SIX PARENTS DESCRIBE IDEAL ADULT LIVES FOR THEIR CHILDREN WITH SIGNIFICANT COGNITIVE DISABILITIES

by

BARBARA ANN JORDAN-WHITE

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy
Department of Special Education
College of Education
University of South Florida

Co-Major Professor: Glen Dunlap, Ph.D.
Co-Major Professor: James Paul, Ed.D.
Committee Member: Albert Duchnowski, Ph.D.
Committee Member: Daphne Thomas, Ph.D.

Date of Approval:
February 14, 2003

Keywords: disability, mental retardation, civil rights, voting, family perceptions

© Copyright 2003, Barbara Ann Jordan-White
ACKNOWLEDGEMENTS

I would like to acknowledge the contributions of the doctoral committee members. Each member was very supportive and the committee worked extremely well as a cohesive unit. This cohesive unit made the completion of this document possible.

I would like to thank Dr. Paul, my co-chair, for introducing me to the idea of pursuing a Ph.D. in this field. Additionally, I would like to acknowledge the emotional, academic and financial support Dr. Dunlap, my co-chair, offered me during this long journey. He dedicated countless hours to my education. His belief in my work and perspectives was crucial to the completion of this document.

I would also like to acknowledge the contributions of Cassandra D’Amario. Her expertise in the field of disability studies is unparalleled. It has been an honor and privilege to learn from her and to be her mother.
# TABLE OF CONTENTS

## CHAPTER ONE: INTRODUCTION

- Research Problem: 4
- Research Question: 6

## CHAPTER TWO: LITERATURE REVIEW

- Parents’ Perception: 8
- Adult Issues for Individuals with Significant Disabilities: 22
  - Autonomy: 25
  - Vote: 28
  - Marriage: 29
  - Sexual Consent: 30
- Adult Development and Life Cycle Research: 32

## CHAPTER THREE: METHOD

- Design: 39
- Sampling Procedures: 41
- Participants: 45
- Data Collection: 50
- Instrument: 51
- Data Analyses: 55
- Limitations: 56
<table>
<thead>
<tr>
<th>Chapter Four: Results</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autonomy and Mutuality</td>
<td>57</td>
</tr>
<tr>
<td>Employment</td>
<td>57</td>
</tr>
<tr>
<td>Residential</td>
<td>63</td>
</tr>
<tr>
<td>Voting</td>
<td>68</td>
</tr>
<tr>
<td>Social Relationships</td>
<td>72</td>
</tr>
<tr>
<td>Marriage</td>
<td>78</td>
</tr>
<tr>
<td>Sexual Consent</td>
<td>85</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chapter Five: Discussion</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpretation of the Findings</td>
<td>102</td>
</tr>
<tr>
<td>Relationships</td>
<td>102</td>
</tr>
<tr>
<td>People with Disabilities in General</td>
<td>105</td>
</tr>
<tr>
<td>Family Values</td>
<td>108</td>
</tr>
<tr>
<td>Mutual Relationships</td>
<td>109</td>
</tr>
<tr>
<td>Conclusions</td>
<td>110</td>
</tr>
<tr>
<td>Implications and Limitations</td>
<td>111</td>
</tr>
<tr>
<td>Personal Reflections</td>
<td>114</td>
</tr>
</tbody>
</table>

REFERENCES                                                                 | 117  |

APPENDICES                                                                 | 138  |
| A: Categories                               | 139  |
| B: Interview                                | 143  |
| C: IRB Consent Form                         | 153  |
LIST OF TABLES

TABLE 1 Description of participants 150
SIX PARENTS DESCRIBE IDEAL ADULT LIVES FOR THEIR
CHILDREN WITH SIGNIFICANT COGNITIVE DISABILITIES

Barbara Ann Jordan-White

ABSTRACT

The purpose of this research was to investigate parents’ perceptions of ideal adult lives for their children with significant cognitive challenges. Additionally, this researched investigated what role disability played in participants' concepts of ideal adult lives for their children with disabilities. For the purpose of this dissertation, significant cognitive challenge was defined as a person having an IQ below 50 and an expected need of 24 hour a day care during adulthood. Six participants were chosen. Each participant received a copy of the interview protocol before the interviews. Each parent participated in two face-to-face interviews and one follow up telephone interview. All interviews were taped. Transcripts were reviewed for reoccurring properties or themes.

The following four reoccurring properties were found. Family values played an important role in the formulation of participants’ answers. Participants placed a high priority on caring relationships for their children in adulthood. The way participants create the meaning of disability and adulthood played an important role in how participants formulated their answers. Participants did not envision a change in their relationship with their children as they matured into adult.

Implications of these findings point to an increased understanding of
the transition to adulthood of people with significant disabilities. This study pointed to the importance of listening to families and uncovering disempowering assumptions that limit the opportunities of people with significant disabilities in adulthood.

Further research is needed on relationships of people with significant disabilities. More research on the mutuality in adult-to-adult relationships when one member has a significant disability is warranted. More research and discussion on the way people create the meaning of the constructs adulthood and disability is warranted.

This research has implications for professionals in the field, lawmakers, people with significant disabilities and their families.
CHAPTER ONE
INTRODUCTION

The transition from adolescence to adulthood is one of the most stressful times for the families of youth with significant disabilities (Ferguson, Ferguson, & Jones, 1988; Thorin & Irvin, 1992). For the purpose of this study, a person with a significant disability was defined as a person with a primary or secondary diagnosis of mental retardation (IQ below 50) and a present and expected future need for 24 hours a day of supports. A significant disability can place barriers, cause confusion, and stress for parents when attempting to envision quality adult lives for their children with disabilities. The following paragraphs contain a discussion of reasons for the increase in stress and confusion that parents experience during the transition phase. The first three reasons are frequently cited in the literature and the fourth reason, although not frequently cited, is an emerging issue for parents of young adults with disabilities.

The first reason for confusion is the cultural norm of less active parental involvement in the daily life of the child, coupled with a need for more involvement of parents with young adults with significant disabilities (Ferguson & Ferguson, 1986; Thorin, 1992; Thorin, Youanoff, & Irving, 1996). Traditionally, adulthood is associated with the young adult moving out, getting a job, and becoming independent. As many parents of teens/young adults without disabilities watch their offspring acquire jobs, go
to college, and socialize with their friends, parents of young adults with significant
disabilities are often required to provide more supervision and assistance to their son or
daughter with a disability. The reasons for this are twofold; first, there is a change in
service systems that occurs when the young adult reaches 21 years. Second, for parents
whose young adult has a physical disability, the daily care-taking tasks that require
lifting become increasingly difficult.

The second reason cited in the literature for the stress and confusion of parents is
the transition to adulthood is a relatively recent phenomenon for individuals with
significant disabilities. Before the Free and Appropriate Education Act (FAPE), parents
usually made birth to death arrangements for the care of their children with disabilities
by placing the child in a private or state institution that provided cradle to grave services
(Ferguson et al., 1988). Because there were no services at any age for a child with
significant disabilities, there was no break in services at the age of 21 years to mark a
new phase in the life of the individual with a disability and their family. Now, mandated
school services cease at the age of 22 years for individuals with disabilities causing an
imposed graduation that serves as a marker for adulthood. However, this age or marker
is imposed on families by external organizations and not a decision made by families, or
even a decision collaboratively made by the person with a disability, their family, and
the adult service system. Additionally, the ability of the individual with disabilities to
make his/her own choices about life traditionally has not been affected by this particular
transition to adulthood.

The third reason cited in the literature for the stress and confusion of parents
during the transition to adulthood of their son or daughter with a significant disability is
erratic adult services and long waiting lists. It is common for individuals with
disabilities to spend five or more years on a waiting list for adult services. When adult
services are received, they usually consist of placing the individual with a disability in
one of the following models: Intermediate Care Facility (most restrictive), group home
(less restrictive), or supported independent living (least restrictive). Families are not
asked what they want but are told the residential model for which their family member
is eligible (Racino, Walker, O'Connor, & Taylor, 1993). This continuum of care
philosophy does not take into consideration the diversity of needs and desires
individuals with disabilities and their families have. Although not cited in the literature,
this lack of attention to the individual’s wishes and family’s needs could account for
some of the stress parent’s experience.

The fourth reason for parents’ stress during the transition to adulthood of their
son or daughter with a disability is associated with the supported independent living
movement. The supported independent living model, although offered in a continuum
of care manner, was founded on the assumption that all individuals, regardless of the
level of their disability, have the right to (and with the proper supports were capable of)
a lifestyle similar to their non-disabled peers. However, the new opportunities offered to
individuals with disabilities have the potential for causing stress and confusion for
parents during the transition phase.

The new opportunities individuals with significant disabilities may begin to
access are the traditional expectations of adulthood such as moving out, getting a job,
dating, and getting married (Cote, Allahar, & Anton, 1996; Garber & Dubas, 1996;
Mandell, Porter, & Tesson, 1994; Modell, 1989). However, since historically a life long
child status has been conferred on individuals with significant disabilities, there are no magazine or journal articles to guide parents and individuals with disabilities through this new territory. What type of supports would be needed to ensure that people with significant disabilities would be safe and successful when accessing the traditional roles rites and rituals of adulthood? What are parents' perceptions about their young adult with a disability experiencing traditional adulthood markers?

Research Problem

Although the transition to adulthood of individuals with disabilities has been identified as the most stressful period for parents (Ferguson et al., 1988; Thorin & Irvin 1992; Thorin, Yovanoff, & Irvin, 1996), the literature review yielded very limited information on parents' perception of an ideal life for their young adult with disabilities. There was limited literature on parents' perceptions on the construction of adulthood (Ferguson et al., 1988), dilemmas faced by parents in the transition to adulthood (Thorin, et al., 1996), and parents' expectations of adulthood (Turnbull & Turnbull 1988). However, very limited literature was found on parents' perceptions of quality adult lives for their children with significant disabilities. If more were known about parents' dreams for adulthood, current services could be modified to incorporate parents' desires for their family member with a disability and potentially reduce the amount of stress experienced by parents. The voice of the family to include family values, dreams for a quality life, concerns about safety issues, and visions of their children with disabilities successfully negotiating the rights and rituals of adulthood, are needed to assist the field in serving adults and adolescents with disabilities in a sensitive manner. The literature on families' perceptions about their young adult with a significant
disability accessing the traditional rights to adulthood such as voting, consensual sex, and marriage is extremely limited. This study will fill a void in the literature.

Ascertaining the role disability and family value played in the family’s conceptualization of an ideal adult life for their family member with a disability was important. If a parent’s vision of a quality adult life for their son or daughter with a disability did not include certain traditional markers of adulthood because of family values and traditions, then knowledge about these family traditions and values would assist the field in understanding families. More knowledge about families’ feelings and family traditions regarding adulthood could heighten respect for families’ diverse needs.

Additionally, if parents express a strong belief that no person with a disability should access certain traditional markers of adulthood, then knowledge about the reasons for this belief can generate discussions on the rights of people with significant disabilities and expose underlying assumptions help by parents.

The goal in this study was to gather, in a systematic manner, a description of parents’ perceptions of their young adult/adolescent’s ideal adult life and to ascertain what role family culture and the person’s disability play in the conceptualization of this ideal life. Parents were asked to visualize adult lives that offered their children with disabilities optimal opportunities to achieve mental and physical health. Parents were asked to describe how they envisioned their children accessing adult roles that had not traditionally been associated with individuals with significant disabilities such as voting, marriage and sexual consent. They were also asked to describe how they envisioned other individuals with disabilities similar to their children accessing the traditional rights and roles of adulthood. Parents were also asked how their visions of adulthood for their
children with disabilities differed from visions they would have had if their children did not have disabilities. This assisted in determining the role disability played in parents’ perceptions of ideal adult lives for their children.

**Research Question**

What type of life would parents ideally like to see for their son or daughter with a significant disability? What type of employment, residential situation, social life, and use of leisure time would be considered ideal by families? What would it take to meet their young adult’s physical, mental, and spiritual needs? What role does the family member’s disability and family culture play in the construction of the ideal adult life of their family member with a disability?

The supported independent living model driven by the fundamental concept of normalization provides new opportunities for individuals with disabilities. What do parents see as the potential concerns and barriers to individuals with significant disabilities accessing such new opportunities as voting, marriage, and consensual sex? Do parents buy into the concept of normalization for their family member with a disability? What are parents' perceptions of an ideal adult life for their family member with a disability?

This study was conducted to systematically gather information on how parents envisioned their children with disabilities accessing the traditional markers of adulthood. Parents’ perceptions of ideal adult lives for their children with disabilities and the role disability and family values played in this conceptualization were investigated.
Systematic descriptive information was gathered through the investigation of the following questions:

1. What are parents’ perceptions of ideal quality adult lives for their children with disabilities? Including:
   a. Successfully accessing the traditional markers of adulthood
   b. Describing ideal relationships with their children in adulthood
   c. Describing the supports needed to ensure their children’s’ physical and mental health in adulthood.

2. What role do their children’s disabilities play in parents’ conceptualization of ideal adult lives for their children with disabilities?

3. Do parents’ visions of ideal adult lives for their children with disabilities differ from their visions of ideal adult lives for the general population of people with disabilities?
CHAPTER TWO

A REVIEW OF THE LITERATURE

The purpose of this study was to gather detailed descriptions of parents’
perceptions of ideal adult lives for their children with significant disabilities and parents’
visions of quality life for individuals with disabilities in general. Literature related to this
study was reviewed and organized into the following three sections: (a) perceptions of
parents of people with significant disabilities on issues related to adulthood, (b) adult
issues for individuals with disabilities, and (c) adult development and life cycle research
for individuals without disabilities.

Parents’ Perceptions

The first section is a review of the literature covering the perspectives of parents
of adolescents/young adults with disabilities on issues related to adulthood. A computer
search was conducted using the following key words: parents/family,
perspectives/attitudes, adulthood and mental retardation. The following criteria were
used for inclusion in this section: (a) participants in the study or article must include at
least one parent of an individual with a disability, (b) the individual with a disability
must be between the ages of 14 years and 21 years, and (c) some aspect of adult
concerns must be discussed (e.g., employment, residential placement, community
inclusion, voting, consensual sex, marriage). The literature is very limited on parents’
perceptions of ideal adult lives for their children with disabilities.
The most relevant article to this study revealed by the literature search was about the perspectives of parents of children with significant disabilities on transition issues (Ferguson, Ferguson, & Jones, 1988). This ethnographic study explored parents' interpretation of the events and relationships surrounding the transition of their children with severe disabilities from school to adult life. In this qualitative study, 15 families were interviewed. Participants were divided into two groups based on the age of the family member with a disability. Six families were in the pre PL 94-142 group (family members with a disability ranged in age from 14-40 years), and nine families were in the post PL 94-142 group (family members with a disability ranged in age from 21-30 years). A unique feature of this research project was that families were asked general questions about their perceptions and experiences, not about one particular program or a comparison of two models.

The following three types of transitions were identified: bureaucratic, family life, and adult status. "Bureaucratic" transition was defined as changing from one service system (public school) to another (adult services). "Family life" transition referred to the changes the family went through because of the transition of their family member with a disability into adulthood. This transition consisted of those changes in family routine due to the family member with a disability no longer going to school. Most parents reported no or limited adult services immediately following graduation from school. The "adult status" transition refers to the deeply personal changes that occur within the person with a disability. Although these changes are very ambiguous...
and difficult to define, a majority of parents mentioned some type of inner recognition that a transition had occurred with their son or daughter with a disability.

Differences were found between the pre and post groups. Parents raising their children before the Free and Appropriate Education Act (FAPE) did not experience the transition of their children with severe disabilities to adulthood. Although biologically the transition occurred, their children had birth-to-death arrangements made for them and there was no expectation that “adulthood” in the traditional sense would be reached.

Data analysis revealed four distinct types of coping skills. The first coping strategy was “abandonment by professionals”. This strategy was characterized by the complete powerlessness of the parent in any relationship with the service bureaucracy. “Surrender”, the second coping strategy, was characterized by a relationship pattern with professionals that involved the parents’ repeated deferrals to professional opinion and explanation for what might otherwise have appeared to be inadequate services. The third coping strategy, “assimilation with professionals”, was found more in the older, pre-FAPE generation. Parents who felt compelled to become professionals because of the lack of appropriate services employed this strategy. The following quote is representative of the attitudes of parents who use this strategy, "If you wait for the bureaucracy to come to you, they might not get there. And then if they do come to you, they might not do it the way you want it done" (p. 182). The fourth and final coping strategy was engagement with professionals. This pattern had two forms. Parents working eagerly with professionals in constructive patterns of active involvement characterize the first form. Parents who perceived an adversarial relationship with professionals characterize the second form. The pattern that both types of engagement
exhibit was an expectation of separate but equal parent and professional responsibilities. This final strategy was present only in the younger, post-FAPE parents. Although this unique study offers valuable insights into the experiences of parents of young adults with disabilities during their transitions into adulthood, parents' perceptions of the ideal adult life for their son or daughter with a disability were not discussed. Because data have not been gathered on parents' perceptions of an ideal adult life for their son or daughter with a disability, it is probable that current services are not meeting parents' needs due to lack of knowledge about those needs. This dissertation provides information that enlightens the field and enables professionals to better understand and serve parents, thereby possibly lessening the stress felt by parents during this difficult phase.

Another relevant article revealed by the literature search consisted of a discussion about dilemmas faced by families during their family members with a disabilities' transition to adulthood. This quantitative study by Thorin, Yovanoff, and Irvin (1996) consisted of an examination of the results of a questionnaire sent to 103 families. The purpose of the study was to determine what dilemma families faced most often during their children with disabilities' transition into adulthood. Parents were asked to rate 14 dilemmas according to importance and relevance to their lives. Six dilemmas were identified as being significant to parents' lives.

The first dilemma was "Wanting to create opportunities for independence for the young adult and wanting to assure that health and safety needs are met". This present study provides information on the type of opportunities for independence that parents envision for their children with disabilities as well as their concerns about their
exhibit was an expectation of separate but equal parent and professional responsibilities. This final strategy was present only in the younger, post-FAPE parents. Although this unique study offers valuable insights into the experiences of parents of young adults with disabilities during their transitions into adulthood, parents’ perceptions of the ideal adult life for their son or daughter with a disability were not discussed. Because data have not been gathered on parents’ perceptions of an ideal adult life for their son or daughter with a disability, it is probable that current services are not meeting parents’ needs due to lack of knowledge about those needs. This dissertation provides information that enlightens the field and enables professionals to better understand and serve parents, thereby possibly lessening the stress felt by parents during this difficult phase.

Another relevant article revealed by the literature search consisted of a discussion about dilemmas faced by families during their family members with disabilities’ transition to adulthood. This quantitative study by Thorin, Yovanoff, and Irvin (1996) consisted of an examination of the results of a questionnaire sent to 103 families. The purpose of the study was to determine what dilemma families faced most often during their children with disabilities’ transition into adulthood. Parents were asked to rate 14 dilemmas according to importance and relevance to their lives. Six dilemmas were identified as being significant to parents’ lives.

The first dilemma was “Wanting to create opportunities for independence for the young adult and wanting to assure that health and safety needs are met.” This present study provides information on the type of opportunities for independence that parents envision for their children with disabilities as well as their concerns about their
children accessing these new opportunities. "Wanting a life separate from the young adult with a disability and wanting to do whatever is necessary to assure a good life for him or her" was the second dilemma identified. This present study provides a description of what parents' conceptualize as good lives for their children with disabilities and their perceptions of ideal relationships with their children with disabilities in adulthood. The third dilemma identified by this study was "Wanting to provide stability and predictability in the family life and wanting to meet the changing needs of the young adult with a disability". This present study consists of descriptions of the roles families would like to play in the lives of their children with disabilities in adulthood. The fourth dilemma was "Wanting to create a separate social life for the young adult and wanting to have less involvement in his or her life". In this present study, multiple questions were asked on parents' perceptions of ideal social lives of their children with disabilities thereby providing the field with a more complete description of issues surrounding this dilemma. "Wanting to avoid burnout and wanting to do everything possible for the young adult" was the fifth dilemma identified by parents. The final dilemma identified by parents was "Wanting to maximize the young adult's growth and potential and wanting to accept the young adult as he or she is". This present study provides a more detailed description of parents' definitions of their young adults with disabilities maximizing their potentials. Although it is important to have these dilemmas identified, this study adds to our knowledge about these dilemmas by providing a description of parents' perceptions of ideal lives for their children with disabilities.
Thorin and Irvin (1992) conducted an earlier study on family stress associated with transition to adulthood of young people with severe disabilities. In this study 42 members of 19 families were sent questionnaires and asked to describe three specific transition-related stressful concerns expressed by anyone in their family within a number of broadly defined areas of potential concerns. The most frequently mentioned concerns were getting along with others, self-care capabilities, responsible behavior, and sexuality. The concerns rated most stressful were residential, disruptions to family routine, and dealing with agencies and professionals. This study provides detailed information on parents' concerns about issues of sexuality and describes parents' perception of an ideal residential situation for their son or daughter with significant disabilities.

Gallivan-Fenlon (1994) studied family, service provider and student perspectives on the transition from school to adult life. In this qualitative study, families, students, and professionals, were interviewed about their expectations for future employment of 11 students with moderate or severe/profound cognitive impairment. Families and professionals held lower expectations than did the students. Most students envisioned themselves employed in the community with supports. Most parents and professionals expected their young adult to be in a sheltered workshop or day center. A six-month follow-up after graduation revealed that only two of the 11 students were employed in the community. Of the remaining nine students, five were "sitting at home", one was in a day center, and three were in sheltered workshops. In follow up observations students who were experiencing the reality of the lower expectations were described as depressed and disappointed at their post-school
outcomes. It is unclear whether the reason for the parents' lower expectations was increased knowledge about the lack of appropriate adult services, or other reasons.

Hamre-Nietupski, Nietupski and Strathe (1992) conducted a study of 68 parents, asking them to rate the following areas of curriculum: functional skills, academic skills, and friendship/social relationship development according to importance and relevance to their child's life. Results indicated that parents of students with severe and profound cognitive impairment rated friendship/social relationship development higher than did parents of students with moderate disabilities. Conversely, parents of students with moderate disabilities rated the functional life skills area of school curriculum higher than did the parents of students with severe/profound cognitive disabilities.

Strobino's (1988) paper, presented at the Annual Meeting of the American Association on Mental Retardation Family Support, entitled "Services in Hawaii: The parent's perspective", provides another description of parents' perceptions. A questionnaire was distributed in Hawaii seeking information on parents' perspectives on family support services. The 625 questionnaires, distributed via 24 support agencies, yielded 234 usable surveys. The services most used were financial and medical assistance, adult day programs, and transportation. Services not used but wanted were information and referral/advocacy, parent support groups, and counseling. Parents identified the most important services as respite day programs, leisure and recreation programs, and information/referral agencies. This study provided important information on what parents' perceived as the most wanted and used services. When answering a questionnaire about services, parents may tend to think in terms of available services, or services offered elsewhere but not in their area.
Brotheron's (1988) article "Transition into adulthood: Parental planning for sons and daughters with disabilities" consisted of a discussion of parents' perceptions of planning needs. In this study 48 parents were interviewed via telephone and asked to identify their greatest planning needs. The three greatest planning needs were living situation, socialization, and employment. A positive relationship between planning for adult needs and family functioning was also identified.

Rousso (1988) explored the relationship between parental expectations of adolescent women with physical disabilities' success in the heterosexual arena and the amount of socialization that actually occurred. "Success" was defined by the age of the woman with a disability when she experienced her: first date, first kiss, first sexual contact, first experience with intercourse, first steady relationship, and first recollection of masturbation. The majority of participants were white, heterosexual, single, and in their twenties or thirties with some degree of college education. The study consisted of 43 women, 31 were disabled prior to adolescence with the remaining 12 disabled after adolescence. The range of disabilities included mobility impairment, brain and neurological disabilities, blindness, and deafness. Results indicated that all the participants recalled beginning to masturbate at about the same age. However, the mean age for all the other indicators of success (first date, kiss, etc.) was lower for the women who acquired their disabilities after adolescence. In comparing themselves to their peers, almost three-fourths of the women disabled prior to adolescence felt they had experienced their first social and sexual markers later than did their non-disabled peers. The participants were also asked to what extent their parents expected them to actively socialize, get married, and bear children. Additionally, they were asked to what extent
their parents expected them to complete high school, complete college, and get a good job. Parental expectations were not statistically different for the two groups, but some important trends were identified. Parents of participants disabled prior to adolescence had higher educational and career expectations coupled with lower social expectations than did the parents of participants disabled after adolescence. The participants’ heterosexual expectations for themselves were positively correlated with their parents’ expectations to a statistically significant degree. Additionally, when the participants were asked to identify which factors were the most influential in shaping the image of who they would become as adults, mothers were mentioned most frequently and fathers were in the top five.

Tossebro’s (1996) article, “Family attitudes to deinstitutionalization before and after resettlement: The case of a Scandinavian welfare state”, also consisted of a discussion of family perceptions/attitudes and adulthood. In this quantitative study two sets of questions were compared, one completed in 1989 and the other in 1994. The questionnaires (591) were sent to parents/relatives of individuals with disabilities who were being moved from an institution into a group home located in the community. The results indicated parents were generally opposed to the resettlement, but found it more satisfactory after the fact. The more the parents were involved with the resettlement process the more they were likely to be pleased with the outcomes.

Hornstein (1997) shared her perspective in the article “How the religious community can support the transition to adulthood: A Parent’s perspective”. This article was a discussion of ways Jewish community centers, camps, youth groups, and social clubs could provide opportunities to prepare youth with disabilities for life among the
general population. Hornstein emphasized how the ability to be in real situations with non-disabled peers benefits both disabled and non-disabled youth. Specific curricular suggestions are made to assist non-disabled peers in learning about their peers with disabilities.

Turnbull and Turnbull's (1988) article on parents' expectations for vocational opportunities for their children with mental retardation consisted of a literature review on parents' attitudes towards supported employment. The discussion centered around what the authors noted as the most comprehensive study to date, a mail survey of a representative sample of 660 parents/guardians whose sons and daughters were receiving adult services from mental retardation agencies in Virginia (Hill, Seyfarth, Banks, Wehman, & Oreloge, 1987). The findings of this study showed 12% of respondents expressed a preference for competitive employment for their sons or daughters with disabilities. Parents of persons with mild and moderate mental retardation preferred placement in a sheltered workshop, and parents of persons with severe and profound disability selected an activity center as the optimal placement. All parents expressed a low interest in improving working conditions and increasing wages.

The authors cautioned against focusing exclusively on parents as the target for intervention for raising expectations (the way the original article did) and examined factors that contributed to parents' expectations such as professional expectations and general societal influences. The authors noted the influence negative expectations of teachers and supported employment staff have on parents' ability to formulate inclusive supportive employment for their children with disabilities. The authors referred to activity centers and traditional sheltered workshops as a form of institutionalization and
called for profound changes in the system including increased opportunities for personal
decision-making, future planning, friendships, and summer jobs.

In a discussion of a study of parents’ perspectives on transition of their sons and
daughters from special education in Colorado (Mithaug, Horiuchi, & McNutty, 1987),
parents reported that their family members primary need was psychosocial. It was noted
in this study that when formal education ended, segregation and isolation increased. The
Turnbills are parents of an adult with disabilities. They discuss their dream for an ideal
adult life for individuals with disabilities in very general terms. The authors envision
and advocate for individuals with disabilities to learn, work, and live with their friends.

Turnbull and Ruef’s article (1997) “Family perspectives on inclusive lifestyle
issues for people with problem behavior.” is also relevant to this study. In this study, 17
families of children, youth, and adults with mental retardation who exhibited problem
behavior (pica, aggression towards others, property destruction and self-injurious
behavior) were interviewed via the telephone. The age range of the family members
with disabilities was 4-35. As the interviews progressed, the three
interviewers/researchers met to discuss emerging themes and sub-themes. These themes
and sub-themes were used as probes in subsequent interviews to assist in identifying
key themes and sub themes in data analysis. The following categories were identified:
(a) family life, (b) friendship issues, (c) school issues, (d) community inclusion, and (e)
supported living and supported employment issues. All the categories except school
issues are relevant to the topics of this study. School issues were excluded because they
dealt with teacher and administrator competence.
Issues discussed within the category of family life were relationships with siblings, extended family relationships, and home routines. The lack of a close bonding relationship with siblings was frequently mentioned as a problem. Parents expressed that extended family had a hard time establishing a close relationship with the family member with problem behavior. The most frequently mentioned problem in the home was the child's difficulty in being productively involved in home activities.

The subcategories associated with friendship issues are status of friendships, friendships with adults, friendships among children. Over two-thirds of families reported that their family member with problem behavior did not have any friends. Most parents accepted the lack of friends as inevitable. Two parents mentioned intense fear about sexual exploitation; they worried that their son or daughter would be the target of an aggressive encounter. No parent mentioned a vision of his or her young adult having a mutually gratifying sexual relationship. Four of the six people 18 years old and older had at least one friendship. One friend started as a volunteer for a disability advocacy organization that had a program to facilitate friendships at the local high school. The other three friends were former or current staff members. Families of children under the age of 18 cited having the child participate in as many inclusive activities as possible as a main strategy for facilitating friends. Families gave low priority to community inclusion because of time and energy limitations, unavailability of other companionship, and family perceptions of worry, fear, and embarrassment.

Majewicz's (1999) article “Parental attitudes and anxiety in pupils of an elementary school for the mildly retarded” also consists of a discussion of parents' perceptions. In this quantitative study 90 fathers and 90 mothers of children between the
ages of 13-16 years who were attending special schools were administered a questionnaire. The results indicated a positive correlation between both excessive maternal negative attitudes and parental feelings of helplessness, and anxiety in children with disabilities about school. A unique feature of this study is that an equal number of fathers and mothers participated. There was no mention in the article about single parent homes. This is probably indicative of a cultural difference between Polish and American families. The general tone of this article was one of blaming parents for their children’s anxiety about school.

Dunlap, Robbins, and Darrow (1994) conducted a study to determine parents’ perceptions of their children’s challenging behaviors. The authors posit that although many professionals recognize that family support should be tailored to the individual strengths, needs, and circumstances of the family system (Dunlap & Robbins, 1991) there has been very little research to identify the kinds of services and supports that are valued and requested by families that include members with disabilities and challenging behaviors. Additionally, although families are the primary caregivers for most children with disabilities, the literature contains very few reports of families’ views of challenging behaviors. This study consisted of a statewide survey of 79 parents of children with autism and related disabilities about their children’s challenging behaviors and what resources were the most useful. The age range of the family member with a disability was 2-38 years. Data revealed that destructive behavior was reported most frequently in the adolescent group and least frequently in the elementary group. Self-stimulation was reported most frequently in the preschool group and least frequently in the adult group. Withdrawing was the most frequently reported behavior problem in the
adolescent group and tantrums were most frequent in the preschool group. The finding of a higher frequency of destructive behavior of adolescents (12-17) was accompanied by parents' reports that available resources were less helpful. This could be indicative of a reason for increased stress for some parents around the time parents are encouraged to begin planning for the transition to adulthood of their family member with a disability. It is also interesting to note that family members were cited frequently as being a very helpful resource.

Although not about parents' perspectives, Morningstar, Turnbull and Turnbull's (1996) article "What do students with disabilities tell us about the importance of family involvement in the transition from school to adult life?" consisted of a discussion of student perspectives. This qualitative study consisted of four focus groups. Participants included students with learning disabilities, emotional and behavioral disorders, and mild mental retardation. The groups focused on how families influence the development of the participant's personal vision for the future. The results indicated that students perceive family input and support as highly influential.

Valentine, McDermott, and Anderson's (1998) article described the differences between perceptions of African-American and Caucasian mothers regarding the burdens and gratifications of caring for an adult son or daughter with mental retardation. Face-to-face interviews were conducted in the homes of 43 Caucasian and 28 African-American mothers of adults with mental retardation. The interviews varied in length from 40 minutes to 2.5 hours. The caregivers responded to questions related to burdens and gratification on a scale of one to three. The areas of assessment were activities of daily living, caregiver gratification, caregiver burdens, and intimacy. Results showed
Caucasian mothers perceived more burdens and conflicts and less gratification and intimacy than did their African-American counterpart.

Although the literature on parents' perceptions includes potential issues and concerns, dilemmas, and identified stressors, regarding the transition of their son or daughter with a cognitive impairment to adulthood, it does not include what parents perceive as an ideal quality life for their son or daughter with a disability.

Adult Issues for Individuals with Significant Disabilities

The second section covers literature related to issues of adulthood and people with disabilities including the independent living/consumer movement, autonomy, marriage, sexual consent and issues of disability rights. The treatment of individuals with disabilities has gone thorough many transformations, each change resting on differing philosophical views of individuals with disabilities. Individuals with disabilities have been isolated in institutions in order to protect them from society and society from individuals with disabilities (Heal & Haney, 1988). Another reason cited for isolation and separation form society was to provide rehabilitation services. The model of isolation and treatment stems from the philosophy that a disability is a deviance/abnormality that must be cured if possible, and treated to ameliorate the effects of the disability if a cure is not possible. This philosophical outlook, based on the medical model, led to much research on the proper labeling and categorizing of deviance/disability.

Wolfensberger (1972), the father of the concept of normalization has posited that individuals with disabilities should not be isolated but lead as close to a normal life as possible. The concept of normalization facilitated the spawn of the
The deinstitutionalization movement of the 1980's (Racino, Walker, O'Connor, & Taylor 1993). The emphasis was to relocate individuals from large institutions to smaller group homes located in the community. These residences were perceived as a more "homelike" and normal atmosphere in which to house individuals with disabilities. During the early 1980's the focus of the disability field was on issues such as the benefits and limitations of heterogeneous and homogeneous groupings; the optimal size of group homes; site selection and neighborhood reactions; and quality assurance including issues of licensure and regulation. In the heterogeneous verses homogeneous grouping debate characteristics such as age, gender, and ethnicity were largely ignored (Racino et al., 1993) and individuals were defined and grouped by their disability label (e.g., challenging behaviors, medical needs, and mental retardation). People's disability label decided where they were going to live. Additionally, decisions about groupings and other decisions about the lives of people with disabilities were still primarily professional determinations and not the determination of individuals with disabilities or their families. Where a person with a disability lived was tied to the convenience of programming and not human needs. A need not to have one aspect of one's self (disability) be the determining factor in so many decisions made about a person's life spawned the consumer movement, supported independent living, and other empowerment movements.

The supported independent living movement calls for a change in the way individuals with disabilities receive services. An important change in this concept is the separation of housing from the concept of support (Taylor, Racino, Knoll, & Lutfiyaa 1987). The person is considered the central aspect that all planning and supports (both
agency, and natural) revolve around. This new way of thinking calls for a break away from thinking about what currently exists (e.g., place in a group home, funding under the Medicaid waiver for supportive living), and instead, focuses on the person's life. The literature presents a variety of strategies to train agency personnel in this new way of viewing people with disabilities and the services they receive, and to eliminate the personal constraints agency personnel may bring to any decision-making process involving people with disabilities. Common strategies include the use of values-based training such as "Frameworks for Accomplishment" (O'Brien & Lyle, 1988) and "PASSING" (Wolfensberger & Thomas, 1983), or the use of such techniques as personal futures planning (Racino et al., 1993) and "planning alternative tomorrows with hope" (PATH) (O'Brien & Lovett, 1998).

The disability consumer movement, independent living movement and empowerment movement are attempting to deconstruct and redefine the concept of disability (Barton, 1996; Gadacz, 1994; Racino, Walker, O'Connor, & Taylor 1993). This consumer/empowerment movement is a process of both individual and collective empowerment. The primary objectives of this social reform movement are the empowerment of people with disabilities in relationship both to identity formation and the reformation of community relationships (Barton, 1996; Gadacz, 1994). This movement is a struggle by individuals with disabilities to gain control over the "form and content of their own identity formation" (Gadacz, 1994) and to achieve autonomy and independence.
There have been changes in the traditional definitions of autonomy often associated with adulthood. These changes have significant implications for individuals with severe cognitive disabilities in regards to their ability to access roles traditionally associated with adulthood but not traditionally associated with individuals with severe disabilities. In the past, autonomy for individuals with disabilities has been defined as the independence from assistance of others. However, due to recent developments in the fields of family systems and special education, autonomy has been redefined as an individual’s capacity to take responsibility for his/her own actions, to make decisions regarding one’s own life, and to maintain supportive relationships (Crittenden, 1990).

Wehmeyer (1992a) defines self determination as “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life, free from undue external influence or interference” (Wehmeyer, 1992a, p. 305). Wehmeyer posits that being a primary causal agent in one’s life translates into acting autonomously.

Lewis and Taymans (1992) define autonomy as

...a complex concept which involves emotional separations from parents, the development of a sense of personal control over one’s life, the establishment of a personal value system, and the ability to execute behavioral tasks which are needed in the adult world (p. 37).

Autonomy training for a person with a disability in the traditional definition consisted of self-help skills and, specifically, upon caring for oneself without assistance (Cleland & Swartz, 1982; Haring, 1982). When the disabled individual reached adolescence, the emphasis turned to acquisition of vocational skills (Clark & White, 1980). The more recent independent living model is based on consent, choice, and autonomy (Racino et al., 1993) and does not assess independence in terms of mastery of
physical tasks. Rather, this model focuses on the role of individuals with disabilities to make decisions about their own lives. Another emphasis of this movement has been to focus on the resources and opportunities made available to persons with a disability through the political process by influencing policy decisions and law (Turnbull & Turnbull, 1985). However, little attention has been given in the literature to voting supports for individuals with significant cognitive disabilities.

The literature on the development of non-disabled adolescents shows a similar change in the definition of autonomy. Earlier studies defined autonomy in terms of detachment from parents, capacity to function adequately on one's own, individuation, and independence from parents (Blos, 1979; Freud 1958; Greenberger, 1984). More recent works focus on decision-making capacities and acceptance of responsibility. The emphasis is on greater mutuality in the parent child relationship (Grotevant & Cooper, 1986) and the importance of peer relationships (Rubin & Pepler, 1980; Selman, 1981). Again, autonomy is no longer about how much one can do by oneself for oneself, but the accepting of responsibility and making decisions for oneself in a context of social connectedness. Recognizing social connectedness or interdependence as opposed to independence and mutuality in relationships instead of emotional autonomy is a much less limiting view of adulthood.

The definitions of Wehmeyer (1992a), Crittenden (1990) and Lewis and Taymans (1992) do not take into account the family nor do they view self-determination from a family systems framework. Turnbull and Turnbull (1996) posit parents' preferences may run contrary to the assumptions of self-determination. The Turnbells (1996) discuss the cultural preferences of Latin-American families and discuss self-
determination as an Anglo middle class concept. They posit that by concentrating on
being a causal agent and acting in an autonomous fashion, there is an almost exclusive
focusing on one person in a family system. Turnbull posits that the characteristics of the
disability, characteristics of the family, and family interaction should all be taken into
account when considering autonomous behavior and self-determination. Turnbull
cautions that glossing over the differences of disability and family characteristics is not
in the best interest of people with disabilities, their families or society in general.

Wehmeyer (1996) has responded to criticisms about his definition of the term
autonomous by emphasizing that autonomous actions reflect interdependence of
individuals with other people, including families, friends, acquaintances and society in
general. A self-determined action is defined as being free from undue interference or
influence of others with the term undue being purposely vague because what may be
perceived by one individual to be an acceptable level of influence may appear to
another as unacceptable.

The purpose of the emphasis on self-determination and autonomy is to increase
a person's feeling of psychological empowerment. According to Zimmerman (1990),
psychological empowerment consisted of the following dimensions of perceived
control: cognitive personal efficacy, personality (locus of control), and motivational
domains. To experience personal empowerment, a person must have self-efficacy, a
sense of personal mastery over one's environment and the expectation that one can
successfully execute behaviors required to produce specific outcomes with the
expectation that the behaviors will lead to the outcome. Additionally a person must have

27
an internal locus of control or the belief that it was his/her behaviors that resulted in the expected specific outcome.

St. Peter, Field, and Hoffinan (1992) ascribe the principal of reciprocal causation to self-determination. This principal suggests that behaviors of self-determination are also expressions of self-determination. Behaviors of self-determination are causal in ascribing self-determination to one and as such reflect both outcome and etiology.

The old definitions of autonomy would prevent society from viewing anyone with significant physical or cognitive disabilities as ever being autonomous. Recent attention to the concept of interdependence as opposed to independence has helped us realize that none of us are truly independent and it is simply a matter of degree and type of dependence that we have on each other (Condeluci, 1991).

Vote

The right to vote is one of the key bureaucratic indicators that an individual is an adult. Voting signifies that one is deemed old enough to have a say in society by deciding its laws and leaders. In 1971, the right to vote was lowered from the age of 21 to 18 years due to protests concerning the drafting of young men to serve in the Viet Nam war (Novak, 1971). Since making choices, and participating in community life to the fullest extent possible are desirable goals and the philosophical basis of the supported living and community integration models, then individuals with cognitive impairments should join other adults in choosing community and national leaders. Yet, this area has been neglected in the transition literature and curriculum practice for individuals with significant cognitive disabilities.
Marriage

The ability to marry is a traditional indicator of adulthood (Cote, Allahar, & Anton 1996; Graber & Dubas, 1996; Mandell, Porter, & Tesson 1994; Modell, 1989). The minimum age of marriage changes from state to state. Typically, there is a minimum age requirement to marry with parental consent and a minimum age requirement without parental consent. Most states have lowered the age of marriage without parental consent from 21 to 18 years (Robinson, 1978). Formerly the age requirement for marriage differed for males and females; now there is non-discrimination between the sexes in this respect. Most states allow persons age 16 and 17 years to marry with consent of parents or a judge (Golenpaul, 1997). Despite the lowering of the minimum age requirement there is a trend for people to marry later in life with many choosing not to marry (Cote et al., 1996).

According to our laws, parties who wish to marry must have the capacity to do so. For example, if due to drunkenness, mental illness, cognitive impairment or some other issue, one or both parties lack “capacity”, the marriage could be ruled invalid. In most cases questioning the capacity of individuals with cognitive impairments, judges have upheld the presumption of incompetence associated with the label mentally retarded (Kasier, 1992). The right to marriage is a right that does not require any skill or competence criteria for non-disabled adults. The denying of the right to marry to individuals with significant cognitive impairments is an issue that transition professionals, family members, and civil libertarians may wish to investigate, after all a high IQ does not ensure a responsible relationship or happy marriage. Having a description of parents’ concerns about the marriage of their family member with a
disability will be an important contribution to any discussion professionals have on the issue of marriage.

The capacity clause is problematic for individuals with cognitive impairment who wish to marry and reflects societal concerns about marriage and procreation regarding individuals who are labeled mentally retarded. Families who wish to prevent a marriage they feel may cause harm to a vulnerable family member are able to use the capacity clause. Many parents disapprove of their child's choice for a spouse. A key difference between the marriage of persons with and without disabilities is that the parents of a person with disabilities can legally stop the marriage of their child by bringing into question their child's capacity to make a decision on such an important issue. Imagine how many fewer marriages would be performed today if parents of children without disabilities had this tool at their disposal. The legal tool of questioning a person's capacity is a mixed blessing. Parents, family members and concerned professionals can use this tool to protect very vulnerable individuals from harm or as a form of control. This type of control erodes a person's right to the dignity of risk, and the right to make one's own decisions, including making one's own mistakes.

Sexual Consent

In today's society, childhood is considered a time of sexual innocence. Laws exist to protect children and punish adults who do not respect this societal norm. Therefore, the age at which society no longer legally feels the need to protect a person's sexual innocence is an indicator of adulthood. The age of sexual consent is the age at which an individual can become sexually active without falling under a law that was created to protect children from sexual predators. In most states, the age of sexual
consent is 16 years (Golenpaul, 1997). It is interesting to note that 16 years is the average age at which females reached puberty in 1850.

Once again, this aspect of adulthood affects people with severe cognitive impairment. Consent has been defined as the knowing, intelligent, and voluntary agreement to engage in a given activity (Kaeser, 1992; Stavis, 1987). In the case of Commonwealth v. Saltzberger (1951), indicators used to demonstrate an individual’s capacity were the ability to read, write and tell time. In the case of People v. Blunt (1965), capacity to consent was determined by the ability to understand the sexual act, its nature, and possible consequences. Finally, in the 1977 court case of People v. Easley, the ability to appreciate how coitus would be considered within the framework of societal environment was used to determine the capacity to consent to the sexual act (Kaeser, 1992). These standards of competency were established to protect people who are cognitively challenged from sexual coercion. However, these same standards exclude individuals with cognitive impairment from ever engaging in mutual sex. It is important that the need for laws to protect an individual from harm not be so restrictive as to categorically preclude the opportunity for personal choice and the right to privacy (Hepner, 1979; Kaeser, 1992).

Consent must be defined to ensure opportunity to choose to engage in a mutual sex activity and simultaneously protect an individual from sexual coercion. Kaeser (1992) calls for a redefining of consent. He posits that the definition should include a determination of what the individual would want if he/she could advocate and speak for himself/herself and a determination of what is in the individual’s best interest as defined by an interdisciplinary team.
In summary, little is known about adults with significant disabilities accessing the rites, roles and rituals traditionally associated with adulthood. Additionally the research on adults frequently does not take the family perspectives in consideration.

Adult Development and Life Cycle research

The third and final section of the literature review is on adult development life cycle research. The research on typically developing adults differs quite significantly from research concentrating on adults with disabilities. As previously discussed many of the adult issues concerning individuals with disabilities revolve around human rights issues, community inclusion issues, and residential issues. In literature on adults without disabilities, there is an emphasis on continued development throughout the life span. It is because of this difference and the absence of any reference to adults with significant disabilities that the sections on adult issues for adults without disabilities must be considered separately. The omission of adults with disabilities from research on adult development speaks volumes about societies attitude towards individuals with disabilities.

The impetus to consider the entire life from a developmental perspective was brought about in the 1950's when geriatrics and gerontology were established as fields of human service (Levinson & Levinson, 1996). The changes adults encounter as they age are now recognized and attempts are being made to document these changes (Cross, 1981; Erikson, 1963; Havighurst & Albrecht, 1953; Levinson, Darrow, Klein, Levinson & Mckee 1978; Merriam & Caffarella, 1991; Tennant, 1988). The relative newness of this area of research is illustrated by this quote from Levinson and Levinson (1996).
I would rather him be with family than with strangers. He is happy here and I do not want him to move. I never had that much belief that anything good could come from a system. It is just a job for the people but he is my life.

Mrs. Moore also envisioned her daughter with a disability continuing to live with her. Her ideal vision of a residential setting for herself and her daughter with a disability was to live together on a farm in West Virginia. She stated:

I have a dream about living on a farm. When Ashley goes off to school, Morgan and I are going to move to a farm, maybe in West Virginia. I love the peace and quite. I just do not want to be bothered. Well, we would have to get an active social life for Morgan. I have asked her. Sometimes I say 'Morgan when Ashley goes off to college do you want to move to a farm like grandpa's?' She smiles and says 'yes.'

In summary, participants did not envision their children with disabilities living independently in their own apartments. Participants either described a segregated setting with other individuals with disabilities and appropriate supports or a continuation of living with them. Mrs. Green did not want her son Tyrell living with strangers. Her underlying assumption was “strangers” would only view taking care of her son as a job and a meaningful relationship would not be formed. Mrs. White also felt relationships were important in her vision of an ideal residential setting for her daughter. However, her underlying assumption was, group-home staff and other occupants would form a meaningful relationship with her daughter and become a “second family”. More research on relationships for people with significant disabilities is needed.

Voting

The section on voting consisted of participants’ perception of their sons and daughters with disabilities ability to access their right to vote. Participants were asked
"The study of adult development is in its infancy and struggling to establish itself in the neglected space between child development and gerontology" (p. 5).

Cross (1981) describes two schools of research on adult development. The first includes researchers such as Erikson (1963) and Kohlberg (1984) who view development as being a vertical hierarchy from simple, less mature stages to complex, maturer stages. Erikson (1963) described three major consecutive phases of adulthood that involved definite psychosocial crises. The first stage, young adulthood, is characterized with "Intimacy versus Isolation" as the crisis. Erickson posits that since the young adult has emerged from a search for identity, he/she is now ready and willing to fuse his identity with that of others. The young adult is seeking intimacy which Erickson describes as "...the capacity to commit himself to concrete affiliations and partnerships and to develop the ethical strength to abide by such commitments, even though they may call for significant sacrifices and compromises" (p. 263). In this stage adults need acceptance, sharing and a sense of belonging. The consumer movement and inclusion strategies are vehicles that try to create opportunities for adults with disabilities to achieve the feeling of acceptance and belonging, not only from social relationships but also from society in general.

The next crisis to be solved in Erickson's model of adult development is "Generativity versus Stagnation." This stage is characterized by a concern to leave a legacy or other evidence that one's life was lived. An adult in this stage usually develops a need to care for others, get involved in civic activities, and become a more creative and productive individual. The last stage is late adulthood where the psychosocial crisis is "Ego Integrity versus Despair." It is in the senior years that
Erikson claims individuals reconcile successes and failures, and put their lives into perspective. As Erikson acknowledged that progression through the life cycle does not happen in a vacuum. The growth of a person’s self concept occurs in response to and interaction with other people, groups and social-cultural norms. (Darkenwald & Merriam, 1982). Erikson posited that a person’s growth would be incomplete if the psychosocial crisis of each stage was not successfully resolved.

Kohlberg’s (1984) theory of moral development described development throughout the life span. He described a person’s moral development in six stages. Kohlberg posited that in stage one a child develops an awareness of punishment and obedience followed by stage two which is defined as the period when a child demonstrates an awareness of consequences such as rewards, punishment, and exchanges of favors. In stage three, a child demonstrates an awareness of what is socially appropriate behavior. In stage four the emerging adult responds appropriately with regard to law and order. The reasoning behind the emerging adult’s actions is a belief that upholding social order is one’s civic responsibility. The next stage, the second adult stage, is labeled, “prior rights and social contract”. This stage is characterized by a belief that upholding the basic values and legal contracts of society even when they conflict with the concrete laws of the group is the appropriate course of action. Adults in stage six are guided by universal ethical principles such as equality, dignity, and justice (Kirkman, 1994; Romero, 1990).

Many critics question Kohlberg’s methods and consider his stages to be abstract and incomplete (Kirkman, 1994; Tennant, 1988). Gilligan (1982) posits the existence of two different moral orientations, the male orientation (Kohlberg’s), and the female
Erikson claims individuals reconcile successes and failures, and put their lives into perspective. As Erikson acknowledged that progression through the life cycle does not happen in a vacuum. The growth of a person’s self concept occurs in response to and interaction with other people, groups and social-cultural norms. (Darkenwald & Merriam, 1982). Erikson posited that a person’s growth would be incomplete if the psychosocial crisis of each stage was not successfully resolved.

Kohlberg’s (1984) theory of moral development described development throughout the life span. He described a person’s moral development in six stages. Kohlberg posited that in stage one a child develops an awareness of punishment and obedience followed by stage two which is defined as the period when a child demonstrates an awareness of consequences such as rewards, punishment, and exchanges of favors. In stage three, a child demonstrates an awareness of what is socially appropriate behavior. In stage four the emerging adult responds appropriately with regard to law and order. The reasoning behind the emerging adult’s actions is a belief that upholding social order is one’s civic responsibility. The next stage, the second adult stage, is labeled “prior rights and social contract”. This stage is characterized by a belief that upholding the basic values and legal contracts of society even when they conflict with the concrete laws of the group is the appropriate course of action. Adults in stage six are guided by universal ethical principles such as equality, dignity, and justice (Kirkman, 1994; Romero, 1990).

Many critics question Kohlberg’s methods and consider his stages to be abstract and incomplete (Kirkman, 1994; Tennant, 1988). Gilligan (1982) posits the existence of two different moral orientations, the male orientation (Kohlberg’s), and the female
orientation. The female orientation emphasizes human caring and responsibility for others over justice and individual rights.

Because during the time of Erikson’s (1963) work most adults with disabilities were institutionalized, they were not given the opportunity to resolve even the first psychosocial crisis. Although isolation, loneliness, and a need for friends was identified as needs of individuals with disabilities (Amado, 1993; Grenot-Scheyer, 1994; Meyer, Park, Grenot-Scheyer, Schwartz & Harry 1998; Moninalika & Harry 1999), these needs have only recently received attention in the disability literature.

The second school of thought on adulthood posited six distinct phases or cycles of development (Neugarten, 1968; McCoy, 1977; Levinson, Darrow, Klein, Levinson, & Mckee, 1978, Levinson & Levinson, 1996). These cycles of adulthood represent a series of distinct life experiences that describe general growth and change, not growth toward a higher stage.

Neugarten (1968) concluded that social clocks were as important as biological clocks. People attempt to manage events to coincide with societal expected norms. “Off timed” events lead to crisis (Boucouvalas & Krupp, 1989; Neugarten, 1968). Neugarten posits that cultural timelines are an important cultural context in which to view the individual life. Unfortunately, the cultural timelines used were dominated by one culture and did not take into account the variety of perspectives and timelines from other cultures. Neugarten herself acknowledged the challenge of today’s researchers in social clock influences to integrate the conflicting images from different perspectives. For example, consider the, 70-year-old wheelchair user versus the 70-year-old mountain climber, (Neugarten and Neugarten, 1987). I posit the image of the 70-year-old
old wheelchair user on the basketball court is also an image that needs to be integrated into social timelines.

Levinson and his associates (1968, 1996) found that both men and women experience similar eras of development that are characterized by a sequence of events. Levinson identified the following eras of human development as childhood (0-20), early adulthood (17-45), middle adulthood (40-65), late adulthood (60-85) and late-late adulthood (80 up). Levinson found great gender differences in the early adult era and predicted that a lessening of this difference would occur in the future due to an evolution of society towards gender equity.

McCoy (1993) keyed her developmental stages to the periods already defined by Levinson and his associates (1996). Such markers as leaving home, mid-life examination and preparation for retirement characterize McCoy’s stages. Merriam and Cafferella (1991) call the theory building based on the psychological perspective as highly biased towards the Caucasian middle class male perspective. However, these maps do provide insight into one perspective of adulthood. Merriam and Cafferella posit that there is no right or best way to develop as an adult.

Another way of discussing adulthood is in relation to social roles. Havighurst (1952, 1953, 1956, 1957, 1960, 1972), a life stage theorist, explored the relationship of developmental tasks for adults and social roles. According to Havighurst (1956), a developmental task is dynamic, driving and leads a person to learn a social role. For example, finding a mate and getting married leads a person to learn the social roles of suitor, fiancée, bride/groom, and wife/husband.
Whether one discusses adulthood according to social roles, moral development, or life stages, it is clear that individuals with significant cognitive disabilities have been given very limited consideration in research on adult development. One reason for this oversight may be that, traditionally, people with significant cognitive disabilities have not had the opportunity to experience the same stages of adulthood as their peers without disabilities. Knowing how parents envision their young adults taking on the roles of husbands/wives, boyfriends/girlfriends, employees and citizens will benefit the fields of special education and adult life cycle research. Even though adults with significant cognitive disabilities have unique issues and concerns due to their disability, they are a vital and integral part of society and should be considered in research for people without disabilities.
CHAPTER THREE

METHOD

This chapter describes the method and procedures utilized in this study in the following order: (a) design of the study, (b) sampling procedures, (c) participants, (d) instrument, (e) data collection, (f) data analyses, (g) limitations of the study.

Design

This study used descriptive research methods. The researcher, a parent of a teenager with significant disabilities, conducted two in-depth, interactive interviews with primary caregivers of adolescents with significant disabilities. The fact that the researcher is from the participant pool can be perceived as advantageous because participants are more willing to disclose personal difficult information to another person of like background (Gall, Borg, & Gall, 1996). Having a researcher from the participant pool can also be perceived as disadvantageous because of participant bias. This researcher accepts the responsibility for her interpretive role. Denzin and Lincoln (1994) state:

Researchers carry into their work the sensitizing possibilities of their training, reading, and research experience, as well as explicit theories that might be useful if played against systematically gathered data, in conjunction with theories emerging from analysis of these data (Corbin & Strauss, 1990; Glasser, 1978; Strauss, 1987).

Michelle Fine (1994) wrote about the process of “othering”. She is a white middleclass scholar who writes to describe and interpret the voices of others. She posits
that her power of translation comes from her whiteness, middleclassness, and education more than from the stories she tells. She posits that when African-American, Latino, Asian, or Native American scholars work with their respective populations they are much more likely than she to be heard as biased, self-interested, and without the appropriate perspective that emotional distance offers. I will also be more likely to be heard as biased because of my personal experience of being a parent of a person with a significant disability. Conversely, Harlan Hahn (1983) concluded that when non-disabled researchers study those with disabilities, more is learned about the researcher’s terror of disability than about the person with a disability. I posit that a researcher who is not a parent of a person with a significant disability would disclose as much about their terror of having a child with a disability as they would about parents’ perspectives.

As researchers, the best we can do is to acknowledge ourselves as taking on an interpretative role and include in our process safeguards that will allow us to recognize when we are hearing the participants’ voice and when we are hearing our own. The best way to address interviewer bias is for the interview to state her prejudices, and underlying assumptions. Prior to this research project the researcher was a firm believer in the concept of normalization, and her daughter was in as inclusive of an environment as possible. Her dream of an ideal adulthood for her daughter included an equal power structure in relationships, voting with supports, living in her own apartment or continuing to live in the family home if she chose with supports (Jordan & Dunlap 2001). Since the interviews, the researcher has made some changes in her daughter’s leisure time activities. Her daughter used to exclusively participate in leisure activities not
specially designated for people with special needs. Now she participates in a variety of leisure time activities including segregated activities created for people with disabilities.

Six participants were chosen. The interview protocol was sent to each participant at least two weeks before the first interview was scheduled. This was to allow participants to review the questions and ponder their responses. Two participants declined participation after reviewing the instrument. Two other participants were chosen. Both interviews with the six participants were taped and transcribed. One month after the second interview, a follow-up telephone interview was conducted to see if respondents agreed with answers previously given. There were no changes noted.

An interview was chosen because the information needed for this study was not directly observable and questionnaires did not allow for probing follow up questions to ensure clarity of answers. Additionally, face-to-face interviews were chosen to facilitate opportunities to build trust and rapport with respondents, thus making it possible to obtain information that the individual probably would not reveal by any other data collection method (Gall et al. 1996). A semi-structured interview was chosen to gather depth of information and to clarify vague statements. This process involves asking a series of structured questions and then probing more deeply using open-form questions to obtain additional information. Greater depth can be obtained from a semi-structured interview than from a structured one (Gall et al. 1996).

Sampling Procedures and Participants

To be eligible for participation in this study, participants were required to have their children with significant disabilities living with them. For the purpose of this study, significant disability was defined as a secondary or primary diagnosis of
moderate to severe mental retardation (IQ < 50) with a need for 24 hours a day of supports. Parents of individuals with mild mental retardation were excluded from this study because this study focused on parents who perceived a future need for 24 hours a day of supports for their young adults with disabilities. The family member with a disability was between the ages of 14-21 years. This range was chosen because 14 years is the age at which transition Individual Education Plans are suggested in the Individuals with Disabilities Education Act (IDEA) (Florida Department of Education, 1997) and at the time of this study, 21 years was the age individuals with significant disabilities graduate or leave school. Some school systems continue to offer day programming for the individual with a disability after the age of 21, but this was not a mandated service at the time of this dissertation.

Participants in this study consisted of birth, adoptive, and foster parents. To meet eligibility criteria the family member with a disability had to be in the participant’s home for at least 10 years. All participants were the primary caregivers. Primary caregiver was defined as the parent, foster parent, or legal guardian who performed the majority (60%) of the care taking activities for the teen/adult with disabilities.

The number of parents of adolescents with severe disabilities living at home is relatively small. The prevalence of mental retardation in the general population, as determined in 1992, of individuals between the ages of 6 and 21 is 0.97% with less than 3% of that falling in the severe to moderate range (Turnbull, Turnbull, Shank, & Leal 1995).

A USF Institutional Review Board (IRB) form was filled out and approved. The IRB number for this research is 98.400. Samples of the IRB, consent form and
supporting documents are located in the appendix. All participants signed a consent form. School districts within two neighboring counties (Hillsborough and Pasco) were contacted for assistance in identifying potential participants. After reviewing the interview protocol, both counties declined assistance to the researcher in identifying potential participants because of the sensitive nature of the questions. Pasco County was particularly concerned with the question inquiring about parents’ perception of a staff member having a sexual relationship with their adult son or daughter with a disability.

The researcher then contacted United Cerebral Palsy of Tampa Bay, The University of South Florida’s Center for Autism and Related Disabilities, Professors, and her daughter’s teacher for assistance in seeking potential participants.

United Cerebral Palsy, a major provider of respite and supported employment services, identified four participants. Of the four participants identified, three were single parents and one was from a multi-generational household. The teacher of the researcher’s daughter identified four participants, two of whom agreed to participate. One was a single parent and one was a foster parent.

Demographic information such as marital status, employment status of the caregiver, and living situation (number of people in the household), were obtained before the interview. This was accomplished either by asking the participant directly during the telephone call to schedule the interview or by obtaining the information from the referral agency or person. All parents taking part in this study participated in two face-to-face interviews. Due to the unusual and sensitive nature of the questions and because the interview questions contained areas that the participant might not have previously considered, all participants received a printed copy of the interview.
instrument prior to meeting. Within one week of receiving the interview instrument, the researcher called participants to discuss any concerns or questions. Two participants declined participation after reviewing the interview protocol. One potential participant stated the interview protocol contained too many emotionally difficult questions. The other participant stated a chronic illness would prevent her from participating. The researcher’s daughter’s teacher referred both of these potential participants to her. Both participants placed their children with disabilities in group homes within a few months of declining to participate.

Purposeful sampling techniques were employed. Purposeful sampling is the process of selecting participants or cases that are “information-rich” (Gall et al., 1996). Although attempts were made to request participants from diverse backgrounds, due to the relatively small size of the target and accessible population, neither stratified nor proportional sampling was deemed appropriate. However, specific attempts were made to include participants with the following characteristics: (a) multigenerational household, (b) single parent, and (c) lower SES (eligibility for a free school lunch was used as an indicator).

Gender was expected to be a relevant variable especially in parents’ expression of concerns regarding marriage, consensual sex, and other social interactions. One reason for this expectation is that, historically, different genders had different minimum age requirements for marriage (Golenpaul, 1994). Although, currently, states have the same requirement for both genders in regards to marriage and consensual sex, many
cultures still assign different roles according to gender. Parents of an equal number of
males and females participated in the study in order to describe possible differences
based on gender.

Participants

The SES, and family makeup of each participant were described along with a
detailed description of the functioning level of their son or daughter with a disability.
Six participants were chosen that met the participant criteria, three had daughters with
disabilities and three had sons with disabilities. Three family members with a disability
attended self-contained classrooms for people with trainable mental retardation and
three attended classrooms for people with profound mental retardation. Four
participants were single parents. One participant was from a multi-generational
household. Three participants had children who received free or reduced school
lunches. The following paragraphs provide a description of participants and their
children with disabilities. Pseudonyms were used to protect the privacy of participants.

Mr. Brown was a single father of three children with disabilities, Sam an 18-
year-old with Down syndrome, Jean a 16-year-old with Down syndrome and John a 10-
year-old with Spinal Bifida. During the interviews, Mr. Brown discussed both Sam and
Jean. However, only the answers for Sam were included in the results because the
design of the study required an equal number of boys and girls. Mr. Brown used to work
as a guard at a penal institution. He left that job to care for his terminally ill wife. The
Browns adopted all three of their children. Mr. Brown received financial support from a
program in New Jersey where he adopted his children. Since Mrs. Brown’s death
several years ago, Mr. Brown’s brother moved in with the family.
After the interviews with Sam's father, I had the opportunity to meet and socialize with both Sam and Jean. Additionally, I have been able to assist Sam with identifying and laying the groundwork to achieve some of his goals for adulthood. I was also able to assist Mr. Brown with securing part-time employment while his children are in school. Sam attended a self-contained TMII classroom located at his neighborhood high school. He is very friendly. He has a moderate speech impairment but can be understood with practice. He can feed himself and take care of most of his personal needs. He needs assistance in the form of prompting for his personal grooming, showering and shampooing. He needs assistance to do small household chores such as the laundry or preparing a snack. Sam was one of the higher functioning participants. Sam is very active in his church and plans to work for the church's youth ministry when he graduates. Sam was eligible for free school lunches.

Mrs. Smith was married with two children. Her husband worked at the post office and she worked at McDonalds. Mrs. Smith's son was a typically developing 20-year-old college student. Her daughter, 15 years, attended a self-contained classroom for students with trainable mental retardation at a school for exceptional students.

Jody, Mrs. Smith's daughter was present at both interviews. I have not had an opportunity to socialize or work with Jody or her parents since the interviews. Jody spoke in two and three word sentences. She often initiated communication. Her speech was very clear and easily understood. She was a very attractive, friendly, warm, young 15-year-old lady. She sometimes needed reminders to pull up her garments and clean herself after toileting. She could feed herself independently but could not prepare any of her own meals. In the past, she had behavior issues and was "Baker acted" by the school.
system several times. According to her mother, Jody has greatly improved her behavior both at home and at school. The Smiths had a strained relationship with the school system. The staff at Jody's school had requested her parents be investigated for child abuse several times. Although the relationship remained strained, there had not been any allegations of abuse in several years. Until a few years ago, it was not uncommon for Mrs. Smith to be called three or four times a week to pick up her daughter from school due to uncontrollable behavior. Because of her responsibilities to her daughter, Mrs. Smith found it necessary to decline promotions offered to her by her employer.

The Smiths called the Family Network on Disability (FND) a family support organization run by parents to assist her with this problem. The Smiths and a representative of FND met with the school system and solved the problem.

Mrs. Green was married. Her husband worked in a local brewery. She had three children one 24-year-old biological son, one 14-year-old adopted daughter, and one 17-year-old foster son. Mrs. Green had a small cosmetics business that she ran from her home. The interviews centered on Mrs. Green's foster son Tyrell. Mrs. Green has been Tyrell's foster mother since he was an infant.

Tyrell was a well-dressed attractive teenager. He attended a self-contained classroom for students with profound mental retardation in a regular education high school. Tyrell had cerebral palsy. He used a wheel chair for transportation. He needed total assistance in all of his personal care. Tyrell was non-verbal. He had a big smile that lights up the room. He could communicate likes and dislikes through his behavior. He would turn away from undesirable activities and smile when he was pleased with an
activity. Tyrell attended the same classroom as the researcher's daughter. Tyrell was eligible for free school lunches.

Mrs. White was a single parent of two children. She worked for a consumer information service. She had a 14-year-old daughter with a disability and an 11-year-old son. She had been divorced for several years and had an amicable relationship with her ex-husband. Her daughter, Rachel, attended a classroom for trainable mentally handicapped students at a local center for exceptional education. The para-professional in Rachel's classroom provided respite for Mrs. White after school and on some weekends. Rachel could feed herself, but needed total assistance preparing her meals. She needed assistance with cleaning herself after toileting, showering and shampooing. Rachel loved to repeatedly watch the movie Roger Rabbit. She was described as having a very gentle spirit and being very charming.

Mrs. Hughes was a single parent and had been so for many years. She worked in the office of a national cellular telephone company. The office was small and she was often the only person there. Both interviews took place in her office. We were not interrupted. Mrs. Hughes had two sons, a 23-year-old typically developing son and Charlie, a 21-year-old who had a severe and profound mental disability. Both of Mrs. Hughes' sons lived with her at the time of the interviews. Charlie attended a self-contained classroom for people with profound mental retardation at a local exceptional center. Charlie was incontinent, could feed himself but needed assistance with all other areas of his personal care. Charlie communicated with headshakes and his behavior. He would pace and become agitated with activities he did not like and smile and attend to activities he liked. Charlie rode his school bus to his mother's office and stayed with her.
for a few hours before they go home together. Mrs. Hughes described Charlie as having an excellent sense of time. She said he could tell when it is time to leave her office and he often got up to go to the door without any prompting at the correct time. I met Charlie during the interviews. Charlie was eligible for free school lunches.

Mrs. Moore was a single parent of two high school girls. She did not work outside of the home. She had been divorced for several years. Her divorce was not amicable and she had a strained relationship with the girls' father. Morgan, her oldest daughter was 17-years-old and had a severe disability, Jennifer, her youngest was 16-years-old. Morgan had cerebral palsy and used a wheelchair. Morgan attended school at her local high school with her sister who does not have a disability. When tested by the school psychologist Morgan tested in the trainable range of mental retardation. She was served in a self-contained classroom for students with severe and profound mental retardation because the school staff determined that would be the best place to meet her needs. Morgan was in the same classroom as the researcher’s daughter. Morgan had her 17th birthday a few weeks before her mother’s first interview. Morgan could move her eyes in a back and forth direction to indicate no and smile to indicate an affirmative answer. Morgan experienced oxygen deprivation during the birthing process. The Moores sued the hospital where their daughter was born and did receive a large settlement in the form of a trust fund for Morgan. Her father receives payments from the fund after the divorce. Mrs. Moore has custody of Morgan. The trust fund enables Mrs. Moore to stay in the home and care for her two daughters.
### Table 1

**Description of Participants and Their Children with Disabilities**

<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Marital status of participant</th>
<th>Ethnicity</th>
<th>Name of Child</th>
<th>Level of disability</th>
<th>Free lunch y/n</th>
<th>Gender of Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mr. Brown</td>
<td>Single</td>
<td>Euro-American</td>
<td>Sam</td>
<td>TMII</td>
<td>Yes</td>
<td>Male</td>
</tr>
<tr>
<td>Mrs. Smith</td>
<td>Married</td>
<td>Euro-American</td>
<td>Jody</td>
<td>TMII</td>
<td>No</td>
<td>Female</td>
</tr>
<tr>
<td>Mrs. Green</td>
<td>Married</td>
<td>African-American</td>
<td>Tyrell</td>
<td>PMII</td>
<td>Yes</td>
<td>Male</td>
</tr>
<tr>
<td>Mrs. White</td>
<td>Single</td>
<td>Euro-American</td>
<td>Rachel</td>
<td>TMII</td>
<td>No</td>
<td>Female</td>
</tr>
<tr>
<td>Mrs. Hughes</td>
<td>Single</td>
<td>Euro-American</td>
<td>Charlie</td>
<td>PMII</td>
<td>Yes</td>
<td>Male</td>
</tr>
<tr>
<td>Mrs. Moore</td>
<td>Single</td>
<td>Euro-American</td>
<td>Morgan</td>
<td>PMII</td>
<td>No</td>
<td>Female</td>
</tr>
</tbody>
</table>

#### Data Collection

Each of the six participants received a copy of the interview protocol before the interview, had two face-to-face interviews and one month later a follow-up telephone interview. All face-to-face interviews were taped and later summarized. Two interviews took place in the participants’ home, two interviews took place in a small restaurant, one interview took place at the participant’s place of employment, and one interview took place at a local park. The researcher did not know any of the participants before the interviews. However, one participant’s wife (Mr. Brown) facilitated the creation of a parent advocacy group that assisted the researcher eight years prior to this study.

Interviews lasted from one and a half to three hours, with most being approximately two hours in length. The interviews were very interactive. Many participants asked the researcher about her plans for her daughter’s future.
One month after the second face-to-face interview, a follow up telephone call was made to the respondents. During this call, the researcher summarized the respondents' answers and asked if there have been any changes due to further consideration of a question and if the summary was accurate. There were no changes or corrections made. This member check technique was used to allow research participants to judge the accuracy and completeness of statements made in the researcher’s report.

Instrument

An interview instrument was developed because there was no existing instrument that gathered parents’ perceptions on the following questions: 1. What do parents perceive as ideal adult lives for their children with disabilities? 2. How does that perception differ from a perception parents would have if their children did not have disabilities? 3. What type of opportunities and options would parents like to see for individuals with disabilities in general? The instrument included detailed questions about parents' perceptions of their children with disabilities right to access areas typically offered to non-disabled individuals such as voting, marriage, and consensual sex. The initial interview instrument began with three open-ended questions on the general lifestyle and dreams parents have for their child with a disability, the role their child's disability plays in that dream, and perceptions of adulthood for individuals with disabilities in general. This was followed by more specific questions on voting (10 questions), autonomy and mutuality of relationships (7 questions), social relationships (16 questions), marriage (7 questions), sexual consent (14 questions), employment and leisure time (6 questions), and residential (4 questions). There were a total of 67 questions in the initial interview instrument. The initial interview instrument was pilot
tested with two participants. Information from the pilot test was used to test for validity, and to alert the researcher to communication problems, threatening questions, evidence of inadequate motivation on the part of respondents, or other clues that suggest the need for rephrasing questions, or revising the procedure.

Pilot participants did not identify any threatening questions but agreed that the interview should be read by participants prior to being interviewed. Another strategy used to lessen the threat of the instrument was having the interviewer from the respondent target population. Respondents will often discuss sensitive areas more freely with someone who has similar characteristics (Gall et al., 1996). Additional reasons for having pilot participants was to test for item reliability and validity. Sometimes the same item can be interpreted differently by different respondents. This can threaten the reliability and validity of the interview. Pilot participants suggested revising several ambiguous questions. The first pilot participant found many of the interview questions to be redundant. The interview was revised and many of the redundant questions were eliminated. The revised instrument was tested on another pilot participant. She too found the interview questions redundant. After discussing the first three open-ended questions all the other questions seemed redundant. If one uses the open ended questions at the beginning then the more specific follow-up questions should be asked as a probe or not used. Additionally, if one asked the more specific questions before the open ended questions then the latter seemed redundant. The final version of the interview protocol contained five questions on autonomy and mutuality of relationships, nine questions on employment and leisure time, four questions on residential options,
seven questions on voting, fourteen questions on social relationships, nine questions on marriage, fourteen questions on sexual consent and eight questions on health concerns.

Another method for increasing the reliability of the interview was having two separate interviews and a follow up member check one month later. In this follow up telephone discussion, the researcher gave an oral summary of the previous interviews to the respondent, then the respondent was asked to comment on the accuracy of the summary, and to discuss any changes due to further consideration of the subject on the part of the respondent. This is a process called member check where research participants judge the accuracy and completeness of statements made in the researchers' report (Gall et al., 1996).

Construct validity is the extent to which a particular instrument has shown the ability to assess the construct that it purports to measure. The purpose of this study was to measure the construct of parents' perception of ideal adult lives for their children with disabilities, and the role their children's disability plays in their concept of an ideal life. Although no single item of evidence is sufficient to establish construct validity, a knowledgeable professional in the field reviewed the instrument to check for construct validity. This professional also checked for content validity or the extent to which inferences from the instrument adequately represented the content or conceptual domain that the instrument purports to measure. The professional also checked for inadequate wording, ambiguous or poorly defined terms, and over all question bias in order to check for reliability.

Consequential validity refers to the fact that test scores (including self report measures), the theory and beliefs behind the construct, and the language used to label
the construct, also embody certain values and have value-laden consequences when
used to make decisions about individuals or groups of individuals. These values and
consequences need to be checked to determine whether the inferences made from test
scores and the way test scores are used to make decisions are valid (Gall et al., 1996).
There is no standardized system to check for consequential validity. Consequential
validity was important to this study. For example, some participants stated a preference
of no sexual involvement for their children with disabilities. One way to interpret this
would be to suggest that parents are overprotective and in denial of their young adults
emerging sexuality. A more family friendly interpretation of such an outcome would be
to explore the family values and note what role disability actually played in the
participants desire for no sexual activity.

To check for consequential validity, an individual, who was a parent of a person
with a disability, reviewed the results. She was alerted to check for value-laden
inferences made about families. She noted no inappropriate value laden perspectives.

Although the same interview protocol and interviewer were used a variety of
different probing questions were asked of each participant. Additionally, the interviews
were very interactive with most participants asking the researcher questions about her
daughter similar to the questions in the interview protocol. The researcher frequently
spent 30 minutes in pre or post interview discussions with participants.

Some participants stated that these conversations changed their perspective and
answers to interview questions. The challenging and probing questions asked by
participants caused the researcher to reconsider several of her perspectives and practices
with her daughter.
Data Analysis

The SES and family makeup of each participant were described along with a detailed description of the functioning level of their son or daughter with a disability. The researcher thoroughly reviewed the summarized transcripts and designed preliminary categories. A professional, with a Ph.D. and a minimum of 20 years in the field, reviewed these categories to determine clarity and face validity. Categories that were judged not to have a clear definition were redefined. After it was agreed that the definitions were clear and had face validity, the researcher and two independent raters assigned each written answer to one of the categories. Each independent rater had a degree in the field of special education or a related field. Counting the number of agreements and dividing the total by the number of agreements for each item calculated inter-rater agreement of the two independent raters. The inter-rater agreement was low for some of the participants. The researcher reviewed available transcripts marked by the raters, however four of the transcripts for the second rater could not be located. The researcher questioned the second rater but without the transcripts to refer to the rater could not recall why she marked responses to certain categories. The researcher arranged to have another independent rater review the transcripts and assign the responses to categories. This rater also had a degree in special education. The rater was left with clear directions to keep all copies of the marked transcripts. The interrater agreement was then calculated and for each participant ranged from 96% to 100%. The overall inter-rater agreement was .99.

The transcripts were reviewed to find recurrent properties that ran throughout the transcripts. The researcher discussed these reoccurring proprieties with the second
rater and the parent who checked the transcripts for consequential validity. Both reviewers noted that the properties the researcher identified were in the transcripts. This is also a method of "triangulation" suggested by Denzin (Denzin 1978; Lincoln & Guba, 1985).

Limitations

This study investigated the relativity new phenomena of the transition to adulthood of people with significant cognitive disabilities. Although there is literature on parents' perspectives (Turnbull & Turnbull, 1978) there was extremely limited research on parents' perspectives of their children with disabilities accessing the traditional rights and roles of adulthood (Jordan & Dunlap 2001). This initial study has yielded important information for the filed.

This study consisted of a convenient sample of participants that yielded information rich descriptions of their dreams for the future for their children with disabilities. The interviews were interactive in order to delve deeply into the complexities of parents' concerns for their children with significant disabilities accessing some of the traditional roles of adulthood.

Certain steps were taken to maintain the integrity of this study including a member check, inter-rater agreement and triangulation. These steps were taken to raise the reliability of this study. The results of this study are not meant to generalize to a larger population. The themes uncovered in this study are offered for thoughtful contemplation to all who are concerned with the equal rights of citizens and the quality of life of adults.
CHAPTER FOUR

RESULTS

The purpose of this research was to better understand parents’ perceptions of ideal quality adult lives for their sons or daughters with disabilities, and to determine if their hopes and dreams for their children differed from what they would have envisioned for people with disabilities in general. Additionally, participants described the roles they believed the disability played in the creation of their visions of an ideal adulthood for their son or daughters with disabilities. Two interviews were conducted with each of six parent participants. In the first interview, participants discussed autonomy, residential, employment, and voting issues. During the second interview, participants were asked to describe ideal social lives, marriages, and sexual relations for their children with disabilities. This chapter presents the findings of those interviews. The responses to the interview questions were organized into the following sections: autonomy and mutuality, employment, residential, voting, social relationships, marriage, and sexual consent.

Autonomy and Mutuality

Adulthood has traditionally been associated with autonomy. As children mature into independent adults, their reliance on their parents to care for them is lessened. This change in need could cause a change in the relationship between the parent and child, as the child becomes an adult. The purpose of the questions in this section on autonomy and mutuality were to identify any changes experienced participants in their
relationship with their own parents as they matured into adulthood. Additionally, inquiries were made to discern participants' expectations regarding similar changes in their relationships with their children with disabilities as they matured into adulthood. Participants also described their perceptions of potential barriers to achieving the ideal adult relationship with their son or daughter with a disability.

Four of the six participants described experiencing a change to a more mutual relationship with their parents as the participants matured into adulthood. The remaining two participants did not have a continuous (from childhood to adulthood) relationship with their parents and, therefore, did not experience any change in their relationship with their parents as they matured into adulthood. The chronological age at which this change occurred varied greatly among the four participants. The age range of participants when the change in relationship occurred was from nine years to the early thirties. The four participants who experienced a change described the change as occurring when they succeeded at certain tasks traditionally associated with adulthood such as moving out of the family home, or becoming employed. None of the participants envisioned a similar change occurring in their relationships with their children with disabilities as they transitioned into adulthood. Three of the four participants who described experiencing a change to a more mutual relationship with their own parents also described their children with disabilities succeeding at certain tasks traditionally associated with adulthood such as employment in the community with supports, voting with supports, or getting married. However, it is very important to note that envisioning having their sons or daughters with disabilities achieve tasks traditionally associated with adulthood did not seem to facilitate participants
envisioning a change to a more mutual relationship with their children with disabilities as he or she transitioned into adulthood.

When asked to describe potential barriers to an ideal adult relationship with their sons or daughters with disabilities, parent participants described a variety of barriers. Some barriers were more related to the disability such as behavior problems, lack of ability to self-care, and inability to communicate. Other barriers involved interference from a former spouse or state agency, gaining custody of the young adult with a disability.

Mr. Brown is one of the participants who did not have a close continuous relationship with his own parents from childhood to adulthood and, therefore, did not have any experience with a change to a more mutual relationship with his own parents or foster parents. Mr. Brown was abandoned by his parents and was raised in a series of foster homes. He described his relationship with his son with a disability, as ideal and he did not envision that relationship changing as his son matures into adulthood.

Mr. Brown stated:

I was raised in foster homes and I was an abused child so I have no experience in the realm of normal childhood, so I cannot answer that. I was always made to feel dumb and I produced dumb things. I encourage my children to do the best they can and reward them for that. I really don’t see it [his relationship with his son and daughter] changing that much other than, they are adults. I am trying to establish responsibility and I don’t really see it changing that much.

Mrs. Smith was the other participant who did not experience a change to a more mutual relationship with her parents as she transitioned into adulthood. Her mother passed away and her father was not present in her childhood. Mrs. Smith stated:
My father lives up north and my mother was dead when she [Jody] was a couple of years old. My dad grew up after we were grown. He was not much of a father. My mother had mental problems. My dad is a super dad now and I would not take anything for him. However, I cannot say there is any difference other than Dad was not around when I was younger.

Mrs. Smith envisions a continuation of her current relationship with her daughter as she matures into adulthood. She envisioned her relationship with Jody as an adult “Just as it is now” When Jody was younger, Mrs. Smith had more difficulty with controlling her daughter’s behavior. Mrs. Smith explained:

The only difference would be when she was little she would not bring it back [exert self-control over her behavior] you could not explain discipline to her. The staff at Mormickins [a local school for exceptional children] had Jody ‘Baker Acted’ four times and she hated it. She has grown up so much I can explain to her why she is not going today and she would not spit she would just understand. When she sees the men who ‘Baker Acted’ her, she goes up and beats on them, so sometimes I have to keep her home. She is calmer now that she is older.

During our interview Jody came into the room several times and said, “I good girl now. No room. No time out.”

Mrs. Green was the participant who experienced the change in her relationship with her parents at the youngest age. She believes her parents treated her more like an adult because she performed tasks traditionally associated with adulthood at an early age. She stated:

My mother treated me like an adult, course she said I was mature for my age, when I was nine I was cooking and cleaning. When I was twelve, I was shopping for the house and taking care of my little brother. I was always entrusted with lots of responsibility.

Mrs. Green did not envision her relationship changing with her son with a disability as he transitioned into adulthood. She said, “I do not see the relationship too much different now than when he is an adult.”
too hard to think about an ideal adult relationship. I cannot think of him as an adult. I cannot see it.

Another participant, Mrs. White, Rachel’s mother, described a change in her relationship with her own mother as she matured into adulthood. She described a change in her relationship with her mother when she moved out of the family home. She stated:

Yes. I was in my early twenties. I left home when I was 18. They started treating me like an equal and I started sharing my secrets with my mom, now she is like my best friend. My mom and I went out and drank margaritas and sang barefoot in the snow. It was so much fun. I hope that my kids feel that way about me when they grow up; my daughter is 15 and my son 11. That’s hard because in so many ways I will always see her as a little child but I need to stop thinking of her that way. Maybe one day when she is out on her own, maybe in a group home situation or whatever, I will be coming over just to go shopping or whatever, but I will always feel very mothering to her and my mother still feels that way too.

Mrs. White cited her daughter’s behavior as a barrier to achieving an ideal relationship. She believed that her daughter’s lack of ability to communicate plays a large role in her behavioral issues. Mrs. White also cited her daughter’s hormonal changes as a reason her inappropriate behavior increased. She said:

She is going through hormone changes. She has gotten worse at biting and banging herself. The other day we were riding in the car and she pulled my hair, very, very hard, so it is things like this that have to do with her disability. If she were a normal functioning child, this would not be an issue.

In summary, although all participants with a close continuous relationship with their parents described a change to a more adult-like, mutual relationship with their parents, no participant envisioned a similar change occurring with their son or daughter with a disability. The chronological age of participants at the time of the change to a more mutual relationship varied greatly. Participants described the change
in their relationship with their parents occurring when they began achieving certain
markers traditionally associated with adulthood. One participant, Mrs. Hughes, could
not envision her son with a disability as an adult. All the participants envisioned a
continuation of their current relationship with their adult son or daughter with a
disability.

Three participants cited their children with disabilities’ inappropriate behavior,
lack of communication skills, and lack of ability to care for one’s personal needs as
potential barriers to ideal adult relationships. Two participants cited state agency or
family interference with custody of their son or daughter with a disability as a
potential barrier to an ideal adult relationship.

Employment

The employment section of the interview consisted of asking parents to
describe their vision of an ideal employment situation for their sons or daughters with
disabilities. Four participants described the ideal employment situation as working
either part time or full time in the community with supports. Of those four
participants, two immediately envisioned their son or daughter working in the
community and two participants initially described a sheltered workshop for their
daughters, but during the interview began envisioning their daughters having other
opportunities. Three of the four participants who envisioned community employment
had sons or daughters who were served in classrooms for students with trainable
mental handicaps; the fourth had a daughter who was served in a classroom for
students with severe mental handicaps. Two participants with sons, who received
services in self-contained classrooms for students with severe and profound mental
impairment, described the ideal employment situation as working in a sheltered workshop or some other form of closely supervised, simple, repetitive assembly-line work. Five participants would have envisioned college, more work hours and a more career-oriented future for their sons or daughters if they did not have disabilities. Mrs. Hughes envisioned no difference in the ideal employment situation her son with a disability from a vision for her son without a disability. Mrs. Smith envisioned having less control over her daughter’s future if she did not have a disability.

All participants envisioned their son or daughter with a disability going out into the community and engaging in enjoyable leisure activities. Mrs. White envisioned her daughter going dancing or out to the movies. Mrs. Hughes envisioned her son coming home from his work program and going bowling, to the movies, or dancing. Mrs. Moore envisioned Morgan going out with her friends a couple of times a week. She envisioned her going to dances, to restaurants, the mall, and sporting events.

Mr. Brown, one of the participants, who immediately envisioned his son working in the community, stated, “I see Sam working in a normal job. He is in CBT [Community Based Training] at school and he has been working in several local department and drug stores. As far as wages, I really do not know.” According to Mr. Brown, Sam has volunteered with the youth group at his church and plans to work at the church when he graduates from school.

Initially, Mrs. Smith, Jody’s mother, envisioned her daughter attending a local adult day training center after graduation. After discussions with the researcher she envisioned a combination of day activities for her daughter. She said:

I have seen kids at McDonald’s [a fast food restaurant] that
work a lot of hours and everyone expects too much out of, I hear that WalMart
hires people like her but she is not ready for
that; she would not want me to leave her.

The interviewer then suggested she have a respite worker transport and assist
her daughter. Mrs. Smith then seemed very happy with WalMart as a work place.
However, she clearly stated:

I would like for her to work in an environment like a
School. I do not want her mainstreamed too much. I want
her around kids like her. I do not want her isolated, but it is a very non-
accepting society. Kids, like at MacDonald's Training Center [a local adult
training center], are like her and people are trained to be around people like her
and I would like her to be in a center. I want her to get up work for a couple of
hours at WalMart come home, eat lunch, and then go to some kind of school.

When asked what her expectations for Jody would have been if she did not
have a disability, she said, “Well I would have expected her to go to college and she
would have to have a job from about age 15 or 16.” Mrs. Smith also stated that if her
daughter did not have a disability she would then have less control over her daughter’s
future, including aspects of employment.

Mrs. Green envisioned her son doing:

Anything that deals with assembly-line work, using his hands. He is good. He
does not have to look. He can just put things together. They need to teach him
more skills. He needs everyday survival skills. He loves Legos. He will not
build anything; he just takes things apart and puts them back together. He likes
those little bead things.

When asked what she would have envisioned for her son if he did not have a
disability, Mrs. Green stated, “He would work more hours. I would like for him to go
to college, but he could go to a technical school but I want him to have a job that he
really enjoys.”
Mrs. Moore, Morgan’s mother, had previously thought about her daughter’s interest and had envisioned a job that would be compatible with her perception of her daughter’s personality. Morgan’s mother stated:

I want her to work in a place where there would be a lot of people all the time. She would be in heaven if she could be a ticket sales person for the Bucs [local major league football team] games. She is a real people person. She could not make it for many hours: just a couple because of her physically and because she has never really been challenged with many things. If she were a ticket taker at sporting events or at concerts then she could go in and enjoy the event herself. She would need someone to sit with her while she does it. She could hit the switch that says ‘Welcome. How many tickets’, and she would be happy.

When asked how her vision of an ideal employment situation differs for Morgan and her sister who does not have a disability, Mrs. Moore said, “Well from her [Morgan’s sister] growing up she really has been putting her school career towards college. She wants to be a sports therapist.”

In regards to her own son, Mrs. Hughes said, “I see him working in a structured workshop of some type five days a week doing something involving music, but I do not know if that is realistic. Maybe a radio station.” Mrs. Hughes envisioned no difference in the ideal employment situation for her two sons even though one has a severe mental disability. She stated, “Bottom line. If my children are productive and stay out of jail I am happy.”

Mrs. White admitted her conversations with the interviewer made her rethink the issue of work. She stated:

It is very difficult to envision her working because she doesn’t do a lot of things. Her teacher said that she could see her doing laundry at a hotel because she can fold clothes. She likes to make beds. She just loves to touch fabrics. Her teacher is teaching her assembly-line kind of things.
When asked if these tasks were to prepare her for a sheltered workshop, Mrs. White replied "yes." When asked how that made her feel, she replied, "well either or."

Mrs. White wants her daughter to like her job. She said:

I do not want her to go to her job like so many Americans and say "I hate this job." She won’t do that. It would be nice if she had something with diversity during the day, yet still have a solid routine. She likes to know what is going to happen. The school tests her for a very limited range for employment. However, her teacher is wonderful. Her teacher says that having a job to do gives you a purpose, but after discussing equal opportunity and employment issues with you, I think differently. I want my daughter to have someone besides her father, her brother, and myself to care about her. I have close friends and people that if my family dies they would become my family.

Before our interview, Mrs. White and the researcher casually discussed issues pertaining to employment and disability. Mrs. White questioned the researcher about her daughter who has a disability. Mrs. White and the researcher discussed the researcher’s daughter, who attends a self-contained classroom (in a general education high school) for people with profound mental retardation. The discussion consisted of questioning the assumption that most people with moderate and severe mental retardation enjoy working for a few dollars a day at a repetitive task. When asked how her vision of employment for her daughter with a disability, Rachel, differs from her son’s, Mrs. White declared, “I want my son to have a career!”

In summary, out of the three participants that have sons, Mr. Brown was the only participant who immediately envisioned his son working in the community. He is also the only participant with a son who was served in a classroom for the trainable mentally handicapped. Mrs. Hughes and Mrs. Green both envisioned jobs in a
sheltered workshop for their sons with a disability. Both Mrs. Green and Mrs. Hughes had sons who were served in classrooms for people with severe mental retardation.

Mrs. Moore, whose daughter was served in a classroom for people with severe mental retardation, immediately envisioned her daughter working as a ticket taker at concerts and sporting events. Mrs. Smith could envision her daughter who was served in a classroom for students with trainable mental handicaps, working at WalMart with someone to assist her during all of her working hours. Mrs. White initially envisioned a sheltered workshop type of job for her daughter but after discussions decided, she wanted to consider other options. She did not describe a concrete vision of a job in the community for her daughter but did describe a concrete vision of the type of community friendships she would like for her daughter to develop. She wanted her daughter to develop relationships with people that could become her “second” family.

Five of the participants would have envisioned more work hours, college, or a more career oriented future for their sons or daughters if they did not have a disability. All participants described their children with disabilities as enjoying leisure activities in the community.

Residential

The residential section of the interview asked participants about the ideal residential setting for their sons or daughters with disabilities. Participants also were asked if their ideal residential vision differed from a vision they may have if their sons or daughters did not have a disabilities.

Four participants described their young adult sons or daughters with disabilities as living in an idyllic segregated setting, group home, or in a home owned by the
parent participant. Two participants described the ideal residential setting for their son or daughter with a disability as living with them. Participants often cited having their son or daughter with a disability being around people who cared about them as a reason for choosing their ideal residential option. Interestingly, some participants felt the quality of relationships that their son or daughter with a disability would develop would be of a higher quality if they were living in a group or other segregated setting while others felt the quality of their relationships would be best if they stayed at home.

Two participants mentioned owning the home or small group home in which their children with disabilities lived.

Four participants would expect their son or daughter with a disability to be living in their own home, requiring no supervision and be self-supporting if he she did not have a disability. Two participants visions of ideal residential settings, for their sons did not differ (other than the need for support) from a vision they would have if their sons did not have disabilities. The two participants whose vision did not differ if their sons did not have disabilities are the two participants whose sons were severed in classrooms for students with severe mental handicaps.

There was a variety of ideal residential settings described by the four participants who did not envision their children continuing to live in the family home. Mr. Brown described owning an apartment building for people with disabilities. He stated:

Ideally, it would be my dream to be able to open up an apartment building. An apartment building, where someone, well, I would be that person, kept an eye on him [Mr. Brown’s son, Sam] and said things like ‘That does not happen here’. Jean (his daughter who also has a disability) would need one more person in the apartment. The other person could have a disability or not. Sam
could be alone as long as there was no kitchen. He could come down for meals in a community dining room. I would still want to own the apartment because I care. If something is broken, I would fix it. Some people look at people with disabilities differently and those people would not fix things. In New Jersey, when I was going to school, special kids were not separated and I always stood up for them when the other kids picked on them. Jean talks but unless you were with her 24 hours a day, you could not understand her because of the thick tongue.

When asked if he was going to have cameras in the apartments to monitor his son he answered:

No. In the hallways and balcony areas, yes, for the purpose of making sure no one is entering the room who does not belong, but in their rooms, no. The caretaker would be screened by me. I would have record checks and the whole nine yards. Ideally, they would be students who need a place to live, and parents who want a job. Raising kids, you know whom you can trust your children with and whom you can’t.

Mrs. Hughes also envisioned owning the residence in which her son lived. She described her ideal residential vision:

I would love it if I could buy a house and have Charlie live in it and possibly one or two roommates and have house-parents and be able to come and go as I pleased. I could just drop in and stay there whenever I wanted to. My sister is a realtor. I want a place that anyone can come and visit but it would be his own house. The roommates I envision having a disability and the house parent would be there just to monitor things and be realistic. There would be a room for me to come and stay whenever I want to.

Interestingly, when asked how this dream differs from an ideal vision for her son with out a disability, she stated, “Except for the house-parent, it doesn’t.” Ideally, Mrs. Hughes and Mr. Brown both wanted to own and monitor their children’s adult residence.

Mrs. Smith had a more traditional view for her daughter, Jody. She envisioned Jody living at home for as long as possible and then moving into a group-home. The Smiths have visited several group-homes where they have placed their daughter on a
waiting list. Even after the researcher explained the concept of supported living for people with mental disabilities to her, Mrs. Smith stated, “Well I just do not see her ever being anything but an adult child. I just do not see it. That [supported living] is just too new-fangled. My ideal is a nice group home.”

Mrs. White described her ideal residential setting for her daughter as:

Beautiful nice segregated setting. If once you are old, you become senile, you get to go to a place where someone looks after you, and interesting activities are offered, then why can’t you have someone do it for you before you get old? However, I like the social situation, but how do you know how much the person will actually take them out and stuff. That is why so many people keep their children at home. I want my daughter to have someone besides her father, her brother, and myself, to care about her. I have close friends and people that if my family dies they would become my family and I want her to have that. In addition, I see the other people in a group home as becoming her family. There again, the problem you may have is that these people do not pick each other so they may not get along, but ideally, I would like her to have another family. I would like to have a little bit of my life back. Rachel doesn’t tell much, so a person could be mean to her and take advantage of her. I had this idea, you know, how they have a university village for the elderly. Well a beautiful complex that has safeguards, they would have a medications center, but with the feel of a college dorm. It would have gardening on site, jobs, and on site. If you wanted to help in the kitchen, you can. It would be a retreat type of atmosphere. It is horrifying to think about what could really happen.

Mrs. White’s statement regarding her daughter having some to care about her indicates that she places importance on relationships when considering an ideal residential setting for her daughter with a disability.

Mrs. Green ideally envisioned Tyrell living at home with her. Her reasoning for this decision is similar to Mrs. White’s. Both participants were concerned with the quality of their children’s relationships. She asserted:
to describe the type of supports their children would need to vote successfully. This section of the interview elicited many remarks from participants. Four participants stated they had not previously considered their sons or daughters with disabilities voting. The researcher, a strong voting advocate, encouraged the participants to view their family members with disabilities voting. Even with this encouragement, three of those four participants still did not envision their sons or daughters with disabilities accessing their right to vote. Those three participants did not feel their children with disabilities would understand enough about voting to make a choice. One of those three participants described supports that would enable her daughter to vote independently even though she felt her daughter’s vote would lack meaning to her daughter because of her inability to understand her choices.

Two participants immediately described their children with disabilities as being able to vote independently with appropriate supports such as training on the process and pictures on the voting ballot. Those two participants described their children with disabilities as needing someone to assist them in the voting process either by physically voting for them or by providing hand-over-hand assistance. Interestingly, the children of these two participants were served in classrooms for students with severe mental handicaps.

One participant, Mr. Brown, envisioned his son voting and would register his son under the participant’s own political party to expedite getting him into the system. Two other participants stated they already had knowledge of their children’s preference for a political party either because of general knowledge of their children’s likes and dislikes, or because of previous frequent discussions about political issues.
Four participants had no concerns about individuals with disabilities accessing their right to vote. Two participants described being concerned about people with disabilities being fairly informed about all candidates without being unduly swayed. However, one participant believed that no person with a significant mental disability should vote.

Mrs. Green was one of the participants who immediately envisioned her son accessing his right to vote. Mrs. Green stated:

I am for that. I really am. I had said that before. To be honest, when I told my daughter, she said, ‘Now mama, be for real!’ However, I am. I know what he needs, and I know what he wants and I know he cannot pull down a lever, but I could do it for him. It doesn’t matter to me if I take him in and pull the lever or if we do it by absentee ballot, just as long as his vote counts.

Mrs. Moore expected both of her daughters to vote. Voting is very important to her and her family. She stated:

Morgan could make a choice if someone would explain the options to her. She watches TV news with me and I talk to her about what is going on. She wanted Gore to win. We watched the campaign. I do not force my opinions on her. She will choose a side or a politician to root for by herself. It is like choosing your favorite team. Both of the girls wanted Gore. Morgan would smile and we would cheer when he was ahead in the polls. Well, as I said, I have been discussing politics and current events with Morgan all along. She would probably register democrat. Most of her choices seem to be democrats. Well, the way we live by making politics a part of our daily lives and by talking about what is going on in our state and in our country. Morgan would naturally make a choice. She would shake her head or eyes for ‘no’ and smile or shake her head for ‘yes’

Mrs. Moore would be concerned if someone other than herself assisted Morgan in the voting process. She stated:

Yes, it concerns me, but I cannot think of any safeguards. I would not want someone using Amanda’s vote and taking it away from her by saying, ‘we are voting for so and so,’ and then actually voting for someone different. I could see a group-home being unduly swayed and all voting the same way. However,
I do not have strong concerns about individuals with disabilities accessing their right to vote. It is important that people vote.

Mr. Brown initially stated that he did not think his son could vote, however, after discussions with the researcher, he envisioned his son voting for one issue with support. He stated, “Sam will not be able to vote. He would probably be influenced easily. He does not understand politics, as in what is good and what is not good, and he is a people-pleaser, so he will go with what the group wants.” The researcher asked “If he had supports, then could he make a choice?” Mr. Brown replied:

If he had supports to understand what he was doing and why he was choosing this person over that person, then I could see it. However, without that, then he cannot. Then you run the risk of the person who is trying to help him vote trying to influence him to his politics and I really do not know. I would not push the voting issue with him. I would try to explain both sides and respect his wishes. If he decided to go Republican, do I keep him? Yes, well, it is his decision. Sam would need assistance in the voting booth or vote absentee ballot. If there were one issue Sam could vote. He could understand one issue. However, with a variety of candidates, he would not make an informed choice. If I had to look into every issue, to explain it to him, then that would make me a better voter.

The researcher asked how he felt about Jean, Sam’s sister, who also has Down syndrome, voting. He replied:

That would be difficult to say, but it is her right to do that. I have no doubt about that. I would not like it if someone took my child’s right away. However, as far as really voting, I do not think she will ever do it. She would need support in the form of explaining the issues and then you run the risk of partiality.

The researcher asked “Well, is she being denied a right because no one is taking the time to explain it to her?” Mr. Brown replied:

No, if out of the clear blue sky, she said, ‘I want to vote’, then I would say, ‘OK let’s talk about it.’ She would need to initiate it. In the TMII classrooms, students are trained to do certain things. For Jean, I just do not see voting being too much of an issue. Because Sam is higher functioning, I could see
him voting and being very proud of himself. I think that Sam could vote for one issue. I don’t care who catches the dogs. I am not really that up on the voting issue. I could see a whole class voting by absentee ballot and having the teachers explain that there is no right or wrong answer.

When asked how he would assist his son with choosing a political party under which to register, he replied, “I would just register them under my party just to get them in.”

Mrs. White did not believe her daughter should vote, however, when probed she did describe the supports that her daughter would need to successfully vote. Mrs. White said, “I think it would be inane at this time. I can’t think through all the bull crap that the politicians say. If Rachel went in there, she would be just playing with the buttons.”

When asked about voting for her son without a disability, she stated:

Well, I would like to see him vote if he wanted to. She would not even be choosing the cute guy in her particular situation. It is too bad that they don’t have pictures of the candidates next to the names. She could go up and touch the picture or pull a lever next to the picture. She could do that all by herself and not have anyone in the booth with her. Rachel orders from the menu at McDonald’s because they have a picture menu. If they had the pictures, then she could vote for the cutest, if she wanted too. Well, I think the general population of all kinds of people with disabilities should vote, but I don’t think Rachel would really be choosing. It would be like someone else voting twice.

Mrs. Hughes did not envision her son with a disability ever voting. she said, “Never thought about it. He is not capable of making decisions like that. He might comprehend it but he doesn’t wipe his butt, so understand, voting just isn’t important.”

When asked how she felt about her son without a disability voting she stated “I don’t care if Josh votes or not. It is not high one my list of priorities for either one.” Mrs. Hughes also stated that she believed everyone with and without a disability that was capable of understanding should have the right to vote. However,
she did not know who should make the determination of who is capable of understanding the voting process.

Mrs. Smith could not envision her child voting. She stated, "She can't. She does not understand. No way. She would not understand. She cannot vote. It is wrong for her. I do not want to say 'no retarded person should vote' but for Jody she would not know what she was doing." When asked how she felt about her non-disabled son accessing his right to vote she stated, "Of course he can. He is not retarded he can understand."

In summary, politics and voting were important to Mrs. Moore and Mrs. Green. Morgan, Mrs. Moore's daughter, and Tyrell, Mrs. Green's son, were both served in classrooms for people with severe cognitive challenges. Mr. Brown initially could not envision his son voting, but after discussing the concept with the researcher, felt that Sam could vote for one issue. Sam is served in a classroom for students with trainable mental handicaps. It is interesting that the label severe and profound mental handicap and trainable mental handicap did not appear to influence participants' concept of whether or not their children with disabilities could vote. It is also interesting to note that the two participants who stated voting was of importance to them personally had no trouble envisioning their children voting.

Voting supports mentioned by the participants included having the issues and candidates explained, hand-over-hand assistance, and pictures next to the candidates' names on the ballot. Mrs. Green and Mrs. Moore's children would need hand-over-hand assistance in the voting process while Mr. Brown and Mrs. White's children could vote independently with pictures on the ballot. Mrs. White
did not believe her daughter would be making an informed choice, even though she could vote independently if pictures were included on the ballot.

Mrs. Smith and Mrs. Hughes stated people who could not understand the voting process should not have the right to vote. However, no suggestions were made about who should determine who can and cannot understand the voting process.

All other participants felt that all people should have the right to vote. There was discussion about people being unduly swayed or being tricked into believing that they had voted for a particular candidate when they had not. No participants suggested any safeguards to prevent people with disabilities from being taken advantage of in the voting process.

Social Relationships

This section of the interview concentrated on the types of relationships that participants would like for their young sons or daughters with disabilities. Participants were asked about their perceptions of the dating process and how they envisioned their children with disabilities accessing this social ritual. The following paragraphs describe the participants’ responses to the interview.

When asked to describe the ideal adult social life for their children with disabilities, five participants described their sons or daughters having the supports to go out with friends and have fun. Those participants described their children needing a personal care assistant, companion, or other typically developing adult to monitor them during social activities. Five participants did not have a different vision of an ideal social life for their children with disabilities other than the need for supports to achieve the ideal social life. One participant did not want her daughter with a disability
socializing with peers without disabilities or ever dating because of her disability. Two participants described their children as already having a friend without a developmental disability.

All participants would question the motives of a typically developing peer who would want to date their sons or daughters with disabilities. Five participants believed that the general population of people with disabilities should have the opportunity to date. However, one participant did not believe that people with disabilities who function in the lower range of mental ability levels should be allowed to date.

When asked to describe an ideal adult social life for his son Mr. Brown stated:

I want functional normal interaction and as normal of a social life as we can get. For the most part, he does pretty good. He is nineteen. If they [Sam and his sister Jean] did not have disabilities a normal pattern of life would occur. I am trying to get that for Sam. I want Sam to associate with people who have a positive outlook on life and stay away from people who are always down on something. Sam would need someone to monitor him during his social interactions. I have no problem with Sam dating. Two years ago he [Sam] wanted to take his girlfriend out, so mommy and daddy went with him. We let them have their own table and we chaperoned. We let them have their privacy and they had a good time. I have no problems with it. Now with Jean, I do not know. I am not sure she would be capable of drawing the lines where they need to be drawn. He [Sam] doesn’t want to work in a store or in a factory. he wants to work in a church, get married, and have a baby. I have no problem with that. Sam probably cannot produce a child. Not with my daughter, I am afraid that someone will take advantage of her and get her pregnant. She is biologically capable. He is not. So Sam and I have discussed it and I asked him if it would be a problem if he could not have a baby and he said ‘no’ if his wife and he could not have one they would adopt.

Mr. Brown stated that he worries more about Sam in social situations.
because of his disability. He worries about people taking advantage of him; he worries that a waiter or cashier will make him pay more because he cannot accurately figure out a bill. When asked what concerned him about Sam dating a person with a milder, similar, more significant or no disability he stated:

I have no concerns about a milder or no disability, however, with a more significant disability I would need to be sure that there were more supports in place that if something happened to the other person he would be able to cope with it. For example, if the person had seizure problems he would need more support to handle it. With Jean, I don’t see her handling someone with a more significant disability. A milder one I would feel more comfortable because that person could help her. No disability? That is great, if that happened, that would be great.

Mrs. Green, like Mr. Brown, wants her son to have a normal social life. She wants him to have the opportunity to have friends, date, and the possibility of falling in love. She said:

This child needs to have strong feelings for that person until it bothers them so much to be away from them that you have a bad situation. In a way, you have more control because they have a disability. How do you honor your responsibility while respecting their rights as an adult? Well, you have to honor their feelings because, to be honest, if you want them to be normal, they have the right to get hurt. They can make bad choices and they can get hurt. This is hard. Well yes, because nobody wants their child normal or not so normal to get hurt. That is what you spend a lifetime trying to avoid. However, there is something about your special child, you feel like you have to step in and protect them a little bit more. For one thing, your normal kid can get hurt and he can learn how to get over it, but sometimes it seems that your special child never gets over it. It shouldn’t be, but then again it might be different than you think. You might be able to keep them away for a little while and then they could forget. I truly believe that people do not trust in God enough. He has his way of protecting everybody, even though we cannot understand it. That is what we are trying to do, protect them from all kind of negative ideas about them. You got to protect them so they know they are as good as the rest.

When asked with whom she would like Tyrell to socialize, she stated:
I don’t think you can discriminate. You know, I want him to have a variety of people because everybody can learn from everybody. I am what people consider ‘normal’ and I have handicapped people in my life. I learn from them. I am not saying that I am an advocate for gay rights or just macho people, but just all types. You should be able to associate with all types.

When asked with whom she specifically did not want Tyrell to associate, she emphatically replied, “Perverts”. Mrs. Green wants her son to have normal typical relationships, as does Mr. Brown and Mrs. Smith, but unlike Mrs. Smith, she believes the best way to accomplish this is for him to have the same opportunities as other people, including the opportunity to get hurt. She believes that the general population of people with disabilities should date, if they want to. However, when asked how she would feel about a person without a disability dating Tyrell she stated:

That is a good question. Because when you start talking about that with a mother then the first thing you think is why would they want to date my boy if they did not have a disability. That is the first question. What is the hidden reason for their interest? Until you can get those questions answered that would be the biggest problem. I would want to know in my child’s case, why? Because some people have no arms and no legs, some people fall in love with these people and some people just pretend to fall in love with them. Some people do it just for the fame, the attention, to get money out of them, or to see if they can make them do what they want. They just want the power. Every parent is concerned about that for his or her child. Is this the right boy for you? Is this the right girl for you? Do they want you for you or do they want you for some other reason, so that would not be any different. If there were no communication skills, I worry more. However, if there were some communication skills, then even if it were just showing cards, then that would be better. See, most people they fall in love because they hear and like the things you say. If there is no communication then you are not learning about that person. What do you like about that person? Are they for real about my child or are they just going to play with my child?

Mrs. White would like her daughter Rachel to socialize with people and out in the community. However, she described her daughter as having no friends. Her vision of an ideal social life for Rachel does not differ from a vision she would have for a
child without a disability. Rachel would need the support of a companion to assist her with going out. Mrs. White would consider allowing her daughter to go out with a member of the opposite sex and have fun but she would question the motives of a person without a disability who wanted to date her daughter.

Mrs. Hughes has the same vision of an ideal social life for her son Charlie as she does for her son without a disability. She said, “It is not really different because I want him to go out and keep out of trouble.” She would like Charlie to go out with a companion once or twice a week, to dances, bowling, and putt putt golf.

Unlike Mrs. White, who described her daughter as having no friends, Mrs. Hughes described a friendship between her son, Charlie, and a person without a disability:

A friend of ours has a twelve-year-old-boy and his parents died. This twelve-year-old boy is the worst troubled person in the world. He has been in trouble with the police. Charlie is his best buddy and it is sincere. He is honestly concerned and interested in Charlie. Well, if I let Charlie associate with this boy, there aren’t many people worse.

Although Mrs. Hughes does not believe Charlie will ever date, she would not object to him dating as long as he had a chaperone. When asked how her feelings about Charlie dating differ from her feelings about his brother who does not have a disability, she stated that she does not get involved with whom Charlie’s brother dates. She has no choices with Charlie’s brother without a disability. However, she has much more control over Charlie’s social life, because of his disability.

Mrs. Moore was the only participant who felt, her daughter with a disability, Morgan, already had an ideal social life. She would like her current situation to
continue. Morgan went to the homecoming dance. She has friends and is very popular.

Mrs. Moore stated:

Morgan has had the same best friend since she was in elementary school. I would walk into the cafeteria, and there would be Julie feeding Morgan. She comes over now that they are older to talk with Morgan. She says Morgan is her best friend and that she can tell Morgan anything and she knows it is safe. Morgan cannot talk. Anyway, she has a very active social life. Everyone should have friends. What if Morgan had to go to one of those schools where there are no normal kids? She would not have the friends she has now. Sometimes I think about that.

When asked with whom she wanted Morgan to socialize, she said, "The people she has are good people. They are like her only without a disability." It is interesting to note that Mrs. Moore has a very broad definition of her daughter, she does not view her disability as a salient feature. Morgan is very easy to communicate with, friendly, outgoing and readily answers questions. When asked what type of people she did not want Morgan to socialize with she stated:

I do not want her around negative people, people that will look at her different. You know a boy in ESE asked her to the dance. He is very high functioning. He may just have an emotional disability or maybe very mild mental. But anyway, it was weird because his mom said to me, 'I am glad Morgan went to the dance with Sean. None of the normal girls would go with him.' Well, it wasn't like that Morgan is a great person, it was like she thought of Morgan as being the poor girl in the chair and her son as not having a disability, when he was in ESE.

Morgan is the only person with a disability who had already started dating. She also goes to the mall with her friends. Mrs. Moore stated that because of the wheel chair, she has to transport Amada to the mall in her van where she meets her friends. She also makes herself available via cell phone in case Morgan has a bowel movement and needs changing.
When asked about Morgan dating a person without a disability Mrs. Moore replied, “I would wonder why a typically developing person with all the choices out there would choose her.”

Mrs. Smith had a different philosophy about dating for individuals with mental challenges:

She has the mind of a three-year-old. Everyone buys her small clothes because everyone sees her as a baby. I tell them to get her a large because she has a 36C chest, but no one can see that because they all think of her as a baby. If she had the mind of a 15-year-old I would ‘bite the bullet’ and let her date, but they would have to be Down syndrome or retarded. That would be OK if she were about 15 in the mind, but since she is not she can never date.

When asked about having a social life that is not dating Mrs. Smith responded:

Oh, yes, she could go to a group church event. She could do that twice a week. A lot of us parents are trying to make it where someone has the responsibility of setting this up, otherwise it does not get done. Someone has to care for the kids. I do not want her to socialize with typically developing boys or girls even in a group. Because they have a tendency to do one of two things, everyone takes care of her, let her completely run the show, and lead them around by their nose or they totally ignore her. They never ever give her a chance. My son’s friends all want to be her friend. So, she wants them to play with her like she is a little kid and she thinks it is cool that they will do little four-year-old things. She leads them all around and bosses them. She says, ‘Sit down. Throw the ball,’ and they let her tell them what to do. But that is not being a friend. They just do not want Rob [her son] mad at them and they do not want to hurt her feelings. So, I would like for her to be in groups of retarded children.

It is interesting that Mrs. Smith wanted typical social interactions for her daughter, but the only way she felt Jody can receive typical social interactions is to socialize only with people with disabilities. When asked if she thought people with mental handicaps in general should date she replied:

I really do not think so. I do not think they are able to control their emotions. I think that when they have urges, I think that should be squelched. They could never understand everything that goes along with it. There are movies about
these things. There was a retarded girl that fell in love with a retarded boy and they had a baby. However, these two weren’t really retarded. They had functioning IQ’s and Jody does not. Those guys were just slow.

Mrs. Smith constructs the meaning of disability or mental retardation to mean being a perpetual child. If a person achieved a marker associated with adulthood then they were deemed not retarded and no longer a perpetual child but only “slow” (a new term with a different definition).

In summary, five participants envisioned their sons or daughters with disabilities dating and going out with friends and having fun. They also envisioned their children with disabilities needing a companion, personal caretaker or other form or supervision to monitor them during social activities. One participant felt her daughter already had an ideal social life. Interestingly, only two participants described their children as having friendships with people without disabilities. One participant’s daughter, Morgan, developed her friendship in elementary school with a girl her age and the other participant’s son developed his friendship with a younger boy who was a friend of the family. Both participants who had friends who did not have disabilities were served in classrooms for students with severe mental retardation.

Marriage

This section of the interview explored participants’ view of marriage for their sons or daughters with disabilities. Participants described the ideal marriage for their son or daughter with a disability and explored issues of control over their children’s decision-making capabilities.
Of the six participants, three had a daughter with a disability and three had a son with a disability. It is interesting to note that no participant envisioned marriage in their daughter’s future. Two participants with daughters did not want the legal entanglements of marriage, such as shared assets and guardianship issues. Although these two participants did not envision marriage in their daughters’ future, they felt that the general population of people with disabilities should have the right to be married. The third participant did not envision her daughter being married because she is “mentally retarded” and, therefore, envisioned her as being in perpetual childhood. She also felt that people who functioned in the lower range of ability levels should not be allowed to marry. The three participants with sons did not describe any objections to the general population of people with disabilities getting married. One participant, Mr. Brown, easily and immediately envisioned his son marrying and living with a spouse. The two other participants with sons did not object to their son marrying, but felt that their sons would have difficulty understanding the concept of marriage and not be able to communicate their desire to be married. Five participants stated that they would be concerned about the motives of a person without a disability marrying their son or daughter with a disability. One participant would be concerned about his son’s ability to care for a spouse with a more significant disability.

Mr. Brown immediately envisioned marriage for his son. The church was very important in the life of Mr. Brown and his family. He envisioned maintaining control over his son’s medical decisions and having a say in all other decisions of consequence. Even if Mr. Brown’s son married a person without a disability, Mr. Brown would not want Sam’s spouse to have guardianship. Mr. Brown would rather
his son marry a person with a similar or milder disability. He stated, "That way I know both of them are understanding what they are doing."

When asked about marriage to a person without a disability, he said, "As long as I could see that there was genuine love and concern there would be no problem." Mr. Brown envisioned the married couple living in an apartment without a kitchen that he (Mr. Brown) owned. He envisioned monitoring and supports being in place, even if his son's wife had no disability. However, he did envision the married couple sharing their finances.

Mrs. Green also envisioned her son getting married, although she expressed concerns. She stated:

Well, that is what I was thinking. Of course, I would want to know if they want him because they want him and not because they say, 'Well this boy, he is a paycheck.' Yes, the parents want to get what they can for their child, but they want the money so they can offer their child better things. However, if someone else come in, is it for the child or the money?

The interviewer inquired. "What if he could get married and you could still oversee his finances?" Mrs. Green answered,

I would not have any problem with that. I could make sure things are taken care of. However, if he is married, he should give and do for the other person. However, I do not want everything taken from him. Based on the things I was saying about his communication skills, it would be difficult. It would not matter if the person had no disability or a mild or severe one but I wish it would not be as severe as his is.

Mrs. Green described Tyrell's inability to effectively communicate as a barrier to marriage. She has not discussed the concept of marriage with Tyrell. She stated, "I just cannot explain it. He will just have to go through it. I cannot discuss it [marriage]
because I cannot communicate with him.” Even though certain behaviors such as his being very happy when someone was around or sad when that person left would indicate how he felt about a person, to actually decide that he wanted to be married would be difficult.

Mrs. Hughes, when asked if she would consider allowing her son Charlie to marry stated, “If I believed he was happy, yes. I do not believe that would happen.” When asked if she would consider allowing Charlie to marry a much higher functioning person Mrs. Hughes replied, “I cannot imagine that scenario, but I guess I would be OK with a higher functioning person if they were sincere. I would let them have his guardianship, but I cannot imagine that scenario. I cannot imagine a higher functioning person being interested in Charlie. Does that sound cold?”

When asked how she would know if Charlie wanted to get married, she replied:

That is it. I do not think I would know. I know he can say if he wants a drink or something to eat, but do you want to get married, I do not know. He cannot grasp what marriage means. He was three when I got divorced, so he does not even have an example to talk to him about. My other son will not jump into marriage because of that. I just don’t imagine it with him being severely retarded. I just don’t imagine it. I cannot see him married to a person with a milder disability. I just cannot see someone being interested in him. I see him in a group home and going out in a group to social occasions, but I don’t see marriage.

Participants with daughters felt differently about marriage. Mrs. Smith would never consider allowing her daughter Jody to marry. She wants Jody to live in a group home that has only females. She does not believe in the mixing of genders in group homes.

Mrs. Smith explained:
I do not believe in it. No marriage for people with disabilities. There was a lady who had a girl with a disability, and you could not tell unless you talked to her and I found out that she is raising her grandchild. Her daughter should not have had a baby. I do not think there should ever be an age that the person with a disability is weaned from their parents. Let us say a 25-year-old man comes along and says that he wants the 19-year-old girl with a disability to live with him. He could say that she does not need the permission of her parents, but I do not think for retarded people that should ever be true. Never. If someone came to me and said, 'I've got a guy that it would be cute to set Jody up with,' I would just hear a friend. I would not and do not care for people going around and saying,' Jody's got a boyfriend.' The bus drivers and everyone thought she and Jeffery were cute. They encourage that kind of thing. Society seems to get a kick out of it. Jody would never want to be married because I will never expose her to the concept of marriage.

Mrs. White is another participant who did not envision marriage in her daughter's future. Mrs. White stated:

Why get married? She does not understand what that means. Why not just live together? I would not let her marry because it is not necessary. If she wanted the ceremony, fine but not the legal marriage. I would question the motives of a person without a disability. They would have to really convince me they loved her. Still they could live together. The legal aspect of marriage concerns me. I am divorced. I just do not see the reason for marriage.

Mrs. Moore was also uncomfortable with the legal aspects of marriage. Although Morgan, Mrs. Moore's daughter with a disability, was already dating, her mother did not envision Morgan ever getting married. She stated, "No, that is different. Morgan has a lot of money attached to her and I just do not see marriage. There is no reason for it. I would be worried about someone taking her for her money. Dating, having fun. Yes. Marriage. No."

When asked how she would know if Morgan wanted to get married, she stated:

Well, she may not know that much about it. She was hurt by the divorce too. I suppose if someone asked her she would say 'yes' or 'no,' but legally I would never allow someone else access to her trust fund. Morgan
needs that money to live a comfortable life and stay out of group homes or other institutions. If someone really loved her, then he could live with us. She could see him all the time, and she would have the companionship. As long as I do not have to take care of him too. He would have to have his own personal care assistant. I would want someone mild-mannered that really loved her. Even then, too much money involved.

When asked how she would feel about Morgan marrying someone without a disability she stated:

As I said before, marriage is serious. Why would anyone without a disability want to deal with a disability? I just do not see it. That other higher functioning person, [her date for the school dance] neither he nor his mother seemed like they cared for Morgan. Well, he just loves Morgan and loves to take her wheel-chair out on the floor to dance. The thought of that family having a say over Morgan and her trust fund is too much.

When asked about the type of safeguards that would have to be in effect to ensure Morgan's safety if she were to marry or live with someone, Mrs. Moore stated:

She would have to be close by or still live with me. They could live together, but no marriage. Her trust fund concerns me, and the nature of people, when they get a whiff of large amounts of money, they get greedy. People with normal brains are taken all the time. She would not get married but let's say someone moved in with us when Morgan looses interest in him, he is gone.

In summary, no participant with a daughter envisioned her daughter getting married. Of the three participants with daughters, two participants would allow their daughters to live with someone but not be legally married, while one would not allow her daughter to have any type of marital or adult relationship.

All participants with a son with a disability would allow their son to marry. Two participants did not envision their son having the ability to communicate that he wanted to get married, but would allow him to marry if he could. The third participant's son had already informed him that he wanted to get married after
graduating from school.

Five participants questioned the motives of a person without a disability who would want to marry their sons or daughters with disabilities. Only one participant, Mrs. Hughes, would sign over guardianship to a spouse without a disability.

Sexual Consent

The section on sexual consent consists of participants' perceptions of their children with disabilities ability to engage in consensual sex. All participants stated they would have envisioned a mutually gratifying relationship that included consensual sex for their children if they did not have disabilities. However, all but one participant had difficulty envisioning consensual sex as part of their children with disabilities’ future as an adult. Mr. Brown was the exception. All participants except Mrs. Smith believed that their children with disabilities had shown or would soon show the ability to enjoy sexual pleasure. Mrs. Smith believed that her daughter’s cognitive disability would prevent her from enjoying sexual pleasure. Four participants believed that their children with disabilities would enjoy the sex act but objected to their children ever having sex because they might hurt their partner, get hurt by their partner, or would not understand the sexual act. Four participants felt their sons or daughters’ cognitive disabilities would prevent them from being able to consent to the sexual act. Two participants felt their sons would be able to consent to the sex act. All participants stated they would feel uncomfortable with and question the motives of a person without a disability who wished to have sexual relations with their children with disabilities. No participant envisioned consensual sex in their daughter with a disabilities’ future as an adult.
Mr. Brown envisioned his son having consensual sexual relations within the bounds of matrimony. Mr. Brown stated:

Sam would need to be married. There would still be monitoring, but at that stage the monitoring would be like a couple sharing the apartment. For Sam, I am not worried about him being taken advantage of by his wife and he would be monogamous. I do not believe in divorce. If something abusive happened, then I would say, 'Divorce no problem,' because my children’s safety comes first. I would help Sam understand the best I could how to protect himself, and before they both were engaged to be married, I would have them both tested for HIV. The same for Jean [his sister] but the possibility of pregnancy scares me with her. It literally scares me! With Sam, it is not likely to happen and Jean would be on birth control. With Sam, I have told him you can always adopt. My preference would be for Sam’s spouse to have the same disability or be higher functioning. That way I know both of them understand what they are doing. As far as the spouse having no disability? Yes. As long as I could see that there was genuine love and concern, there would be no problem. When my wife got ill we just put all of our efforts into taking care of her. For Sam, I am not really worried about him being sexually coerced by his wife. Jean [his daughter] would have the personal care assistant.

Mrs. Green also envisioned her son having consensual sex in his future.

When asked if her son had shown any indication that he had the ability to enjoy sensual pleasures, Mrs. Green stated:

Not yet, I have watched for that, but not yet. I am wondering how is he going to be and what he going to do. Is he going to sit in front of people and touch himself or what? I heard a disability does not stop that [sexual intimacy]. I always visualize that he would be playing with himself one day, but when parents talk about it, I never heard of people talk about it going farther, with guys it is mostly just playing with themselves. I have no idea how exactly it might happened. I would have no idea. I believe they would find their own way. There is just something about nature, that some things just come natural and you do not have to teach anybody. I worry about it because I also have a girl. I worry about her getting hurt or about someone listening when she says ‘no’, but I worry about someone not listening to her. The main concern is that you may not know until it is to late and then again, you may know.

Mrs. Hughes did not envision sexual intimacy in her son’s future. When asked if Charlie had shown any indication of the ability to enjoy sensual pleasure,
Mrs. Hughes stated:

His teacher taught him to masturbate in his room and if he needs to masturbate then he goes in his room and does it. To what degree he can experience it, I am a mom, and I don't know and I don't want to know.

Although Mrs. Hughes would envision a mutually gratifying relationship that included consensual sex for Charlie if he did not have a disability, she stated:

No. I just don't. I just cannot envision it because of his mental age. I do not think he would understand it. I am sure he would enjoy it, but I don't think he would understand what was happening. I would worry about him hurting someone. He is very big and I would worry about him not understanding and hurting someone. If he is becoming involved in that situation and someone says stop I do not know if he would, so I would not want to open up that can of worms. It takes over four people to hold him down to get a little bit of blood. He may be capable of rape. Sex is a fragile thing for someone who does not have a disability, so I worry about him getting hurt mentally. Sex is a fragile thing. There are so many ways you can get hurt. If he did not have a disability, well, then the same issues would apply, but he would know what he was doing and could make choices. I do not envision sex anywhere in Charlie's life because I still envision him as a three-year-old because of his mental age. There is not any condition under which I can envision it. Not that I know of because of his mental age. If he went from six to sixteen then I could envision it, but not as long as his mental age is three. If a person were higher functioning, then that person could have sex, then that would be fine. But Charlie, he doesn't talk. He cannot take care of himself. Sex at his present mental level, I do not think it would be consensual because he cannot understand it.

When asked how she would feel about a person without a disability engaging in sexual intimacy with Charlie she stated, "The no disability would worry me because I would wonder why. I can envision other people loving Charlie without disabilities but to have sex with him I just do not see it."

Mrs. Smith did not believe any person with a lower functioning disability should engage in sexual activity. When asked if her daughter had ever shown any indication of the ability to enjoy sensual pleasure, she stated:
She will play with her breast and her genital area; however, I do not see that as sensual pleasure. I see that as something a two and three-year-old would do. She does not do anything other than that. I never disciplined her for it and I do not allow anyone to say Jody do not do that because if they did she would start doing it all the time.

If Jody did not have a disability, then Mrs. Smith would envision consensual sexual relations in her daughter's future. However, because Jody has a disability Mrs. Smith does not believe that she should ever have sexual relationships. She stated:

No, sex does not go with here age mentally. Knowing Jody the way that I do it would be strictly someone taking advantage of her. She would not know what was supposed to be pleasurable and what wasn't. It [sexual relationships] would not be something she would ever initiate. She sees it on TV and it bores her to death or she will say 'EWW' when they are kissing. She would not like it. She cannot understand it and she has indicated that she doesn't like to think of it. Never will I let it [her daughter having a sexual relationship] happen. If she did not suffer from really bad PMS, I would never consider a radical hysterectomy. What does she need a period for? She would be on birth control, if she did not have bad PMS. The doctors suggested that. Her father says he worries because her periods are messy. She cannot care for herself. I would never let anyone ever say that I let her date, because if she did get pregnant then everyone would say well you let her date, you encouraged her.

Mrs. Smith feels so strongly about Jody never being perceived by anyone as sexually attractive she stated:

I will always want the staff to consider her a child. Moreover, never let her be unsupervised. She looks great. Physically, she is a knock out. So, I never want her unsupervised. A lot of people think we are terrible because we do not put braces on her teeth but she looks too good already. God forgive me, I should get her braces so she can have straight teeth. She would not let a dentist put his fingers in her mouth anyway. She has very bad gag reflex. They had a guy come out and talk to me about neglect because I would not take her to a dentist. Damn school nurse turned me in. People go to school, they get a degree, and they think they can take care of retarded children. Under no circumstances can Jody have sex. None.

Mrs. Smith does not believe that people with disabilities in general should
have sexual relations. She stated:

They are the most loving, sweetest, people on earth and they should be cherished. They should not be encouraged to do that [have sexual relations]. There would be no retarded kid Jody’s level ever doing that on his or her own. It is the normal mentality type of people that encourage that. They do not have that in them and it is just society pushing that on them.

Mrs. White also felt her daughter’s cognitive disability prevented her from consenting to sexual acts. Mrs. White described Rachel as having shown that she could enjoy sensual pleasures, but she did not ever envision Rachel having consensual sex as an adult because of her disability. She stated:

Yes. With ‘consensual’ being the key word with Rachel. Having her disability, I just don’t know how consensual that would be. Well, when I was her age, I realize that I did not comprehend what it was all about, the consequences, but I knew that this is what it was and this is what it meant. You know, that we were going steady, and it meant we were in love, and I knew that was what it meant. However, Rachel just really could not understand all that. If you can’t understand then can you consent? I see it as maybe two different things, being able to enjoy and being able to consent. I am sitting here thinking and I got this vision and let’s say that Rachel and one of the little boys in her class came over. Let’s say that they were watching TV in one room and the boy’s mother and I were talking in the other room. I don’t know how I would react. I know her father would feel like she should never have that, but then he would feel that way if she were typically developing. The other thing I am thinking is that I don’t know what it would feel like to be older and have it be your first time. I was younger and you know that feeling if you taste something and it burns your tongue then you are not willing to try it again. Well, it did not actually feel that good my first time. The first time it kind of hurt. So I am not so sure Rachel would ever want to. You know I have become so used to rolling with the punches, taking things as they happen that I have not put much time into thinking about her social development. It’s been just one day at a time. And, of course, I have my daughter’s best interest always at heart, but until I met you, Barb [the researcher], I have never really thought about it. At this point in time, I would not trust a person without a disability who wanted to have sex with my daughter. There are so many other people without a disability that a person could be with. I don’t trust one that would want to be with her. Why would they want that [sexual relations] for my daughter? As pretty as she is, she doesn’t engage in conversation and she doesn’t have any interest other than watching Roger Rabbit. I could not image a normal functioning person being
interested in my daughter. I would wonder why they had an interest and I would chase that person away. I would wonder if it was because they knew that she couldn’t tell what they were doing to her. I would wonder why. There is so much to consider when you are typically developing, the possibility of disease, the emotions involved, the hurting someone or getting hurt, there is just so much to consider. My main question would be, ‘Why?’ If they told me they were in love with her, would I believe that? If I thought, that person could be sincere because, shoot, I get a special feeling around my daughter. She has a special spirit. Well, I would want to do a criminal background check. If I thought he was in it for himself or because Rachel was an easy target, I would stop him in a heartbeat. I believe that if she were normal, she would not fall for that shit either.

Mrs. White continued to describe her feelings about the possibility of her daughter being taken advantage of sexually and about her daughter’s burgeoning sexuality. Although Mrs. White did not come up with realistic concrete solutions to the dilemma of her daughter’s vulnerability and sexual nature she openly discussed potential issues:

Rachel is a very strong person. It takes five of us to hold her down to look in her ear at the doctor’s office, so I can’t imagine someone being able to hold her down and doing that [forcing sexual relations] without hurting her. Therefore, if she did not kill the person, then I guess she is consenting. Sometimes she will reach for my hand and want me to rub her between her legs and I say, ‘No we do not do that.’ Well, she reaches for her father’s hand and her teacher’s hand too. She does more bad behavior with me than with her teachers. She also tried to hump her brother. There have been times when company was visiting that she would sit on someone’s lap. While on the lap, she would wiggle around and it is funny because that is what she does just before she starts humping. People think she is just positioning herself on their lap and they will say, ‘Oh that’s OK’. Then I say, ‘No it is not OK’. Rachel would have to be well into her twenties before I would consider it [sexual relations] Even in my death I want someone to be there, to be her companion, to care for her, to protect her and not let her run amuck. How can I do that? I do not know. I guess I will just have to haunt her and her caretakers after death. Well, it would be different if she could talk and say, ‘Mom I did not like this’. Then it would be different.

As Mrs. Smith continued to imagine her daughter leading a life that included the traditional roles of adulthood, she worried about her daughter becoming a
mother. She stated:

The thing I wonder about is well, let's say ideally she moves out into an apartment and she and her companion have a mutually rewarding relationship, I just don’t want her to have a baby. Under no circumstances, she cannot have kids. She does not like kids, and she does not like puppies or anything like that. She would be a terrible mother. Therefore, I understand that what you have to go through to have your child’s tubes tied is something else. You know they say just put them on the pill. Well, the pill can be forgotten. My friend is pregnant because she forgot to take her pill. I wish it were easier as her mother to say, ‘Hey, if you are going to do this, then let’s go to the doctor and get this done’. They say it is easier if you have it [tubal ligation] done before the age of 18, for reasons of consent. However, do you really want to do this when you are not sure she will ever have sex? It should be easier to do and you should not have to go to court. If she did not have a disability, oh yes, of course, she would have sex as an adult, but with a disability, no.

Mrs. White, when asked to describe the conditions under which she would be comfortable with her daughter having sexual relations stated, “Having known the person a long time, knowing that this person truly, truly cares for her, that would open up my mind. However, she would need to be older, well into her twenties, before I would consider it.”

Mrs. Moore also did not envision consensual sex in her daughter’s future.

Mrs. Moore was very concerned about her daughter’s physical safety. When asked if her daughter had shown any indications of enjoying sensual pleasures Mrs. Moore replied:

Oh yes, she has orgasms, I know. I change her and sometimes there is a lot of, well, not really, discharge because it, well, it is that white clear stuff. Boy, she has a lot of it sometimes and I can tell she has had an orgasm. Well, of course if she did not have a disability I would envision her having consensual sex as an adult. Her sister, Carrie, knows about birth control, marriage and divorce. She will make her own decisions. I do not know if she will tell me. We are close but you just never know. For Morgan, I do not know about sex. Morgan is so delicate. I just cannot imagine it. No, I am afraid she would get hurt. She could be hurt and how could you be sure she wanted to. She could
get hurt during the act too easily. Well, considering her physical disability coupled with her inability to tell me, she is just too delicate. She could get hurt. I cannot imagine it. Well, she may enjoy it; she does have orgasms. But how could you keep her safe and from being hurt? She would have to be protected from pregnancy and the rest. I do not know how you could protect her. She could get hurt.

When asked how she felt about the possibility of Morgan having consensual sex with a peer without a disability she stated:

Well, I would question the motives of a person without a disability. I mean relationships are so complicated and if you throw in a person who cannot talk, it is hard to see how that relationship can sustain itself, especially if one person is typically developing. Well, as for more disabled, that is hard to imagine too. How would a person more disabled be able to make those choices? Someone would have to initiate the relationship. I just do not know I guess someone milder or with the same disability is preferable. However, I really do not see her ever having sex. She is tiny and fragile. The other thing is what if you change your mind in the middle. That is hard enough for people without disabilities. If she were in bed how could she call out if she needed help? I just do not see sex in her future life. I am not trying to take something away from her but I just do not see it.

When asked how she would feel about a staff member attempting to have consensual sex with her daughter with a disability Mrs. Moore replied:

No. That relationship by itself would, well, that would be taking advantage of her. If he really loved her, why would he need to be paid to take care of her? I would be concerned that aside from her being physically hurt someone would just be using her and that is too painful to think of. She can have a relationship with non-staff for companionship but I do not see sex as being part of it. The problem would be how to protect her.

In summary, all participants would envision a mutually gratifying relationship that included sexual intimacy for the future of their children if they did not have a disability. However almost all (Mr. Brown, Sam’s father being the exception) had difficulty envisioning how consensual sex could be part of their family member with a disabilities future as an adult. Because Sam had already informed Mr. Brown that
he wanted to get married and have children Mr. Brown assumed sex would be part of Sam’s life although only after marriage. He was not particularly worried about Sam being sexually taken advantage of in marriage. He also has a younger daughter with Down Syndrome and he expressed more concern with her being sexually exploited in a dating situation although he was not concerned about her being sexually exploited in marriage.

Five participants felt their family member with a disability had shown the ability to enjoy sensual pleasure and masturbation was cited as the chief indicator of the family member with a disability’s ability to enjoy sensual/sexual pleasures. One participant Mrs. Smith, Jody’s mother described her daughter playing with her breast and genital area however she did not define this act as masturbation or seeking sexual/sensual pleasure. It appears Mrs. Smith defines mental retardation as never growing up, as always being a certain mental age. The term mental age has been and still is used by many professionals in the field. Additionally Judy believes that a person of a certain mental age will perceive the world in a certain way regardless of that person’s physical age. She made such statements, as “No sex does not go with her mental age.” Although some may view a parent describing a teenager playing with her breast and genitalia as not being sensual or sexual in nature as a classic case of “denial”, it is important to remember that when two and three year-olds explore their bodies many people do not attach significant sexual meaning to that experience. The term mental age and the perception of the person with as disability as being in a state of forever childhood is a way many people, professional, staff, parents and the general community construct disability. Mrs. Smith was the only participant who
constructed the meaning of disability as being in a state of forever childhood. Mrs. Smith did not believe her daughter should access voting, socializing with friends without disabilities, dating, consensual sex or marriage. These results are consistent with the construct of mental impairment as being in a state of forever childhood.

The other parent who cited her son as not having shown an indication of enjoying sensual pleasure, Mrs. Green had not noticed her son masturbating but she expects Tyrell to start at anytime. She believes that all people have sensual and sexual feelings and that her son will also have these feelings. Ermine's mother admitted difficulty in envisioning her son engaging in a consensual sexual relationship. One reason she cited for her difficulty in envisioning this type of experience for her son was that in discussions with other parents of young males with disabilities intercourse or mutually gratifying sexual experience were not discussed. She did not know the typical sexual pattern of males with significant developmental disabilities. Parents often discuss masturbation. Some parents have expressed concern about their family member with a disability masturbating in public. Tyrell's mother wondered if that would be a problem for her son. She is not opposed to Tyrell having a sexual relationship and when asked how she would address the issue of AIDS she stated that she would have her husband teach him to use a prophylactic.

Parents of females were especially reluctant to envision a consensual sexual relationship as part of their daughter's adult life. When asked about their children having consensual sex as adults, all participants with female children envisioned no sexual activity in their daughters' futures. Mrs. Moore believed that her daughter had
the ability to consent to the sex act and enjoy the sex act but was concerned about her daughter’s physical fragility. She could not envision safeguards that would keep her daughter who is very small in stature from getting hurt during the act. Jody’s mother did not believe that her mental age would allow her to enjoy or understand sex. She would not know “what was supposed to be pleasurable and what was not”. Mrs. Smith also noted that when her daughter saw kissing on television she makes a noise to communicate her disgust. Sex would not be something that she envisioned Jody ever initiating. Jody was described as having a very sensitive gag reflex. Mrs. White also questioned whether her daughter would enjoy the sex act.
CHAPTER FIVE
DISCUSSION

The goal of this study was to gather in a systematic manner a description of participants’ perceptions of their children with disabilities’ ideal adult lives, and to ascertain what role family values and the child’s disability played in the conceptualization of this ideal life. There is very limited literature regarding parents’ perceptions of quality adult lives for their children with significant disabilities (Jordan & Dunlap, 2001). If more were known about parents’ dreams for their children’s adulthood, then current services could be modified to incorporate parents’ desires for their sons and daughters with disabilities and potentially reduce the amount of stress experienced by parents during this transition time. Additionally, more knowledge of parents’ perceptions would assist the field in serving adults with disabilities and their families in a more sensitive manner. This chapter consists of a discussion of the salient findings described in Chapter four. Included is an interpretation of the findings, implications for further research and personal reflections.

Interpretation of the Findings

What were participants’ perceptions of ideal quality adult lives for their children with disabilities? Participants described a variety of ideal adult lifestyles for their sons or daughters with disabilities. However, common reasons for their varied descriptions were present. Participants exhibited similar underlying assumptions, and reasons for
envisioning their particular type of ideal adulthood for their children with significant disabilities. Understanding these underlying assumptions and reasons is important.

Relationships

Participants envisioned a variety of residential settings for their children with disabilities. Some envisioned their sons or daughters living in group homes or other segregated facilities while others envisioned their children continuing to live with them. Although the visions of ideal residential settings differed, the reasons for envisioning a particular setting often had a common theme. Participants attempted to envision the place where their children would have empowered, meaningful, caring relationships. One participant envisioned her daughter living in a group home because she envisioned the other people in the group-home becoming her daughter’s “second family.” In contrast, another participant envisioned her son continuing to live in the family home because she assumed that staff would be just “doing a job” while assisting her son and not really care about him. Another participant expressed a desire for her daughter to have meaningful friendships but felt strongly that the only people who could provide this type of relationship for her daughter were other people with similar disabilities.

Having their children enjoy meaningful relationships with people who genuinely cared about them was a high priority. Participants found meaningful relationships far more important than having their children access the rights and rituals traditionally associated with adulthood.

The majority of participants described concern over the motives of a person without a disability who wished to date or marry one of their children with a disability.
One of the reasons some participants cited for the assumption that a typical person would not be genuinely interested in a person with a significant disability was the inability of the person with a disability to effectively communicate. Several participants described good communication as not only essential to a good relationship, but a prerequisite for a person gaining enough knowledge about another person to care about him or her or fall in love. Participants also noted a difference in the interest of their children with disabilities and peers without disabilities. One participant stated that all her daughter liked to do was watch Roger Rabbit and self-stimulate. She had difficulty envisioning someone without a disability finding those interests of enough value to sustain a long-term relationship.

Even though two participants described their children as having “real” friendships with peers without disabilities, both had difficulty envisioning a person without a disability wanting to have an intimate relationship with their son or daughter. Mrs. Hughes stated, “I can picture someone loving him but not wanting to have sex with him.”

Having their children associate with people who genuinely cared about them was extremely important to participants. The field could benefit from research on the types of relationships people with significant disabilities form. Detailed descriptions of true friendships and caring relationships could increase our knowledge about the formulation of relationships and ability to facilitate these types of relationships.

Additionally, the type of relationships people with significant disabilities form with caretakers and professionals is worthy of investigation. Professionals would benefit from reflecting on the types of genuine caring relationships they have formed.
with people with disabilities. Detailed descriptions of the caring relationships professionals and paid staff form with people with disabilities would assist parents in understanding the type of relationships their children with significant disabilities are likely to form as adults.

This researcher was under the assumption that people with disabilities who lived in their own homes with supports had more opportunity to form meaningful mutually respectful relationships. However, participants differed in their views of the best environment for optimal opportunity to form meaningful relationships. Some participants felt living in a group home with other people of a similar disability would provide their children with optimal opportunity to form meaningful relationships, while others believed living at home with the family would assure that their children were around people who genuinely cared for them. Concrete knowledge about which housing options offer the best opportunity for people with significant disabilities to form relationships with peers would be beneficial.

*People with Disabilities in General*

Participants were asked how their ideal visions of quality adult life for their children with disabilities differed from visions they had of quality, ideal lives for individuals with disabilities in general. Even though many participants did not envision their children with disabilities ever voting, getting married, or having sexual relations, all participants, except one, felt the general population of people with disabilities should have the right to access these rituals of adulthood. This finding is relevant and indicates that even though participants wrestled with the existential dilemma of a belief in equal rights and an intimate knowledge of their children's
vulnerability, they held firm in their belief of equal access to the traditional rights and rituals of adulthood for the general population of people with disabilities. The delicate balance of the rights of an individual and the practicalities of how each individual's disability is manifested, is a conundrum with which the researcher and many of the participants struggle. If we posit the following two underlying assumptions: first, every person with a disability has the right to equal access to all the rights and responsibilities afforded people without disabilities, and second, that people with disabilities are more vulnerable and need assistance with accessing the rights and rituals of adulthood, then we need to detect what part of the person with a disability's vulnerability or barrier can be attributed to the limitations of the disability, as opposed to the interactions of society to the disability, or the preconceived assumptions of people without disabilities.

An example of a vulnerability or barrier that results from a person's disability is a person with a severe cognitive disability's inability to count money. A person without the skill of counting money will need assistance when paying bills and balancing a checkbook. The assistance or remediation training needs to be provided directly to the person with a disability.

An example of a vulnerability or barrier that arises from the interactions of society to the disability was evidenced in chapter four. Mrs. Smith described her son's friends as not having a genuine or typical relationship with her daughter with a disability. She stated that Randy "ran the show" and her son's friends acquiesced to her demands. The assistance or remediation training for this type of barrier needs to be provided to
both the person with a disability and the person without the disability (society), since
the barrier is caused by an interaction.

Mrs. Smith also showed an example of a vulnerability or barrier caused by the
preconceived assumptions of a person without a disability. Mrs. Smith constructed the
meaning of disability as being a forever state of childhood. Following this assumption,
she did not believe that people who functioned in the lower range of mental
capabilities should be allowed to vote, have consensual sex or be married. Mrs. Smith
continually asserted that her daughter was cognitively a child and in her construct of
mental retardation firmly believed that her daughter would forever remain emotionally
a child. This belief made voting, marriage and sexual relations inappropriate not only
for her daughter but for the entire population of people with significant disabilities.
Assistance or remediation training for this type of barrier would be provided to the
people who shared the disempowering construct (society).

The way a person constructs the meaning of disability has strong implications for
the opportunities afforded people with disabilities (Holzner, 1968; Jordan & Dunlap,
2001; Kelly, 1955). Participants created their visions of ideal adult lives for their
children from a variety of sources, including family values, personal knowledge of
their children, societal underlying assumptions, and religious values. In truly trying to
understand parents' perceptions it is important to cull out the variety of influences to
determine why a participant may not wish for her son or daughter with a disability to
access certain rights and rituals of adulthood. If the reason is due to intimate
knowledge of their child with a disability's likes and dislikes, then the real issue may
be determining what the person with a disability would want if he or she could
advocate for himself. If the reason for a parent not wanting her son or daughter to access a ritual of adulthood is concern for the physical safety of her son or daughter, then an explanation of the appropriate supports may assist in addressing the parent's concerns. Better understanding of perceptions promotes better communication. Further explorations into the philosophical and practical dilemmas faced by people with significant disabilities and their families may assist parents in negotiating the poignant transition to adulthood.

**Family Values**

Family values played an important role in the type of traditional adulthood rights and rituals parents envisioned for their children with disabilities. This is consistent with Bronfenbrenner's family system theory (Bronfenbrenner, 1979). Bronfenbrenner posits that in a family system each member affects the other members. He advocates respect for the family system. By family values, I mean the personal experiences, likes, dislikes and value systems of participants. Participants who were active in politics or valued the voting process immediately envisioned their sons or daughters voting, even though their children were served in classrooms for students with profound mental retardation. Conversely, many participants whose children were higher functioning did not envision their sons or daughters voting. Additionally, these participants did not place a high priority on voting in their own lives.

The participant who held the church and Christian value system as very important immediately envisioned his son being married and having consensual sex within the bounds of that marriage. Conversely, the three divorced participants did not envision marriage in their children's future. However, divorced participants envisioned their
sons or daughters with disabilities living with a companion without the legal entanglement of marriage.

People with disabilities are linked to their families and families are linked to their member with a disability. Maintaining respect for a person's family values is especially important during the transition to adulthood for people with significant disabilities. The family is often a very important source of emotional support and firmly established long-term relationships.

Mutual Relationships

Participants did not envision a change to a more mutual relationship with their children with disabilities as they became adults. This is interesting because of the six participants four described a change in their relationship with their own parents as they matured into adulthood. These participants described the change as occurring when they reached certain traditional markers of adulthood. Even though some of these participants could envision their children eventually, with appropriate supports, succeeding at some of the same markers of adulthood they did not envision their relationship with their sons or daughters changing. This phenomenon deserves further investigation.

If people with disabilities are to be valued equally as adults, then the power structure of their relationships should parallel the relationships of typically developing adults. If this is not happening within the family or with others in society, then this phenomenon warrants thorough investigation.
Conclusions

Most participants struggled with the existential dilemma presented by the desire to offer every opportunity to their loved one with a disability and the reality of the limitations that some disabilities exhibit. The struggle to tell which limitations are a result of false learned underlying assumptions; or old, outdated, limited constructions of meaning for concepts such as disability, independence and autonomy, and which perceived limitations are a result of the "real" vulnerabilities attributed to some disabilities is difficult but important to determine. When one can ascertain that preconceived notions of a person's disability are placing barriers for that person, then enlightening a society or changing certain societal beliefs or policies can empower people with disabilities to live fuller more enjoyable adult lives. Additionally, if a limitation is because of vulnerability or need for support caused by a person's disability, then this too can be addressed. This dissertation does not solve this dilemma but does serve to bring to light these issues for further research of this long-term problem.

Implications and Limitations

This dissertation brought to light certain issues that have implications for people practicing in the field and for researchers. Participants placed importance on genuine caring relationships for their children with disabilities. Professionals in the field could devote increased time to the nurturing of such relationships. More research on relationships of people with significant disabilities is warranted. Positive caring relationships provide richness to every life. A better understanding of which residential and employment situations encourage close caring relationships would be
of interest to parents and people with disabilities. Additionally when a professional is attempting to communicate options for adulthood to a parent, such as residential and employment options, more attention could be paid to describing the types of caring relationships that the different options may provide.

Even though no participant envisioned a change in their relationship with their children as they became adults, teachers, therapists, and behavior specialists need to reflect on what changes they have in the power structure of relationships with adult students with disabilities.

More research is needed on the perspectives of parents to facilitate a better understanding of family relationships. Additionally, more research is needed on the power structure of adult-to-adult relationships when one member has a significant disability. Discovering if people with disabilities ever reach the same level of adult-to-adult relationships as their non-disabled peers, would be important information. Additionally, information on how to encourage relationships between parents and their children with disabilities that have more mutuality or a more equal power structure may benefit the field and people with disabilities.

It is important to remember that a person does not construct meaning in a vacuum. Society plays an important role in how people create meaning. By addressing the perceptions and signals sometimes subtle and sometimes not so subtle of society in general, professionals in the field can influence how people will create the meaning of disability and its relationship to adulthood. This may encourage participants, especially people with young children with disabilities, to create a more empowering meaning of disability and more empowering relationships for people with disabilities. If
professional are made aware of society’s disempowering signals and the strong effect
these signals can have on the way people with disabilities are treated, then change can
occur. By understanding how society influences the way we construct meaning, and
how that construction of meaning influences the opportunities and options for people
with disabilities, people in the field can have a better understanding of not only their
own disempowering beliefs but those of others. This may assist professionals in
communicating with parents and promote a more collaborative atmosphere between
professionals and parents.

Another important issue in the consideration of power structures in relationships of
people with significant cognitive disabilities is their legal standing as “competent”
adults. Lawmakers and judges play important roles in a person with significant
cognitive or mental disability’s ability to make decisions. When a person is declared
legally incompetent, a family member often becomes the decision maker. Some states
have recognized that people with significant cognitive disabilities can make their own
decisions but need some assistance to advocate for their decisions. In these states a
person can be assigned a guardian advocate and remain legally competent. Because
parents of people with significant cognitive disabilities can legally make decisions for,
or legally advocate for, the decisions made by their sons or daughters with disabilities,
communication with parents is essential for professionals in the field.

Professionals and researchers recognize that input from the family is important
(Fox, Vaughn, Dunlap, & Bucy, 1997). Participatory research is a growing and
important area of research (Vaughn, Dunlap, Fox, Clarke, & Bucy, 1997; Turnbull,
Friesen, & Ramirez, 1996; Turnbull & Turnbull 1993; Whyte, 1991). A parent (The
author) initiated and conducted the current research that delved into the perceptions of six parents, and another parent reviewed the findings to check for sensitivity to family needs. The findings of this dissertation show that families are extremely concerned with the quality of relationships that their sons and daughters will experience in adulthood. It also points to the importance of family values in the choices a person makes in adulthood. Future research should focus on these parent driven issues.

The movement to empower families is broader than just families of people with cognitive disabilities (Fox, Vaughn, Dunlap, & Bucy, 1997; Dunst & Trivette, 1994; Schwartz, 1997; Singer & Powers, 1993; Turnbull and Ruef, 1996; Westbound & Fagan, 1989). This larger movement that attempts to strengthen and empower all families through advocacy in policy and political matters had largely ignored special issue associated with families of special needs children and adults. Additionally, this larger movement has been typically ignored by researchers in the field of special education (Bowman, 1994; Schwartz, 1997). The findings of this dissertation are most likely applicable to a much wider audience than just people with significant cognitive disabilities and their families. Parents are parents first and parents of people with significant cognitive disabilities second. As parents, their concerns about the quality of relationships their children will form in adulthood is probably echoed in concerns of parents of children with mental disorders and parents of children without disabilities. Although there is much discourse about mainstreaming children with cognitive disabilities, discourse should include mainstreaming research and advocacy.
Personal Reflections

This researcher is a parent of a young adult with disabilities. Being a parent of a child with a significant disability who was transitioning to adulthood during the course of this research filled me with many emotions. This section includes my personal thoughts about this research.

The fact that participants did not envision a change to a more mutual relationship with their children with disabilities was very perplexing and disturbing to me. Traditionally parents have led professionals and legislatures down a path of increasing opportunities and equal rights for people with disabilities. Equal power, equal valuing and equal rights in society are extremely important to people with disabilities. Living in a society that sends devaluing messages to people with cognitive challenges has always been a source of enormous pain for me. As my daughter approached adulthood, the one thing I truly wanted for her was a type of adulthood where her status as an equal citizen would not allow any devaluing practices.

I started this dissertation with a firm philosophical and emotional belief in the basic premise of normalization. I wanted my daughter to have as close to a normal adulthood as possible. The concept of “adult” seems very simplistic, but when you are discussing the concept of adulthood and disability many potential issues surface. My first task was to look at the rights and rituals typically accessed by people without disabilities. Then I culled out rights and rituals that required an examination, such as a driver’s license. This left such rituals as voting, marriage, employment, moving out of the family home, and consensual sexual relations. I was unaware of any road maps that described typical adult life for people with significant disabilities. Group homes seemed very non-typical.
As I read about supported living and people with disabilities owning their own homes, I envisioned more and more opportunities for Cassandra. During the interviews, I discussed my excitement about the possibilities of our children having fulfilling adult lives. I wanted disability to truly be defined as simply needing more supports. Being the parent of a person with a significant disability, places one in a unique position. Because society has not had a long-standing historical record of fighting for or giving people with significant disabilities true respect and true rights, and people with significant disabilities cannot advocate for themselves without supports. Parents must assist society with providing these rights to our children. I do not mean to imply that society wishes to deny people with disabilities their inalienable rights but society simply for the most part does not think about it. Therefore, it is important that efforts be made to expose people with significant disabilities to all of their inalienable rights as an adult without the insistence that accessing the right is mandatory. I firmly believe the voice of families must be heard and heeded with the understanding that they are part of the society that has the devaluing underlying assumptions about people with disabilities.

However, my strong desire to have my daughter have full adulthood with equal access to all of its traditional rights does cause me to struggle with the finding that participants did not envision a change to a more equal relationship with their children with disabilities when those children reach adulthood. How can I expect society to treat my daughter as an equal if I do not treat her that way? I am not questioning participants’ love and devotion for their children but I struggle with this finding.

There is a beautiful change that occurs when instead of saying to your child “Now you do this because it is what the teacher wants and it is good for you” to saying “I
really love you and I wish you would do this but you are an adult now and the choice is yours.” Offering that respect is a beautiful way to pay homage to a person’s value and as with many benchmarks, the joy of having a child with a disability reach it is so much more rewarding.

Believing with all my heart and soul in my daughter’s worth, value, equality and ability to make her own choices brings about many day to day dilemmas and potential problems. Sometimes I have had to compromise that belief, and that too was extremely painful. There is a need for much more discussion about the role of adulthood, equal rights and people with significant disabilities.

I hope this research will generate discussion and thought about the constructs of adulthood and disability. Parents play a very intricate role in the transition of their children to adulthood. It is important that their views be understood and respected. More discourse and research is needed on the existential dilemma of providing people with significant needs with equal rights and access to the traditional roles of adulthood, while ensuring their safety.
REFERENCES


Brotherson, M., Berdine, W., Sartini, V. Transition to adult services: Support for ongoing parent participation. Remedial and Special Education 14, 4-51.


Grenot-Scheyer, M. (1994). The nature of interactions between students with severe disabilities and their friends and acquaintances without disabilities. Journal of the Association for Persons with Severe Handicaps, 19, 253-262


122


124
McCoy, M. J. (1993). A comparison of Havinhurst’s adult social roles and
developmental events by gender, age and socioeconomic status levels. (Doctoral
dissertation, University of South Florida, 1993). Dissertation Abstracts International,
54, 4333A

Years, 10, 14-19.


Meyer L. H., Hyun-Sook, P., Grenot-Scheyer, M., Schwartz, I. S., Harry, B.
Brookes.

Macro-micro connection in the pathways to adulthood (Vol. 6). Greenwich, CT: Jai
Press Inc.

Michael, D. (1965). The next generation: The prospects ahead for youth of

Modell John, (1989). Into one’s own: From youth to adulthood in the United

friendship. Mental Retardation 37, p221-231.


128


Toronto: National Institute on Mental Retardation.


APPENDICIES
APENDIX A

CATEGORIES

Autonomy and Mutuality

1. A change to a more mutual relationship occurred with the participant and his or her parents as the participants reached adulthood.

A change to a more mutual relationship did not occur with the participant and his or her parents as the participants reached adulthood.

2. When asked to describe an ideal relationship with their adult son or daughter with a disability, participants described a continuation of the current relationship.

Participants found an ideal adult relationship too difficult to envision.

Category I

When asked to identify barriers that might prevent participants from achieving an ideal relationship with their adult son or daughter with a disability participants described personal characteristics of their son or daughter's disability such as communication, self-care or the presence of inappropriate behavior.

Category II

When asked to identify barriers that might prevent participants from achieving an ideal relationship with their adult son or daughter with a disability participant envisioned no barriers to an ideal relationship because he already has the ideal.

Category III

When asked to identify barriers that might prevent participants from achieving an ideal relationship with their adult son or daughter with a disability participant's cited
external barriers such as an outside agency or x husband intervening and taking away child/young adult.

Employment and Leisure Time

1. Participants described the ideal employment situation for their son or daughter with a disability as working either part time or full time in the community with supports.

Participants described the ideal employment situation for their son or daughter with a disability as working in a sheltered workshop.

2. Participants would envision college, more work hours and a more career oriented future for their son or daughter if he/she did not have a disability.

Category II

Participants envisioned no difference in the ideal employment situation for their son or daughter with a disability if that same son or daughter did not have a disability.

Category II

Participants stated if their son or daughter did not have a disability the participant would have less control or their son or daughters future including aspects of employment and the person with a disability would have more control over their own future.

Participants envision their son or daughter with a disability going out into the

136
community and engaging in enjoyable leisure activities.

Residential

1. When asked to envision an ideal living arrangement for their son or daughter with a disability, participants described a segregated setting with other individuals with disabilities. Participants described their son or daughter living with them when asked to describe an ideal adult residential setting for their son or daughter with a disability.

Category I

2. Participants would expect their adult son or daughter to be living in their own home, require no supervision and be self-supporting if he/she did not have a disability.

Category II

Participants' vision of an ideal residential setting for their son or daughter with a disability did not differ because of their son or daughter's disability.

3. Participants would like to see a wide variety of residential options available for people with disabilities.

Voting

1. Participants would like for their son or daughter with a disability to vote.

Participants do not envision their son or daughter with a disability voting because he/she is not able to understand the process.
2. Participants described their son or daughter with a disability as being able to vote independently with appropriate supports such as training on the process and pictures on the voting ballot.

Participants described their son or daughter with a disability as needing someone to assist them in the voting process either by physically voting for the person with a disability or by providing hand over hand assistance.

3. A) Participants did not find anything about individuals with disabilities accessing their right to vote that concerned them.

B) Participants were concerned about people with disabilities being fairly informed about all candidates without being unduly swayed.

4. Participants would register their son or daughter with a disability under their political party.

Participants already have knowledge of their son or daughter with a disability’s preference for a political party either because of general knowledge of their son or daughter’s likes and dislikes or because of previous frequent discussions about political issues.

Social Relationships

1. A). When asked to describe the ideal adult social life for their son or daughter with a disability, participants described their son or daughter with a disability having the supports to go out with friends and have fun.
B). When asked to describe the ideal social life for their son or daughter with a disability, participants did not want their daughter with a disability socializing.

2.A). Participants do not have a different vision of an ideal social life for their son or daughter with a disability with the exception that their son or daughter with a disability needs more supports to achieve the ideal social life.

3. B) Participant has a different vision of an ideal social life for their son or daughter with a disability. If their son or daughter did not have a disability participants would allow their daughter to socialize at the age of 15.

4. ) Participants envision their adult son or daughter with a disability needing a personal care assistant, companion or other typically developing adult to monitor them during socializing activities.

5. Participants would question the motives of a typically developing peer who wanted to date their son or daughter with a disability.

6. A) Participants believe that individuals with disabilities in general should have the option to date.

B). Participants do not believe that individuals with low functioning mental disabilities should be allowed to date.

Marriage

1. Participants would allow their son or daughter with a disability to get married.

Participants would not allow their son or daughter with a disability to get married.
2. Participants would be concerned about the motives of a person without a disability that wanted to marry their son or daughter with a disability. Participants would be concerned about their son or daughter with a disability’s ability to care for a spouse with a more severe disability.

Sexual Consent

1. Participants would envision a mutually gratifying relationship that included consensual sex for their adult son or daughter if he/she did not have a disability.

2. Participants had difficulty envisioning consensual sex as part of their adolescent/young adult family member with a disability’s future as an adult.

3. A Participants believed that their family member with a disability had shown or would soon show the ability to enjoy sensual/sexual pleasure.

B Participants did not believe that their family member with a disability could enjoy sexual pleasure.

4. A. Participants believed their son or daughter with a disability would enjoy the sex act but objected to their son or daughter having sex because they might hurt someone, or be hurt during the sex act, or would not understand the sex act.

B. Participants felt that their family members cognitive disability would prevent their son/daughter from being able to consent to the sex act.

C) Participants felt that their son/daughter would have the ability to consent to the sex act as an adult.
5. Participants stated they would feel uncomfortable with and question the motives of a person with out a disability who wished to have sexual relations with their son or daughter with a disability.
APPENDIX B

Interview Questions

Directions: The purpose of this interview is to gather information about your perception of an ideal adult life for your son or daughter with a disability. Please view the interview questions before your interview. Some of the areas typically considered in adulthood such as voting, marriage, autonomy, and consensual sex, might not be areas that you have previously considered for your son or daughter with a disability. Please consider carefully how your child with a disability could successfully access these areas of adulthood. I respectfully request that even if you would not like your son or daughter with a disability to access a specific area of adulthood that you consider assisting in creating a vision of how other individuals with similar disabilities might successfully access these areas of adulthood. I respectfully request that even if you would not like your son or daughter with a disability to access a specific area of adulthood that you consider assisting in creating a vision of how other individuals with similar disabilities might successfully access each area of adulthood. Your opinions and your desire not to have your son or daughter access a specific area will be noted. Please feel free to refuse to answer any question that causes you to feel uncomfortable. All interview are confidential.

Interview 1

Autonomy and Mutuality of Relationship

1. In many families, there is a change in the mutuality of relationships as children grow into adulthood. This change usually consists of moving toward a more equal
relationship. Can you describe how or if this change happened in your relationship with your parents?

(PROBE) Has a change toward a mutual relationship occurred with any non-disabled children? Please describe the change and how it occurred in each relationship in as much detail as possible.

2. How do you envision your relationship with your son or daughter with a disability changing as he or she matures into adulthood?

3. Please describe in as much detail as possible your vision of an ideal adult relationship between you and your son or daughter with the disability. Please include what type of outside support, if any would be necessary to maintain this ideal relationship.

4. Can you identify any barriers that might prevent you from achieving this type of relationship with your child, as he or she becomes an adult? If so, please describe in as much detail as possible.

5. What role if any does your child’s disability play in this change in relationship?

(PROBE) If you have any other children without disabilities, is there a difference in the way that relationship changed as your child without a disability matured into adulthood?

Employment and Leisure Time

1. Please describe the ideal employment situation for your son or daughter with a disability? Include the type of supports that would make this dream situation possible?
APPENDIX B (continued)

2. How does this differ from a vision you would have for your non-disabled children?

3. What types of activities does your son or daughter with a disability enjoy?

4. How would you like to see your son or daughter with a disability spend his/her time?

5. With whom would you like to see your son or daughter spend his/her time?

6. Please envision and describe an ideal week for your son or daughter with a disability. Include ideal day and nighttime activities and approximate desired frequency of each activity?

7. What type of clubs, organizations, or churches would you like for your son or daughter to be a member? Please describe the types of supports that your son or daughter would need to participate in these organizations.

8. How does this vision differ from a vision you would have if your son/daughter did not have a disability.

9. Does this vision differ from what you would like to see available for people with disabilities in general?

Residential

1. Please describe the ideal living arrangement for your son or daughter with a disability. Please include the type of supports and safeguards that would be necessary to maintain this arrangement.

2. How is your vision of an ideal living arrangement for your son or daughter with a disability different from a vision of an ideal life for your son or daughter is she/he did not have a disability?
APPENDIX B (continued)

3. What type of residential options should be available for adults with disabilities and their families?

4. Where do you think your son or daughter with a disability would like to live? Please describe the type of supports that would be necessary to make this happen and any concerns you may have.

Voting

1. How do you feel about your son or daughter with a disability accessing their right to vote?

(PROBE) How do you feel about your non-disabled children (if applicable) accessing their right to vote?

(PROBE) Is there a difference between your feelings about voting for your children with and without disabilities? If yes, please describe the nature and the reasons for this difference.

2. Try to visualize your son or daughter with a disability successfully voting and describe this image in as much detail as possible. Please include such details as who would assist your son or daughter with the voting process, what type of assistance would be needed, and what type of safeguards and supports you would like to see provided.

3. Is there anything about individuals with disabilities accessing their right to vote that concerns you? Please explain.

4. Please describe in as much detail as possible how you would best assist your son or daughter with a disability in choosing a political party under which to register.
APPENDIX B (continued)

5. How would you determine for whom your son or daughter wishes to vote?

6. If someone other than yourself assists your son or daughter with a disability with voting please discuss any concerns you would have about your son or daughter being influenced in the voting process by the individual assisting him or her. Please include suggested safeguards to prevent this from happening.

7. Is there anything about voting we forgot to ask that you would like to discuss?

Interview II

Social Relationships

1. Describe the ideal social life for your son or daughter with a disability.

2. Does this description differ from what you would envision as an ideal social life for a non-disabled child/young adult?

3. Does this description differ from what you would like to see available for individuals with disabilities in general?

4. Describe the type of people you would like for your young adult with a disability to have as friends.

5. Does this differ from how you would feel if your son or daughter did not have a disability?

6. Describe the type of people with whom you do not want your son or daughter with a disability to associate.

7. Does this differ from how you would feel if your son or daughter did not have a disability?
8. What types of safeguards need to be in effect to monitor your young adult’s social interactions?

9. What concerns you about your son or daughter with a disability having friends that have a milder disability, similar disability, more significant disability, or no disability?

10. How do you feel about your son or daughter with a disability dating?

11. Does this differ from how you would feel if your son or daughter did not have a disability?

12. Does this differ from how you would feel if your son or daughter did not have a disability?

13. Is this how you feel about dating for individuals with disabilities in general?

(PROBE) What concerns you about your son or daughter with a disability dating people with a milder disability, similar disability, more significant disability or no disability?

14. What safeguards would need to be in place for you to feel comfortable with your son or daughter with a disability dating?

Marriage

1. Would you consider allowing you son or daughter with a disability to marry?

2. Please discuss your feelings on the issue of marriage for individuals with significant disabilities. Please include such issues as effects on guardianship, disability income, and safety issues.

3. How would you know if your son/daughter wanted to get married?
APPENDIX B (continued)

4. Please describe in as much detail as possible what an ideal marriage would look like for your adult son or daughter with a disability. If you are strongly opposed to your son or daughter with a disability ever marrying, please discuss your reasons why and consider describing what an ideal marriage would look like for a person with a disability similar to your son or daughter's that is not related to you. Include where they would live, what type of supports would be necessary, qualities of an ideal spouse, and type of activities you envision them enjoying together.

5. Would you feel more comfortable if the spouse of your son or daughter with a disability had a similar disability, a milder disability, a more severe disability, or did not have a disability? Please explain in as much detail as possible the reasons for your answer.

6. What type of safeguards should be in place to ensure your son or daughter's safety from exploitation or abuse in a marriage? Explain in as much detail as possible.

7. What concerns would you have about your son or daughter with a disability getting married? What role does his/her disability play in your concerns?

8. How would you know if your son/daughter wished to get divorced?

9. Would you prefer to see your son or daughter with a disability enjoy the companionship of a loved one without the legal entanglement of marriage? Please explain.

**Sexual Consent**

1. Has your son or daughter shown any indication that he or she has the ability to enjoy sensual pleasures?
APPENDIX B (continued)

2. If your son or daughter did not have a disability would a mutually gratifying relationship that included consensual sex be something you would envision for his or her future as adult?

3. Please describe the conditions under which you would be comfortable with your adult son or daughter having consensual sex if he or she did not have a disability.

4. Please describe the conditions under which you would be comfortable with your adult son or daughter with a disability having consensual sex.

5. What role does your son or daughter's disability play in your comfort level with issues pertaining to consensual sex?

6. What concerns you about your son or daughter with a disability having consensual sex?

7. Please discuss your concerns on the following issues:
   - AIDS, sexually transmitted diseases, and pregnancy.

8. Would you feel more comfortable if your adult son or daughter with a disability’s sexual partner had a more significant disability, a milder disability, a similar disability, or no disability? Please describe the reasons for your answer in his much detail as possible.

9. What type of safeguards would need to be in effect to ensure that your son or daughter with a disability was consenting to the sex act?

10. Can you imagine a situation in which your son or daughter could have consensual sex with a paid staff member?

11. Would it make any difference if the paid staff member were off duty?
APPENDIX B (continued)

12. What type of relationship would your son or daughter with a disability need to have before you would feel comfortable with him/her having sex?

13. What type of safeguards would you like to see in place to protect your son or daughter from sexual coercion?

14. Was there anything about sexual consent that was not discussed that you would like to discuss?

Health

1. Many people need mental or spiritual counseling in their lifetime. Some examples of issues that may cause a need for counseling are depression, anxiety, marital problems, and loss of a loved one (grievance counseling). Do you envision your son or daughter having any issue for which he/she could benefit from counseling?

2. How would you know if your son/daughter were experiencing a mental health issue?

3. What type of special training would a mental health professional need to adequately meet your son/daughter's needs?

4. What type of mental health training would staff working with your son/daughter need to adequately meet his/her mental health needs?

5. What type of additional training would clergy need in order to adequately assist your son/daughter with a counseling need?

6. How is the general condition of your son or daughter's physical health?

(PROBE) Has your daughter visited a gynecologist?
7. Do you envision your son or daughter visiting a doctor or dentist on a regular basis as an adult?

8. What type of supports does your son or daughter need while visiting a physician?
Appendix C

USF Institutional Review Board-Behavioral/Social
Consent to Participate in a Research Study

Title of Study: Case Studies of Community Inclusion
Principal Investigator Name: Glen Dunlap  Telephone #: 974-6111

Department: Child and Family Studies  Mail-point
MHC2113A  Tel #: 974-6111

Purpose of Study
The purpose of this research study is to gather information about your perception of
due a quality adult life for your son or daughter with a disability. Additionally we would like
your perception of what supports your son or daughter would need to successfully
negotiate the following traditional markers of adulthood: voting, marriage, sexual
consent, employment, and residential change. You are being asked to participate in
this study because you are the parent of a person with a disability.

Duration and Location of the Study

Your participation in this study will last for approximately 8 weeks and consist of two
face to face interviews approximately 2 hours in length and one follow-up telephone
call, approximately 15 min in length. The interviews will take place at your home or
other mutually agreed upon meeting place (e.g., local restaurant) The number of
people who might take part in this study is 10.

Procedures

You understand that during this study, the following procedures will occur: You will be
interviewed. You will receive a copy of the interview questions prior to the interview.
You will be asked to give your consent to audio taping of the interviews. You may
refuse the audio taping of the interviews without any consequences. The audio taping
is to insure accuracy of note taking and final report. Please allow at least 2 hours for
each interview.

You may refuse to answer any question that causes you to feel uncomfortable without
any consequences. Our interest is in your perception of an ideal quality adult life for
your son or daughter with a disability.

Potential Risks
You understand that there are no anticipated risks associated with the study from your
participation in this study.

APPROVED THRU
JAN 2000

152
APPENDIX C (continued)

Benefits
- You understand that there will be no direct benefits of your participation in this study, but there may be possible benefits to others that may include improved adult services and supports for individuals with disabilities living in the community.

Confidentiality
The confidentiality of the records shall be maintained unless otherwise required by law. Confidentiality of records will be maintained by FMH/USF Center for Autism and Related Disabilities. Interview notes and tapes will be assigned a number or color and names will not be used. Limits to strict confidentiality include. Authorized research investigators, agents of the Department of Health and Human Services and the USF Institutional Review Board may inspect the records from this research project. The results of this study may be published, but they will not include your name, your son or daughter’s name, nor any other information that may identify you or your son or daughter.

University of South Florida Injury Statement
In the event that you sustain an injury or illness as a result of participating in this research, please be aware that medical treatment for the injuries or illness may not be available from the University of South Florida (USF). USF does not maintain an emergency medical department nor does it provide medical treatment in all disciplines of medicine. If you become ill or sustain an injury which you believe is related to participation in this research, immediately contact one of the persons listed on page 1 of this form, and if emergency care is needed seek emergency attention from your nearest local hospital.

Compensation for Participation
- You will not be paid for participation in this study.

Volunteering to Be Part of this Research Study
You understand that participation in this study is voluntary. You understand that you may withdraw from the study at any time without penalty or loss of services, to which you are otherwise entitled. You also understand that the investigator has the right to remove you from the study at any time.
Questions and Contacts
If you have any questions about this research study, you may contact Glen Dunlap 974-6111 or Barbara Jordan 974-6441. If you have any questions about your rights as a person taking part in a research study, you may contact a member of the Division of Compliance Services at the University of South Florida at (813) 974-5638.

Your Consent—By signing this form I agree that:

- I have fully read or have had read and explained to me in my native language this informed consent form describing a research project.

- I have had the opportunity to question one of the persons in charge of this research and have received satisfactory answers.

- I understand that I am being asked to participate in research. I understand the risks and benefits, and I freely give my consent to participate in the research project outlined in this form, under the conditions indicated in it.

- I have been given a signed copy of this informed consent form, which is mine to keep.

Signature of Participant  Printed Name of Participant  Date

Signature of Witness  Printed Name of Witness  Date

Investigator Statement
I have carefully explained to the subject the nature of the above protocol. I hereby certify that to the best of my knowledge the subject signing this consent form understands the nature, demands, risks and benefits involved in participating in this study.

Signature of Investigator  Printed Name of Investigator  Date

Signature of Witness  Printed Name of Witness  Date

Institutional Approval of Study and Informed Consent
This research project/study and informed consent form were reviewed and approved by the University of South Florida Institutional Review Board for the protection of human subjects. This approval is valid until the date provided below. The board may be contacted at (813) 974-5638.

APPROVED IIRU
JAN 2000
APPENDIX D

October 9, 2001

Glen Dunlap, Ph.D.
Child & Family Studies
MHC 2113A

Dear Dr. Dunlap:

Your Final Report for the protocol entitled, “Case Studies on Community Inclusion”, IRB # 98.400 has been reviewed and accepted by the Institutional Review Board 02 under expedited review. This action will be reported at the next convened IRB 02 meeting on October 19, 2001.

As a reminder, if the sponsor and/or investigator are still analyzing the data, it is your responsibility as Principal Investigator to report the final results of the study, when available, to the IRB committee.

If you have any questions regarding this matter, please do not hesitate to call one of the IRB staff of the Division of Research Compliance at 974-5638.

Sincerely,

Louis Penner, Ph.D., Chairperson
USF Institutional Review Board 02

LP: lb

cc: LAO
APPENDIX D (continued)

Institutional Review Board
University of South Florida Social and Behavioral Studies Assurance No. MRA 1284-02XM
Research Progress Report

Type all answers
NOT TO BE USED TO CHANGE PRINCIPAL INVESTIGATOR.

INB File No. Continuing Review Final Report
1. General Information
   Principal Investigator: Glen Dunlap
   Address: Child and Family Studies, DARES, MLC2, L3A, RMII
   Dept/College: Child and Family Box No. MLC2, Tel/Fax: 974-6111
   Studies
   Co-Investigator(s): Barbara Jordan White

2. Protocol Information
   Title of Project: Case Studies on Community Inclusion
   Sponsor/Grant agency: CANID
   Protocol No/Identifier: INB#98.100

3. Continuing/Final Report Information
   No. of subjects initiated since last review: Yes
   Total no. initiated into this project: 
   Are you continuing to recruit new subjects? 
   No 
   If yes, attach most current informed consent(s).
   How many recruited subjects have withdrawn/dropped? 
   Explain why: No subjects dropped out.
   Summarize the research hypothesis or purpose of this project and procedures:
   The purpose of this project was to gather information about the quality of the life of individuals with
   disabilities living in the community. Information was also gathered on parents' perception of their son or
daughter's ability to access the traditional markers of adulthood such as voting, marriage, and
employment.
   Summarize ALL of the data derived in this project from inception to date and/or attach abstracts,
reprints, progress reports, pertinent to this study.
   See attached reports.
   Were benefits of this research expected? Were they realized? Explain.
   The results of this study were used and other data to assist in the creation of a publication describing
   the current status of adults with autism. This publication is being used to educate policy makers.
   Does the present data justify continuation of the study? Explain.
   The study is complete
   Does the risk/benefit ratio justify continuation of the study? Explain.
   There were no risks associated with this study
   At this time, are you revising the Informed Consent to include any significant new findings which
may relate to the subject's willingness to continue participation?
   Yes 
   No 
   If yes, please attach a copy of the revised consent form and highlight all revisions.

156
APPENDIX D (continued)

Adults with Autism in Supported Living in Florida:
In depth Interviews and Observations with 4 Individuals

Barbara Jordan
University of South Florida

Executive Summary

In the spring and summer of 1999, the Center for Autism and Related Disabilities (CARD) conducted a series of interviews and observations to determine the status of individuals with autism and related disabilities living in independent supported living. The purpose was to obtain a rich understanding of the lives and the circumstances affecting a small number of individuals. The study was intended to complement and enrich parallel efforts being undertaken by CARD to establish an improved understanding of the status of adults with autism and related disabilities in Florida.

ARC’s and supported living agencies within CARD’s catchment area rendered assistance in identifying participants. Although ARC’s were providing supports for individuals with a variety of types and levels of disability, most individuals with autism for whom they provided services resided in group homes or lived with their families. Additionally, the supported living agencies we contacted reported serving a very limited number of people with autism. Parent to Parent identified one participant, CARD identified one participant, a supported living agency identified one participant, and a participant suggested her friend also participate.

Of the four adults with autism or related disabilities who participated, three were living in supported independent living but not working and one was in supported employment but living at home with her family. Two participants had autism and a severe cognitive impairment, one participant had severe visual impairment and moderate cognitive impairment, and one participant had a severe hearing impairment and moderate cognitive impairment.

The three participants who were living in apartments with supports were interviewed four times and observed three times with a two week interval in between visits. The families of the participants living in supported independent living were interviewed 4 times with a three week interval between each interview. The participant living with her family was interviewed three times and observed in the community once; her family was interviewed three times. The average length of interviews was two hours with a range of four to one hours and the average length of the observations was one hour.

All participants were interviewed in person by the same interviewer. All participants were asked the same questions in the same order. All interviews were taped and summarized. The summaries and tapes were reviewed to detect themes and patterns.
Participants were asked to comment on the themes and patterns revealed by the data analysis. No changes were noted, however not all participants have responded. These interviews/observations yielded the following results:

**Independent supported living was preferred to living in a group home or intermediate care center.** All participants cited increased personal freedom, increased ability to make choices (e.g., when to get up, when to go to bed, when to eat, what to eat), and increased opportunities to go into the community as reasons for preferring to live in their own apartments/houses. All participants living in their own homes had visited a group home setting for at least two days before moving into an apartment/house.

**Agency timelines were described as insensitive to family needs.** All families mentioned the inconvenience to their families of trying to work around agency-imposed timelines. The three families with family members residing in apartments with supports were informed of the necessity to move their family member in a short amount of time. This short notice caused families to have to prepare for their family member’s move into the community in a hurried fashion. One family was called after waiting years for service and told that there was an opening for her son and if she did not act quickly it would be 10 years before she would receive any further offers of assistance. Another family received repeated notices that their son could move to an apartment then a few days later they were informed that there was no money to facilitate a move. Another family was promised that her daughter would receive in-home training in life skills before she moved into an apartment. This training never took place. This participant with a disability commented that she wished she had more time to prepare for the move both physically and emotionally. These agency-imposed timelines left no time for families to emotionally prepare themselves or their family member for the move.

**Agency staff lacked knowledge about the role of guardian advocates.** Some agency staff seemed to place themselves in the role of “protecting the individual with a disability from the parent.” One support caseworker disclosed that she did not invite the parents to the monthly support meetings because she felt that they unduly influenced their daughter’s decisions. When asked, the participant with a disability stated that she would like to have her parents present for the monthly support meetings but was afraid to push the subject because she did not want to hurt her caseworker’s feelings. Her parents were her guardian advocate.

**There was concern about a lack of financial disclosure.** All families were uncomfortable with the agencies’ refusal to disclose how much money they were receiving for the support of their son or daughter and how that money was distributed. When one family did receive some disclosure they found several discrepancies.

**Lack of safeguards and concerns regarding abuse and neglect.** The lack of systematic safeguards to prevent abuse/neglect was an overriding concern of all parents. All parents with individuals residing in supported living mentioned at least one example of abuse/potential abuse and neglect. Parents did not believe the system had sufficient
mechanisms to provide their family members with protection. This was an overall concern of all parents. During the 6 month period of our interviews, one family discovered instances of abuse, and filed charges with local police for unlawful detention.

When the individual with a disability is nonverbal, there is no adequate way to check on the personal care attendant to see if he or she is acting appropriately. The consideration of respecting the privacy of the individuals with a disability, and the roommate/personal care attendant without a disability, is stronger in a supported independent living situation. The abuse one roommate received was extreme and went undetected for months. Additionally, when staff members suspected the abuse, no one reported it to the authorities or parents.

**Productive use of time.** All four families mentioned a concern about use of time. Families were concerned with boredom and lack of opportunity to go out. No individual with a disability was gainfully employed. The one participant who was gainfully employed in the community lost her job a few days before the first interview. The two individuals with disabilities who were capable of independent speech and both stated that they did not believe that an interesting and enjoyable job would be available for them. Those parents stated that they were especially interested in having their family member work, but that the supports were not available. All individuals were in need of assistance to maneuver in the community. This caused added financial concerns if a person with a disability wished to go to an event with a cover charge or ticket price. Generic yearlong passes to amusement parks museums etc. are not available for “personal assistants,” causing added barriers and expense for individuals with disabilities who wish to frequent such establishments. Outings for individuals without live in personal care assistants occurred during regular business hours and many social events occur during evening hours. Outings seemed to coincide with the interest of the personal care assistant.

**Relationships.** The interviews and observations were designed to explore the presence and development of relationships with disabled and non-disabled peers as well as possible changes in relationships with family members.

**Friendship development with peers with a disability.** All participants except the participant living in her family’s home had regular contact with disabled peers. The two participants with severe cognitive functioning did not show an interest in interacting with their peers with disabilities. Both staff and family discourage one participant from interacting with her disabled peers. All participants showed an interest in interacting with non-disabled peers.

**Friendship development with non-disabled peers.** All families expressed an interest in then family member with a disability having non-disabled friends. Although all participants went out into the community on a regular basis, no individual with a disability had such a friend. Most community outings consisted of more than one person with a disability being assisted by a staff person. This was not the case when family members went out with participants. How often a participant went out into the
APPENDIX D (continued)

community and the frequency of conversations with community members seemed to
concur with the skill and comfort level of the personal care assistant. Neighbors seemed
to have an interest in the health and safety of participants, yet no one visited on a regular
basis just to socialize. The skill level needed in the planning and carryout of facilitating
interactions between non-disabled peers is complex and no staff member, agency owner,
or family member had received training in this area.

Relationships with family members: All families wanted their grown children with
disabilities to have a life of their own. All families of participants living in supported
independent living reported having more personal freedom in their own lives after their
family member with a disability moved. All families were very involved in the life of
their family member with a disability. All families were frequently called upon to render
assistance to their family member with a disability either through working with the
support coordinator to acquire better services or by rendering the needed service
themselves.

Relationships with staff: All participants living in independent support living had at least
one staff member who introduced them to their friends, or spent personal time with them.
ABOUT THE AUTHOR

The Author received a Bachelor of Arts degree from the University of South Florida, College of Fine Arts, and Department of Art in 1984. She continued her educational studies and received a Master of Science degree in art education in 1990. After teaching for 5 years, she entered the doctoral program in 1995.

Currently Barbara is employed by the state of Florida’s Department of Education as an independent educational mediator. She mediates disputes between parents and school districts regarding issues concerning children with special needs.

While working on her doctoral degree, she was employed as an intern supervisor and research assistant. Additional, she ran a support coordination business, Future Solutions Now, which provided people with developmental disabilities and their families with comprehensive supports.