

DISSERTATION  
TRANSITION TO ADULTHOOD:  
EXPERIENCES OF PARENTS OF YOUNG ADULTS WITH DEVELOPMENTAL  
DISABILITIES

Submitted by  
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In partial fulfillment of the requirements  
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Colorado State University  
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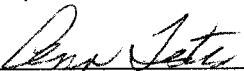
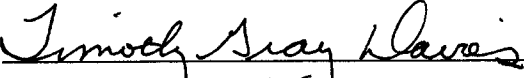

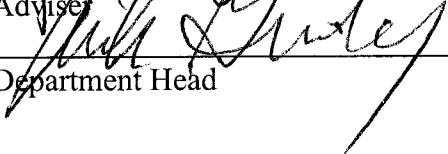
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WE HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER OUR SUPERVISION BY ROSEMARY C. TOBIN ENTITLED TRANSITION TO ADULTHOOD: EXPERIENCES OF PARENTS OF YOUNG ADULTS WITH DEVELOPMENTAL DISABILITIES BE ACCEPTED AS FULFILLING IN PART REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY.

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## ABSTRACT DISSERTATION

### TRANSITION TO ADULTHOOD: EXPERIENCES OF PARENTS OF YOUNG ADULTS WITH DEVELOPMENTAL DISABILITIES

This study used a phenomenological approach to understanding the process of transition from the perspective of families of young adults with developmental disabilities. Some of the primary sources of the tension during transition appeared to be located in the family striving for a vision of quality life for the young adult and garnering the resources to achieve the vision.

The main themes which emerged from the in depth interviews with nine families whose sons and daughters had developmental disabilities, included both internal themes, those which involved the family directly and external themes, those which had an impact on transition but were generated outside of the family system. The internal themes provided detail about the intensity and long-term nature of parent involvement during transition, the need to develop and maintain relationships, which support the young adult and the need to develop a vision of the future. The external themes were reflected in tension resulting from negotiating for services from educational systems and adult service agencies.

Families in this study were going beyond filling in the gaps in the school and adult service systems. The experiences illustrate that families were the “net” under school transition services and adult living supports. They went beyond advocating and

created their own options to fulfill their visions for a quality life in the community. For families in this study who had a member with a disability, the issue of quality of life is infused into the operation of the family system. Quality of life is a subtle yet powerful force influencing decisions.

Quality of life theory can assist in understanding the motivations of families during the transition process as they strive to achieve a quality life for their sons and daughters. In contrast to the efforts of families focused on an individual, the systems families encounter are establishing programs for groups of people. Quality of life perspectives can provide a framework for the development of strategies and programs that are aligned with family values and designed to meet the needs of young adults with developmental disabilities.

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*Heal the past, live the present, dream the future.*  
*Mary Engelbreit*

Reflecting on how I have come to this point in my life I am mindful that while writing is a solitary pursuit, this dissertation would never have come to fruition without the support and encouragement of many loving people. My deepest thanks to my inspiring children, Ben, Brady and Meg, my wonderful and thoughtful parents, Pete and Dolly, my compassionate sisters and enthusiastic brothers along with all the awesome “Out-Laws”, my dear Aunts, Peggy Haunt and Marialyce, and my persistent running buddies, Nancy and Sandy, you all nurtured my spirit and helped me gain confidence every step of the way.

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## CHAPTER 1: INTRODUCTION

During the past two decades the transition of youth with disabilities emerged as an important focus of special educational research and practice. This focus stemmed from reports based on outcome studies both at the state and national levels. The research found that students with disabilities exited high school with significantly lower levels of employment and lower wages than their peers without disabilities (Peraino, 1992). In addition, students with disabilities were less likely to enroll in post-secondary educational programs and the majority of the students were still living in their parent's home (Peraino, 1992). This chapter will describe the period of time referred to as transition and what is meant by the term "transition" and associated legislation.

### *Transition*

Several state and national follow-up studies report post high school outcomes for students with disabilities. In Colorado, a follow-up study of students who received special education reported graduates were typically living at home with parents and those who worked earned low wages (Mithaug, Horiuchi & Fanning, 1985). In addition, these students had limited social activity and few, if any, friendships. In Texas, graduates had more success securing employment through the efforts of family members and friends than with the support of adult services. Those who were employed received low wages and most were living at home with their parents (Special Education Effectiveness Study, 1997). In Iowa, follow up studies of students with disabilities showed significant

differences among various disability groups (Sitlington, Frank & Carson, 1991; Sitlington & Frank 1993; Frank & Sitlington, 1993). Outcomes for students with severe/profound disabilities one and five years after graduation showed that all of the young adults who were employed had worked in sheltered workshops or work activity centers. In addition none of these individuals lived independently or semi-independently (Sitlington, Frank & Carson, 1991). Only 18.5% of Iowa students with labels of mental disabilities had achieved even low criteria for successful transition outcomes (Frank & Sitlington, 1993). For students with learning disabilities, 38% met the criteria for success and 50% were living independently.

When examining national data, differences among various disability groups were also evident. Students with labels of mild cognitive disabilities had an employment rate of approximately 44% (Peraino, 1992). For students with more severe cognitive disabilities the employment rate was estimated to be about 20% (Haring & Lovett, 1990). The jobs these individuals attained were generally entry level and low paying positions.

Statistical information from the National Longitudinal Transition Study (1989) reported that individuals with disability labels of mental retardation had less opportunity for gainful employment and those that did secure jobs received low wages and generally worked only part time (Wagner, 1996). In addition, these young adults had few friendships and little opportunity to engage in recreational activities within their communities. Nearly 70% of this population lived at home after leaving high school and fewer than 10% ever participated in post-secondary education (Peraino, 1992). As a result of the follow-up studies of the 1980's the issue of "transition" gained national attention

leading to in legislation, programs and research to address strategies to bring about positive changes in the quality of life for individuals with disabilities.

In 1990 the reauthorization of federal legislation, the Individuals with Disabilities Education Act (IDEA, P.L. 101-476), first mandated a statement of needed transition services be incorporated into a student's Individualized Educational Plan (IEP). The law states the definition of transition services as:

a coordinated set of activities for a student, designed within 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 adult education, adult services, independent living or community participation. The coordinated set of activities shall be based upon the individual student's needs taking into account the student's preferences and interests (IDEA, P.L 101-476, 20 U.S.C., 1401[a][19]).

### *Collaboration*

As mandated by the federal legislation, transition policy targeted changes in programs and services for youth with disabilities with the intention of securing better outcomes and improved quality lives for young people. In order to manage the complexities of transition, team members, including educators, adult service providers, parents and students have to engage in collaborative practices across disciplines and agencies. Each transition team member must take risks, communicate and contribute for the purpose of achieving a greater outcome than they might have with individual efforts (Wehman, 1996; Rainforth, York, & Macdonald, 1992).

In addition to collaboration among transition team members, empirical studies have identified a variety of strategies that promote positive transition outcomes including vocational training, parent involvement, interagency collaboration and service delivery

(Kohler, 1993). A 1997 study identified specific support strategies that had a positive effect on transition outcomes. These included: identifying co-worker, peer and family support, identifying student's preferences and choices; teaching choice making and decision making; and teaching skills to promote social acceptance and independence (Hughes, et al., 1997).

A synthesis of effective transition practices revealed that various school, personal, and family factors contributed to students' involvement in their transition planning and services (Lehmann, Bassett, Sands, Spencer, & Gliner, 1999). School factors included provision of special education services in general education classes, student enrollment in general education classes, quality communication and teamwork, administrative support for transition planning, positive value for student involvement and opportunities for students to be involved in all facets of transition, including planning, implementing and evaluating. Student factors included worker competence as perceived by teachers and the ability to self regulate. Lastly, family factors included parenting in a non-controlling atmosphere and a positive value for student involvement.

The spirit of transition as outlined in IDEA placed responsibility on parents, educators and other transition team members to ensure that individuals with disabilities had a primary decision making role in planning for their future. The emphasis on student preferences and needs signaled a marked change in the manner in which decisions for students with disabilities should occur. Previously decisions such as choice of school, type of job, and nature of instruction were the purview of the school system, special education teachers and other adults concerned with the well being of the student. As greater emphasis was put on acknowledging the value of individuals with disabilities as

full and equal citizens, the importance of personal choice gained recognition. The concept of self-determination emerged as transition team members recognized the importance of student involvement in making decisions that impacted their quality of life.

### *Self-Determination*

Self-determination emerged in the late 1980's and early 1990's as a component of successful transition planning for individuals with disabilities. Several authors have defined characteristics of this concept as including an individual's ability to define goals, take initiative to achieve those goals, demonstrate assertiveness, creativity, pride, self-advocacy and self actualization (Ward, 1988). Wehmeyer (1996) suggest that self-determined individuals communicate choices and make decisions free from undue external influence or interference. Field, Martin, Miller, Ward and Wehmeyer (1998) suggest a definition that summarizes common themes:

Self-determination is a combination of skills, knowledge, and beliefs that enable a person to engage in goal directed, self-regulated, autonomous behavior. An understanding of one's strengths and limitations together with a belief in oneself as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults (p.2).

Having choices and making decisions that influence an individual's quality of life are some of the common and distinguishing features of any definition of self-determination. Self-determination is not a one-time life event, but is better described as an ongoing process. "Acquiring the personal characteristics which lead to self-determination is a developmental process that begins early in childhood and continues throughout adult life" (Ward, 1988, p. 2). In order to avoid "learned helplessness", individuals with disabilities must experience control and decision making in situations beginning early in life (Overmier & Seligman, 1967). For example,

in a study of students with learning disabilities and mental retardation, Wehmeyer (1993) found a tendency for these students to avoid responsibility and have others make their decisions.

Wehmeyer (1993) argues this behavior is consistent with a lack of opportunity to learn choice-making skills and is not a characteristic of these students.

In 1989, the Office of Special Education and Rehabilitation Services (OSERS) introduced self-determination as a priority and began funding three-year model projects to develop strategies for assisting students in having more input into decisions that affect their lives. In all, twenty-six projects, over the span of seven years, were initiated nationwide, creating information that shaped program development, highlighted effective practices and influenced public policy (Ward & Meyer, 1999). Follow up research indicated that students who demonstrated characteristics of self-determination were more likely to be employed and enjoy higher wages and achieve more positive adult outcomes (Wehmeyer & Schwartz, 1997). Self-determination was recognized as a characteristic of successful transitioning with implications for practitioners, students and their families. In general self-determination research called for a paradigm shift from "helping" to empowering students to make choices and decisions to direct their lives (Lehmann, Deniston, Tobin, & Howard, 1996).

Self-determination has implications for changes in the roles of all members of transition teams including, students, parents, and educators and services providers. Literature suggests that students must learn skills and have opportunities to practice those skills associated with self-determination from childhood through the transition years (Lehman, 1997; Field et al., 1998) and demonstrate active involvement in transition planning (Martin, Marshall & Maxon, 1993; Wehmeyer, 1993).

Educators and service providers must learn strategies for collaborative planning and practice as well as embrace the changes that result in the expansion of their roles beyond their schools and agencies (Salembier & Furney, 1994). The locus of control over choice is meant to shift from professionals to individuals with disabilities (Wehman, 1992). "This is more than an initiative, priority, or theme. It should be the only way to provide services. If service providers do not honor this need for student-or client-focused way of planning services, they will eventually be out of business" (Wehman, 1992, p 15).

### *Family Role*

Juxtaposed against the initiative of transition and the movement towards promoting student self determination is the role parents' play during their children's passage from school to adult life. Research indicates that parent involvement in the transition process improves outcomes for young adults with disabilities (McNair & Rusch, 1991; Rainforth, et al., 1992; Benz & Halpern, 1987; Morningstar, Turnbull and Turnbull, 1995; Field & Hoffman, 1999). The roles of the family members include, providing opportunities for students to make choices, communicating an expectation that the young adult will be a contributing member of the community (Wehmeyer, 1993), taking an active leadership role in transition planning (Wehman, 1996), and serving as role models (Morningstar et al., 1996; Field & Hoffman, 1999).

For youth with mental retardation, developing self-determination skills can present significant challenges, particularly due to challenges with communication (Field & Hoffman, 1999). In spite of the challenges, it is important for all young adults to gain self-determination skills. A key strategy for teaching self-determination is modeling, specifically, parents modeling self-determined behaviors such as demonstrating positive

adaptation to challenging life events (Field & Hoffman, 1999). Parents frequently have developed these skills through their experiences of negotiating for services with educational and human service systems.

As young typical adults approach the age of 21, involvement and control over their lives by their parents generally fades. For parents of young adults with disabilities the reality is in stark contrast requiring an increase in the level and intensity of involvement for an extended and somewhat uncertain amount of time (Brotherson, Berdine & Sartini, 1993; Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995). The desire to support the needs of their sons and daughters with disabilities combined with desires for personal freedom as their children grow up presents families with difficult decisions (Thorin, Yovanoff, & Irvin, 1996). In addition, limited resources in the adult services system places demands on families to organize personal and informal resources necessary to meet the needs of the young adult with disabilities.

### *Purpose*

The effort to support the development of self-determination, advocate for quality life opportunities, and protect their own quality of life presents challenges to families whose son/daughters are in the process of transition. In fact, as suggested by Lehmann (1997), potential exists for contradiction, conflict and confusion between educators, adult service providers and individuals with disabilities and their families. How then do family members create a balance between seemingly opposed life goals? The purpose of this study is to examine parents' experiences during the process of transition, utilizing a phenomenological approach. Through the telling of lived experiences this study will

attempt to uncover the processes of how families manage the inherent dilemmas faced during transition and how they perceive the effectiveness of their efforts.

### *Definition of Terms*

*Transition.* "A coordinated set of activities for a student, designed within an outcome-oriented process, that promotes movement from school to post-school activities, including post secondary education, vocational education, integrated employment (including supported employment) continuing and adult education, adult services, independent living, or community participation" (IDEA, 1997).

*Self-determination.* "Self-determination is a combination of skills, knowledge, and beliefs that enable a person to engage in goal directed, self-regulated, autonomous behavior. An understanding of one's strengths and limitations together with a belief in oneself as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults (Field et al., 1998, p.2).

*Persons with disabilities.* For the purposes of this study the label of disability will refer to individuals with mental retardation except where noted as having other expanded meaning in the literature. Cognitive disability presents specific challenges for transition teams to acknowledge and address. In addition, throughout this study the researcher will attempt to acknowledge and respect the innate value of all persons regardless of a disability label. Thus, the manner in which persons with disabilities are referred to is by using the descriptor of the person first and the disability label second.

*Parents.* The term parent will be used to denote biological parents of the individual with disabilities as well as legal guardians.

*Natural supports.* The term describes supports for an individual with disabilities provided in a work, residential or community setting by a person who is not a primary source of paid support, e.g., a school peer, a co-worker, or a participant in a community recreation event.

*Young adult.* In the literature of special education and transition a young adult is an individual with an identified disability between 14 – 21 years of age.

#### *Delimitations*

The process of transition has implication for all individuals involved including students, educators, adult service providers and parents. The scope of this study will focus on subset of those individuals, specifically parents. Through the stories verbalized by the parents the interactions with the other players in the process will be explored. Literature suggests that transition outcomes vary among disability groups; therefore the group of students requiring transition services for the purposes of this study is limited to those experiencing developmental disabilities. It is the perceptions of the parents of these particular students on which the study will focus.

#### *Limitations*

As with all qualitative research, the generalizability of the information is limited due to the small numbers of participants interviewed. Yet, the purpose of utilizing a qualitative methodology is to explore the interactions of a complex variety of variables in naturalistic settings as perceived by the participants.

#### *Significance*

To date the research has focused on young adults in school settings or those just leaving the educational arena (Hanley-Maxwell et al., 1995). This qualitative study will

extend the literature by focusing on the time period significantly after school services have concluded (up to five years beyond mandated educational services). In light of the dilemmas faced by families and the recognition of the importance of parent involvement in the transition process, the information gleaned from this study will inform educators and adult service providers about the challenges facing families during the on-going process of transition. Through a better understanding of the challenges families face during transition, strategies that assist families in addressing the challenges can be identified.

The information will assist all the participants in transition planning in understanding the complex and varied roles parents undertake during transition. Such outcomes may influence the methods utilized to inform families of the transition process and provide them with the tools that will encourage and maintain their involvement. In addition the information should assist transition-planning teams in determining appropriate actions when the involvement of parents or other family members is not available.

The information drawn from the experiences of families during the transition process should have implications for families of younger students as they seek out strategies in preparation for successful transition. Educators and service providers will have information to better understand the challenges facing families and gain insight to strategies that enhance effective parent involvement during this important time for youth with disabilities. Lastly administrators and policy makers will have information as to the effects of transition on families in their communities and assist them in making decisions

that eliminate barriers to positive transition outcomes and promote opportunities that enhance the quality of life and community living for youth with disabilities.

## CHAPTER 2: LITERATURE REVIEW

The following review of the literature focuses on the transition to adulthood of typical adolescents and the impact of transition on youth with disabilities and their families. Strategies that support successful transition are discussed, as well as the roles of families and professionals engaged in transition planning and activities.

### *Adolescent Development*

Traditionally, adolescence has been described as a time of turmoil, distresses and conflict between the adolescent and his/her family. More recent research indicates that it is actually a time of gradual change with families responding with recognition of a child's needs for individuation as well as providing information and experiences to prepare the child for adulthood (Erikson, 1968). According to Erikson (1968) the unique developmental task of adolescence is the exploration and discovery of the identity of the individual. Other psychologists believe that adolescent behavior is shaped by what the individual observes in the environment and chooses to model (Bandura, 1986).

Transition to adulthood involves changes in relationships among and between members within a family system. Normative transitions include the stress of adolescents beginning to leave home, establishing identities and roles outside of home and beginning post high school training (Olsen, et al., 1983).

During the period of transition from childhood the adolescent begins to develop critical thinking and decision making skills (Keating, 1990; Santrock, 1996). Research

indicates that skill development in making choices increases with experience resulting in older adolescents being more skilled at decision making than are younger adolescents and children (Keating, 1990). Yet, the ability to make competent decisions is influenced by the complexities of stresses in the environment such as time constraints and emotional influences (Keating, 1990).

The role of the family during adolescence is to provide a safe environment of trust and acceptance from which the adolescent can explore new roles and establish an identity. If parents push an identity on an adolescent, the individual may not adequately explore varied roles and future options, resulting in identity confusion (Erickson, 1968).

Educational and social institutions are structured such that graduation from high school marks an important transition for students towards adulthood (Pallas, 1993). The completion of high school and the movement into other environments is an important symbol of "launching" a new adult into the world (Olsen, et al., 1983).

#### *Adolescence and Disability*

While all families with young adults face typical stresses the experiences are intensified for families whose adolescents have disabilities (Everson & Moon, 1987). In comparison to families of typical adolescents, parents whose sons and daughters have disabilities show greater discomfort with the transition process from school to adult life and have less optimistic visions of the future (Whitney-Thomas & Hanley-Maxwell, 1996). The presence of a disability presents challenges to the normal expectation of transition to adulthood after graduation (Whitney-Thomas & Hanley Maxwell, 1996). For these families transition is more of a source of stress and anxiety than a cause for celebration.

Lehmann (1997) found that many mothers whose children experienced disabilities take on the role of case managers as their sons and daughters prepare to exit high school and enter adult life. The role of case manager is a distinct contrast to mothers of typical students who report having less involvement and influence in their son or daughter's lives. The mothers of young adults with disabilities reported engaging in similar child-raising activities as their counterparts (mothers of typical young adults) yet, in addition they performed tasks intended to increase the acceptance of their adolescent within the school and community as well as planned for the adolescent's safety while constantly evaluating risks. These additional tasks resulted in mothers who were less likely to be part of the work force or if they worked outside of the home, did so on a part-time basis (Lehmann, 1997).

Zetlin and Turner (1985) found that in families with a young adult with mental retardation, 85% reported coping with behavior problems as well as typical stresses of adolescence. The problem behaviors ranged from temper tantrums, yelling and rebelliousness to violent and delinquent behaviors. Additional sources of stress for families during transition include social-sexual adjustment, limited vocational options and career choices, guardianship and advocacy, financial security and needs for recreation and leisure.

### *Transition Outcomes*

The reality is that successful transition of young adults with disabilities from school to adult life has not yet been achieved. In studying a variety of state and national data, Peraino (1992) found that longitudinal studies show only 49% of the youth with mild disabilities are engaged in paid work after being out of school for one year. For

young adults with severe disabilities only 15% are employed. In addition, the personal relationships for individuals with severe disabilities are generally limited to other individuals with disabilities or paid professionals. Unfortunately, in light of transition requirements in IDEA '97, many school systems have set up systems to support transition that actually disenfranchises students from the community into which they will transition. In a 1990 New Hampshire study, 60% of individuals with developmental disabilities reported loneliness as a problem (Nisbet, Covert, & Schuh, 1992). If successful transition outcomes are to be realized for individuals with severe disabilities, families and professionals must be willing to support activities that will address all areas of transition: employment, residential options, relationships and community involvement, and determine courses of action to achieve quality lives.

#### *Transition Components*

Several key components of successful transition as identified in the literature include collaboration among the various stakeholders, changes in professional roles and the presence of parental involvement. In order to manage the complexities of transition, families and professionals have to engage in collaborative practices across disciplines and agencies. While the role of case manager may fall to the mother of the student (Lehmann, 1997), any member of the team could be appointed to fill the role (Rainforth, et al., 1993). Schools are not generally structured to support collaboration; in fact, schools promote classroom teacher independence and separateness (Rainforth, et al., 1993). Collaborative work requires a change in roles of all the members of a transition team. Each team member must take risks, communicate and contribute for the purpose of achieving a

greater outcome than they might have with individual efforts (Wehman, 1996; Rainforth, et al., 1993).

The outcome of successful transition should be meaningful employment and independent living opportunities (Everson & Moon, 1987). An implied goal is that the transition proceeds smoothly without interruption in services. Collaborative transition planning, which includes the student, family members, educators and adult service providers, is the starting point for successful outcomes. Families and professionals must consider the complexity of the process of transition and prepare to address the world of work, residential needs and social connections and opportunities. During transition families rely on educators and other professionals to provide information about options for the future as well as teach students the skills necessary to be successful in the community (Whitney-Thomas & Hanley-Maxwell, 1996).

#### *Roles of Professionals during Transition*

Hanley-Maxwell et al. (1995) suggest that if student and family needs are to be met the roles of special educators have to change to assume non-traditional roles that extend beyond instruction in school and provide services utilizing flexible hours and working with students in their homes. Secondary education teachers would prepare students for transition, facilitating the identification of future environments the students is likely to access and provide training in the skills needed in those environments (Everson & Moon, 1987). Because schools are the primary providers of services to students during the transition years, secondary education teachers need to initiate the transition process. The teacher's role may include participating on interagency councils, planning with

students and families, coordinating the transition plan, and ensuring optimal student and family participation in transition planning (Everson & Moon, 1987; Wehman, 1996).

Educators need training in working with families and assisting them in developing transition plans for the future to meet the needs of students with disabilities (Hanley-Maxwell, et. al., 1995). Special educators must be willing to work with families to assess the roles and responsibilities they would like to assume, and for those families who have fewer skills or opportunities to be involved, educators must be prepared to assume a more active role in the transition of those students (Brotherson, et al., 1993).

Job development should be seen as a joint responsibility between educators, vocational rehabilitation counselors (Everson & Moon, 1987), and students and families (Ferguson, Ferguson & Jones, 1988), and not the sole responsibility of any one person. Morningstar et al. (1996) reports that students with disabilities are more likely to secure employment through parent contacts than through professional agency sources. By the final year of school the transition team should include a representative of vocational rehabilitation to assure that plans for future employment or post-secondary education are in place.

### *Roles of Families During Transition*

The process of transition is actually one that begins in early childhood with families encouraging their children to develop skills in decision making and choice as well as facilitating the development of social skills and independence for community living (Brotherson, et al., 1993). "The expression of choice leads to independence and is a means for enhancing individual quality of life" (p. 47). As children grow older, families begin the process of career exploration by assigning chores, providing allowance, and

encouraging older children to work during the summer months or after school (Turnbull & Turnbull, 1990). Parents also influence their children's future by imparting their values and acting as role models regarding work and reinforcing expectations of community living (Brotherson, et al., 1993; Morningstar, et al., 1996; Field & Hoffman, 1994). Morningstar (1997) found that students indicated that family members and extended family members influenced their career choices and assisted in a variety of ways in finding and securing employment opportunities.

The importance of parent participation in the transition process is enhanced because of limited adult services available after graduation. The roles of the family during transition may include providing material support, emotional support and acting as an advocate for appropriate services (Hanley-Maxwell, et al., 1995). In addition, families may become the backup system for limited services and in spite of desire to have their son or daughter leave home, parents may have to face the fear of "life-long burden" associated with providing support indefinitely over the lifetime of the individual (Hanley-Maxwell, et al.). For these reasons, as students with disabilities leave the system of mandated educational supports and services for families, the transition to adult living is stressful and may provoke anxiety and fear of the future (Ferguson, et al, 1988; Nisbet, et al., 1992). According to Hanley-Maxwell et al. (1995) "...if these parents could have one wish, it would be that the type of system (e.g., school in which they were engaged) would continue into the future" (p.9). Ferguson et al. (1988) report that families describe three types of transition: a) bureaucratic, b) family life transitions, and c) status transitions.

### *Bureaucratic Transitions*

In bureaucratic transitions, the professionals working with students and families change from persons associated with school systems to persons representing adult service agencies. These changes are a source of stress as families move from the familiar system of public school to the arena of complex adult services (Brotherson, Berdine, et al., 1993; Brotherson, Houghton, et al., 1988).

Transition from a public school system results in movement away from a system of entitlements and guaranteed rights to parent involvement into service systems with eligibility criteria and cultural norms where parent involvement has been historically more passive (Irvin, Thorin & Singer, 1993). As noted by Irvin et al. (1993) families who took an active role in educational and transition planning may find their involvement in adult service systems is not welcomed due to the movement for normalization which places the individual with disabilities at the center of decision making. IDEA (1997) encouraged family involvement in planning whereas the concept of normalization places the individual with disabilities at the center of decision-making. Further, Irvin et al. (1993) describe that the change in focus may be a cause of conflict between adult service providers and families. Professionals may perceive families as overprotective while families may feel their input is not valued and they feel shut out. In addition families are in the position to be the backup for gaps in adult service plans. So while their input is minimally valued their commitment to support may be assumed. As a result, families and service providers may spend time actually talking past one another. What the service provider considers a good transition to employment for a young adult may result in a dramatic change in a family's daily routine and considered a poor fit, as family members

have to provide transportation and intermittent support for a young adult with sporadic work hours (Irvin, et al., 1993).

### *Family Life Transitions*

Family life transitions include all the changes and disruptions of typical family routines, schedules and accepted responsibilities. The limits of existing systems for transition affect students and their families as well, and families ultimately hold responsibility for their children after they leave the school services (Irvin, et al., 1993). These limits may leave families struggling with the continuity of daily activities once the student leaves the school system. Ferguson et al. (1988) reported that transition from high school often results in changes in daily routines of family life in an effort to provide supports for a young adult with disabilities. Failure for a young adult to move from school to work can lead to disruption of routine family life (Irvin, et al., 1993). Even if employment has been secured prior to graduation if the work hours are not “in sync” with other family members everyone's schedule may need to change. In addition, future changes in employment may result in a continuous need to adjust the daily schedules of the family. Details such as transportation that were once addressed by school programs may become the responsibility of the family upon exiting the school system. Irvin et al. (1993) found these types of everyday challenges were as significant in promoting family stress, as were predictable large life-changing events.

While research indicates families understand the need for continued and long-term involvement and support of their offspring (Hanley-Maxwell, et al., 1995), families may respond in a variety of ways to the need to create their own solutions to gaps in service delivery (Irvin, et al., 1993). Ferguson et al. (1988) describe three approaches to self-

reliance that families demonstrate. The first response is characterized as resigned and passive as families state their fatigue and resignation to the continuous struggles. This can cause some families to respond with resentment and burnout. Secondly, family's passivity is replaced with a sense of injustice and families try to find solutions on their own. Thirdly, parents may respond by relying on their own natural supports and long-term group advocacy. Yet, relying on others to help address the disruptions means families must reciprocate when other families need support. As families discover they have to create their own solutions to gaps in service delivery they may become isolated and resentful (Irvin, et al., 1993).

### *Status Transitions*

Ferguson et al. (1988) described status transitions as the process of achieving adulthood in the eyes of the family. Status transition is more than the achievement of a chronological age, it is "the complex amalgamation of parental feelings that want to encourage independence without ignoring vulnerability; to applaud the adult and protect the child" (Ferguson et al., 1988, p.185). Increased independence and self-determination are culturally valued outcomes of reaching adulthood. Parents and professionals frequently differ in their perspectives of the meaning of adulthood (Ferguson, Ferguson, Jeanchild, Olson, & Lucyshyn, 1993). Professionals may assess adult status by thinking about generic symbols of adulthood such as chronological age, physical separation from family and having a job and then determining the discrepancy between the individual and the social standards. In contrast, families are more likely to see adulthood in terms of one's ability to make self-preserving decisions as opposed to broader social symbols.

Hanley-Maxwell et al. (1995) reported in their study that parents wanted the transition process to slow down and be more synchronized with the students' needs as opposed to the chronological age. Parents indicated feeling as if students were pushed into residential and community services. In addition, the families felt that services should extend beyond the age of 21 and last until the student is really settled. The contrasting views of adulthood by parents and professionals can lead to misunderstanding, confusion and conflict if the issue is not discussed openly.

#### *Family Experiences in Transition*

When asked to define transition, parents responded by describing a movement from school to employment but when asked of their vision and hopes for the future most families responded with answers that addressed residential and social arenas (Hanley-Maxwell, et al., 1995). In a study of 48 families with young adults with disabilities, the parents placed residential and socialization needs ahead of employment as priorities (Brotherson, et al., 1988). Many of these families sought residential options first and then sought to work out the details of employment and socialization opportunities. Families whose young adults transitioned into a residential setting away from home reported perceiving their children as "growing up" regardless of the severity of the disability label. Those families whose sons and daughters still lived at home were perceived as dependent (Brotherson, et al. 1988).

#### *Dilemmas of Transition*

In combination, the need to promote opportunities for self-determination and the reality of the need to provide supports to their children with disabilities creates several

dilemmas for families during the transition process (Thorin, et al., 1996). As outlined by Thorin et al. (1996) these dilemmas include:

1. Wanting to promote independence for their son/daughters with disabilities while meeting health and safety needs.
2. Wanting to have a life separate from the individual with disabilities yet not losing sight of the need for long-term involvement.
3. Wanting to provide stability for the family and continuing to meet the challenges posed by the needs of the individual with disabilities.
4. Wanting to do whatever is necessary for the young adult while avoiding burnout on the part of the parents.
5. Wanting to promote high expectations for the individual with disabilities and still accept the individual as he/she is.

After leaving mandated school services the ultimate responsibility for youth with severe disabilities often primarily rests with the family. Unless and until families can secure adequate supports from adult service agencies, they become the case managers and providers of support for their sons and daughters. Quality of life for individuals with developmental disabilities depends on the family's perceptions of current and future challenges as well as the resources (e.g., time and money) available to devote to creating successful transition outcomes (Lustig, 1996). This study seeks to understand the meaning of transition from the perspective of parents and to provide information for families and professionals regarding the ways families cope with family lifestyle changes that are influenced by the existence of a disability.

## CHAPTER 3: METHODOLOGY

This chapter begins by describing the rationale for the method of research, phenomenology. The chapter proceeds with a description of the phenomenological approach, a detailed account of the specific methodology the study utilized and a narrative about the participants who engaged in the study. The conclusion of the chapter is a discussion of the role of the researcher as it pertains specifically to this inquiry.

### *Rationale*

Qualitative methodology was employed in this study to gain descriptive information from parents, whose children with disabilities have transitioned from the public educational system. The detailed accounts of their lived experiences through the process illuminated the essence of the meaning of the transition experience for parents. As indicated by Taylor and Bogdan, 1994, exploring the perspectives of those engaged in the phenomenon is part of the tradition of qualitative method, which, since the early 1980's, has contributed to the understanding of the experiences of persons with disabilities. In this study the experiences of parents, who engaged in the transition process with their sons and daughters, illuminated the implications and significance of parenting a young adult with a disability.

### *Overview of Phenomenology*

The qualitative approach this study utilized was phenomenology. Phenomenology is the study of the meaning people ascribe to events they experience. Moustakis (1994)

describes phenomenology as the science of describing what ones perceives, senses and knows. In phenomenology, the researcher is committed to understanding the social phenomena the participant's experience (Patton, 1990). In this study the phenomenon of interest was the experience of transition from mandated public educational services to adult living, as experienced and perceived by parents of young adults with cognitive disabilities. Description of the phenomena is the commitment in phenomenology as opposed to explanations or analyses.

In phenomenological inquiry the researcher has a personal connection to the social phenomena being investigated (Moustakas, 1994; Cresswell, 1998). The researcher's personal connection to this inquiry was as a parent of a young adult with mental retardation who has experienced transition from school to adult living. An essential component of phenomenological research is the detailed description of the researcher's perspective and connection to the investigation. A detailed personal account of the researcher's perspective, Epoche, was completed and is included at the end of this chapter.

The process of phenomenology takes place through four phases, Epoche, phenomenological reduction, imaginative variation, and synthesis of meanings and essences. While the phases are introduced here in a linear fashion the actual process proceeds with revisitation of prior phases. For example, it may be necessary for the researcher to continue to strive towards openness to the data by repeatedly raising awareness of the Epoche. Likewise, a return to textural description of the reduction phase, allows the researcher to gain a new horizon perspective and inform the phase of synthesis.

Epoche is the first phase in the phenomenological research method. Epoche means to refrain from judgment. The Epoche phase is one of preparation, allowing the researcher to set aside familiar ways of knowing and understanding. Epoche prepares the researcher to engage in viewing the phenomena a new way, a fresh way. Everyday judgments and understandings are set-aside in an effort to be open to new perspectives of a phenomenon. In the phase of Epoche the researcher provides a detailed personal perspective of the experience under study and achieves openness to the accounts of the other research participants (Moustakas, 1994). While it may be argued that true openness is impossible to achieve, the process of Epoche raises the individual's awareness of perceptions, judgments and meanings which results in clearing a pathway for the reception of information in a field as free of judgment as possible. The value of Epoche is in engaging the researcher in an examination of personal biases while enhancing openness to new perspectives.

In the phase of phenomenological reduction each experience is viewed singularly. Each statement is given equal worth. Moustakas, (1994), describes this as "horizontalization" of the data. Horizontalization of the data is gaining multiple angles. That is, the sifting through phrases and eliminating those that are void of meaning to discover what is really authentic of the experience. "No one or even multiple perspectives exhausts the possibilities of knowing and experiencing. New perceptions always hold the possibility of contributing knowledge regarding any object" (Moustakas, 1994, p. 53). Each experience is defined through descriptions of perceptions, feelings, and thoughts detailed with sounds, shapes and colors. The result of reduction is "a textural description of the meanings and essences of the phenomena" (Moustakas, 1994, p. 34). In

phenomenology, perception is the primary source of knowledge. Textural description utilizes detailed descriptions of the individual constituents of the experience and is intended to be extensive, leaving nothing out. It is a pre-reflective portion of the process. After completing the horizontalizations, the researcher, clusters the statements into themes.

In the next phase, imaginative variation, the researcher reflects on the meaning of the experience from a variety of possibilities for the purpose of grasping the structural description of the experience (Moustakas, 1994). Structural descriptions involve acts of thinking, of reflection, of imagining and reorganizing of information to arrive at meaning. "Perceptions bring textural description to life, in explicating the "what" of our experience; whereas reflection and conceptualization ferret out undisclosed meanings" (Moustakas, 1994, p.81).

The final phase in phenomenological research is that of synthesis of meanings into statements of the essences of the experience. Through the four stages of phenomenological research inter-subjective knowledge of the essences of the experience is revealed. The challenge in phenomenological research is to explain whole phenomena by its parts and derive meaning by exploring many different vantage points, thereby arriving at a description of the essences of the experience.

#### *Procedure*

Interviews with family members (both mothers and fathers) were audio taped and transcribed verbatim. In addition, the researcher developed field notes for analysis. Field notes were a written record of the researcher's observations and interpretations at the time of the interviews. Data analysis techniques utilized an inductive method of content

analysis to identify, code and categorize the primary patterns or themes (Patton, 1990; Miles & Huberman, 1994).

### *Identification of Participants*

A process of purposeful sampling was utilized to secure names of participants for the study. The criteria for participation included families whose sons or daughters had a label of developmental disability, and had graduated or aged-out of educational services between two and five years prior to the study, specifically those students who completed school services by the spring of 1999. The intent was to interview families of young adults with disabilities, who had been away from mandated educational services between two and five years and who had participated in the educational system under the transition mandates of the Individuals with Disabilities Education Act (IDEA 1990 & IDEA 1997). This study targeted families of young adults who qualified for services through Developmental Disabilities Services (DDS). “DDS is the office that provides leadership for the direction, funding and operation of community based services to persons with developmental disabilities within the state. (Colorado Department of Developmental Disabilities, 2002, p. 1).

The following steps were followed to locate and involve research participants.

- Materials were developed describing the research study for distribution to families. (Appendices B and C)
- The study proposal was reviewed and approved by the human subjects committees of Colorado State University (CSU) and the Developmental Disabilities Services (DDS). Confidentiality of the potential participants was achieved by having DDS address the initial packet for mailing. Those people who chose to be a part of the study self-

identified and stated agreement to participate by returning contact information form to the researcher.

- The researcher requested the agency identify families of young adults who met the research criteria. The aspects of the inclusionary criteria were the following:
  1. Persons with a developmental disability are those who have a “disability that is manifested before the person reaches twenty-two years of age, which constitutes a substantial disability to the affected individual, and is attributable to mental retardation or related conditions which include cerebral palsy, epilepsy, autism, or other neurological conditions when such conditions result in impairment of general intellectual functioning or adaptive behavior similar to that of a person with mental retardation” (Colorado Revised Statute 27-10.5-102).
  2. Young adults who finished receiving services from the public school system between spring of 1994 and spring of 1999 (resulting in students who had been out of the school system between two to five years).
- The Developmental Disabilities Services (DDS) unit mailed a packet to families who had young adults who met the criteria. The packet included a letter of endorsement from the DDS agency director, information about the study, an invitation to participate and a contact data form to complete and return to the researcher indicating a willingness to be involved in the study (Appendices B, C, D). The researcher provided the postage paid packets and the DDS agency addressed and mailed the packets to the families who met the criteria (Appendix A), thus ensuring the confidentiality of the families.

Forty-nine families received a packet and twenty-six returned the form indicating agreement to participate. The list was furthered narrowed to ten families who were available for an interview in a six-week period of time during the July and August. Nine interviews were completed and the tenth was canceled due to scheduling conflicts of the family.

#### *Interview Procedure*

Prior to conducting interviews, the researcher read the consent statement, queried for understanding and requested participants' signatures on the document.

Using the criteria set forth by Colorado State University a consent form (Appendix F) was developed and included the following sections:

1. Insurance of confidentiality;
2. Permission to tape record interview;
3. Permission to publish study results;
4. Right of the participants to withdraw from the study at any time; and
5. Permission to involve the family in the process of member checking

Interviews were conducted face-to-face using a semi-structured interview. The researcher developed a set of questions and associated prompts to structure the interview. The use of questions lent consistency to the kind of information gathered from each interview and yet allowed for open-ended responses.

*Interview Protocol*

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Interview Question	Possible probes
1. Tell me about your son/daughter	<ul style="list-style-type: none"><li>▪ How might you describe your son/daughter to new friends or neighbors?</li><li>▪ Tell me about the kinds of supports your son/daughter needs, at home, work and in social settings e.g., communication supports or assistive technology.</li><li>▪ Tell me about your son/daughters behavioral characteristics, e.g., self-control, emotional adjustment etc.</li></ul>
2. Tell me about your experiences as a parent since your son/daughter exited high school?	<ul style="list-style-type: none"><li>▪ In what ways are things the same as when your son/daughter was in high school and in what ways are things different?</li><li>▪ In what ways has the parent-child relationship changed?</li><li>▪ What things helped in the transition?</li><li>▪ What were the barriers to successful transition?</li></ul>
3. Please describe for me what a typical day and week is like for your son/daughter.	<ul style="list-style-type: none"><li>▪ Since he/she left high school how has the schedule changed? For student and family members.</li><li>▪ Is your son/daughter currently employed? If yes, how long has he/she had the job? How many hours per week? Is the work paid or volunteer? What type of support is needed? Transportation? How did the young adult get the job?</li><li>▪ What, if any, services does your son/daughter receive from an adult service agency?</li></ul>
4. What is your role now in supporting your son/daughter's transition?	<ul style="list-style-type: none"><li>▪ What types of support does your family provide for your son/daughter?</li><li>▪ Please describe what types of planning occur now that your son/daughter is out of school?</li><li>▪ How does this planning differ from the types of planning that occurred in school?</li><li>▪ What are the sources of support for your family e.g., friends, other families, professionals.</li></ul>

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5. Did the school system prepare you and your son/daughter for life after school?
    - What would you tell other parents whose son/daughters are still in high school that might enhance the process of transition?
  6. What resources do you think would help you in supporting your son/daughter?
    - Who can your son/daughter depend on for support or assistance?
  7. What are your concerns for the future given your son/daughters current situation?
  8. What are your hopes for the future?
- 

### *Description of Participants*

In addition to the consent form, the families completed a data information sheet, which requested information about other family members, education and income levels of the parents, age, birth date and place of residence of the young adult with a disability (Appendix G). The following section provides summary information about the families and their sons and daughters. The names of all the participants were changed in the text of the study in order to protect the confidentiality of the family members and other individuals mentioned in the interviews.

*Parents.* Three of the families were single parent households, and the other six were two parent households. The parents were engaged in a variety of occupations including owning their own businesses, employed in a community business, working in the field of education and the health care profession.

The parents' educational levels were slightly better than the average reported for adults in the state. Within the state 86.9% of adults over the age of twenty-five have completed at least a high school education (US Census, 2000). All of the parents had completed a high school education and, of the sixteen individuals (six two-parent households and three single parents, one of whom reported the other parent's educational level) who reported an educational level, twelve had some college education, six had a bachelor's degree and four had graduate degrees. The average level of education for both mothers and fathers was that of having some college education or having received a two-year associate's degree.

The families reported income levels spanned a range on either side of the state median income for households within the state. The median income for a household of four in the county was \$58,000 (Larimer County Economic Development Corporation, 2001). The median income level of the participants was between \$60,000 and \$80,000 per year and the income range was between \$20,000 -\$40,000 (see Appendix G, income range indicated by family on data form) and \$100,000 or more per year.

Both parents (if it was a two-parent household) were invited to participate in the interview. Only one of the six fathers chose to participate. All but two of the interviews were conducted in the home of the family. One interview was conducted at an outdoor coffee shop near the participant's place of business and one other was conducted at the

home of the researcher. Interviews occurred at various times during the day and evening hours. The dates, times and locations for the interviews were set at the mutual convenience of those being interviewed and the researcher. Each interview took between 90 – 120 minutes. Eight of the nine families had other children in addition to the focus individual. The range of additional siblings was one to five.

*Young adults.* Table 1 is a summary of the demographic information about the families and young adults involved in the study. In total, four of the families had a son with a disability and five had daughters. The average age of the young adult with a disability label was twenty-six.

One of the young adults was living with her parents and the others had a variety of residential arrangements, which included, host homes (2), parent-owned host home (3), group home (2), and apartment with supports (1).

The young adults previously attended one of four different high schools that were located within two different school districts. The populations within both school districts were served by one Developmental Disabilities Services (DDS) agency. All of the individuals with disabilities left the school system when they reached the age of twenty-one years. See Table 1.

As previously mentioned, the young adults qualified for services through the Developmental Disability System (DDS). In spite of similar disability labels that qualified them for services through the developmental disabilities system, the range of abilities among the young adults varied widely. These young adults experienced disabilities that required support to either learn independent living skills or have a responsible person provide support or a direct service. For example, some of the young adults were able to

live in supported living environments. Yet, in order to live independently they needed support and monitoring of virtually every aspect of their lives from cooking and shopping, medical care, money management, household maintenance, organizing recreational activities, transportation and access to the community, as well as job development and retention. The other young adults needed direct assistance or another

Table 1

*Demographics of Participating Families*

Parent Name(s)	Young adult's name	Gender	Age	Number of siblings	Place of Residence
Carla M.	Jeff	M	24	1	Group home
Teresa S.	Janelle	F	27	1	Host home
Carolyn H.	Monica	F	25	5	Lives with parents
Michelle K.	Alex	M	26	1	Host home- parent owned
Helen R.	Deborah	F	26	0	Host home-parent owned
Ann S.	Lucy	F	26	1	Host home-parent owned
Rachael and Mark W.	Paul	M	24	3	Group home
Joyce H.	Sue	F	27	1	Host home
Karen J.	David	M	25	1	Apartment with supports

person to actually do daily living tasks for them such as cooking, shopping, dressing and grooming. “Well, Deb needs total support 24 hours a day” (Helen, mother of Deb).

The families related verbal portraits of their son/daughters first in terms of their strengths and endearing personality traits. “Alex is 25 yrs old. He’ll be 26 in August. He’s a big kid. He’s very outgoing and friendly” (Michelle, mother of Alex). “I have a

delightful 26 year old daughter” (Teresa, mother of Janelle). “ Lucy is a very warm, friendly, outgoing, loving person who happens to have a developmental disability” (Ann, mother of Lucy). “As he's grown, he's just become a marvelous human being... He's cute....he has a wonderful sense of humor.” (Carla, Mother of Jeff).

It was clear in the texts of the interviews that these families were dealing with a wide variety of needs that were part of everyday life with these young adults. Joyce’s daughter, Sue, was living in a host home and had part time employment. Sue’s needs for support in her home were minimal and in her employment the needs were met with natural supports or contracted services through an adult service agency. “...for the most part she gets by with just a little bit of supervision. But she seems to have a really good rapport with all of her bosses and they tell her what to do. And if there is a problem, then they call her job coach in” (Joyce, mother of Sue). David lives in his own apartment with some support. He also needs a relatively small amount of support in his work environment.

*At work he's been doing it for so long that he doesn't need a whole lot of support there. They want, we try to introduce something new every now and then just to keep it exciting. Every now and then the job coach will come and instruct him in something new. But it's always just real small steps (Karen, mother of David).*

In contrast to David, Jeff needs more direct and intensive support as noted by the following description from his mother. “...he does not have a sense of danger. Cars don’t mean anything as far as being there. So he needs, the support he needs is somebody, he needs to be in basically 24 hour contact with a responsible adult” (Carla, mother of Jeff).

Similarly, Paul needs assistance in all aspects of daily living including personal grooming and hygiene.

He needs assistance dressing. I would say that is one of the areas with the greatest potential but pretty much he's been dressed by other people. So if you put it over his head, he can get his arms through it but depending upon who's dressing him and how much they expect him to do. And he can pull his pants up but he can't button it. He has no fine motor skills. He can do some of that but he does need assistance. Cannot shower by himself, can't brush his teeth, can't shave (Rachael and Mark, parents of Paul).

### *Data Collection*

Data collection was a two-part activity including conducting interviews and verbatim transcription of each interview. For the purpose of checking the transcribed record for accuracy, the researcher viewed the transcribed results while concurrently listening to the individual tapes of the interviews and made changes within the documents as needed. The transcribed interviews comprised the data sets for analysis. The nine transcribed interviews yielded a total of 174 pages of single-spaced text for analysis. The researcher notes were not coded but were referenced in the process of transcription review for purposes of text clarification and during analysis for insight into context related to understanding referenced stories or passages. In addition, when the taped interview was not clear enough to achieve an accurate transcription, the participants were contacted by phone for verification of the wording of the text.

### *Data Analysis*

The researcher followed four major steps associated with the phenomenological approach to data analysis as detailed by Patton (1990).

1. Through the process of Epoche the researcher attempted to uncover and clarify personal bias associated with the issues involved in transition. The process of Epoche assisted the researcher in becoming aware of personal bias associated

with the phenomena and allowed the researcher to suspend judgment of the information gleaned in the collection and analysis of the data.

2. Reduction of the data involves bracketing the key phrases, stories or experiences as noted in the verbatim transcripts of the participants. Each segment was considered equally at this point in the analysis.
3. The next phase in analysis was clustering of meaningful segments, eliminating extraneous information and identifying themes.
4. The final step resulted in a description of the meaning, the essence of the phenomena of transition.

### *Validity*

In qualitative research, the researcher is considered the research instrument. The researcher raised awareness of personal subjectivity and identified personal bias prior to conducting interviews (Lincoln & Guba, 1985) through development of Epoche. In addition to Epoche, in an effort to increase the validity of the study, a process of member checking was utilized after the concepts were clustered and grouped to reveal emergent themes (Lincoln & Guba, 1985).

Seven of the nine families reviewed and responded to a section of the findings (parent involvement theme) and confirmed the summary. After reading the text about parent involvement during transition one mother stated that it was comforting to know that other families have similar experiences during transition, “what a great realization to know we were not alone in our battles. Other parents went through the same process and continue to struggle with decisions”. Yet another mother stated her recognition of the commonalities of the shared experience in the following quote; “when I read through this,

I realized how much in common families with children with disabilities share. We may go through the problems at different times but sooner or later we all seem to face the same difficulties.” In response to the following summary regarding parent involvement

*Text: parent involvement for the families who have a son or daughter with a disability is a multi-faceted and on-going responsibility, one that changes over time, and demands flexibility, but does not really reach a conclusion, as long as the individual with a disability is alive.*

One mother circled the phrase and made the following comment “This is the best description I have ever seen of my life.”

### *Reliability*

The researcher utilized HyperResearch software to assist in the management of the data and create an easily followed audit trail with information traceable to the original source material. The methods of data collection, audio taped recording of interviews followed by verbatim transcription increased reliability of the study. In addition, the researcher took field notes observing and noting environmental details that enhanced description of the interview setting and were utilized to clarify portions of the transcribed text. Follow up notes were made during and directly following each interview. Finally, two researchers reviewed the data and reach consensus regarding the initial coding.

### *The Role of the Researcher*

#### *Epoche*

As a parent of a son with Down syndrome, I have been involved in the process of making transition decisions since my son, Ben, was 14 years old. He is now 27 years old and in many ways still in the process of transitioning. I continue to experience a variety of dilemmas as I attempt to navigate the complex course of transition with my son.

I believe in the value of inclusion for individuals with disabilities and therefore have advocated for employment and residential opportunities in the community, as opposed to institutionalized residential settings and sheltered employment. It has been difficult to target Ben's preferences, as he needs first-hand experiences in order to comprehend the characteristics of the work or residential settings before he is able to make an informed choice. Unraveling the complexity of his perceptions of desirable settings is challenging, as his verbal communication is also limited.

In addition to the challenges Ben's disability has presented, I have encountered difficulties with educational and adult service systems, which have not always shared the value of inclusion, or have been reluctant or slow in implementing practices to support individuals with disabilities in inclusive settings. We have also faced the challenge and frustration of having eligibility assured only to run into the barriers of waiting lists due to limited financial resources of adult service agencies. Generic services (e.g., parks and recreation programs) and social networks have also frequently been less than adequate to fill in service provision gaps.

Limited time and limited personal financial resources have also presented problems in balancing needed supports with identified interests for Ben. Yet, the issues that complicate the process are not simply financial. I am continually faced with issues of balancing:

- the need for independence with the need for interdependence,
- the promise of opportunity with the risks associated with the endeavor, and
- the desire to promote self-determination without forsaking the responsibility of guardianship.

These are some of the challenges of parenthood, amplified in intensity, with the "gift" of disability. While the presence of a disability has posed challenges to my value system and my parenting skills it has caused me to be more thoughtful in the decision-making processes I engage in with all my children. Ben has been my greatest teacher in the discovery of my own strengths, gifts, talents and passions. I have chosen to engage in this study to more fully understand my own and others' journeys and experiences as parents of young adults with disabilities.

At the time Ben was preparing to finish high school and we were having discussions about his dreams for the future, his father and I separated and subsequently divorced. This lifestyle change posed a crisis in my life resulting in the need for me to return to school, work full time and begin learning how to cope as a single parent. I was less available to provide supports to Ben, and less able to advocate for him - all at a time when he was also experiencing loss and grief of his own. In his last years of high school he continually experienced behavior challenges in a school environment that was not supportive of inclusion. I believe that some of his behavior reflected his frustration in not being welcome in general education classes and not having anyone available to make the modifications he needed to be successful. His final high school year was spent almost entirely out of the school and in a one on one situation with an aide doing a variety of activities in the community.

It became clear that Ben needed more support after school each day. I was able to get some supported living funding to hire a college student to work with him several days a week after school. The knowledge that Ben was being encouraged to do activities other than watch TV was a relief. After a year of this type of support Ben was placed at the top

of the “waiting list” for residential services through the developmental disabilities system. This move to the top of the list was considered an emergency, primarily because I was less and less able to cope with the daily stresses of work, school, and parenting. I had to sign a letter that stated that I believed Ben to be in danger of being homeless to secure residential services. Ben moved into a supported living apartment at age 19. That was certainly well before I believed he was “ready”, but we both needed some space from one another and when the system created the opportunity, we accepted. It was February of his senior year.

Ben left high school during the spring of 1995 with a certificate of attendance, not a diploma. At the graduation ceremony he was seated at the end of all the students as opposed to alphabetically like the other students and he was able to walk up and receive his certificate. This was a metaphor of his high school experience – he was present but never a valued part of the student body and was regarded as having nothing to contribute. I believe that this bothered me far more than it did Ben.

During the time Ben was in his apartment he attended a school sponsored transition program. He had some opportunities to work, learn how to use public transportation and explore community leisure activities. The behavior issues continued to be evident both in the school-supported program and the residential program. Ben moved home for a period of approximately 2 months after an incident at the apartment program when I no longer felt the environment was safe and supportive of Ben’s needs.

In cooperation with the developmental disabilities system, we were able to establish Ben in a “host home”. Ben’s job coach took on the role of “host” and Ben lived with this young woman and her parents in a rural setting for approximately 8 months.

During this time Ben was happier and more successful day to day. We learned that Ben needed to have a secure personal relationship with anyone who chose to provide him support and when we knew his host home situation was ending we began searching for a similar situation. During the interview process we encountered several couples that seemed eager to take on the challenge of being host home providers. I remember one couple I particularly liked. The problem was that when I asked Ben how he liked them he replied “fine”. But when asked if he would like to live with them – his response was “not so much”. We were back at square one with Ben living at home indefinitely. Quite by accident I ran into an old acquaintance that told me she was a host home provider for a young man with Down syndrome and she was considering hosting another young adult. In fact, she had read an advertisement that was seeking such a situation. It was our recruitment advertisement seeking a host home for Ben. Ben agreed to interview Joan and spend some time getting to know her and her family. Ben seemed to know right away that he could live with Joan. Ben has now lived with Joan and her family for five years. This is a very long time for a host home and the stability has been wonderful for Ben and a lifesaver for me. While Ben is now currently unemployed, the loss of his job has been due to the economy, not poor performance. In the past three years he has been employed part time at a video store, part time in a grocery store and part time as a seasonal worker in a nursery/greenhouse. Ben seems to be thriving. I believe that the stability of his host home has allowed him to feel secure and become mature enough to manage the challenges of his employment.

The supervisor at the video store seemed to genuinely like Ben. She saw him as a contributing employee and part of her whole staff. She told us Ben was taking initiative to

greet customers and ask them if they needed any help. In addition she directed the other employees to assist Ben when he asks for help but to never do a task for him. The owner of the nursery/green house gave him a letter of recommendation that spotlighted his positive work ethic and friendly manner with customers.

The relationship between Ben and me has steadily improved since he moved out of the house. We have the opportunity to interact as adults and I am not placed in the situation of having to oversee and attend to his daily needs. From Ben's perspective I don't "nag" him anymore. We communicate about things that are of interest and important, instead of feeling aggravation with one another. Ben still experiences behavior challenges from time to time and our team meets to address concerns and celebrate successes about every three months.

My hope for the future is that I will be able to help Ben purchase a home of his own which will allow him to hire the supports he needs with the stability of knowing he won't have to move if things don't work out. He could choose to have a roommate or to live alone. Ben will always need a fairly high level of support to keep his employment secure and to troubleshoot problems, as well as have residential support to help him organize and attend to his daily living tasks.

Reflecting on these past years of transition I realize that Ben did not have the transition that I had hoped he would. Circumstances beyond our control were the catalysts of change. None-the-less Ben is experiencing a reasonable quality of life with opportunities to spend time with his family and feel loved, opportunities to participate in recreational activities and travel, to develop friendships, contribute in the world of work and live in the community. Right this minute things look good – but it is all relative. I

know that at any time the circumstances may change and we would have to regroup to plan how to support Ben either in a different work setting or a different residential setting. The values I hold for Ben to live and work in an inclusive environment have directed his transition and will continue to be a guiding force as future challenges arise.

I am also aware of the additional supports and resources that allow my family to pursue choices for a quality life. These include the support and encouragement of my extended family. I am fortunate to have family members who understand the challenges we face and unconditionally provide encouragement, support and personal and financial resources. In addition, I have colleagues who are aware and knowledgeable of best practices in transition and adult living and who are willing to provide their assistance whenever asked. I also have access to financial resources such as a job that provides a reasonable income and insurance that covers much of the costs of mental health therapy for Ben and myself, as needed.

As I began this study the biases I needed to continually guard against included values I hold such as inclusiveness and self-determination. These have been the values that have guided my choices and actions where Ben was concerned. I was challenged to not be judgmental about choices other families make that do not align with my values. In addition, although the past several years have been difficult for me personally, I believe that they have served to break down prejudices I held about single-parent families and I've learned to be less fearful of unexpected change. During this time I have gained a new appreciation of my own, Ben's and my other children's capacity for resiliency and endurance.

## CHAPTER 4: FINDINGS

### *Phenomenological Data Analysis*

Chapter Four is organized to display the elements of phenomenological data analysis. The data analysis took place in four phases. The first phase is that of horizontalization or reduction/coding of the data. The second phase is clustering of meaningful segments. The third phase involves elimination of extraneous material and identification of themes. The final phase is a description of the meaning, the essence of the phenomena.

### *Phase One- Horizontalization*

In first phase of analysis, a process that involved line-by-line review of the text of each interview or case completed horizontalization of the data. HyperResearch 2.0, a qualitative data analysis program was used to name and record first level codes and the exact portions of text assigned to each code within each interview or case. Reduction of the data involved bracketing the key phrases, stories or experiences as noted in the verbatim transcripts of the participants. In this first phase of phenomenological reduction each experience was viewed singularly and each segment was considered equally.

Table 2 shows an alphabetical listing of the first level coding that resulted in an aggregate total of 70 individual codes among all nine cases.

Table 2

*Alphabetical Listing of First Level Codes*

Acceptance	Fears	Personal chara (characteristics)	Strength
Accommodation	Feeling guilty	Physical desc (description)	Success
Activities	First	Pos impct of dis (possible impact of disability)	Support need
Adjustment	Forced fit	Provider	Sys (system) challenge
Advice	Friendships	Public perception	Sys (system) constraint
Advocacy shift	Frustration	Question decision	Sys (system) response
Challenge	High need	Questions self	Tenuous
Com (community) Participation	Hope	Rel (relationship) change	Then and now
Communication	Indep (Independence)	Relationship	Trans (transition) decision
Complex	Instability	Residence	Trans (transition) expectation
Concern	Lack of choice	Risk	Trans (transition) impact
Conflict with sys (system)	Lack of preparation	School prep (preparation)	Trans (transition) interim
Control	Letting go	School prog (program)	Volunteer
Currt (current) setting	Meaning	Self deter (determination)	Wait list
Disability des (description)	Neg (negative)per first	Sib invol (involvement)	What works
Expectation	Par rel (parent relationship)	Sib response	Work
Fam (family) relationship	Parent freedom	Source of support	
Family crisis	Parent invol (involvement)	Staff turnover	

Utilizing the qualitative software program, HyperResearch, the researcher was able to include a definition or description of the meaning of the code term. While most of the codes were self-explanatory, the following information provides some detailed descriptions of codes that needed a more explicit definition.

Com participation: Community participation; a category describing a day program for young adults with disabilities.

Curnt setting: Current Setting; the description of current residential or day program for the young adult with a disability.

Disability des: Disability description; characteristics of the disability label.

Fam relationship: Family relationship; relationship of the parents and siblings with the young adult.

First: Initial description of the young adult by the parent(s).

Neg per first: Negative person first: examples of phrases that do not utilize person first descriptions.

Par rel: Parent Relationship; relationship between the young adult and the parent.

Parent invol: Parent Involvement; examples of parent involvement during transition.

Personal Chara: Personal Characteristics: personal characteristics of the individual with a disability.

Physical desc: Physical description of the individual with a disability.

Pos impct of dis: Possible impact of Disability; Possible impact of the presence of a disability on the young adult or the family.

Rel change Relationship Change; changes in the relationship between the young adult and the parent.

Self Deter; Self Determination; examples of choice or decision making on the part of the young adult with a disability, or examples of parents encouraging self-determination.

Sys Challenge: System challenges evident during transition.

Sys Constraint: System constraint; Evidence of limitations of adult service systems during transition.

Trans impact: Transition Impact; examples of the impact of transition on the young adult and/or the family.

Trans interim: Transition interim; time between education services ending and adult services beginning.

### *Phase Two - Clustering of Meaningful Segments*

In phase two the source material and its associated codes were reviewed and summarized for each question of the interview. The following section summarizes the responses of families within each of the eight primary interview questions.

Summary of Question 1. The purpose of the first interview question was to get a detailed description of the young adult from the perspective of the parents.

**Question 1.** Tell me about your son/daughter. Prompts included; describe your son or daughter as you might to a new friend or neighbor. Describe the types of supports your son or daughter needs at home, work and social settings. (e.g., Communication supports, or assistive technology). Tell me about your son/daughters behavioral characteristics. (e.g., Self-control, emotional adjustment etc.)

Among the nine interviews 28 codes were identified within the scope of the first interview question. Further analysis of the individual codes and the associated source material (text) resulted in some groupings of similar codes within the interview question.

Table 3 shows the variety of codes within each interview for Question 1 and the color-coding shows which codes were pooled to make four categories.

The first category (within question 1), sources of anxiety during transition, combined the codes of challenge, constraint, concern, staff turnover, support need and system challenge. Within this category are descriptions of some of the various events and situations that result in a families unease during the process of transition. In their opening conversations, families first began to describe some of the challenges they encountered as their sons and daughters transitioned from school and home, to adult living with supports provided by someone other than a family member. For example according to one mother, involvement with a number of support providers precluded her daughter from establishing relationships that supported her transition to adulthood. “And she (Sue) got so lonesome (living in her own apartment) and of course when you have to rely a lot on providers, it just doesn’t work because they come and go so often” (Joyce, mother of Sue).

Another mother described a situation in which the person providing support had limited understanding of the emotional needs of her daughter.

She (Lucy) is a very emotional person. Always has been and I think always will be. And I think this is part of when we have run into problems with our host home situation, it's been on an emotional level.... And we are sort of at the point now of trying to determine if perhaps her provider is a, still going to be a good provider for her or perhaps it's time to find someone new. (Ann, mother of Lucy)

In another family their son’s first experience with an adult services program was too isolating and confining.

He goes to BB (Adult service agency) during the week. He's part of their...they used to call it community program but they've got another initial for it now but

Table 3

*Codes for Question 1*

**Question 1.** Tell me about your son/daughter. Prompts included: Describe your son or daughter as you might to a new friend or neighbor. Describe the types of supports your son or daughter needs at home, work and social settings, e.g., communication supports, or assistive technology. Tell me about your son/daughters behavioral characteristics e.g., self-control, emotional adjustment etc.

Parent's name(s)	Joyce	Carolyn	Karen	Michelle	Cara	Helen	Teresa	Ann	Rachael and Mark
<b>Codes</b>	challenge		Challenge	Activities	Accommodation	Complex	Curnt setting	Challenge	Challenge
	Curnt setting	Constraint	Curnt setting	Com partic		fears	Disability des		Com partic
	Disability des	Curnt setting	First		Disability des	First	First	Concerns	
	Expectations	Expectation	Personal chara	First	High need	High need		Control	Disability des
	First				Physical desc			Curnt setting	First
	Letting go	First	Support need	Personal chara		Physical desc		Lack of choice	
		person first	Work		Strength	Staff turnover	What works		
	staff turnover	personal chara				Success	work	Personal chara	
	success	Physical desc				Support need		Public perception	
	Support need	Staff turnover				Tenuous		Questions self	
								Residence	
								Support need	
								Sys challenge	
								Trans interim	

basically, when he first when to BB, he was very unhappy because they had him in like a basic skills type of classroom. They didn't go anywhere and he was just tied up in that classroom. (Rachael and Mark, parents of Paul).

Another challenge for these young adults is the area of communication. This code was significant and as such the strategies for communication that the young adults utilized was highlighted as a separate category. Many of the young adults whose families participated in these interviews had significant communication challenges. Some utilized communication devices while others relied on limited vocabulary, sign language or self-devised systems (pointing, directing, or behaviors) to express their needs, wants and feelings. As illustrated by this quote, “She does not communicate well. She has very limited communication but she gets across to us what she needs and what she wants and is very easy going.” (Cathy, mother of Monica) Over the years parents became very adept at reading complex sets of indicators leading to an understanding of the needs and preferences their sons and daughters communicated.

In some situations one young man communicated verbally and in others he communicated his needs or feeling though his behaviors.

He communicates beautifully. He has his own language and you'd have to be around him a little while to understand all of it. Most of his phrases are very clear.... And Alex became really, really behavioral. And that was his way of letting us know, this isn't working. And he wouldn't be cooperative. He didn't want to go. He was unhappy while he was there (Michelle, mother of Alex).

Similarly Lucy's limited vocabulary resulted her expressing frustration through her emotional behavior.

She was just angry at everybody. She was angry at her provider and she was angry at her dad and just angry. And I think a lot of that stemmed from she has all of these feelings and this frustration and she can't express it verbally (Ann, mother of Lucy).

Paul was able to communicate his needs through the use of some sign language and physical prompting of those around him.

We call it 'pull and point'. He pulls you to the door where he wants to be and then he points to what he wants. And he does have 3 signs – eat, drink, and more and those are the most pertinent to his life. He'll use them when he's hungry (Rachael and Mark, parents of Paul).

Similarly Jeff uses strategies that communicate his needs and sometimes attempts verbal responses.

So his communication - he gets his needs known. He doesn't always get them met but he gets them known. He can make his needs known. He can interact a little bit communicatively. He doesn't carry on a conversation but he does answer questions, sort of. (Carla, mother of Jeff)

The third category can be described as the environments or settings in which the young adults are presently engaged, both residentially as well as employment or day activity programs. To arrive at this category the codes of current setting, activities, community participation, residence and work were pooled.

Eight of the nine young adults were living away from home in a variety of situations including group homes, host homes, and a supported living apartment. One mother described the options of a host home in the following quote, "A host home is the best thing that we have come up with so far. And I'm not saying it's always going to be the best thing but it sure is right now. (Joyce, mother of Sue) Another mother described the supports her son needed to live in his own apartment. "And then the, at home, [his apartment] he'd be real lazy unless he had some support. So he needs reminders to clean his bathroom, to do his dishes. He does enjoy cooking" (Karen, mother of David). The residential settings are not always ideal as described by this mother. "Right now she is

living in a host home and has been for approximately 3 years. That has been an adventure.

She is having some ups and downs with that. (Ann, mother of Lucy)

The young adults were involved in a variety of daytime activities. Three were employed in part time positions, one individual was launching an entrepreneurial enterprise and five of the young adults were in day activity programs that included some volunteer work and recreational experiences. The following quote describes the variety of daily activities in which one young man is engaged.

He's at BB (adult service agency). He's in the day program but it's called community participation – the CP class. Now they do a beautiful job. They incorporate pleasure and recreation and work. He does meals on wheels. He delivers the little newspaper flyers. (Michele, mother of Alex)

Another family described a different set of activities as part of a community participation program.

...we called him Speedy Delivery Guy cuz they set it up where he would go with whoever ran the errands - go to the bank, pick up cleaning, stuff like that. And they saw how Paul responded so now it's a whole day full that he goes out and does things out in the community. (Rachel and Mark, parents of Paul).

Some of the young adults had access to a variety of recreational opportunities such as those described by Teresa regarding her daughter, Janelle.

She lives in a host home right now. And she's involved in all kinds of activities through parks and recreation. (Like what?) Let's see - cooking class and she likes to do the trips [parks and recreation sponsored], the day trips, like to IMAX and they are going to the Zoo. And she likes to do the craft class. I think she signs up for everything. It's the whole kitandkaboodle - movie night, restaurant night. And then she's involved in Special Olympics so she does softball right now. In the fall it will be bowling and maybe volleyball if they have it, I don't know. Basketball, um swimming, and track and field - anything, she does. (Teresa, Mother of Janelle)

Another young woman was occupied by more solitary recreational options.

Oh, she, well she loves, she's on a kick now lately in the last 6 months of watching black and white movies. Now if this has anything to do with her eyes, I'm not sure. But she comes home. She sits in front of the TV and watches her movies and then when it's time for us to watch the TV, she goes off and plays her tape recorder. She's got a hundred tapes. My children have, you know, they had tapes where they are talking to her or anytime some occasion is going on, I'll put the tape recorder on in the background. And she just relives all that and just laughs and giggles and dances to herself out here by herself. And entertains herself that way. (Cathy, mother of Monica)

In the prompts for Question 1 was a probe asking about the kinds of supports the young adult needed. The fourth category of codes within Question 1 was that of sources of support for the young adult during transition. The codes included within this category were parent involvement, friendships, family relationships, relationships and sources of support.

Within the responses all the families described some of the varied ways they supported their sons and daughters. The involvement of parents included acting as advocates with adult service systems as noted in this quote,

They warehoused him and he did not like that. There were people in there with behavioral things like screaming or whatever and that made him very edgy so we had to fight, push them into getting him into a community program and so gradually we got him out a few hours a day. And now he's out pretty much most of the time (Rachael and Mark, parents of Paul).

One mother spoke of her involvement in providing specific training for attendant care and her sense of relief when she was able to find a housemate to take on her role as a caregiver.

At any moment it could crumble away but since the beginning of February, Deb has had the most excellent, excellent housemate who moved in and she's responsible. She's actually me Monday through Friday. I'm not consulted about schedule or coordination. They are independent. Deb and Francie call their own shots. Deb has therapy and a part time job. She volunteers a couple of places. This whole schedule is generated by Deb and Francie. I need to coordinate at some

point because we are a one car family so there will be at some point a phone call saying what time do you need the van today. (Helen, mother of Deb)

Some families invested in real estate in order to secure a place of residence for the young adult and the individuals who provide support services.

The thing is Alex is so capable. He could probably be left alone for 2 days and he would function just fine. But he's still in a 24-hour care. He lives with Bob who's been his provider. It will be 7 years this December. We own the home with them out at Franklin Park [neighboring town]. (Michelle, mother of Alex)

Additional sources of support identified by the parents can be characterized as supports that come from being in relationship with others. One young woman was included in her provider's extended family and their activities.

And oh and there's, yeah - usually there's something - like next week is Polly's (granddaughter) birthday so then there's always the big birthday parties and she always goes to all the families things like that. (Joyce, mother of Sue)

In another situation the host home provider helped the young adult participate in activities that he might not otherwise experience.

If there's any opportunity out there that he thinks there's a tiny little chance it might click with Alex; he's right there doing it. And I had a fit. 'Oh, he can't get on that Jet Ski. He can't do that.' Oh, you couldn't get him off. He (Bob, provider) took him to San Diego for a month. He took him out and [they] stayed with one of Bob's friends and stayed a month. (Michelle, mother of Alex)

One family reported that their son's employer was a source of support by noticing and responding when the young man showed signs of ill health.

Yes, he's worked there for 6 years, when they first opened. It's really cool cuz the people at work also kind of are caretakers for him. Cuz when he's not feeling well, when he wasn't feeling well, they said 'we're concerned about David'. (Karen, mother of David)

Another example of support in a work environment is the employees managing the needs for job coaching as they arise without the intervention of an adult service provider.

At work it's pretty minimal. She knows her job and she doesn't need much supervision - real minimal. They just do it in-house there. They don't have anything to do with any of the agencies. They don't want any of the agencies coming in. They, you know, we talked about it and they said if anything comes up, we'll take care of it. And there have been things that have come up and they have taken care of it. You know and it's been very appropriate. (Teresa, mother of Janelle)

In summary, through question one, as families described the current situations for their sons and daughters they identified some of the sources of anxiety during transition such as residential situations, employment or day programs, staff turnover and challenges regarding communication. Via this question families began to describe some of the sources of support during transition, which included families and friends as well as those individuals who take on the responsibility of providing support and assistance in daily living and employment environments.

*Summary of Question 2.* After the initial introduction and descriptions of their sons and daughters, parents were asked, through Question 2, about their experiences as the young adults were leaving the mandated services of school.

**Question 2.** Tell me about your experiences as a parent since your son/daughter exited school services. Prompts included; in what ways are things the same as when your son/daughter was in high school and in what ways are things different? In what ways has the parent child relationship changed? What things helped in the transition? What were the barriers to successful transition?

The responses of the nine families to question 2 and the associated prompts are documented in Table 4. Thirty-seven codes were generated through the responses. The color-coding illustrates the regrouping of similar codes into categories.

The first category, system issues during transition, included the codes of staff turnover, system challenge, system constraint, transition impact, transition interim and waiting list.

The families indicated that the futures they anticipated for themselves and their sons and daughters were not easily or quickly achieved when the young adult left school services. While all of these young adults qualified for services through the Developmental Disability System (DDS), unlike educational services, which are mandated under IDEA 1997, the services through DDS were frequently limited or delayed due to lack of funding. The young adults needed supports in daily living and in general, organizing every aspect of their lives. One mother described the challenge of securing enough support for her daughter to live in a supported living setting.

You know we've been through a lot. And it's been an eye opener. We started with her own apartment. We started with a roommate. That lasted 3 days, maybe, and then she came back home for awhile and then she went into her own apartment. . . . Well she needed supports as far as cooking, shopping, community exposure - you know going to the concerts or what have you, laundry, house cleaning which we, for awhile we had a housekeeper and then they [adult service agency personnel] said 'no, we can't do that anymore.' So she needed help with the cleaning of her house. Paying bills, balancing checkbook - you know the whole gamut. . . . Then it was the, unless somebody did the organizing and took her some place and coordinated friends, she didn't leave her apartment, she just sat there. And I think that was really a hard, and I think that still is a hard part of it. To this day, if somebody didn't help her organize, well, let's do this. Let's sign up for these things through parks and recs. Or which of these things do you want to sign up for? Or what do you want to do next week or things like that. If it's left just up to Sue, it's real hard for her to do that. She needs - that's a real big barrier that I can see. She has no idea of how to go about it just on her own. (Joyce mother of Sue)

Table 4

*Codes for Question 2*

**Question 2.** Tell me about your experiences as a parent since your son/daughter exited school services. Prompts included: In what ways are things the same as when your son/daughter was in high school and in what ways are things different? In what ways has the parent-child relationship changed? What things helped in the transition? What were the barriers to successful transition?

Parent's name(s)	Joyce	Carolyn	Karen	Michelle	Cara	Helen	Teresa	Ann	Rachael and Mark
<b>Codes</b>	Challenge	Friendship	Currt setting		Com partic	Challenge	Challenge	Expectation	Adjustment
	Friendships	Staff turnover	Relationship	Challenge	Currt setting	control	communication	Hope	Challenge
		Sys constraint	Self deter	Communication		Frustration		School prog	Concern
		Wait list	Source of support	Conflict with sys		Lack of prep		Sys constraint	Expectation
	Success		Staff turnover	Hope				work	High need
	Support need		Trans impact				Source of support		
				Provider relationship		Relationship	Sys challenge		Relaionship
				Sys constraint		School Prep	Sys constraint		School prog
				Sys response		School prog	Sys reaponse		Sys challenge
				Trans impact		Self deter	Then and now		Sys consraint
				Trans interim		Source of support	Trans impact		Then and now
						Staff turnover	Trans impact		Trans impact
						Support need	What works		What works
						Sys constraint			
						Trans interim			
						Work			

When school services ended several families found themselves in situations with no supports and the family members needing provide support and direct service. “But then she graduated and then they had no place for her – BB [adult service agency] - for Monica to go. She was on a waiting list. And so she was home with me for about 4 months” (Carolyn, mother of Monica). Even when families believed they understood the changes that would occur after school services ended, many related experiences of confusion and frustration with their introduction to the adult service system, as illustrated in the following quote,

The transition from there from CTB [school program] to adult services was awful... I'll tell you about my transition - the bad thing that happened when we started dealing with adult services. I was promised SLS [supported living services] services. And um, they kept saying, ‘yup, you'll get it; yup, you'll get it’. And I was commuting up to CC (another town) at that time, driving back and forth and I was getting stretched. Janelle was already in her apartment.... So they called and said ‘sorry, you're not getting it; we don't have the funding. There's a waiting list’ (Teresa, mother of Janelle).

The second category within Question 2 is the role of family members during transition. The codes that comprised this category included, parent involvement, relationship change and parent relationship. As their sons and daughters were transitioning from services provided by the educational system to adult living, families found themselves having to make adjustments in their routines in order to accommodate the needs not met by adult services and in some cases having to coordinate or provide direct support as illustrated by the following example.

Well, first of all, I helped her interview all the people that she wanted to work for her. And then we would get someone good and they would last a month or they would graduate and go on or what have you. So whenever someone didn't show, then I was on call. Plan B - I was Plan B (Joyce, mother of Sue).

Even when families thought they had secured the supports necessary, they ran into the challenge of finding part-time workers, or the workers themselves were unreliable. As demonstrated in the following story, this created stressful situations for families.

Paul was going nuts cuz he was home all the time. We had SLS [supported living services] people. We'd line them up because I was working days and Mark [father] was working, trying to work, and trying to make appointments around these SLS people. And they would either not show up; they'd bail because Paul is a handful. Or the SLS coordinator couldn't find people that were interested in working with Paul. So we had all these SLS dollars and hours and we couldn't fill it... It was too stressful at home. You know I've got to work. I have stress cuz I have scheduling at work and I have scheduling at home and it was too much (Rachel and Mark, parents of Paul).

The third category within question 2 was creating social connections with service providers. The codes included in this category were, friendship and relationship. The issues for families concerning relationships were varied. Family members found themselves and the young adults interacting with new people with whom they had to develop new relationships as shown in the following quote from Michelle regarding her son Alex.

I think first of all he [host home provider] really cares about Alex. That's A #1. I think [it is] because Alex is so happy [that] he has a relationship with Bob. They are just like best friends. Bob never refers to him in any other way but as his roommate. He says, "Hi, I'm Bob, Alex's roommate." He has a great deal of respect for Alex. He values him as a person (Michelle, mother of Alex).

While the previous quote seems to illustrate the ideal relationship, connections such as that are not easy to achieve. Sometimes the independent nature of the work of supporting an individual with a disability creates some confusion between the distinction of being a friend and being an employee. The blurring of the boundaries of friendship and acting as a caring support provider combined with the instability of direct service support

can create difficult situations for young adults seeking to achieve a life in the community as shown in the next example.

Yeah, and here we are trying to hire people to become his friends and he doesn't understand that they're still employees and they have to live by those rules and not the rules of friendship. It's just so hard for him to understand...and he got a little lonely to begin and so. He had a couple of helpers but the helpers never stay very long. You know two or three months and then they moved on to something else.  
(Karen, mother of David)

In summary, question two yielded three categories of responses. Within the first category, system issues, families described the confusion they experienced trying to understand and access adult services that were limited and in some situations delayed due to lack of funding. Secondly, families described role changes as parents experienced the stress of providing direct services and having an expanded case management role. As the young adults moved from school to adult living the services they needed were not always immediately available. It was challenging for families to understand the adult services system, which frequently resulted in confusion and frustration. In the third category families described the stress associated with developing relationships with all new service providers after leaving school programs.

*Summary of Question 3.* Question 3 and the associated probes facilitated further conversation with families of their experiences during transition and focused on the specifics of day-to-day activities.

**Question 3.** Please describe for me what a typical day and week are like for your son/daughter. Probes included; since he/she left high school how has the schedule changed? Is your son/daughter currently employed? What types of support are needed on the job? What if any, services does your son/daughter receive from an adult service agency?

Table 5 illustrates the various codes assigned to the responses to question 3. The average number of codes within each interview for this question was five when the total responses from one interview (which had 22 codes) were viewed separately. Within the responses for question 3, families described the various living environments that were in place for their sons and daughters as well as the daily activities and work in which the young adults were engaged.

With the exception of one individual, all of the young adults were living away from home in settings where they received support. The families reported varied amounts of involvement that ranged from occasional contact to regularly scheduled visits home with family members. “And since I don't see him very often, I rely on everybody else's input that sees him especially Kristine and Samantha [relatives]” (Karen, mother of David). In contrast in another situation the family provides weekly support. “...and we have Lucy with us. She comes home usually every Wednesday evening and has dinner with us and sticks around for about an hour or so. And then she's here from Saturday morning until we take her back on Sunday evening about 5 o'clock” (Ann, mother of Lucy).

Three of the young adults have part-time jobs which they have had since they were still in school. One of the individuals does volunteer work and four of the young adults are involved in daily programs called “community participation”. Families expressed varied levels of satisfaction with these situations.

Table 5

Codes for Question 3

**Question 3.** Please describe for me what a typical day and week are like for your son/daughter. Probes included: Since he/she left high school how has the schedule changed? Is your son/daughter currently employed? What types of support are needed on the job? What, if any, services does your son/daughter receive from an adult service agency?

Parent's name(s)	Joyce	Carolyn	Karen	Michelle	Cara	Helen	Teresa	Ann	Rachael and Mark
<b>Codes</b>	Activities	Com partic	Challenge	Ccom partic	Com partic	Source of support	Parent invol	Challenge	Com partic
	Challenge	Curnt setting	Curnt setting	Success	Sys constraint	Volunteer	Self deter	communication	Expectation
	Curnt setting	Fears		What works	Then and now			Conflict with sys	High need
	Fam relationship	Parent invol	Physical des		Work			Control	Letting go
	Parent invol		Source of support					Expectation	Parent invol
	Residence		Sys response					Family crisis	Sys constraint
	Sys constraint		Trans impact					Fears	Sys rewponse
	Work							Feeling guilt	
								Indep	
								Lack of prep	
								Par rel	
								Parent freedom	
								Parent invol	
								Pos impact of dis	
								Question decision	
								Self-deter	
								Sib invol	
								Source of support	
								Staff turnover	
								Support need	
								Sys challenge	

They have an office building and a workshop, well not a workshop, but it's a place, a room where they draw or watch TV. I don't know if you would call it a recreation room but it's basically, they're not doing that much or they...I don't know why. She's just not really happy; does not want to go to school. She still calls it school (Carolyn, mother of Monica).

In contrast, a different situation exists within the community participation program organized through another adult service organization as illustrated in the following account.

Okay, he has wonderful days. His life is so good. He gets up and the same time every morning... and gets ready and goes out and waits for the van. The van picks him up about 8:30. He goes to BB [adult service agency] for the day; gets home at 2:00....they first start at BB and then they go out and either they go out on an outing or they do their papers or they do their meals on wheels or they go to Lake Liberty or they go to the mall or they go to the coffee shop or they do whatever they're going to do (Michelle, mother of Alex).

Of those involved in community participation, three of the families had hopes that the young adult would have some sort of supported employment job in the future, in spite of limited resources for support.

There's just not the funding; the personnel; it's just not possible. So the best that they can do is what they're doing now where a whole little group can do it. I just know that Alex is happiest working. And that's what he, I said why can't he stock vending machines? Why can't he work at a grocery store and stock shelves? Why can't he?...And I just keep doing that and it's not happening and so at this point in my life this is where my frustration is and his dad's too. We'd just like to see that happen for Alex. Because I know he feels good when he feels productive. I know his self-worth is there and he feels it when he's working. So I don't where we are going to be with that years from now (Michelle, mother of Alex).

In the case of Lucy, her mother hopes that a job experience will be in her future. "I think she, there are certain jobs she would really enjoy doing, and I would love to see her have that opportunity if that's what she wants" (Ann, mother of Lucy).

For some of the young adults, while a job might be desirable the parents' perception is that it would have to meet specific criteria in order to be successful, as noted in the following account.

I'd like to see him have more... The thought of – he cleaned lockers for one summer at the summer work program and the thought of cleaning lockers for 8 hours or whatever is not something he can do. He is, intellectually he needs to be stimulated. So he needs the kind of job where he can be doing something with his mind but it also needs to be a short enough time period that he can take his mind and go with it where he wants to go (Carla, mother of Jeff).

In summary, for all except one individual, the young adults had transitioned out of the family home and into a variety of supported living situations. The one young adult remaining at home did so because the family felt the home provided the best environment to meet the needs of their son, as long as the parents were able. Some of the young adults had part-time jobs and the others were involved in community participation activities. Several of the families whose young adults were involved in community participation activities were hopeful for future employment opportunities. The families identified the economy and the lack of available support as barriers to employment.

*Summary of Question 4.* Many of the families began to describe the types of involvement they had with their sons and daughters through question 3, which was a bridge to question 4, in which the families were specifically queried about their role in supporting the young adults.

**Question 4.** What is your role now in supporting your son/daughters transition? The probes included; what types of support does your family provide for your son/daughter? Please describe what types of planning occurs now that your son/daughter is out of school? How does this planning differ from the types of planning that occurred in school? What are the sources of support for your family e.g., friends, other families, professionals?

Table 6 shows the range of codes identified within the text material for question 4 regarding parental roles, other sources of support and the types of planning that occurs now in contrast to the development of an Individualized Educational Plan (IEP) while the young adults were still a part of the school system.

Families described a wide range of activities that are a support to their sons and daughters. As mentioned previously, several of the families acted as a source of respite care for host home providers.

Alex comes home every Wednesday; every Sunday; one whole weekend every month. I mean Alex's home here a lot. And if we're not here, when Bob leaves, we go stay there. Alex's been coming home Wednesdays and Sundays since he went into LL [residential living program]. I have never, unless I'm out of town, I have never, ever missed the Sunday having Alex home (Michelle, mother of Alex).

Other families spoke of less involved in day-to-day activities and acting in the role of a resource to direct service providers.

We're mom and dad. If he's having a rough go of it, like I've had those providers call me and say, 'Paul's not happy and I can't seem to help him. He had a seizure and I'm not sure what to do.' They will call us in that respect.... We still go to the doctor if they make an appointment at a convenient time.... We're there to support him if he needs us (Rachael and Mark, parents of Paul).

But, the involvement of the parents is not always sought out or welcomed as shown by the following quote.

Sometimes I feel as though in dealing with the different agencies; in dealing with people at BB [adult service agency], at DD [adult service agency] or even dealing with her own provider, that I am viewed as either being to lackadaisical about things or not really being as concerned as I should be, or just plain dumb.... I just want to go up and shake people and say, 'you know, I carried this child in my body. I've been with her for all of this time and we've been through a lot and by golly I think I know how she is going to react to situations or how she's going to cope with this or you know, please listen to me. I'm not just talking through my hat' (Ann, mother of Lucy)

Table 6

*Codes for Question 4*

**Question 4.** What is your role now in supporting your son/daughter's transition? The probes included: What types of support does your family provide for your son/daughter? Please describe what types of planning occurs now that your son/daughter is out of school? How does this planning differ from the types of planning that occurred in school? What are the sources of support for your family, e.g., friends, other families, professionals?

<b>Parent's name(s)</b>	<b>Joyce</b>	<b>Carolyn</b>	<b>Karen</b>	<b>Michelle</b>	<b>Cara</b>	<b>Helen</b>	<b>Teresa</b>	<b>Ann</b>	<b>Rachael and Mark</b>
	Challenge	Challenge	Friendships	Concern	High need	Par rel	Expectation	Control	Adjustment
	Indep	Com partic	Relationship	Par invol	Hope	Self deter	hope	frustration	Concern
	Par rel	Concern	Sib invol	Relationship	relationship	Source of support	Par invol	Source of support	Par invol
	Parent invol	Conflict with sys	Sys response	School prog	Work		realnship	Sys response	Relationship
	Rel change	Expectations		Source of support			School prep		Source of support
	Source of support	Source of support		Sys response			Sys challenge		Sys challenge
	Strength	Sys response		Work			Trans expectation		Trans interim
	Sys constraint	Then and now							What works
	Then and now	Trans interim							
		What works							
		Work							

In regards to sources of support, some families have joined informally with other parents who are experiencing the same types of transitions and challenges. Together they share ideas, problem solve and in general provide one another support through friendship as illustrated in the following scenario.

But once a month, Rita, Mary, and I and then, Paula, Rita's daughter, and Kevin and Lucy and usually someone she invites – we all go out to dinner. And all of the kiddos sit – everybody sits at different tables. The 3 of us ladies sort of sit together and so we have just this grand gabfest and compare notes, talk about things and see what's going on. That's probably the closest that I have to support (Ann, mother of Lucy).

Over the years occasional visits were a source of support to families as noted by this account, “ And you know the interesting thing is there are still certain moms that I visit with on a regular basis – like Pam, and Barb (Joyce, mother of Sue).

In summary, the family roles changed once the young adult exited public school services. For those young adults living away from home, parents were a resource for direct support staff as providers of information and in problem solving. In addition, many families gave direct providers a break by providing respite on a regular basis.

As families faced the new challenges of transition they often sought support from other families in similar situations. Together the families shared ideas about solving the problems of supporting a young adult in achieving a high quality of life.

*Summary of Question 5.* In question five, families were asked whether school programs prepared them for life after educational services ended and for any advice they would offer to families who still had children in school.

**Questions 5.** Did the school system prepare you and your son/daughter for life after school? Prompts for question 5; what would you tell other parents whose son/daughter is still in high school that might enhance the process of transition?

Table 7 shows the spread of codes assigned to the text of responses to question 5 among the nine interviews.

Seven of the nine families involved in this study indicated that the transition from school services to life afterwards was very stressful. Families experienced delays in service or services that did not meet the day-to-day needs of the young adult. While most of these families were satisfied with the school's transitional program (for students 18 to 21) and its services, it was not a period of time in which a bridge to future environments was prepared. "When he turned 21 and they threw him out" (Rachael and Mark, parents of Paul). When asked if the school system prepared them for life after school, Joyce responded succinctly, "No. I don't think it's real world". Even the families, who indicated satisfaction, did so conditionally. "I think for us they did. I know for all of people they didn't. Because we didn't ask them to do vocational transition" (Carla, mother of Jeff)

For these families and young adults, the twenty-first birthday was the beginning of a new journey, with few maps, guides or resources to assist them in planning a route or reaching a desirable destination. Services and programs after school programming ended were very different than those services which families and students had grown accustomed. "And I just really felt that we were very much on our own. That we just had to figure it out because there was no one there to even give us a hint" (Ann, mother of Lucy).

Table 7

*Codes for Question 5*

**Questions 5.** Did the school system prepare you and your son/daughter for life after school? Prompts included: What would you tell other parents whose son/daughter is still in high school that might enhance the process of transition?

<b>Parent's name(s)</b>	<b>Joyce</b>	<b>Carolyn</b>	<b>Karen</b>	<b>Michelle</b>	<b>Cara</b>	<b>Helen</b>	<b>Teresa</b>	<b>Ann</b>	<b>Rachael and Mark</b>
	Advice	Advice	Advice	Advice	Advice	advice	Advice	advice	Advice
	Friendships	School prep	Personal chara	Forced fit	Challenge	Conflict with sys	expectation	School prep	concern
	Parent invol			School prep	Trans expectation	Frustration			Fears
	School proep				Trans impact	School prep			hope
	Staff turnover					School prog			Relationship
	Trans impact					Self deter			

When asked about the advice they would give other families who still had young adults in school the families spoke about needing to prepare for the future, but to also be aware that plans may have to change,

But you know, be prepared to try several different things before you find something that works. And hopefully you find something that works and know that even when you do find something that works, there's always that shoe ready to drop, you know (Joyce, mother of Sue).

Some families suggested identifying potential careers as a key to successful transition.

I would tell them to find a career or something that their child is interested in and can feel worthwhile and that they are contributing. And have a reason to get up just like everybody. We all need a reason (Carolyn, mother of Monica).

Another family suggested contacting support agencies and recognizing the strengths and interests of the young adult as important aspects of transition, as noted in the following quote,

I would say, start asking questions; start planning. Contact your agencies. Not only BB [adult service agency] but maybe even just really be on top, if you are on a waiting list, find out where. Do you want to be on a waiting list? Are you interested in residential services? And find out what's available and what it's going to take to get onto that list. Seriously, seriously think about employment issues because we're just always painted this happy rosy picture and it just doesn't happen. It just doesn't. I would say, you know, really stop and think and really look hard at your young person's capabilities and their strengths and their talents. And see if there is some way that that can't be parlayed into an employment situation (Ann, mother of Lucy).

In other situations families identified the need to support the desires of the young adult as shown in the following situation.

Get rid of your expectations, cuz he's going to have his own. So we just kind of stepped back and we just let things take their course. We didn't say this is where he ought to be. He told us this is where he wants to be. And that really took a lot of pressure off of us, and a lot of pressure off of him. And I think that helped a lot (Karen, mother of David).

In addition to career exploration and the identification of interests, the following quote suggests that having high expectations and looking for role models are important pieces of planning for the future.

Oh, I do have advice. It would be dream big. Don't imagine that you have this figured out. Don't imagine that you know what your child's future is. If your child has any sort of communication obstacles, you may have little to no idea what their capacity is yet. And the fact that they are in junior high and you still don't know, it means nothing. It means nothing. It's just persevere and dream big. Watch them for their interests, their passions and insert those elements at every opportunity and then stand back and watch and see what develops. Don't decide academic vs. vocational. Continue to offer both. Watch and see what other people are doing who have family members who have a similar profile. To look for mentors.... So anyway, for people to have, it's like seek out, find those examples that can show you what those possibilities are. Why would you try so hard if you always thought it was always going to be just like this? So seek out those stories, make connections with – it doesn't take a lot of people – it only takes one who can show you your possibilities (Helen, mother of Deb).

In summary, families described school programs as satisfactory, but not as a bridge to preparing the young adult and family for the future. Leaving the familiarity and security of school was stressful, especially when life beyond the classroom was not predictable. The lack of preparation for the next environments caused families to feel abandoned by the school system.

Based on their own experiences family members would advise other families preparing for transition to learn about adult services and develop a plan for transition based on the student's and family preferences. They also suggest that families adopt a flexible attitude, knowing that plans will usually have to be adjusted as time goes on. In addition they suggested that families seek out other role models in families who are in the midst of transition and to have high expectations for the futures for their sons and daughters.

*Summary of Question 6.* In question 6 families were asked to identify the types of resources that would help them in supporting their sons and daughters.

**Questions 6.** What resources do you think would help you in supporting your son/daughter? Who can your son/daughter depend on for support or assistance?

Table 8 displays the range of codes identified within the source material for question 6. The primary resource that families identified was that of human resources, to provide a variety of supports for the young adult.

The lack of human resources is sometimes a safety concern as illustrated in the following example, “and the other thing is the staffing level at LL [group home] home is bare minimum. When all of the guys are up, they have 2 people to help feed and bath and those things.” (Rachael and Mark, parents of Paul).

Several families indicated a need for additional personnel and time to support their sons and daughters in cultivating and maintaining friendships. “But I think too she needs to be with other people. She needs a friend. I just feel so bad about her not having a friend like she had with Patty [friend in school].” (Carolyn, mother of Monica)

Human resources were also identified as important in securing employment and maintaining a job as described by one mother,

I keep coming back to[a job] – the hang up is finding it...I’ve asked every, actually we’ve even called meetings beyond our yearly meeting, we’ll call a meeting. We need to do this; we need to do this. So we haven’t had it happen yet. I think that he could do something but once again, then you’d have to have that, who goes along with them. Like a job coach, yeah. There’s just not the funding; the personnel; it’s just not possible. (Michelle, mother of Alex).

Table 8

*Codes for Question 6*

**Question 6.** What resources do you think would help you in supporting your son/daughter? Who can your son/daughter depend on for support or assistance?

<b>Parent's name(s)</b>	<b>Joyce</b>	<b>Carolyn</b>	<b>Karen</b>	<b>Michelle</b>	<b>Cara</b>	<b>Helen</b>	<b>Teresa</b>	<b>Ann</b>	<b>Rachael and Mark</b>
<b>Codes</b>		friendships	Support need	Frustration	Challenge	---	hope	---	Concern
		Frustration		Sys challenge	Family crisis		Source of support		fears
		Hope		Sys constraint	Sib response		What works		
				Sys response	Source of support				
					What works				

In summary, the families identified a need for financial resources which would be used to secure reliable personnel for providing support in residential environments, to do job development and to provide support in employment situations.

*Summary of Questions 7 and 8.* The final two questions of the interview focused on the fears and hopes for the future in the lives of the families who have adult members with disabilities.

**Questions 7.** What are your concerns for the future, given your son/daughters current situation?

**Question 8.** What are your hopes for the future?

While question 7 is the specific question in which fears were queried, families voiced fears and concerns throughout the interview as demonstrated by the recurrence of such codes as challenge, fears, and concerns throughout all the tables illustrating the range and pattern of various codes. Table 9 represents the distribution of codes among all the responses of the participants for questions 7 and 8.

Table 9

*Codes for Questions 7 and 8*

**Question 7.** What are your concerns for the future given your son/daughter's current situation?

Parent's name(s)	Joyce	Carolyn	Karen	Michelle	Cara	Helen	Teresa	Ann	Rachael and Mark
<b>Codes</b>	fears	Concerns	Concern	Concern	challenge	Fears	concern	Concern	-----
		expectations	Relationship	Fears		Par rel		Sys constraint	
		Fam relationships	Staff turnover	Relationship		Self deter			
		Fears		Risk		Sys response			

**Question 8.** What are your hopes for the future?

Parent's name(s)	Joyce	Carolyn	Karen	Michelle	Cara	Helen	Teresa	Ann	Rachael and Mark
<b>Codes</b>	Hope	Hope	Concern	Hope	Hope	hope	Hope	hope	fears
		acceptance	Hope		Trans impact				Hope
			Par rel						

The fears that the families expressed ranged from statements that were somewhat abstract in contrast to statements that were specific and pragmatic. The following two quotes are examples of somewhat vague concerns. “I guess my concern is sort of his fading into stagnancy. Not being able to continue the challenging, challenging him with the reading and even the exercising and getting out with a group.” (Carla, mother of Jeff) Another vague description is as follows, “The nightmares is any one of our kids would be isolated and alone and unhappy and under challenged.” (Helen, mother of Deb)

Among the more specific fears is the loss of specific supports or ultimately the death of the parents occurring before the young adult. “Absolutely the concern would be living arrangements. What happens when we don’t have Jeannie [host home provider]” (Teresa, mother of Janelle). Another family identified the possibility of losing a host-home provider as being a significant and overwhelming possibility, “#1 if we lost Bob [host home provider]. How do you replace that? And that’s always a possibility.” (Michelle, mother of Alex).

Several families recognized that their sons and daughters might outlive them as noted by the statement, “Well my biggest concern is that I’ll die before she will or John will die. We’ve got our will in place and all that’s set to go. But I don’t know what would happen to Sue. That’s still a scary one.” (Joyce, mother of Sue) None of the families related specific plans in the event of their death coming prior to that of the young adult. “My other concern is when Chuck and I are gone - what will happen?” (Michelle, mother of Alex).

In contrast to fears are the hopes that families have for the future. While most of the families hoped for good health and happiness, three of the families had very specific

hopes that described a future where the young adult was supported as a member of a community and where their contributions were recognized and valued. In the following quote the family related a vision that the young adult would have connections within the community that would secure their future.

[My dream is] You know you have a whole bunch of families and they are part of the neighborhood but there's somebody there to kind of keep an eye on them you know? That would be ideal. That would be the ideal setting. Whether or not it'll ever happen. But you keep pushing, keep hoping. (Joyce, mother of Sue).

Another mother described her dreams for a future that makes it possible for others to benefit from the knowledge and experiences of her daughter, and for her daughter to have the opportunity to experience various joys in life.

I'm hoping that at some point communication becomes simple enough that Deb writes. That she puts forth her experience so anyone can understand it. Because, she is incredible. And I think anybody who got to see or understand it would be, well they would benefit greatly from her perspective. I think she's got a terrific capacity to teach us a lot. And I hope things come to a place where Deb is able to facilitate that for the rest of us. There isn't anything I don't hope for Deb. I hope that she is able to fall in love and experience that idiocy and delight. There is nothing that I don't hope for her. I think that's possible. We've come this far. But it's all driven on Deb's desire because if she doesn't wish it, it will never happen. (Helen, mother of Deb)

In summary, family members experienced fears for the future of their young adult. Some of the fears were global in nature such as the fear that the young adult would be isolated and lonely. Other fears were specific, such as the fear of losing a particular support person or the death of a parent. In contrast families had hopes for the future reflected in statements that describe other people seeing the young adult as a contributing and valued member of a caring community.

### *Phase Three - Development of Themes*

The source materials (text) assigned to each code were analyzed as a collection (across all cases/interviews). The source material associated with each code was the textural description of the code. Further analysis of the textural descriptions allowed for clustering of similar codes. The process required multiple reviews and regroupings of the clustered codes and their accompanying text to arrive at the next phase of data analysis, that of uncovering themes. Analysis of the textural descriptions revealed themes that were common to the experience of transition for these families. Some themes could be described as internal to the family (such as vision, parent involvement, and relationships) and others that reflected external themes (such as issues with school and adult service systems). See table 10.

### *Theme One - Parent Involvement*

As families spoke about transition, their participation in the process and their ongoing contribution, the theme of parent involvement emerged. Several studies, reviewing empirical literature have identified factors associated with successful transitions for young adults with disabilities. Among the best practices cited in reviews of transition literature is parent involvement. (Hughes, Hwang, et al., 1997; Hughes, Kim et al., 1997; Kohler, 1993). In the literature of special education the term parent involvement is used but not explicitly defined as being any different than the involvement of parents in other educational environments.

In the literature about school reform it is noted that parent involvement at the level of secondary school tends to decrease. (Henderson, 1994) Without further description or prior knowledge and personal experience to draw upon, the reader may get the impression

Table 10

*Development of Themes*

Internal Themes		
Theme One Parent Involvement	Theme Two Vision	Theme Three Relationships
<ul style="list-style-type: none"> <li><input type="checkbox"/> Supporting situational needs</li> <li><input type="checkbox"/> Advocacy</li> <li><input type="checkbox"/> Supporting Self-determination</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Fears about the future</li> <li><input type="checkbox"/> Hopes for the future</li> <li><input type="checkbox"/> Advice for other families</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Relationships in the school setting</li> <li><input type="checkbox"/> Relationships in the work environment</li> <li><input type="checkbox"/> Relationships with support persons</li> </ul>
External Themes		
Theme Four School System Issues	Theme Five Adult System Issues	
<ul style="list-style-type: none"> <li><input type="checkbox"/> Transition services in the high school</li> <li><input type="checkbox"/> Personnel, self-contained classrooms, funding</li> <li><input type="checkbox"/> Lack of interagency collaboration</li> <li><input type="checkbox"/> Community based services</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Communication issues</li> <li><input type="checkbox"/> Waiting lists</li> <li><input type="checkbox"/> Few choices</li> <li><input type="checkbox"/> Instability</li> <li><input type="checkbox"/> Lack of trained personnel</li> </ul>	

that parent involvement during transition of a young adult with disabilities is as simple as showing an interest in a student's progress and providing a safe, nurturing family environment from which to "launch" an adolescent into adulthood.

Contrary to the experiences of families of typical adolescents whose involvement decreases during secondary education (Epstein, 1994; Henderson, 1994), the families in this study, who had a young adult with a significant disability, experienced the necessity of increased and active participation during transition. "Everybody is different but with a handicapped child the transition is much different than when your regular kids leave. It's much more drawn out. You worry about them at a different level" (Rachael and Mark, parents of Paul).

The families interviewed provided vivid descriptions of the construct of parent involvement that goes beyond what typical families experience as their sons and daughters transition from school to adult living. In this study families described their involvement during transition as an active and frequently hands-on experience. The differences between these families and "typical" family's experiences seem to reside in factors of intensity, constancy and duration of the process of transition, and in activities that were dissimilar from those of parents of typical teens and young adults

For families who have a son or daughter with a disability, the experience of transition was not an event marked by a celebration such as graduation from high school or leaving home to enter post secondary education. When students left the mandated services of education the efforts to achieve a quality life became more complex as families negotiated a maze of adult services, redefined their roles and pursued supports

beyond the school system. Transition for families meant constant vigilance over day-to-day concerns, as described in the following quote,

When she was home in her apartment, every night at 9:00 she would call me. And we would go through the list. 'Now did you lock your door? Did you check behind the door?' Every night. And if I called her and said 'you know I'm going to bed early tonight,' it didn't matter. She still called at 9:00. It was such a routine (Joyce, mother of Sue).

Several families described the need for frequent adjustment and hands-on action as noted in this scenario,

She had lived on her own for four years in an apartment and that was with supported living services and that took a lot of effort on my part to help her maintain that. Even with the supported living service- I mean we tried 20 some hours with that - and that did not work. It was just too many people in our life and lack of consistency and so I finally made the decision to go for the host home.... You know, honestly, I would say it [transition] was when she went into the host home. ...So it took about 4 years for transition and I say that because of, because of the involvement that I had. To mean transition is that you go into the adult system and for Janelle to have the most amount of independence with the least amount of family involvement. I mean that's how I, I mean for her, that's how I kind of looked at it. And I was involved. I was actively involved for all those years when she was in an apartment. And so to me where I truly feel that piece had really happened is when she moved in with Polly [host home provider] (Teresa, mother of Janelle).

When adult services were delayed these families experienced stress associated with the need to provide full time direct care, as the following quote illuminates,

"We need to be away from each other for awhile. And um, I don't mind taking her with me but every day that she is home, I take her out. She's never home all day. That means that I am the other care provider (Carla, mother of Monica)

Parents' experienced constant apprehension as their sons and daughters left home, wondering if their basic needs were being met and always knowing that once a plan for support is in place that circumstances may require a change.

But you know, be prepared to try several different things before you find something that works. And hopefully you find something that works and know that even when you do find something that works, there's always that shoe ready to drop, you know (Joyce, mother of Sue).

*Supporting situational needs.* Families spoke about taking on a variety of roles in response to situational needs such as acting as a case managers and providers of direct service through a variety of activities such as, developing opportunities for work or recreational activities, providing transportation, advocating for additional resources, interviewing service providers, bookkeeping and paperwork required by adult service systems. "Well, we're there anytime there's a decision to be made. Anytime there's a new caseworker, or payroll or the checkbook things. So we're, still there to support her anyway that she needs it" (Joyce, mother of Sue).

In the following situation one mother spoke about her experiences as a job developer and coach. "I was the main support (for a job) and I'm also the main reason why we're not doing it still. Because it became unwieldy and I did not have enough time to be that support person" (Helen, Mother of Deb).

Lucy's mother, Ann, recognized her daughter's need to interact with young adults her age so she provided transportation for a college student to come and do an activity with Lucy.

This young lady didn't always have transportation so that's what made it a little hard to get to the grocery store. So I would have to go pick her up and bring her to our house and make sure that ingredients were there. And they would cook a little something and then I would have to take her home (Ann, mother of Lucy).

Most families reported ongoing involvement anytime a medical concern arose, as described by the following quote.

And there was a period of time where I really had to take off and be gone from work for days just to get the testing (medical) done, and visit with the doctors. There wasn't anybody else that I felt besides me that could do that (Karen, mother of David).

Teresa also spoke about needing to closely monitor the services that were to be provided by workers with an adult service agency, and finding that workers were not always showing up. The agency contracting for the services disregarded her suggestion that direct service providers should be supervised. Other families voiced similar concerns regarding monitoring and stated that the providers were usually young, untrained people, who did not really understand how crucial their support was to the young adults for whom they were working, and that these part time workers did not stay with the jobs for very long. "And that's the part that was really hard to get them to understand. 'It's an hour. I'm only here for an hour'. Yeah but, that's an important hour for Sue" (Joyce, Mother of Sue).

For these families it means being available as problems arise and acting as back up anytime paid support persons are unavailable.

So whenever someone didn't show, then I was on call. Plan B - I was Plan B. And then as far as supervising - I made sure that they did what had to absolutely be done. Like send in pay stubs into SSI or things like that. Things that couldn't be passed over from one week to the next. Some of it you kind of let slide, but a lot of it, you can't (Joyce, mother of Sue).

Providing support can be short-term but for some families the level of support they provided was intense and long-term. The intensity exemplified by the following account of one family in which the young adult needed a high level of support to have her personal needs met. Her family was frequently the primary source of the support, "Our weekend person, so called anyway, was hired at the beginning of the summer but couldn't

begin until August 1. So I've been the weekend person still" (Helen, mother of Deb).

Acting as the back up for support and providing direct care was a role in which families were often engaged during the process of transition.

*Advocacy.* Families discussed situations in which they had to actively monitor the services and then advocate for changes in the services their sons and daughters were receiving, or in some instances provide the resource themselves. In the following scenarios families responded to needs their son and daughter identified and communicated through their behaviors. Families used terminology, such as "fight" and "battle", which described the situations as adversarial and difficult.

Paul's family advocated for a change in the approach to overall services that were provided.

When he first went to "BB" [adult service agency], he was very unhappy because they had him in like a basic skills type classroom. They didn't go anywhere and he was just tied up in that classroom. They warehoused him and he did not like that...we had to fight - push them into getting him into a community program and so gradually we got him out a few hours a day. And now he's out pretty much most of the time (Rachael and Mark, parents of Paul).

In another situation, Lucy's family identified a need to advocate for an employment opportunity as a high priority.

I had to really think about the battles I wanted to fight and choose them carefully. So one of the ones I chose to do was to go in and say, Lucy needs a job. And you guys at "BB"[adult service agency] are not doing what I think you need to be doing. She's not happy. She has more potential (Ann, mother of Lucy).

Deb's mother spent time learning the system rules and then advocated for supports that were initially denied.

And you just have to keep asking, why not? You know, you have to keep going back to the definition of the funding and saying, well; this falls into the definition

of the money. How can we make this work? And what becomes the most effective is saying, you have to give it up to them and you have to challenge them (Helen, mother of Deb).

In an effort to stabilize the residential situations, three of the families have invested in homes for their young adults to live in, with agency provided supports. With the location secured, families were able to concentrate on bringing appropriate supports to their young adult and be relieved of the stress of needing to relocate as support person turnover occurred. While this did relieve some dimensions of stress it was also a source for other stressors.

I'm not very aggressive person and trying to confront all of this and the other problem is we purchased the town home that they are living in. Which has again has caused some feelings with the provider. And, but it was, they had like 30 days to move from their previous residence. Time was getting very short and nothing was coming up and at that point of time my basic concern was Lucy's happiness, safety, health, whatever. So we stepped in and said we are aware of a little place that's just about a block and a half down and we'd be thinking at the time, this is what we want for Lucy. We don't want her moved from pillar to post. We want some place that will be her place. And, like I said, the provider wasn't happy with us, about this, I think probably because she felt that we weren't letting her do her job (Ann, mother of Lucy).

*Supporting self-determination.* Families described transition as a time when they were striving to release some of their parental roles and support their sons and daughters in making (or participating in making) their own decisions and choices. Along with the release of control came a responsibility to step back, observe, and then step back in as necessary – constantly monitoring, always striving for balance.

And I decided like to just step, another step back. I didn't know if what I had worked out with Deb was truly reflective of her needs or if I hadn't projected on. You know, it's like, I had come to my style with Deb through my own trial and error. But it didn't mean it was the right thing. It was just what I thought. But I could be mistaken. So I stepped back and thought, Okay, Deb is agreeing to these activities. Let's see what happens....You're always rebalancing. Because you don't just stop from being the person who makes all the decisions. You're clumsy

and graceless about it sometimes. And what I've told people who are housemates is, you know, part of your job is pushing me out of the door....And I continually step back so that I'm not micromanaging. And now I feel like I need to watch that I haven't stepped back so far that Patty (support person) feels unsupported. That when she is feeling under water, I want me to be the first person that she calls (Helen, mother of Deb).

Families took risks in an effort to assist the young adult to achieve new levels of independence and when things didn't work out the parents experienced feelings of guilt. As Joyce states her daughter Sue's first experience living away from home in an apartment was challenging. "...but she didn't like it when it came to night time and the weekends. Loneliness was a big factor. I think it put more guilt on me than anything when I realized how lonesome she was. That was hard."

In another family acknowledging the need for relief from day to responsibility for the young adult also caused a sense of guilt.

And at that time too, I had [come]to the conclusion soon after she had moved out that you know, it wasn't a hard thing to have her move out. I really thought it was really going to just tear me apart. But I think we were both ready at that time for her just to be, try something new and go in a different direction. It wasn't until a couple of years ago, well, maybe this last year and I'm just second guessing myself now. Did we do the right thing? I know that there are times when she's not happy (Ann, mother of Lucy).

Striving to achieve balance required that the family let the young adult take the lead and speak for himself or herself and then act in a support role as needed. When David needed some medical testing done, Karen decided to let the professionals work with David without her, in an effort to have him speak for himself. "When he did the sleep lab, I said, I'm leaving him. You'll have better communication with him without me there. Because if I'm there, he always turns to me and waits for me to answer the questions" (Karen, Mother of David).

One mother identified the need for self-determination as a life skill necessary for her daughter's future well-being and safety.

Yeah, I could be killed. And everyone – and it can happen to anyone. And that's why I put the most energy into getting Deb to describe her own needs. Our focus has been to push Deb in situations so that she's the one who decides if someone is doing an incompetent job or needs to be fired. Because the day will come that I can't make the call. And the sooner Deb's able to make that discrimination, the safer she is (Helen, mother of Deb).

Parents indicated that they had achieved new levels of balance when they realized that they had new and different relationships and roles with their sons and daughters.

When Paul would visit his parents shortly after he moved into the group home, his parents related that he did not want to have to go back to the residential setting. Now they recognize that not only had he adjusted to his residential setting he was comfortable and happy. "He loves to visit – short visits and then he wants to go back to his routine...it's a lot like our other kids", "OK, mom and dad, it's great to see you but I'm out of here" (Rachael and Mark, parents of Paul).

With the release of having responsibility for day-to-day activities, some of the parents found that interactions with their sons and daughters became more congenial and less negative, as noted by the following quote.

You know, she'll sit there and tell people she loves them. She'd never do that with me. That's just happened this last year... We're driving along in the car, right down here on Elm as a matter of fact, and she says, 'you know mom, I love you a lot.' And I cried...I get to be the mom for the first time instead of sitting there and having to keep on her, always crabbing about stuff...the part that is different is that she wants to hang out with me, more as a mom/daughter/friend, and before she was always so mad at me (Teresa, mother of Janelle).

All of these families live within close geographic proximity to their son or daughter with a disability. While the experience of living away from the parents' home

was seen as a positive event, being geographically close was also important, so the family was readily available to respond and take action when needed. The physical location of the young adults home to the parent was also a consideration as families looked at the possibility of their own retirement.

Yes, we've had guardianship for Paul and it's now somebody who's our age- my brother. But we told our kids we don't expect them to ever have to take him into their homes to take care of him but they know they will always look out for Paul the way that we do now. And they're more than happy to do that. In fact they look after Paul now.... But the sort of longer term part of the deal is as we get closer to retirement age, there is well, where would you like to retire vs. well if it's outside of [this state], what do you do with Paul? (Rachael and Mark, parents of Paul).

Parent involvement doesn't end as the young adult leaves home it changes. It may mean less day-to-day responsibility, but it involves a need for the families to stay abreast of what is going on day-to-day, and always remain vigilant as circumstances change or the needs of the young adult call for change. In summary, parent involvement for the families who have a son or daughter with a disability is a multi-faceted and on-going responsibility, one that changes over time, and demands flexibility, but does not really reach a conclusion, as long as the individual with a disability is alive.

### *Theme Two – Vision*

The second theme identified within this study was that of vision. The dictionary definition of “vision” is “the act or power of anticipating that which will or may come to be” (Random House Dictionary, 1987). In generations past when there was little hope or vision for the future of individuals with significant disabilities, they were abandoned in institutions. It was a vision, that people with disabilities had worth and potential, that drove families to successfully advocate for the right of their children to a free and appropriate public education. That advocacy resulted in the passage of legislation that

eventually became IDEA '97. In addition advocacy efforts of this sort were the catalysts of the movement to close inhumane institutions and provide supported living opportunities to individuals with developmental disabilities. A clear and specific vision seems to be a powerful mechanism for actions families are willing to take to assure desirable futures for their sons and daughters (Turnbull, Turnbull, Shank & Leal, 1995). When the vision for the young adults' potential future lacks clarity or the resources needed are absent or delayed, the quality of life of the young adult may be tenuous.

*Fears.* The textual descriptions within the codes of fears, hope, expectations and advice revealed the family's visions for adult living for their sons and daughters. The fears families had played a part in developing a vision, in that the families were consciously aware that they wanted to create a life for their sons and daughters that was in direct opposition to their fears. Families spoke about a variety of fears including the death of the parents before the young adult.

Well my biggest concern is that I'll die before she will or Joe [father] will die. We've got our will in place and all that's set to go. But I don't know what would happen to Sue. That's still a scary one.... I know that several of my family members would take her but it isn't here, you know. So that would mean moving her clear across country. And I don't think that's what I want her to do. So that's one of those things we're still working on. You know, you just want them in a spot where you know they will always have a house and they will have some supports. And they will always have fun things in life to do. And then once that's settled, then you can die in peace. But I don't know how we're going to get to that point yet (Joyce, mother of Sue).

For another family the hope for the future rested with siblings. "My other concern is when John and I are gone what will happen. Who's going to watch over. But then you've got to trust that your daughter is going to step in and do what's right" (Michelle, mother of Alex).

In contrast another family related a desire to develop a plan that would relieve siblings of responsibility in the event that the parents were unable to provide support in the future.

It was probably about the time that she was 21 that this all sort of jelled for me and all came together and that wait a minute, there might not always be this little support over here that you can depend on or rely on. So you need to be thinking ahead here a little bit and what's going to happen when, you know, I'm 80 yrs old and Lucy's a grown up adult and hopefully still doing well. But maybe I won't be able to take care of her or her dad won't be able to take care of her and it's always been my thought that I don't want to put that on Frank's (Lucy's brother) shoulders (Ann, mother of Lucy).

Health and safety issues were among the other fears that families expressed.

And so it worries me if he did have diabetes, the chances for him getting, keeping his legs in later years would be really bad. It would be difficult for David. Very difficult. So we're trying to keep on top of those things (Karen, Mother of David).

Fear of a future that was without relationships and opportunities is a direction that families actively worked to avoid.

The nightmare is any one of our kids would be isolated and alone and unhappy and under challenged. And I fear that less now than I did before because Deb is more self-directed. She will complain; she will say no. And Deb would hardly ever say no until she was 15. You know she was just a pleaser. It was yes, that's fine; that's okay. I'm fine. And so it was really an achievement when she started saying 'no' to anything (Helen, mother of Deb).

In another situation a family expressed their fears in the following manner,

We didn't want to send him to a group home because we had heard all of these horrible things. You have all these pictures of all of these horrible things. He's not only going to be warehoused at SW (sheltered workshop), he's also going to be warehoused at the group home. That was our biggest fear. If we were forced to do something like that, that the quality of his care would be horrible (Rachael and Mark, parents of Paul).

*Hopes.* Hopes were the positive expression by families of a vision for meaningful futures for their sons and daughters. When families spoke about the hopes for the future

the conversations uncovered expectations that ranged from just staying safe to the desire for lives filled with supportive and loving relationships, opportunities to have their individual gifts recognized, utilized and appreciated and to be valued members of their communities.

In the following quote one mother described hopes that services for residential support would be available in the future, once the parents were unable to provide support.

She's happy just sitting around here but I don't want her sitting around here. I want her to get active because she sits enough in front of the TV. So it really creates more work for us to do and I feel a little frustrated. I've talked to the caseworker and said is there anything in the workshop she could do? And I said basically it's the same things that CP [adult services day program] can offer then. With her limited ability, she really can't do too much.... So I have her signed for a group home. Oh, since she was 18, so 6 years ago. They did call me about oh a year ago and said there was an opening. And I said 'no, I put our name on the list when we cannot take care of her. I really want to have her here and my husband does too. We just feel better about her being here.' Which I know, I don't know, maybe it's hard to cut the apron string. It's worse with her. Basically that's all that's going on around here then. Yeah because our life centers around her which is fine with us. We're happy (Carolyn, mother of Monica).

In another situation, a mother described a desire for her son to secure a job and realize the sense of accomplishment that employment can bring.

I would really like for Alex, somewhere to just find a job. I keep coming back to that. But darn it, some way, somehow, I think there's something out there for him. He's so eager to please and so enthusiastic and so ready for it.... So my hope for him is – I know he'll always stay where he lives because we own that and hopefully Bob will be with him but we'll just keep that. That's probably where Alex will grow old. It's a great feeling....and I just would like for Alex to stay healthy. He's very healthy. I would hope that that stays in place for him. And that he would have some sort of gratification for his energy. Somewhere to channel all of that energy into something that works for him down the road. I guess that's all I want for Alex. And safe – always keep him safe (Michelle, mother of Alex).

Several families noted employment as a hope for the future that would fulfill a need for the young adult to be productive, as noted in the following excerpt,

I'd like to see him have more.... intellectually he needs to be stimulated. So he needs the kind of job where he can be doing something with his mind but it also needs to be a short enough time period that he can take his mind and go with it where he wants to go.... The best hopes for the future is that he will eventually be able to hold down jobs. That there will be some sort of job open that he would be excited about doing. Jeff does best when he is excited about something. So that he would be able to have more of a full life than going out to CP [adult service agency's community participation program] everyday and coming back to his group home and sitting. Continue the growth (Carla, mother of Jeff).

Living away from home has provided one family the opportunity to develop a more adult relationship with their daughter and a sense of a more hopeful and positive future outlook.

And she is, she is progressing especially in the last 3 years. Being away from mom and you know and knowing that mom isn't going to be there to pick up the messes and to fix things. I think that she has come to the realization that well, okay, I don't maybe like this, but I know I can do it. And she has and she does. So she has grown as a person and it has been a good thing. It's been a good thing for both of us. The bottom line it is it has been. And I think it will continue to be. I don't know if maybe not with this provider but it will continue to be good thing. She needs to have that, that experience, that adult experience, that living away from home experience. She needs to do that. And as time goes and I'm beginning to discover some other options (Ann, mother of Lucy).

In the next quote Joyce expressed her hope for a community that would embrace her daughter and recognize and appreciate her gifts,

And I think the thought of having a place like Mary (another parent) talks about you know with one apartment and several other ones around.... I just think that somewhere down the road I think something like that would be possible. Where maybe you have a whole.... bunch of families and they are part of the neighborhood but there's somebody there to kind of keep an eye on them you know. That would be ideal. That would be the ideal setting. Whether or not it'll ever happen. But you keep pushing, keep hoping. ...That would be the ideal situation if I could find a spot like that where we had some retired people, some young people, some kids, some handicap adults but maybe the whole community kind of looking after you. And you know really it is not so far fetched (Joyce, mother of Sue).

One mother spoke enthusiastically of expansive dreams without barriers clouding her vision,

And I hope that she can just do anything. I'm hoping at some point we can live out of the country for chunks of time and that we develop a way for that to be possible for Deb. I'm hoping that at some point communication becomes simple enough that Deb writes. That she puts forth her experience so anyone can understand it. Because she is incredible, and I think anybody who got to see or understand it would be, well they would benefit greatly from her perspective. I think she's got a terrific capacity to teach us a lot. And I hope things come to a place where Deb is able to facilitate that for the rest of us.... I hope that she is able to fall in love and experience that idiocy and delight. There is nothing that I don't hope for her. I think that's possible. We've come this far. But it's all driven on Deb's desire because if she doesn't wish it, it will never happen.... The hopes are still blue sky. I hope that Deb will continue becoming a very self-directed woman who can make her decisions, communicate them and pursue them. That she would have her own friends and interests and that I hope that I get to be one of them (Helen, mother of Deb).

*Advice.* Additional details about vision were gleaned from the advice the families in this study would offer to families who were just entering transition. In the following example, much like her hopes for her daughter, Helen's advice to families is to dream and plan expansively.

Oh, I do have advice. It would be dream big. Don't imagine that you have this figured out. Don't imagine that you know what your child's future is. If your child has any sort of communication obstacles, you may have little to no idea what their capacity is yet. And the fact that they are in junior high and you still don't know, it means nothing. It means nothing. It's just persevere and dream big. Watch them for their interests, their passions and insert those elements at every opportunity and then stand back and watch and see what develops. Don't decide academic vs. vocational. Continue to offer both. Watch and see what other people are doing who have family members who have a similar profile. To look for mentors.... So anyway, for people to have, it's like seek out, find those examples that can show you what those possibilities are. Why would you try so hard if you always thought it was always going to be just like this? So seek out those stories, make connections with – it doesn't take a lot of people – it only takes one who can show you your possibilities.... So anyway, just don't imagine you know where your kid is going to go. Don't build walls. Don't think this is as far or as good as it's going to get. Don't do that. Suspend your disbelief and just wait and see (Helen, mother of Deb).

As related by Joyce in the following quote, learning from other families' experiences can be a helpful strategy.

And you have, you find other people that have gone through it. And you start talking and picking people's brains and pretty soon, you know, okay, this didn't work, but let's try this. It works out. It works out in the end. But it's not easy (Joyce, mother of Sue).

Some family's advice was to gather as much information as possible prior to the time of transition as noted in the following quote.

To gather as much information as possible from all the sources as possible. The next steps – the teachers at the school, the counselors at the school, PTI [parent information and training center]. To gather as much information so that when it all hits you like a brick you've got some padding underneath. Emotionally it's not anything anyone can prepare you for. And so to have the concrete, this, yeah you heard that this was going to happen so to gather as much information and to get as set up as possible. Knowing what other opportunities are out there even though you don't take advantage of them (Carla, mother of Jeff).

Another example of advising families to gather information was described as a process of asking questions and deliberately reflecting on the possibilities.

I would say start asking questions; start planning. Contact your agencies. Not only "BB" but maybe even just really be on top, if you are on a waiting list, find out where. Do you want to be on a waiting list? Are you interested in residential services? And find out what's available and what it's going to take to get onto that list. Seriously, seriously think about employment issues because we're just always painted this happy rosy picture and it just doesn't happen. It just doesn't. I would say, you know, really stop and think and really look hard at your young person's capabilities and their strengths and their talents. And see if there is some way that that can't be parlayed into an employment situation (Ann, mother of Lucy). Focusing on career opportunities was the advice offered by another family.

I mean that's (transition) the time to focus on jobs. Really start working on that job development. If you need some work on skills, let's get on it. And I think that's something that parents have to understand.... It's time for them to grow up and they're not little kids (Teresa, mother of Janelle).

In the following quote Rachael and Mark described the consequences of delaying planning for the future.

Have your ducks in a row...A guaranteed program some place. And plus we weren't ready. I think we were living in a cave. We just didn't get out there and visit everything and look at what was out there. We were naïve (Rachael and Mark, parents of Paul).

### *Theme Three – Relationships*

Families identified relationships as an important aspect of life, which helped the young adult in school, in work situations and in the community. When the relationships were positive and supportive, parents expressed feeling of success and satisfaction. When relationships were absent, the results were feelings of frustration and uncertainty as to what to do, or recognition that it was time to take action and make a change.

*Relationships in school settings.* In the following narrative a peer helper program provided a young man the supportive relationships he needed to be welcomed within the community of school.

There [in Junior High] were some really nice little girls that have now as adults in the community – we'll take Alex into a restaurant or grocery store – and one of these kids would invariably would say, 'I was Alex's peer helper when we went to Junior High'! So it had an impact on them as well. And I think that is really phenomenal. I just, they had to find the right kids though to be the peer helpers. Because you just couldn't take these kids out into a public school and have them behave and do the things you wanted them to do unless things were pretty set. His peer helper in high school was a great big huge guy named Tom who was on the football team. I have a video of them. And he was just cool. And he just became Alex's buddy and there he was. Alex hung out with the football team. Alex ate lunch at the football team's table. So he became accepted through his peer helper (Michelle, mother of Alex).

In the following account Helen described a period of time when the lack of relationships in the school setting created an unworkable situation for her daughter.

They sent her to a high school where nobody knew her. Not the students, not the staff and they didn't even have trained staff so she hung out there 2 years. And it

was just a source of great aggravation for 2 years and the third year, she finally just said 'get me out of here' (Helen, mother of Deb).

*Relationships in the work setting.* Relationships among co-workers can be an incentive for keeping a job as related in the next passage.

Yeah and I think when he decided to quit volunteering at the hospital, there was a change of staff. And the staff didn't make his job fun anymore. They said, 'okay, David, put these labels on'. He was putting labels in alphabetical order – file folders. And they just didn't, they didn't encourage him. They didn't treat him like a person. It was, 'here, come and do this work.' The people that were there before, he would dress up for them. He loved to wear a tie because the women at work would say 'ooh, David, you look great today.' You know and they really helped lift his self-esteem a lot. And then the next group didn't. And I think that was one of the reasons he was willing to give it up. (Karen, mother of David)

Karen continued the theme of the importance of relationship in the work environment through the following example.

Yes, he's worked there for 6 years when they first opened. It's really cool cuz the people at work also kind of are caretakers for him. Cuz when he's not feeling well, when he wasn't feeling well, they said we're concerned about David. He seems a listless. He's sitting down on more often, on the job than he was. So it's nice to have them.... But he just likes the people. Mostly that's why he works. He likes the people (Karen, mother of David).

*Relationships with support persons.* In the next example, Ann related the need for persons providing support to forge a relationship with her daughter and not make assumptions based on a disability label.

And for years and years we have fought that perception of this little round peg needs to go into this round hole. And it's just not going to work. And people just don't seem to follow though with that even people who work with our kids. Just perceive them all sometimes I think as having very similar capabilities or talents and that is not right. They need to take the time and make the effort to learn about each person and what their strengths are and what their talents are and how best to take advantage of those things (Ann, mother of Lucy).

The relationships that some of the families and young adults have benefited from are those of support providers. These individuals seem to share the families vision and

have established a personal commitment to the young adult and are directly involved in making the vision a reality.

If there's any opportunity out there that he [the host home provider] thinks there's a tiny little chance it might click with Alex; he's right there doing it.... He took him to San Diego for a month. He took him out and stayed with one of Bob's [host home provider] friends and stayed a month. I think first of all he really cares about Alex. That's A #1. I think because Alex is so happy; he has a relationship with Bob. They are just like best friends. Rick never refers to him in any other way but as his roommate. He says, 'Hi, I'm Bob, Alex's roommate.' He has a great deal of respect for Alex. He values him as a person.... And now he's just part of our family at every family function. It's always that Bob is included. He comes for Christmas; he comes for Thanksgiving. He's part of our family.  
(Michelle, mother of Alex)

In another example, through a supportive relationship a young woman was able to achieve a meaningful adult life.

And so the support that Polly [host home provider] gives I think is just consistency with routine and that that helps Janelle. 'We go to bed at this time; we get up,' you know. You have healthier food to eat by far than when she did when she lived in the apartment. That was always crazy. They cook together; they go do things together. Polly is a year younger than Janelle and it's wonderful. I mean it's just a wonderful match.... The family [providers family] has been very inclusive; Polly's family lives here. She goes with them. They have a cabin up in Rock Ledge and they take off and go up there and spend the night and you know they have family gatherings and Janelle goes with. They go down to grandmas down by Arcadia and Janelle went and spent a week down there with grandma.... I think Polly, when we've talked, she looks at it as just as much a benefit for her as Janelle. That's it's really two way, anyway. So that's been, you know, that's been great (Teresa, mother of Janelle).

#### *Theme Four - School Issues*

*Transition services within the high school.* Another theme supported in the textural description was school issues. Seven of the nine families involved in this study had young adults who experienced a "social graduation" from High School and continued with educational services from the school system through a community based transition program that was a collaborative effort of two public school districts. Only one of the

families related an experience with the transition from high school that met the needs of her son. Jeff *stayed* in a High School program until the age of 21 years old.

I think for us they did. I know for all people they didn't. Because we didn't ask them to do vocational transition. We didn't have him in CTP [community based transition program]. We weren't looking for them to find him a job or to get him out – we did do the “Next Steps Workshop” and all that. And they made sure his guardianship was taken care of and all that kind of stuff. .... I think they did okay with us because we didn't ask for the vocational things per se and the fact his two friends were with him was so nice (Carla, mother of Jeff).

Most of the other families indicated that the services in the school programs did little to prepare the young adult for their next environment. Four of the families gave a resounding “No”, in response to the question of ‘did the school system prepare you and your son or daughter for life after school?’ “No, I don't think it's real world”(Joyce, mother of Sue).

For one family the high school experience had few redeeming qualities,

Then we went to high school that was a total fiasco. People had no clue what to do with Deb. The paraprofessionals didn't know. Certainly the people that they hired in the resource room were clueless. I mean it was such a bad situation. I was angry for so long. ... Well, high school was the biggest disappointment ever. Even though Deb stayed 'til 21, but she did drop out for a year and then went back for the last year and a half. It was so frustrating and it really killed her quest for academic achievement. Junior High had been so great and then you know, high school was just a black hole (Helen, mother of Deb).

While Deb had had a wonderful experience in Junior High, the High School experience was a disappointment, and not a bridge to her future and adult living. In the following account Deb relates her feelings as her daughter went through the graduation ceremony.

And you know they had asked everybody to hold the applause and you know. But then when Deb went across, nobody held anything. The place became a roar. Even though there was that wonderful thing that happened, I sat there and I, my emotion was rage. I was so angry at what had happened at high school. You know Deb was

graduating and they weren't just giving her an attendance certificate (Deb graduated with a diploma). She had worked hard. She had learned a lot. She had done well. But I sat there and I was just angry. Just so angry. Junior high was the way it could have been. And to get to the place where people, when we first went into that building, (Junior High) they had never had a student like Deb. We'd prepped them well. We had a really well trained aide who worked excellent with each teacher... We had paved the way, figured out the way to do it. And it had been a success for Deb and for each of those teachers. They had all gotten so excited about Deb's progress, what they had learned as teachers and what other students had learned in class. I mean it was just one rosy glowing ball experience. And then to go from that to complete, you know, back to cave days. I was just in a rage. Quietly, nobody knew it. But I sat there and was pissed. That was our last day. She made it through but she could have had an education, and she didn't (Helen, mother of Deb).

*Personnel, self-contained classrooms, and funding.* Some of the families cited lack of trained personnel and self-contained classrooms as barriers to transition.

Chances are those people just tried to, I'm sorry, they tried to survive through their days. And some of the other people that were in his classroom were total medical, weak, fragile people. So much time was spent with them, dealing with them that anything we set up for Alex, usually was forgotten (Michelle, mother of Alex).

In addition, some families noted that lack of funding for adequate staff to support the needs of the students prevented transition progress. "And again, it was, because of lack of personnel and lack of funding, you know, they did the best they could with what they had available (Ann, mother of Lucy).

In the following situation the family described an instance where a trained professional seemed to lack the skills and knowledge to provide a successful transition experience.

They stuck him with a vocational teacher who just didn't have the background and was not prepared. They just didn't know what to do with him.... Yeah, he wasn't into a lot that was going on there. He mostly just sat around and fidgeted. And there was a student in the class that screamed a lot and in a small room where you have a screaming person, he was just agitated all of the time. And he had a teacher who wanted us to medicate him because she was having a hard time with him. So

in general the high school experience for Paul was not good (Rachael and Mark, parents of Paul).

*Lack of interagency collaboration.* In the following story Ann describes transition as a solitary process lacking collaborative interagency supports.

Up until she got into the last year of high school, I hadn't really thought about, oh gee, what's going to happen when she's not in school?...I just really felt that we were very much on our own. That we just had to figure it out because there was no one there to even give us a hint (Ann, mother of Lucy).

One mother indicated that high school was a very stressful period or time and as the end of educational services approached she felt that neither she nor her daughter were prepared for the next environment. Due to the stress of the situation, the mother also indicated that she might have been unable to benefit from any preparation the school personnel may have provided.

"I, you know, I don't know. For me it's hard to sit here and say - because they could have been saying things but I wasn't hearing. I mean so it could have been. My initial response would be no, they didn't do enough to prepare you for it" (Teresa, mother of Janelle).

*Community-based transition services.* The seven families whose young adults participated in a community based transition program reported varied experiences and expressed varied levels of satisfaction. As described by one mother in the next quote, the community based program provided her daughter with a variety of enjoyable experiences,

I would say the positive thing was the whole – her being able to exit at the same time as her peers. That she had been in high school with; had seen, hung out, rather than that staying there forever. I just – I don't support that for these guys. I think that they need to have that continuation and move on. She got to go through the graduation ceremonies with the graduation party. I mean all of that was wonderful for her and really had some closure. And then she went into CTP [a community based transition program]. You know she was really fortunate because that was when there was a lot of involvement with SS [local university]. And so she got to go to classes and you know, to class – she went to some of the classes

through the OT [occupational therapy] program; through the P.E. – physical education, and dancing (Teresa, mother of Janelle).

Teresa continued by reporting that having Janelle learn to manage the transportation system was seen as an achievement but the end of community-based services provided by the public school signaled the end of progress.

They were very inclusive so she you know – that was wonderful. That whole transition time. She really got the bus system down pat. She had already been riding that with the school and stuff but that's when they really started pushing that she ride on her own, home. She loves the bus now. She rides it wherever she wants to go.... the transition from there, from CTP [community based transition program] to adult services was awful (Teresa, mother of Janelle).

Transition planning is meant to assist young adults with disabilities to move from school to post school environments and achieve positive outcomes that match their interests and preferences. As noted by the following account, service delivery beyond the age of twenty-one was not always a seamless transition.

Then she graduated from HS [the high school] and then she went to CTP [community based transition program] for 3 years until she was 21. And you know she really liked that group. She had a buddy – she had a girlfriend, RT, something like that. And they would get along so well. They would just look at each other; not say a word and the two of them would just giggle. Neither one was much of a communicator. But people had told me how the two girls would get along. They were such buddies.... I think RT went to the workshop before Monica graduated in January. So she was quite sad. They said she kept sitting by the door waiting for RT to come. And um, otherwise she adjusted well for the next few months. But then she graduated and then they had no place for her – “BB” [the adult service agency] - for Monica to go. She was on a waiting list. And so she was home with me for about 4 months (Carolyn, mother of Monica).

In addition, the adult services were not able to provide an environment that supported employment experiences, as had the school program.

But now when she was with CTP [community based transition program] they would take her once a week to a nursing home where she helped fold towels. And they said she was doing a good job. She would only be there maybe about an hour and a half or so. But she enjoyed doing that. And another time they had her filling

candy vending machines. That's what she did when she was in CTP [community based transition program]. They found more to keep her active in things she likes to do (Carolyn, mother of Monica).

Having positive experiences end and finding that adult services seemed less supportive was disappointing to families, as described in the following statement.

The transition from high school to CTP [community based transition program] was great. The people from CTP came over to a lot of separate meetings. They got to know Paul so they knew who he was before he came over. That transition was good... there were people there (community based transition program) that wanted to be with Paul rather than the other experiences... Paul is much smarter than people give him credit for. Even though he can't verbalize, it takes him a little longer to process things but they would ask him to do things and give him ample time to respond. And I think part of that too is that just, um, he wasn't being pushed and shoved... Then he was 21, they kicked him out and he was in SW [adult agency sheltered workshop] for six months. So we tried SLS [supported living services], which was a disaster (Rachael and Mark, parents of Paul).

The school based programs were able to meet some of the needs of transitioning students yet, they fell short in that they did not prepare students and families for life after the mandated services of the public school systems. Additionally, they were not able to create linkages to adult community services agencies and achieve a smooth transition from school to post school environments.

#### *Theme Five – Adult Service System Issues*

As families spoke about the process of transition for their sons and daughters several concerns surfaced. Some of the problems seemed to cluster under the theme of issues with adult service systems. Most of the families proceeded to engage with adult service agencies with vague or only partial knowledge of what to expect and who or what agency should be accountable for support services. While the transition from public

school to adult services is meant to be a bridge to adult living the experience was frequently seen as less than positive as demonstrated by the following account.

But I think the biggest thing after transition was the fact that she was coming up to her 21<sup>st</sup> birthday and we knew services were going to stop as far as school stuff. But, I just remember what was so stressful at this time was, where do we go from here? Who do we turn to? Who is going to tell us what to do or give us some help? Help us find a direction? That was the biggest thing because I knew stuff was going to change when she was 21 (Ann, mother of Lucy).

*Communication.* One of the specific issues that families faced was communication with personnel within the adult service system. Some families experienced uncertainty about who to get information from as noted in the following quote

One of the things – and this was the go around about his housing is that I’m never sure of who to call and talk to about anything. Because the staff at work gets their information about Jeff’s day from, whoever they get it from. The staff at the house [group home] all they can tell me is ‘well this was on the log’. The woman, the supervisor of the house that works out at BB [adult service agency] is hardly ever there. Though she does see Jeff because he comes to BB to go to work. So it’s hard to know who to talk to (Carla, mother of Jeff).

Another family related their experience with the lack of regular communication, resulting in a sense of being ignored.

When you get into adult services, you don’t have anybody to fight with because you know what they will do? They’ll ignore you. And they can ignore you forever. And they’ll pass you around forever. So you can never find anybody to fight with. I mean it is such a huge system and the way that they have it tied up, I believe, is that it just wears you out. I mean even with the SLS [supported living services] program and trying to deal with that. There is no consistency. People pass it on to someone else (Teresa, mother of Janelle).

*Waiting lists.* Many of the families experienced challenges and frustration with supports that were delayed, resulting in their sons and daughters being on waiting lists for services.

I’ll tell you about my transition – the bad thing that happened when we started dealing with adult services. I was promised SLS [supported living services]

services. And um, they kept saying, yup, you'll get it; yup, you'll get it. Janelle was already in her apartment...so they called and said sorry, you're not getting it; we don't have the funding. There's a waiting list (Teresa, mother of Janelle).

The lack of services resulted in families experiencing periods of time that were confusing and unproductive.

Things were going to change dramatically but again, from the time when we had first moved out here in '91, we had been told, 'Lucy when she is 21 yrs old, well, she's going to be considered an adult and chances are that she will move into a group home or she will move into a sort of sheltered environment and she will have a job and things will be so good.' Well, and of course here she was 21. And pretty soon 21 and we had the graduation from CTP [community based transition program] and we sat for like 6 months. And I had no idea. I thought okay, I'll just sort of keep her here at home and we'll just see what we can figure out. (Ann, mother of Lucy).

Many of the families in this study related experiences of needing to rely on their personal resources for extended periods of time. "After the end of high school, Deb as at home. "We didn't have like a day program. We just wung it on our own", (Helen, mother of Deb)

In the following example, Ann, expressed her sense of frustration after her daughter had been home and without services for six months.

So after about 6 months of that I thought, ohhhhh what am I going to do? I don't have the training to be a job developer. I don't job coach. I have no idea. Through little things that have happened in the past, I knew that she needed help finding a job and help maintaining a job. She needed a job coach on duty to help get her along there. So we just, it got to be time for her IP and I just practically begged BB [adult service agency]. I said I don't know where to go. I don't know what to do. Help us. (Ann, mother of Lucy)

One family spoke about how they juggled their work schedules when their son had no consistent day services.

I would let him sleep longer than if he was going to BB [adult service agency]. Usually he would get up around 8:30; give him a bath, gave him breakfast and then if I had some errands that I could run that were appropriate where you could

take Paul to do, then we might those kinds of things. Then we'd come home and if it was a day where we might have an hour or 2 of SLS [supported living services] time, we'd have to be here waiting for the person to show up if they showed up. If they didn't well, Paul would spend time in his room. I would have to cancel appointments.... Yeah, we started to think oh my gosh, maybe we're not going to ever to get a day program or how many years will this go on? Do we have put him in an unfriendly, undesirable setting to get the day program because it was started to be explained to us if he was living in a group home, there wouldn't have been this period of nothingness. You would have gone right into BB [adult service agency]. (Rachael and Mark, parents of Paul).

*Few choices.* Some families reported that after experiencing the effects of waiting lists, when services were offered they were not what the family really wanted for the young adult, but fearing the consequences of no services families sometimes agree to services that did not meet the needs of their sons or daughters.

So it did happen quite quickly. And it just so happened that this provider was the only one that CC [adult service agency] had available and so it was, in some ways, a little aggravating in that. And of course at that time we weren't sure we wanted to take the slot. We didn't want to lose the slot. That was important for us at that time. But there was not another opportunity to find another person or to interview another person (Ann, Mother of Lucy).

In the following situation one mother described her uncertainty about maintaining eligibility if she chose to limit the amount of time her daughter participated in an adult service agency program.

I only quit [my job] last August. And that's when they also, that's when we talked about cutting back her time to just 4 days. And they didn't want me to cut back. You know, I was keeping her home. And they said 'you know if you keep her home or have an excuse that she's not going to go this day, they're going to cut your time. You may be sorry because you know, who knows in the future you may want her to be going 4 days instead of'. Well it started out with 5 so we've cut that to 4 and I was thinking about 3 and they said 'do you really want to do that?' And I said 'well maybe I really don't want to do that, you know'.... I don't know. I'm afraid to take her out. I'm really at a point that I don't know what is the best for her. She was going for 5 days a week. And so I said she really doesn't need 5 days a week. So now we've got her down to 4 days a week (Carolyn, Mother of Monica).

*Instability.* In a variety of ways, families spoke about system constraints that made the transition to adult living difficult. When families were on waiting lists for services funding seemed to be the issue but, once money was available, the challenges did not end. Even after young adults were receiving funding for services, families experienced a lack of trained individuals available to provide services, and a high turnover rate among part time service providers.

You know I honestly, truly, thought ‘you know Sue will go into an apartment’. I mean really and truly this is what will happen. She’ll go in an apartment. She’ll have a roommate. They’ll have some supports and it’ll be really successful and everything will be fine.’ What a blow! So, then we backed off from that. No roommate. So then she’s in her own apartment. Okay, so then I think, ‘this will work. All of the supports and we’ve got it all in place.’ But this doesn’t work out either. No, you’re just too dependent on people you really can’t depend on. I mean you hire them and think, ‘Oh they’re great!’ Then they don’t show up (Joyce, mother of Sue).

Retaining supported living providers was a challenge for families and had emotional implications for the young adults.

And so she was home with me for about 4 months. And um, supported living services offered a one on one for Monica. I think that was a couple of days a week. So an individual would come. The problem was they’d last 3 months and then quit. And it takes Monica awhile to adjust and bond to these new people. And when she would finally feel it, they left. It was just so frustrating (Carolyn, mother of Monica).

Supported living services (SLS) were meant to reduce waiting lists for adult services but the program was not always a satisfactory solution.

It was the one (transition) afterwards from CTP [community based program] to nothing. Well, again, we got hit with that staff turnover type deal. Some lady came out and interviewed us and then quit 2 weeks later. Right, we always had somebody different. The whole SLS [supported living services] experience was horrible for the same reason. We dealt with 3 different people in that in short amount of time. Three different ones for Paul because of the turnover (Rachael and Mark, parents of Paul).

In the following story Paul's family related their concerns about SLS [supported living services] as well as uncertainty about residential services.

So we were on a waiting list for a group home but were not pushing. We were doing fine with him up until then. And then that 6 months really taught us a lot because Paul was going nuts cuz he was home all the time. We had SLS [supported living services] people. We'd line them up because I was working days and Mark was working, trying to work, trying to make appointments around these SLS people. And they would either not show up; they'd bail because Paul is a handful. Or the SLS coordinator couldn't find people that were interested in working with Paul. So we had all these SLS dollars and hours and we couldn't fill it. Yeah, the staffing levels have bothered me. That was the main thing too that we were concerned about putting him into a group home. The institutional thing – one person for a whole bunch of people. We have run into occasions where that's really been a problem. Usually it's 2 people, caregivers, to 5 men. But we went to that picnic we talked about ... So the lady, caregiver, that came with the guys from GH [group home] came by herself with 5 guys, figuring somebody there would help her. She said the person who was supposed to help her didn't show up. She said I'm so glad you guys came. Because we helped them watch, because it's on the lake – you could end up with somebody in the lake. But you know what we've seen those scenarios way too much (Rachael and Mark, parents of Paul).

Even when funding was available several families reported difficulty in finding services providers to fill the positions.

From last August, the beginning of August until February where we didn't have SLS [supported living services], we had the funding for SLS but we didn't have the employees. So for that amount of time Deb and I just had home care – those 11 visits a week. And the rest of the time we were unsupported (Helen, mother of Deb).

*Lack of trained personnel.* Beyond direct service providers not being dependable, some families reported that by the time funding trickled down to the level of direct service provision, there was not sufficient funding to hire skilled people. Those that were hired did not appear trained to work with individuals with significant support and communication needs as illustrated in the following quote,

But the SLS [supported living services] providers just didn't seem to understand that when you committed to a certain time, you came. They kept saying, 'well you

didn't give us enough training.' I think the main thing was a lot of the SLS providers were not trained enough in the field and Paul just intimidated the heck out of them. He was lower functioning than what their experience base had been and so he wasn't like, well you can go to the park and say 'let's play catch', or 'Paul, you stay here'. Paul just takes off (Rachael and Mark, parents of Paul).

The following is another example of the difficulties families experienced in hiring skilled service providers. "She had some providers that were wonderful and did that piece very well. But then there others that were – and I would say the majority were the others. But the good ones were very few and far between" (Teresa, mother of Janelle)

The themes uncovered through this analysis seem to suggest that families undoubtedly will be confronted with a variety of challenges as their sons and daughters transition to adult living. Yet, the development of a positive vision for the future combined with caring and supportive relationships can be the incentive to persist in seeking opportunities to achieve quality lives.

#### *Phase Four – Determining Meaning*

The last phase of data analysis is a description of the meaning, of the phenomena. The question this research sought to address was: How do families create a balance between the seemingly opposed life goals of supporting the development of self-determination and advocating for quality life opportunities for their sons and daughters with disabilities, while at the same time securing their own quality of life? In this study, rather than identifying conflict and internal struggles of managing the dilemmas the parents who shared their transition experiences seemed to have developed a vision for the future that did not put the two elements in conflict. Thus, the management of the dilemma was achieved through the alignment of family goals with desired outcomes for the individual with disabilities. In other words, the families perceived their own quality of life

in terms of the quality of the environments and supports they were able to assure for their sons and daughters who experienced developmental disabilities.

### *Managing the Dilemmas*

While the process of transition did create tensions, the source of the tension appeared to be located in the family striving for a vision of quality life for the young adult and garnering the resources to achieve the vision. The resources to support the vision included not only financial resources but also human resources in the sense of finding and engaging in interdependent relationships with service providers and other individuals who made a personal commitment to the vision of quality of life for the young adult.

Relationships between the young adult and other individuals beyond the parents provided additional stability to quality of life.

As noted in the literature review, Thorin et al., (1996) outline five dilemmas families face during the process of transition of their sons and daughters. Applying the findings of this study the dilemmas can be further grouped into internal or external dilemmas or tensions to be addressed by families during transition. These dilemmas are:

1. *Wanting to promote independence for their son/daughters with disabilities while meeting health and safety needs* (Thorin, et al., 1996). This is an example of an internal tension and relates to the theme of parent involvement. Families displayed constant vigilance over the health and safety needs of their sons and daughter while at the same time they found ways to honor both verbal and nonverbal desires of the young adults.
2. *Wanting to have a life separate from the individual with disabilities yet not losing sight of the need for long-term involvement* (Thorin, et al., 1996). This is

yet another example of internal tension, one that in reality never goes away as long as the young adult is alive. This reality influenced choices family made regarding careers, retirement and more frequent events such as vacations.

3. *Wanting to provide stability for the family and continuing to meet the challenges posed by the needs of the individual with disabilities* (Thorin, et al., 1996). Again this dilemma is one of internal tension. Realizing that they most likely will not outlive their offspring, families related a desire to secure the future for their sons and daughters with disabilities as much as possible. Most related that their experiences during transition taught them that securing the future would be an ongoing task subject to change. In addition, those families who have other children expressed a desire that they would be a source of caring support for the sibling with a disability yet, not carry a burden of lifelong responsibility.
4. *Wanting to do whatever is necessary for the young adult while avoiding burnout on the part of the parents* (Thorin, et al., 1996). Identifying the financial resources to recruit qualified individuals that would provide support to the young adult was noted as a critical component of successful transition to adult living in the community. Negotiating the maze of adult services, waiting lists, and coping with frequent staff turnover were examples of the external tensions to which families responded during transition. The successful transition of a young adult with significant support needs can be expensive both in terms of financial and emotional family reserves. Finding a balance of internal family strengths, and external resources (financial and human) seemed to be a necessary factor for achieving a quality transition.

5. *Wanting to promote high expectations for the individual with disabilities and still accept the individual as he/she is* (Thorin, et al., 1996). Developing a vision of a quality of life for a young adult with a disability caused families to constantly question that “which is”, measuring it against “what might be possible” and always temper it with what is communicated as desirable by the young adult.

The young adults in this study seemed to transition from school programs that were perceived by their parents, primarily mothers, as not adequately preparing the family and the student for adult living in the community. In addition families related that they were not adequately linked to adult services prior to leaving the school environment.

Families and the services systems they access do not necessarily share the same dreams for young adults with disabilities, thus families have to guard against settling for available services versus continuing to advocate and strive for services that match their vision for quality life. The dreams families had for their sons and daughters were not sought out and acknowledged by the adult service providers. This resulted in a perception by families that the adult services did not to have the resources and capacity to effectively meet the needs of these youth with developmental disabilities. The end result was a lack of collaborative planning between the educational system, the adult service systems, and young adults and their families.

The themes that emerged in this study describe efforts of families to achieve a positive quality of life for the young adult with disabilities. To achieve that vision of quality of life families sought the support of educational services and adult service agencies. If those proved to be insufficient, they advocated for changes or, in many cases developed alternatives among their own networks of support and utilized their personal

resources to arrive at suitable solutions to achieve a reasonable quality of life for their sons and daughters. Some examples in this study were parents who invested in property to secure a stable residence for the young adult. Other families made career changes, which allowed them to be the providers of direct support while services were delayed or to provide the services themselves rather than accept services they perceived as being sub-optimal.

The actions families engaged in reflected their belief in the inherent value of the young adult. That belief was at the core of the actions families carried out to match their belief with an equivalent lifestyle, or quality of life. The essence of the transition experience is that families go beyond filling in the gaps of the school and adult service systems. Families constantly monitor the living and work (or community participation) situations for their sons and daughters. They seek creative options when the status quo does not adequately provide the quality of life they envisioned for the young adult. They go beyond advocating and create their own options, rather than wait for things within systems to improve.

## CHAPTER FIVE

### *Quality of Life*

A key to understanding the motivation of families striving to achieve positive transition outcomes rests in understanding the vision families develop for the young adult's future. The vision itself is rooted with in the context of quality of life theory. The following section describes the concept of quality of life, its' theoretical underpinnings, definition and use in the evaluation of programs and services for persons with disability. The section also explores quality of life and its' contribution to understanding transition from the perspective of parents who live the experience.

#### *Theory*

The concept of quality of life developed out of Optimal Theory (Myers & Speight (1994). The theory grew out of the need to have a comprehensive framework for understanding issues of diversity such as gender, race, ethnicity, class, and age within the field of psychology. Optimal theory has its roots in the tradition of African culture and emphasizes the interconnectedness of all humanity and that each individual is a unique embodiment of the human life force (Myers, Speight, Highlen, & Cox, 1991). Myers & Speight (1994), explain that societies operating within an optimal framework strive to achieve balance between spiritual and material aspects of reality, as a means of achieving a sense of self. "A key tenet of optimal psychology and these other alternate worldviews

is the inseparability of the spiritual and material aspects of reality in which all is seen as the individual and unique manifestation of infinite spirit” (p. 58).

In contrast societies described as sub-optimal base their sense of themselves on external criteria. This gives rise to “isms” such as classism, materialism and sexism. Myers & Speight (1994) suggest that a sub-optimal worldview fosters the belief that one criterion is better or superior to another, such as male and female, or the color of skin, or cultural variations. The result of this orientation leads to efforts for domination, control or oppression.

Optimal theory framework, rooted in humanistic principles and spirituality, is the basis of the work which viewed an individual with a label of disability as a contributor and valued member of society as opposed to views that portrayed an individual with a disability as someone to be isolated from society, segregated, pitied or fixed. Most notable are the works of Nijre (1970) and Wolfensberger (1983) in which they develop the principle of Normalization and practices to support the concept in the lives of individuals with disabilities.

Within the concept of Normalization persons with disabilities have access to the same opportunities and environments as typical citizens (Nijre, 1970). Through Social Role Valorization, (SRV) Wolfensberger (1983) expanded the concept of Normalization to include persons with disabilities having not only access to opportunities and environments but additionally, developing social relationships and being seen as persons assuming valued roles in the community such as, employee, voter, and neighbor. With the influence of SRV and Normalization advocates and family members began the movement to “de-institutionalize” and assist persons with disabilities to relocate from institutions

and segregated settings to residences, employment and adult living in community settings.

Yet, simply changing the place of residence does not assure improved quality of life in the community. In fact, decentralizing services without policies and procedures that support full inclusion in community environments, access to generic services and the development of social relationships, can inadvertently be as isolating and dehumanizing as any large congregate facility (McVilly & Rawlinson, 1998).

The families involved in this study appear to have values that align with Optimal Theory. It is evidenced in the language they use to describe their sons and daughters and in the efforts in which they engage to secure opportunities for full life for the young adult within the community. The follow two quotes provide examples of the manner in which the parents described their sons and daughters. "She's outgoing; she's friendly. She loves to be involved. She's not afraid to come and ask somebody a question." She's just a friendly outgoing young lady." (Joyce, mother of Sue). And similarly, another mother stated, "I have this delightful 26 yr old daughter...(Teresa, mother of Janelle).

Families expressed hopes for the future in which their young adults were valued members of their communities. Joyce envisioned her daughter living in an intentional neighborhood, as part of the community,

I just think that somewhere down the road, I think something like that would be possible. Where maybe you have a whole[neighborhood], like where Jim [former teacher] lives, Aspen Grove. You know, you have a whole bunch of families and she is part of the neighborhood but there's somebody there to kind of keep an eye on her you know. That would be ideal. That would be the ideal setting. Whether or not it'll ever happen. But you keep pushing, keep hoping. (Joyce, mother of Sue)

Michelle indicated that the dreams for her son were not necessarily those of the agencies providing support, and because of that it was important that she and her family keep putting forth their vision for quality life. “You don’t ever accept, that they, whoever ‘they’ are. Whether it’s the schools, DDS [developmental disabilities agency] or social service – it doesn’t matter who ‘they’ are. You never, ever accept what they say if you know that you want something more for your child. And I live by that.

### *Definitions of Quality of Life*

The concept of Normalization was a catalyst for change in supporting quality lives for persons with disabilities. Several definitions of quality of life, as they relate to individuals with disabilities, have been presented in the literature. The difference between the definitions is primarily that of subjective versus objective measures. Some authors, such as Taylor and Bogdan, (1990) argue that quality of life is strictly a subjective matter such that persons having similar experiences may not view the experiences in the same manner and therefore the only valid view is that of the individual.

Felce and Perry (1995) take a holistic view of quality of life and define five areas of well being which need to be considered including, physical well-being, material well-being, emotional well-being, and productive well-being (Felce & Perry, 1995). Goode (1990) suggests that quality of life for any person is achieved when the individual is able to meet his or her needs in major life settings such as work, school, home and community as well as satisfy societal expectations in those same areas. Similarly, Karan, Lambour, and Greenspan (1990) suggest that quality of life is the ability to secure a lifestyle that satisfies an individual’s unique wants and needs. In addition, Edgerton (1990) maintains that cultural lifestyles and values also influence quality of life.

Proponents of quality of life (QOL) evaluation suggest that measurements be multifaceted and include measurement of program components as well as seek out subjective responses from those personally affected by disability and/or those closest to them such as family members (Halpern, 1993; McVilly, 1998; Parmenter, 1994). “The central idea of this orientation is simply that we can best judge the quality of any service by measuring the benefits experienced by consumers of that service. This approach is therefore concerned primarily with individual consumers. The vast majority of conclusions about services must arise from aggregation of the life experiences of the individuals receiving the services” (Conroy & Feinstein, 1990, p. 227).

While the families in this study were the ones who articulated a vision for their young adults, they listened to the desires of the young adults and took cues from the behaviors when they young adults could not put a voice to their wishes. Helen expressed some of her hopes for her daughter, realizing that the direction the plan took was primarily dependent on the desires of Deb.

I hope that she is able to fall in love and experience that idiocy and delight. There is nothing that I don't hope for her. I think that's possible. We've come this far. But it's all driven on Deb's desire, because if she doesn't wish it, it will never happen. It doesn't matter how many opportunities you put in front of her, if its' not something she wants, it won't ever happen. (Helen, Mother of Deb)

Similarly, Michelle demonstrated the need to attend to her son's behaviors as his form of communicating. “And Alex became really, really behavioral. And that was his way of letting us know, this isn't working. And he wouldn't be cooperative. He didn't want to go [to a school program]. He was unhappy while he was there.”

O'Brien (1984) proposed combining process evaluation, that looks at the day to day operation of services and is concerned with organizational procedures and policies,

with outcome evaluations, which evaluate what services actually accomplish for an individual. O'Brien defined five organizational accomplishments that promote QOL for persons with disabilities. The accomplishments are measured in reference to the individual's presence in the community, participation in activities, exercise of choice, the degree to which their competence is displayed and recognized, and ways in which their human rights and dignity are respected.

In their review of issues and methodologies for measuring quality of life McVilly and Rawlinson (1998) stated the need for objective quantification of quality of life in order to justify public expenditure on decentralized community-based services as opposed to more cost effective centralized services. They further predicted that failure to demonstrate a measurable improvement in quality of life could result in a return to more traditional institutional and restrictive programming and services. The issue of quality of life versus cost efficiency surfaced in a 1999 decision of the United States supreme court, in *Olmstead v. L. C.*, 119 S. Ct. 2176 (1999). The decision of the Supreme Court determined that denying persons with disabilities services in the most integrated setting appropriate was discrimination under the Title II of the Americans with Disabilities Act of 1990 (ADA). The Court ruling stated that, "Unjustified isolation...is properly regarded as discrimination based on disability...institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life...confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

While the importance of including persons with disabilities in QOL evaluations is documented (Halpern, 1993; Dennis et al., 1993; McVilly & Rawlinson, 1998), the issue of reliability among persons with intellectual disability to accurately answer questions and give useful information is uncertain (Hensel, 2001; Taylor & Bogdan, 1990). Several factors influence reliability including, the level of the individual's disability, their stage of development and their expectations based upon life experience and cultural factors (Borthwick-Duffy, 1990). The literature suggests that persons with intellectual disability tend to provide positive responses to questions and/or provide responses they believe the interviewer will receive favorably (Sigelman, Budd, Spanhel, & Schoenrock, 1981). In order to avoid or diminish the effect of respondent unreliability, evaluations should avoid yes/no formats, provide for interviewer training and gather proxy responses from persons such as family members, friends, and advocates (McVilly & Rawlinson, 1998; Borthwick-Duffy, 1990).

Halpern (1993) points out that personal choice is an essential element of quality of life and that persons who have not made many choices in their lives may need to be taught how to choose. Yet, provision of choice does not presume that an individual's choice should supercede responsibility of those who provide support to the person with disabilities. In some instances Halpern (1993) suggests that attending to a persons quality of life may mean making choices for a person who may be making choices that are detrimental to themselves or others. This view is shared by Edgerton (1990), as he stated, "It is clear that we cannot abdicate all responsibility for setting limits to an individual's freedom of choice. We cannot ignore risks to public health, nor can we ignore some kinds

of self-injurious behavior, and we must obviously draw the line at behaviors that harm others. But few instances are as clear-cut as these” (p.152).

For families in this study who have a member with a disability, the issue of quality of life is infused into the operation of the family system. Quality of life is a subtle yet powerful force influencing decisions and creating a sense of dissonance and recognition of the need for change when the current situation (whether it be a residential option or employment for the individual with a disability), seems less than acceptable.

The quality of life of the young adult and the parents (primarily reported by mothers) appears to be reciprocal. Perceive unhappiness in their son or daughter, was an indicator for families to examine the situation more closely and make a decision in order to address the problem. At times this creates feelings of guilt on the part of the parents, as stated in the following quote from Ann,

I have up and down days. It seemed like after a couple of years, all of a sudden it hit me that oh, I've taken my baby and shoved her out of the door. Oh my gosh! And there are times I feel really guilty for doing that. But then I stop and I think that if she was back here we would fall into the same bad habits that we were in before .... And I just know, you know, that it's better for her to be away to learn and grow and discover her own potential. She can do this and she needs to know that she can (Ann, mother of Lucy).

Several of the families expressed feeling of guilt as they made decisions for their sons and daughters highlighting the dilemma of achieving quality of life for the individual and preserving the parent's as well (Thorin, et al., 1996). These examples seem to support the concept as reported by Dennis et al., 1993, that QOL of an individual with a disability is linked to those closest to them, specifically, family members.

### *Work as a Component of QOL*

In considering QOL issues from a holistic perspective, it is important to examine the issue of meaningful and productive work. The quality of a person's work life can be viewed as a subset of overall quality of life. In examining work as a component of QOL Kiernan and Marrone (1997) state that work is an important aspect of adult living as it provides people with a mechanism for establishing identity, a place in society, economic independence, and access to a peer group. In addition, like QOL, the quality of work life can change over time as factors that influence job satisfaction change. The issue of job satisfaction changing over time was exemplified in this study when David, a young adult with Down syndrome chose to give up a volunteer position after his co-workers changed positions and the new employees were less inclusive.

I think when he decided to quit volunteering at the hospital, there was a change of staff. And the staff didn't make his job fun anymore. They said okay, David, put these labels on. He was putting labels in alphabetical order – file folders. And they just didn't, they didn't encourage him. They didn't treat him like a person. It was here, come and do this work. The people that were there before, he would dress up for them. He loved to wear a tie because the women at work would say ooh, David, you look great today. You know and they really helped lift his self-esteem a lot. And then the next group didn't. And I think that was one of the reasons he was willing to give it up (Karen, mother of David).

The relationships in the work environment were critical to the young adults in this study, keeping their jobs. The co-workers demonstrated caring and respect for the individuals who were employed. David's co-workers noticed a change in his work pace and were able to alert his family to a serious health concern. Janelle's co-workers chose to problem-solve among themselves as natural supports as opposed to relying on the intervention of a job coach. Sue's employer valued her skills and gave her opportunities to learn new tasks and thus experience personal growth in the work environment.

Carolyn described the type of work her daughter was engaged in while in a school transition program and she expressed some frustration and wondered why that same opportunity could not be afforded to her daughter through an adult service agency.

But now when she was with CTP [school transition program], they would take her once a week to a nursing home where she helped fold towels. And they said she was doing a good job. She would only be there maybe about an hour and a half or so. But she enjoyed doing that. And another time they had her filling candy vending machines. That's what she did when she was in CTP. They found more to keep her active in things she likes to do (Carolyn, mother of Monica).

Similarly, Michelle described her efforts to get her son Alex employed; "I just know that Alex is happiest working....I said why can't he stock vending machines? Why can't he work at a grocery store and stock shelves? Why can't he?" (Michelle, mother of Alex).

In this study, seven of the nine families expressed a desire or expectation that their son or daughter would work as a means of gaining personal fulfillment and having the opportunity to contribute to the community as a responsible adult. Work was a component of the vision these families had for a quality adult life for their sons and daughters.

It is critical to involve persons with a disability in decisions about identifying, obtaining and maintaining employment (Kiernan & Marrone, 1997). Yet, without experiences in varied work environments and with various types of work, young adults will not be equipped to make a fully informed choice (Halpern, 1993).

#### *Choice and Self-determination as Components of QOL*

As stated previously, being able to make choices is an essential component of QOL and for persons with developmental disabilities the skill of choice making may

need to be directly taught (Halpern, 1993). Choice making is also a fundamental component of self-determination. In a recent exploration of the relationship between QOL and self-determination, Wehmeyer and Schalock (2001), demonstrated that self-determination is a predictor of successful adult living and needs to be an educational outcome in preparing youth for successful transition. “The development and acquisition of these [self-determination] component elements is lifelong and begins early in life...As such, promoting self-determination as an educational outcome will require a purposeful instructional program, one that coordinates learning experiences across the span of a student’s educational experience” (Wehmeyer & Schalock, 2001, p.13).

While families did not use the specific term, self-determination, several spoke of the need to attend to the verbal communications and nonverbal demonstrations from their sons and daughters that indicated choice. As noted in the following quote one mother recognized that self-determined behavior was a critical life-skill worth teaching.

Yeah. I could be killed. And everyone – and it can happen to anyone. And that’s why I put the most energy into getting Deb to describe her own needs. Our focus has been to push Deb in situations so that she’s the one who decides if someone is doing an incompetent job or needs to be fired. Because the day will come that I can’t make that call. And the sooner Deb’s able to make that discrimination, the safer she is (Helen, mother of Deb).

### *Relationships as Components of QOL*

Karan, Lambour et al., (1990) state that quality of life and transition are lifelong concepts and highly personal. In addition, events of transition involve both planned and unplanned events and this type of change can produce stress. Social supports are a powerful mediator of life’s stresses and the presence of meaningful supportive

relationships can function to reduce the negative impact of stressful events (Karan, & Bothwell, 1997).

Among the most important relationships for young adults in transition is that with the parents. As stated previously, parent involvement is a key factor during the extended time period of transition.

#### *Aspects of Parent Involvement*

Wehman (1996) indicated that parent involvement is a multipart process for families who have a son or daughter with a disability. Wehman describes parent involvement during transition as having three aspects; first, demonstrating an awareness and knowledge of transition planning. The families who participated in this study indicated varied levels of knowledge about what to expect after services from the educational system ended. They also revealed varying degrees of specificity regarding transition plans and anticipated outcomes of transition planning and services for their young adults. While IDEA speaks of the need to provide training for families, school systems do not give high priority to parent training due to the need to focus on such issues such as teacher re-training, recruitment and retention. Families have few opportunities to learn about transition planning and frequently it becomes a hands-on learning process with families wishing they had started sooner.

The second aspect of parent involvement is following up, to assure that plans are implemented (Wehman 1996). The families in this study described the ongoing nature of parent involvement, the factor of constant vigilance over a long and unspecified length of time. If the transition plans for the young adult were unclear or lacking specificity

monitoring such a plan would be irrelevant. Transition plans with a clear focal point should result in focused monitoring efforts by families.

Wehman's third feature of parent involvement is accountability, assuring that transition plans are working and achieving positive outcomes. As the lives of these families unfolded, the role of advocating for appropriate supports and services is a key aspect of parent involvement and efforts to achieve desirable futures for young adults with disabilities. But an additional factor is the family's willingness and ability to provide hands on support whenever the need arises. Parent involvement as a factor in successful transition outcomes should not be misunderstood as a passive activity of observation. This study had shown that parent involvement spans a broad continuum from monitoring at a distance to providing direct support, frequently for a long and indeterminate period of time. The following quote from one mother describes the length and types of support necessary for her daughter during transition.

I say that [transition took four years] because of, because of the involvement that I had. To mean transition is that you go into the adult system and for Janelle to have the most amount of independence with the least amount of family involvement. I mean that's how I, I mean for her, that's how I kind of looked at it. And I was involved. I was actively involved for all those years when she was in an apartment. And so to me where I truly feel that piece had really happened is when she moved in with Alice [host home provider] (Teresa, mother of Janelle).

### *Relationships beyond the Parents*

For individuals with disabilities family members, friends, educators, para-professionals, and direct service providers are some of the people who are important as social supports. For individuals with limited communication skills it is critical that social supports are available to interpret and express the communicative intent of behaviors that indicate personal preferences (Karan, Lambour, et al., 1990). Likewise the events of

transition are stressful to families and other persons providing support to individuals with disability. It is important that programs pay attention to the needs for support of caregivers as well as to the individuals who need the support (Karan, Lambour, et al., 1990).

Families in this study described their interactions with other parents as an important source of support which allowed them to discuss concerns, compare situations, problem solve and in general act as an emotional support outlet.

These families also recognized the need for social supports for their sons and daughters; yet, they also found this to be a difficult task to achieve. In the following scenario one mother describes the events of a change during transition that resulted in the loss of a personal friendship, which seemingly could not be reacquired.

Then she graduated from HS [the high school] and then she went to CTP [community based transition program] for 3 years until she was 21. And you know she really liked that group. She had a buddy – she had a girlfriend, RT, something like that. And they would get along so well. They would just look at each other; not say a word and the two of them would just giggle. Neither one was much of a communicator. But people had told me how the two girls would get along. They were such buddies.... I think RT went to the workshop before Monica graduated in January. So she was quite sad. They said she kept sitting by the door waiting for RT to come. .... She needs a friend. I just feel so bad about her not having a friend like she had with RT. I had called T's and taken RT and Monica out for lunch and brought RT over here but it just still wasn't the same. RT just kind of sat there and didn't really talk. And Monica was just kind of one wording at her, you know. It was just a, it was kind of disappointing (Carolyn, mother of Monica).

Several of the young adults and families in this study had established relationships with individuals that were providing direct services. These relationships were critical to the quality of life for both the young adult and the parents. Families identified these relationships as a vital factor in creating and maintaining quality living situations.

I think first of all he really cares about Alex. That's A #1. I think because Alex is so happy; he has a relationship with Bob. They are just like best friends. Bob never refers to him in any other way but as his roommate. He says, "Hi, I'm Bob, Alex's roommate." He has a great deal of respect for Alex. He values him as a person (Michelle, mother of Alex).

For some of the families the thought of losing the connection with the service providers was their greatest fear as expressed by this mother,

Absolutely the concern would be living arrangements. What happens when we don't have Polly? Will we be fortunate enough that because of Polly that there's a network out there that someone will step up and say you know I'd really like to do this with Janelle (Teresa, mother of Janelle).

Another mother expressed a similar concern, "number one, [fear] if we lost Bob [service provider]. How do you replace that? And that's always a possibility"(Michelle, mother of Alex).

Other supportive relationships which families identified were extended family members such as grandparents and cousins, and friends from church who had established a relationship with the young adult. Establishing relationships that support the young adult as well as the parents demonstrates the need to attend to the concept of interdependence as a priority.

The experiences of families who have a son or daughter in the process of transitioning from school to adult living indicate that the process is lengthy and intensive. The families involved in this study pointed out that transition is a continuous process of planning, implementation, observation, evaluation and balancing the details of their own lives (e.g. careers, use of financial resources) with those of their son's or daughter's, to ultimately achieve a integrated quality of life for the entire family (See figure 1).

## Integrated Quality of Life

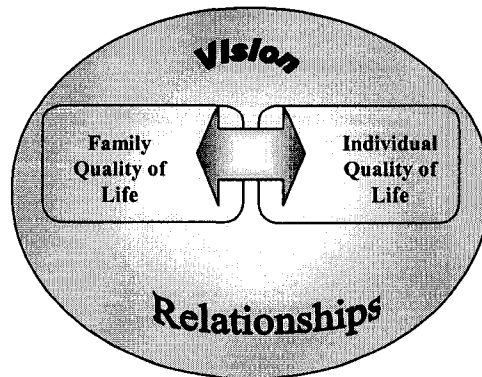


Figure 1. Integrated quality of life

Families continuously monitor the quality of everyday life, while also striving for long-term quality of life. The long-term quality of life (QOL) appears to be tenuous and dependent on the family achieving a quality of life for the young adult that can be maintained in the future, even if the parent(s) are no longer alive. The future stability of the QOL of the young adult seems dependent on an actual and articulated vision for adult living in the community combined with achieving relationships with people who will commit to taking on the challenge of the supports necessary to maintain the vision.

The experience of transition can be viewed as a critical and extended time in which families are trying to secure a reasonable quality of life for the young adult and garner available resources to support the effort. The process can be likened to a journey, one in which the initial path on which the journey began has to change due to washed out bridges (lack of available resources), unforeseen barriers (confusing rules and regulations), multiple detours (changing support personnel), and limited supplies (limited human services and few employment opportunities). The result is a trip that takes much

longer than expected and may result in an entirely different destination than initially targeted. The process is frequently very solitary in nature, forcing families to rely on their own ability to maneuver complicated adult service systems, depend on the family resources to achieve quality outcomes, and live with the unsettling reality that solutions are tenuous in nature and can change at a moments notice.

The supports that have been in place to date in school transition programs are failing to prepare families and young adults for smooth and successful transition to adult living in the community. And the adult services designed to assist families and young adults fall short of providing supports that achieve a high quality of life, as envisioned by families. The result is families striving to piece together supports, invest personal resources, and juggle multiple roles and responsibilities to support their sons and daughters to achieve positive futures. None of the families interviewed related having achieved their ideal, as evidenced by the fact that many families stated a continuing hope for employment in a community setting or expressed fears regarding the tenuous nature of residential settings.

#### *Conclusion and Recommendations*

Families in this study were going beyond filling in the gaps in the school and adult service systems. These families were constantly monitoring the living and work or community participation situations for their sons and daughters. They were seeking creative options when the status quo did not adequately address the needs of the young adult and the family vision for a quality life. They went beyond advocating and created their own options, rather than wait for things to improve.

### *Barriers to Successful Transition*

As perceived by parents, young adults in this study transitioned from school programs that did not adequately prepare and link them to resources in the next environment and adult living in the community. In addition adult services did not seem to have the resources and capacity to effectively meet the needs of these youth with developmental disabilities. Both school systems and adult service systems appear to be struggling to survive amidst competing demands. The end result is a lack of collaborative planning between the systems and inadequate services to young adults with disabilities.

#### *Competing Demands within School Systems*

Curriculum in secondary school is currently focused on assessment and accountability (Darling-Hammond, 2000). School districts are directing their resources towards academic courses designed to result in higher test achievement (Perkins-Gough 2000). Transition is frequently viewed as a separate piece of curriculum and teachers struggle to infuse transition requirements into academic classes through contextually based coursework (National Transition Network, 1997; Heumann & Warlick, 2000).

#### *Competing Demands within Adult Service Systems*

Adult service systems are struggling to recruit, compensate and retain workers for direct service work such as job coaching, job developing and providing direct support in residential and community settings (Bradley, Taylor, Mulkern & Leff, 1997). Direct services workers report little opportunity for training and leave after a short period of time in jobs that have little promise as a career (Braddock & Mitchell, 1992).

Schools and adult service systems have little motivation to collaborate as was envisioned by the transition requirements of IDEA because both environments are

struggling financially and the workload continues to grow at a rate higher than the increase in the number of service providers. For families, this results in waiting lists or accepting services that are not what they would otherwise choose. The pressure to accept services under the fear of not getting any support is demonstrated by the following description,

But when Paul turned 21 and he had nothing and we had nothing – it was a real eye opener. Yeah, we started to think oh my gosh, maybe we're not going to ever to get a day program or how many years will this go on? Do we have put him in an unfriendly, undesirable setting to get the day program because it was started to be explained to us if he was living in a group home, there wouldn't have been this period of nothingness. You would have gone right into GH [residential program] (Rachael and Mark, parents of Paul).

#### *Recommendations*

While both school systems and adult service systems have made great strides towards providing inclusive settings in which students and young adults learn and live, work and recreate, the complex issue of appropriate funding must be addressed and resolved in order to achieve high quality of life for individuals with disabilities.

#### *Strategies that Promote Quality of Life*

Families, educational and adult service providers must seek out and implement strategies that support quality of life for individuals with disabilities. Strategies that promote QOL for individuals have the potential to provide the impetus for collaborative change within family, school and adult service systems. Among those strategies are:

1. Purposefully teaching skills of self-determination from an early age and across the life span (Wehmeyer, 1992; Ward, 1988; Field, et al., 1998).

2. Using person centered planning as an assessment tool and a means of establishing a vision for a positive future (Butterworth, Steere & Whitney-Thomas, 1997).
3. Recognizing the importance of providing families a multitude of opportunities in varied formats to learn about transition (Wehmeyer & Schalock, 2001).
4. Engaging families and individuals with disability labels as decision makers within educational and adult service systems (Connors & Epstein, 1994).

Self-determined individuals, their friends and families have historically spearheaded legislative changes that have resulted in opportunities for individuals with disabilities to have access to education, and employment and the right to full citizenship (Wehman, 1996). Individuals with disabilities need to learn the skills of self-determination, beginning at an early age, to be ready to direct their lives and make informed decisions regarding their futures (Ward, 1988).

In discussing “person centered planning” (PCP) it is important to note that the strategy is not a simple process of completing information on a designated form with predetermined questions or guides. The process can assist families in expanding their vision of outcomes, assist in expanding circles of support, and facilitating positive change. The impact of PCP is most significant when the participants are committed to change and share a common set of values regarding positive outcomes and life in the community for individuals with disabilities (Mount & Zwernik, 1988). With a positive vision of the future, families and young adults have meaningful goals to strive towards and achieve. Without a vision, the outcome is uncertain and more likely to be less than satisfactory.

Families, along with their sons and daughters, who have a clear vision of adult living that promotes choice, respect and opportunities to be contributing citizens, will be the catalysts of change (Wehman, 1996). In order to develop a vision for a positive future families need access to information about transition services, including post-secondary education, community based employment options, adult services systems, and other assistance programs such supplemental security income (SSI).

In addition to information, families and young adults need opportunities to expand their visions of the future. Finding adult mentors who are examples of individuals with disabilities living in their communities is one such strategy.

#### *Achieving Quality Life Outcomes*

Long-term involvement with an individual with disabilities is essential to ascertaining an accurate picture of quality of life (Edgerton, 1990; Hanley-Maxwell et al., 1995). Parents and other family members are the primary consistent thread throughout the lives of individuals with disability and as such need to develop on-going supports and services that respond to changing needs that support and enhance quality of life for an individual with a disability. Achieving quality outcomes for young adults with disabilities requires the combined efforts of families and those who support them (See figure 2).

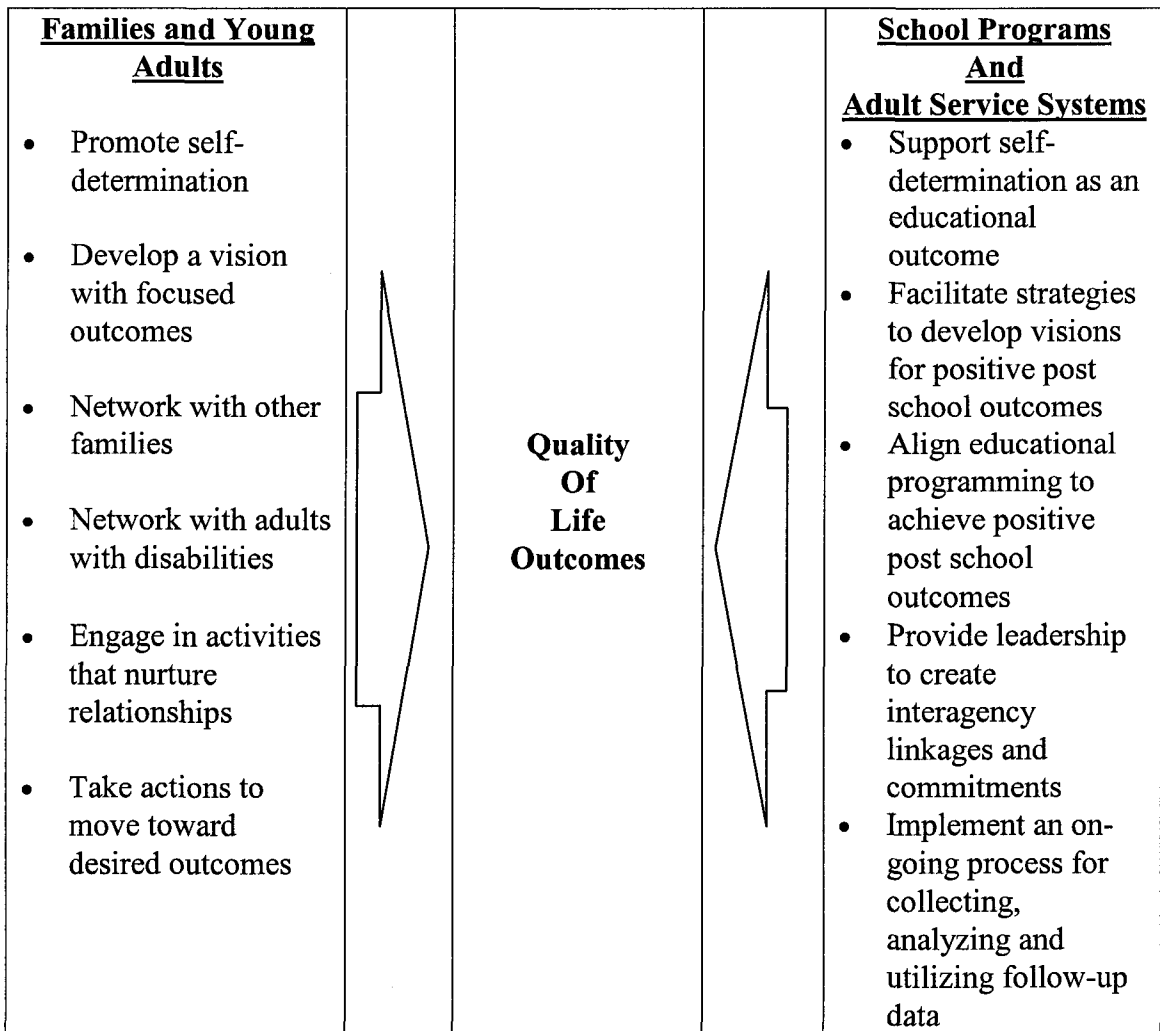


Figure 2. Collaborative Support for Quality of Life

The experiences of those involved in this study describe families as the “net” under school transition services and adult living supports. For young adults with active and committed families the future is secure until such a time as the parents are unable to provide any needed support or perhaps die. Not all families are willing or able to commit to such a demanding level of support. Transition services need to address these huge gaps and develop solutions for individuals with disabilities who do not enjoy the loving

commitment of family, as well as develop secure options when family members are no longer able (or choose not) to provide direct and ongoing support.

The challenge seems to be developing a vision for individuals with disabilities that is connected to the individual's interests and preferences and is supported by people who have committed to relationships, not just a paycheck or a job. Because educational and adult service systems plan for groups of people with disabilities and in contrast, families focus on an individual, total agreement in the manner of service delivery may never be achieved. None-the-less, systems that commit to the optimal theory of viewing individuals with disabilities will ultimately transition their practices to strive for quality life in communities. These future communities, as described by O'Brien (1993) would achieve outcomes that provide choice and participation, resulting in respect for and recognition of the contributions all its members.

In summary, the process of transition is complex and requires a commitment to quality outcomes for young adults with disabilities. The process requires collaborative efforts of young adults, their families and members of their circles of support including extended family, friends, acquaintances, educators and adult service providers, to plan and implement strategies that lead to positive future outcomes. Quality of life perspectives assist in understanding transition, from the point of view of the parents of young adults with challenges and can provide a framework for the development of programs designed to meet the needs of these young adults.

#### *Future Research*

This study builds on the work of Ferguson et al. (1988) and Hanley-Maxwell et al. (1995) by elaborating on the extensive time frame in which transition occurs and the

intensity of the roles that families play in the process. Future research should document the usefulness of specific strategies that support successful transition outcomes, such as person centered planning and student driven planning processes. While these seem like promising practices, until they are proven to support successful transition they will remain on the fringe of practice, available to only a few individuals and families. If the strategies are proven they should then become important components of teacher preparation programs and professional development programs for educators and adult service providers.

Additional research should explore the impact of school reform on transition programs and outcomes for youth with disabilities as well as families' perceptions of school reform efforts.

This study indicated that young adults with significant support needs depend on others, primarily family members, to monitor, manage and effect change, as they are generally not able to do that for themselves. Future research might explore how this compares to families who have typical adolescents and to families whose youth experience other specific disabilities to further illuminate the types of policies that need to be in place to support families' and youth in transition to achieve positive transition outcomes.

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## APPENDICES

## APPENDIX A: Steps to recruit participants

MEMO

TO: Debbie Lapp  
From: Romie Tobin  
DATE: May 8, 2001  
RE: Recruiting families for Dissertation project

**STEP 1.** Enclosed are the envelopes to mail to families who have young adults who have been out of the school system for a period of two to five years. Each pre-stamped envelope contains the following:

- Letter from me to the families
- Agreement to participate sheet
- Pre-addressed and stamped return envelope (for the participant sheet)

I need you to add the letter to the family, from Tim O'Neil.

I measured for the cost of postage per envelope and included a blank piece of paper to simulate the weight of the letter from Tim.

**STEP 2.** In addition I am leaving you a bundle of pre-stamped, reminder letters that need to be mailed week after the initial information. Please send it to all the families you sent the initial information packet.

Bottom line is you need two sets of labels to complete both phases of the recruitment process. After I hear from potential families I will notify you so you can inform the appropriate Foothills Gateway staff that some of the families may need some counseling support after the interview.

Thanks for all your help. Please let me know if you need anything else or if you have questions.

Romie Tobin  
736 Parkview Dr.  
Fort Collins, Co 80525  
(970) 226-2077 (hm.)  
(303) 866-6876 (wk)

**APPENDIX B: Letter from Researchers to Families**

Letterhead – Colorado State University

May 10, 2001

Dear Parent or Guardian,

Hello! My name is Romie Tobin. I am a doctoral candidate at Colorado State University in the School of Education. I also work for the Colorado Department of Education as a consultant for families and as a consultant in the area of transition.

As part of my doctoral program I am conducting a study of families' experiences about their son/daughter transition from High School. I have a specific interest in this research as my own son, Ben, is a young man with Down syndrome and is now 26 years old. The purpose of the study is to record the experiences of transition from the perspective of parents and guardians. The information will assist in the documentation of strategies that promote quality lives for young adults with disabilities as well as identify barriers to successful transition and how families cope with these challenges.

I am seeking parents of young adults with developmental disabilities who are willing to participate in an interview about their experiences during transition. I anticipate the interviews will take approximately an hour to an hour and a half. The information from the interview will be tape recorded and then transcribed for data analysis. All of the information from the interviews will remain confidential and will not be traceable to you nor your son or daughter.

Please complete the information on the enclosed stamped letter and return it within one week. After the letters are returned, participants will be contacted to set up a convenient time and location for an interview. Should you have any questions prior to completing the response letter please feel free to contact me at either of the following numbers, hm. (970) 226-2077 or wk. (303) 866-6876.

Sincerely,

Romie Tobin

APPENDIX C: Letter from DDS Director



## FOOTHILLS GATEWAY, INC.

Main Office: 301 W. Skyway Drive, Fort Collins, CO 80525 (970) 226-2345 Fax: 226-2613  
Support Services Office: 211 W. Magnolia, Fort Collins, CO 80521 (970) 416-9449 Fax: 416-5801



March 20, 2001

Dear (name of family)

Foothills Gateway, Inc. has agreed to assist in a research project about Transition by contacting families whose sons and daughters completed their educational program and have been out of school for a period of two to five years. Two CSU researchers from Colorado State University, (CSU), Romie Tobin, MS.Ed and Dr. Jean Lehmann, Ph.D. are conducting the research. Ms. Tobin now works for the Colorado Department of Education (CDE) as a consultant to families and as a consultant in the area of Transition. She is also the mother of a young adult with Down syndrome, Ben, who is now 25 years old. Ms. Tobin is seeking families who are willing to be interviewed about their experiences during the time their son or daughters were transitioning out of public education services and entering adult life. This project is being conducted by Ms. Tobin as part of her Doctoral Dissertation.

Enclosed is a letter describing the research and a pre-addressed and stamped postcard indicating your willingness to participate. Please note you are under no obligation to participate in this project. Thank you for considering this opportunity to assist in expanding the understanding of families' experiences during the process of Transition.

Sincerely,

Timothy S. O'Neill  
Executive Director  
Foothills Gateway, Inc.

### **MISSION STATEMENT**

*The mission of Foothills Gateway, Inc. is to facilitate a coordinated community effort dedicated to challenging and supporting Larimer County citizens with developmental disabilities to achieve their maximum potential and independence.*

APPENDIX D: Participant Response Form

**I am willing to participate in the study:**

**TRANSITION TO ADULTHOOD:  
EXPERIENCES OF PARENTS OF YOUNG ADULTS WITH  
DEVELOPMENTAL DISABILITIES**

**NAME** \_\_\_\_\_

**ADDRESS** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_ **ZIP** \_\_\_\_\_

**PHONE NUMBER (S)** \_\_\_\_\_

**Best times to reach me:**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

(Letter included a stamped return envelope addressed to the researchers)

APPENDIX E: Reminder Flyer

# Just a Reminder !

Approximately one week ago you received information about a research project involving parents of young adults with developmental disabilities. If you plan to participate but have not yet responded please do so by completing the information sheet and mailing it to the researchers immediately. You may also contact the researchers directly at the following numbers.

**Romie Tobin**  
**(970) 226-2077**  
**or**  
**(303) 866-6876**

**Jean Lehmann**  
**(970) 491-5169**

# Thank You !

## APPENDIX F: Consent Form

TITLE OF PROJECT: Transition To Adulthood: Experiences Of Parents Of Young Adults With Developmental Disabilities.

PRINCIPAL INVESTIGATOR: Dr. Jean P. Lehmann, PhD.

CO-INVESTIGATOR: Romie Tobin, Ms.Ed.

CONTACT NAME AND PHONE NUMBER FOR QUESTIONS/PROBLEMS:

Dr. Jean P. Lehmann, PhD  
Director of Graduate Programs  
School of Education  
(970) 491-7661

PURPOSE OF RESEARCH: The purpose of the proposed study is to understand the process of transition (life beyond high school) from the perspective families whose sons or daughters experience Developmental Disabilities, and to explore how families manage the challenges of transition and the perceived effectiveness of their efforts.

PROCEDURES/METHODS TO BE USED: You will be asked to participate in an interview with, Romie Tobin. Romie is one of the researchers and the parent of a young adult with a developmental disability. The interview will take between one hour and an hour and one half. The interview will be audio taped and then transcribed, word for word. All of the tapes and transcribed pages will be kept in a locked storage for five years at Colorado State University (CSU). After five years the tape filament and the typed pages will be shredded and placed in the trash.

RISKS INHERENT IN THE PROCEDURES: During the interview you will be asked to discuss you dreams for your son or daughter. You may choose to not answer any of the questions asked. The discussion may cause you to feel emotions such as fearfulness of the future or grief of lost dreams. If you experience this type of emotional stress during or after the interview you may contact your Case Managers at Foothills Gateway, Inc. The phone number is (970) 226-2345. All of the case managers at Foothills Gateway, Inc. have been informed about this project.

It is not possible to identify all potential risks in research procedures, but the researchers have taken reasonable safeguards to minimize any know and potential, but unknown, risks.

BENEFITS: The interview process may result in an opportunity to review and report the successes as well as challenges you have encountered in parenting a young adult with a label of developmental disability. Your information may benefit other families who have children with disabilities. The lessons you have learned about transition will be used to inform transition practices and services in the future.

**CONFIDENTIALITY:** No real names will be used to identify the location of this study, nor will real family names be used. In this way none of the information will be traceable to you, other members of your family or other families participating in the interviews.

**LIABILITY:** The Colorado governmental Immunity Act determines and may limit Colorado State University's legal responsibility if an injury happens because of this study. Claims against the University must be filed within 180 days of the injury. Questions about participants' rights may be directed to Celia S. Walker at (970) 491-1563.

**PARTICIPATION:**

Your participation in this research is voluntary. If you decide to participate in the study, you may withdraw your consent and stop participating at any time without penalty or loss of benefits to which you are otherwise entitled.

Your signature acknowledges that you have read the information stated and willingly sign this consent form. Your signature also acknowledges that you have received, on the date signed, a copy of this document containing 2 pages.

\_\_\_\_\_  
Participant name (printed)

\_\_\_\_\_  
Participant signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness to signature (project staff)

\_\_\_\_\_  
Date

APPENDIX G: Family data form

**Family Data**

Name \_\_\_\_\_

Date of Interview \_\_\_\_\_

Student's Date of birth \_\_\_\_\_

Residence of student \_\_\_\_\_

Other family members

Name	Age	Location of residence
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

**Highest level of education:**

Mother \_\_\_\_\_

Father \_\_\_\_\_

Family Income (check one)

20,000 – 40,000/yr

\$40,000 – \$60,000

\$60,000 - \$80,000

\$80- - \$100,000

Over \$100,000