

Autism and Transition to Independent Living:  
Exploring Changes in Family Functioning  
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Paper presented at the annual conference of the  
Association of University Centers on Disabilities  
October 27-31, 2002  
Bethesda, Maryland

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#### Introduction

According to Taylor (1987) all persons, despite the severity of disability, belong in the community. Supporting people with disabilities to acquire community living as an alternative to institutions is a commitment by both advocates and policymakers. Community based programs effectively foster independence and participation in the community for Americans with disabilities, and such services advance the best interests of Americans. Unfortunately, funds allocated for community based services are extremely low in most states.

For example, within Kentucky's Supports for Community Living (SCL), assisted independence options for adults with disabilities are nearly nonexistent. According to Kenning (2001), Kentucky ranks 48th in spending on the mentally retarded and 50th spent on community based services. The result has been aging parents struggling to care for their disabled children; working parents unable to find day care; and disabled adults trapped at home, bored and isolated, because of lack of services or work programs. Nearly 2000 individuals with disabilities are on a waiting list for services and 7000 are living with parents who are 60 years old or older (Yetter, 2002b). Thus, a major group currently denied community services are individuals with severe disabilities who live at home with their families (Lakin, Hayden, & Abery, 1994).

Callahan and Garner (1997) note that family is the foundation of support and security for many individuals with severe disabilities. Adults with disabilities live with their families or continue to have their families involved in their daily lives (Mallory, 1995). What role does the family play in obtaining community services for the adult?

The family is often most attuned to the individual's specific preferences and can communicate to others his or her visions and preferred options (Turnbull, Blue-Banning, Anderson, Turnbull, Seaton, & Dinas, 1996). Adults with disabilities have relied upon their own family to advocate when necessary. In a study that examined student perspectives of family involvement, students cited parents, brothers and sisters, aunts, uncles, and grandparents as people they rely on for assistance in securing long term supports, employment, and housing (Morningstar, Turnbull, & Turnbull, 1995). Thus the extent the family becomes involved may largely dictate the number of options and opportunities that will be available for individuals with severe disabilities during adulthood (Callahan & Garner, 1997).

Because of shortages of services, and because individuals often need their family to advocate for them, the family must actively pursue community supports and services. But this requires that the family has the wherewithal to "work the system" so as to attain these supports and services. This set of empowerment skills (Hagner & Marone, 1995) underlies the presumption that the families of individuals with disabilities hold the responsibility to seek comprehensive information about services and supports in order to establish independent assisted living. Yet it is clearly an open question as to how many families, and to what extent, actually possesses these empowerment skills (cf. Kosciulek, 1999; Lee, 1997).

Furthermore disability policy has provided little information regarding models and theories that develop ways to enhance empowerment (Zimmerman & Warschusky, 1998). Current ill-conceived disability policies (Hagner & Marone, 1995) reflect the scarcity of useful paradigms for determining factors that influence consumer empowerment and quality of life. In contrast, increased family empowerment is critical and leads to increased community integration and quality of life among people with disabilities (Kosciulek, 1999). Thus, if independent assisted living is the goal, then families and individuals must become empowered in order to obtain services and gain more control and quality over their own lives.

Finally, Mallory (1995) states, that the developmentally disabled (DD) individual's transition phase and its respective impact on the family have not been adequately addressed or acknowledged within the context of social policy. The impact of disability policies must ultimately be measured by the degree to which they contribute to the improved quality of life of people with disabilities (Kosciulek, 1999). Yet little is known about the transition to adulthood for developmentally disabled individuals. This general statement applies to the likelihood that DD adults will attain community assisted living, the impact on the family during this transition period, and the emotional loss for the individuals involved. Those who would improve policies for developmentally disabled adults relevant to this issue clearly need better information on the dynamics of transition to community assisted living.

#### Purpose of the Study

The book *Independence Bound* (Marquette, 2001) offers insights into how a mother and her autistic son survived family crises as they journeyed through the transition phase (from school to adulthood) toward the goal of independent living. The book focuses on Marquette becoming empowered to seek assistance and create supports for her son as well as her own psychological self explorations with separation anxiety. Her perspective represents an insider's view of family structure and function and the struggle to access community services for the adult (Taylor & Bogdan, 1994). Designing an independent living arrangement for a man with autism, without the direct support of an agency, would seem to be risky, compared to the security inherent in state programs. However, it was the only alternative in this case, given current policies for adults with developmental disabilities, where shortages abound and these individuals wait for services or suffer from a lack of program coordination and funding.

The research value of exploring family issues in a case study such as *Independence Bound* comes from the rich detail of family life. These dynamics are both independent of state policy (families that have children with disabilities are destined to face the transition from school to adulthood) and related to those policies (the impact of shortages whereby those children wait on a list indefinitely). Unfortunately, in a system where few options are available and services are difficult to obtain, families who want independent living have no guide to follow.

Specifically, this study examines Marquette's (2001) efforts to establish independence for her autistic son while waiting for assistance from the Supports for Community Living state program. Marquette's actions and feelings during a major family transition are subjected to formal study: the details and supports that made community assisted living a reality and the psychological travail that accompanied these family changes. The analysis may add to the research base regarding transition to independent assisted living for developmentally disabled adults.

#### Policy Definition

On the national level The Americans with Disabilities Act (ADA) (1990) promotes the goal for persons with disabilities to live in community based settings, rather than institutions. The Supreme Court in *Olmstead vs. L.C.* (1999) confirmed that states must design and implement programs reflecting that policy goal. In addition President Bush's

Executive Order No. 13,217 (2001) on community based alternatives for DD adults buttresses these legislative and judicial perspectives. Supports for Community Living, the Medicaid funded program, is Kentucky's attempt to implement these policy initiatives from all three branches of government.

"Policy" as a term is ambiguous. Since there are many implied definitions of the word, it is important to provide a clear explanation relevant to the policy studied. This is certainly the case regarding who receives adult disability services and when an individual can anticipate receiving them. To help clarify, Guba (1984) offers eight definitions of policy. Several of these definitions could apply to this study, given the comprehensive nature of laws and court cases that are applicable.

Guba's (1984) first definition examines goals and intents of the policy. Congress delineated these in the ADA (1990). Guba's second definition depicts policy as "the accumulated standing decisions of a governing body by which it regulates, controls, promotes, services, and otherwise influences matters within its sphere of authority" (p. 64). This is consistent with the regulations in the Supports for Community Living Waiver as issued by the Cabinet for Health Services, Department for Medicaid Services. Guba's eighth definition, "policy is the impact of the policy-making and policy-implementing system as it is experienced by the client" (p. 69) implies policy-in-experience. Such a study would provide insight through interviewing clients or their families about their experiences while seeking independent living within the community-based alternative to institutions.

However, this paper focuses on Guba's (1984, p. 64) fifth definition, which examines policy as "sanctioned behavior, formally through authoritative decisions, or informally through expectations and acceptance established over (sanctified by) time." According to Guba the policy question for this definition is, "What expectations should be set for families who have an adult with autism who seek the goal of independent living during the post high school years, either as a priori prescriptions or as modified through experience?" (p. 68). For this study, the policy lens is families' reactions to the emphasis of ADA toward placing individuals with disabilities into the community to live rather than in an institution or continuing at home with the family.

#### Resources Versus Need

In Kentucky, the Cabinet for Health Services, Department for Medicaid Services established the Supports for Community Living program for residents who are Medicaid recipients. SCL is an alternative to institutional care for an individual with mental retardation or developmental disabilities. Applications for SCL services for an individual who meets the level of required care for the Intermediate Care Facility for the Mentally Retarded (ICF-MR) are reviewed at the time a program placement becomes available. At that time the Department of Medicaid Services determines the appropriateness of the SCL program services to meet the individual's need. Approval for these services does not guarantee that the service will be available or provided, nor does it guarantee eligibility to Medicaid benefits (Statement of Emergency, 2001). Currently, the SCL program has over 2000 individuals with disabilities waiting for services.

SCL offers an array of services which support the individual to remain in or return to the community in the least restrictive setting. Medicaid recipients within SCL program are covered by provider agencies approved by the Department of Medicaid which may include some or all of the following services: Support Coordination, Community Habilitation Service, Supported Employment, Residential Support Service, Community Living Supports, Behavior Support, Psychological Services, Occupational Therapy, Physical Therapy, Speech Therapy, Respite, and Specialized Medical Equipment and Supplies. (See Definition of Terms section below for meanings specifically related to assisted living.)

The individual or legal representative (family) shall be informed prior to admission to Supports for Community Living or an Intermediate Care Facility that SCL services are an alternative to ICF services and shall be given the choice between SCL and ICF services.

While the SCL program is designed to assist the developmentally disabled individual, the reality is that most of these people have great difficulty in advocating their need for the SCL services. Therefore, family members often have the full responsibility for seeking and obtaining services for the adult. Family members have typically acted in behalf of their child throughout the school years. In addition, many family members have been granted some degree of legal guardianship of their adult child.

The family's involvement is critical in obtaining services for the family member. Yet in a system where services are insufficient to cover all of the many individuals with disabilities, some families are left to discover on their own ways to find these services and services. There is no "one stop shop" that offers assistance and explains strategies that empower families. For the families who lack the necessary skills to seek and obtain adult services, the alternative for the adult with a disability is to continue living at home, waiting for services.

Even if a family is fortunate enough to find services to establish independent living for their DD adult, there is as yet no guide or developed research model that assists the family through the psychological aspects of this transition. Families have been so focused for years with their child's schooling that the transition years following high school come as shock and denial.

#### Definition of Terms

**Autism**--a brain disorder that typically affects a person's ability to communicate, form relationships with others and respond appropriately to the environment. Some people with autism are relatively high functioning with intelligence and speech intact. Others are mentally retarded, mute, or have serious language delays. For some autism makes them seem closed off or shut down; others seem locked into repetitive behaviors and rigid patterns of thinking. Although people with autism do not have exactly the same symptoms or deficits, they tend to share certain social, communication, motor, sensory problems that affect their behavior in predictable ways. Emerging in childhood, autism affects about 1 to 2 people in every 1000 and is three to four times more common in boys than girls. (Neuwirth, 1997, p. 3)

**Behavior Support**--"shall include systematic application of techniques and methods to influence or change a behavior in a desired way" (Statement of Emergency, 2001, p. 12).

**Community Habilitation Service**--shall be furnished in the community or a nonresidential setting and enable an SCL recipient to participate in a community project as a volunteer, access community resources, and utilize a variety of assistance and training to interact with the environment. (Statement of Emergency, 2001, p. 10)

**Community Living Supports**--shall facilitate independence and promote integration into the community for an SCL recipient residing in his/her home and provide supports which shall not be diversional in nature and shall include: 1. Assistance; 2. Activity training; 3. Laundry; 4. Routine household care and maintenance; 5. Activities of daily living; 6. Personal hygiene; 7. Shopping; 8. Use of money; 9. Socialization; 10. Relationship building; 11. Leisure choices; 12. Participation in generic community activities; and 13. Therapeutic goals. (Statement of Emergency, 2001, p. 11)

**Empowerment**--"refers to the ability to access and control needed resources, make decisions, solve problems, and interact effectively with others to obtain needed resources" (Dunst, Trivette, Gordon, & Pletcher, 1989, p. 132).

**Intermediate Care Facility**--An institution which specializes in providing an intermediate level of care to [developmentally disabled] clients residing in the facility. The intermediate level of care provided includes the provision of shelter, food (including special diets), laundry and personal care services and a program of active treatment if participating in the Medical program. (Health Care Programs, n.d.)

**Residential Support Service**--shall be twenty-four (24) hour support promoting integration into the community for an SCL recipient residing in alternative living arrangements and shall include: a. A staffed residence which shall be in a home rented or owned by the provided agency; b. A group home which shall be licensed in accordance with 902 KAR 20:078; c. A family home which shall not have greater than three (3) individuals who are not family members living in the home; or d. An adult foster care home which shall not have greater than three (3) individuals age eighteen (18) and over who are not family members living in the home. (Statement of Emergency, 2001, p. 11)

**Respite**--shall be furnished in a variety of settings on a short-term basis due to absence or need for relief of those individuals providing care to an SCL recipient unable to administer self-care that resides in a family home, foster home, or their own home and shall be limited to 1440 hours per calendar year. (Statement of Emergency, 2001, p. 12)

**Support Coordination**--"shall include coordinating, planning and monitoring supports for an SCL recipient and be provided by a support coordinator" (Statement of Emergency, p. 10).

**Supported Employment**--shall be intensive, ongoing support for an SCL recipient to

maintain paid employment in an environment in which individuals without disabilities are employed and shall: 1. Not be available under a program funded by either the Rehabilitation Act of 1973 or PL 99-457 proof of which shall be documented in the individual's file; and 2. Not include work performed directly for the supported employment provider. (Statement of Emergency, 2001, p. 10)

Supports for Community Living Waiver Program--This program was developed for Kentucky residents as an alternative to institutional care for an individual with mental retardation or developmental disabilities who meet the level of care criteria for placement in an Intermediate Care facility for Mentally Retarded (ICF-MR). The program allows an individual to remain in or return to the community in the least restrictive setting. Waiver recipients shall be allowed to retain from their own income for their basic maintenance needs an amount equal to the Supplemental Social Security Income (SSI) basic benefit rate plus the SSI general disregard. (Cabinet for Health Services, 1998, p. 3.1)

#### Literature Review

Providing direct care for an individual with autism or another severe developmental disability (DD) has become an increasingly difficult task as society changes. Several decades ago adults with autism were left under the care of a stay-at-home mother. However, the U.S. now has escalating numbers of individuals requiring direct care and fewer family members available to provide the needed care. According to Singer and Irvin (1991) societal changes have made the job of being a caregiver more difficult because of women in the workforce, increasing numbers of single parents, and the rise of poverty.

However, even as families find it more difficult to care for adults with DD, there is a critical shortage of services for these adults; this has become a daily hardship for tens of thousands of families in the United States. Families seek services and struggle to provide meaningful daily activities for their adult who has aged beyond school (Sullivan, 2001). These shortages represent a national crisis in residential services for adults with developmental disabilities, and especially to those with autism (Sullivan). For families contemplating the transition to community assisted living, this lack of services can be devastating.

But this realm of policy is relatively new and not widely understood. For policymakers and researchers, three areas of the literature are relevant to the transition to independent living for the young adult with a developmental disability. First, issues of family structure and function during the transition phase to adulthood for individuals with developmental disabilities are examined. Second, psychological stresses during this transition are explored. Finally, quality of life issues are related to access to community resources. These three areas all affect families' coping abilities during this transition process.

#### Family Transition Phases

Ferguson, Ferguson, and Jones (1988) examined how families with children who have disabilities experience their child's transition from childhood to adulthood. They challenged how professionals define transition as a single process that entails a shift from special education to adult services. For the families in this study, the findings revealed that transition is a much more complex process. The experience constitutes three distinct types of change associated with turning 21 years of age: (a) bureaucratic transitions, (b) status transitions, and (c) family life transitions.

Bureaucratic transition involves "the process whereby the agencies and professionals involved with a family change from representatives of the special education system to representatives of the adult services system" (Ferguson et al., 1988, p. 180). According to Callahan and Garner (1997) this transition may be viewed in a variety of forms:

1. the individual with a disability or the family surrender to the unquestioned expertise of the professional and the decision-making power of professionals
2. the family representing the individual accepts that no help is available
3. the family assumes the role of professionals because other forms of support are not available
4. the family interacts with professionals to achieve outcomes that are supportive for the individual with a disability. (pp. 55-64)

The guarantees of the Individuals with Disabilities Education Amendments Act (IDEA, 1997) often turn out to be a spot on a waiting list or the opportunity to enter a sheltered workshop.

The second type, status transition, is the "process as constructed by the parent whereby the status of a son or daughter changed from child to adult" (Ferguson et al., 1988, p. 184). "Children" become adults and begin to establish an increased level of independence and autonomy (Callahan & Garner, 1997). This is difficult and confusing for the family. The family has often been told in past years that their son or daughter probably would never achieve any level of independence and certainly would never be capable of seeking a job or living independently. This non-independence has been difficult for parents to accept. Now as expectations to include individuals with disabilities into society have improved, parents are being asked to readjust their goals. "[P]arents are being asked to alter long-standing assumptions concerning their relationship with their children" (Callahan & Garner, p. 60).

Ferguson et al.'s (1988) third type, family life transition, focuses on changes in family structure and function due to leaving high school. For special needs students, this milestone represents potentially wrenching adjustments compared to regular education students. The changes in family structure frequently produce overwhelming stress. For example, major life events such as death, divorce, loss of a job, economic stress, and daily hassles can become chronic stressors when confronting and handling the adult's problematic behaviors (Singer & Irvin, 1991). Strategies that have been identified to help families cope with these tensions include time for parents to be alone together, to spend with their other children, to be with their child who has a disability, and to participate in family activities.

#### Autism and Stress on the Family

The family who has a child with a severe disability may experience confusion anger, helplessness, and feelings of depression (Konstantareas & Homatidis, 1989). Increased demands to care for a child with a disability place stress on families. As an individual with autism or other developmental disabilities enters adulthood, normal tensions are compounded for both the family and the individual with the disability. As Marquette (2001) noted, when facing transition with her adult autistic son, "I remember the difficult times when I felt completely overwhelmed, unable to see past my present circumstances" (p. 23).

Sharpley, Bitsika, and Efremidis (1997) report there exists a distinct lack of understanding about autism among the general public as compared with other disabilities such as Down syndrome. This can lead to opposition or a lack of tolerance toward the inappropriate and sometimes aggressive behaviors which children with autism often exhibit.

Gray and Holden (1992) indicate parents often experience great difficulty parenting a child with autism and trying to live a normal family life. Parental anger, depression, and anxiety are often linked to the gender of the parent and the level of social support they receive. Parents need social support and services. However, Sharpley et al. (1997) indicate that services to provide assistance to parents are often insufficient to meet their needs. In addition, they report that parental stress raising a child with autism was shown to contribute to illness.

A study of 219 parents of children with autism was conducted by Sharpley et al. (1997) to determine whether parental well-being (anxiety and depression), daily stress, and being stretched beyond limits arose from parenting an autistic child. The independent variables were parent gender, age of child, parental health, access to other family members, and level of understanding of the child's problems by family members (p. 19). The study defined social support as assistance which provided respite for those immediate family members who handled the day-by-day demands of parenting the child with autism. Mothers reported a higher amount of stress than the fathers, due to the likelihood of the mother as the primary care giver (64.4% of the respondents were female). When parents reported their capability of handling their child's behavior, 81.9% were sometimes stretched beyond their limits. Nearly half (46.4%) reported these feelings from 1 to 5 times per month. Both parental well-being and the presence of family members who had a clear understanding of the child's difficulties produced a significant main effect, i.e., parental ill-health negatively affects the dependent variables while understanding reduces the various stress related measures. In contrast, having access to other family members for respite did not significantly reduce the stress measures. In effect, it was the degree of understanding (empathy) that was crucial, not the family assistance per se.

#### Family Empowerment

There is a distinct disconnection from the community for families with a developmental disability because of problems related to their care-giving role (Covert, 1992). Unfortunately, when families and individuals seek services or activities, their choices are based on the availability of services or on the avoidance of undesirable alternatives. In other words, their choices may not be their true preferences (Kosciulek, 1999). Family empowerment can be important when providing support services to care-giving families. Empowerment is defined by Stein (as cited in Kosciulek, 1999, p. 203) in terms of internal/psychological and situational/social aspects.

The internal/psychological factors include a sense of control, competence, confidence, responsibility, participation, solidarity, and community. The situational/social aspects of empowerment include control over resources; interpersonal, work, and organizational skills; decision-making powers; self-sufficiency; mobility; and "savvy" or an ability to "get around" in society.

Problems that families face can affect their empowerment, e.g., fatigue, smaller than usual amounts of leisure time, negative reactions from people in the community to their son or daughter with disabilities, and a lack of access to the normal methods of creating social contacts (Singer & Irvin, 1991, p. 279). Parental beliefs about the stressors they face are strongly related to how well adjusted they are as a family (Singer & Irvin, p. 281). Families exhibit different coping styles; some could be considered proactive while others are reactive and occur without conscious planning. The range of styles includes active problem solving, avoidance of problems, and efforts to manage emotional reactions to problems such as living one day at a time.

The families that use active problem solving tend to be more successful in their caregiver role (Singer & Irvin, 1991). Taking this into consideration, another approach to reducing stressors in families is helping parents improve their problem solving skills and change their cognitive views. Turnbull (1988) suggests reinforcing family coping skills as a means of reducing stress. This helps empower families to make and evaluate choices based on their own standards.

Singer and Irvin (1991) show that families who perceive adequate availability of community resources have a higher degree of general life satisfaction and are better able to cope with stress. For example, Cole and Meyer (1989) surveyed parents of 166 students with severe disabilities to identify those community resources that were utilized by families. Families who had access to more external resources were capable of choosing in-home placement for their child until age 21, which was an indication that the families' caregiver role was not seen as overwhelming.

The community resources that were most highly correlated with plans for in-home placement were various forms of respite care, for both in-home and out-of-home situations; fiscal resources for medical expenses; and the availability of professional expertise from physicians, dentists, and special education consultants. Parents find public services most beneficial when they offer a wide range of individual choice and flexibility (Knoll & Bedford, 1989). Accordingly, the availability of community resources and the match between the family perceptions of what they really need and what they actually receive are two important variables which impact their adaptation to the role as caregiver (Singer & Irvin, 1991).

Dunst, Trivette, and Cross (1986) found that in order for the connection to the community to be perceived as satisfactory, there must be a match between the families' perceived need, the kind of support they receive, and who gives the support.

#### Emotional Loss

Progress has been made in developing principles and strategies that promote the self determination and the inclusion of people with disabilities into the community. But rarely do professionals or leaders in the field of disability discuss how an adult with a disability and with limited resources impacts the lives of the people around him or her. Seldom do researchers address how fragile caregivers or the family can become while caring for their disabled adult and desiring a normal life experience for him or her.

Often when families find services they are urged to place their disabled adult on a waiting list. During that period, families often feel closed and trapped. Families anticipating services are shocked when they find out how isolated and dependent they become. Life does not stop after the age of 21. The family's provision for the adult

requires intense support, often causing the family increased stress and despair (Covert, 1992).

There has developed a considerable literature dealing with emotions and loss generally. It remains the case, however, that emotional loss related to special needs children has not received much attention. Kubler-Ross (1969) first identified the stages of grief during the process of working through a loss. She studied how dying people accept death, the ultimate loss. Since then, mental health professionals have observed that people go through these stages whenever they face any loss. The loss could be a five dollar bill, not receiving an expected letter--or it could be significant--divorce or the death of a spouse or loved one (Beattie, 1987). Accepting the loss requires that one progress through the following five stages: denial, anger, bargaining, depression, and acceptance. Through grief, one experiences intense feelings such as love, sadness, fear, anger, relief, compassion, hate, or happiness.

Murray (2002) examined loss and grief in adolescents, noting that grief is often the result of confronting the possibility of one's own death or illness as well as another's. In addition, she stated that experiencing loss in other areas of life can produce grief. Some other examples include rejection by a group, victimization, limited intellectual and physical capabilities, and negative family circumstances. Others who have written on grief and loss include Bowlby (1961) on the process of mourning; Tyc (1992) on youth with disabilities; Parkes (1971) on the study of psychosocial transitions; Downey and Coyone (1990) on childhood effects of unresponsive parenting; Miller and Omarzu (1998) examining research on loss; Glick, Weiss, and Parks (1974) on bereavement; and Wortman and Silver (1989) on myths of coping with loss.

#### Denial

The first of Kubler-Ross's (1969) five stages is denial. When faced with a loss the individual experiences shock, numbness, panic and refuses to acknowledge reality. Often the individual responds to loss with statements such as "No, not me, it can't be true!"; "It's no big deal!" (to lessen the importance of the loss); or "I don't care" (denying any feelings of the loss) (Beattie, 1989, p. 122). Denial functions as a buffer when one experiences shocking news or events. It allows individuals to collect themselves and with time, mobilize other, less radical defenses (Kubler-Ross).

"In times of great stress we shut down our awareness emotionally, sometimes intellectually, and occasionally physically," explained Jewett (1982, p. 29). "A built in mechanism operates to screen out devastating information and to prevent us from becoming overloaded. We shut out our awareness of things that would be too disturbing to know" (p. 23), Jewett continued.

#### Anger

When individuals stop denying their loss or circumstances, they experience anger, which is the second stage. The first response to loss or catastrophic news ("No, this cannot be happening to me") has to give way to a new reaction, when awareness finally dawns: "Oh, yes, this is happening, it was not a mistake." Anger may be directed toward anything and anyone and projected into the environment almost at random. People may blame themselves, God, or anyone around for their loss (Kubler-Ross, 1969).

#### Bargaining

The third stage is bargaining. The individual makes attempts to avoid the inevitable, which is accepting the loss or facing catastrophic news (Kubler-Ross, 1969). Beattie (1987) explained, "Sometimes the deals we negotiate are reasonable and productive: 'If my spouse and I get counseling, then we won't have to lose our relationship.' Sometimes bargains are absurd: 'I used to think if I just kept the house cleaner, my husband won't drink anymore,' the recollection of a wife of an alcoholic" (p. 124). Kubler-Ross (1969) explains that most individuals do not keep their promises; in other words, they are like children who say, "I will never fight with my sister again if I can go out and play" (p. 95). In tragic circumstances most bargains are made with God to try and buy more time to live, or to take away the very thing that is causing pain or loss. Psychologically, promises may be associated with quiet guilt. The guilt needs to be communicated and revealed. For example, a mother overwhelmed with responsibility and caretaking may bargain with members of her family to assist her, thinking that if everyone did a part, the family could continue as it had functioned before. Therefore, the solution at the time for the overworked mother seems to be to draw help from others. Unfortunately, the "fix" for the mother is merely a band aid approach, appearing to ameliorate the solution. This permits the family to exist and function as before, but

only temporarily until another "crisis" occurs.

#### Depression

According to Kubler-Ross (1969) this fourth stage is mourning at its fullest, which is the essence of grief. When the individual finally recognizes that the bargain has not worked, he/she becomes exhausted from the struggle to ward off the reality. When the individuals make the decision to admit what life has conjured, they become sad, and sometimes deeply depressed. This stage of the process begins when the person surrenders to the numbing reality of the situation. The depression stage will end only when the process has been fully worked through.

#### Acceptance

Acceptance, the fifth stage, should not be mistaken for a happy stage. It is rather an accommodation to feelings. "It is not a resigned and hopeless 'giving up,' a sense of 'what's the use?' or 'I just cannot fight it any longer,' though we hear such statements too," explains Kubler-Ross, (1969, p. 124). According to Beattie (1987) this stage marks the time that the individual finally is at peace with what is. The person may not be comfortable with the circumstances and changes but believes some benefit may have accrued from the change or loss even if it cannot be fully understand how or why. The individual has accepted the loss, however minor or significant.

The stages of grief are not only normal but represent a necessary process. Individuals who face the reality of loss must first guard against the blows of life with denial until ready to deal with them. They must feel anger and blame until these feelings are rid from their system. Then they must try to negotiate and when that fails, depression awaits. Finally acceptance represents a catharsis of feeling. The person doesn't necessarily have to let the stages dictate behavior. The individual's well being and full acceptance of loss is dependent on time spent in each stage. Anderson (1981) writes,

Healthy are those who mourn. Only very recently have we begun to realize that to deny grief is to deny a natural human function and that such denial sometimes produces dire consequences. Grief, like any genuine emotion, is accompanied by certain physical changes and the release of a form of psychic energy. If that energy is not expended in the normal process of grieving, it becomes destructive within the person... Even physical illness can be a penalty for unresolved grief... Any event, any awareness that contains a sense of loss for you can, and should, be mourned. This doesn't mean a life of incessant sadness. It means being willing to admit to an honest feeling rather than always having to laugh off the pain. It's not only permissible to admit the sadness that accompanies any loss--it's the healthy option. (p. 11)

#### Quality of Life and Community Access

Access to the community increases quality of life for individuals with disabilities and their families. Rights are privileges that everyone in society should enjoy. "Personal freedom and control over one's life are cherished rights within our society" (Stancliffe & Parmenter, 1999, p. 107).

How is quality of life (QOL) measured? The composition of this concept remains controversial with little agreement concerning its precise definition (McVilly & Rawlinson, 1998). Quality of life is defined by Donegan and Potts (as cited in McVilly & Rawlinson) in terms of cultural standards and norms and with reference to the desires, needs, experiences, and aspirations of the individual. Characteristics that reflect quality of life for nondisabled individuals are the same criteria that reflect quality within the lives of individuals with disabilities. Choice and control are essential to that quality. Thus, having personal freedom to choose and the option to control one's life are major factors exhibited within an individual's independent life (Stancliffe & Parmenter, 1999).

Participation within the community is another aspect of quality (Lakin, Hayden, & Abery, 1994). Dalrymple (2001) reports that being comfortable and accepted within the community means being treated as an individual. Being part of the community means having the opportunity to interact and form relationships with other community members (Kosciulek, 1999). To be part of the community is to be a family member, neighbor, schoolmate, friend, church member, shopper, coworker, and significant other (Kosciulek). Being part of the community implies belonging, which means being a member of clubs, organizations, and associations as well as being a consumer of services. It means being known as an individual, or a unique person. It does not, however, carry the burden of being labeled, a ward of the state, a client of an agency, or the recipient of another's

altruistic acts (Taylor, Bogdan, & Racino, 1991, pp. 253-258).

While individuals with disabilities have these same human needs for belonging and participating, for choosing and exercising control, many individuals with developmental disabilities such as autism require some assistance and various supports in order to participate within a community activity or community setting. Furthermore, an individual with a disability may require assistance and supports in order that independent living is a possibility. Dalrymple (2001) offers a view:

Their needs can appear to be too great. However, their needs are not so different from those of others. They may require more time, more patience, more planning, and more understanding. They often do not respond well to time or social pressure. Each individual with autism requires a commitment and willingness from those who interact with them to individualize and learn about them. Sometimes people with autism can advocate for themselves, if we listen. Often they need someone to help them. (p. xvi)

Unfortunately, the belief among society and some adult service providers is that individuals with autism are not capable of employment or living independently (Smith, Belcher, & Juhrs, 1995). This same belief can be extended to most adults with a variety of developmental delays. However, with necessary supports provided to the individual, full integration into the community is possible.

Ed Roberts, a leader in the disability movement, provided a definition of independence and a way to view supporting individuals with disabilities in independent living. He affirmed that independence should be measured according to the extent of an individual's quality of life. He further suggested that independence should be measured by the quality of one's life with adequate supports, not measured by the tasks one performs without assistance (as cited in Ward, 1996).

When community services are lacking and include long waiting lists, the individual's quality of life is negatively impacted. Individuals and their families are dependent upon a choice of options and opportunities that positively impact one's quality of life. If no activities outside the home are available for the adult with a disability, the individual often becomes increasingly engaged in repetitive activities. For example a certain number of adults with autism have had tendencies to dominate the life of their family with increased repetitive-obsessive behaviors. The longer the behaviors occur, the less the person may become interested in leaving the home (Wing, 2001).

The solution for both the individual with autism and the family is an appropriate residential service that offers community participation and activities (Wing, 2001). Serious problems exist with respect to adapting the individual to the community for families who have not been able to access services or who have had no other choice but to keep their adult at home beyond the age that most young adults typically leave to reside in the community (Hayden, Spicer, Depaepe, & Chelberg, 1992). Limited services may affect family functioning when no other options for their adult with a disability are provided.

#### Community Access and Costs

Providing community services to individuals with developmental disabilities has increased their opportunities to live in typical neighborhoods, grow and develop, and enjoy inclusion, by making choices in their social and economic lives. Realistically, this struggle has just begun, for a majority of individuals with developmental disabilities who still live in institutional settings or remain in the home waiting for services (Lakin et al., 1994).

Many adults with developmental disabilities are living with elderly parents who fear for their children when they die or become unable to care for them (Yetter, 2002a). Sullivan (2001) claims, "Agencies report a constant stream of calls from parents crying (sometimes literally) for help for their child (young adult living at home without services)" (p. 2). Sullivan continues:

When a family can no longer handle their relative at home (for example, because of no or inappropriate services, divorce, death of a spouse, illness, old age), negative behavior escalates, people and property get damaged, the use of psychotropic drugs increases and, not uncommonly, physical restraints are used. At this stage, clients--especially those with autism--are too often abused and injured. Some have died. Parents are desperate. Aging caretakers (often single mothers, often living alone with their middle-aged child), knowing how difficult it is to adequately care for an adult with autism, are often prisoners in their own homes, with little or not relief in sight. (pp. 5-6)

At a time when demands on families are increasing, government is providing little in the way of assistance or support (Covert, 1992). The most critical issue (to providing residential services in the community) is woefully inadequate funding (Sullivan, 2001). "People are just kind of struggling and hoping to hang on till their number comes up," said Maureen Fitzgerald, director of the Kentucky Division of Protection and Advocacy (cited in Yetter, 2002b, p. A3).

The costs of providing community living services for an individual with a developmental disability are significantly lower than provision of care in an institution. Yetter (2001) reported the operating costs at Oakwood, an institution in Kentucky. The annual budget for a 400 bed facility increased from \$29 million to \$41 million. To provide residential services for one individual at Oakwood costs approximately \$102,000. Kentucky spends nearly \$50,000 a year per person in the Supports for Community Living program, according to state auditor, Edward B. Hachette, Jr. (cited in Yetter, 2002a). Concerns of the programs regarding efficient use and management were reported. Yetter (2002a, p. A1) reports Hachette as saying, "The Medicaid-funded program could serve at least 100 more people if it were better managed." Providing community based services through the Supports for Community Living is the costliest per person served among similar programs in eight Southeastern states (Yetter, 2002a, p. A1). Thus the cost of \$50,000 per person appears on the high side. However, even at this rate, placing individuals with developmental disabilities into the community requires half the costs of institutionalization, offers individuals increased opportunities to experience control over their lives and to experience the dignity that comes with community living, and in many instances facilitates supported employment opportunities.

#### Summary

For the young adult with autism or other developmental disabilities, the literature substantiates the need to explore family dynamics during the transition phase from high school completion to achieving community assisted living. Ferguson et al. (1988) examined family structure during this period, finding that the process is complex. Three distinct subtypes of transition were noted: bureaucratic (the operations of agencies and professionals); status (changes in degree of family control over the child's fate); and family life (internal changes within the family). A major factor is the stress within families living with autism or other disability conditions and how families perceive necessary supports for their child. Strategies for empowering the family are viewed as significant for establishing supports and services within the community. Studies on families with autism (e.g., Singer & Irwin, 1991) suggest that more knowledge about the disability conditions and about available community support services and resources leads to more effective proactive planning, and in turn to reduced levels of stress.

Families experience emotional loss when their child with a disability becomes an adult. In addition, families assume the lead role of searching and accessing community resources for their child. Handling emotional loss and responsibilities in care giving while searching for services are a tremendous burden. The increased stress on every member of the family can turn daily life into survival mode. The family's accommodation to these emotional changes can be viewed through Kubler-Ross's (1969) stages of grief: denial, anger, bargaining, depression, and acceptance. However, research is nonexistent regarding how the family living with autism or other developmental disability psychologically approaches their child's adulthood and how the family prepares to access community services and supports.

A key consideration is defining quality of life for the young adult with a disability (see McVilly & Rawlinson, 1998). Individuals with disabilities want and deserve the same things that normal folks do: freedom to choose and control daily life and participation in a community, including forming relationships with neighbors, coworkers, friends, and family. The key to all of these is independence. For individuals with disabilities the essential element is sufficient support to engage in these activities to the extent that they are capable.

But the supports and community resources necessary to allow individuals with disabilities to achieve independent, assisted living are simply not there. Only recently has society moved to make independent living for individuals with disabilities a reality. Adequate resources, governmental structures, and knowledge of the transition process are all lacking at this point. In Kentucky the Supports for Community Living program is virtually unavailable to the many individuals waiting for community services, and the lack of commitment by policymakers to fund mandated policies suggests this situation may

not change soon. Because current state supports and resources are not adequate, many families face the challenge of how to manage the transition to independent assisted living on their own. Findings within the literature indicate that families are dependent on services and supports in order to cope and function as a unit. Most importantly, families want services and support that will function for their adult child's benefit. Families want their young adult to enjoy a positive quality of life.

#### Methods

This analytic study (based on Marquette, 2001) explores one mother's journey through the transition phase into independent living for her son with autism. The paper focuses on changes in family structure and function within a milieu of statewide shortages of critical resources. Two perspectives are explored. Ferguson et al. (1988) provide a guide to changes in family structure during transition. In addition, Kubler-Ross's (1969) model provides the framework for examining the loss that is experienced as a family with a developmentally delayed young adult faces the transition from the protected environment of high school to the uncertainties that follow.

Identifying methods to determine how the family becomes empowered to seek and obtain independent living for the adult with autism within the political arena of limited state funds and few community services offers numerous areas of investigation. One possibility is studying the effectiveness of family participation with the professional team in school/agency meetings during the transition phase to adulthood. A different option for investigation would be to examine the student's connection to adult services after high school has ended. Another study could utilize quantitative survey methods to determine the variables that reflect the needs of a family during the transition phase. Lastly, it would be interesting to conduct follow up interviews with families two to three years after their adult's high school days ended to determine the patterns and themes that led to the family's success in achieving access to community living services.

Instead, this research represents a case study (Yin, 1989) of one mother's experience of the transition from high school to community assisted living for her autistic son, Trent. The study extracts pertinent information from the book, *Independence Bound* (Marquette, 2001), offering a glimpse into the reality one family faced as the mother worked to design independent living for her son amidst family crises.

This study necessarily depicts numerous events in Trent's life. One person in particular is central to his transition to community assisted living. A pseudonym is used to protect his identity. Others are identified merely by their role. All instances culled from *Independence Bound* are autobiographical in nature.

As indicated above, this is a policy focused study. Guba's (1984) fifth definition is utilized to guide the analysis: policy is the action of the persons who actually implement a formal set of policy guides. This restatement of the formal definition calls attention to the work/routines/strategies of the professionals who implement policy. But in the current case, where resources and statewide supports for implementing transition to assisted living for adults with disabilities are lacking, the professional is not the relevant figure. Instead, it is the parents, who are left to manage as best they can when the system is under funded and does not provide adequate assistance.

Accordingly, in this study, the policy question for Guba's (1984) fifth definition can be restated as: What are the expectations for families who have children with autism or other developmental disabilities when seeking independent living in the post high school years? The analysis searches for patterns from the story of a mother seeking and reaching the goal of placing her son in an independent living arrangement. Marquette's (2001) *Independence Bound* functions as a rich history of the journey she and her son experience, even though he continues to wait for community services from the SCL program.

The analysis itself is based on unobtrusive measures (Webb, Campbell, Schwartz, & Sechrest, 1966), specifically document analysis (cf. Berelson, 1952; Lindkvist, 1981). In particular, the analysis focuses on changes in family functioning. The document analysis protocol (see Appendix) was developed based on Ferguson et al.'s (1988) family structure model on transition and Kubler-Ross's (1969) stages of grief. Ferguson et al.'s third type of transition, internal changes in family life during the transition from high school to adulthood, is relevant; the first and second types of family transition are beyond the scope of the current study. Once the protocol statements were developed, the family experiences detailed in *Independence Bound* were examined vis-à-vis the Ferguson et al. and Kubler-Ross theoretical frameworks. The protocol statements guided the extraction of data.

## Results and Analysis

The policy question (Guba, 1984, definition 5) explored the concept of family behavior as a mother sought independent living for her adult son with autism. How did the mother handle grieving her loss and facing her fear for caring for her son's needs while waiting for SCL services? How did she become empowered to seek unknown and frightening options for community participation for her son within a system of critical shortages of services? For this paper Guba's fifth definition shifts from professional behavior to family functioning because ultimately it is the family who bears the brunt of the effort in the transition of a young developmentally disabled adult to assisted living. These family responses to the transition process are examined from the perspective of Ferguson et al.'s (1988) third transition type, family function, and Kubler-Ross's (1969) stages of grief.

### Family Life Transition

Ferguson et al. (1988) developed a model of change for families with special needs children who experience the transition from student to adulthood. Three distinct types of transitional process are identified: bureaucratic, status, and family life. The focus here is the third type, family life transitions, and the emphasis is on structural and functional changes during this period of transformation. However, as Ferguson et al. note, all three types are interrelated; in what follows, some of the overlapping between these domains is noted.

### Changing Structures and Networks within the Family

What structural changes occurred in Trent's family? The analysis reveals five separate structural components that are central to the transition from high school to independent assisted-living. But webs of social structures are known to be linked inextricably and the current case study confirms this general proposition. Of the five structures, three are distinctly rooted in the bureaucratic transition type: graduation from high school, assisted-living arrangements, and financial support. But these bureaucratic structures produce concomitant changes in family life, detailed below. The other two structures--divorce and relocation, and changes in employment--are more centrally located in the family life transition dimension. Among these structures are housing patterns, community and family networks, and job routines. Thus Trent's transition from high school to adult life was multidimensional, impacting the family dynamics that changed the way his family functioned and made decisions.

High school graduation. First and most obvious was graduation from high school. While actually a bureaucratic transition, the first of Ferguson et al.'s (1988) three types, this rite of passage also signifies taking on new and different life structures and experiences. High school had provided a structured environment for Trent where he received instruction, learned skills, and enjoyed interactions with familiar teachers and classmates. For an individual with autism, high school constituted normal (and comforting) routines. For the developmentally delayed young adult, the abrupt ending of these supports represents a structural change that goes far beyond the "new beginning" experienced by most American teenagers.

For Trent, this meant having to fill the six hours that had been spent at school, but with no consistent pattern of job and/or further schooling. Most high school graduates enter the military, training programs, college, or the work force, but these routine activities are anything but for a young adult with a developmental disability. However, Trent did continue his job at a nearby grocery store for two hours, twice a week from 10 to 12.

In addition to his job, Trent spent an additional 8 hours of participating in the community with a community coach, who worked with Trent on the alternate days of his job. This coach introduced Trent to new environments, while helping him to adapt socially to other people. He also reinforced self help skills already practiced in school, such as shopping at the grocery store and running errands such as going to the social security office and doctor's office.

School had offered Trent 30 hours a week (approximately 6 hours a day) of activity and involvement. After school ended Trent's week involved a total of 4 hours of work and 8 hours of participation with a community coach. These two activities, job and community coach, left 18 unstructured hours that had previously been scheduled. The additional time was consumed by watching TV at his grandma's house, and on occasion helping his grandma with yard work. Weekends involved more unstructured time as well as

walking his dog in the park.

Only months later, after Neil was referred to Marquette, was she able to create some structured weekend time. (See below, Independent assisted living.) Marquette arranged with Neil to work with Trent in the community on weekends only, since Neil lived in another town, one hour away. Among other activities, Neil took Trent to a bowling program offered by Special Olympics every Saturday afternoon. This relationship continued for several months.

Divorce and relocation. The second major change was the break up of the family, which initiated a series of secondary changes during the transition phase. Trent's father left the home three months after Trent's graduation, another structural change, this time in the composition of the immediate family unit. At first, Trent responded minimally to this event. By the second month, Trent began to ask his mother about his father. In order to explain this, she sought a book on divorce. One of Trent's enjoyable pastimes had always been listening to stories read by his mother. Reading had been one additional tool that helped facilitate understanding of his world.

As Marquette sought books that explained parental separation and divorce using pictures and low vocabulary, she could only find books that spoke to small children as the audience. After searching a number of book stores, Marquette found age appropriateness through the cartoon format versus photographs or drawings of small children.

The first day Marquette read the book several times, hoping Trent would understand that his parents would never live together again. In the weeks following, Trent began to show an interest in understanding his family situation as he asked his mother to read the book several times a day. One day after the third week, he abruptly refused to look at the book, hid it from view, and rarely asked about his father. Marquette believed that Trent began to understand they were not going to live together as a family again. She later realized that Trent needed to grieve and saw how the book helped him face his father's absence.

The divorce led Marquette to make difficult but necessary choices regarding the care for Trent, Trent's younger brother, and herself. In order to meet her financial needs she moved away from their home and neighborhood. This was difficult as Trent was still adapting to the loss of a structured daily routine from school. He also had his job at a nearby grocery store, and that meant he had to leave a situation that was working out well, yet another structural change. In addition, he would have to say goodbye to his familiar neighborhood where he walked his dog and rode his bike daily. Such changes in routines are known to produce negative reactions in individuals with autism. Yet moving was financially necessary. Confusion and fear about the unknown overwhelmed Marquette as she proceeded with her decision to change neighborhoods (one more form of structural change).

Marquette had a close relationship with her brother. When he discovered her need for a place to live, he offered to purchase the house next door to his own. This afforded Marquette both financial assistance and family support. Moving next door to family marked a new and unknown life. Marquette recalls her brother's compassionate act as generous at a time she needed it the most. Although Marquette's nuclear family structure splintered because of the divorce, her brother's kindness brought her under the protection of her extended family. The move provided a comfortable, safe place during a traumatic time. The new home also allowed Trent additional contact with extended family and offered Marquette assistance in caring for Trent at a time when both were emotionally fragile. Yet even this re-connection to her family represented another change in family structure.

Employment. Marquette's divorce necessitated working due to financial obligations. While she had been previously employed, her husband had always been the primary family breadwinner. Her job had provided supplemental income but had been scheduled around her family's needs, especially having a developmentally disabled child. Now she had no choice. Yet the increased child care responsibilities following Trent's graduation were simply too much. Unemployment, a major structural upheaval, followed. So too did depression, not surprising given the combination of unemployment and the changes she had recently endured.

Meanwhile, as noted above, Trent had continued his job at a local grocery store. The funding under the Community Based Work Transition Program (CBWTP) had provided the job training during high school, but the source of support for his job coach following

completion of high school changed to Community Employment, a supported employment vendor. A person-centered planning (PCP) team helped create this job for Trent. After graduation, the individual with a disability and the people who advocate for him/her have some difficult decisions to make. Person-centered planning is one mechanism that can help facilitate the process. This is the chance for friends, family members, and people who know the individual through work or school to participate as a team. The intention is to discuss what is important to the individual and what is needed for success at home, work, and in the community, so that a plan can be designed.

According to Abery and Stancliffe (1996) since the mid-1980s there has been a growing dissatisfaction with traditional methods of service planning. The individualized service plan (ISP), individualized habilitation plan (IHP), and individualized education program (IEP) all placed decision-making power in the hands of the professionals, while people with disabilities and their families took a back seat. In reaction to this common practice, person-centered planning was developed to help empower people with disabilities and their families. Numerous variants of this process have been developed, including Personal Futures Planning (Mount & Zwerik, 1988), LifeStyle Planning (O'Brien, 1987), and Planning Alternative Tomorrows with Hope (PATH) (Pearpoint, O'Brien, & Forest, 1993)--all cited in Abery and Stancliffe.

The PCP team consisted of persons who met in Trent's behalf to discuss what he needed in order to live in the community, including how to attract resources. The team members included two employment specialists from Community Employment, a case manager through Seven Counties Services, the current community coach, Trent's job coach from high school, family members, and friends. Meeting times were set by Marquette. The discussion explored Trent's likes and dislikes, i.e., the types of environment for employment and leisure that might promote success and inclusion. A brainstorm session involved everyone's participation and input. Further meetings were set after follow-up action steps were taken by team members.

Even with the support of the team, it was difficult for Trent to maintain a job because of changing family circumstances and the lack of understanding by employers. The grocery store job entailed working in the produce department sorting out rotten fruit, putting up displays, and packaging fruit and candy. Trent liked categorizing and placing items in a bag so the activities matched his interests and ability. This job lasted eight months after high school graduation but ended when the family moved for financial reasons. Trent then found a job at the YMCA that lasted only a month. Trent worked in the men's locker room gathering towels, and in the laundry area washing and folding towels. He even learned to operate the elevator and move the laundry crate over seven floors. This job appeared to work well as it paired Trent with another coworker. However, when the supervisor asked both Trent and the coworker to move their work to the basement the last 30 minutes of his shift, Trent was unable to adjust to such an abrupt change in routine. He created a major scene, which resulted in his termination.

Trent's third job was at Papa John's Pizza, just a few blocks from the supported employment vendor that served him. His tasks involved folding pizza boxes, preparation for the weekend shift, and relieving the coworkers to focus on other tasks in the restaurant. Trent handled the first two and a half months, until he obsessed on moving around items on the shelf. His increasing obsession interfered with his focus on folding pizza boxes. Again he was terminated.

During this period Trent's behavior deteriorated. His tendency to obsess increased and even routine trips to a store with his mother became difficult, frequently resulting in a scene. Marquette decided against further efforts at finding him a job. Trent's day was increasingly spent in front of his grandmother's TV. The one exception to this was that he continued his activities in the neighborhood with his community coach for 12 hours a week.

It was not until about six months later, after Trent had made the move to independent assisted living, that Marquette considered again employment for Trent. About three months after Neil began to live with Trent (see description below); the team that met in Trent's behalf discussed creating the ideal job for Trent. One of the specialists at Community Employment suggested that Trent and Neil be hired as a team. The task sought for Trent would be a continuous routine that kept him in a particular area. Kmart was targeted and hiring both Trent and Neil was negotiated, whereby each became an employee but worked as a team, placing security tags on clothing. This situation has worked well, as the two of them have been paired on the job for upwards of two years.

During these struggles with Trent, Marquette's unemployment had lasted six months. Finally she was ready to go back to work. She was offered a position as a part time consultant with a nearby school district. This allowed her to work a few days a week while still being available for Trent. Although she was dependent on her brother and mother to assist with Trent on the days she worked, the part time job provided possibilities for growth.

Independent-assisted living. During the months that Marquette and Trent lived next door to her brother, several opportunities emerged. One of Trent's job coaches at Community Employment referred a young man to work with Trent. Neil, a potential community coach, stayed with Trent on weekends, which opened more time for Marquette to enjoy friendships and leisure activities. Marquette experienced such relief that she accepted an opportunity to visit Panama for ten days with a university classmate she had reunited with on her new job. This freedom offered her the confidence to consider living apart from Trent.

Neil turned out to be the answer to the need for additional adult care. His experience in working with adults with disabilities made him a perfect fit for part time assistance. His skills in working with Trent were so effective that Trent made progress in social skills and was able to expand his repertoire of experiences. Neil's work made the distinction between adult day care (passive) and assisted independence (proactive) obvious. Now, for the first time, the move to full time community assisted living seemed viable.

The weekend arrangement with Neil had been a Godsend. Neil's calm and consistent approach provided the support and instruction that evoked Trent's motivation. Marquette and Neil agreed to try a live-in arrangement with Trent. Marquette left the house so Trent would have the comfort of his familiar surroundings and family next door. By her leaving, Trent had to adjust only to his mother moving out and Neil moving in rather than the additional change of moving to another house (one major structural change avoided).

For both Trent and his mother, the move first to part time and later to full time assisted independence away from the family represented the ultimate structural change in the lives of the family. Yet the change was not easy for either of them. Trent experienced a setback shortly after Marquette left. But with daily visits from his mother, he eventually accepted his new life. Marquette's visits occurred immediately after work and on the one day a week she set aside to work collaboratively with Neil to increase Trent's community adaptation.

Marquette also struggled. When she moved into an apartment, another structural change, she recalls, for the first time in 23 years, being free of Trent's daily dependence on her. She had mixed emotions: recognizing the sudden freedom to come and go, feeling displaced, and experiencing guilt about leaving Trent. To make matters worse, her youngest son left for college so that she was now alone. Difficult times, however, provide the impetus for growth. She could now move forward with her own life, apart from her previous Marquette-Trent identity.

Program funding. The changes represented by Ferguson et al.'s (1988) bureaucratic transitions produced concomitant changes in family life structure. But these changes required supportive resources; programs for DD adults do not come cheaply. Such programs typically produce long term resource efficiencies in that the costs of the community programs are less than the costs of institutionalization; in addition, community participation for the adult increases quality of life for both the adult with DD and the family (see Singer & Irvin, 1991). While these programs are clearly worthwhile, they still require programmatic security for the individual families who face these challenges.

Social Security Insurance is one resource that allows many individuals with DD to contribute to their share of expenses within the home. Along with SSI, Trent received medical insurance from Medicaid. Both of these sources, representing federal commitments, helped offset his basic living expenses and meet his medical needs.

At the state level, the Supported Living Program (SLP) in Kentucky funded the requisite personnel who helped connect Trent to community activities, people, and settings. To access the funding from SLP, Marquette wrote a grant to hire a community coach for Trent for several hours a week. (See above, High school graduation.) The Supported Living Program grant for the community coach, from State Emergency Funds, was accessed through Seven Counties Services located in Louisville. When Trent exited high school, Marquette requested the funding to assist his connection to the community and

maintain the skills he learned during high school. This funding source was the first Trent received that gave him an opportunity to participate in the community without dependency on his family.

Community coaches represent an important element in helping developmentally disabled adults fit into the community. The authors' experience suggests that those who work in the field of services for these adults are aware of the problem of high turnover. That has certainly been the case for Trent. Including Neil, Trent has had six different community coaches during a two year span. However, the authors are not aware of published research on this issue.

Neil's community coaching stint, however, turned out to be unique. As noted earlier, Neil started working only on weekends. (He is still the only weekend community coach Trent has had.) After he agreed to accept the position to live with Trent full time, Marquette rewrote the Supported Living grant to transfer funding for Neil's community coaching to salary as a live-in assistant.

Community coaching continued after Trent began living independently with Neil. The funds for these community coaches continued to be available through State General Funds funneled through Seven County Services. This source is versatile enough to fund short term supports that include but are not limited to respite, crisis interventions, and case management. For example, allocations for respite personnel provided Neil two afternoons free from duties with Trent. Respite for Trent involved much more than caretaking. Trent learned domestic self help skills such as preparing a meal, baking, and simple household tasks. These activities increased Trent's self reliance and were enjoyable for him.

To summarize, several funding sources helped support Trent's needs as he entered post high school life. First, he received monthly Social Security Insurance (SSI) that helped defray expenses while living with his family. Medicaid health insurance was a further SSI benefit. Second, State General Funds initially provided a community coach, and later funded respite for Neil's time away from Trent. Third, the Supported Living Program covered Neil's salary as Trent's live-in assistant. A small portion of the SLP grant also supported a community coach/art therapist for Trent.

#### Changes in Family Functioning

What changes occurred in family functioning? Within six months of Trent living next to his uncle and grandmother, he withdrew into the comfort of his house. In addition, his dependency on his mother, grandmother, and uncle increased. Trent rarely wanted to leave his house. He had a job coach, but the jobs at Papa Johns Pizza and then the YMCA lasted only a month, as he became obsessed with his routine or arranged items on a shelf. In addition to the short term jobs, Trent had a community coach for a few hours a day, three days a week. Although this service was designed to increase Trent's independence, interaction, and motivation within the community, the community coach merely kept Trent from sinking deeper into withdrawal. Trent's community activities did not increase his motivation to participate. In fact, he began to obsess more frequently and more intensely when Marquette took him on errands. The combination of Trent's obsession to arrange items and Marquette's own decreased functional ability made outings so difficult that she attempted them less often.

Trent's desire to interact with others decreased as he withdrew from the one activity Marquette had always been able to depend upon: walking his dog in the park. In addition, Trent's behavior plummeted when he refused to leave home, instead compulsively watching the never ending TV. This obsession tied him further to the house. He left cooperatively only when his uncle came and made him walk his dog.

Trent's regression caused Marquette great difficulty in coping with her life. Just getting to work on time and staying all day was a major accomplishment. Job demands increased just as she had greater responsibility in caring for Trent. Marquette finally resigned her position. For the following six months, she experienced depression and withdrew: accepting unemployment insurance, staying home with Trent, and resting.

At this time Marquette and Trent were at best surviving, but in a surprisingly comfortable manner. In fact, choosing unemployment reduced stress for both of them. Trent had no demands as he was often allowed to sit in front of the TV. Marquette no longer had to meet the schedules of a work day. Some days were better than others. Trent improved somewhat, agreeing to leave the house to help his grandmother with yard work, clip bushes, or wash the car. He resumed walking his dog in the park. Still, his preference was to stay confined at home. Sometimes when he became bored he would rip his

shirt out of frustration and anger.

Marquette had no reason to leave the house except for groceries or medications. Lacking motivation, her energy level was low. But withdrawing from life allowed her to recoup. She filled her time with reading uplifting, motivating self-help books and stories of people who overcame huge obstacles. The reading and rest opened new possibilities. Despite their problems, she believed their present circumstances could improve.

Her road back to normal living started with setting time aside to meet a friend, treat herself to a movie, or just exercise. One of her favorite pastimes was reading in the coffee shop in a nearby book store, an activity that helped pull her out of depression. Her brother and mother next door were available to care for Trent, making it easier to leave for short periods of time. The gift of time nurtured healing as she struggled with her illness.

Finally, as Marquette's depression lifted, she returned to work on a part time basis. But even a reduced schedule necessitated adult care for Trent. While Marquette's brother and mother helped, more assistance was needed. As noted above, Neil's community coaching on weekends was crucial. His success with Trent led to the decision to try full time independent assisted living. But as positive as this development was, such a momentous change did not come easily for a person with autism.

One example from Trent's new life illustrated the depression that he experienced. Trent appeared despondent for several months and experienced a significant decrease in appetite. Every afternoon he stood at the door waiting for Marquette to visit. When she left, Trent clung to his mom as she walked to the car, asking if he could go with her. Yet as painful as this was for both mother and son, the changes that were initiated represented the beginning of the successful transition to community assisted living. That arrangement now constitutes what is hopefully the structural underpinning of a normal adult life for both Trent and his mother.

#### Family Life Transition in Perspective

The intent of Kentucky's Supports for Community Living (SCL) policy was to provide assistance to individuals with mental retardation or developmental disabilities to live and participate in the community. But the path to independent living following graduation is uncertain at best. Following graduation from high school, Trent had been on the SCL waiting list for over four years; obtaining independent living without the SCL program proved to be extremely difficult.

Because of creative resources and supports designed by concerned people who participated as a team in Trent's behalf, Trent currently lives independently. But these other supports are not secure for the long term, nor are they available to many of those on the SCL waiting list. Unfortunately, there are far more individuals with a disability waiting in desperate need of assistance and support than there are "Trents" who have somehow managed to achieve community assisted living.

The goals of the SCL program support an individualized independent assisted living design. The specific model applied to Trent's life was successful. It led to growth and improved quality of life for Trent and his family. But resources for SCL are limited, and increasing numbers of individuals are on the waiting list for services. Individuals who are homeless or who have no living parents are considered emergency cases and are first to receive entry into the SCL program. This prioritization based on need is clearly warranted. But it is important to note that Trent's success story occurred without support from SCL. While Trent was on the waiting list, the arrangements that Marquette made, and the resources for them, came from programs other than SCL. Trent's name finally worked to the top of the SCL list. However, by then he had already achieved community assisted living. Given SCL's criteria for accepting emergency cases first, SCL has still not offered Trent any services. Again, the issue is long term. Will these alternative resources remain secure in the many years to come?

As for the supportive services themselves, some of SCL's Medicaid regulations are restrictive, focusing mainly on providing therapy to the individual living in the community. Yet other programs are more inclusive and focus on assistance that helps the DD individual participate in community life. The distinction between the two approaches is noteworthy and raises important policy questions. How typical is it to center various therapies around the life of the individual with a disability? Is individual therapy restrictive, comparable to a self-contained special education class? In contrast, friends/neighbors, employment, leisure activities, and community settings are not

therapies; rather these are more like typical adult routines. This flexible approach was the emphasis for the community assisted living design. Participation in the social routines of the neighborhood facilitated Trent's adaptation to and acceptance of his new life. This, far more than assistance directed to him as an individual, offered Trent quality of life.

Perhaps the key is to avoid separating the two approaches. Clearly some individualized assistance (therapy) is needed by DD individuals as they develop skills necessary for independent living. But the individualized assistance is most effective when delivered in the context of actual participation in the community, a point of view fully consistent with the ideal of the least restrictive environment.

Meanwhile, waiting for services following high school graduation impacted the entire family, not just Trent, confirming Ferguson et al.'s (1988) theory on transition and the family. Family crises and major life changes faced Marquette. Ending the past and beginning anew required difficult choices. While the Ferguson et al. work is useful as a general guide, no specific model has been developed to assist family movement through the transition phase toward independent living for adult children with autism or other developmental disabilities. In fact, families have few options that empower them to seek guidance, receive support, or achieve independent living as the young adult and the family move through the separation process, with its concomitant issues of housing, security, job possibilities, socialization, and even grieving.

Two factors complicate this transition, already problematic because of the lack of established structures and practices in this evolving area of developmental independent living. First, the outcome is clearly in doubt. Given shortages in resources, traditional public attitudes about the disabled (they should be institutionalized or live with their family), and the lack of existing models to follow, it is not surprising that many families do not even attempt independent living arrangements for their disabled young adults, nor that success is elusive for some who do. This specter of failure is itself an additional barrier.

Second, the emotional bonds that tie a disabled child to the family are unusually strong. Infants are totally dependent on adults for their care and survival. This helplessness is one trigger in the developing maternal and family bonds. Normal children gradually become more independent, with "teenage rebellion" a recurring stage in this drive forward eventually separating from the family and establishing their own lives (Lefrancois, 1986, p. 500). However, this process is prolonged when the child has a disability. The more severe the disability, the more dependent the child is and the greater (and longer) is the continuing need for assistance from the family unit. Over time, this dependence creates a stronger bond emotionally, socially, and in matters educational, physical, and financial. For the family that does manage to establish independent living, the breaking of this intensive bond represents one more barrier to the successful navigation of the transitional stage.

In sum, both Trent and Marquette lived through a number of structural changes following his graduation from high school. These changes in circumstances necessitated concomitant changes in family functioning as they faced the unfamiliar possibilities that life offered. While these accommodations were not always easy, they eventually led to new opportunities. Acceptance of a new independent life for Trent was only achieved by facing challenges and accepting help. Primary to these changes was Marquette detaching herself from daily care. Collectively these actions moved the family through the transition phase to Trent's independence.

#### Stages of Grief

Ferguson et al.'s (1988) theory on family life transition for developmentally disabled adults would not, at first glance, seem related to Kubler-Ross' (1969) stages of grief theory. Yet internal changes occur within the family at the time the child graduates from high school. Grief sets in at that time, often unbeknownst to family members. Their young adult with autism or other disability may be without services or on a waiting list with few other options. The unprepared family feels shock because the school has always provided services. Graduation occurs abruptly, but the family's capability to handle the change may not keep up with the unexpected demands. The result is increased stress, anxiety, and sometimes a break down. Depending on how the family recognizes and handles these circumstances, different reactions to grief are likely. There is no guarantee that an individual works through all of Kubler-Ross's five stages. The depth of response, progress through the stages, and the eventual resolution of the

grieving process are all dependent on both the particular family situation and the individuals' capabilities for recognition and change.

#### Denial and Family Functioning

Although disability policies include provisions for enabling adults with a disability to live in the community, impact on the family is not explicitly recognized. How the family as a unit begins to manage the change during the transition phase needs further study. What are the processes by which the family becomes empowered and eventually releases the adult with a disability to new situations and people so that independent living can become a reality? Such information could then become the basis of policy provisions that recognize the changes at the level of the family unit.

Marquette's (2001) *Independence Bound* describes ways her family functioned prior to Trent's graduation, including what happened during family crises. Each member of the family moved through the motions of life for his/her own benefit, an escape which marked the denial of serious problems. The denial stage became the survival mode through these years, with deeply embedded patterns of functioning.

Marquette eventually recognized her denial about lack of support from her husband. Other than financial assistance, he was unable to provide for Trent or her needs. She had been wasting energy trying to figure out how to keep the family working when it had really been dysfunctional. For example, for many years she believed that Trent's father was seeking independent living for Trent. It turned out, though, that Trent's father never acknowledged, nor was he willing to accept, Trent's disability. As she finally recognized her denial, she accepted new family arrangements different from what she had always believed was the right way to live.

"Right" implied all of Marquette's perceptions regarding the ideal of a family staying together and offering full support to one another, especially for the one with the greatest needs. But this image was not real. In fact, she experienced shock when she realized that her ideal family life had never existed. With this insight, she could no longer continue living in those circumstances. Recognizing these patterns as nonsupportive, dysfunctional, and damaging marked the end of her denial stage. Essentially, Marquette abandoned past modes of behavior, in this case a broken marriage. New patterns of family functioning developed as she sought assistance and supports for her son.

#### Anger and Loss

As Marquette's life changed, she examined her previous denial. Guilt followed. She recognized the mistakes that had kept her in denial. Some examples are described in *Independence Bound*. When she saw that her assistance for Trent was something he could do for himself, a part of her rationalized the continuation of that behavior. When she considered placing Trent in an adult day program rather than community services, she rationalized the immediate benefits and the continued security of current arrangements. As she thought about leaving a marriage partner who never accepted Trent's disability, she rationalized staying for economic reasons. A breakthrough came when she understood that guilt always haunted her. The only way that she could leave these feelings behind was to identify the guilt itself.

In effect, movement toward independent assisted living was only accomplished through her explicit awareness of the choices that had previously occurred at an unconscious level. She now recognized that her hidden anger was masked by guilt and fear that kept both her and her son from seeking new opportunities. When she had tried to be the perfect caretaker, regardless of her negative feelings and dread, she felt like distancing herself further from Trent. Underlying all this was anger: why me? Why did Trent have to have autism? But these feelings simply reinforced her guilt: how could she even entertain such feelings about her son. These feelings of self blame produced a downward spiral of guilt and anger.

#### Bargaining

The bargaining stage came when Marquette held onto her fixed values about providing for Trent. Her actions included seeking out family members and state agencies to provide assistance to Trent. She believed that family and agency supports would furnish the structure Trent needed. With his routines set up, she could reconstruct her own day. She convinced herself that all would be fine if the supports came through.

Marquette tried to convince Trent's brothers to arrange certain times to take him on an outing or stay with him when she needed to leave. Often they were busy with their own lives--going to school and working--which made it difficult for them to follow

through. When she asked assistance from her brother, he was more available. Unfortunately, her dependency on family never seemed adequate for her own and Trent's needs.

The agency services she sought included personnel for assisted living. Trent was dependent on others to go with him as he participated in the community and on his job. Other assistance involved hiring a respite worker to stay with her son, which freed her to spend time with friends, socialize, or pursue career goals. These options seemed the only way to survive while caring for her son.

Marquette had assumed that if she could just arrange everything she had imagined, life would work out for the family. She had wasted time worrying and making arrangements that left her unrealistically dependent on others. She often engaged in the "if only's": if only Trent's brothers and father would help; if only the right services were granted; if only the right persons would appear to help support Trent on a job; if only others would..., then everything would be okay. Trent could hold a job and have structure within his day. This was her way of bargaining with herself instead of facing the truth about the family's needs--hers, Trent's, and his siblings' (beginning their own adult lives).

The bargaining stage ended when she finally realized that her arrangements did not work. Others were not able to provide the help she asked for and agency supports did not always come through when she desperately needed them. Her sense that she could continue as Trent's primary caretaker if only she had the necessary supports proved unrealistic.

#### Depression and Healing

The breakthrough did not come without pain. Resignation to overwhelming circumstances brought depression. For a period of time, Marquette was unemployed. Depression meant rest and time to contemplate her next step. Sometimes during this phase, she had Trent spend a full day watching television, a "baby sitting" tool that made her feel more guilt. Withdrawal followed as her family fell apart. She felt sorrow and the loss of not having a son capable of living on his own. As part of the cycle, this "betrayal" of her son inevitably increased her guilt and depression.

At the time, it was difficult to see that this illness was beneficial, but the depression helped move her toward the acceptance stage. Depression dulls the senses generally, especially toward those who interact with the person suffering from depression. This inevitably created instances when Marquette was less attentive to Trent's needs (TV all day being a prime example).

During the troubled times following Trent's graduation, Marquette sometimes spent less time with Trent to care for her own needs. Ironically, this helped her progress beyond this stage. As Trent participated with his community coach and later lived on his own, he became less dependent upon family for daily supports and activities. By "ignoring" him, at least by her usual "all Trent, all the time" standards, Trent was both freed and forced to do more for himself. Trent gained acceptance within the community, had opportunities to make choices, and learned personal freedom. Marquette experienced her son's growing independence as a new kind of security. Knowing Trent was moving toward independent living and an increased quality of life brought her peace. She perceived this as growth for both Trent and herself.

In effect, when Marquette faced her feelings and cared for her own needs, she gained insight into her situation. She opened herself to the changes in Trent and was better able to advocate for him. She learned not to fear any emotion, even a negative one. She recognized feelings by labeling them. When she denied negative sentiments, they sometimes had serious consequences toward her health and well being. When she responded to a particular feeling with guilt, its hold on her was stronger. Finally, she learned to request outside assistance without embarrassment or shame.

As the depression began to lift, Marquette had realized that she did not have to assume sole responsibility for Trent. Other people, and Trent himself, could be relied upon to provide both assistance and opportunity. Yet this was difficult in practice. Her own survival was still day to day and letting Trent try new situations and meet new people went against all her protective maternal instincts. But her own lethargy and inability to meet all Trent's needs forced her to be more receptive to help. In turn, she found others to be more responsive. Watching her son grow she experienced less guilt over not doing everything for her son, a transition that evoked inner calm.

#### Acceptance, Empowerment, and Survival

During the tough times, Marquette survived by giving into the "now" moment. She needed to do activities for herself just for the sake of doing them. Likewise, for

Trent, and perhaps especially so, activities had inherent value, constituting normal community routines, although it took her awhile to recognize this benefit. She learned that sometimes it was important not to manage Trent's behavior completely. This led to greater participation in activities with the family. For example, she did food preparation with him, just to enjoy cooking together. Rather than "teaching," she learned that activities could be fun merely for the experience. She accepted who and what she and Trent were, and appreciated any offer as a gift, whether it came from family, a neighbor, or a respite source. The key point was that the assistance helped Trent participate in the community.

As Trent participated with his community coach and then later moved to assisted living, he became less dependent upon family for daily supports and activities. Marquette stepped aside as his community coaches, job coach, and living assistant instructed and supported Trent in various activities. She allowed others to make suggestions regarding Trent's community participation. Perhaps most difficult, she learned that her own suggestions were not always the best for Trent. In fact, as she gradually withdrew from her role as direct caregiver, Trent became more self determined and less dependent upon his family.

However, Trent's growth necessitated changes in Marquette. She finally recognized that she had to give up day-to-day control of Trent's life if he was going to progress. This represented the ultimate stage in the cycle of grief: acceptance of the "loss" of her son as he commenced a life of independence in the community. This was a dream realized, one that she had never fully accepted as possible.

#### Perspectives on the Stages of Grief

As Marquette had moved through the process of empowerment, she increasingly allowed Trent to do things for himself. As she worked with his community coaches or job coach in ways that built his self determination, she put less emphasis on completing petty tasks that would reinforce his dependence. When she had done too much for him, she recognized that she had rationalized her actions, thus reinforcing his dependence on her. She realized that Trent also had a responsibility toward choosing a life of independence, separate from her.

Marquette's progress through crisis, depression, giving up control, and seeing Trent's growth all affected her perceptions about community living. She finally understood that her negative perceptions regarding independent assisted living were associated with fear and loss. Independent living for Trent would mean leaving her. But as she saw his growing independence in the positive light of actual experience, she could label her beliefs about independent living and categorize them as myth.

Marquette discovered that her negative responses had been based on her belief that independent living could not really work for her son. Previously she saw this dream as a false sense of security. Her dysfunctional marriage had not been secure at all. While not everyone she asked could or would help, others could and did. Doing everything for her son had been stifling for both Trent and herself. She discovered there was nothing to lose by abandoning dysfunctional patterns as she recognized the role that denial and fear had in perpetuating these behaviors.

#### Empowerment and Security

Over time, Marquette (2001) viewed security as forward movement for Trent and herself. She redefined family empowerment and noted critical action steps that helped Trent through this transition to independent living. Based on the personal experiences described in *Independence Bound*, Marquette now includes both introspection and political savvy, going beyond previous definitions of empowerment. Family empowerment constitutes examining patterns of family functioning, recognizing dysfunctional emotions and behaviors, acquiring insight about disability programs, developing political skills for negotiating bureaucratic agencies and regulations, accessing available resources, and initiating movement toward independent functioning for both the adult with the disability and the family. This new definition is consistent with the goal of least restrictive environment. Although not every adult with a developmental disability may be capable of independent assisted living, all are deserving of progress toward as much independence as possible for them.

Marquette also views security differently than before. Some of the previous patterns of decision making were based on guilt and fear of the unknown. Unrecognized at the time was her grieving for her son's loss (high school) and her family's disintegration. Despite her fear, family crises fostered new patterns. After struggling

(the stages of grief) she gradually accepted new goals and perspectives on disability. She redefined security for her son as the most independent life for which he was capable, given community assistance. Only after she abandoned familiar patterns and stifling emotions could she find the courage to seek independent living for Trent.

Some of the options that Marquette sought for Trent included enjoying health, having autonomy, taking chances, and establishing opportunities for new relationships. These normal social behaviors became securities in their own right, considerably altered from the family's previous life. Peace and tranquility came from knowing that Trent was establishing a sense of belonging and identity within the community. Security now meant that Trent had trained persons who provided instruction and friendship, had variety in his daily routine, held a job, and had recreational pursuits.

With the lack of state services and critical shortages of resources, it was easy for a family with a developmentally disabled adult to feel abandoned by society. Negotiating changes in family functioning and finding resources to fund them had not been easy. Because policies in the area of assisted community living for adults with disabilities are so new, they are often both incomplete and under funded. But ultimately Trent and others like him are worthy individuals. Although they may have a disability, they deserve the chance to grow into adulthood. Marquette learned to view Trent's new beginning as a journey with no foreordained destination. An independent life, with all its risks and rewards, was Trent's right as a person.

The final product of Trent's new life could never turn out to be what Marquette expected. No one can predict what independence and choice foretell. Independent living had to be tried in order to experience its benefits. Likewise Trent's mother could never know in advance how this new experience would change her life. This simple statement seems obvious. But fear of the unknown is a major factor in the inertia that binds so many individuals to their present, often dysfunctional, life patterns.

#### Recommendations

Policies have been developed under the 1997 IDEA Amendments regarding the transition to post high school years for individuals with developmental disabilities. Collectively these policies are designed to facilitate learning the skills that increase independence within the community. Adult individuals with autism are often dependent on their family for access to services and resources. Families are impacted by the transition years, just as are the individuals with autism or other developmental disabilities. Often families are the strongest advocates for their young adult. Both the family's movement through this process and their ability to become empowered in order to advocate for their young adult need to be further studied. For example, the family's level of empowerment for accessing resources for independent assisted living greatly impacts the outcome. But this requires a sense of savvy representing political capital (Miller, 1995). Based on this study family empowerment also includes psychological introspection. This reconceptualization is in contrast to the more usual sense of "consumer empowerment" which is more narrowly focused on resource acquisition (cf. Kosciulek, 1999).

#### Policy Considerations

How can disability policy support individuals with autism and other developmental disabilities regarding community assisted living? There are three related recommendations. First, policy should be designed to facilitate entitlement for all eligible individuals. Second, this entitlement should include sufficient funding to meet demand. Finally, provisions need to be developed to support both families and individuals with developmental disabilities during their family's movement through the transition phase. This is a critical time for family functioning, a phase in which family crises are all too common.

Policymakers need to hear the experiences of families facing this transition to independent living for their children with autism or other developmental disabilities. In addition, policymakers need to understand the stresses on individuals with DD and their families during the critical transition phase of life. This is a period of wrenching change for the family. Both Ferguson et al.'s (1988) family transition model and Kubler-Ross's (1969) stages of grief are relevant here.

Because the transition to adult assisted living is a relatively new phenomenon, the Ferguson et al. (1988) model of three distinct types of transition provides a guide for policymakers on how to address the complexities of this process. The bureaucratic transition suggests the need to develop seamless structures among the various

governmental institutions involved--the school, local, state, and federal agencies--as well as supplemental institutions such as supported employment, university centers on disability, or community counseling agencies. This will be a daunting task as the terrain is new whereas the issues of turf are familiar and enduring. One model to look at is the interagency consortium that has evolved in the Syracuse area (see Magyar, 2002).

The second type of transition in the Ferguson et al. (1988) model focuses on status changes. While little work has been done in this arena, policymakers should be aware of the need to examine legal parameters for both the family and the developmentally delayed young adult. Changes in society's approach to assisted living are very likely to result in an evolution of legal and custodial policies. As new problems arise, proactive thinking will be incumbent upon all involved.

The focus of this study has been the third transition type in the Ferguson et al. (1988) model, family life structures. Changes in structure and function are common during this transition period but have been seldom studied. In addition, the use of Kubler-Ross' (1969) stages of grief model was helpful in understanding the struggles faced by one family during this stressful period following high school graduation. In this area of family function, the policy implications have less to do with legalities and more to do with education and support. Families will need information in addition to access to counseling and resources as they move as a unit through the stages of grief during the transition phase. This will assist them in becoming empowered to create a new way of functioning, and eventually learn to allow their young adult to move on to independent living. Therefore, it is critical to develop policy that includes strategies for family empowerment to advocate for and have access to tools that will assist them in securing supports and services. The changes in family structure and function that are part of this transition phase into independent living should not be taken lightly.

Finally, this study highlights the problem of resource inadequacy. Full funding for assisted community living is needed at a juncture during which services are being cut due to the increasing gap between tax revenues and public expenditures. Not surprisingly, groups who have little power or resources themselves (special needs children and adults) are among the first to be sacrificed during budget cuts.

But funding is only part of the story. As this case study demonstrates, job and community coaches tend not to have long tenure in their jobs. This means that developmentally disabled adults cannot depend on long term, stable relationships with their coaches in these community assistance roles. Perhaps even more crucial, how many "Neils" are available as live-in assistants? This is an unknown, but policymakers clearly need to be aware that individuals with (a) Neil's skills and (b) Neil's willingness to be a live-in assistant as a career may be rare. There already exists a problem in finding qualified job and community coaches. Live-in assistants represent a role that requires both more skill and commitment (complete lifestyle saturation) than even the job and community coaches.

#### Implications for Future Research

Research is nearly nonexistent regarding the transition from high school to community assisted living for families with a DD child. Findings within the literature indicate that families are greatly dependent on services and supports during this transition period but little has been written regarding how families create new patterns of functioning through these stressful years. Further, how do families obtain and support an improved quality of life for their developmentally delayed adult. The current case study needs to be supplemented by extensive qualitative research on how different families experience this transition. Planning is a must. Families who do not plan where and how their adult with autism will live will likely have less desirable alternatives, such as a more restrictive setting that may exclude their son/daughter from the community, or even more likely, continued residence in the home. Given the current shortage of resources and programs for assisted living, there is a need for research on what families already know and on how best to provide information on available services to these families.

Families need strategies to advocate consistently for their adult with developmental disabilities. Even given sufficient knowledge and resources, guiding a young adult with a DD through the tangle of different governmental agencies, quasi-private organizations, and the labyrinth of complex policies and regulations requires a considerable sense of political savvy in how to negotiate the system. Many

families, for reasons having to do with economics, educational level, and political contacts, may not have sufficient understanding or competence to engage these institutions successfully. Yet research on this general topic, perhaps subsumed by the notion of family empowerment, has not been much applied to the transition process. What are these psychological, financial, and political variables? How can families be helped to attain them? Research is virtually nonexistent on these issues.

A community coach can be invaluable to the individual with a disability. First, the coach can connect the DD individual to various settings within the community that he/she would otherwise not experience. New activities, meeting new people, and practicing new and already learned skills increases the individual's competence and independence. At the very least the community coach's service relieves the individual from isolation at home and provides brief respite from the care giving role. Yet little is known about this issue, from supply and demand to training to actual daily practice.

Finally, families typically face wrenching emotional changes when facing the transition of their DD child to post high school life. Yet few studies have examined this process (the current study is an exception here). There is a need for further exploration of the variables that are significant in the family's movement through their emotional responses to having their young adult live independently. While Kubler-Ross' (1969) model can be a start, it is obvious that research in this area is only beginning.

#### Conclusions

This has been a case study based on Marquette's (2001) Independence Bound on the transition to independent living for a young man with autism, despite being on a long waiting list for the Supports for Community Living program in Kentucky. The entire process seemed nearly impossible for mother and son. Although Marquette was ultimately successful in her efforts to help her son achieve independent living, there are few models to guide a family with a developmentally disabled young adult through the transition process to independent living, and the available research offers little guidance for this life stage.

This policy analytic paper moves beyond the existing research base by exploring family dynamics as Marquette (2001) established independent living, even as she struggled with family crises during the transition phase. The case study was framed by the Ferguson et al. (1988) model of transition to adulthood for families with children having developmental disabilities and by Kubler-Ross' (1969) Stages of Grief. Specifically, family structure and function and psychological adjustments as the son faced life after graduation from high school were found to affect decisions about and changes in Trent's future.

The current case study has a positive ending. Marquette struggled with the emotional bonds to her autistic son, stronger by far than the usual life stage wherein teenagers strike out on their own. Marquette initially resisted this change as she moved through the stages of grief. Yet her efforts to help Trent eventually paid off: an independent life both for Trent and for the rest of the family, freed to start new lives, unburdened by the care requirements of an autistic adult. But a key fact remains. There are many "Trents" out there for whom this transition to adult life has not gone well. What about them?

Although the current analysis is based on a single case, the results can provide important information when the body of personal experiences are ordered by a theoretical framework. As Yin (1989) notes, case studies are not designed for theory testing; rather the strength of the case study is its ability to examine a single instance in great depth, with the possibility of generating hypotheses. Examples include personal accounts of people's written reflections (Hayden & Albery, 1995). Further, a strong autobiographical element has often driven scholarly interest (Marshall & Rossman, 1995). This disciplined inquiry into Marquette's (2001) Independence Bound is well grounded as a research strategy. Such an approach is particularly germane for this topic where there is little systematic research on the transition to assisted independent living for young adults with developmental delays.

Particularly relevant here is the evidence favoring a sociologically-based understanding of how individuals with developmental disabilities fit into a community. In contrast to assistance based on individual needs, the strategies that worked best for Trent were community-based, i.e., assistance in helping Trent fit into the normal routines of community life: job, shopping, recreation, errands, and living on his own. This distinction already exists within the literature (cf. Albee, 1980), but the notion

that society/medicine/psychology should promote a competency-based approach rather than an individual deficit "medical model" remains the minority position. It is noteworthy, however, that the assisted living approach to community participation, not individual treatment, is consistent with the ideal of least restrictive environment.

The question can be raised as to the generalizability of transition experiences for an adult with autism to the experiences of individuals with other developmental disabilities. There is reason to expect the experiences to be somewhat similar. The focus of transition will fall on each family of the adult with a disability, especially in the context of critical shortages of supports and resources from governmental institutions. The struggles of different families should be similar, both externally in terms of finding facilities, resources, and assistance, and internally in terms of changing family role patterns, regardless of the handicapping condition. Ultimately, whether differences in the handicapping condition moderate these external and internal similarities will require additional research. However, what is clear is the urgent need for both more research and improved programmatic supports for the many families facing transition to assisted living.

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## Appendix

### Document Analysis Protocol

The following two sets of questions guided the extraction of information from Marquette's (2001) *Independence Bound*.

1. Ferguson et al.'s (1988) third type of transition, changes in family life status during the transition from high school to adulthood.
  - a. What structures and networks changed within the family?
  - b. What changes occurred in family functioning?
2. Kubler-Ross's (1969) stages of grief model for examining changes in emotional response to loss.
  - a. Evidence of denial?

- b. Evidence of anger?
- c. Evidence of bargaining?
- d. Evidence of depression?
- e. Evidence of acceptance?

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