,' that would be ideal. But, that is not there. You have to go out and either run into it accidentally or somebody else tells you about it."

About accommodations in high school, Paul's mom describes that, "there were a couple of teachers that just couldn't treat him like a normal student and also understand he has a disability. And so, he was normal student, but there are certain things that he couldn't do. I think the kids got used to him, too. Paul never liked to be the center of attention, although he had a service dog all through school. I think he did pretty good because the halls in the facility at [high school] were not that great. And the other thing we kept saying was to make sure you can get in the room, make sure you have a desk for him . . . and I think after the first year they had a pretty good feel, and Paul had a good aide."

Developmentally, the initiation of accommodation requesting and problem solving sometimes shifted from family to participants themselves. Char recalls thinking about the negotiation process: "I didn't know at first, I was you know, a freshman in high school, an 8th grade kid, what did I care. But, people woke me up and were telling me, 'Char, you have other options, but you have to request them and the counselors won't come to you and advertise it, you have to go to them and request it'." Char describes her role in seeking accommodations and taking some authority. She said, "I usually go in, like the week before classes start, at least in high school and junior high I did. Not so much in elementary school because my Mom and Dad had to go with me. I pretty much go in and explain to the teacher, even if I've seen them in the hall for quite awhile, and say, "Hi, I'm Charlene and I'll be taking your such and such class. I don't know how much you know about me, but here are just a few simple ground rules that I would like you to be aware of. I'll be bringing a laptop in to type a bunch of things. I'm a pretty independent person. If I need any assistance, I'll ask. Sometimes it takes me a little bit longer to write

notes - which is why I bring my laptop. But, if I don't have my laptop, I need extra time to copy the notes. I may ask you to; if they're overheads, to borrow them and copy them or may run photocopies instead of taking my own notes. If that's a problem, we can work around it. But, I just want you to know that's basically how I do things.”

At times the obligation to lead accommodation negotiation became a source of conflict. Wes and his grandparents told about the district assigning him to a special education program with more severely involved students at a high school in the city. This resulted in Wes experiencing more migraine headaches and sickness. They resolved the problem with a confrontation that resulted in his return to his neighborhood school. Vanessa's foster parents were largely frustrated by augmentative communication technology devices, and were disappointed with work site training and accommodations that were a part of her community-based transition program. The conflict appeared to be unresolved and school representatives were hoping that Vanessa be removed from the foster care family she had been with for most of her life.

The detailed nature of accommodation sometimes resulted in burnout. Char was proud, but relieved about all the teaching and negotiating she and her family had to do with the district regarding accommodations. She says, “I'm relieved to be done with it, to have that part of my life, that chapter closed, because I'm sick of it, it's been ten years and it's been a big effort. It's been a really big effort.” Paul's mom described about planning with the school and adult services agencies, “I think what happens with Paul and I is we just say, ‘How long can we wait?’ We just go ahead and do it, or just ignore it for awhile and then get back to it . . . That's where we are now. We should change the DVR counselor, and I just don't have the energy to do it right now. And I don't even know if we're on the books anymore or not.”

School program changes, environmental challenges, and participants and families as being somewhat complicated and requiring compromise often characterized specific classroom performance issues. Specific changes were often not termed “accommodation” and were sometimes still unclear, misunderstood or unresolved by participants. Wes received specialized instruction, he describes this by saying, “we had a new teacher, she

came and there were some other kids in the same class I was that needed help. So she would write out notes and then at free-time, anytime she had during the day in class with the kids, she would pick, after we did our work, she would help us with our health or she would say 'this period we're just going to work on health because you kids are behind.' But I was never behind, I would just do [homework] as soon as I got it."

In discussing he and his mother's work with schools and other agencies, Paul expressed unresolved feelings: "I guess we really haven't done our job. Really it's just kind of been staying with what's working, kind of just using these things as kind of an excuse, and just getting discouraged, more complaining about it than doing anything about it. So, I don't think we've done our best job but we haven't really gotten the right answers. You know you get four or five different answers and it's been frustrating and confusing and you don't really know what to do. I've done a lot of it on my own, my mom has helped me but it's just . . . you come up with an idea and you look into it and it kind of doesn't go anywhere."

That assistance is needed as part of school participation, that technology permits greater independence in some activities, and that a re-setting of expectations occurs for students, families and teachers brings attention to the skills these individuals need to develop as part of living with disability. For some participants the realization of their role in seeking and negotiating accommodations brought with it a sense of self. Char advanced to taking charge of negotiating a special exercise program at school, she described: "I take a swimming class and a weight training class, both, because I sat down with my therapists at the end of my freshman year and said, 'okay, I love you guys, but, I need to know what kind of things are normal human activities that will allow me to keep my flexibility and keep my mobility.' I said, 'because I don't want to be 20-something in college and 'oh yeah' I have to go to therapy so someone can stretch me out. How practical is that?" Paul addressed advocating about his personal needs and needs for other's who use wheelchairs. He described that, "You just got to tell them what you can and can't do and kind of just tell them what you need in terms of doing your job better . . . I think you just find somebody helpful, explain it and just tell them what you need. When

you can't do something, just say you can't do something and get the proper help for it. That's not real hard advocating about that, you just come across people that aren't real understanding and you kind of explain the best you can but some people just don't relate with it all that well. But I think most of my friends and family, everybody kind of helps me with what I need and does what they have to do." Paul feels that his ventures into community advocacy have been more frustrating because of a lack of understanding and how others might view him. He described, "I think it's hard to advocate for [others with disability], you know I've been doing this stuff for disabled seating and things for wheelchairs . . . things for wheelchairs aren't what they should be and its tough to know how to advocate for that and have it be better. So that's always a frustration, when I'm trying to deal with these people and explain to them I might feel a little bit less happy about it because there a lot of things that are just obstacles to even just get that far. I think that maybe I come off the wrong way sometimes where people think I'm just in a wheelchair and just going to complain about it."

Self-determination was sometimes evident in discussions about school needs and accommodation planning, but often family continued to articulate needs for their children. In terms of planning, Barb's mother notes, "looking at transitioning, going away to school, questions that would come up in my mind would be, you know, environment, she can't really tolerate heat very well and she can't tolerate cold very well. So, does that limit her as far as where she would go to school? Accessibility, you know I think of another young man that's at the university with Duchenne who can't reach up to get button for the elevator. Just kind of looking at those issues, and not knowing exactly where she wants to go and stuff it makes it kind of hard." Tom would like an end to school and no added work, but his mother describes that she was "frustrated with [school plans] this last year. Because, going into high school now, this was three years ago now, I at that time had really wanted things to be focused on vocational things and I guess to a certain point it has, but now him becoming a senior, that is just something I really want to see done this year." At times, families remained somewhat reliant on the school's experience to plan and provide for them. Trisha's grandmother says, "in my last IEP meeting, they said Trisha will go to [high school program] a little bit longer, the teacher

told me that she is trying to find something that she feels I would like and we could participate in for Trisha to move on.”

Transition Dilemmas

Human Assistance.

Accommodation planning and negotiating brought with it some issues that may be distinct for these individuals because of their uses of technology and need for human assistants. Selection of participants in this study was purposeful, in terms of the individual's needs and uses of assistive technology and other types of special concerns related to medical care. The nature of ongoing disablement and requirements for special devices, accessible environments and human assistance brings forth a set of challenges with transition. These issues are perhaps not unique to individuals who are reliant on technology, but are important in understanding the consequences these dilemma have as part of transition planning and outcome expectations. These participants are confronted with continued needs for human help in their day to day living, a need that exposed their vulnerability. They were also found to be cycling through assistive technology devices and services and often getting stranded or burdened with change. These participants who are in transition continued to encounter inaccessible communities within which they can only hope for better acceptance.

Evident from school and transition stories across participants, was that many performance challenges were not easily solved by technology alone. Many accommodations required a combination of changes in learning or testing materials. An elaborate system was described that provided Jacob with school handouts and homework. Char negotiated for not taking tests using mark-sense forms and having extra time and computer use for standardized tests. Trisha, Vanessa, and Paul used provisions of human helpers, either fellow students or aides. As described in prior examples, manipulation and communication impairments were also difficult to accommodate for by physical changes or uses of technology alone. Sometimes this need was subtle or not even acknowledged. While in high school, Paul had different needs. In terms of technology, Paul's mom recalls, “he didn't use any for the first few years, but they did give him . . . he used or had

friends manage a tape recorder . . . He did have a computer in his senior year, but no, he really didn't have any of that. Some kids would share notes with him. He really didn't need it at the time." For others, the need for assistance was viewed as changing and maturing with experience. Char described, "it used to be harder when I was younger because I thought people would laugh if I said, 'Will you help me?' I thought that to someone who isn't disabled, they would think that was a sign of weakness. Now, I've gotten to a point here, hey, if I need help I'm going to ask for it. Sometimes it's really hard to swallow my pride and ask for help because I'm a very independent person, but there are just things that sometimes if people don't know me, it's not going to happen. So, you just get to the point that, hey, you say, if I want to be successful, and I want to do this, it has to happen. And, I've very, very rarely asked someone to help me and they've refused."

Although mobility enabled some sense of independence, this was not always the case within school environments or between locations. Nearly all students and graduates told stories about transportation experiences. Sometimes these involved special systems for busing to and from school (e.g., Trisha, Paul, Wes, Vanessa) or involved particular problems with special events the school had planned, but had not planned for these students with mobility dependence (e.g., Char, Paul, Jacob). Mobility, particularly between locations, usually involved human companion and was sometimes a way for kids who were technology reliant to give special acknowledgment to a friend or other student. Barb goes out sometimes on the city bus, but only when with a sibling or friend. Special arrangements for Paul's bus transportation allowed him to pick a few friends to ride with him.

Needs for and use of human help at home, at school and in community were sometimes acknowledged, but often the ongoing need for helpers was taken for granted or not expressed. For family and some service providers the perpetual need for human help highlighted their impressions of the individual's vulnerability and needs for better skills to fend for themselves and be protected.

Barb is viewed by her mother as unskilled in negotiating with people she will need to rely on to provide services. Addressing Barb's skills in telephoning and negotiating with community merchants was an IEP goal that Barb's family wanted as a

part of occupational therapy program at school. Although indicating a concern for Barb's naiveté, her mother was also surprised at Barb's independent response to participation in this study. Barb wrote a letter to express her interest, without informing her parents. Although consent procedures were followed, her parents were somewhat uncertain about letting her respond as she wished to scheduling and participating with interviews.

Char recognized a certain degree of vulnerability she has as a younger person. She described that, "my family members and therapists they have helped me develop skills and have taught me how to do things that benefited me when I was 5-yrs-old, and that will still benefit me when I'm 50 or 60 something. So, those are the ones who have taught me . . . I think it's a protectiveness that your parents want to shelter you because you're little. You're a young child in the first place. Secondly, you happen to have a disability which in some cases makes you, depending on the extent of your disability, more fragile."

Sometimes one's assistance needs and vulnerability necessitated careful planning. Trisha's grandmother describes her Saturday job and what she needs to provide in support: "So she only works from 9 until 12, so she wanted to know about a bathroom part, so I told her that I'd fix that. I told her I'd have her go to the bathroom before she leaves home, and Trisha does hold her urine very well, and then if anything come up I would be close to her, to the phone all she'd have to do is call me, I would get up and get her and get her home to get to the bathroom and get her back. So, in other words I'm on duty, on call all the time, no matter where I go and what I do, I'm on call. You know, sometimes I get called and sometimes I don't. But at least one way that you can reach me, if you can't reach me at home, you can reach me in my car. But I make it be the serious point with the car phone, and I carry it with me all the time to make sure."

Uses of assistive technology can also create dilemmas for service providers. The nurturing of independence may be at odds with one's hope to be helpful and protective. Trisha's teacher indicates the challenge that helpful people at school have in sometimes undermining the student's opportunity to direct their activities. She says, "I think part of the problem is me! And all of us, since we know it takes her time to do things we will figure out a shorter way to do it, than having her go through the process. We may even

teach her short cuts that aren't [helpful], I mean inadvertently perhaps, so it's a big learning process. For instance, if she wanted to go to the teen health center and make an appointment, I would say 'well, do you want me to write you a note asking for an appointment?' But I finally have broken myself of this bad habit, so now I say, 'want someone to open the door for you' because she can't do that at the center, but that is all we're going to do, 'you'll have to go down and ask yourself. Do you think there is anything you can do before you go to make the lady in the teen health center understand.'" So you see it's me, I mean all of us, we get to be like family, not so objective, so we need to retrain . . . to make her more successful, I have to get out of the way. So, now we do this hard hearted pushing her out into the world, but still now people in the teen health center are familiar with having her there and they will 'Oh Trisha, need an appointment' rather than waiting for her to communicate."

A focal point of conversation with participants and other informants was related to uses of assistive technology. Evident in conversation was that such systems were necessary and often preferred over dependence or other lesser technology, but also problematic in terms of technology change. Vulnerability was also expressed relative to uses of technology as many participants, family and service providers acknowledged the often awkward or disappointing process of acquiring, maintaining, and using and changing assistive technology.

Cycling with technology.

A cycle with assistive technology is experienced because of several natural changes (See Table 4). Initially, the use of adaptive devices and technology is addressed as a way to augment function and facilitate acquisition of independence in age appropriate activities. This process necessitates careful evaluation of needs and goal setting about particular outcomes related to manipulative skills, mobility, and communication. Then a decision about selection of particular technology is needed from a growing number of options or products. Final selection is often dependent on access to products through suppliers and funding of technology through insurance, out-of-pocket money, or other resources. When acquired, use of technology must then be learned and practiced. Skill development with technology most often requires coaching by service

providers and family, and effective use may be contingent on experience with the technology in different environments and with different people. With some skills developed and regular use established, technology will need to be maintained or serviced and ultimately it will need to be renewed. A cycle of maintenance is necessary with technological devices due to power needs and mechanical functions, and occurring at some point will be dysfunction with the device that requires problem solving and repair. Next in cycle is often the need to explore new technology because of changing needs or capacity of the user, the inability to repair and replace used technology, or new technological invention that may improve upon opportunities for operation and function by the user. Many of these natural changes result in the re-initiation of evaluation, goal setting, selection and acquisition. Resulting next is the receipt of new technology that must be learned. Although experienced with old technology, users must adjust to new features of technology systems that invariably means changes in operation or control, altered programming, and different needs for maintenance and repair.

Table 4: Cycle of Technology: The cycle may be viewed as a natural part of living with a reliance on technology, but can involve getting stuck or stranded in cycle.

- Evaluate, select, set goals and acquire technology
- Learn and begin use of technology
- Skill development: advance use of technology in different places
- Maintain, service and renew technology
- Problem-solve dysfunction and repair
- Explore new technology, set goals, and acquire technology
- Apply, learn and adapt to new technology
(changes in controls, capacity and feedback)
- Skill development with new technology (repeat)

For participants in transition, a common experience for them was becoming impeded, stranded or left waiting within the technology cycle. A functional challenge or limbo status with new technology was often apparent and this left them either in waiting,

perplexed about their needs or new technology, struggling to re-develop skills, or a combination of dilemmas. For example, Barb was unsure about computer use and her family couldn't transport her power wheelchair. Trisha's new communication device was taking a while to learn. Tom had restricted transportation with the wheelchair he could operate and had little access to computers. Wes experienced various transportation limits and questions about his computer skills were being raised. Char debated about use of manual versus power wheelchair, transportation limits, and computer use efficiency. Vanessa was not making voluntary use of her communication device and her family never understood computer interface. Paul has an operable but incomplete new computer with failed components and a variety of questions about transportation and use of a new wheelchair that is on order. Jacob's new communication device is difficult to use at community college, and his wheelchair control is hazardous and limits his transportation.

Dilemma's about technology and pragmatic problems with use of particular devices in usual and new environments revealed a number of trends among these participants. First was that technological devices often fail and might be repaired with delay or replaced with delay by products that have similar yet new features and service challenges. A common report was that of experiencing a decline in skills and independence with new devices that participants had yet to master. A third pattern among participants was them being introduced to new technology concepts and products, but being met with skepticism about use or value to them. Finally, some families had interest yet intimidation with new technology, yet students or graduates had few if any hopes for new technology or beliefs that they would make better use of their current technology in the future.

Participants had routine stories about their devices failing. Regarding his wheelchair, Wes commented, "I couldn't use the old one anymore, it was falling apart." Renewal or replacement for failed technology was challenged by family efforts and funding. Wes comments, "It's basically, you get one, use it 'til your dead. You know, it breaks down and we'd have to take it in to get it fixed right away. And it took a lot of time on [grandma's] part, a lot of gas money on our part, and we both just said hey, 'I need it.' And we had to have the doctor go through all his stuff, he's threatened them

once, but they don't want to mess with him this time. They sent it to us." Regarding her assistive technology devices, Trisha says that "quite often power runs out with my power wheelchair" and sometimes the computer power is out "when I have homework." Her grandmother notes, "She just got this new, the old one she had is completely gone, it's down there on the floor. I mean [the old one (Touch Talker)] don't work at all. So it's just about ready to be dumped." Tom was recently measured for a new manual wheelchair because, "the other was too small, I can't get into it." The new one has "brighter color, is lightweight and folds up." He cannot self-propel a manual wheelchair, so his school therapists initiated him getting a power wheelchair, and it is kept and used at school because the family cannot transport it. Tom is "in and out" of it at school, and enjoys using it whenever he can. He would like to have his family be able to transport the power wheelchair, and unrealistically says that he would "pay for it."

About technology in general, Paul's mom describes, "It's just like [every]thing! Equipment . . . equipment takes six months to get! You've got to continually follow through. It's the same thing. And when time is of the essence, you find other ways." Regarding his new wheelchair that was on order and other equipment for use at home, she expressed her frustration by saying, "well, why didn't I just make a phone call and check!? I'm again relying on somebody to . . . that I think should do their job! It's not . . . I can never do that. Why do I make that same mistake all the time, or why does Paul do that? And we do that every time. Now we're sitting with it after six months, with a shower chair that was ordered for Paul that doesn't work. The opening is too large. He falls through! Am I supposed to be the expert on that, too?! Aren't there people that can help you out?"

Others had difficulty making use of malfunctioning or poorly maintained devices. Jacob's start in community college was problematic. His educational assistance described, "He tended not to take it quite as seriously at first. He also had many more technical problems. The computer was down, the Light Talker didn't work, he was sick. So, it was just a whole bunch of difficulties." Barb describes her experience of "getting a new (power wheelchair) every four or five years, I think. [Because] it doesn't work anymore, it usually goes dead or I outgrow it." Her father performs maintenance, and

Barb understands the importance. We have to “pump the tires and make sure the back and seat fit me so I don’t get sores.” Barb’s mom identifies the importance of this process and the decisions to seek new equipment. She says, “My husband does the maintenance work basically. Because the batteries, they need the water, tires . . . he’ll change a flat and when things break down he’ll unscrew them and fix them up. But, she’s fairly easy on them. The electrical chair, you burn that out in so many years. There’s not much you can do about that, you just need to get yourself a new one or your throwing money away basically because your wheelchair’s burned out. And she uses them hard, so, I mean she utilizes them a lot, so she runs them down. That is one thing you do have to do. I would advise anybody, that once your wheelchair is burned out, go for a new one because you’re just wasting your money, you could put it into something that’s going to work for you and you’ll be where you need to be.” About wheelchair breakdowns they have experienced she adds, they are “miserable, wish we had two of them at one time, so we could have one in the shop and one where she needs it, I mean she needs it, she needs it.”

Getting new technology is not as common as failing technology, but may have its own consequences, and may cause a decline in function while new skills are developed. About his wheelchair, Paul says, “Well that’s the big pain in the butt. There’s nothing really wrong, it’s just things are not, it’s never simple to get them and just getting it to work the way you want it to, there’s so many different designs in terms of the person using it. But actually the wheelchairs worked pretty well, there really aren’t any breakdown’s, just occasional things that go wrong with it. [Ordering] the new wheelchair really hasn’t been as hard as we thought, I mean we got approved and now just have to see about [actually] getting it . . . [and making it] work.”

Communication devices are particularly problematic with renewal that invariably involves receiving new devices. Vanessa’s therapist comments that, “It is changing so fast, that the vendor/producers say that [a communication device] has a five year obsolescence. But, it is changing faster than that!” Trisha received a new communication device (i.e., Liberator) a few months back, but she said “it is taking me a long time to get to know [how to] use it.” Although Trisha is just learning use of her new communicator, her teacher identifies some challenges. She says “I’ve told her the goal for her is that she

write longer and longer communications with the proper . . . she makes grammar errors, she's about the third grade level I'd say. She uses just a few words, as of course she would, I'm not saying this as bad, but she tends to give you the shortest answer possible, and that's not bad for communication but it doesn't help her develop her English and her writing skills and her literacy. The new device makes it even a little harder to write." However, she also notes that with "the brand new device, one of the things she's very fascinated about learning is how to write songs, they were trying to learn how to teach her to use it to write any song she wanted and not just the pre-programmed ones."

At the time of interviews for this study, Vanessa had nearly abandoned regular use of her communication device and her wheelchair disrepair was becoming a "problem for seating comfort and function," according to her therapist. Attempts to develop use of communication technology were described by her former speech therapist. She says, "The first thing we thought of was just giving [her] some communication boards to be able to talk about what [her] needs were. And then we started making those communication boards grow, and she was carrying, you know like 15 communication boards around, and by that time we made the decision to go electronic." However, "The Dynavox came pretty late. It came about her 10th or 11th grade. But we knew she would be here until she was 21, and we a made a promise to go through that long process of changing [from communication boards]." Currently, Vanessa makes use of the Dynavox only when demanded, and no communication boards were present during interviews.

Change in communication devices and methods have also been a problem for Jacob. He writes, "We started working together [at school]. The first thing we worked on was how to use scanning on the computer for communication. Believe me it was very easy to learn. I learned it without seeing the computer in six days. I listened to the beats of the scanning. I liked it. My speech therapist bugged me to change to Morse Code. I did not like using it until I got my light talker. The scanning on the light talker is very slow and very hard to use." At community college, his educational aide was worried about decline. She says, "[Jacob] is suppose to be starting with the Liberator, which will give him more flexibility. On the other hand, I'm a little terrified if he starts trying to use it in class, because that learning period will put him behind. In this English as a second

language, if you're not working up to snuff, you can be out because there is such a long wait list."

All participants commented about being shown some new technique for using technology or some new device that had different features. Most often these efforts met with skepticism. Although shown adapted computer use strategies to enhance speed, Wes was comfortable sticking with his current methods of keyboarding. Char described, "I'm trying to work out which kind of laptop I want to get for college, because once I graduated, the laptop that I used now is property of the school district, so it's returned for other students to use, which is fine with me. That's perfect, that's why it's there. Which means...I have to get one myself. So I'm going . . . CD-ROM drive? . . . Pentiums? . . . all kinds of stuff." Regarding special features, she described, "I did try at one point to use some sort of word prediction software, but felt that that didn't know my vocabulary and writing style well enough that it was guessing words and phrases that didn't fit. So, I felt that wasn't helpful." She has also explored other keyboard modifications, but with no apparent benefit, "I tried some at one point and sort of felt that again, they slowed be down."

Barb had a similar impression of new computer input technology. Using a home computer that her family bought, Barb works on "reports for school" at home, but has no use of a computer at school. Because of her hand dysfunction, some computer use adaptations have been explored. She says, "at the hospital they showed me a program, it's like word prediction, and you only type in a couple of letters and then, you can pick the word you want and it will print the rest of the word out for you. But I haven't used it at home . . . it might help if I get tired." Her family was also doubtful about this new technology. Her mother comments that they have, "Seen a little bit of it at . . . some of it might be helpful, like the word voice recognition, that doesn't seem like it's applicable at all. I mean it doesn't pickup her voice, just spends more time for them decoding her voice than it ever gives a thing back. That's useless."

Paul discussed seeking assistance about technology needs but was disappointed. He describes, "they wanted to help me go to one of the clinics to assess what you needed but that took a lot of red tape and paper work so we've found a lot of times it's just easier

to do it yourself." About his developing and changing relationship with technology, Paul goes on to say, "I started working with a computer and kind of understanding CD-ROM and that stuff. I just didn't really know a great deal about the Internet yet, until I got out of high school and then I started to get interested in it. I think it would have been something that would have been more helpful if I could have used it during school. But in the special-ed room I would use the computer a little bit, I mean they had like a Macintosh computer or something but that was about the extent of it." Currently Paul used family resources to buy a new computer, although further changes are needed. He describes, "I do just fine with what I have and so I've been doing the voice recognition more and I've kind of become a little bit better with that and I've had people show me, it's just the microphone not working really affects that. So I'm going to have to go about finding another one, but it's just . . ." He elaborates by saying, "I don't think technology's been a real big problem, it's just annoyances really. An unnecessary thing . . . getting something to work after it breaks down is a pain. So this microphone's annoying, that's the one annoyance that I have right now . . . it was working just fine, I don't know what I need to do, it's just a lot of work to get it back to where it needs to go and find another one. It was working and now it doesn't. That's my next project." According to his mom, Paul's current problem is an example of a technology reality. "Unfortunately, I think he was right on the edge of new devices and new device activation. Again, I think he had to do the research. We got somebody that was selling their product, all information either wasn't assimilated or not given to Paul regarding, once you get the device and pay for it, the training?" Paul's therapist describes challenges she feels the system creates because of a lack of understanding about needs of particular people and outright funding limits. She says, "it was tough with him just because, and unfortunately any funding sources don't seem to realize this about MD and the progressive nature of the disease, and yes he might not need this today but down the road I will guarantee he will need this. But the reality is we're not really meeting kids needs." Paul's therapist, experienced with advising about assistive technology use in school, also indicates that technology solutions are often not as easy or useful as they may sound. She gives an example that doctors often ask or

demand that "If kids can't write, just give them a keyboard . . . it doesn't really work that [way or that] well."

Hopes for improved function with technology was still expressed by some family members and service providers, but enthusiasm was not specific to any known or understood technology. More often, for family members, was intimidation and confusion about making use of technology. With enthusiasm and plans for home modifications, specifics are a puzzle to Trisha's grandmother. She said, "I'm just kind of wondering how this is gonna work. I mean . . . as I get into this technology thing I don't [know], there was a drawn out picture, the fella drew this out and I don't know how they're going to do it, but I wanted to do it officially, so she could use it you know. I mean [the door] either locks itself, or she pushes a button and it open by itself, or some kind of cord or something, I don't know."

A change in abilities also contributes to technology change. Tom's mom comments that, "He's fine in the house, and when they mentioned the power chair, it's like well if you think that is something he'll really get some use out of, but for me it just never . . . Yes of course for his age, I won't always be there to push him around, so it never entered my mind. You get a stereotype in your mind about people who need power chairs, like only the most affected would need a power chair, it just never dawned on me. But, he loves it, I'm sure it's good for him." Regarding computer use and other technology, Tom's mother says, "I don't know how much he does that anymore at school. I just haven't followed it as closely as I should have, but I was thrilled about the word processing thing for him because actually he seemed to be strong in that area, much stronger than if he's writing. As far as other technology, we just haven't I think been exposed too much."

Her speech therapist said that technology had helped Vanessa by "enhancing the opportunity to expose her personality." But, she also discussed the implementation problems with her communication devices. With a student who has an electronic device, we try to maintain it. [Her teacher] was awfully good at it, you know. If he wanted something on there, he'd put it on right then and then I would have to document it later. Now we also did some training, and both her foster parents went to the training, through

training with [the vendor] on being able to at least add [words or messages] on it. But they weren't comfortable with it. We practiced a few times here, but they said they really weren't very comfortable doing that. And then Vanessa had a foster sister, Heather? She got pretty good at it! She could add things on. She would take things off that we had put on that she didn't want. So, we had a good give and take. But Heather moved out of the their home." About her use of the computer, she goes on to comment, "I think, I'm not sure that [her foster mom] knows how to turn the computer on. That's why we wanted the Dyna-Beam device ready for [Vanessa] to act independently. It just wasn't close enough to the mark."

About needs for support, Jacob's therapist and godmother comments, "there really has not been a person to pull it all together and oversee it as I did, when he was with our system. And I think in his case, because I am so close to him, I've taken some of that role as a volunteer. And that's not been very satisfactory, because I am too busy and I can't give him the time he needs. About his family, she comments, not only do they not speak English, "but they don't know how his (communication technology) system works. It all is a mystery to them."

Given experiences of device failure, functional challenges with change, and skepticism about new technology it is perhaps not surprising that participants had few hopes about new technology and also do not view themselves as dramatically improving their function with existing devices. For example, Vanessa has hopes for social engagement but does not view technology as vital to those efforts. Barb has a deliberate but slow means of using the computer, yet current voice input technology is not satisfying to her or her family. Tom is trying to make better use of his power wheelchair, and computer, but has unclear or extraordinary expectations for himself and makes no mention of technology. Char seeks using a bungee-cord solution for her sitting while driving challenges, but views herself as getting by with existing methods in school and work. Paul acknowledges the advances in CD-systems and the Internet and potential improvements in voice input, but has no particular hopes that these could be helped to himself. Jacob personally hopes for a different method to control his power wheelchair and envisions getting some sort of laptop computer to be mobile with in the future. In

thinking about what technology might enable Jacob writes, "Many disabled people are using computers everyday at home, at work, and at schools. Without technology, the disabled wouldn't be able to work with other people." In high contrast, he indicates that he enjoys opportunities provided by the Internet, but his experience is that "social discomfort with the disabled is the most significant barrier that needs to be overcome."

As they transition, participants faced losing contact with the school community with whom they had felt membership. Maintaining a friendship network was often a challenge, and among graduates a recognized loss. Maintaining a personal network outside of family members was facilitated for some by uses of technology. Char, Wes, and Paul had worked out arrangements for going out with friends by gaining comfort with them in transfer assistance and having friends drive their vehicle. Another means of maintaining or developing friendships was by use of the Internet. Wes, who went into a transition program after high school, used e-mail and voice messaging to keep in contact with friends who had gone off to college or had jobs. Char was cited to have broadened her circle of friends through e-mailing. Vanessa had been outfitted with technology to enable communication over the Internet by use of her Dynavox, but family could not make use of the technology. Jacob looked to the Internet as his way of being in touch with others and drawing in a broader community of those with and without disability. Paul used e-mail and other web-based resources to keep in contact with friends at college and to explore his interests, including sports. His mother comments, "Paul handles some of his other needs on his own. I know his one friend, they go on the Internet with some of these telephone numbers . . . I don't want to know anything about these 'chat places' and girls, and we've had a few experiences that haven't been positive. But, Paul will handle those without telling me, which I'm glad! Because I don't think I can deal with every issue." Among those in high school, they too looked to the Internet as a possible means to communicate and were seeking that kind of access at some points in the future. Trisha wanted her grandmother to connect at home for e-mailing, and Tom also wished they had "the Internet."

What appeared to be recognized by many participants was a need for them to take the lead in communicating and keeping in touch with others. Those who had left high

school recognized the lost feeling of membership and worked to maintain or re-establish some connection with others from their school community (e.g., Wes, Char, Paul, Jacob, and Vanessa). Mobility challenges and communication impairments seem to necessitate that they take a lead in attempting to maintain relationships which for their peers who are not disabled has largely shifted to new relationships in environments of post-secondary education and employment. The Internet enables an ease of communication and is a modern and popular technology. As such, it has been put to use by some to preserve a personal network outside of family.

Hopes as part of transition.

A hope of these individuals in transition was to find a more accessible community. They hoped for better transportation and access. The accommodation challenges in school were generalized to the community at large where barriers had often been and were still being encountered. Physical solutions were sometimes evident to them, but they viewed specific planners and the public at large as not being insightful about accommodations or as being unwilling to implement solutions. In describing his encounters with accessibility, Paul says, "There are a lot of people who are helpful, but . . . with elevators and parking spaces and people parking in front of ramps . . . most people don't realize or are just oblivious to stuff." Wes identified a problem with access and said, "I know that there are some places that don't have, wheelchair access. They need to have more disability parking space. Yeah, they [also] need to make wider parking spots, more accessibility in places." He contends that, "they should, the people that make these things should ask handicapped people how to do these things. Because they don't know what to do and they go 'well, they just draw it on a piece of paper and go oh that's fine' you know. Then somebody like in my case comes along, they park, sometimes my grandma's had to park in the aisle-way so I can get out, and then have to pull the van in. That's what I mean, they need to make this more accessible for handicapped people. Because they just don't, they just don't understand or just don't want to do it." In discussion of personal futures, participants often hoped for a more accessible and accepting community. Barb's mother views access as a challenge. She described, "I would like to see more accessibility, out in society, its ridiculous even access to the

University here, all the curbs and all like that, that's mean to a person in a wheelchair! So it is a constant battle for Barb, she's going to really have to get tough! Char acknowledged the challenge of accessibility that influenced her decisions about college. She said, "I just thought that maybe if I'd been in college a few years and I know what that's like . . . then I might go out of state for graduate school, or something like that. But I need to know what it's going to be like before I start through in a bunch of other things. One thing at a time, I don't want accessibility and where I am and things like that to make it so that it is impossible for me to pursue an education. I think that would not be in my best interest." Sometimes one's future success hinged on finding the right kind of social acceptance. Paul commented that, some people get lucky and get in the right situation, I don't think I've been lucky and found that person that I want to work with yet who would understand me and just forget about all this other BS that you have to do." Wes's transition program director related that for him "social training" may be important. She says, "What's in the acceptable realm of communicating with people, with strangers, with your boss, you know, trying to teach people to pick up cues, it's not easy, but we do a lot of it. Because I do know that jobs are lost mostly because of social skills and not because of technical skills."

For participants, the mission to create a more accessible and accepting community may develop or be sought out as a way for them to contribute. Using their experience and expertise with disability many participants had been involved with disability advocacy or were developing an expectation for themselves to become advocates. In part, a reason for participation in this study came from a hope to contribute to the understanding about issues being faced by those who used technology as part of schooling and transition. In addition, Barb had become involved with wheelchair sports racing, and Tom and Trisha continued to be involved with disability sports organizations. Wes articulated about needs the disabled had for access to community and activities to participate in. Char used her experience with disability in camping programs, and is seeking professional training to work with special need students. Both Paul and Wes involved themselves with advocating for disability access to new sport stadiums. Paul hoped to use his experiences and special needs with a software company to develop improved computer access

methods. Jacob hopes to use the WWW for business and networking between the disabled and non-disabled.

Desired by individuals who have technology reliance is a community with acceptance that they have not yet experienced. While many developed a good feeling of membership and perhaps view themselves as being pioneers and creating changes that would help others in the school community, they were seeking and hoping for a situation that they had yet to experience. Acknowledged by some participants, family members and service providers is that many will be left dangling with a likelihood that their hopes will be unfulfilled.

Chapter 4: Discussion

For students whose disability creates a reliance on technology as part of function, their stories about transition planning and outcomes draw attention to challenges faced in decision making during this period. Suggested earlier was that the time of transition for these youth could either be chaotic and unpredictable or ordered and easy to estimate. Among the participants in this study, transition is best described as tentative and indefinite.

Addressed first are the proposed research questions. Given that the nature of phenomenology is to suggest understanding, answers to research questions are not definitive. Rather, discussion of each question unites ideas about participant's views and when appropriate suggests implications for parties involved with transition; these being students, families, and service providers. Next, a review of technology-use challenges leads to suggestion of a model for understanding and addressing uses of technology and related accommodations to enable participation, performance and productivity within school and subsequent post-graduation environments of function.

The first research question asked about participant's conceptualizations or aspirations about the preparation and process of transition from school to adult life. While participants are involved in high school, efforts at meeting obligations of classroom work appear to be meaningful to one's organizing of daily routines to complete work. With a few exceptions, participants strove to be successful in academics and viewed themselves as having success and earning the right to graduate. The meeting of course or curriculum obligations was a particular issue for those who strove to earn a diploma and for those who saw themselves advancing to post-secondary education. For a few, the completion of high school was simply consequential for their transfer to a dedicated transition program within the school district. This opportunity may or may not have fit with the student's desire to conclude schooling with the student group they were a part of, nor have coincided with hopes of being done with school or moving on toward other goals. But for families, and with recommendations by service providers, extending the student's involvement with school beyond 12th grade may be a logical way to provide structure and

have students receive services until adult programs can be fully utilized at age 21 and beyond.

The extension of schooling may be seen as a benefit for organizing the student's time and perhaps for giving some direction to employment as an adult. However, for most families whose child was not college bound, their hopes for development of employment were negligible. Except for the college-bound, family's had no high aspirations that their children would obtain economic self-sufficiency. Although work was valued, they were often stressed by the impact that token levels of job payment might have on their receipt of social security benefits, including health insurance. Likewise, few participants or families anticipated major changes in independent living status or residential changes and made no connection between schooling and skills that would enable independent living. Although social contacts were valued within school, neither participants nor families gave responsibility to schools or transition programs for such outcomes. Most took actions on their own to assure some extension of social engagement through activities they organized in extended family networks or by other opportunities such as church organizations or community based disability groups and programs. Even with negligible success in traditional transition outcome areas, students and graduates aspired to experience change. Participants and families were often unsure about what would happen, yet confident that life afforded an outcome that would be satisfying. Like other studies regarding transition out of school programs, desires for greater independence and new pursuits are frequently framed within a context of family support and the ongoing need for assistance (Whitney-Thomas & Handley-Maxwell, 1996).

For graduates who transitioned into post-secondary education, they typically found that the demands placed on them in college were much greater than they had expected. High school preparation was often viewed as insufficient and they wished it had been more demanding so as to prepare them better for college. Nevertheless, most high school students and graduates felt that they had worked or were working hard in high school. For educators, feedback they provide to students about their schoolwork may need to focus on issues of content as well as scope, timeliness, and presentation. Use of a computer as a means to complete assignments or tests was sometimes compromised in

the school setting and often led to a need for human assistance to complete work. This circumstance usually led to reduction of assignments or extended and flexible due dates for schoolwork. Such moves may create work habits that would not meet expectations in post-secondary education or in employment settings.

Among graduates and students not bound for post-secondary training, academics continued to be important, but participation and the efforts made depended on utility of the work. Skills being sought were often tied to employment and participation in the community. Family members, service providers, and participants themselves sought relevancy between school activity and use of skills in community living after completion of high school. Whether it was skills, behaviors, or knowledge, they sought clear and specific links between school content and community living. For these students, performance levels needed to be made practical to life after school and consequences of skills and behaviors realistic to community expectations.

Special educators have placed an emphasis on community-based curriculum and community experiences for many years, as expressed in IEP procedures. For participants in this study, uses of assistive technology and other accommodations created logistical problems with transportation, accessibility, and communication. These kinds of special challenges confronted both school systems and families as they attempted to include students in the school community and community at large. Ultimately, these students learned from these experiences that planning and negotiation was needed in order for them to be involved. Self-advocacy and disability group advocacy needs became evident to them, and some felt that they were developing skills to effectively deal with individuals or systems that needed change. Part of transition plans and community experience seemed to help students realize that what they had worked for in school accommodations, would need to be generalized to the community at large. Striving to participate in the community was both a goal and a challenge. Being a much bigger and less clearly organized system, community advocacy was often expressed as an idea with an unclear audience. Sometimes participants found a means to be involved, such as in sports stadium planning or with community busing agencies, but gauging their influence was difficult to determine and their aspirations of finding a more accessible community

as part of transition may continue as either a challenge or chronic disappointment. Pierce (1998) used methods of phenomenology to study experiences of full-time wheelchair mobility users. All participants in that study also had feelings of frustration concerning access within the community. Like participants in transition, adults in Pierce's study also expressed a desire for involvement of people with disability in development of public and private facilities.

The second research question asked participants about activities and collaborations they experienced or perceived as part of the preparation and process of transition from public education. For all participants, a clear record of transition planning was a part of school records, and was acknowledged by them through discussion of the IEP or services received while in school. However, their role in the school's transition planning, and the school's part in overall planning were not seen as pivotal features. Collet-Klingenberg (1998) also found that there "existed a gap between the expressed importance of student and parent involvement by school staff and service providers, and the actual degree of their involvement in transition related activities" (p.76). Rather than assuming a lead role, students and families sought to meet the obligations of the IEP process so as to assure services, such as therapy or work programs. They often did not identify school providers or the school organization as being particularly helpful in guiding or directing transition, or linking them with adult service agencies or programs. Most who sought out these links did so on their own or by use of other resources such as health care agencies, other families, or friends and neighbors. Financial benefits through social security were typically sought and were arranged for those who were approaching or beyond age 18. Less clear for some participants and families was what to expect from agencies such as DDD and DVR. For current school program participants, use of these agencies was not considered important until they reached age 21, even though some school IEP records show an invitation or even attendance by adult service agency representative in meetings. The oldest of the graduates had sought and made use of DVR to assist with evaluation and funding of technology for post-secondary education or employment. These relationships were partially successful, but also a source of

frustration due to lack of understanding or agreement about the individual's needs and plans or his or her time limited opportunities.

Special education resources were usually appreciated by students and families, and seen as a benefit to them. But aside from decisions to extend school to age 21, neither schools nor special education providers were viewed as critical to the decision-making done within families regarding their next moves after leaving school district programs. This finding is consistent with warnings about traditional IEP and Transition Planning. Hagner, Helm, and Butterworth, (1996) contended that "traditional agency-centered planning has not fostered sufficiently productive relationships between paid service providers and unpaid support resources nor has it served to maximize the community inclusion of individuals" (p.159).

Family led planning may be desired, but was not clearly established with these students and families. The long history of efforts with schools, health care providers, and other agencies sometimes accumulated to have families of these participants reach a point of temporary resignation of a leadership role. Letting the school plan and provide services was acceptable to some families or inspired them to ask schools to address particular concerns without pressing for service programs as rigorously as they had done in the past. A challenge for schools and families is to let go of adversarial relationships and move toward a productive planning process that addresses priorities of the student and family. Although IEPs are called for within schools, it appears to be difficult for schools to both customize programs and still address transition mandates. For families, they may have some burnout with advocacy roles within schools, and are confronted with a new adult services system that seems to necessitate new learning and perhaps different tactics used to help address their children's needs. Participants themselves may also be ill equipped for such a role in planning. Students in transition, including those with disability, may be unsure about their desires and need to explore several pathways before selecting and sticking with one plan. It may be asking too much of these students to take a lead role in planning for futures they have not explored or become committed to.

Person-centered planning, like personal futures planning (Mount, 1994), may be useful to explore in order to organize the lead role that families and students can have in

school transition programming. As previously described, person-centered planning has strengths and weaknesses. The planning technique may be particularly difficult for those who have inadequate communication skills. Carnaby (1997) observed that in planning meetings, those participants who needed others to speak on their behalf were often excluded from discussion, and that in general they had no influence on the format of the meeting or on the proceedings and decision making outcomes. Nevertheless, striving to have students and families take a leadership role appears to be necessary despite obstacles.

A goal of person-centered planning is to seek novel and creative ways to address the student's goals. Creating community hospitality is one component of such planning that may be a direct result of participation and collaboration between families and others in the community (Hagner, Helm & Butterworth, 1996). For these students with technology reliance, the type of planners involved should be unique. Transition planning would likely need usual commitments of the student and their family, but also could involve technology service providers that are familiar with post-secondary or work environments. Assistive technology providers may help anticipate expected changes with performance demands and other technology cycle needs. Technical experts may also help bridge gaps that appear to exist as families move from school systems to adult service agencies that have different priorities in providing funding assistance. Another idea to explore is the inviting of other assistive technology users who might serve as role models for students in transition. Many participants in this study did not have technology using advocates that could help them anticipate ways to deal with other community systems and environments. The creative nature of person-centered planning could be put to use with those students who are technology reliant, a procedure that promotes self-advocacy and one that may help develop new ties with supports outside of the school system.

Aside from the process and procedures with transition, a third question asked about what initial transition outcomes were expected and how these transitions were understood. Plans for transition were characterized by achieving success at completion of schooling, but then moving toward other activities that may be desired, indefinite or unsure. Many plans could be described as tentative or tenuous. These terms are less

optimistic than what Hagner, Helm, and Butterworth (1996) termed “unplanned events” (p.167) although they too had found that planning outcomes resulted in “a few clear plans” and “only a few planned outcomes [being] achieved” (p. 167). The tentative and tenuous nature of outcomes is shown by Char’s expectation of enrolling in a 4-year college program but settling for community college to begin post-secondary education and hopes to proceed later to a university. Vanessa hoped for some opportunities for work, but instead she went to a special community college program that provides her with activity and no plan for educational or work outcomes. Paul expected to be able to intern in the sports broadcasting field with hopes of getting employment. This outcome never materialized beyond temporary engagements. Some new hopes were developing for him. Jacob began his trial with community college during high school, and years later still finds himself developing his language skills, but having exhausted his negotiated DVR benefits. His prospects for further college are marginal.

For those participants still in school, plans for the future are also tentative, and although viewed positively by students and families, a wide range of actual outcomes may transpire. Barb seeks not only high school graduation but also Head Start credits for college to pursue her dream of working with animals as a veterinarian. But, she might decide to attend a local community college or settle for doing office work for her pediatrician. Trisha thinks about going on in school and working in a doctor’s office, but her drooling and dependence with toileting may actually restrict any further vocational programming within the school district itself. Tom would like to be done with high school and is adamant about not going on through age 21 with schooling. He has a variety of work ideas, but his mother is simply hoping for some success in extending his work training trial as a stock clerk in a local grocery. Wes was proud of finishing high school, and reluctantly began a transition program for which employment is a desire but complicated by perceived threats to SSI benefits and health insurance. Although he may play a role in managing his grandparent’s assisted living home, Wes would prefer a job with the Seahawks where he could use his developing, but still basic computer skills.

The tentative nature of outcomes relates to what Murphy (1987) called *liminality* (p.131), wherein people with disability are moving toward but do not arrive at the desired outcome. In describing the liminal state, Murphy suggests that those with disability become stuck in transition, at the threshold but perpetually short of arriving at the place they hoped to get. "The disabled spend a lifetime in a suspended state. They are neither fish nor fowl; they exist in partial isolation from society as undefined, ambiguous people" (p. 131). The liminal nature of those with disability has implications for the choices individuals face with school transition. Pathways and moves may involve them trying to find a unique niche, struggling to compete for employment, or learning to manage with their own resources and public assistance programs. Anticipated is that one's inevitable failure to reach a goal would result in disappointment. This outcome was not evident with these participants. While some that had graduated were disappointed, they remained hopeful about future activities and expressed a feeling of satisfaction that they and family had done as well as they could. For many the status quo or liminal state was acceptable and they continued to be nurtured by new goals and ideas for engagements in education, work or other lifestyle change.

Specific to these participants, a fourth research question asked how issues of disability and uses of technology were regarded as part of transition planning and outcomes. Disability led these students to understand that they were unique, and often the acknowledgment of one's special status led them toward learning to advocate for themselves and to extend that concern toward younger students that would come after them. Those who felt successful in negotiating hoped that systems and environments re-designed for them would improve upon or ease the experience that others would have who face similar challenges with disability.

The special circumstances that many arranged or endured during high school caused them to stand out in the student group, and they were sometimes given special acknowledgement and confirmation. This feeling appeared to be a part of one's sense of membership or belonging within a group. However, feelings of membership and acknowledgment also created a sense of loss or inevitable change as part of transition. Maintaining friendships and a personal network other than family was sometimes strained

by transition out of high school. Valued by those participants who had departed from high school were a few special friends who could help with transportation, or who kept in touch by Internet or telephone. For graduates, many had not yet re-established a sense of membership in a new setting, but they and families worked at maintaining participation in other community based groups such as church or special activities with programs for the disabled. Knox and Parmenter (1990) also found that among graduates with disability there was a greater concern about one's integration into the community than there was with integration in the school itself. This may be attributed to students feeling some success with membership in a school environment, but having lesser success, feelings of assurance, or sense of acceptance in the broader community where they lived.

Uses of technology as part of participant's disability experience appeared to have subtle but meaningful influence on decisions regarding transition. In this study participant's regard for technology, expressed both in stories about their experiences and hopes for the future, reinforce the adage that "technology alone does not end all the difficulties that accompany disability" (Galvin & Scherer, 1996, p.1). Technology affords some benefits to function, but also necessitates new skills in managing devices as well as human assistants. Assistive technology providers and support service personnel have been concerned with issues of device abandonment, primarily owing to poor matching of the person to appropriate technology (Galvin & Scherer, 1996). Suggested is that abandonment of assistive technology can be from 8-75% based on a review of literature, and is most commonly attributed to a "failure to consider user opinions and preferences in device selection" (p.4). These students who relied on technology provided a few examples of abandonment, usually because of poor sizing and fit or dysfunction of the device while in use. But for them, it was more common to have uses of assistive technology disrupted by getting stuck or stranded in a cycle of assistive technology change. As previously described, the cycle of technology change often posed problems for participants and families due to a change in support for maintenance of devices or inadequacy of training with new devices to reach equal or better performance levels. Getting stuck with technology may have contributed to the tentative nature of transition outcomes.

Most striking was that participants viewed his or her uses of devices in a steadfast way. These individuals were often loyal to the assistive technology devices they had, not really wanting alterations but having to make a change at times due to breakdown, diminishing skills, or new performance demands. While a few solicited a technology change process, most often new technology was thrust upon them. Ongoing use of existing devices was most often anticipated. Maintaining one's current skills was also desired, with few new hopes or dreams that new technology would become a means to improved function or opportunity. Exchange of devices, or particular control features, was often anticipated, but looked at cautiously by users. Perhaps based on prior experiences, participants seemed to understand that new technology might threaten their current function and that new skills promised with new devices might not be realized. Given this attitude, participants had few goals that were dependent on changes or enhancements of technology. Many had been shown and encouraged to make changes with assistive technology that they had avoided or perhaps followed but were experiencing marginal success.

These participants' experiences with using technology at school concur with the impressions of some special education teachers who were surveyed about integration of assistive technology in the classroom. Based on a survey of several hundred teachers and related service personnel, Derer, Polsgrove, and Rieth (1996) found that barriers to effective uses of assistive technology at school were often reported as problems due to equipment availability, time, expense, and knowledge. Problems with effective uses of technology in the classroom is captured in one respondent's attitude, saying, "the time necessary to acquire one piece of equipment make it a problem before you even get started" (p. 72). Noteworthy with this survey were teachers' recognition that assistive technology use was often limited by context, meaning that a large percentage of devices were used at school only, and other devices were often used at home only. Greatest discrepancies between school and home use were in uses of communication devices, positioning devices, and adapted toys. In addition, teachers observed an extremely low frequency of assistive technology being used in work or vocational settings.

Context specific function with technology (e.g., school, home, or work setting) may reflect the complexity of accommodations needs for these individuals. Important to understand about use of technology is a continued need for human assistance and the changing nature of assistance needs. Devices afforded users a greater degree of independence, particularly with mobility and communication. This being so, most of these participants with disability continued to have needs for assistance in personal care and managing of the living environment. Enhanced mobility and communication provided increases in freedoms of travel and interaction, at times affording lesser direct assistance or supervision at home, at school and in the community. Nevertheless, some assistance was still necessary in all of these environments. Enders and Leech (1996) point out that "for people with disabilities, the need for a support system is no less pervasive or necessary than for others, but such a system always includes technological support, adaptive strategies, and personal assistance (people support)" (p. 32). Use of technology does not overwhelmingly reduce the need for human assistance, but rather, changes the kind of help that users have a need for. Often, much more sophisticated help is necessary to maintain technology and problem solve around technology fit and operation. Technical assistance with seating systems, power wheelchair controls, communication device programming and computer interface were often cited as factors that required help from a trained therapist or equipment supplier or vendor. For purposes of maintenance, specific family members were sometimes delegated to be primary sources for maintenance needs and be available for problem solving.

Enders and Leech (1996) propose that for each environment that someone with disability functions in, they require dedicated planning and negotiating for technological support, adaptive strategies, and personal assistance. For some technology users, transition involves moves toward functioning in new environments. Some graduates will move away from familiar service providers and even family care providers. In those cases transition would necessitate a dedication to planning for accommodations, often involving the coaxing of assistance from others and or the training, directing and managing of paid assistants. Although use of accommodations on a trial and error basis might be appropriate, students seemed to need guidance about their needs and how to ask

for accommodations that included a need for human assistance. Although skills in directing care providers is suggested as a means to enable self-management and self-determination (Sands & Wehmeyer, 1996), few examples of such training were evident with participants in this study. Barb's mother encouraged the school's occupational therapist to address her daughter's ability to communicate and negotiate with community businesses, and Char had been encouraged to negotiate her own program for exercise and fitness with other school personnel. However, for these participants and others, the specific nature of accommodations being used in high school where sometimes non-specific or were suggested by service providers rather than those with disability themselves. With the exception of explicit needs for physical accessibility that participants advocated for, most other accommodation were suggested or offered by parents, teachers and therapists. This experience may lead these students who use technology to have a misunderstanding about the negotiation for accommodations outside of schools. In most other environments and perhaps in schools too, the burden to communicate needs for accommodation falls upon the person with disability themselves.

A final research question addressed participant's notions of success in education, employment, independent living, and community participation expressed by participants and their support network. When asked about feelings of success, students and graduates were positive about the lives they were leading and the hopes they had for their futures. The oldest graduates noted a few disappointments, and fault was often cast toward service providers and systems. Nevertheless, they continued to describe personal satisfaction with themselves and thought that they had done the best that they could. No regrets were described. The most compelling idea expressed by participants was their desire to find a community that provided greater access and acceptance. Many had strove to create access and acceptance in school systems and they had tangible examples of how they and family had made that happen. The seeking of community change in terms of access was often more abstract and difficult for them to articulate. Many participants seemed to feel a duty to advocate for others with disability, but finding a way to do so and feeling successful in those activities was uncertain.

A final part of this discussion is to propose a model for assistive technology transition planning. As seen in Figure 5, identification and blending of outcomes from use of assistive technology and other accommodations is suggested. The participation, performance and productivity model is suggested to help organize evaluation and outcome planning for specific uses of technology, human assistance, and alterations in other features of contexts in which individuals function. The illusion of the diagram is intentional to reflect the sometimes obvious but often unrecognized elements that may optimize function.

Evaluating, planning and appraising the utility of assistive technology and other accommodations is typically based on expectations for function and the meeting of specific demands within different contexts (e.g., home and community versus school and work setting.) Proposed in the model are three elements of function that differ from each other in significant ways. Participation denotes taking part or sharing. Performance refers to the ability to carry out and execute an activity in a particular way. Productivity implies a capacity to bring about something abundantly or efficiently so as to create good value.

In both home and community settings one would plan differently to address participation versus performance versus productivity. The nature of places and demands for function within them are specific and distinct. In terms of uses of assistive technology and other kinds of accommodations, evaluating and planning for environments and activities urging participation is distinct from planning that would enable performance or the meeting of productivity demands. It is simplest to suggest that participation is a primary concept in recreation, leisure or social gatherings and environments. Performance might be the leading priority in independent living and in addressing function within school and work settings. In contrast, productivity could be thought of as a vital measure in competitive education and employment. The nature of planning for uses of technology, accessibility changes, provision of human assistance, and other alterations of activities would be different based on functional priority.

Some difference in accommodation planning could be as follows. Participation relates to being there, sharing in the event and perhaps benefiting from the encounter. The

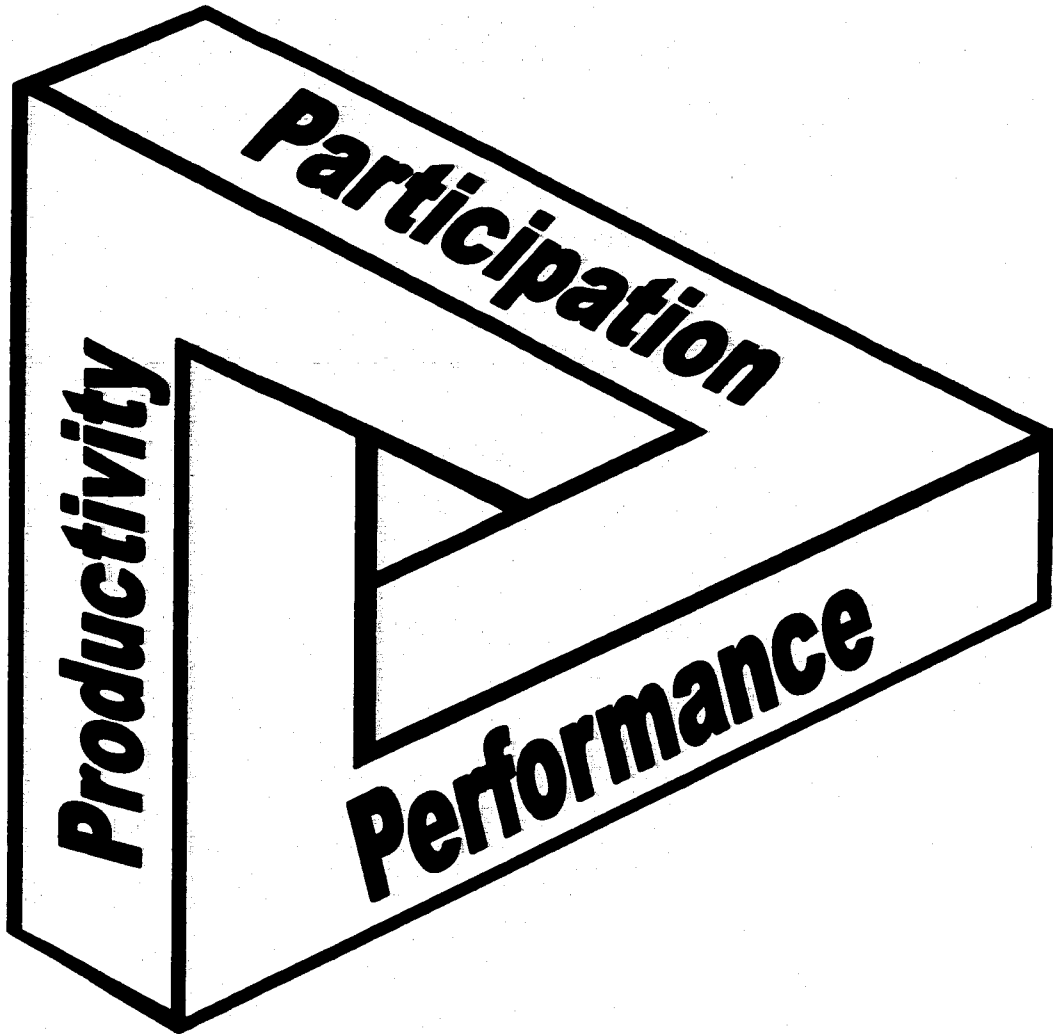


Figure 5: Assitive Technology Transition Planning Model

opportunity for participation comes by providing access, acknowledgment, and sometimes the planning of a special role within a setting or as part of an activity. Performance addresses issues of engagement, as well as needs for some degree of independence and/or the coaxing, organizing and managing the assistance of others. Performance is an outcome based and determined by both the process and products of activities. Process issues relate to levels of independence and assistance, timeliness, and degree of involvement or contribution to the product. Product issues relate to completeness and quality of that which is produced, and in some cases the competitiveness of the product as it is compared to the work of others. Methods to enhance performance come from strategies to enable autonomy or independence in conducting one's own activities. Environmental changes, uses of technology, and directed supervision of human assistants are features of performance enhancement. Implied with a concern for performance is the meeting of clear expectations for products or the outcomes of performance. Standards are often based on timeliness and scope of completed work. When productivity is the lead concern, an assumption of performance independence and quality are often made. In a productivity priority condition, the obligations of technology and accommodations are to assure competitive performance with a rate and quality worthy of acknowledgment (e.g., good grades) or payment (e.g., wage). In these contexts, a high degree of independence is required, with very specific human assistance needs that are managed by the individual with disability. *Reasonable accommodation* is the key term used to obligate or excuse an educator, and employer, or another kind of manager within the productivity context from making changes in the environment.

School settings, given the mandate of education for all, have one of the longest histories of accommodation practices (e.g., Section 504 of the Rehabilitation Act, and PL 94-142). Legal rights to accommodations in the community at large, both in places of business and workplaces, has come more recently (e.g., American's with Disability Act). Considerable differences in priorities for function in these different environments creates a challenge for accommodation planning and implementation. Related to accommodations for students in schools, it appears that highest priority is given to ease of participation. By contrast, performance demands do not appear to stress independence,

timeliness, and quality. A need for clearer and more consequential performance demands in schools may be necessary. Schools also appear to have uncertain or few if any obligations for productivity.

Environments to which students with technology reliance transition as young adults are likely to have much different priorities and practices in addressing accommodations. Function in the community at large may be handled effectively by technology and accommodation methods that prioritize participation. More challenging are effective uses of technology and accommodations that enable competence in performance and competitive productivity. These kinds of challenges may be largely unmet or are addressed by radically different levels of function than those expected in schools. The overall challenge of accommodation and integration of assistive technology in environments such as post-secondary education and employment may in part account for the general difficulty that adults with disability face. As noted earlier, adults with disability have been shown to have less success in completing post-secondary education (Wagner & Blackorby, 1996) and unemployment of those with disability has remained at about 70% overall during the past 20 years (National Organization on Disability, 1998).

Research Design Weaknesses, Limitations of Study

The bulk of transition outcome studies reported this past decade have been either follow-up designs in which a cross-sectional group is appraised at some point in time after exiting school, or follow-along designs in which a cohort or panel is selected and measured repeatedly over time. Most studies have been surveys or structured interviews, and they served a descriptive purpose, assessing dependent variables or themes relating to employment, post-secondary schooling, residential and social status, and community participation.

In quantitative studies that used survey methods, sampling procedures are of particular concern as threats to validity because of the likelihood of non-response and problems of attrition with repeated sampling. As previously noted, a bulk of secondary special education students seem to disappear and are unavailable for study, and a loss of subjects in repeated measures clouds the confidence that real changes in remaining

subjects reflects what is happening to the population of interest. Even among those subjects responding, different impacts of aging, unique history or period effects on cohorts (e.g., changes in educational mandates, assistive technology legislation), and interactions with testing (e.g., survey questions) clutter the interpretation of findings and changes in findings over time. Use of repeated measures in follow-along, and the likely use of measures that have a social value connotation, are likely to influence subjects and weaken direct comparison and generalization of findings to non-studied populations. Generalizations of some findings become obsolete due to historical changes in programs, opportunities and social venues. Experiences of graduates in the 1980's are likely to be different from graduates in the 1990's based on changing school programs, economic factors and evolving public policy. New century (2000's) graduates will face new circumstances necessitating ongoing inquiry and interpretation.

For the most part, longitudinal studies have involved ex post facto designs, commonly leading to after the fact data analysis technique in which naturalistically formed groups of individuals and information about them are appraised to determine associations within and across groups. A precaution with this approach is that without randomized selection, findings of correlation or significant differences in measured variables can be noted, but not attributed to a cause. For example, while having a job during the high school years is associated with better employment time and income as young adults, the high school job itself cannot be regarded as the cause of later success. Both conditions may reflect a personality characteristic or family resource variable not previously considered or explicitly measured. Likewise, professional services provided to facilitate competitive employment at high school ages has not been demonstrated to assure better outcomes experienced by those who were assisted in employment versus those who proceeded on their own to find jobs.

Another major concern with ex post facto study approaches relates to criterion group designations. Common to nearly all special education outcome studies has been a reliance on school districts use of federal definitions of disability categories. While these designations might be construed as more rigorous than other naturalistic group

memberships, considerable variation in definitions and uses of definitions occur. For example, the NLTS is based on 1985 special education enrollment of secondary students who were qualified at younger ages. Since 1985 new categories for qualification have emerged (e.g., traumatic brain injury). The criterion grouping challenge is particularly important in considering students with physical disability. As done with the NLTS, special education categories of orthopedic impairment and other health impairment are commonly blended, and a population of students with physical disability who are not enrolled in special education are not studied. Since the peak age of enrollment in special education occurs in elementary school, large numbers of students are known to leave special education but remain in school. In addition, rather than having accommodations organized as part of special education, some student's have needs meet by general accommodation mandates under Section 504 of the Rehabilitation Act and the modern equivalent the Americans' with Disability Act. For example, Dudgeon, Massagli and Ross (1997) showed that many curricular modifications were made for students with spinal cord injury who used assistive technology, but only 6 of these 19 secondary students were enrolled in special education.

A final observation regarding threats to quantitative transition research designs is that few if any have been experimental, wherein students are randomly selected and assignment to conditions such as the receipt of particular transition services or other kinds of interventions. Programmatic changes in transition practices over a period of years are generally applied to all students and no evidence of experimental research with specific transition practices is evident. Issues like earlier engagement with transition planning (e.g., at age 14), explicit use of person-centered planning, receipt of vocational counseling and job trials, and a wide variety of other suggested transition practices do not appear to have been studies using experimental group or single subject research designs.

The qualification criteria for special education enrollment can be seen as limiting perceptions about disability across all youth. Since passage and subsequent re-authorizations of education for all legislation, approximately 10% of all children are enrolled in special education. This matches the nationwide estimate of disability at

approximately 10% (Disability in America, 1991), but health impairments and chronic diseases are judged to affect nearly 30% of all adolescents (McAnarney, 1985).

Designations used for special education and the selected study of these students to portray outcomes of physically disabled youth may be misleading. A broader look at qualifying students for appraisal of physical disability and their transition experiences may need to look at school populations outside of special education.

Qualitative Limitations

Some of the weaknesses inherent in quantitative studies also apply to interpretive works such as this investigation. The purposeful selection of participants results in the identification and highlighting of transition ideas, outcomes and themes that may not reflect issues or experiences of many other individuals in transition that are reliant on technology. The focus of the present study was on understanding the experiences of a small number of unique individuals; generalization beyond the 8 participants reported here should be done cautiously. In addition, the limited time of follow-along makes conclusions about outcomes premature. In inquiry such as phenomenology it is more common to assert that the findings do not generalize to represent the population, but rather that the ideas themselves can help bring understanding of the issues that members of the population may experience at certain times. Miles and Huberman (1994) point out that the best use of generalization with qualitative research is analytical rather than literal for the sample studied to similar populations. In this discussion three specific threats to integrity of the study and generalization of findings will be reviewed. These include issues of sampling, thematic analysis and the audience being addressed.

Sampling restrictions.

Assistive technology reliance by students and young adults is by nature unique. This is reflected in the few numbers of such youth in school systems relative to other student groups, the novel and individual characterization of these individuals in the literature, and because of the dynamic changes occurring with technology both for disability and for general engagement in the community at large. This being said, it is important to point out that the criterion for selection used in this study was relatively broad and resulted in a good deal of variability in diagnosis and types of technology uses.

Among the eight participants, they had chronic as well as progressive medical disorders with related motor and sensory impairments that included muscle disease, spinal cord injury, and brain injury. These diagnostic features create high contrast in motor and sensory skills, such as differences between weakness versus spasticity, normal versus absent sensation, and a variety of vision and hearing impairment. A high contrast in skills is also evident because of differences in cognitive skills. Based on school records and acknowledgment by participants and informants, several of these individuals had normal intelligence, some were characterized as learning disabled, and still others were designated to be mentally retarded. Differences in motor, sensory and cognitive skills may constitute much different strategies being used to select, train and monitor uses of technology. Contrasts in diagnostic features and implications for utilization and cyclical changes in assistive technology should be explored further.

Thematic bias.

In phenomenology, collection of data and interpretations from data may be viewed as unique to the investigator. In this study concerns for credibility with participants and auditability with peers were raised. Credibility of findings was addressed by receiving feedback from participants regarding themes and how these impressions may influence transition experiences. Interviews with participants included them hearing about interpretation of stories and themes and them giving feedback about impressions regarding their own experiences and other participant's stories. A limitation is this approach was that participants heard about impressions during the course of interviews and were not provided with the opportunity to review and study written descriptions about themselves or presentation of thematic analysis. This more rigorous move would have required an even longer level of involvement with participants and was not practical given available resources.

The nature of interpretations with qualitative inquiry is building a case for themes that are expressed through statements from participants. Good auditability is expressed by organization of narrative materials and memos so that direct citations and procedures can be cited. While this level of organization was implemented, two potential threats still exist. The first is that a single investigator may have systematically shaped and thereby

limited what participants and informants shared about their experiences with transition. This threat could result in either an exaggeration of particular issues that became evident to the investigator, or perhaps an avoidance and outright missing of important issues and themes that were not perceived and attended to in data collection or thematic analysis. This problem was partially addressed by having explicit, but open-ended questions to frame the interviews and to follow the leads given by the person being interviewed. Critique of interview methods was provided informally by colleagues who listened to or read interview transcripts, but this process could have been more systematic and formal. Another way to address this threat would be to involve a number of investigators in conducting interviews, as well as interpreting and coding documents. Once again this strategy was beyond the scope and resources available at this time.

Audience limitations.

Assistive technology user's perspectives were the primary focus in this investigation and other informant's views were used to corroborate, clarify and enrich understandings about the user's experience. Other important themes and different issues may have been expressed had the focus been placed on either family members or service providers. The many influences on transition and differing priorities that parties involved with transition may have warrants the specific study of these other transition participants. This particular investigation was conducted because of the absence of assistive technology user's perspectives on transition. Techniques used here sought to give a voice to students using technology and to serve as an addition to the broad literature regarding transition policy and practices. As such the audiences for this work are the targeted and restricted to other participants in transition. Findings have been written to share the user's of assistive technology experiences with transition so that service providers can have a better understanding about what these kinds of students face in high school and the immediate years following completion of their schooling. These data may also be analyzed and reported in order to inform policy makers, parents and families, and even other assistive technology users themselves.

Further Research

Persistent outcomes that are disappointing and the multiple factors that appear to influence transition certainly calls for ongoing research efforts that would bring better understanding and strategies to address this challenge. Specific to youth that are reliant on assistive technology a variety of research questions need to be explored using a variety of investigation tactics. Qualitative methods are suggested for a more focused analysis of the experiences and thoughts of particular kinds of technology users. As noted earlier, the broad array of diagnostic groups and types of technology reliance in this study could be narrowed to determine what contrasts may be expressed by those who make uses of medical technology as well as other kinds of assistive and information technology. Only a few in this investigation made use of medical technology. Others, who make use of a respirator, adaptive feeding programs, bowel and bladder care routines and other medical technology could help to bring focus on different concerns relating to school function and transition. Feelings of membership may have different characteristics, and it is likely that assistance needs would pose special challenges to safety and medical supervision. Other technology use differences could also be explored through purposeful selection of participants. Although all participants in this study made use of wheelchairs, differences may exist between manual, power, or combination wheelchair uses. Augmentative communication users also may be more varied in how they regard technology reliance and their abilities to influence transition. Computer use was also highly variable and worthwhile to explore might be different uses within primary and secondary versus post-secondary education, as well as for recreation and employment.

Common to all participants in this study were motor impairments, but variations in sensory skills and cognitive function should be focused on in further qualitative studies. Mental retardation as a component of multi-handicapping disorders could be explored in terms of how cognitive disability affects prescription, training and uses of assistive technology. Opportunities within transition programs for those who have a combination of technology reliance and cognitive impairment should also be evaluated.

Qualitative methods are suggested to further bring out the perspectives of those who are relying on technology, and those who are supporting them at home, in school,

and other parts of the community. Nevertheless, research that address interventions that support transition can also be suggested and this calls for uses of quantitative tactics used in program evaluation and single-subject or group investigations. Examples could include identification of and careful monitoring of technology reliant students within school programs. These students are often blended across special education categories or are not even enrolled in special services. Research that carefully explored student characteristics might better describe and make known the population of youth with disability in school programs. Likewise, this population's receipt of special services, other means of accommodation, and their level of integration within school programs could be made clearer.

Single-subject methods could be undertaken to investigate the advantages or limitations that might be experienced with different kinds of technology. Outcomes in participation, performance and productivity could be measured to contrast not only uses of different devices, but also utility of specific access features and accommodation methods. This research method would seem to fit well with the individualized nature of technology device prescription and implementation factors that are context specific.

Small group research design might also be called for in order to address programmatic use of person-centered transition planning methods. Uses of methods like personal futures planning could be judged relative to traditional planning procedures, or other particular program offerings such as assistive technology user mentoring, adult service agency agreements, enrollment in work programs or transition programs that extend schooling to age 21. At present, little to no group research exists that has effectively experimented about use of different transition planning practices with any disability groups that are in transition out of high school. Small group research designs might be the most costly and difficult to implement, but results from these kinds of studies would likely be more powerful in influencing system change at the school level and policy change as well as program funding at both state and federal levels.

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Appendix A
Interview Questions

Probe Questions With Near Gradates

| Research Question/ Reference | Lead Probe Question(s) Near Graduate |
|---|---|
| Conceptualization/Aspiration for Preparation and Plan for Transition | How does it feel to be finishing high school? What do you hope or expect to happen once you This period of time finishing school and moving called "transition." What are your thoughts about |
| Activities associated with Transition | Are there particular things that you or others are doing to prepare for finishing high-school and moving on? Who has been involved in your planning? (e.g., teachers, others?) How have they been involved? Have you worked with them, and how have they together regarding your transition? |
| Transition Outcomes Expected and Experiences | You said you had a hope or plan to (above) after What else are you expecting to experience as a What if any plans do you have for yourself in 2 from now? |
| Implications of Disability and Technology | In what ways does having a disability a need to (or other devices specific to participant) influence plans? What may change about your disability and use your future? |
| Notions of Success | Describe your sense or feeling of success in the school or education; work or employment; living community participation of citizenship |

Probe Questions With Graduate

| Research Question/ Reference | Lead Probe Question(s) Graduate |
|---|--|
| Conceptualization/Aspiration for Preparation and Plan for Transition | How did it feel to finish and graduate from high school? What has happened since you graduated? The period of time from high school and moving on in life is being called transition. What have been your thoughts about transition? |
| Activities associated with Transition | Were there particular things that you or others did to prepare for finishing high |

| | |
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| | <p>school and moving on? Who was or is involved in your plans and process of transition (e.g., family, friends, teachers, others). How have they been involved? How did they work with you, or each other?</p> |
| Transition Outcomes Expected and Experienced | <p>You are now (above). Is this what you hoped for after high-school? What are you now experiencing? Have your ideas or plans changed from those you had while in high-school? What if any plans do you have for 2 or 5 or 10 years from now?</p> |
| Implications of Disability and Technology Reliance | <p>In what ways do you think or feel that having a disability and need to use technology influence or affect your status and plans? What if any changes in disability or uses of technology have occurred since graduation? What future changes are you anticipating?</p> |
| Notions of Success | <p>Describe your sense or feelings of success in the following areas: school or education; work or employment; living or residence; community participation of citizenship</p> |

Probe Questions With Family Member of Near Graduate

How do you feel about (Participant's Name) finishing high-school?

What do you hope or expect for him/her after graduation?

This period of time is being called transition.

What are your thoughts about (Participant's Name) transition?

What particular things has (Participant's Name), you as family, or others done to help with planning and moving into transition?

What kinds of outcomes do you expect once (Participant's Name) finishes high-school?

What do you expect them to experience as a young adult?

What are your thoughts and feelings about (Participant's Name) disability and needs to use technology?

How have these things affected plans and procedures of transition out of high-school?

Describe your sense or feeling of success for (Participant's Name) in the following areas:

- school or education;
- work or employment;
- living or residence;
- community participation of citizenship

Probe Questions With Family Member of Graduate

How did you feel about (Participant's Name) graduation and moving on after high-school?

What has been happening with (Participant's Name) since graduation?

This period of time is being called transition.

What have been your thoughts about (Participant's Name) transition?

How were (Participant's Name) or you as family, or others involved in planning and participating in changes after high-school?

What has (Participant's Name) experienced since graduating? What was hoped for?

How are things going for (Participant's Name)?

What are your thoughts and feelings about (Participant's Name) disability and need to use technology?

How have these things influenced (Participant's Name) transition and present status?

Describe your sense or feeling of success for (Participant's Name) in the following areas:

- school or education;
- work or employment;
- living or residence;
- community participation of citizenship

Probe Questions with Services Provider of Near Graduate

What do you hope of expect for (Participant's Name) in finishing high-school and moving on?

This period of time is being called transition. What do you think (Participant's Name) will transition to after leaving high-school?

What has (Participant's Name), his/her family, and others (including you) done (if anything) to prepare (Participant's Name) for finishing high-school and moving on?

What do you expect (Participant's Name) to experience after leaving high-school and moving on to young adult life?

How you think or feel that (Participant's Name) disability and need to use technology influence the outcomes he/she will experience?

What do you think would be successful for (Participant's Name) in the following areas:

- school or education
- work or employment
- living or residence
- community participation of citizenship

Probe Questions with Service Provider of Graduate

What did you hope or expect for (Participant's Name) in finishing high-school and moving on?

This period of time is being called transition. What has been happening with (Participant's Name) since graduating? How has he/she transitioned?

What did (Participant's Name), his/her family, and others (including you) do (if anything) to prepare (Participant's Name) for finishing high-school and moving on?

What has (Participant's Name) experienced after leaving high-school and moving on to young adult life?

How you think or feel that (Participant's Name) disability and need to use technology has influenced his/her outcomes and experiences?

What do you think would be successful for (Participant's Name) in the following areas:

- School or
- Education
- Work or employment
- Living or residence
- Community participation of citizenship

Appendix B
Transcript Codes (Alphabetical)

Accommodation: Where participants describe needs and how those were being addressed or managed at home, school, or other settings. (154 passages)

Advisor: Where an advisor, someone who is or has provided guidance, is spoken about. (21 passages)

Assistance: Where participant or other informant discusses needs for human help and systems in place to provide help, and impact performance. (41 passages)

Community: Where expectations for others (outside of family) are mentioned. Needs for acceptance, access, and understanding by others. (75 passages)

Dilemmas: Points where unknowns or conflicts seem to arise, impacting his/her decision making about either school/work options, or in relation to technology and accommodations needs. (90 passages)

Effect: Impacts from accommodation regarding participation, performance, and/or productivity. (46 passages)

Feelings: Anticipation or expression of emotions or feelings regarding the transition process or expected outcomes. Includes when “giving up” or “not following through” is expressed, as well as “tension” and “conflict.” Also includes family or service provider’s sense of the participant’s vulnerability to harm or mistreatment in systems or in community at large. Includes “We (I) don’t know” or points uncertainty in the future is expressed. (122 passages)

Family: Where participants describe family or parent’s expectations or actions that relate to their status of future plans. (106 passages)

Graduation: Discussion of preparation or participation in high school graduation ceremony, events (15 passages)

Hopes: Discussion of desires for present or future transition outcomes. (181 passages)

Membership: Indications of group status, association with friendship, class members, etc. (62 passages)

Pioneers/Advocacy: Where participants describe themselves as unique, being the first to encounter programs, needing to request accommodations and instruct others about his or her needs. (99 passages)

Planning and negotiating: Descriptions of specific planning or negotiating with school system or other people are addressed, including IEP processes. (78 passages)

Resources: Issues of access to new technology or service help with technology and lack of resources available. When issues of money or funding are discussed. (29 passages)

Role Model: Where a role model or someone who has been through issues is identified. (11 passages)

School or School/Organizations: Where participants mention school, service providers including therapists, inclusion, and/or other organizations they know of regarding benefits or services. **Inclusion:** Discussion of "inclusion" or issues of participation in school programs. (285 passages)

Self: Where participants speak about themselves, their goals, beliefs, determination, and aging. (166 passages)

Technology: Description or discussion of assistive technology, adaptive aids, or other environmental accommodations. (227 passages)

CURRICULUM VITAE

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EDUCATION

| | |
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| 1978 | Bachelor of Science Occupational Therapy University of Washington Seattle, WA |
| 1983 | Master of Science Rehabilitation Medicine University of Washington |
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