Planning for the Future of Individuals with Developmental Disabilities

Dianna L. Payne Broadbent

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PLANNING FOR THE FUTURE OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

by

Dianna L. Payne Broadbent

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

MASTER OF SCIENCE

in

Family and Human Development

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ABSTRACT

Planning for the Future of Individuals with Developmental Disabilities

by

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This descriptive study examined the current status of future planning preparation by caregivers for individuals with developmental disabilities, including mental retardation (DD/MR) in the State of Utah. Other descriptive variables identified areas of planning in which the caregivers required assistance, perceived barriers to future planning, and preferences regarding conveyance of planning information.

Persons with developmental disabilities were identified by the state computer system as either on the waiting list for or currently receiving services through the Division of Services for People with Disabilities. The targeted sample was narrowed to persons with developmental disabilities over the age of 20 years who resided with a caregiver.

Surveys were sent to 1,049 households, and 397 eligible responses (37.8%) were analyzed to find trends in response patterns. Caregivers indicated areas in which plans for the person's future had been established. Elements of
planning were found in the areas of guardianship, and future caregiving or residential arrangements.

Most caregivers stated that the components of future planning were overwhelming. They were unsure of the areas in which they needed to plan, unaware of services that were available for the person with DD/MR, and dismayed by the fact that funding for current service needs was unavailable through the state developmental disability agency. Families also denoted emotional barriers to planning for the future.

Respondents were asked to indicate methods of obtaining information they had used previously, which techniques were most helpful in conveying knowledge, and in which manner they would prefer to receive information about planning for the future of the individual with DD/MR. Caregivers indicated a need for planning information presented in a one-on-one setting with a knowledgeable caseworker. They stated the necessity of referrals to financial planners and lawyers familiar with the unique planning needs of persons with DD/MR, as well as the need for financial assistance to pay for costs associated with making formal plans. Findings and implications for assisting caregivers with planning for the future of their family member with developmental disabilities are outlined.

(108 pages)
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Dianna L. Payne Broadbent
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Several factors have resulted in an increase in the past 30 years of the number of individuals with developmental disabilities who live in their home communities. These factors include the aging of America, brought on by better health care and longer life expectancy, as well as the deinstitutionalization movement of the 1970s (Bigby, 1996; Braddock, 1999; Mary, 1998; Palley & Von Hollen, 2000; Seltzer, Greenberg, Krauss, & Hong, 1997). This action resulted in supports being offered to assist families to maintain the individual with developmental disability (DD/MR) in their community or home rather than placing them in an institution or intermediate care facility for persons with mental retardation (ICF/MR). The term "developmental disability" as defined by the State of Utah is used throughout this study. "Developmental disability is disability attributable to Mental Retardation, cerebral palsy, epilepsy, autism, another neurological or other condition closely related to Mental Retardation. These types of disabilities begin before the age of twenty-two and are likely to continue indefinitely" (Division of Services for People with Disabilities, 2000, p. 12).

Supports to assist families who have children with DD/MR, including respite and supervised living services, are offered by states through a joint program with the federal government, called the Medicaid DD/MR Home and
Community-Based Waiver. Through Title XIX of the Social Security Act, the federal government waives some requirements for individuals to qualify for Medicaid. Medicaid then pays approximately 70% of the costs to support the person in the community, and the state developmental disability agency matches the rate with the remainder. This approach saves the federal government money, and it permits states to pay just a portion of the support costs; thus allowing them to serve more people than they could otherwise, owing to inadequate funding provided by state legislatures.

The philosophical change from institutional care, however, has not been adequately funded by government agencies (Palley & Von Hollen, 2000). Because of severe budget deficits in most states, and the continued slashing of funds allocated for human services, the trend toward institutionalization could return. While families usually try their best to meet the ever-changing needs of their family member with disabilities, they sometimes must reach out for assistance. If essential supports are not there, institutionalization may be the only option.

Due to increasing demand for developmental disability services, in 1999 the State of Utah Division of Services for People with Disabilities developed a formalized weighting instrument to prioritize the need of individuals on the waiting list. When eligible individuals require supports, they may choose to have their needs met in the community, which at present means being placed on the immediate service needs waiting list, or they may choose placement in an ICF/MR. For families in crisis, ICF/MR placement is often the only feasible option.
when funding for community services is not available. After recently contacting all the ICF/MRs in the State of Utah, however, the primary researcher found openings rare, with waiting lists at most facilities.

Parents surveyed by Llewellyn, Dunn, Fante, Turnbull, and Grace (1999) noted the lack of available placements as a frustration. They stated that options for out of home placements funded by the government were dwindling, and there were no alternatives for families who could not pay privately for residential services. Llewellyn et al. reported that "families felt strongly that this was unreasonable, and that placement options should be available if that is what families wanted and needed" (p. 43).

Supports needed by families to assist them in keeping the individual with DD/MR in their homes and communities change with each stage of life; stages of the family's life as well as stages of the individual's life (Baker, Blacher, Kopp, & Kraemer, 1997). Infancy and childhood bring rewards and challenges different from those of the teen, adult, and elder years. If families could be guided through planning issues that arise at each life stage, including the possibility that state developmental disability agency funds may not be available, alternatives to institutionalization might be investigated.

The extent to which families in Utah have already planned for the future, and areas of planning for which assistance or information is required, is unknown at this point. During my eight years as an intake and support coordinator in the Northern Region, families have often stated that they have not thought of the future, especially in the area of living arrangements. Sometimes it is a surprise to
families when the individual with DD/MR suggests that they want to live on their own in the community. Many parents affirm that they have not considered options other than having their child remain at home with them.

Guardianship is one area in which caregivers indicate familiarity. This aspect of future planning is being raised more often during Individual Education Plan (IEP) team meetings at the high school level. Some parents attest to confusion about the necessity of obtaining guardianship, however, as they have been given advice both for and against this action.

The shortage of government funding of services for individuals with developmental disabilities, coupled with the increasing number and longevity of persons with disabilities, increases the importance of future planning for these individuals. This study surveyed families of individuals with DD/MR who are currently receiving, or on the waiting list to receive, services through the State of Utah Division of Services for People with Disabilities. Participants were asked about the current status of their planning to meet the future needs of their family member with developmental disability, information needs they may have to facilitate future planning, obstacles to planning, and formats for information presentation that would be most conducive to conveying and retaining the knowledge. Results will be utilized by the Division to offer essential information to families to assist them in planning for a smooth continuum of life-long supports for individuals with developmental disabilities.
The following definitions are provided:

**Caseworker**: A worker from the state developmental disability agency who assists families in deciding upon supports that can be of benefit to their unique individual and situation, advocates for the individual’s best interests, and monitors services to assure they are being implemented as desired by the individual and family. See Support Coordinator.

**DD**: Developmental disability.

**DD/MR**: Developmental disability/mental retardation.

**DD/MR Waiver**: The Medicaid approved plan for a state to provide home and community-based services to persons with developmental disabilities in lieu of institutionalization in a Title XIX facility. The U.S. Department of Health and Human Services Health Care Financing Administration and the state Division of Health Care Financing must approve the waiver request. Waiver services include supports and services paid in part by federal Medicaid funds such as respite, community living, day/work support, employment, family support, and other services or items as identified by physicians or disability professionals.

**Developmental Disability**: Disability attributable to mental retardation, cerebral palsy, epilepsy, autism, another neurological or other condition closely related to mental retardation that begin before the age of twenty-two and are likely to continue indefinitely.

**Division**: State of Utah Division of Services for People with Disabilities.

**DSPD**: Division of Services for People with Disabilities.
Guardian: Someone appointed by a court to be a substitute decision maker for a person deemed to be incompetent of making informed decisions. The powers of a guardian are determined by a judge and may be limited to certain aspects of the person's life.

ICF/MR: Intermediate Care Facility (for persons with) Mental Retardation.

IDEA: The Individuals with Disabilities Education Act. IDEA is a Federal legislation requiring a free and appropriate public education for all students, requiring states to provide students with disabilities adaptations and education in regular classrooms or the least restrictive alternatives possible.

IEP: Individual Education Plan.

Individual Education Plan: A plan of education for a student with disabilities made with a team of people, including the student, the parent(s), the teacher, and other individuals who have interaction with the student. This planning meeting is held on a yearly basis.

Informed Consent: A decision based on knowledge of advantages and disadvantages and implications of choosing a particular course of action.

Medicaid: A federal funding source that requires a state match authorized under Title XIX of the Social Security Act that provides health care assistance to qualified persons. In addition, other available medical benefits are outlined annually in a Medicaid State Plan and include many different health-related services.
Mental Retardation: A type of disability manifested by significantly below average intellectual functioning (e.g., a score of 70 or below on the Wechsler Intelligence Scale for Children or Adults, WISC III or WAIS III or a score of 68 or below on Stanford-Binet, Fourth Edition) existing concurrently with related limitations in three or more adaptive skill areas: self-care, expressive and/or receptive language, mobility, capacity for independent living, self-direction, or economic self-sufficiency.

MR: Mental retardation.

Natural Supports: The family and people in the community who provide support or services at no charge to the person with a disability.

Provider or Provider Agency: The person or company that contracts with the state agency to deliver supports to a person or people with disabilities.

Social Security: A federal program that provides income to individuals and their family members if the individual has worked and paid into the social security program. Benefits are figured according to the amount of money the person has paid into the system over their lifetime in the workforce. Benefits are paid to the surviving spouse and children under the age of 18 years and to disabled children for the rest of their lives.

Special Needs Trust: A trust set up for the benefit of an individual with developmental disabilities. The trust may be used for the supplemental needs of the individual and is not designated to be used for the support of the person.

SSI: Supplemental Security Insurance.

Support Coordinator: See caseworker.
Supplemental Security Insurance: The income individuals with DD/MR receive from federal benefit programs sponsored by the Social Security Administration.

Title XIX (Medicaid): The federal program that provides funding for programs and services to be offered to persons with developmental disabilities.

Transition: A time of change from one family stage to another. Used by school districts and disability agencies to refer to the age at which mandatory school services end and eligibility-based adult services begin.

Trust: A legal financial document outlining the assets of persons and their distribution in case of their death or incapacity.
In studying families, it is necessary look at the ways in which life events are interpreted by society. Life course theory defines circumstances in an individual's and family's life based on social and historical occurrences (Kain, 1993). Society fashions both personal and social meaning from life events based on several factors. These include the point in the individual's and family's life in which significant events occur, the era in which the person is born and the family lives, and the social norms at the time.

Life course theory divides time into ontogenetic, generational, and historical units (Bengston & Allen, 1993; Price, McKenry, & Murphy, 2000). Ontogenetic time refers to the individual's development over time: change as the person acquires, and loses, skills from infancy to death (Bengston & Allen; Klein & White, 1996). It also refers to the family's stage of development, and the length of time they are in each stage, as well as the cohort group (e.g., Baby Boomer or Generation X) to which each family members belongs (Bengston & Allen; Price et al.). Generational time looks at the individual's position within the family: their role, expectations, and identity within that changing role throughout life (Bengston & Allen; Klein & White; Price et al.). Historical time refers to the events within the period or era that influence decisions of the individual or family (Bengston & Allen; Kain, 1993). For example, during the depression era, it was common practice to place children with DD/MR into institutional settings. This
was a socially accepted and approved way of handling the event of the birth of a child with developmental disabilities (Baker, Blacher, Kopp, & Kraemer, 1997).

Social change, brought on by family, societal, and economic reconstruction, made this practice unacceptable by the early 1970s. At that time, a movement to get individuals with DD/MR out of institutions and back into local communities began.

Conceptually, life course theory can help researchers understand how variables outside of an individual can cause certain events in the person's life. Empirically, using life course theory can help researchers map out their questions and the direction of their research. They can consider the perspective from which they will look at a problem, and take historical events and popular culture into consideration when devising their research strategies and questions. Considering the multiple factors that can influence an individual's development increases the validity of research results. Because life course theory uses a multidisciplinary approach, it can be applied to most social research topics to achieve a more global view.

Practically, it makes sense to use a life course perspective to incorporate all variables impacting the topic under consideration. Researchers can also use data from previous studies to complement current research (Kain, 1993). Using information collected generations ago, or in a diverse culture, can assist investigators in defining societal and cultural differences, or with recognizing the factors that have affected individuals during distinct periods of their lives. The life course perspective allows those who study family issues to analyze many
aspects of an individual's development by considering multiple time frames, including personal change, family events, and historical occurrences; thus providing a more complete picture of the issue being studied.

Life Course Planning

Taking a life course perspective, the current study gathers ontogenic and generational information about individuals with DD/MR and the caregivers with whom they live. Information is gathered about the person's position within the caregiving setting, the relationships between the individuals in the home, and their roles within the family unit. It also examines aspects of caretaking such as the type and amount of care the person with DD/MR requires, and their specific disability.

The extent of planning that has occurred, and the barriers to planning efforts, are influenced by the societal context and era in which we live as well as by broader historical events that are occurring every day. For example, a 26-year-old person with DD/MR who lives with his mother, father, and younger sister, has unique planning needs. The parents may assume that the sister will shoulder caregiving responsibilities if something happens to one or both of them. If the sister is a member of the armed forces, and has been deployed overseas to serve in a war, world events change the situation dramatically. With economic factors affecting the parents' retirement assets, and no funding for residential supports through the state developmental disability agency, other arrangements must be considered.
Family members are most familiar with the individual with developmental disability, and see them in a variety of settings throughout their life. Their perception of the individual's abilities and skills can be very astute and advantageous in planning long-term goals at different stages of the person's, and the family's, life course (Thorin & Irvin, 1992). Families usually know what type of services and supports they would like to have available to meet their child's unique needs, both before and after leaving the school system (McDonnell, Wilcox, Boles, & Bellamy, 1985). If parents have not planned for their own eventual incapacitation or death, however, their wishes regarding their child's future may remain unknown. Quality support and education must be offered to families to facilitate their participation and follow-through in the planning process (Goodall & Bruder, 1986; McDonnell & Hardman, 1985; McDonnell, Wilcox, & Boles, 1986).

State developmental disability agencies offer eligible individuals funds for supportive services, such as respite, family support, day programs, or community living assistance. These supports are presumed to effectively buffer stress and assist families to keep the individual with developmental disability in their home or local community, rather than placing them in an out-of-home situation, such as an institution or an intermediate care facility for persons with mental retardation (ICF/MR) (Baker et al., 1997; Blacher & Baker, 1994; Braddock, 1999; Desrochers, Hile, & Williams-Mosely, 1997; Hanneman & Blacher, 1998; Haveman, van Berkum, Reijnders, & Heller, 1997; Heller, Miller, & Hsieh, 1999; Lakin, 1998; Llewellyn et al., 1999; Richardson & Hawks, 1995; Seltzer & Heller, 1998).
Developmental disability agencies operate on budgets funded by state legislatures; and appropriations for disability services, already sparse, continue to be slashed. In the 2002-2003 fiscal year, funding for developmental disability services in the State of Utah was cut by 4.8% (M. Rasmussen, personal communication, July 31, 2003). In the 2003-2004 fiscal year, this already reduced budget was cut by another 6% (M. Rasmussen, personal communication, July 31, 2003). Because families can no longer rely on their state or federal governments to be there with funding when the care needs of their family member with developmental disabilities become too great, planning for the future is essential more now than ever before.

Having a child with developmental disability brings special challenges to families at all stages of life. They must face a future with a child who may never be totally independent, and who may require caregiving supports throughout life. Planning for that type of future, however, is not easy. Families become used to the government providing the special services required by their family member with DD/MR. This assumption is supported by the provision of early intervention supports and school special education services. After the transition from school services, however, families are often surprised by the sudden cessation of assistance they have relied on for over 20 years (Fee, 1999). They may be unprepared to handle the daily care they must provide to the individual with developmental disability if government assistance is not available for an adult day program, supported employment, or necessary respite services.
Families may receive Social Security benefits to assist with the individual's living expenses, but the cost of the average adult day program, ranging from $27.90 to $74.16 per day (G. Truhn, personal communication, July 14, 2003), is prohibitive to most families. It is nearly impossible for an average family to pay for this support, especially on a lifetime basis (Varnet, 1988). Even if the person's entire SSI benefit were used to pay for day services, it would not cover the costs. For example, the maximum SSI benefit that can be received each month in the State of Utah is $552 (Department of Workforce Services, personal communication, July 14, 2003). If a day program cost $30 per day, four weeks of weekday attendance would amount to $600: $48 more than the person's income for the month.

It has been shown that caregivers with a strong network of natural supports, such as family, friends, and neighbors, are less likely to consider out of home placement for their individual with developmental disability (Freedman, Griffiths, Krauss, & Seltzer, 1999). While natural supports could mitigate the need for placement by lessening perceived caregiver stress (Greenberg, Seltzer, Kraus, & Kim, 1997; Hanneman & Blacher, 1998), our highly mobile society often results in relatives being located quite far from each other. This limits the ability for shared caregiving responsibilities by family members (Hand & Reid, 1998). When natural supports are not available, families often turn to the state developmental disability agency to request formal supports from a provider agency (Smith, 1997).
While families may wish to care for their family member at home, there may be circumstances that prohibit this endeavor. Klein and White observed that "if a family or individual is 'out of sequence' with the normative ordering of family events, the probability of later life disruptions is increased" (1996, p. 132). For example, subjective appraisals of caregiving burden increase when the individual with developmental disability is diagnosed with a coexisting mental illness or physical health problem (Baker et al., 1997; Heller, Hsieh, & Rowitz, 1997). Mental illness and other behavioral problems make daily life more uncertain for family members due to the unpredictability of the person's actions (Greenberg et al., 1997; Pickett, Cook, Cohler, & Solomon, 1997). Heller et al. further stated that problem behaviors are a major determinant of subjective burden among caregivers. Externalizing behaviors, such as aggression and severe tantrums, are very serious behavioral manifestations with which caregivers find it difficult to cope (Baker et al.). The increased stress on the family caused by this abnormal life course event may result in an out of home placement as a coping mechanism to keep the family unit intact (Blacher & Baker, 1994; Klein & White).

Another reason that families may be unable to care for their family member at home is increased longevity of persons with developmental disability, which has resulted in more individuals with developmental disabilities outliving their parents or living with aged caregivers (Bigby, 1996; Lakin, 1998). Twenty-five percent of individuals with DD/MR live with family caregivers who are over the age of 60 years, and 35% live with caregivers between the ages of 41 and 59 years (Braddock, 1999). Thus, caring for an adult with DD/MR has become a
normative experience for many of their mid- to late-life parents. Older parents usually do not see a need for formal services unless they are unable to care for the person themselves (Smith, 1997). However, some of them will live long enough to need help to continue their own independent lifestyle, and may need to plan for this eventuality.

It has been shown that over 60% of persons with developmental disability live with family members until a crisis occurs (Fee, 1993). Many families do not plan for a future in which the primary caregiver will not participate. It is apparent that, as parents age and become unable to meet the demands of caregiving for their adult child, alternative arrangements should be made (Pruchno, Patrick, & Burant, 1996; Seltzer, Greenberg, Krauss, & Hong, 1997; Smith, 1997). It is often not understood, however, that planning for the future is important at each life stage, as family circumstances change due to life events, and the factors of stress and coping.

The normative societal concept of a family begins with the birth of a child. The life course of the individual child then progresses through their childhood, teen years, young adulthood, and older adulthood. Significant life course events are dictated by the social norms for families, with the time spent at each stage predicting when transitions, or shifts from one stage to another, should occur (Klein & White, 1996).
Stage 1: Childhood

If the child receives a diagnosis of developmental disability at birth or shortly thereafter, medical supports may be the first service required (Heller et al., 1997). Medical insurance is a must for individuals with medical and related needs, which is often why the state developmental disability agency is approached during early childhood. The Medicaid card that is granted with the Title XIX DD/MR waiver program covers most medical needs, surgeries, and items such as wheelchairs. For families with no insurance, Medicaid acts as a primary insurance. For those with additional health insurance, Medicaid is a secondary or tertiary source of support.

Gathering information about the disability, and attending infant programs, are often the next steps for parents of children with DD/MR between birth to three years of age (Baker et al., 1997). Supports are offered to assess the child's level of developmental delay, as well as to educate parents about the disability and ways in which they can assist their child to make progress. Early intervention services follow infant programs, and are offered through school districts for children from the ages of three to five years of age that have, or are at risk of acquiring, a developmental disability. The transition to elementary school occurs when the child reaches the age to enter kindergarten. At this point, the person's special education program begins in earnest, and may continue until the person is 21 or 22 years of age, depending upon the state in which the person resides. In the state of Utah, eligible individuals with developmental disabilities who have
not earned enough credits for high school diploma may remain in school until they turn 22 years of age (Utah Code Annotated 53A-15-301).

Out of home placements are very rare in the elementary-aged population of children with developmental disability, even though research has shown that subjective caregiving burden and time demands are highest at this stage of the child's life (Haveman et al., 1997; Heller et al., 1997; Smith, 1997). Children with complex medical issues, however, may require placement in a facility that can meet their intensive physical and medical needs (Brun, 2000).

Other than therapeutic needs, the most common services requested by families at this point are respite and summer daycare assistance. While daycare costs are a responsibility of every family with children of this age, it is sometimes very difficult to find a daycare provider for children with developmental disabilities who have accompanying maladaptive behaviors or specialized health needs. Families are loathe to leave their children with people who may not be familiar with handling the behaviors exhibited by their child, or who might not fully understand their unique health and safety issues.

State agencies contract with private providers of respite and summer activity programs who are familiar with the particular needs of individuals with developmental disability. Because costs for specialized respite and day supports usually exceed the amount that parents can afford to pay out of pocket, the state developmental disability agency may be approached to pay for these supports, which bring much relief to families. These resources are an important source of assistance for low-income families, whose finances are usually strained in an
attempt to provide needed care for the person with developmental disability (Harmon, 2001c; Smith, 1997).

A normal life course event at this stage in a middle to upper class child's life is the beginning of a college fund to assist with expenses upon their entry into post high school education. Parents of persons with DD/MR may begin a similar fund, using a special needs trust, to build an account to pay for their child's adult day program and other necessities if government funding is not available when their child leaves the school system. Special needs trusts are an important form of planning, because persons with developmental disability may never be capable of supporting themselves (Varnet, 1998b); and parents want to ensure that their children will have the necessary funds available to maintain comfortable lives when they are gone (Fee, 1999; Pearce, 1993). While parents often do not like to think of their own mortality, it is especially important to plan in advance when they have a child with developmental disability. Guardianship arrangements should be investigated at this stage of the child's life in case of early parental death (Fee, 1993, 1999).

During the teen years, children with developmental disability continue their public education provided for under the Individuals with Disabilities Education Act (IDEA). At the end of the senior year of high school, when the student is around the age of 18, school services usually shift from an academic-based approach to a vocational focus. The "post-high" program continues until the age of 22, when the individual faces another transition: this one to adult services. Because individuals with disabilities in the State of Utah are entitled to a free, appropriate
public education between the ages of three and 22 years (Utah Code Annotated 53A-15-301 (1) (a)), Division policy does not allow payment of day program supports prior to the age of 22.

Out of home placement at this age is most often the result of intense care needs for an individual with severe disability (Baker et al., 1997) or extreme maladaptive behaviors (Heller et al., 1997). Parents may be physically and emotionally unable to deal with the intensive needs of their developmentally disabled child (Baker et al.; Haveman et al., 1997; Seltzer, Greenberg, Krauss, & Hong, 1997; Smith, 1997). The "child" is now adult-sized; and, if they are aggressive, they can harm themselves or others. Destruction of property, socially offensive behavior, and defiant behaviors are some common maladaptive behaviors in this population.

The normal life course process for families at this stage of life involves the preparation for their teenager to leave home and begin independent adulthood. At the point when most parents are looking forward to their children leaving home to go to college or embarking on an independent life, parents of individuals with developmental disabilities are realizing that they will never be in that position with this child. The non-normative task of continuing to provide caregiving for an adult child may increase family stress and may compromise their ability to cope with the situation. Looking ahead at the responsibility of the care of the person for the remainder of their lives can result in a sense of dismay and hopelessness when trying to deal with dangerous behaviors.
While the societally aberrant task of caregiving for their adult child may seem overwhelming to some parents at this stage of the life course (Haveman et al., 1997), children with developmental disability also understand that they will not have a "normal" life like the rest of their peers. The breach of expected life course events may cause internal stress in these individuals (Cook, Cohler, Pickett, & Beeler, 1997). Their peer group is graduating from high school and going on to live independently; perhaps obtaining employment, entering college, serving missions for their churches, or enlisting in the armed forces. Persons with developmental disabilities are told that they are going to four more years of school. They are not going to be able to move out, because they cannot take care of themselves; and they may not be safe in the community without supervision. If interested in serving the religion of their choice, it must be in a different capacity than other people their age. Serving in the military is not an option due to their disability.

If the person's family has been able to meet all their needs up until this point, they are introduced to the state developmental disability agency and possible support options during IEP meetings at the school. It is essential for families to get the individual on the waiting list for supports so that the developmental disability agency can project the upcoming need into their budget request to the legislature.

Planning needs at this stage of life include looking ahead to the person's life after school services end, and addressing the issue of long-term day supports and living arrangements. Researching guardianship issues and types of trusts to
provide for the long-term needs of the person with DD/MR are essential planning aspects of this stage of life (Fee, 1999). Pearce (1993) recommended that families create an explicit long-term plan and review it at least once a year to ensure accuracy.

*Stage 2: Young Adulthood*

The early years of adulthood are the juncture at which support patterns for individuals with developmental disabilities diverge. Up to this point, school services, which are mandated by federal and state governments, have provided each person with specialized supports based upon their unique needs. The severity of disability guides service requirements for each person beyond the transition from school-based services. Supports at this point are eligibility based, and contingent upon the availability of funding allocated to the state disability agency by the legislature.

Institutional and family norms at this point in the life course focus on work and education (Klein & White, 1996). Individuals with DD/MR that are capable of employment may seek assistance from a variety of sources to locate and maintain a job. Family contacts and religious and private employment agencies, as well as state rehabilitation offices, are options for short-term support in this endeavor. Each alternative may help the person with developmental disability to locate a suitable job placement, and provide job coaching and intervention to enable the person to learn the skills necessary for that position. If long-term job supports are required, however, the state developmental disability agency is
ordinarily approached to provide ongoing funds to assist the person with supports necessary to keep their job, such as job coaching or social skills development.

Those with moderate to severe developmental disabilities, though, customarily rely on the state disability agency to assist with funds for a day program at a work activity center or sheltered workshop. These supervised habilitation programs offer a variety of activities to increase the individual's independence with daily living, social, behavioral and communication skills. Transportation services that enable the person to get to and from their day program are an additional support requested in conjunction with day services.

Out of home placements at this stage are attributable to many factors. If funds to pay for adult day programs are not saved in a special needs trust or received from the state developmental disability agency, parents generally are unable to quit their jobs to ensure that their child is supervised around the clock. Finding daycare for an adult often is nearly impossible. When someone can be found to watch the person, the cost may be prohibitive. If the ceaseless caregiving burden has increased, and the person with developmental disability cannot be left unsupervised due to safety issues, the cumulative effect of stress due to the disruption in the normal life course of the family may lead to institutionalization of the individual with DD/MR (Greenberg et al., 1997; Hanneman & Blacher, 1998; Klein & White, 1996).

Planning needs at this stage of life are similar to those of the teen years. If guardianship was not obtained around the age of 18, now is the time for it to be considered. The issues of long-term day supports, living arrangements, and
trusts continue to be essential planning aspects at this stage in the life course. Even though it may be the family's inclination to care for their individual with developmental disability on a life-long basis, Seltzer and Greenberg (1997) encourage families to make alternate arrangements for residential care in the case of an unforeseen decline in parental health. The plan suggested by Pearce (1993) continues to be an appropriate way to formalize long-term arrangements.

Stage 3: Older Adulthood

Older adulthood presents its own set of difficulties, as both parents and the individual with developmental disability are aging (Bigby, 1996; Smith, 1997). This is the time of life when future planning makes the most difference. While out of home placements in childhood or the teen years can be attributed to severe maladaptive behaviors on the part of the child with developmental disability, placements in adulthood often are the result of a lack of planning or crisis situations (Bigby). Formal planning may not have been done if parents assume that a sibling or relative will take care of the individual if they are no longer able (Baker et al., 1997; Griffiths & Unger, 1994; Jaffe-Ruiz, 1984). Klein and White (1996) noted that societal norms expect siblings to watch out for each other. These family members may not be able or willing to assume such a responsibility, however, and an institutional setting may be all that is available at the time of need. Jaffe-Ruiz (1984) observed that siblings often feel that they have responsibilities, but not many rights, when it comes to future planning issues for their brother or sister with DD/MR.
Planning needs at this stage of the life course center around the issues of long-term financial, medical, and living arrangements. If proper planning has not been done, individuals with developmental disabilities may be forced to move to an institutional location if they are unable to obtain community supports through the state disability agency.

With suitable guidance, families can make sound plans so that the person with developmental disability does not have to move to an institutional environment or suffer a decrease in the quality of their life upon the incapacitation or death of their parents or primary caregiver (Fee, 1999; Harmon, 1999, 2001a; Pearce, 1993; Seltzer, Greenberg, Krauss, & Hong, 1997; Varnet, 1988, 1998a, 1998b; Vogel, 1998). While it may be essential for families to plan so that they may pay privately for supports, if and when funding from the state developmental disability agency becomes available, it is imperative that the person with disabilities is not deemed ineligible for supports due to an excess of benefits, or because of poor planning (Varnet, 1988, 1998a, 1998b; Vogel).

The current literature regarding studies of future planning for individuals with developmental disabilities is very sparse. Bigby (1996) surveyed families of 62 adults with intellectual disability that had moved away from the family home at an average age of 52.5 years to determine the status of their future planning efforts. Her findings suggest that parents frequently make informal, sporadic plans for succession of caregiving. Often they had designated someone to assume responsibility, although not necessarily to provide care, for the individual with mental retardation. Residential plans had been made by 30% of the parents.
surveyed in her study. These plans included placing the name of the individual on a waiting list for community residential services and arranging for a sibling or other relative to assume caregiving responsibilities. Financial plans made by the families were usually elementary wills that designated a sibling as the main recipient, with the understanding that they would provide for the person with DD/MR.

Bigby's (1996) study queried the actual implementation of the plans to determine whether they were successful. Results showed that about a third of residential plans made were changed. Over half of the sample had moved at least once since the designated arrangement, with a little under half moving two times, and several individuals had changed residential placements three or more times. Overall, the results indicated that residential planning does not equate with success or stability in future placements. It also was apparent that parents relied heavily on informal caregiving arrangements and conducted financial planning more than residential preparation (Bigby; Campbell & Essex, 1994).

Although research demonstrates that there are reasons for the importance of future planning, and indicates the rationale behind the lack of planning, there has not been a comprehensive study of the current status of families regarding future planning for their family members with developmental disabilities who remain at home.

While areas important to planning for the future have been delineated, the readiness of families has not been queried. Requesting information from families of individuals with developmental disabilities regarding their current planning
status, the areas in which they require assistance for planning, the barriers to planning, and the preferred methods of presentation of planning information, will yield useful information for agencies and families alike in their quest to improve the quality of life for individuals with developmental disabilities.

Barriers to Planning

There are several practical reasons for the dearth of planning for future caregiving. They include a lack of knowledge about the components of planning, uncertainty over where to begin the planning process, concern over the costs involved with planning, and the need for a knowledgeable attorney and/or financial planner (Brunetti, 1995; Heller, 1998; Varnet, 1988, 1998a; Williams, 1999). Parents also have different levels of energy, education, and problem-solving abilities (Brotherson, Berdine, & Sartini, 1993; Seltzer & Heller, 1997).

Emotional issues, including pride, the denial of one’s own mortality, and the discomfort associated with the planning process, may interfere with future planning (Harmon, 2001b; Varnet, 1998b, 1999). Physical and emotional stress brought on by the challenges of providing daily care to an adult child with developmental disabilities also influence the process. Caregiving is a time-consuming, often unrewarding, experience for families (Haveman et al., 1997; Heller, 1997; Heller et al., 1997; Pruchno & Patrick, 1999; Pruchno et al., 1996; Seltzer, Greenberg, Krauss, & Hong, 1997; Seltzer & Heller, 1997; Smith, 1997).
Knowledge Aspects

Campbell and Essex (1994), in their interviews with parents and other caregivers for individuals with developmental disabilities, found that a major barrier to future planning was lack of knowledge. Smith (1997), in his study of aging families of adults with mental retardation, found that information regarding permanency planning issues, including guardianship and financial planning, was cited as the greatest unmet need of parents. While families may understand that planning for the future is critical, they might not have received information regarding the essential components, thus contributing to their feeling overwhelmed and unprepared. Campbell and Essex found that caregivers felt uninformed about the availability of state services. The caregivers noted that the professionals on whom they relied often seemed to be unfamiliar with future planning issues. Parents sometimes received conflicting messages about what services or supports were important in their unique circumstances. Often one professional would advocate for a service, such as obtaining guardianship, yet another professional would oppose the action, thus confusing families about the planning process.

Once families begin to consider planning for the future of their family member, they realize that there are several components to the planning process. They may feel overwhelmed by the complexity of legal, financial, habilitation, residential, medical and guardianship issues (Russell, Grant, & Joseph, 1993). This can result in uncertainty over where to begin the daunting task of future planning and make it easier to justify postponement of the procedure.
Financial Aspects

The cost of obtaining legal advice and services is another reason cited by families as an explanation for deferment of permanency planning. Security and peace of mind, for both parents and the individual with DD/MR, is one benefit of having an accurately composed estate plan (Rotman, 1986). Another benefit is retaining the money that would have been lost due to court costs and lawyers' fees to settle an estate with no plan in place. It is also possible that a correctly drawn will may lessen estate taxes (Harmon, 2001a; Marzluf, 1995). While caregivers may worry that legal planning can be a prohibitive expense; the cost of not having a will properly drawn may surpass any current monetary consideration (Thorp, 2002).

Harmon (2001b) noted that when a parent dies without a will, any decisions they may have made regarding guardianship, habilitation, and residential issues for their child with a developmental disability may never be known or honored. He asserted that laws concerning estates and wills rarely consider the special circumstances of parents who have a child with developmental disabilities. Finding a lawyer versed in the special aspects of disability law can be a formidable task (Williams, 1999). Prior to having any type of will or trust drawn up, families should investigate whether their chosen attorney or financial planner has experience in this area (Schlesinger & Scheiner, 1992; Varnet, 1988, 1998a; Vogel, 1998). If a will is not properly drafted, it can result in the loss of government benefits for the person with DD/MR, thereby decreasing their overall quality of life or standard of living (Daugherty, 1999; Thorp, 2002;
Varnet, 1988, 1998a, 1998b; Vogel). If persons with developmental disabilities inherit estates large enough to exceed the asset cap for SSI and Medicaid, they can lose not only these benefits, but their community-based supports as well.

The State of Utah Division of Services for People with Disabilities' policy (2000) states that if a person cannot participate in the Medicaid program, they will receive only the state portion of funds allotted for their supports. This action would result in an automatic 70% reduction in already minimal funding for needed supports.

*Emotional Aspects*

Emotional issues also interfere with future planning. Some families are fiercely independent and do not want to rely on the government to provide assistance to them or their family member with a disability. While this is a noble thought, the reality is that the cost of residential and/or community services have increased to the point that it's nearly impossible for families to leave a large enough estate to pay for supports needed over the disabled person's lifetime (Varnet, 1988). Other families may not want the government to know too much about their personal dealings. They commonly refuse to share any information regarding their personal income, finances and assets; information that is required to be disclosed in order to qualify for government benefits.

Often, the day to day routine of caring for an individual with developmental disabilities is a time-consuming and emotionally exhausting effort for families. They do not have time to think about future planning, because managing today is
all they can handle (Baker et al., 1997; Harmon, 2001b). Caring for a child is a non-normative life course task once the child reaches adulthood, and families spend an average of 15-30 hours per week meeting the care needs of their adult with developmental disabilities (Haveman et al., 1997). Braddock (1999, p. 158) noted that the aging of society directly influences the demand for developmental disability services. He stated, “As the lifespan of persons with developmental disabilities increases, they require long-term care for longer periods of time.”

Many people find it hard to confront the thought of their own mortality (Harmon, 2001b). They are not comfortable with the planning process, because it upsets them to think about someone else caring for their child. They often feel that no one could care for their child as well as they have, and when they do not have anyone they can trust to take over the caregiving role, it adds to their stress (Varnet, 1998b). Conversely, planning may not occur because caregivers think that family members know what they want to have happen after they become unable to continue caregiving duties or upon their death. They may assume that other family members will take care of the person with developmental disabilities (Gorelick, 1996). Often these assumptions are erroneous. When planning for the future, it is very important for caregivers to communicate with everyone their expectations regarding the future of the person with disabilities (Brunetti, 1996a, 1996b; Fee, 1999; Gorelick; Griffiths & Unger, 1994; Pearce, 1993).
Information Required for Future Planning

Although few studies have been conducted that show how people plan or the extent to which they plan (Griffiths & Unger, 1994), some private businesses, journals, and individuals concerned with future planning issues have developed educational materials or websites dedicated to special needs planning. For example, Met Life, an insurance company, has worked in conjunction with Exceptional Parent magazine to place information on the website www.Eparent.com. MetLife has their own division, called MetDESK (MetLife's Division of Estate Planning for Special Kids) that is specifically geared to special needs planning. This information is available on their website, www.metlife.com/Desk/Docs/division.html. Another website with information geared to assist caregivers is www.Caregiver.com. This site also has information regarding the importance of future planning along with specific information about documents that should be prepared.

Thorp (2002) has prepared a comprehensive overview of estate planning considerations for individuals with disabilities. His target audience for the article is attorneys who represent families with members with disabilities, but it is written in a manner easy to interpret by families and others with an interest in future planning for individuals with disabilities. The article encompasses life planning issues such as ethical problems, fallacies in planning, the importance of a team approach in planning, cost issues, psychological issues, living arrangements, education, employment, social activities and quality of life issues. Different types
of public assistance are explained, as is the process for administrative appeals of denials. The article also focuses on guardianship, wills, trusts, and tax implications in planning, and it outlines how to start making a special needs plan.

Future planning for individuals with developmental disabilities should be adjusted to reflect the different life stages of persons and their families (Pearce, 1993). This life-course perspective reflects the complex nature of the demands of caregiving and how they change depending upon the stage of the family, the obligations of family life, and the unique demands of the disability type (Seltzer & Greenberg, 1997).

Families of individuals with DD/MR usually have been involved with special services from the time that the disability was identified. This could be as early as birth, or upon entering an early-intervention program between the ages of three to five years. During that time they have attended so many meetings and received so many booklets, pamphlets, and letters, that information overload may occur long before the individual reaches adulthood. Perhaps parents and families would respond better to a different method or timeline for information about future planning. A study is needed, therefore, to examine family information needs regarding future planning and preferences in regards to conveying the information about these issues. The outcome would be a method of presenting the information to families that would fulfill their unique needs, captivate their interest, and result in action.
Objectives

Objectives of this study include discovering the answers to the following questions: (1) What is the current status of future planning preparation of caregivers with an individual currently either on the waitlist or in Division services? (2) In what specific areas (i.e., financial, medical, residential, and emotional) do caregivers require assistance or additional information to facilitate future planning for their individual with developmental disability? (3) What are barriers to future planning? (4) What are the preferred formats for presentation that would be most conducive to conveying and assisting families in retaining essential planning information?
CHAPTER III
METHODS

Research Questions

A descriptive study design was used to gather information from caregivers with whom individuals with developmental disabilities over the age of 20 years lived. The person with DD/MR was either on the waitlist for, or already receiving, services through the Division of Services for People with Disabilities in the State of Utah. The approach for this study was selected to examine these research questions.

Research question #1. In which areas have caregivers currently planned regarding the future of the person with developmental disabilities (DD/MR)?

Research question #2. In which areas of planning do families require assistance?

Research question #3. What are perceived barriers to planning for the future of the individual with DD/MR?

Research question #4. What are preferred delivery methods for future planning information?
The sample consisted of caregivers or families of individuals with developmental disabilities over the age of 20 years who were either on the waitlist for, or received services through, the State of Utah Division of Services for People with Disabilities. Caregivers of individuals with birthdays prior to 1983, who were identified as living at home by the State's computer system, were surveyed to determine the influence of life stage on the status of future planning. This cutoff was chosen because as individuals with developmental disabilities approach the age of 22 they transition from mandatory school services, which provide six hours of support each day, to eligibility- and funding-based services provided through the state. This is the age at which parents or caregivers are forced to consider the future of the person, at least as it pertains to day or vocational supports.

The sample was purposive and included the desired population known within the study area. Of the 1,197 surveys originally sent, 219 were returned because of address problems. While 155 were sent again to forwarding addresses, no new addresses could be found for 64 individuals, reducing the survey size to 1,133. Additionally, 29 of the forwarded surveys were returned with no other address available, reducing the sample size to 1,104. Once the surveys were returned, 55 were deemed ineligible due to the current living situation or age of the person with DD/MR. The final eligible sample size was determined to
Three hundred ninety-seven of the returned surveys met the criteria of the study and were included in analyses, yielding a return rate of 37.8%.

Sample Characteristics

With a final sample size of 397, data first were analyzed for general demographic information. Table 1 specifies the distribution of survey returns broken down by region of the state. Central Region includes Salt Lake, Summit, and Tooele Counties. Northern Region encompasses Box Elder, Cache, Davis, Morgan, Rich, and Weber Counties. Western Region is comprised of Beaver, Garfield, Iron, Juab, Kane, Millard, Piute, Sanpete, Sevier, Utah, Wasatch, Washington, and Wayne Counties. Eastern Region enforms Carbon, Daggett, Duchesne, Emery, Grand, San Juan, and Uintah Counties. A map outlining the regions of the Division is included as Appendix A.

Table 1

Distribution of Returned Surveys by Region (n = 397)

<table>
<thead>
<tr>
<th>Region</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central</td>
<td>149</td>
<td>37.5</td>
</tr>
<tr>
<td>Northern</td>
<td>122</td>
<td>30.7</td>
</tr>
<tr>
<td>Western</td>
<td>103</td>
<td>25.9</td>
</tr>
<tr>
<td>Eastern</td>
<td>23</td>
<td>5.8</td>
</tr>
</tbody>
</table>
Individuals with developmental disabilities. Persons with DD/MR in this study ranged between 20 and 62 years of age, with a mean age of 31.35 years ($SD = 10.2$). Males accounted for 51.5% of the sample ($n = 394$). Most of the individuals with disabilities had never been married (99.2%, $n = 388$). Table 2 specifies types of developmental disabilities experienced by the people in the sample. Mental retardation was the most common disability recorded, with 73.5% of caregivers listing it as a diagnosis of the individual with DD/MR. Seizures were

<table>
<thead>
<tr>
<th>Type of Disability</th>
<th>$n$</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental retardation</td>
<td>288</td>
<td>73.5</td>
</tr>
<tr>
<td>Seizure disorder/epilepsy</td>
<td>93</td>
<td>23.7</td>
</tr>
<tr>
<td>Down's syndrome</td>
<td>77</td>
<td>19.6</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>61</td>
<td>15.6</td>
</tr>
<tr>
<td>Other</td>
<td>58</td>
<td>14.8</td>
</tr>
<tr>
<td>Autism</td>
<td>46</td>
<td>11.7</td>
</tr>
<tr>
<td>Mental illness</td>
<td>33</td>
<td>8.4</td>
</tr>
<tr>
<td>Brain injury</td>
<td>13</td>
<td>3.3</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>3</td>
<td>0.8</td>
</tr>
</tbody>
</table>

Table 2

Developmental Disabilities of Sample According to Caregiver Response

($n = 392$)
a reported disability for 23.7% of persons, and Down's Syndrome was noted for 19.6% of individuals. It is common for persons with developmental disabilities to have more than one diagnosed condition, so the total of these categories adds up to more than the 397 individuals from whom information was received. Other disabilities reported (15.1%) included vision impairment or blindness (2.0%), hearing impairment or deafness (2.5%), varied syndromes (4.5%), communication disorders (1.0%), and various other incapacities experienced by individuals. Most individuals with DD/MR were reported to be in excellent (15.8%, \( n = 393 \)) or good (58.0%) health, with a total of 73.8% of individuals in these combined categories. Fair health was indicated for 19.8% of individuals with disabilities, and 6.4% had poor health.

Caregivers. Caregivers that completed the survey were mostly married (75.7%, \( n = 383 \)) females (87.0%, \( n = 392 \)) who ranged in age from 30 to 87 years with a mean age of 59.1 years (\( SD = 11.4 \)). Length of caregiving for the person with DD/MR was reported by 84.5% (\( n = 393 \)) caregivers as all of the individual's life. The primary caregiver's relationship to the individual with developmental disabilities was usually that of mother (79.3%, \( n = 386 \)). These findings concur with those of earlier studies (Gorelick, 1996; Griffiths & Unger, 1994; Heller et al., 1997; Pruchno et al., 1996) that note women historically have been, and continue to be, the primary caregivers to persons with DD/MR. Table 3 specifies the relationship of the primary caregiver to the individual with DD/MR.
### Table 3

**Relationship of Primary Caregiver to Individual with Developmental Disabilities**

(*n* = 386)

<table>
<thead>
<tr>
<th>Relationship</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>306</td>
<td>79.3</td>
</tr>
<tr>
<td>Father</td>
<td>43</td>
<td>11.1</td>
</tr>
<tr>
<td>Sister</td>
<td>15</td>
<td>3.9</td>
</tr>
<tr>
<td>Other relationship</td>
<td>8</td>
<td>2.0</td>
</tr>
<tr>
<td>Grandmother</td>
<td>5</td>
<td>1.3</td>
</tr>
<tr>
<td>Brother</td>
<td>4</td>
<td>1.0</td>
</tr>
<tr>
<td>Aunt</td>
<td>3</td>
<td>0.8</td>
</tr>
<tr>
<td>Grandfather</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td>Friend</td>
<td>1</td>
<td>0.3</td>
</tr>
</tbody>
</table>

Interestingly, the number of caregivers reported to have excellent (18.3%, *n* = 393) or good (55.5%) health totaled the same percentage (73.8%) as the response to this question for individuals with DD/MR. There were more caregivers with fair health (21.9%), however, and fewer in poor health (4.3%) than reported for the persons with developmental disabilities.
Procedures

Approval for study participation was obtained through the Utah State University Institutional Review Board, and the Department of Human Services' Protection of Human Rights Review Committee. Once approval was received, the assistant research director of the State Division office in Salt Lake City compiled a mailing list using the State USSDS computer system as a means to meet criteria in sampling methods. Questionnaires were color coded to reflect the region of the State to which they were sent. If families contained more than one individual with a disability, they received a questionnaire for each person.

Each packet contained a letter on State of Utah Division of Services for People with Disabilities letterhead, signed by the principal investigators. The letter requested the assistance of the families in gathering information regarding future planning, explained the goals of the study, and stated that the results would be used to assist families with the process of future planning. A self-addressed, stamped envelope was included to encourage a prompt response, as well as to improve the likelihood of response. The letter included a contact name for questions regarding the survey, and another contact name for questions regarding human rights issues. A list of workers and phone numbers for each Division office was on the back of the letter. This option enabled survey recipients to contact a local office or a familiar person at the Division rather than having to make a long-distance phone call to the student researcher. Anonymity was ensured even in this instance, as responses to the questionnaire did not contain identifying information, the survey was sent statewide, and each survey
was assigned an identification number based on the order of its entry by one of four Division workers.

Approximately 2 weeks after the first packets were distributed, a postcard was sent to survey recipients with a reminder about the survey and its intent. The postcard requested that they complete the questionnaire if they had not yet done so and included the phone number of the primary investigator who worked for the Division in case they had questions. The postcard also stated the importance of the research, and thanked those that had participated for their contribution to the Division, as well as to all families of individuals with developmental disabilities.

Survey Instrument

The questionnaire (see Appendix B) was eight pages long and was presented in a four-page, double-sided format. The first section consisted of demographic information for both the individual with developmental disabilities and the primary caregiver. Data collected included each person's age, gender, and marital status. Also reported was the type of developmental disability, number of people in the household, and relationship between household members and the individual with disabilities. The caregiver was asked what their relationship was to the person, how long they had been caring for them, and to rate their own overall health status.

The second part of the questionnaire discussed the current status of planning for the future of the individual with DD/MR. The first section of this part asked about legal aspects of planning such as guardianship, representative
payee status, and whether the individual had a health care directive in place. The second section of this part reviewed financial issues for the person with disabilities, including their monthly income, whether or not they paid rent, and if they were claimed as a dependent on someone’s tax return. Inheritance issues, legal trusts, burial plans, and life insurance policies were also addressed. Medical aspects of planning were covered in the next section of the survey, including items such as the type of health insurance the individual with DD/MR held, overall health status, medications, and personal care assistance. The last part of the current planning status section detailed residential aspects of the individual’s life, asking what plans, if any, had been made in case the primary caregiver became incapacitated or was no longer able to provide care. Another issue addressed in this section was the involvement of the individual with DD/MR and other family members in the planning process.

The third part of the survey instrument dealt with resources, including state services, and barriers to planning for the future. Families were asked whether the individual with developmental disabilities currently received or was on the waiting list for services through the Division of Services for People with Disabilities, and if services (or additional services) would be required in the event of the caregiver’s incapacitation or inability to provide continuing care. Families were able to indicate barriers to planning and resources needed to assist in planning for the future. There also was a comment section in which the family could discuss any aspect of future planning. A note at the end of the questionnaire thanked participants and let them know that they could contact
their local Division office to speak with someone about future planning or Division services.

Data Analysis

Data were compiled by four Division workers after approximately eight weeks had elapsed from the mailing of the first survey packets. Results were entered into an Access database file so that they could be used with Excel or SPSS for quantitative analysis of demographic and response information. The primary investigator used SPSS 11.5 when conducting analyses.

A content analysis of the open-ended question at the end of the survey was conducted and the information used for anecdotal accounts to support results of the quantitative data.
CHAPTER IV

RESULTS

Data analyses yielded information from which we were able to answer all research questions posed at the beginning of this descriptive study. Anecdotal comments supported quantitative information gathered from the survey instrument.

Research Questions

Current Planning Status

1. In which areas have caregivers currently planned regarding the future of their family member with developmental disabilities (DD/MR)?

The family's current status of future planning for the individual with developmental disabilities was addressed in the second section of the survey instrument. Legal, financial, medical, residential, and support service aspects of planning were queried.

Legal aspects of planning. Legal aspects of future planning encompassed guardianship, future caregiving, representative payee status, and health directives for the person with DD/MR. Families were asked whether individuals were their own legal guardians, if someone else was the person's legal guardian, or if guardianship was in process. In her nine years of working with the DD/MR population, the primary researcher has noticed that parents often feel they are their child's legal guardians even after he or she has reached the age of 18.
years. This is due to the parents' feelings that the person with developmental disabilities usually needs assistance when making decisions requiring informed consent. The survey question clarified legal guardianship as having gone to court and possessing a document verifying guardianship. The relationship of the guardian to the individual was specified, as well as the type of guardianship obtained.

The sample was nearly evenly split, with 46.8% of 357 caregivers stating that the person with DD/MR had a legal guardian. Another 9.2% stated that guardianship proceedings were in progress, and 44% of the individuals with DD/MR were stated to be their own legal guardian. When a guardian had been appointed, it was most often the person's mother (77.8%) or father (10.8%), but nearly 10% named another relative or person as guardian.

When guardianship is sought for a person with developmental disabilities, the court often limits the areas in which guardians may make decisions for the person. One hundred forty-four respondents detailed the type of guardianship held for the individual with DD/MR. Caregivers of 77.0% of the persons with a guardian reported that the guardianship was plenary, which covers all medical, habilitative, legal, financial and residential decisions. The remaining 17.4% of guardians elucidated guardianship to include one or more of the following areas: legal (14.2%), medical (3.4%), financial (2.7%), habilitative (0.7%) and residential (0.7%). Another 3.4% of respondents, who claimed that the individual with DD/MR had a legal guardian, stated that they did not know the specific areas in which guardianship was held.
Caregivers were asked if arrangements had yet been made "in case the current legal guardian or primary caregiver becomes incapacitated or can no longer provide care." Over half of the families responded affirmatively (57.1%, $n = 347$). When arrangements for a future caregiver had been defined, the relationship of the individual who would assume caregiving responsibilities was most often a sibling of the person with DD/MR (61.8%, $n = 333$). Sisters (35.4%) were more likely than brothers (26.4%) to be named as subsequent caregivers for the individuals with disabilities, as shown in Table 4. This finding is consistent with that of Griffiths and Unger (1994), from their survey of parents and siblings of adults with mental retardation.

Representative payees are persons whose names appear on the SSI or Social Security checks along with the individual with developmental disabilities. This person is supposed to assist the person with DD/MR in spending their monies appropriately to ensure that their basic food, clothing, and shelter needs are met. They must furnish a report to the Social Security Administration each year outlining the way in which the monies were spent on behalf of the individual. The majority of the 370 caregivers who answered this question reported that the person for whom they cared had a representative payee (82.7%). Ordinarily the payee was the individual's mother (72.2%) or father (18.3%).

The final aspect of legal issues surveyed was that of a living will or other health care directive. Of the 372 caregivers that responded to this question, 8.1% reported that the person with developmental disabilities had a health care directive in place.
Table 4

Relationship of Future Caregiver to Person with DD/MR (n = 333).

<table>
<thead>
<tr>
<th>Relationship</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister</td>
<td>118</td>
<td>35.4</td>
</tr>
<tr>
<td>Brother</td>
<td>88</td>
<td>26.4</td>
</tr>
<tr>
<td>Father</td>
<td>54</td>
<td>16.2</td>
</tr>
<tr>
<td>Non-relative</td>
<td>22</td>
<td>6.6</td>
</tr>
<tr>
<td>Mother</td>
<td>21</td>
<td>6.3</td>
</tr>
<tr>
<td>Aunt</td>
<td>13</td>
<td>3.9</td>
</tr>
<tr>
<td>Uncle</td>
<td>7</td>
<td>2.1</td>
</tr>
<tr>
<td>Friend</td>
<td>6</td>
<td>1.8</td>
</tr>
<tr>
<td>Grandmother</td>
<td>3</td>
<td>0.9</td>
</tr>
<tr>
<td>Grandfather</td>
<td>1</td>
<td>0.3</td>
</tr>
</tbody>
</table>

Financial aspects of planning. Financial issues addressed in this survey included the person with DD/MR’s monthly income, rent payment, whether their income was essential for the household to meet financial obligations, their tax dependency status, and inheritance, trust, burial plan and life insurance planning. Supplemental Security Income (SSI) was reported as the most prevalent type of monthly income received by individuals with DD/MR (57.7%, n = 397).
Respondents indicated that Social Security benefits either augmented SSI or were the primary source of income in cases in which a parent had retired or passed away (36.8%, \( n = 397 \)). Social Security Disability Insurance (SSDI), which is paid based on the earnings of the individual with DD/MR while in the workforce, or from that of a retired parent, was an income source noted by 3.0% \((n = 397)\) of caregivers. Another source of income was from part-time employment or stipends earned from jobs at work activity centers or sheltered workshops (19.4%, \( n = 397 \)).

The survey included individuals with disabilities who lived within their caregiver’s home. Rent was paid by 80.1% of the 356 individuals whose caregivers responded to this question. The average amount of rent paid was $189.25 \((SD = $184.49)\). When asked if the individual’s income was necessary for the household to meet monthly obligations such as making the mortgage payment, paying the utilities, buying groceries and paying other bills, affirmative responses were made by 64.5% of the 352 families who answered the query. Almost 70% of 356 respondents indicated that the individual with DD/MR was claimed as a dependent on a family member’s tax return.

It was uncommon for the individual with disabilities to have a trust (13.1%, \( n = 367 \)). When asked if the trust would affect the person’s eligibility status for entitlements such as SSI and Medicaid, 86.5% of the 37 individuals who responded to this question stated that the trust would not affect benefits. Not many individuals with DD/MR had a formal burial plan (17.1%, \( n = 381 \)), although a few caregivers commented that the "plot only" had been purchased.
Approximately 29% of caregivers remarked that the individual would receive an inheritance \((n = 341)\) or had a life insurance policy \((n = 377)\).

*Medical aspects of planning.* Medical information is vital for future caregivers to receive to ensure the health and safety of the individuals for whom they assume responsibility. Medical questions addressed in the survey included health insurance coverage, overall health status, diagnosed health conditions of the individual with disabilities, medications, allergies, doctor visits, and personal care assistance. Of the 397 caregivers who responded to the survey, most reported that the individual with DD/MR had health care coverage through Medicaid (82.1%), which recipients of SSI benefits usually have, or Medicare (35.0%), which Social Security recipients receive. Sometimes individuals were covered by more than one health insurance plan, the most common being a combination of Medicaid and Medicare (24.7%). Some individuals reported being covered by Medicaid, Medicare, and a tertiary insurance (4.8%). Two percent of caregivers reported that the individual for whom they cared had no health insurance of any kind.

The majority of individuals with disabilities were reported as being in excellent or good health (73.8%, \(n = 393\)), whether or not they were diagnosed with another health condition, which 44.3% of 370 caregivers noted. Approximately two-thirds of 390 respondents indicated that the person with DD/MR took medications for various physical or mental health conditions, or to minimize maladaptive behaviors. Allergies to food or medicine were reported in 23.1% of 363 cases.
Caregivers reported that most individuals saw a doctor either once a year or less (48.2%, n = 390) or every two to six months (44.1%). Mothers had primary responsibility for scheduling (82.7%, n = 388) and transporting (81.1%, n = 386) individuals to appointments. Mothers also assumed chief responsibility for personal care assistance required by the person with DD/MR (87.5%, n = 305). The majority of caregivers reported that the individual with disabilities required personal care assistance of some type (73.7%, n = 388). The most common kinds of help required were those of meal preparation, laundry, grooming, and housekeeping. Table 5 expounds upon these findings. The average number of hours per day of personal care assistance furnished by caregivers was 7.2 (SD = 8.3, n = 381). This finding is somewhat higher than that reported by Haveman et al. (1997), in which caregivers reported spending an average of 15-20 hours per week meeting the care needs of their adult with developmental disabilities.

*Residential aspects of planning.* In the first part of the survey, caregivers were asked if arrangements had been made in the event that the primary caregiver could no longer provide care. In this section, the question was rephrased to specify future residential placement. While plans for succession in caregiving responsibilities were reported by over half (57.1%, n = 347) of caregivers; in this section, families reported that specific future residential plans had been made in ten percent fewer (47.7%, n = 365) cases.
Table 5

*Personal Care Services with Which the Person with DD/MR Requires Assistance*  
(*n* = 307).

<table>
<thead>
<tr>
<th>Service</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meal preparation</td>
<td>262</td>
<td>85.3</td>
</tr>
<tr>
<td>Laundry</td>
<td>250</td>
<td>81.4</td>
</tr>
<tr>
<td>Grooming</td>
<td>217</td>
<td>70.7</td>
</tr>
<tr>
<td>Housekeeping</td>
<td>208</td>
<td>67.8</td>
</tr>
<tr>
<td>Bathing</td>
<td>176</td>
<td>57.3</td>
</tr>
<tr>
<td>Dressing</td>
<td>134</td>
<td>43.6</td>
</tr>
<tr>
<td>Toileting</td>
<td>129</td>
<td>42.0</td>
</tr>
<tr>
<td>Transferring</td>
<td>127</td>
<td>41.4</td>
</tr>
<tr>
<td>Lifting</td>
<td>75</td>
<td>24.4</td>
</tr>
<tr>
<td>Feeding</td>
<td>69</td>
<td>22.5</td>
</tr>
</tbody>
</table>

Of the 255 caregivers that specified where the individual would reside if they were unable to continue providing care, 45.9% indicated that the person with DD/MR would live with a sibling. A parent was specified 39.2% of the time, and eleven percent of caregivers stated that the individual would live in their own home with support.
These findings are similar to those of Bigby (1996), who surveyed parents of 62 individuals with intellectual disability who had moved out of the family home. Her study found that, while most parents had designated someone to assume responsibility for person with DD/MR upon their incapacity or death, few had made comprehensive plans for their adult child's care.

Individuals with developmental disabilities are often overlooked in the process of future care arrangements. Families sometimes assume that they are unable or unwilling to participate in decisions affecting their lives. This issue was addressed by three questions on the survey instrument. The first asked whether the person with DD/MR was "aware of where they would live if their current caretaker dies or becomes unable to provide continuing care." The second question asked if "the person was involved in the decision about their future residence." The third query dealt with whether the individual with DD/MR was aware of who would assume caregiving responsibility in the event of the current caregiver's incapacity. Less than half of the caregivers responded affirmatively to these questions. Several caregivers wrote a comment in the margin next to these questions, stating that the person was too severely disabled to participate in these decisions.

When asked who had been involved in decisions regarding the future of the individual with developmental disabilities, it was generally the person's mother (81.4%), father (63.0%), brother (34.3%), sister (38.8%), or a combination of these family members.
Receipt of state services. Another aspect of current future planning is the receipt of state supports for the individual with DD/MR. Supportive services include respite, family support, day programs, transportation, and residential services. Supports become essential once the individual transitions from mandatory school services at the age of 22 years. Most higher-functioning individuals with developmental disabilities require support to maintain a job, and they usually work part-time so that their benefits are maintained. Individuals who are unable to work because of the severity of their disabilities customarily attend sheltered workshops or work activity centers, where the cost of attendance is prohibitive for most families to pay privately (Varnet, 1988). The state, with the assistance of Medicaid, pays for these supports, if funding is available. Otherwise, the family must make private payment for services or arrange supervision for the individual on their own.

Table 6 details responses from caregivers regarding whether or not the person with DD/MR was a current recipient of state services and, if so, the type of support received. There were 377 replies to this question, with 77.7% of respondents indicating that the individual with DD/MR received services through the State of Utah Division of Services for People with Disabilities. Another 10.3% reported that their family member was on the waitlist for services. Some caregivers (2.0%) were unsure about whether their family member received supports through the state, and 9.8% stated that the person did not receive supports.
Table 6

*State Services as Reported by Caregivers of Individuals with DD/MR (n = 377)*

<table>
<thead>
<tr>
<th>Response</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Program</td>
<td>120</td>
<td>30.2</td>
</tr>
<tr>
<td>Transportation</td>
<td>122</td>
<td>30.0</td>
</tr>
<tr>
<td>Respite</td>
<td>95</td>
<td>23.9</td>
</tr>
<tr>
<td>Family Support</td>
<td>68</td>
<td>17.1</td>
</tr>
<tr>
<td>No Services</td>
<td>40</td>
<td>10.1</td>
</tr>
<tr>
<td>Summer Program</td>
<td>15</td>
<td>3.8</td>
</tr>
<tr>
<td>Residential</td>
<td>10</td>
<td>2.5</td>
</tr>
<tr>
<td>Do Not Know</td>
<td>8</td>
<td>2.0</td>
</tr>
</tbody>
</table>

Because the surveys were sent only to those individuals on the waitlist or in services through the Division, these last two responses appear to indicate that almost 12% of families are unaware of the source of funding for their family member’s supports. This suggests that families need more education about the Division and its role in the supports that their family members receive so that they are aware of the source of funding for services, and service options, for the individual.

Services necessary upon the current caregiver’s incapacity or death were indicated as transportation (37.7%), supported employment (33.3%), residential
services (32.7%), family support (31.8%), respite (28.3%), day program (27.7%), and summer day program (5%). Almost 13% of caregivers were not sure what services would be needed at that time, and, interestingly, 2.5% stated that no supports would be needed in the case of the current primary caregiver becoming unable to continue providing care.

About 3% of caregivers listed other services they felt would be necessary if they were not able to provide continuing care. Comments noted that all services would be necessary, financial assistance, home health services, an increase in the amount of current support, or an out of home placement.

An interesting note is that only a third of the individuals with DD/MR were said to be on the waiting list for these needed services. Another 17.6% of caregivers did not know if the person was on the waitlist, and 49.1% said they were not.

**Assistance Required for Planning**

2. *In which areas of planning do families require assistance?* Caregivers sometimes need information from professionals in order to make optimal decisions for the future of their family member with DD/MR. If plans are not made with consideration of the person’s current state and federal benefits, the individual could end up losing these entitlements. If an individual’s income and assets exceeds approximately $2,000 in any given month, their Medicaid and SSI benefits may be suspended. Therefore, if the wording of a trust document states that the money is to be used for the person's support, it is counted as an
asset to them, and benefits may be lost. If burial plans, life insurance policies, or inheritances name the individual with DD/MR as a direct recipient, the same rule applies. If, however, a trust is designated as a special needs trust, then the sole intent of the trust is to supplement the person's lifestyle, enabling them to use the money for items not covered by their SSI or Social Security income, yet allowing their entitlements to continue. Additional food or clothing, entertainment expenses, vacations, and more may be purchased from the trust monies. Once a special needs trust is arranged correctly, burial plans, life insurance policies, and inheritances can name the trust as the beneficiary, with no risk to the individual's entitlements (Thorp, 2002; Varnet, 1988, 1998a). The importance of finding a lawyer with specific experience in planning issues pertinent to individuals with developmental disabilities cannot be overstated (Williams, 1999).

When asked what resources were needed to assist in planning for the future of their family members with disabilities, caregivers indicated resource knowledge, legal, and financial assistance as their top priorities (see Table 7).

Perceived Barriers to Future Planning

3. What are perceived barriers to planning for the future of the individual with DD/MR? While many caregivers understand the importance of planning for the future of their family member with DD/MR, there are many barriers that prohibit the accomplishment of planning activities. Deterrents may include health concerns of the caregiver or individual, the need of the individual's income to
Table 7  
*Future Planning Resources Requested by Caregivers of Individuals with DD/MR*  
(n = 318)

<table>
<thead>
<tr>
<th>Resource Needed</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource Knowledge</td>
<td>135</td>
<td>42.5</td>
</tr>
<tr>
<td>Legal</td>
<td>133</td>
<td>41.8</td>
</tr>
<tr>
<td>Financial Assistance</td>
<td>94</td>
<td>29.6</td>
</tr>
<tr>
<td>Benefit Information</td>
<td>83</td>
<td>26.1</td>
</tr>
<tr>
<td>Trust Information</td>
<td>68</td>
<td>21.4</td>
</tr>
<tr>
<td>Financial Planning Information</td>
<td>64</td>
<td>20.1</td>
</tr>
<tr>
<td>Guardianship Information</td>
<td>57</td>
<td>17.9</td>
</tr>
<tr>
<td>Counseling</td>
<td>26</td>
<td>8.2</td>
</tr>
<tr>
<td>Medical Information</td>
<td>22</td>
<td>6.9</td>
</tr>
<tr>
<td>Referrals</td>
<td>20</td>
<td>6.3</td>
</tr>
</tbody>
</table>

make ends meet, or the financial aspect of planning. Emotional barriers of the caregiver may also hinder planning. Examples include increased stress when thinking about their own death or incapacity, worry over who would assume caregiving responsibility, and not wanting to acknowledge that there would be an eventual need for another caregiver.
When asked to indicate issues that impeded the planning process, over half of caregivers identified confusion about what needed to be done. Worry about costs associated with planning, unfamiliarity with available services and being unsure of where to start in the planning process were other reasons most often cited. Table 8 details the perceived barriers to planning indicated by respondents.

Qualitative comments from caregivers regarding obstacles to planning included remarks about the primary caregiver being overwhelmed with the care of other family members; the caregiver being reluctant to relinquish control of the individual; and uncertainty about the specific service needs the person with DD/MR will have at the time that other arrangements are necessary. Almost 40 percent of the remarks (38.6%, n = 44), however, concerned the lack of funding from the state agency for necessary services. Many caregivers expressed concern, because funding for current service needs was not available. They wondered if funding for essential supports would be attainable for the person with DD/MR when services were absolutely necessary.

Preferred Methods for Information

4. What are preferred delivery methods for future planning information?

Table 9 highlights responses regarding presentation of planning information. Caregivers were asked what types of information presentation they had utilized in the past, which methods were most helpful to them, and in which format they would prefer future planning information presented to them. Choices covered
Table 8

Perceived Barriers to Planning for the Future of Individuals with DD/MR (n = 322)

<table>
<thead>
<tr>
<th>Barrier</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unsure of what needs to be done</td>
<td>162</td>
<td>50.3</td>
</tr>
<tr>
<td>Worry about cost</td>
<td>125</td>
<td>38.8</td>
</tr>
<tr>
<td>Do not know services available</td>
<td>108</td>
<td>33.5</td>
</tr>
<tr>
<td>Unsure of where to start</td>
<td>97</td>
<td>30.1</td>
</tr>
<tr>
<td>Worry about who will take over</td>
<td>72</td>
<td>22.4</td>
</tr>
<tr>
<td>Do not want to think about it</td>
<td>44</td>
<td>13.7</td>
</tr>
<tr>
<td>Stress</td>
<td>35</td>
<td>10.9</td>
</tr>
<tr>
<td>Health issues of caregiver</td>
<td>29</td>
<td>9.0</td>
</tr>
<tr>
<td>Too busy/no time</td>
<td>21</td>
<td>6.5</td>
</tr>
<tr>
<td>Need referral to a lawyer</td>
<td>19</td>
<td>5.9</td>
</tr>
<tr>
<td>Inconvenience</td>
<td>15</td>
<td>4.7</td>
</tr>
<tr>
<td>Just never thought about it</td>
<td>9</td>
<td>2.8</td>
</tr>
</tbody>
</table>

brochures, group meetings with other parents, full-day conferences, half-day conferences (both a.m. and p.m.), topics at monthly family support meetings (a.m. and p.m.), or one-on-one meetings with support coordinators. Caregivers also had the option to indicate other methods not on the survey.

Formats used in the past were identified by 292 caregivers as primarily one-on-one meetings with support coordinators, brochures, and group meetings.
Table 9

Methods of Information Presentation Reported by Caregivers of Persons with DD/MR.

<table>
<thead>
<tr>
<th>Method</th>
<th>Used in Past (n= 292)</th>
<th>Most Helpful (n = 266)</th>
<th>Preferred (n = 314)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>One-on-one meeting with caseworker</td>
<td>195</td>
<td>66.8</td>
<td>195</td>
</tr>
<tr>
<td>Brochures</td>
<td>118</td>
<td>40.4</td>
<td>68</td>
</tr>
<tr>
<td>Group meetings w/other parents</td>
<td>105</td>
<td>36.0</td>
<td>60</td>
</tr>
<tr>
<td>Topic at family support meeting (p.m.)</td>
<td>31</td>
<td>10.6</td>
<td>15</td>
</tr>
<tr>
<td>Topic at family support meeting (a.m.)</td>
<td>24</td>
<td>8.2</td>
<td>25</td>
</tr>
<tr>
<td>Full-day conference</td>
<td>20</td>
<td>6.8</td>
<td>13</td>
</tr>
<tr>
<td>Half-day conference (a.m.)</td>
<td>19</td>
<td>6.5</td>
<td>17</td>
</tr>
<tr>
<td>Half-day conference (p.m.)</td>
<td>12</td>
<td>4.1</td>
<td>9</td>
</tr>
</tbody>
</table>
with other parents. Qualitative comments regarding other methods included speaking with lawyers and providers of DD/MR services, and meetings with school personnel. The manner of presentation used in the past reported by 266 caregivers as most helpful of those were one-on-one meetings with support coordinators and brochures. When asked about preferred methods of presentation for future planning issues, 73.2% of caregivers (n = 314) indicated they would prefer a one-on-one meeting with a support coordinator.
CHAPTER V
DISCUSSION

Future Planning

The findings of this study support previous work by authors who found that families require quality support and education to facilitate their participation and follow-through in the planning process (Goodall & Bruder, 1986; McDonnell & Hardman, 1985; McDonnell et al., 1986). Planning for the future of individuals with developmental disabilities involves several areas. Legal, medical, habilitative, and residential issues are important to consider when making arrangements for the person's future care. Resources required by families and barriers to planning in each area are addressed. Caregivers surveyed in the present investigation indicated that they were aware of the need to plan for the future of their family member with developmental disabilities, but asserted that they required information, referrals, and assistance to complete the planning process.

Legal Planning Issues

In the current sample, guardianship already had been arranged for almost half the individuals with DD/MR. A little over nine percent of respondents stated that the process of obtaining guardianship for their family member was underway. Guardianship information as a required planning resource was noted by 17.9% of participants. This finding compares favorably with that of Smith
(1997), who found that parents cited guardianship information as one of their greatest unmet needs. Future caregiving arrangements were reported to be in place by 57% of caregivers in the present study, and 61.8% of respondents stated that siblings would assume caretaking responsibilities.

Legal plans had been made for the persons with DD/MR in some instances. Over 80% of caregivers had established representative payee status for their family member. Almost 30% of respondents indicated that the individual with developmental disabilities had an established life insurance policy, or was expected to receive an inheritance after the death of the caregiver. Burial plans had been set up for 17% of the individuals, and trusts were arranged for 13%. Eight percent of the persons with DD/MR in this study had living wills or other health care directives established.

While these findings are quite different from those of Bigby (1996), who reported that 50% of the 62 caregivers in her study had made a financial plan of some type for the individual with DD/MR, it may be accounted for by the smaller sample size of her study. Another reason for the difference may be the qualitative nature of her study, which allowed a broader interpretation of what constituted a "financial plan" for the individual. As stated previously, parents of individuals with DD/MR have indicated confusion regarding specific future planning arrangements that must be made. Professionals on whom they rely often give contradictory advice regarding specific steps necessary for their family member's future (Campbell & Essex, 1994).
It is very important for these arrangements to be set up correctly, or they may affect the individual's ability to maintain their entitlements such as SSI or Medicaid, thus decreasing their overall quality of life or standard of living (Daugherty, 1999; Thorp, 2002; Varnet, 1988, 1998a, 1998b; Vogel, 1998). If a plan is set up so that the individual can cash it in for a monetary sum, it is counted as an asset to them and will disqualify them from receiving entitlements. Special needs trusts may be set up so that the income is not counted as an asset to the individual. Directing inheritances or life insurance policies correctly to the special needs trust will ensure that the individual can benefit from the life course event without it resulting in a loss of benefits and a lower quality of life. Finding a lawyer or financial advisor that is familiar with issues pertinent to individuals with disabilities is a must when making legal arrangements for future of persons with developmental disabilities (Schlesinger & Scheiner, 1992; Thorp; Williams, 1999).

Implications for state developmental disability agencies include assisting families of individuals with developmental disabilities to begin the financial planning process at an early stage in the life course. The Division could work in conjunction with school districts and early intervention providers to acquaint families with financial planning information, specifically about special needs trusts and the costs of services for individuals with DD/MR. This would enable caregivers to comprehend the amount of money that may be needed for their family member's future services, and promote an awareness that government
agencies may not be able to assist them with the costs associated with these needed supports.

**Medical Planning Issues**

Medical issues surrounding future planning are twofold. On one side, the current caregiver should ensure that plans are made if they themselves have medical issues that might cause a decline in their ability to provide care for the person with DD/MR. The other side deals with preparing the future caregiver for the specific medical needs of the individual. Seltzer and Greenberg (1997) encourage families to make alternate arrangements for residential care in the case of an unforeseen decline in parental health.

Medical planning information was noted as a needed planning resource by almost seven percent of caregivers in the current study. Health issues of the caregiver were cited by nine percent of respondents as a barrier to making future plans, although only 4.3% ($n = 393$) indicated that they were in poor health. This finding concurs with Smith's (1997) statement that older adulthood presents its own set of difficulties, as parents are aging as well as the individual with disabilities.

Future caregivers should be prepared to supervise the medical issues of the person with DD/MR. They need to know about the person's health insurance coverage so that it would not lapse after the incapacitation or death of the current caretaker. Diagnosed health conditions must be conveyed so that medications are given properly and potential life-threatening allergies are avoided. Almost half
of the respondents to the current questionnaire indicated that their family 
member with DD/MR had diagnosed health problems other than the primary 
disability. Sixty-eight percent of the individuals took medications, and 23% were 
reported to have allergies to food or medicine. Some form of personal care 
assistance was required by nearly three-quarters of the current sample.

These data suggest that the health care status of the individual with DD/MR and the caregiver do not factor much into planning for the individual's future. This issue is very important for the future well-being of the person with DD/MR, since research has shown that over 60% of persons with developmental disability live with family members until a crisis occurs (Fee, 1993). Implications for developmental disability agencies include educating families about the importance of including health care needs in future planning.

**Habilitation Planning Issues**

Habilitation as it pertains to individuals with developmental disabilities includes supports that are offered to build skills. Schools, sheltered workshops, work activity centers, and employment offer habilitation opportunities for persons with DD/MR. Funding for habilitative supports was cited by respondents to this study as being both an essential resource for and a barrier to planning. Because of the dearth of funding for state services, it is essential for families to plan ahead so they may pay privately for these supports if possible until funding becomes available from the state agency (Varnet, 1998b; Vogel, 1998).
Because the cost of participation in habilitative programs is almost impossible for the average family to pay on a continuing basis, the person with DD/MR may not receive any supports while waiting for state funding for day services after the transition from school services. This may result in significant declines in the social, communication, and vocational skills of the individual with DD/MR. Implications for the state developmental disability agency include a higher cost of service to remediate the skill loss once funding is received for day supports. Another possible outcome is an increase in institutionalization due to the inability of the family to meet the supervision needs of the individual.

The Division may need to review the level of day supports they are offering to individuals currently in services. If they can apportion the available funds between all those over the age of 22 years, whether currently in services or on the waiting list, a partial program could be had by all. This approach could assist caregivers with their efforts to maintain the individual within their home rather than seeking an institutional placement.

Residential Planning Issues

Freedman et al. (1999) noted that caregivers with a strong network of natural supports were less likely to place their individual with DD/MR in an out of home setting. The current study supports this premise, as shown by the information in Table 4. Although caregivers were not asked the extent to which they had discussed their perceived future caregiving arrangements with those that they had designated to provide future care, family members, friends, or non-
relatives were cited as future caregivers in 89% of cases. Only 11% of respondents stated that their family member would live on their own (with supports presumably provided by the Division) in the event of a caregiver's incapacity. Formal planning may not occur, however, if parents have assumed that a sibling or family member would undertake responsibility for the person with developmental disabilities (Gorelick, 1996; Griffiths & Unger, 1994). If the specified future caregiver is unable or unwilling to assume the burden of caregiving, an institutional setting may be all that is available at the time of need if community-based services are not planned for or available through the state agency.

Implications for the state developmental disability agency include the importance of educating families about the need to clearly discuss future plans with all family members and those concerned about the individual with DD/MR. If expectations for each family member are clear regarding their future involvement in the life of the individual with DD/MR, there will be less confusion and uncertainty when the current caregiver is no longer able to provide care.

**Barriers to Future Planning**

Russell et al. (1993) noted that caregivers may feel overwhelmed by the complexity of legal, financial, habilitation, residential, medical, and guardianship issues for which they must plan. This sense of bewilderment can result in uncertainty over where to begin the daunting task of future planning and make it easier to justify deferment of the process. Respondents in the current study
(n = 322) supported the notion, with 50% stating uncertainty about what needs to be done, and 30% noting that concern over where to begin the planning process were major barriers to planning.

Responses to this questionnaire supported findings by Campbell and Essex (1994), who found that caregivers felt uninformed about the availability of state services. Over 30% of respondents in this study stated that a barrier to planning for the future was not knowing what services were available for their family member with DD/MR.

Emotional encumbrances can also hinder the planning process. Harmon (2001b) noted that a caregiver's inability to confront his or her own mortality may impede planning for the future of the individual with disabilities. Parents may not be comfortable with the planning process, because it upsets them to think about someone else caring for their child. When caregivers feel that they do not have anyone they can trust to take over their role, it adds to their stress. Some respondents in the current survey validated these conclusions, with 22.4% endorsing worry about who would take over, 13.7% stating that they did not want to think about it, and 10.9% indicating that stress was an obstacle to planning for the future of their family member with DD/MR.

Another significant impediment to planning noted by these participants was the financial cost of planning services (38.8%). In fact, financial assistance was a needed planning resource identified by almost 30% of respondents. While this concern is understandable, Rotman (1986) noted that security and peace of mind about the future of the individual with DD/MR can outweigh the financial
cost. Marzluft (1995) indicated that the cost of making plans prior to a caregiver's death may actually be less than the costs associated with court and lawyers' fees to settle an estate with no plan in place. Thorp (2002) has endorsed this opinion, noting that attorneys "must emphasize long-term savings, because spending a little more up front significantly lessens the chance of unpleasant surprises later" (p. 27). If formal and legal planning is not conducted prior to their death or incapacitation, any decisions caregivers might have made about guardianship, habilitation, and residential placement may never be known or honored (Harmon, 2001b).

Developmental disability agencies can assist caregivers to acknowledge these common barriers and to overcome them by education about planning and its importance throughout the life course. Attorneys, estate planners, and financial planners can aid the Division in its efforts at education by furnishing a list of anticipated future planning costs. An outline of potential costs, including lost benefits and services, to the individual in the future if no planning is done would be another helpful tool. This cost breakdown might enable caregivers to get a better idea of the ramifications involved in planning, or not planning, for the future of their family member with DD/MR.

Information Needs to Assist with Planning

It is very important for families to receive accurate information regarding all areas of future planning that should be conducted prior to the primary caregiver's decline or inability to continue providing care. As noted by several
authors (Brunetti, 1995; Heller, 1998; Schlesinger & Scheiner, 1992; Thorp, 2002; Varnet, 1988, 1998a; Williams, 1999), it is essential that caregivers find an attorney and/or a financial planner that is abreast of specific legal and planning issues for individuals with developmental disabilities. These planning decisions may impact the person with DD/MR's overall quality of life or standard of living for the future (Daugherty, 1999; Varnet 1988, 1998a, 1998b; Vogel, 1998). Over 40% of respondents in the present study indicated that they required assistance with legal matters, and 6.3% verified that referrals to appropriate professionals were needed to support them with the planning process.

Campbell and Essex (1994), in their interviews with parents and caregivers of individuals with DD/MR, found that knowledge about resources was an important tool in the planning process. Caregivers in the current study corroborated that resource knowledge is the primary requirement to promote planning for the future of the person with disabilities.

Information Presentation

Previous research has suggested that future planning information should be adjusted to reflect the life stages of persons and their families (Pearce, 1993). While children with DD/MR are in school, their parents attend many planning meetings. From professional experience, the primary investigator who works for the Division of Services for People with Disabilities has found that parents of young adults with DD/MR have a difficult time understanding that adult services for their children are not mandatory once they leave the school system. They are
often confused and unprepared for the supervision needs of their family member on a daily basis. Presenting these caregivers with structured planning information at least two years before their child leaves the school system would assist them in each area of life in which they must plan.

The need for caregiver education is apparent from previous research as well as the current study. While the present survey was sent to parents or caregivers of individuals currently either on the waitlist for or receiving services from the State of Utah Division of Services for People with Disabilities, two percent of respondents indicated that they did not know if their family member with DD/MR received supports through the state.

While some researchers have presented ideas about how information should be tailored to meet the individual needs of families, formal research has not been done regarding preferred methods for presentation of planning information. Pearce (1993) felt that future planning for individuals with developmental disabilities should be adjusted to reflect the different life stages of persons and their families. Seltzer and Greenberg (1997) agreed that taking a life course approach when working with families enables planning to reflect the complexity of each family's life stage, obligations of family life, and the unique demands of the individual's disability type. The current investigation, in which 73.2% of caregivers stated that a one on one meeting with a support coordinator or caseworker was the primary method in which they preferred to receive future planning information, appears to validate the use of a life course perspective when working with families of individuals with DD/MR.
Limitations and Recommendations for Future Research

Limitations

The primary limitation of this study is that the findings only can be extrapolated to caregivers of individuals with DD/MR over the age of 20 who have already been found eligible for developmental disability services through the State of Utah. Perhaps families of persons who do not receive, or who have not applied for, state supports have made arrangements so that state services will not be required for their family member with disabilities. It is also possible that caregivers of individuals who are younger than 20 years of age already have made arrangements for future care.

Another limitation is that the sample was limited to individuals identified as living within a caregiver's home. It is conceivable that future planning has occurred in some areas even if a family member is already living in an out of home setting.

Although the number of responses furnished adequate data to answer the stated questions, the response rate was less than 50%. Because we are unsure of the characteristics of non-respondents, we cannot generalize these findings to the entire population of caregivers of individuals with DD/MR in the state.

Recommendations for Future Research

Suggestions for further research to elaborate on findings of the present investigation would include expanding the survey size to include caregivers of all individuals, regardless of age, who are currently on the waiting list or receiving
services through the State of Utah Division of Services for People with Disabilities. Other states could have their developmental disability agencies duplicate the study to see if findings are consistent across populations of caregivers currently aware of services. Exploratory studies conducted with the assistance of school districts, beginning as early as the elementary grades, might assist families to begin the planning process at a much earlier stage in life. Anecdotal comments from caregivers in the current study reflected that, even if they had not yet begun planning, the survey instrument had started them thinking about the planning process.

Conclusion

Responses from caregivers of individuals with developmental disabilities indicated that most families require information to assist them in planning for the future of their family member. Caregivers prefer to meet on an individual basis with their state disability worker to have service options, benefits, and planning information dispensed.

These findings should be helpful to the State of Utah Division of Services for People with Disabilities, in particular, and to other state agencies in general, to assist them in assessing the roles of caseworkers in the lives of the individuals and families they serve. It is important to ensure that caseload size is small enough that support coordinators have the time to personally meet with caregivers to discuss the individual’s unique needs for future planning. Support coordinators themselves must receive education regarding future planning
approaches to make them an asset to families in the planning process. The provision of up-to-date planning information, perhaps in a brochure format, would allow caregivers to supplement the personal future planning assistance they receive from their family member’s caseworker. If families are given the tools they need to assess their particular circumstances, they will be able to more accurately predict the level of state services that will be required for their individuals with DD/MR.

Benefits of caregiver planning to the state include fewer emergency-based supports and the ability to make more accurate projections of the service needs of individuals with DD/MR. This knowledge can assist state developmental disability agencies in making fact-based funding requests to the state legislature each year. Legislatures will then be apprised of the very real need for supportive services experienced by families of individuals with developmental disabilities. By the responses to questions outlined in this study, it is apparent that families need more education about the Division and its role in the supports that their family members receive, so that they are aware of the source of funding for services and service options for the individual.
REFERENCES


http://web6.searchbank.com/itw/seq


Appendix A
Region Map
Division of Services for People with Disabilities (DSPD)

Map by Region
Legend

Central Region  Northern Region

Eastern Region  Western Region
Appendix B

Letter with Informed Consent
Region Contact List
Survey Instrument
November 11, 2002

Dear Caregiver:

The Division of Services for People with Disabilities (DSPD) is interested in gathering information about future planning for individuals with developmental disabilities. If families indicate areas in which they require assistance, the Division can work toward developing training or other materials to make this process easier. This project is also the topic of my Master’s Degree thesis through Utah State University (USU), and the information gathered will be used to fulfill part of my Master’s thesis requirements.

We have enclosed a survey to help us understand your family’s unique needs. This survey is being sent to approximately 1,200 families of individuals over the age of 20 who are currently on the waitlist or are receiving services through the State of Utah DSPD.

Participation in this study will consist of answering the survey, which may take up to half an hour to complete. Please be assured that participation is voluntary and will in no way affect the status of the individual on the waiting list or in the services he or she receives. You may withdraw from the study at any time. A self-addressed, stamped envelope is included for your convenience. All information you submit is anonymous, because the survey does not reveal your identity. PLEASE DO NOT PUT YOUR NAME ANYWHERE ON THE SURVEY FORM! If you have questions about the survey, please contact Dianna Broadbent at (435) 787-3459 or your local contact listed on the other side of this letter.

This project has been reviewed and approved by the Institutional Review Boards (IRBs) at USU and the Department of Human Services. If you have any questions about your rights as a research participant, you may call Mary Caputo, DHS IRB Chair, at (601) 538-4295. Thank you for your prompt reply.

Sincerely,

Dianna L. Broadbent, QMRP
Intake/Support Coordinator

Kathleen W. Piercy, Ph.D.
Major Professor, USU
### Contacts for Local DSPD Offices

#### Central Region:
- **Salt Lake City**: 801-264-7616, Katie Willette
- **Park City**: 435-645-8703, Gail Salowey
- **Tooele**: 435-833-7355, April Taylor

#### Eastern Region:
- **Blanding**: 435-678-1440, Bonnie Kosoff
- **Price**: 435-636-2390, Janet Kinder
- **Vernal**: 435-789-9336 ext. 212, Ercel Johnson

#### Northern Region:
- **Brigham City**: 435-734-4047, Barbara Boswell
- **Logan**: 435-787-3459, Dianna Broadbent
- **Ogden**: 801-626-3481, Tammy Davis
- **Layton**: 801-779-6719, Barbara Wightman

#### Western Region:
- **American Fork**: 801-763-4325, Erin Wiersma
- **Delta**: 435-864-3869, Lyndon Callister
- **Richfield**: 435-896-1281, Lamont Felt
- **Cedar City**: 435-865-5650, Sandy Bowman
- **Provo**: 801-374-7005, Jeanne McNeil
- **St. George**: 435-674-3954, Eileen Allsop
PLEASE DO NOT WRITE YOUR NAME ANYWHERE ON THIS SURVEY!

PERSONAL

Please give us the following information about the person with the developmental disability

1) Individual's age: ____________________________
   a) Gender:       □ Male       □ Female
   b) Marital Status: □ Never married □ Married □ Divorced □ Separated □ Widowed
   c) Diagnosis (check all that apply):
      □ Mental Retardation □ Seizure Disorder/Epilepsy □ Down's Syndrome □ Autism □ Cerebral Palsy
      □ Spina Bifida □ Mental Illness □ Other (specify)________________________
   d) Current residence type:
      □ family or relative's home: □ parent □ sibling □ aunt/uncle □ grandparent □ other (specify)________________________
      □ own home/apartment: □ with supports □ without supports
      □ other (specify)________________________
   e) Number of people currently living in household: ____________
   f) Relationship(s) of people living in household to person with developmental disabilities (check all that apply and indicate # of persons in each category):
      □ mother ____ □ father ____ □ brother ____ □ sister ____ □ aunt ____
      □ uncle ____ □ grandmother ____ □ grandfather ____ □ wife ____ □ husband ____
      □ friend ____ □ other (specify)________________________

Please give us the following information about the person's primary caregiver

1) Caregiver's age: ____________________________
   a) Gender:       □ Male       □ Female
   b) Marital Status: □ Never married □ Married □ Divorced □ Separated □ Widowed
   c) Relationship to Individual with developmental disability:
      □ mother □ father □ brother □ sister □ aunt □ uncle □ grandmother □ grandfather □ wife
      □ husband □ friend □ other (specify)________________________
   d) How would you rate your overall health status?
      □ Excellent □ Good □ Fair □ Poor
   e) How long have you been caring for the person with disabilities? (Please indicate specific duration.)
      □ all their life □ _____ years □ _____ months
PLEASE DO NOT WRITE YOUR NAME ANYWHERE ON THIS SURVEY!

CURRENT PLANNING STATUS

Legal Aspects

1) Guardianship status of individual with DD/MR:

☐ Individual is their own legal guardian
☐ Someone else is legal guardian, has gone to court, and has a document verifying guardianship.
☐ Guardianship is in process.

a) If legal guardianship has been obtained, what is the relationship of the guardian to the person?

☐ mother ☐ father ☐ brother ☐ sister ☐ aunt ☐ uncle ☐ grandmother ☐ grandfather ☐ wife
☐ husband ☐ friend ☐ other (specify) 

b) If guardianship has been awarded, please indicate type(s) (check all that apply):

☐ medical ☐ habilitative ☐ legal ☐ financial ☐ residential ☐ plenary (all areas)
☐ Don't know ☐ Other (specify) 

2) Have arrangements been made in case the current legal guardian or primary caregiver becomes incapacitated or can no longer provide care?

☐ Yes ☐ No ☐ Don’t know

a) What is the relationship of the individual who would assume caregiving responsibility?

☐ mother ☐ father ☐ brother ☐ sister ☐ aunt ☐ uncle ☐ grandmother ☐ grandfather ☐ wife
☐ husband ☐ friend ☐ other (specify) 

3) Representative payee status (whose name is on SSI or other checks to assist person with finances):

☐ person with DD/MR is own payee ☐ someone else is payee

a) If there is a representative payee, what is the relationship of the individual to the Individual?

☐ mother ☐ father ☐ brother ☐ sister ☐ aunt ☐ uncle ☐ grandmother ☐ grandfather ☐ wife
☐ husband ☐ friend ☐ other (specify) 

4) Does the individual with disabilities have a legal living will or other health care directive (e.g., do not resuscitate order) in place?

☐ Yes ☐ No ☐ Don’t know
CURRENT PLANNING STATUS

Financial Aspects

1) Current monthly benefits/income of person [list source(s) and amount(s)]:
- SSI $__________
- Social Security $__________
- SSID $__________
- Other (specify) $__________ Amount $__________

2) Does the individual pay monthly rent or room and board?
- Yes Amount paid per month $__________
- No
- Don't know

3) Is their income essential for the household (e.g., to make the mortgage payment, pay the utilities, buy groceries, etc.)?
- Yes
- No
- Don't know

4) Is the individual with disabilities claimed as a dependent on someone else's tax return?
- Yes
- No
- Don't know

5) Is there an inheritance that the person will get when a parent or other family member dies (this can be through a life insurance policy or other assets)?
- Yes
- No
- Don't know

   a) If so, is the inheritance bequeathed to the individual, to other family members for use for the individual with disabilities, to a trust, or some other distribution on behalf of the person?

   - directly to DD/MR Individual
   - to other family members to care for person with DD/MR
   - to a trust
   - other distribution (specify) $__________
   - Don't know

6) Is there a trust set up for the person with DD/MR?
- Yes
- No
- Don't know

   a) The wording of the trust specifies that it is to be used for (check all that apply):

   - the support of the person with disabilities
   - the medical needs of the person with disabilities
   - the supplemental needs of the person with disabilities
   - the special needs of the person with disabilities
   - other (specify)

   b) Would this trust affect the person's ability to receive public benefits or services through state or federal agencies? (Example, SSI, Medicaid, DSPD, etc.)
- Yes
- No
- Don't know
CURRENT PLANNING STATUS

Financial Aspects (continued)

7) Does the individual with DD/MR have a burial plan?
   □ Yes    □ No    □ Don't know
   a) Is there a cash value on the burial plan that will be given if the document is surrendered?
      □ Yes  Amount $__________  □ No    □ Don't know
   b) If so, to whom is the amount payable?
      □ directly to DD/MR Individual  □ to other family members to care for person with DD/MR
      □ to a trust  □ other distribution (specify) ____________________________  □ Don't know

8) Does the individual with DD/MR have a life insurance policy?
   □ Yes    □ No    □ Don't know
   a) Is there a cash value on the policy that will be given if the document is surrendered?
      □ Yes  Amount $__________  □ No    □ Don't know
   b) If so, to whom is the amount payable?
      □ directly to DD/MR Individual  □ to other family members to care for person with DD/MR
      □ to a trust  □ other distribution (specify) ____________________________  □ Don't know

Medical Aspects

1) What health insurance does the person with DD/MR have? (Check all that apply.)
   □ Medicaid  □ Medicare  □ BCBS  □ IHC  □ None  □ Other (specify) ____________________________  □ Don't know

2) What is the overall health status of the individual with DD/MR?
   □ Excellent    □ Good    □ Fair    □ Poor

3) Other than their disability, does he or she have any diagnosed health conditions?
   □ Yes - Specify the problem(s): ____________________________________________
   □ No
   □ Don't know
CURRENT PLANNING STATUS

Medical Aspects (continued)

4) Does the person take any medications?
   □ Yes □ No □ Don't know

5) Does the individual have allergies to food or medicine?
   □ Yes - list: ___________________________
   □ No
   □ Don't know

6) How often does the person see a doctor?
   □ once a year or less □ every two to six months □ monthly □ weekly or more often

7) Who has primary responsibility for scheduling doctor and other appointments for the individual with DD/MR?
   □ mother □ father □ brother □ sister □ aunt □ uncle □ grandmother □ grandfather
   □ wife □ husband □ friend □ other (specify) ____________________________

8) Who has primary responsibility for taking the person to these appointments?
   □ mother □ father □ brother □ sister □ aunt □ uncle □ grandmother □ grandfather
   □ wife □ husband □ friend □ other (specify) ____________________________

9) Does the person require assistance with daily personal care?
   □ Yes □ No □ Don't know
   a) If required, personal care services include (check all that apply):
      □ bathing □ dressing □ grooming □ meal preparation □ feeding □ housekeeping
      □ laundry □ toileting □ transferring □ lifting □ other (specify) ____________________________
   b) If personal care assistance is necessary, who provides the care? (Check all that apply.)
      □ mother □ father □ brother □ sister □ aunt □ uncle □ grandmother □ grandfather
      □ wife □ husband □ friend □ Home Health Agency □ other (specify) ____________________________
   c) What is the amount (in hours per day) of personal care services given to the individual with DD/MR?
      □ 0 □ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □ 10 □ 11 □ 12
      □ 13 □ 14 □ 15 □ 16 □ 17 □ 18 □ 19 □ 20 □ 21 □ 22 □ 23 □ 24
PLEASE DO NOT WRITE YOUR NAME ANYWHERE ON THIS SURVEY!

CURRENT PLANNING STATUS

Residential Aspects

1) Have arrangements been made for the individual's future residential placement in the event that the primary caregiver becomes incapacitated or is no longer able to provide care?
   - Yes
   - No
   - Don't know
   a) Where would the person live?
      - family or relative's home
      - parent
      - sibling
      - aunt/uncle
      - grandparent
      - other (specify)
      - own home/apartment
      - with supports
      - without supports
      - other (specify)

2) Is the person with DD/MR aware of where they would live if their current caretaker dies or becomes unable to provide continuing care?
   - Yes
   - No
   - Don't know

3) Was the person involved in the decision about their future residence?
   - Yes
   - No
   - Don't know

4) Is the person aware of who would assume responsibility for them and their needs if their current caretaker dies or becomes unable to provide continuing care?
   - Yes
   - No
   - Don't know

5) Who has been involved in the decision-making process regarding the future of the individual with DD/MR? (Check all that apply.)
   - mother
   - father
   - brother
   - sister
   - aunt
   - uncle
   - grandmother
   - grandfather
   - wife
   - husband
   - friend
   - other (specify)
RESOURCES

State Services

1) Does the person receive services through the State of Utah Division of Services for People with Disabilities (DSPD)?
   - Yes
   - No
   - On waitlist
   - Don't know

   a) What service(s) is the person currently provided through the Division? (Check all that apply.)
      - none
      - Don't know
      - respite
      - family support
      - residential
      - day program
      - summer day program
      - transportation
      - supported employment
      - other (specify)________

   b) If already receiving services, will additional supports be required if the primary caregiver becomes incapacitated or unable to provide care?
      - Yes
      - No
      - Don't know

   c) If the individual with DD/MR is not yet receiving services, will DSPD supports be needed if the primary caregiver becomes incapacitated or unable to provide care?
      - Yes
      - No
      - Don't know

2) Indicate services that may be required in either of these events (check all that apply):
   - none
   - Don't know
   - respite
   - family support
   - residential
   - day program
   - summer day program
   - transportation
   - supported employment
   - other (specify)________

3) Is the individual on the DSPD waiting list for these services?
   - Yes
   - No
   - Don't know

Barriers to Planning

1) What has gotten in the way of planning for the future of your family member with a disability? (Check all that apply.)
   - unsure of what needs to be done
   - worry about cost
   - don't want to think about it
   - don't know what services are available
   - unsure of where to start
   - inconvenience
   - health issues of caregiver
   - stress
   - just never thought about it
   - need referral to a lawyer
   - worry about who will take over
   - too busy/no time
   - other (specify)________

2) What resources are needed to assist you in planning for the future of your family member with a disability? (Check all that apply.)
   - Legal
   - Financial assistance
   - Resource knowledge
   - Information about benefits (SSI, Medicaid, etc.)
   - Financial planning information
   - Medical information
   - Referrals
   - Guardianship information
   - Trust information
   - Counseling
   - Other (specify)________
RESOURCES

Barriers to Planning (continued)

3) What method of presentation would be the best to assist you in understanding future planning (Check all that apply.)

☐ brochures ☐ group meeting with other parents ☐ all day conference format
☐ half-day conference format [am] [pm] ☐ Topic at monthly Family Support Council meeting [am] [pm]
☐ one-on-one meeting with support coordinator ☐ Other (specify)

4) What format(s) have you used in the past to assist you in understanding future planning (Check all that apply.)

☐ brochures ☐ group meeting with other parents ☐ all day conference format
☐ half-day conference format [am] [pm] ☐ Topic at monthly Family Support Council meeting [am] [pm]
☐ one-on-one meeting with support coordinator ☐ Other (specify)

5) Which methods were most helpful? (Check all that apply.)

☐ brochures ☐ group meeting with other parents ☐ all day conference format
☐ half-day conference format [am] [pm] ☐ Topic at monthly Family Support Council meeting [am] [pm]
☐ one-on-one meeting with support coordinator ☐ Other (specify)

6) Please comment on any aspect of future planning that wasn't addressed by this survey.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

THANK YOU VERY MUCH FOR YOUR TIME AND EFFORT!!

If you would like to speak with someone about future planning or get information about DSPD services, please contact your local office of the Division of Services for People with Disabilities.
Appendix C

Approval Letters
Subject: Planning for the Future of Individuals with Developmental Disabilities, Research Protocol #020209, Final Approval

Dear Ms. Piercy and Ms. Broadbent:

We appreciate receipt of the requested modifications to your survey, cover letter and postcard. The full subject protocol has been reviewed by Mary Caputo, Chair of the Department of Human Services’ Institutional Review Board (DHS IRB) and Paul Day, Director of Research, Division of Services for People with Disabilities. Based on our review and recommendations, I am pleased to notify you that we have approved the research proposal and your revised survey tool, cover letter and postcard and have received confirmation of the Utah State University IRB approval. Please note our approval will expire on November 4, 2003 (one year from the date of review). You may not conduct any research after this expiration date unless you submit an annual resubmission form that is approved by the DHS IRB. If you suspect that your research will continue beyond the expiration date you must complete the attached form along with a status report, information concerning the number of subjects enrolled, preliminary findings, any adverse events/complaints, and resubmit for subsequent review and approval at least one month prior to expiration. If we have not received your resubmission prior to the expiration date, and if the research is ongoing, you will need to resubmit a full protocol application and request for full IRB approval. Additionally, data collected and/or analyzed during any period of time in which there was not active IRB approval will have to be destroyed or discarded.

In the event that any further changes are made to the research following this approval (e.g., changes in target population, materials to which subjects are to be exposed, procedures to be employed, etc.), please document these changes on the attached and send it to the DHS IRB.

If you need further assistance, please contact Mary Caputo at 538-4295. Once your research is completed, please send a copy of your final report to the DHS IRB to allow its members and the Department to benefit from your research findings.

Sincerely,

Paul Day, Director of Research

Attachment
cc: Mary Caputo, DHS IRB

120 North 200 West • Room 411 • Salt Lake City, Utah 84103 • telephone (801) 538-4200 • fax (801) 538-4279 • www.utah.gov
MEMORANDUM

TO: Diana Broadbent (Payne)

FROM: True Rubal, IRB Administrator

SUBJECT: Planning the Future of Individuals with Developmental Disabilities

Your proposal has been reviewed by the Institutional Review Board and is approved under expedite procedure #7.

X There is no more than minimal risk to the subjects.

There is greater than minimal risk to the subjects.

This approval applies only to the proposal currently on file for the period of one year. If your study extends beyond this approval period, you must contact this office to request an annual review of this research. Any change affecting human subjects must be approved by the Board prior to implementation. Injuries or any unanticipated problems involving risk to subjects or to others must be reported immediately to the Chair of the Institutional Review Board.

Prior to involving human subjects, properly executed informed consent must be obtained from each subject or from an authorized representative, and documentation of informed consent must be kept on file for at least three years after the project ends. Each subject must be furnished with a copy of the informed consent document for their personal records.

The research activities listed below are expedited from IRB review based on the Department of Health and Human Services (DHHS) regulations for the protection of human research subjects, 45 CFR Part 46, as amended to include provisions of the Federal Policy for the Protection of Human Subjects, June 18, 1991.

7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.