The Meaning Elderly Parents of Dependent Adult Children with Developmental Disabilities Give to Their Long-Term Parenting

by

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As Always for James Wesley Ayers

and

Johana Reabekah Ayers

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ABSTRACT

TITLE: THE MEANINGS ELDERLY PARENTS OF DEPENDENT ADULT CHILDREN WITH DEVELOPMENTAL DISABILITIES GIVE TO THEIR LONG-TERM PARENTING EXPERIENCES

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The purpose of this study was to describe: The meanings elderly parents attribute to their life-long parenting of and caregiving to their dependent adult children; how those meanings have changed over time; current parenting and caregiving concerns identified by these parents; and how these concerns impact the day to day life of these parents.

A qualitative design was chosen and intensive interviewing as described by Lofland and Lofland (1984) was used to collect data. The sample consisted of 18 parents, age 60 years and over, who continue to parent their dependent adult children with developmental disabilities. The 18 parents represented 12 families. Parents labeled what they were doing as parenting and objected to the labels caregiver and provider to describe their role. Themes identified from the units "meaning" and "relationships" were the meaning of being a parent of a dependent adult child; the parents' perceptions of the meaning of being a dependent adult child; the relationship between parent and dependent adult child; and the parents' perceptions of the relationship between dependent adult children and their other children. From these themes the theme of lack of developmental closure was synthesized. An additional unit was developed that of "sources of support." In comparing formal and informal sources of support, parents believed that informal sources of support were more available, more consistent, and more trustworthy than formal sources of support. To determine scientific rigor criteria for transferability, credibility, and adequacy were used. Results are discussed and recommendations for nursing practice, policy, and research are given.

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CHAPTER I

PARENTS OF DEPENDENT ADULT CHILDREN WITH DEVELOPMENTAL DISABILITIES

Nurses have provided services to developmentally disabled individuals and their families in many capacities. For example, nurses have provided care to developmentally disabled children who are residents in institutions and long term care hospitals. Nurses have also provided services to families with developmentally disabled members through such agencies as public and private schools, public health departments, acute care hospitals, and health and habilitation clinics (Nehring, 1991). Nurses and other health professionals now are beginning to provide services to aging families who continue to care for dependent adult children with developmental disabilities (hereafter referred to as dependent adult children).

Individuals who are developmentally disabled have severe, chronic disabilities that are attributable to mental or physical impairments, or to combinations of mental and physical impairments that manifest prior to age 22 (Developmental Disability Act of 1984). Developmental disabilities result in functional limitations in at least three of the following areas: Self-care, learning, mobility, capacity of independent living, self-sufficiency, receptive and expressive language, and self-direction. Conditions conventionally included under the umbrella definition of developmental disabilities include cerebral palsy, autism, mental retardation, and epilepsy. The needs of developmentally disabled individuals include lifelong, individually planned and coordinated, interdisciplinary services (Stone & Newcomer, 1985).

Historical Background

Research regarding children with developmental disabilities living with their families began in the 1950s. In 1956 Schonell and Watts reported that the burden of a mentally retarded child on the family was great enough to disrupt the normal family routine and was perceived as a family problem. Parents of young children with developmental disabilities reported experiencing "a great deal of expense, (mainly medical), in trying to find amelioration for the child's condition" (Schonell & Watts, 1956, p. 213). Parents were encouraged strongly to institutionalize their children and it was believed that parents who did not institutionalize their child vacillated about this decision for years (Caldwell & Guze, 1960). In the 1950s and 1960s state institutions (training schools) for developmentally disabled children had long waiting lists and many did not accept children prior to five years of age. Educational and support/ service programs in communities for families with developmentally disabled children, both under and over age five years, were limited. Parents who continued to care for their developmentally disabled children at home had to search constantly, usually without success, for services; they often had to develop small specialized programs to meet the needs of their children.

In Schonell and Watts' (1956) study mothers reported a lack of educational and occupational programs for their children, a need for help in providing care to their child, a lack of knowledge and confusion regarding the causes of their child's disability, and a belief that their child would have a shortened life span while at the same time being concerned about that the child would out-live his or her parents.

Mothers also perceived that there was an increasing understanding of the public towards children with developmental disabilities. Schonell and Watts (1956) further reported that 54% (N=27) of the study population responded that the most pressing problem was concern for the child's future if one or both parents died prior to the child. Many of these parents believed that their other children would not care for the disabled sibling or that the provision of care would place an unfair burden on their other children.

Current Background and Significance

The number of developmentally disabled persons over age 55 years in the United States is approximately 196,000 (Jacobson, Sutton, & Janicki, 1985). However, it is believed that under-reporting and under-use of social services by families of older developmentally disabled individuals result in low estimates. Little is known about the prevalence of specific developmental disabilities among adults; for example, based upon current literature review there are no studies of prevalence after age 20 years for autism and after age 50 years for cerebral palsy and epilepsy (Lubin & Kiely, 1985).

Although developmentally disabled people have higher early mortality rates than do the general population, the differences between the rates have been decreasing in recent years (Lubin & Kiely, 1985). In 1983 Carter and Jancar reported that mortality trends of the mentally disabled reflected those trends of the general population. Lubin and Kiely (1985) speculate that the overall prevalence of developmental disabilities is increasing and that the increase is related to decreased neonatal mortality, increased life expectancy, and improved health care and social services. Jacobson, Sutton, and Janicki (1985) predict that because of reduced early mortality, the number of older developmentally disabled individuals will increase by 39% from 1980 levels in the year 2000 and by 87% in the year 2020.

Older adults with developmental disabilities function within a wide range of ability from complete independence to complete dependence when managing self care needs. Dependent adults generally reside with a family member or in state institutions, long term care facilities, group homes, or foster care. The number of people residing in state institutions in the last 10 years has decreased because of court ordered deinstitutionalization. In one study the percentage of dependent adult children over 55 years of age residing with their families was 22% in California, 13% in Massachusetts, and 10% in New York (Jacobson, Sutton, & Janicki, 1985). Although knowledge of dependent adults is limited, even less is known about parents who provide care to these individuals.

The phenomenon of caregiving by elderly parents to dependent adult children may be significantly different from other situations involving elderly caregivers. This difference may be related directly to the fact that for elderly parents caregiving is inextricably linked to their parenting roles. Parents of dependent adult children have been described by Engelhardt, Brubaker, and Lutzer (1988) as "individuals (who) not only face the normative transition of entering the 'old-old' portion of their lives with the accompanying health difficulties and increased need for assistance, but they are also confronted with the additional strain of caring for their adult dependent" (p.

191). Elderly parents must contend with the probability that the recipient of care will outlive them. This phenomenon is the reverse of the usual caregiving situation in which the caregiver is expected to outlive the recipient of care. Furthermore, elderly parents may have caregiving responsibilities in addition to dependent adult children. The most frequent caregiver to an elder individual is a spouse. If both parents reside together and one is dependent, one parent could be providing care to both a spouse and a dependent adult child. One study documents that 20% of elderly parents of dependent adult children were also providing care to a second family member (Seltzer, 1991a).

In 1991 a pilot study of elderly parents of dependent adult children was undertaken in the Pacific Northwest (Schaller-Ayers). Although the participants were not given the opportunity to confirm the findings,, and caution must be used in interpreting the data, trends from this small data set did emerge. Parental caregiving to a dependent adult child is a complex phenomenon which seems to be evidenced by parental uncertainty, certainty and concern in the present and future for both themselves and their dependent adult child. Concerns reported were related to health of both parent and child, future residence for their dependent adult child, finding appropriate adult activities, legislative changes, financial status, safety, and manipulation of and reaction of others to their dependent adult child. Associated with their parenting/caregiving role, parents reported feelings including love, fear, worry, confinement, frustration, and isolation. Overall, the seven parents interviewed believed that parenting and caregiving to a dependent adult child was a complex process that had "mind-boggling ramifications" (parent, personal interview), and which required one to "hang tough" (parent, personal interview) and prepare for the impact of potential changes.

Parents who were in the earlier studies of the 1950s and 1960s are now approaching or are over 65 years of age, their children are in their 30s and over. Many of these parents have been actively parenting/caregiving for three to five decades. In contrast, the average duration of caregiving for elderly relatives is five years (Stone, Cafferata, & Sangl, 1987). Because of a long history of preferring to care for their child, and a desire to delay or avoid out-of-home placement for their child, these parents will continue to care for their child for many more years.

Purpose of Study

Understanding what it means to be an elderly parent of a dependent adult child, and having an awareness of the parents' concerns and the contexts of their life experiences would assist nurses in understanding the needs and lives of elderly parents. With understanding and a greater awareness of life experiences, nurses should be able to design interventions which can be tested for effectiveness and efficacy. This study was proposed to be the first phase of a program of study to empirically describe the life experiences of elderly parents of dependent adult children. It is hoped that this phase will serve as a foundation for future studies that may lead to the development of new theories and testing of extant theory. The goal for this program of study is to create a greater understanding among nurses and others about the needs and preferences of elderly parental caregivers, to promote and protect health of the elderly parents and dependent adult children, and to identify and test strategies to assist elderly parental caregivers. This goal is consistent with the standards of nursing practice in mental retardation and developmental disabilities which emphasize the need for nursing research for theory development and practice advancement. Therefore, the purpose of this study was to describe: the meanings elderly parents attribute to their life-long parenting of and caregiving to their dependent adult children; how those meanings have changed over time; current parenting and caregiving concerns identified by these parents; and how these concerns impact the day to day life of these parents.

CHAPTER II

REVIEW OF LITERATURE

The focus of this study was to describe the meaning parents attribute to the life-long caregiving and parenting for a dependent adult child, how they believed that meaning has changed over time, and to describe their concerns and how these concerns impact their day to day lives. The review of literature addresses research that focused on elderly parents of dependent adult children. Because the literature about elderly parents of dependent adult children was limited, literature about elderly parents who care for their mentally ill adult children also was reviewed (e.g., schizophrenia and other chronic mental illnesses [CMI]).

Elderly Parental Caregivers for Dependent Adult Children with Developmental Disabilities

The first article about elderly adult parents of dependent adult children appeared in the literature in 1988. A literature search revealed 27 reports of 15 studies pertaining to elderly parents providing care to a dependent adult child. All the studies reviewed were in the disciplines of social work and psychology, and were primarily done east of the Mississippi River or in the British Isles. For the review of this literature methodologies are presented first followed by a discussion of the themes from the studies.

Methodology

Methodological approaches used in studies of elderly parents of dependent adult children were examined; the review focused on conceptual framework, purpose, design, sample, instruments and analysis. A summary table is presented to facilitate comparison across reports (See Table 1). Conceptual frameworks were not included in the table as all but three reports lacked a stated conceptual framework. Seltzer and Krauss (1989), Heller and Factor (1991), and Brubaker and Brubaker (1993) reported conceptual frameworks. Seltzer and Krauss (1989) developed a conceptual framework borrowing from the research areas of family caregiving and families with young developmentally disabled children. Heller and Factor (1991) tested a theoretical model developed to explain out-of-home placement of younger children. Brubaker and Brubaker (1993) examined parental concerns using the ABCX Model of family stress.

The stated purpose of 21 of the 27 reports was to identify or explore characteristics of elderly parents and their utilization or lack of utilization of services and planning. Six of the reports compared differences between elderly parent caregivers and other caregivers. Three reports sought to identify parental needs in caregiving while one report examined the appropriateness of a model to explain permanency planing. Four reports explored the effect of providing care to dependent adult children on mothers' well-being. One study (Seltzer, G., Begun, Seltzer, M., & Krauss, 1991) sought to identify the effects non handicapped children had on their mothers and their siblings with mental retardation. Only Gold's (1987) study sought to identify the elderly parents' perspective on their own and their dependent child's situation. Nine of the 14 articles had multiple purposes.

All studies were quantitative in nature; although two studies (Gold, 1987;

Table 1

Summary of Research Studies About Elderly Parents of Dependent Developmentally Disabled Adult Children

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Brubaker, Brubaker, 1993, Southwest Ohio	To examine how the stressor of aging influences older families providing care to dependent adult children, specifically financial, residential, social and emotional concerns of caregivers.	Descriptive, exploratory. Statistics: percentages. Survey questionnaires mailed, 388 returned, 75% mothers, 12% fathers, 13% others, mean age 59.6 (range 40-87 yrs.). Dependent adult children: 87% lived at home, 13% lived out of home	Specifics of questionnaire development not reported, 86 items. Of 388 participants, 96 also participated in indepth telephone interview regarding issues related to mailed questionnaire.	Financial Needs: medical care, transportation, respite care, in-home care, equipment needs Residential Concerns: plans for future, adequacy of out-of-home placement, Social and Emotional Concerns: concerns as parents age.
Casterta, Connelly, Lund, Poulton 1987 Salt Lake City, Utah	To examine what special needs exist for elders providing care to disabled adult children. Research questions: To determine need for formal support and how adequate needs are met; what are contributions of health competence and socio-demographic factors to service need fulfillment; are there differences between caregivers 60 and older to those between 50-59 years.	Descriptive, exploratory. Statistics: percentage, Multiple regression, analysis of variance. Of 218 invited from 18 agencies, 198 participated, 87% female, mean age 64, 89% of adults with disabilities were children of participants.	Instrument developed for study listing 23 services participants indicated if services was needed and if needed were services received. Health status 1 item, Skill competence (alpha.80) 30 items, Difficulty locating services 1 item.	Caregiver: * age, ethnicity, marital status, employment Disabled adult child: age relationship to caregiver Services: 23 identified services related to economic, emotional, social and physical health matters, what services needed, what services receiving, how difficult to locate services Health status Skills: ability to perform 30 skills

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Engelhardt Brubaker, Lutzer 1988 Southwest Ohio	To examine characteristics of adults with developmental disabilities,caregivers current and future ability and services used. Hypotheses: severity of disability related to amount of services; as parents age amount of services increases; increased feeling of inability increases amount of services used, increased concerns about future increases service use.	Survey Descriptive. Statistics: percentage, correlation, mean. Mailed questionnaires to families providing care to older adults with mental retardation. Sample from 10 counties and 2 independent agencies. Number mailed not reported, 388 returned: 75% mothers, 12% fathers, 13% all others	Researcher developed for this study; 86 items covering specific needs of caregivers and service needs, current and future utilization, severity of disability, demographics. No psychometric statistics reported.	Service needs, current utilization, future utilization, parental age, parental health status, socioeconomic status, disability severity of mentally retarded child, self-help capability of child, level of mental retardation
Engelhardt, Lutzer, Brubaker 1987 Southwest Ohio	To examine reasons for underutilization of services available among parents with children who have mental retardation.	Survey Descriptive. Statistics: percentage. Questionnaire mailed to all 636 families with disabled children in one county, 155 returned. Parents age 56 years and over represented 25.8% of sample.	Instruments developed for study 32 items specific to respite needs. No psychometric statistics reported.	Parental age, reasons for not leaving child with others (8 listed in subscale)

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Gold 1987 greater New York	To identify parental perspective on own and disabled adult children's situation. To ascertain agencies' awareness of experiences with and interest in older parents and disabled adults To identify nature of collaboration and contact between different agency networks.	Exploratory descriptive. Statistics: chi Square, t-test, percentage, cross tabs. Snowball sample 42 parents and 60 randomly selected agencies. Participants represented 88% mothers, 5% siblings, 7% fathers, mean age 71.5.	Study developed interview guide with open and closed ended items, a total of 47 items. Agency instrument-18 items. No psychometric statistics reported.	Caregiver: age, gender relationship, health status, social support, number in household, coping. Developmentally Disabled (DD) person: age, gender, health and functional status, self-care abilities, behavior problems, deterioration of functional status. Caregiving activities: informal assistance, back up, difficulty providing care, services used, concern for future, financial planning, support groups.
Grant 1986 North Wales	To examine the nature of informal care available to older parents, specifically identify factors affecting sources of care.	Descriptive, exploratory. Statistics: means, analysis of variance, percentage. 103 of 114 individuals participated. Recruited from social services and voluntary agencies. Age range of carers: 38-86; 87% female.	Semi-structured interviews, topics: reciprocities between carers and receivers; social support within and outside of family, future options.	Caregiver: age, marital status Dependent adult: age Social support: total number of members, number of kin, friends, neighbors, home visit from 10 identified professionals.

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Grant 1990 North Wales	To comprehend factors predisposing stability and change over time in arrangements for informal care	Descriptive, exploratory, longitudinal. Sample from Grant 1986 study plus 90 additional participants interviewed twice. See Grant & McGrath, 1990 for additional information.	Semi structured interview. Topics future arrangements for care, and strategies to deal with plans. Statistics: percentage, Stepwise discriminate analysis (Wilks Lambda).	Independent variables: Level of physical dependency, problem behavior, number of kin actively involved in care, number of friends and neighbors involved in care, number of health and social services professionals in family care network, age of carer, need for additional help with minding, level of desire for more help to be assumed by family, loneliness of carer, socio-economic class. Dependent variables: Plans to keep dependent adult within family or place outside of family.
Grant McGrath 1990 North Wales	To examine caregiver assessment of unmet needs, explore relationship between management of dependency and unmet needs, identify characteristics of families expressing greatest need for respite care.	Descriptive, exploratory. Statistics: percentage, chi square, stepwise discriminate analysis (for minding variable only). Of a 225 total population using special program all invited 190 participated, 82% mothers, 8% fathers, 7% siblings, 3% others.	Semi structured interview, Dependency measure, Demographics, Impairment and Disability, Structure and Strategies of informal care, Financial Support, Use of health and Social Services, Future Plans, and Unmet Needs. No psychometric statistics reported.	Adult child: self-care level, mobility, continence, sensory impairment, age, communication skills, behavior, community acceptance. Caregiver: age, relationship, health status, financial problems, loneliness, gender, health of spouse. Caregiver assistance needs: personal care needs, * minding needs, home making needs, moral support needs.

Author Date Location	**Purpose**	**Design/Sample**	**Instruments**	**Variables (* = dependent variable)**
Greenberg, Seltzer, Greenley 1993 Wisconsin	To examine well being of older mothers caring for coresident adult child with a disability. Mothers of mentally retarded adult children (MRA) contrasted with mothers of mentally ill adult children (MIA). Hypotheses: Mothers of MIA have more stress and less support than mothers of MRA; Mothers of MIA will have more frustration and lower gratification than mothers of MRA; The diagnosis of adult child will account for significant differences of maternal frustration and gratification.	Descriptive, comparative groups. Statistics: Analysis of covariance, multiple regression. Sample recruited from government agencies, service providers, and study participants. 208 mothers of MRA and 105 mothers of MIA. Mean age of mothers of MRA 64.6, of mothers of MIA 65.82. Insufficient number of fathers to participate	In home interviews: Burden Interview (alpha .87) 29 items, Positive Affect Scale (alpha .91) 10 items, Objective caregiving demands 11 activities, Measure of behavior problems 8 items, Other caregiving responsibilities 1 item, Declining health 1 item, Formal support 2 items, Size of mother's social support system, Family Environment Scale (alpha .86-.89), diagnosis of adult child 1 item.	Mother: age, education marital status, employment Adult child: age, gender, diagnosis Dependent: * frustration, *gratification Stress: direct caregiving to adult child, behavior problems with adult child, other caregiving responsibilities, declining health Sources of support: adult child had job/day placement, case management, size of mother's social support network, family cohesion, family expressiveness, family conflict

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Heller Factor 1988 Illinois	To compare differences between black and white parents with regards to permanency placement issues of dependent children.	Descriptive comparative groups. Random sample of 251, 100 completed forms. Statistics: Means, F tests, Multivariate Analysis of Covariance, Stepwise discriminate analysis. Demographics: mean age 63, 75% white, 25% black, 75% mothers, 2% fathers, 16% siblings.	Hollingshead 2 factor index of social position; caregiver health; inventory of client and agency planning; permanency planning, Relative and Friend Support Resources (alpha .81-.87), Family Support Services Index (alpha .63). No other alphas reported	Parents: socioeconomic level, age, health religiosity ethnicity, social support - relatives and friends, service usage, house hold size. Mentally retarded child: level of functioning. Planning: * living arrangement preference, * living arrangement plans, * financial arrangements.
Heller Factor 1991 Illinois	To examine Cole's placement model for fit with caregivers of older adults. Hypotheses: increased maladaptive behavior, decreased caregiver support, and increased perception of burden increases preference for out-of-home placement. To determine the best predictors for extent of plans made by caregivers.	Model testing. Statistics: percentage, correlation, logistic regression. Sample same as Heller & Factor 1988	Same as Heller and Factor 1988.	Mentally retarded person: level of retardation, adaptive behavior, maladaptive behavior. Parents: relationship to mentally retarded person, age, ethnicity, health status, social support--spouse, relative, friends, formal services use, services needed, felt burden. Planning: * living arrangements preferred, * living arrangement plans, *financial arrangements.

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Holmes, Carr, 1991 England: 3 London Boroughs	To examine caring processes in families with handicapped adults living at home and evaluate effect of type of handicap upon process. Handicaps: Downs & Autism	Descriptive contrast groups. Statistics: chi square, percentage, means. 39 parents from larger study of quality of life of disabled. 43 families eligible, 39 participated, 20 Downs, 19 Autism. Mean age fathers 62 and 56, mean age mothers 61 and 52 respectively.	Handicap Behaviors and Skills Schedule, Vineland Social Maturity Scale, Leiter International Performance Scale, Coping Interview guide developed for this study. No psychometric statistics reported.	Parents: marital status, socioeconomic status, occupation status, age, participation in care of child, methods of coping. Developmentally Disabled person: age, gender, intelligence level, mental age, social age, physical care needs, domestic care needs, supervision needs.
Kaufman Adams Campbell, 1991 Alabama	To examine permanency planning behavior of older parents of adult children with mental retardation and determine what relationships exist between planning and other variables	Exploratory Descriptive. Statistics: chi square, t-test, percentage. 57 parent-child pairs. selection not reported. 65% black, 89.5% mothers.	Caregiver Burden: Cost of Care Index (alpha .96), Stress adapted from Hooyman 1 item, Behavior Development survey (alpha ranged .68 to .94)	Parent: gender, marital status, ethnicity, health status, socioeconomic status. Adult child: gender, adaptive/maladaptive behavior. Caregiving: problems providing care, future plans, proximity of kin, interaction with relatives and friends, church attendance, caregiving burden, worry, future plans, urban/rural.

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Krauss, 1990 Massachusetts Wisconsin	See Seltzer & Krauss, 1991 To examine what motivate elderly parents to continue to have dependent adult children live with parents, to determine plans regarding future, to identify circumstances to consider out of home placement.	Longitudinal study, second data collection point. Qualitative component Statistics: percentages See Seltzer & Krauss, 1991 for sample.	Open ended questions designed for this study	Motivations of maintaining dependent adult child in home Concrete plans for the future Identification of circumstances for parents to consider out of home placement
Krauss, 1991, Massachusetts Wisconsin	See Seltzer & Kruass 1991 To examine coping strategies of mothers who provide care to dependent adult children	Longitudinal study Statistics: percentages, chi-square, p tests See Seltzer & Krauss, 1991 for description of sample	Instrument: Coping Orientations to Problems Experienced (COPE), by Carver, Scheier & Weintrauba, 52 items, 13 subscales, Cronback alpha ranged from .41 to .9.	Subscales: active coping, planning, suppression of competing activities, positive reinterpretation and growth, acceptance, seeking instrumental social support, seeking emotional social support restraint coping, turning to religion, focus on and venting emotion, denial, behavioral disengagement, mental disengagement.

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Lehmann, Roberto, 1993, Colorado	To explore what services are used and what services are perceived as needed by elderly relatives caring for dependent adult children	Descriptive study. Statistics: percentages and p tests. Sample: 148 families identified from state agency, 61 families participated (41%), mean age 68.8 yrs. (range 38-90), 79% parents, 18% primarily sisters.	Forced choice questionnaire designed for this study. Cronbach alpha for personal scale = .97, for instrumental scale = .93 Identification of all services used and anticipated need	Independent ability of dependent adult children to perform 21 tasks of daily living. Personal scale -- toileting, bathing brushing teeth, hair care, dressing feeding. Instrumental scale-- selecting clothes, laundry, communicating, using telephone, shopping, preparing food, using stove, caring for health, maintaining safety (home), maintaining safety (community), crossing street, using public transportation, managing money, cleaning room. Services: used, reasons not to use, and anticipated service needs
Lutzer, Brubaker 1988 Southwest Ohio	To determine respite needs of parents with children who are mentally retarded.	Survey Descriptive. Statistics: Spearman rank order correlation percentage. Sample see Engelhardt, Lutzer, & Brubaker (1987).	A 32 item study developed instrument, no psychometric statistics reported.	Parental age, number of family members, age of mentally retarded person, service needs, information needs, services not needed.

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Rinck & Calking 1993, Missouri	To explore what services families use, how satisfied rural families are with services, what gaps are there in services and how do these compare with urban dwellers, and how is case management viewed by rural and urban families of dependent adult children	Descriptive study Statistics: Percentages, p tests, F tests, Stepwise multiple regression. Sample: 9126 families sent questionnaires, 1438 returned, 795 from urban and 643 from rural areas. One third of sample over 55 yrs. mean age of mothers 47 (range 20-86), mean age of fathers 48.7 (range 20-86)	Instrument developed for this study, 15 case management items, 14 categories of services available, satisfaction with services 14 items, Requesting services 14 items. Reliability measures not reported.	Case management: intake and assessment individual habilitation planning, coordination and monitoring of services, and overall satisfaction Receiving and Requesting services: information, referrals, day programs, sheltered workshop, supported employment, respite care, counseling, support groups, residential placement, specialized therapies, legal services, transportation recreational services, adaptive equipment. *Satisfaction with regional center
Roberto, 1993b Colorado	To examine perceived changes in caregiving role of caregiver and family member with developmental disability as both have aged.	Descriptive study Statistics: percentages, chi-square, p tests, Multiple regression Sample 148 families eligible participants from state agency, 48 participated. All 48 parents were over 60 years, Family member with developmental disability mean age of 48 (range 41-70)	One instrument designed for this study. Modified portion of Developmental Disabilities Profile, alpha coefficient .95. Socialization patterns--listing of all activities Changes in caregiving --14 items.	Socialization: organization meetings, volunteer, walks, church, hobbies, dining out, senior center, cultural center, visits with family, visits with friends Changes: stress, financial burden, emotional burden, physical burden, amount of help needed, amount of help received, time spent with other family members, time spent with friends, social activities. Predictor of change: *change

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Seltzer, G; Begun; Seltzer, M; Krauss 1991 Massachusetts Wisconsin	See Seltzer & Krauss, 1991 To explore the affective and instrumental role of siblings with in cohort of families for mothers and adults with retardation	Longitudinal, time 1 data. See Seltzer and Krauss, 1991 for description and sample. Statistics: two way analysis of variance, ANOVA, and MANOVA	Functional abilities: Barthel Index, 31 items, alpha =.93. Family social climate: Family Environment Scale, alpha .76 Maternal life satisfaction: Philadelphia Geriatric Center Morale Scale, 22 items, alpha .64 to .74. Maternal Burden: Zarit Burden Scale, 29 items, alpha = .91. Parenting stress: Questionnaire on Resources and Stress, 52 items, alpha =.89. Family network: Antonucci & Akiyama Convoy Model.	Functional and health status of adult with developmental disabilities Persons who provide assistance Family Social climate: values and orientation, organizational style of family Maternal well being: maternal physical health, life satisfaction, maternal burden, parenting stress Sibling involvement: pattern of providing support, informal support network, supportiveness of siblings, most involved sibling, instrumental support by sibling

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Seltzer M 1991b Massachusetts & Wisconsin	See Seltzer & Krauss, 1991 (below) for background information. To determine the extent that aging mothers of retarded adult children differ from selected reference groups and to determine how midlife maternal parenting of an adult with mental retardation differs from parenting in old age.	Longitudinal Study, report of second data collection. (See Seltzer & Krauss, 1991.) Statistics: percentage, means, ANOVA, F test. Sample: See Seltzer & Krauss, 1991, plus additional participants from Wisconsin for total of 462 families (half from each state). Mean age 66 years.	See Seltzer & Krauss, 1991, all instruments used except Moos. Additional instruments: Maternal Well-being--OARS Multidimensional Functional Assessment, ETS Basic Skills Task, Word Fluency Task, Spontaneous Picture Description Task, Sentence Repetition Task, Center for Epidemiological Studies--Depression Scale, and Positive Affect Index; Retarded Adult Child-- Stanford-Binet, World Fluency Task, ETS Basic Skills Test, Sentence Repetition Task, Spontaneous Picture Description Task, Maternal psychological resources--Personality in intellectual Aging Context, Cope, Life Orientation Test, Rosenberg Self-Esteem Test. No report of Psychometric statistics or description of instruments in intellectual Aging Context, Cope, Life Orientation Test, Rosenberg Self-Esteem Test. No report of Psychometric statistics or description of instruments	*Maternal Health and Development: physical health, mental health (depression, life satisfaction), functional abilities, cognitive abilities (vocabulary, semantic formation, memory, cognitive ability). *Maternal affective reactions to caregiving: burden, parental and familial stress, parent-child relationship. *Health and development status of adult child: physical health, mental health, functional abilities (ADL and IADL), cognitive abilities (language & general intelligence), maladaptive behavior) *Residential status of adult child Sociodemographic characteristics (parent, family, child), Family social climate, Maternal caregiving responsibilities for adult child, other maternal responsibilities (employment, other caregiving), Recent life events, Formal support to family (number and types of services and unmet service needs), Informal supports, Maternal psychological resources (coping, optimism, self-esteem, locus of control).

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Seltzer Krauss 1989 Massachusetts	See Seltzer & Krauss 1991 To describe the extent well being of aging caregiving mother is a function of adult child and maternal risk and social support provided.	Longitudinal study. Report on time 1 data. Statistics: Bivariate correlation, multiple regression, p tests, means Sample: See Seltzer & Krauss 1991: Massachusetts population only, 227 mother 55 years and over. Mean age 66 years.	Self report maternal physical health, 1 item. Maternal Life Satisfaction: Philadelphia Geriatric Center Morale Scale, 22 items, alpha .64-.74. Maternal Burden: Zarit Burden Scale, 29 items, alpha .91. Parenting stress: Questionnaire on Resources and Stress, 52 items, alpha . 89. Family Social Climate: Family Environment Scale, 10 subscales, alpha .76. Mother's Social Support: Antonucci's Convoy Model Formal Support: number of services	Independent Variables: maternal characteristics--older age, single, less education and less income, retarded child not having Down syndrome, more sever retardation, poor physical health and functional abilities, family social climate, mother's social support network and formal supports. Dependent Variable: maternal well being

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Seltzer Krauss 1991 Massachusetts	To identify to what extent well-being of aging caregiving mothers is a function of adult child and maternal risk factors. To identify to what extent well being of aging caregiving mother is a function of social support provided.	Longitudinal report of first data collection period. Correlation study. Statistics: means, multiple regression, correlation. 203 mothers age 55 and over, volunteers from 3 agencies, 266 met criteria, 227 participated, 203 with complete data. Mean age 66 years.	Maternal well being: physical health self report, maternal life satisfaction--Philadelphia Center Morale Scale (alpha .64-.74) Zarit Burden Scale (alpha .91), Parents' Stress Questionnaire on Resources and Stress (alpha .89), Functional ability of child Barthel Index (alpha .93), Family social climate--Moos Family Environment Scale (alpha .76) Mothers' social support Convoy Model and number of formal services.	Mothers: age, marital status, educational level, socioeconomic status. Mentally retarded adult child: level of retardation, physical health functional health. * Maternal Well being: physical health, life satisfaction, feeling of burden, parenting stress. Family social climate: cohesion, expressiveness, conflict, independence, achievement, intellectual/cultural, active/recreational, moral/religious, organization, control. Social support: informal, formal services received, attendance in day program.

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Seltzer, Krauss, Tsunematsu 1993 Massachusetts and Wisconsin	See Seltzer and Krauss 1991 and Seltzer 1991 for background--continuation of same study. Hypotheses: Older mothers of adults with down syndrome would report more family cohesiveness and less family conflict and have more social support, report higher levels of service utilization by adult children and report lower levels of stress and burden in caregiving than mothers of other adults with mental retardation; Adults with down's syndrome would have better functional ability but poorer physical health than other adults with mental retardation; There would be no differences in pattern of responses between mothers from different states.	Longitudinal study, time 1. See Seltzer & Krauss 1991 for sample. Statistics: Percentages, means, ANOVA, ANCOVAS, p tests, F tests.	Measure of retardation, Functional abilities of adult: Barthel Index, 31 items, alpha = .93. Physical health status by report. Family social climate: Family Environment Scale, alpha = .76. Mother's informal support network: Antonucci Convoy Model. Parenting stress: revised Questionnaire on Resources and Stress, 52 items, alpha = .89. Maternal subjective burden: Zarit Burden Scale, 29 items, alpha .91	Demographics: Mother: marital status, education, employment, income, age, number of children. Dependent adult child: age, gender, level or retardation. Dependent adult child: Barthel Index: subscales of personal and instrumental functional items. Physical health reported by mother. Family Social Climate: Family Environment Scale: cohesion, expressiveness, conflict. Mother's network: size of network and level of satisfaction Formal support: number of services received. Parenting stress: family problems, pessimism, physical incapacitation, and child characteristics. Subjective Burden: caregivers health, psychological well-being, finances, social life, and relationship between caregiver and receiver

Author Date Location	Purpose	Design/Sample	Instruments	Variables (* = dependent variable)
Whittick 1988 England: Lothiam, Fife and Tayside regions	To examine and compare psychological well-being of three groups of caregivers: mothers caring for adult mentally retarded children, mothers caring for young mentally retarded children, daughters caring for parents.	Comparison groups. Statistics: percentage, chi square correlation, Questionnaire mailed 130 about 50% returned. Interviewed 15, method of selection not reported, 25% daughters, 43% mothers of young child, 32% mothers of adult child	General Health Questionnaire, Disability Scale, Services Scale, Psychometric statistics not reported.	*Psychological distress, disability level of dependent person, services received, caregiver relationship to receiver
Whittick 1989 England: Lothiam, Fife and Tayside regions	To examine and compare attitudes and emotional distress to three different groups of caregivers. Groups same as Whittick 1988 study.	Comparison groups. Statistics: correlation, factor analysis, ANOVA. Sample same as Whittick 1988 report.	General Health Questionnaire, Caregiving Attitude Questionnaire developed for this study No psychometric statistics reported.	Caregiver attitudes: *conflict, *love, *positive view of institution. Caregiver relationship to care receiver.
Wood 1991, 1993 Virginia	To determine the extent and characteristics of older developmentally disabled population in Virginia; to describe utilization of services, gaps in services, and information relevant to meeting needs of this population and aged family caregiver.	Survey-exploratory. Purposive sample, 35 people with developmental disabilities, 44 caregivers, 78% mothers, mean age 69.4	Program developed instrument, specific questions of life style, support system, service needs, planning strategies, Burden Interview and Center for Epidemiological Studies--Depression Scale, no psychometric statistics reported.	Caregiver: age gender,relationship to developmentally disabled person, work status, educational level, ethnicity, socioeconomic status, martial status, health status, depressive symptoms. Developmentally disabled person: health status Caregiving: length of time, level of care provided, services used and needed in future, permanency planing, felt burden, financial planning.

Wood, 1991) used closed-ended and open-ended interview questions, and all data were coded and statistically analyzed. The longitudinal study by Seltzer and Krauss (1989), of which there were eight reports used quantitative and qualitative methods of data collection. However very little of the qualitative findings were available in the literature. All studies but Heller and Factor (1991) used either descriptive or comparative groups designs.

Only Heller and Factor (1988, 1991) utilized a randomly selected sample; all other studies used nonprobability samples. The samples appeared to be drawn only from those parents known to agencies. Mothers were more likely than fathers to be participants. None of the papers reported differences between individuals who participated and those who declined to participate. Reported participation ranged from approximately 85% to less than 14%. Mailed surveys (6 reports) had the highest nonparticipation rates.

The instruments utilized were often developed by the researcher(s) for the particular study. Only 13 of the 27 reports provided Cronbach's Alpha for the instruments used. No other reliability or validity information was provided about the instruments. The number of instruments used in any one study ranged from 1 to 28. The number of variables measured ranged across studies from 4 to 36 per study. The findings from the studies are reflective of the population utilized and instruments chosen to index concepts of interest to the investigators. In the two studies that used open-ended questions, questions were predetermined and sought specific information, and therefore reflected information desired by the researchers. The focus of the responses was directed by the researcher rather than by the informants.

Data from all studies were analyzed using one or more of the following statistics: percentages, means, correlation coefficients, and chi squares. Fifteen of the 27 reports used multiple and logistic regression, discriminate function, or one of the types of analysis of variance. Outcome variables included psychological distress, caregiver attitudes, financial planning, permanency preference, permanency plans, and maternal well being.

Themes

The themes from the studies included parental planning, problems encountered, utilization of services, health status, and differences between elderly parents of dependent adult children and other caregivers of disabled individuals.

Parental Planning

A core concern of elderly parents was what would happen to their dependent adult child after their death. Gold (1987) noted that the overall need of parents was "assurance now of a good home when the right time came" (p. 27). Brubaker and Brubaker (1993) reported that the major financial concern of parents was of their dependent adult children's future. Although this was a central concern, a significant number of parents did not make formal arrangements for housing their dependent adult child. Permanency planning varied between 12 and 66% (Gold, 1987; Heller & Factor, 1988, 1991; Kaufman, Adams, & Campbell, 1991; Wood, 1991). Permanency planning was ambiguous and difficult to measure as parents have a wide range of activities that they identify as planning. Permanency planning ranged from submitting an application for group housing (often with exceptionally long waiting lists of 10-15 years or more and no guarantees of admission), to talking with an attorney or family members about future plans, to formal contractual arrangements. Formal contractual arrangements were the least frequent type of future planning for dependent adult children (Gold, 1987; Heller & Factor, 1988, 1991; Kaufman, Adams, & Campbell, 1991). Plans for the future may have consisted only of "hope" that Social Security benefits will meet the needs of their dependent adult child (Wood, 1993). These studies support Janicki, Otis, Puccio, Rettig, and Jacobson's (1985) conclusion that developmentally disabled older adults often first come to the attention of social services when parents are hospitalized or die.

Elderly parents who have maintained a dependent adult child at home were ambivalent about out-of-home placement and the best timing of placement for dependent adult child. Although a majority of parents would have liked to see their dependent adult child in a permanent housing situation while the parents were still alive, many parents felt grief and shame, and feared loneliness around their dependent adult child's placement out-of-home, and planned to keep their dependent adult child at home for as long as possible (Gold, 1987; Heller, & Factor, 1991). Parents also perceived that adequate care was not available any place except in the parents' home (Brubaker & Brubaker, 1993).

Older mothers who placed their dependent adult child in out-of-home environment experienced depression twice as frequently as mothers who continued caregiving (Seltzer, 1991b). Yet, parents who desired to keep their dependent adult child at home often found it increasingly more difficult (Gold, 1987). Parents had to assist their dependent adult child with activities of daily living such as dressing, bathing, and managing behavioral problems, all of which became increasingly difficult as the parents aged.

Parents of autistic adult children tend to report more behavioral problems than do parents of Down's syndrome adult children (Holmes & Carr, 1991). Behavioral problems of dependent adult children increase the parents' concerns about future placement in a good residential facility (Heller & Factor, 1991; Holmes & Carr, 1991), however, Kaufman, Adams, and Campbell (1991) found no significant correlation between behavioral problems and permanency planning for dependent adult children.

Krauss (1990) identified five reasons why parents continue to have dependent adult child live at home: (1) a sense of responsibility to family members; (2) alternatives perceived as inadequate; (3) a perception that the adult child would not be happy living any where else; (4) mutual benefits; and (5) resignation to fate with lack of alternative options. Krauss (1990) also identified that, even with placement plans, many parents do not seriously intend to have their dependent adult child placed outside the home. There was an expressed hope that the parent would out-live the dependent adult child. Parents expressed a fear of passing the responsibility of care to their other children (Krauss, 1990).

Problems Encountered

Problems experienced by parents in maintaining dependent adult children at home included restrictions on their own lives, maintaining their health, managing needs of the dependent adult child when they, the parents, were ill, financial restraints, managing behavior, keeping the dependent adult child occupied, maintaining the health and self-help skills of dependent adult children, safety issues and the extra domestic tasks (Gold, 1987; Holmes & Carr, 1991; Wood, 1991, 1993). The demands of caregiving limited the number of activities of parents. Roberto (1993b) identified the three most common activities of parents as eating out, visiting with family and friend, and attending church. Dependent adult children usually participated in these activities with parents. Wood (1991) found that the level of felt burden was mild to severe in 47% of the parents whereas the level of care to dependent adult children varied from a minimal level of care (19%), to a moderate level of care (52%), to a "constant" level of care (26%). Roberto (1993b) reported that, as parents aged, the felt physical, emotional, and financial burden increased, while the amount of time participating in activities decreased. Loneliness and isolation have been reported as significant problems (Gold, 1987; Wood, 1991).

In discussing problems, elderly parents expressed feelings of being overwhelmed, without hope, and having no peace of mind (Gold, 1987). Gold (1987) found that many parents believed they had no informal or formal support when ill or during times of crisis.

In attempting to handle problems encountered in caregiving dependent adult children, parents were found to use a wide variety of coping strategies. However, Krauss (1991) identified acceptance, positive reinterpretation, turning to religion and planning as the most frequently used coping strategies. Krauss (1991) also found that most mothers who continue to parent their dependent adult child in old age do not use maladaptive coping strategies such as denial, behavior and mental disengagement and focusing on and venting emotions.

Utilization of Services

Problems related to elderly parental caregiving to a dependent adult child were compounded by the increasing age and frailty of the parents and the tendency not to utilize formal and informal assistance (Engelhardt, Lutzer, & Brubaker, 1987; Gold, 1987; Holmes & Carr, 1991; Lehmann & Roberto, 1993). Engelhardt et al. (1988) reported that elderly parents' utilization of services was dependent primarily upon the elderly parents' perceptions of their ability to provide care and the level of the dependent adult child's disability, not parental age, income, or health status. The higher the perception of disability for the dependent adult children, the lower the perception of parental ability to provide care; the perception of being less able to provide care resulted in higher utilization of formal services (Engelhardt, Brubaker, & Lutzer, 1988). This finding was supported by Roberto (1993b), who found that parents' stress and physical burden were higher when the dependent adult child's health was viewed as fair to poor. However it has also been reported that parents do not use services because the parents do not perceive that they need the services available (Lehmann & Roberto, 1993).

The types and utilization of services available to elderly parents varied. Lehmann and Roberto (1993) identified Supplemental Security Income, medical care, transportation, and case management as the most frequently used services of care providers of dependent adult children. Of seventeen identified services and programs available in Illinois for parents of dependent adult children, the most frequent services reported as "needed-and-not-received" were residential program information, out-of-home and in-home respite, recreational activities for dependent adult children, financial and guardianship information, case management, specialized therapies, family counseling and support groups (Heller & Factor, 1991). Grant and McGrath (1990) identified several unmet needs parents experienced in personal care for a dependent adult child, including bathing, respite, transportation, homemaking, and support/company for the dependent adult child.

Parents who planned an out-of-home placement tended to use more services than parents who planned for in-home placement (usually with a relative) (Heller & Factor, 1991). Lack of service utilization by elderly parents may be related to lack of knowledge of services (Lehmann & Roberto, 1993; Wood, 1991), diminished interest in interaction with social systems outside the family (Lutzer & Brubaker, 1988), cost, inability to find qualified help, complexity of the dependent adult child's problems (Engelhardt, Lutzer, & Brubaker, 1988), time available to provide care, and value of providing that care (Grant & McGrath, 1990).

Health Status of Elderly Parent

Health status of the elderly caregiver is of concern if caregiving is to continue. In all studies health status was judged only by self-report. Elderly parents judged their health status to be "fair" in the Heller and Factor (1988) and in the Engelhardt et al. (1988) studies. Seltzer and Krauss (1989), Seltzer (1991b) and Roberto (1993b) found that elderly mothers rated their health to be "good." Age did not appear to influence the perception of health status of older parental caregivers (Gold, 1987; Krauss, 1991; Seltzer, 1991b). Seltzer (1991b) reported that mothers aged 55 to 85 years had similar perceptions of their health across a 30 year age span. However, Wood (1991; 1993) found that while most parents reported their health to be good to excellent, 33% reported that their health had deteriorated in the last five years. In all the studies, parents overwhelmingly reported that the health status of the dependent adult child was good to excellent and about the same as five years ago.

Health status had an inverse relationship to perceptions of ability to provide care. Gold (1987) found that 75% of parents reporting one or more health conditions considered providing care to dependent adult children to be more difficult than those parents with no health problems. Parents tended to attribute problems in caregiving to their own diminished health status and not to problems of their dependent adult child. Lower levels of maternal education, family income, and the dependent adult child's physical health were related to poor physical health of the elderly mother (Gold, 1987).

Mothers' well being has been associated with physical health, life satisfaction, perceived burden, and felt parenting stress (Seltzer & Krauss, 1989). Mothers of children with Down's syndrome reported less family conflict, felt less stress and burden, and had higher levels of satisfaction with informal support networks than did mothers of adult children with mental retardation related to other factors (Seltzer, Krauss, & Tsunematsu, 1993). Involvement of the mothers' other children with the dependent adult child was found to increase mothers' well-being over those mothers whose other children were not involved (Seltzer, G., Begun, Seltzer, M., & Krauss, 1991).

Differences Between Elderly Parents of Dependent Adult Children and Other Caregivers of Disabled Individuals

The caregiving experiences of elderly parents of developmentally disabled children are atypical when compared to other caregivers and parents of other disabled children. The parent-child relationships may vary little over the life time of the developmentally disabled adult child, because neither experience the "normal" transitions that occur with usual life-span development (Whittick, 1988). The time span of caregiving responsibility for the elderly parents may extend over five or six decades (Seltzer & Krauss, 1989), whereas caregiving to elderly relatives tends to average approximately five years (Stone, Cafferata, & Sangl, 1987). Additionally, elderly parent-caregivers of dependent adult children have had different experiences in providing care to their developmentally disabled children than do today's parents of developmentally disabled young children. Health care, community services, educational facilities, and social resources are more available to assist today's families with developmentally disabled children as compared to families forty years ago (Lubin & Kiely, 1985).

Seltzer and Krauss (1989) found distinct differences between elderly maternal caregivers of dependent adult children, younger mothers of developmentally disabled young children and daughter caregivers of older Alzheimer's victims. Elderly mothers of a dependent adult child had stronger parenting roles as a central component of self-identity and smaller social networks than did daughter caregivers and younger mothers. Similarities between elderly maternal caregivers and younger mothers included a strong relationship between maternal well being and family social climate. A perception of a positive family social climate has been found to contribute more significantly to an elderly maternal person's sense of well being than formal or informal support (Seltzer & Krauss, 1989). Additionally, elderly mothers' reports of burden and stress were similar to those of daughter caregivers of Alzheimer's victims. Whittick (1988, 1989) found differences between daughters as caregivers for demented parents and mothers of developmentally disabled children. Elderly mothers reported higher levels of love and less psychological distress than did daughter caregivers. Elderly mothers also reported more love and conflict than mothers of young developmentally disabled children. Furthermore, Seltzer (1991b) found that elderly mothers were more satisfied with their lives and less depressed than were caregivers of elderly relatives.

Other Elderly Parental Caregivers

When chronic mental illness interfered with the independent functioning of adult children, parents tended to assume caregiving responsibilities. Studies indicate that 65 to 84% of caregivers of chronically mentally ill (CMI) adults are parents; many of these parents are over 65 years of age (Belcher, 1988; Francell, Conn, & Gray, 1988). Ascher-Svanum and Sobel (1989) found that older mothers were three times more likely than others to provide care to a CMI adult child. Further, CMI adult children did not have symptoms of mental illness until late adolescence or early adulthood. Caregiving to a CMI adult child generally began when the mother was in her late 40s and 50s (Ascher-Svanum & Sobel, 1989).

Mothers without spouses reported a variety of problems in providing care to CMI adult child. Parents frequently reported frustration related to the reluctance of the child to leave home, increased isolation, undesirable behavior, and fear of harm or damage to the house when the adult child was left alone (Belcher, 1988). The health status of parents declined while providing care to a CMI adult child (Belcher, 1988; Noh & Turner, 1987). Providing care to a CMI adult child tended to result in increased physical and mental exhaustion (Belcher, 1988). Parents' increased psychological distress was related to their low confidence in their ability to manage the challenges of an unpredictable illness, the increased length of time their CMI adult child was in the community, and the diagnosis of schizophrenia for the adult child (Noh & Turner, 1987). Psychological distress resulted not only in decreased health status but also increased the feeling of burden in caregiving. Caregiver burden was related to the unpredictable nature of chronic mental illness and the feeling of helplessness about changing the situation. Feelings of helplessness were exacerbated by the present health care system. Parents often became frustrated by the lack of services, information, access to treatment plans (often because of confidentiality) and options for case management (Francell, Conn & Gray, 1988). Respite care has been found to be helpful in reducing some frustrations and burdens of parents (Geiser, Hoche, & King, 1988).

Elderly parents have attempted to cope with the burdens of care through such strategies as coercion, avoidance, ignoring/acceptance, collusion, constructive measures to ameliorate behavior, resignation and reassurance (Birchwood & Cochrane, 1990). The amount of stress and burden experienced by parents did not significantly correlate with coping strategies used to handle the stress/burden. However, the degree of family member stress and burden was related to the level of behavioral disturbances and social impairment of the affected individual (Birchwood & Cochrane, 1990). Coping mechanisms of these parents also have been identified in specific ways of providing care for CMI adult children. Chesla (1991) identified four types of caring practices utilized by parents with schizophrenic adult children: engaged care, conflicted care, managed care, and distant caring. Engaged care was an extension of the parental responsibilities, and parents found satisfaction in the parenting role. Conflicted care parents were dissatisfied and angry with their situation and tended to see schizophrenic behavior as manipulation; these parents were the most emotionally distressed of the four groups. Managed care parents remained objective and had clear plans for intervention and long-term goals. Distant care parents often were fathers who did not provide hands-on care, leaving this responsibility to mothers.

Preliminary Study Findings

Themes from the literature about elderly parents of dependent adult children were supported by the findings of a preliminary qualitative study completed in 1991

(Schaller-Ayers). Seven elderly parents of six dependent adult children from five families participated in this study. Elderly parents reported difficulty in making permanency plans, behavioral and other problems in providing care, maintaining their own health status, limited services use, and differences with other caregivers. They also reported concerns around maintaining a home, financial security now and in the future, enhancing the development of their children, and the impact of changing legislative and agency policies. Parents also described positive aspects of their long-term parenting, such as togetherness, being loved and enjoying their children.

Permanency Planning

None of the five families had made permanency plans for their children. Parents were concerned about future placement needs and expressed a continuing evaluation of options available. Parents were unsure which services would remain available when placement was desired. For example, "You know where they're cutting out everything and you don't know if there's gonna be a place or what there will be, whether she'll be out on the street or what . . . . How can you make plans when there isn't any, isn't anything to make plans for"? Another parent reported "We thought he was on a group list for about five years and then we found out that he wasn't, he's been on the list for ten years now . . . . You can't go look at them [group homes], you just have to wait until there's an opening." One parent with two dependent adult children said "The group homes don't have the personnel or the ability to handle people [with a comorbidity of quadriplegia cerebral palsy and mental retardation] . . . where they need continuous supervision and continuous help . . . that is going to be a big problem." Some parents expressed a desire to have other children take over their responsibilities when the parents were unable to continue to provide care. However none of the parents expected their dependent adult child to live with their other children; rather they hoped the other children would find the best placement when it became necessary.

Problems Encountered

Parents presented problems encountered in caregiving that have not been addressed in the literature to date. One parent who provided care to his child alone reported "I worry if I should have a heart attack or stroke if she has enough sense to get help, call 9-1-1 or go to the neighbors. I worry that I'll just lie here and die and what will she do." This same father also worried about "I always have to know where she is, you know there are some pretty weird people out there and I'm afraid they'll try to take advantage of her, you know." Another parent reported that "there are some people who would just as soon not to have them [dependent adult children] there, you know. So it's attitudes of people you have to contend with." A father who is an officer in an organization related the following regarding dinner meetings "I have to be at the head table, and that means . . . [my wife] is going to have to be at the head table with me. What happens to these two boys . . . They have to sit alone and they can't be left alone because they can't handle their food or anything . . .. It's so restrictive."

Parents also expressed concern about the dependent adult child getting on the wrong bus, safely preparing meals, being left alone, being manipulated by others to do inappropriate or illegal acts, getting lost, having poor judgment, and having accessibility to public and private buildings. Some behaviors of the dependent adult child were either worrisome or irritating, such as shyness, inability to shop by self, "talking back," and repeated questions on the same topic. For example, one parent who has made family plans 12 months in the future said "He doesn't realize the time, and he thinks it is tomorrow. We have to live with that for a year [meaning frequent repetitious questioning about the activity]. Put yourself in those shoes, and you can just imagine what is---it gets aggravating sometimes, just irritating." Another parent reported that "One friend has a daughter who just, she's unable to control and now that's a hard situation, what do you do?"

Health Status

The seven parents in the study, after an initial hesitation, reported their present health to be good. However, when asked to project health status five years in the future, all responded first that they would not be alive in five years. One parent was legally blind and had cardiovascular problems, two parents had surgery for cancer within the last year, one mother reported a need for bilateral cataract surgery while her husband (post stroke) was also dependent upon her for his care, and another mother had problems with chronic stasis ulcers of both legs.

Service Utilization

All but two dependent adult children attended day programs. One individual has been on a waiting list for a number of years while the other individual's developmental level was too low for workshop placement. The amount of service utilization varied among parents. One 90 year old mother reported "I got tired of having to ask someone to help me with problems." The one family with a dependent adult child not in a day program said "The only respite that we get is up twice a month . . . on Saturdays. So . . . [we] do get a day off where we can go grocery shopping or to lunch with people . . . . There is a couple of hours . . . from nine o'clock to 5:30, so we have to be home by five." Parents reported being unable to find week long respite services, even with a three month notice, and having no one available if the parent becomes incapacitated. Another parent replied that "If we had a little more respite we would be better . . . [able to be] on top of [this]." Low utilization of services may represent a lack of services appropriate to the needs of these parents rather than a deliberate refusal to use available services.

These parents reported a history of starting the first educational and workshop programs in the area, establishing organizations to provide support services, and seeking the development of other services such as Sunday School classes for retarded adults. In finding and developing new activities and services for their dependent adult children parents reported that "I think the trouble with being 65 and over is that you loose your ambition . . . . Our pick up and go has gone" and "Older parents just wear out."

Differences From Other Caregivers

Older parents in this study often compared themselves to today's parents of young developmentally disabled children. One mother said "Well, we were the ones who paved the way for those coming up now and all the new . . . [programs]. We had to find our way and many didn't." Another mother said "I was forced to face a situation that I couldn't get any help. Nowadays they get more help, you know . . . . There are so many things that are different. . . . I had to make it on my own. It was pretty tough at times . . . But nowadays when people have more help, I think they have it easier."

Themes Not Addressed in the Literature

When asked about concerns, several parents discussed difficulty in maintaining a home for themselves and their children and lack of financial security. For example, "Being able to maintain the house and be able to do all of it because it certainly isn't going to get easier . . . . There are so many things that need to be done and you don't get them done . . . but it's to the point where we're elderly people, we just can't maintain a home." In Oregon, many elderly individuals have the option of delaying property taxes on their homes until the house is sold, however, none of the families interviewed had taken advantage of this because home equity was planned to complete a trust fund for the dependent adult child. "I could defer the taxes but I don't want to do that because they are against the property. . . if I die and sell the place then all of that has to be paid and I want to be sure that there is enough left to take care of him."

The establishment of a trust fund that will provide for the dependent adult child was discussed by all parents. Trust funds have to be established in a certain manner so as not to make the dependent adult child ineligible for group homes because of excess income. For example, "The attorney I had draw up the trust and everything . . . he took three or four months to finally complete all the details. . . . I worked so hard to get some money put in a trust. Then try to get everything set up so he could be taken care of without any troubles. . . . With so many bank failures and everything, I'm concerned about leaving money in the bank. . . gosh, after all those years I have worked so hard and did without so many things, and do get it there for him, I sure would hate to lose it." "Right now we have to redo our wills and make sure that the boys are taken care of in the future . . . we have learned that we have our will in disarray. Not set up properly, we have to have those done over again."

Wills and trust funds must be evaluated frequently to determine the impact of new or changing policies. Legislative and agency policy changes can have profound effects on parents and their child. Because of budgetary problems these parents were concerned about a possible cut in services and termination of workshop placements for adults living with families and subsidies to parents who have children at home during the day. Comments from parents included "He needs outside communication on his own away from the family . . . [if his position is cut] what is he going to do? That means he is going to have to come home and go back in the closet like he was 40 years ago." Without day programming one mother predicted "I'll go crazy . . . it would be as bad for her, worse for her . . . just what would she do all day? Sleep late and get fatter." Another mother expressed concern that "The clients that have been living at home . . . will probably lose their [sheltered workshop] jobs . . . That has really got me upset because he--then he will be ineligible to go into a lot of those group homes and I don't know what will happen . . . [the workshop] is his whole life . . . He needs to keep his eligibility for a group home."

Parents also discussed the continuous work of enhancing their child's development through such efforts as supervising meal preparation, teaching adult children to recognize signs and their meanings, and teaching them to socialize and have meaningful relationships; one mother has been trying to teach her child to read for 30 years. Parents also discussed positive consequences and benefits of their long term parenting. One parent replied "If he wasn't here with me I couldn't make it." Another parent said "She's good, she's company, I love havin' her here." Finally one parent's comment "Oh, the good things are having the boys and having fun to be with them. They're good kids, we all enjoy being together." Her husband added "Boy, one real good thing going is that we enjoy doing things together. It is completely a togetherness."

Summary

The phenomenon of long-term parenting to a dependent adult child has only recently appeared in the literature. Most of the studies have been descriptive in nature, measuring the presence, quality, and relationship of a variety of selected variables related to elderly parenting and caregiving. Seltzer, Krauss, and Heller (1991) state "There are a variety of methodological constraints in the existing literature that limit our understanding of the impacts of family caregiving for persons with mental retardation" (p. 16). This view is supported by Roberto (1993a) who states that "Researchers must strive to improve upon current content and methodological limitations in order to enhance our knowledge and ability to meet the needs of this small, but growing, group of elderly caregivers" (p. 18). Lack of conceptual frameworks and methodological weaknesses such as nonprobability samples and use of nonstandardized instruments reduce the ability to generalize findings beyond the study samples. Individuals who volunteered for these studies may be different than individuals who did not volunteer. The role of fathers has been neglected and limits the understanding of the dynamics of interaction and different perspectives in these families (Seltzer, Krauss, & Heller, 1991). The presence of large sample sizes has been buffered by the reliance on self report and participant completion of the study instruments alone that limits the utilization of observational data collection techniques that could enhance findings.

According to numerous authors, all the concepts salient to this complex phenomenon have not been identified (Gold, 1987; Roberto, 1993a; Seltzer, Krauss, & Heller, 1991). The themes of the findings reflect the specific questions asked of elderly parents. Although the findings provide insight into the lives and problems faced by elderly parents of dependent adult children, the context of those themes was lost. The deductive methods, the measures and the quantitative nature of the studies may not have allowed elderly parents to reveal meaningful information that was not asked for or to identify those concepts they believe to be most important in their day to day lives.

The preliminary qualitative study did provide additional insight into the problems of permanency placement planning experienced by elderly parents.

Knowing what people do is possibly not as valuable as the circumstances surrounding what they do. If the context can be appreciated, then the behavior may be understandable. The preliminary study also identified additional concepts for possible study, such the impact on the family of changing policies and financial constraints. Noticeably lacking in the literature were positive consequences of long-term parenting; parents in the preliminary study had both positive and negative comments about their life experiences.

Literature regarding elderly parents as caregivers to non-developmentally disabled dependent adult children also is limited and provides restricted insight into long term caregiving. Parents of CMI adult children may encounter caregiving experiences similar to those of parents of dependent adult children. Both elderly parents face the long term care needs of their dependent adult children, the prospect that care needs may increase as their own health becomes frail, and the knowledge that the dependent child most likely will outlive them. However, unlike parents of developmentally disabled children, parents of chronically mentally ill (CMI) children may have normal early parenting experience. Caregiving to CMI adult children may begin during a time of crisis late in the individual's childhood, while caregiving to adult children with developmental disabilities occurs over the life time of the dependent adult children.

Early research described the presence and quality of a variety of variables include permanency planning, health status, and support programs. Because these studies occurred without support of previous literature, they were broad and descriptive in nature, seeking to identify critical variables that would be useful to providers in assisting these families (Seltzer, Krauss, & Heller, 1991). Now that some literature exists, it is important to explore those domains of the phenomenon that have gaps or have been overlooked.

Empirically grounded data about the lives of elderly parents of a dependent adult child are important because alternative realities may exist that could impact the effectiveness of traditional interventions, services, and policies intended to ameliorate problems experienced by elderly parents. To understand adequately the experience of elderly parents of a dependent adult child it is important to examine the phenomenon from the perspective of those living the experience. Learning from the informant rather than limiting informants to answering predetermined questions allows for describing the complexity of life experiences within the context where it occurs (Lipson, 1991). To date the literature regarding elderly parents of dependent adult children lacks a qualitative quality that allows participants to guide the data.

CHAPTER III

METHODS

This was an exploratory study to identify the meanings elderly parents give to their life-long parenting of a dependent adult child with developmental disabilities and the related concerns of those parents. The study provided an in-depth description of elderly parents' caring for their dependent adult child, how the meaning of parenting had changed over time for the elderly parents, their parenting concerns, and how these concerns impact their day to day lives.

Design

A qualitative, exploratory descriptive design was used. The methodology used for data collection of this study was intensive interviewing as described by Lofland and Lofland (1984). Intensive interviewing, consists of repeated face-to face interviews with participants (Lofland & Lofland, 1984). The purpose of intensive interviewing is to discover and describe the participants' experience in a particular phenomenon and to identify what exists in the phenomenon. Intensive interviewing is consistent with the desired purpose of this research study, which is to identify the meaning elderly parents give to their life-long parenting and caregiving to a dependent adult child with developmental disabilities. This approach enables "the participant's perspective on the social phenomenon of interest [to] . . . unfold as the participant views it, not as the researcher views it" (Marshall & Rossman, 1989, p. 82). In addition, intensive interviewing permits development of concepts grounded in the perceptions of the people experiencing the phenomenon, these concepts are useful for theory development. Data analysis focused on enhancing the understanding of essential features of the experience of elderly parenting.

Setting

Physical and Social Setting

The setting for this study had physical and social aspects, and historical aspects. The physical and social setting included environment, agencies, and population. The historical setting includes national, state and local developments related to families with a developmentally disabled member.

The setting of the study was the El Paso, Texas, metropolitan area. El Paso is in the extreme southwest corner of Texas, bordering New Mexico and the Mexican city of Juarez. Fort Bliss, a large Army base, adjoins the city to the northeast. Residents are primarily of Mexican and European descent; the city is functionally bilingual (Spanish and English). El Paso has approximately 530,000 residents, of which 10% (53,392) are age 65 and over. People of Hispanic origin constitute 69.9% of the population (El Paso Chamber of Commerce, April 27, 1992).

El Paso has six major agencies that provide services to adults with developmental disabilities: the Texas Department of Mental Illness and Mental Retardation (Life Management Program), DARE (Disabled Ability Resources Environment), Torch of Hope, Special Olympics, El Paso Association for Retarded Citizens (ARC) and the West Texas Association for Handicapped. Services provided include sheltered workshops, group residential facilities, home care services, sporting activities, and support groups. Texas is in the early stages of deinstitutionalization of developmentally disabled individuals. Presently there are approximately 7,000 known individuals of all ages with developmental disabilities in El Paso County; of these, 795 are adults who live with families (J. Chowning, personal communication, April 22, 1992).

Historical Setting

The social context in which elderly parents rear children with developmental disabilities is dependent upon the life experiences and social history of those parents. Parents in this study form a group of individuals who have experienced similar circumstances in the raising of their children with developmental disabilities. The experiences of this group of parents are different from those of younger parents because the social conditions and services available to them were different at earlier points in time. The perspectives expressed by the parents in this study can be understood by knowing the social environment within which they parented their dependent adult children. Prior to 1960 the terms "deinstitutalization, normalization, least restrictive environment, community integration, supportive employment and integrated employment, and social support" (Rowitz, 1992, p. 3) were not used in association with mental retardation. Seltzer (1992) stated that to understand family caregiving for a member with retardation one must be cognizant of how the social and health policy environment affects the course of development. Historical factors that affected these parents are presented in terms of national, state, and local developments.

National. In the United States during the 1950s and early 1960s parents continued to be advised by physicians and other health professionals to institutionalize infants with developmental disabilities, and then to forget about them and get on with their lives (Lippman & Loberg, 1985). Concealment of mentally retarded children and adults was common. However, during the 1950s and 1960s national trends and other changes began. In 1950 the National Association for Retarded Children (later changed to the National Association for Retarded Citizens [ARC]) was established. Concurrently, during the 1950s and 1960s an awakening of civil right of various groups emerged; this later spread to individuals with developmental disabilities in the 1970s. See Figure 1: Timeline: Birth and graduation dates for dependent adult children and significant services and organizations started and legislation passed. That summarizes national, state and local developments over a 44 year period.

In 1961 President Kennedy established the first national commission on mental retardation. The commission's report, A Proposed Program for National Action to Combat Mental Retardation, recommended numerous changes that included educational and community services for children with mental retardation and their families (Farber, 1986; Lippman & Loberg, 1985). An outcome of this report was the 1966 establishment of the Bureau of Education for the Handicapped (Education for All Handicapped Children Act of 1975). This was the first act that involved the federal government in the education of children with developmental disabilities.

In 1975 The Education for All Handicapped Children Act opened public schools to children with developmental disabilities. This act required states to provide full educational opportunities to all handicapped children and to enable children with

Time Line: Birth and Graduation Dates for Dependent Adult Children and Significant Services and Organizations Started and Legislation Passed

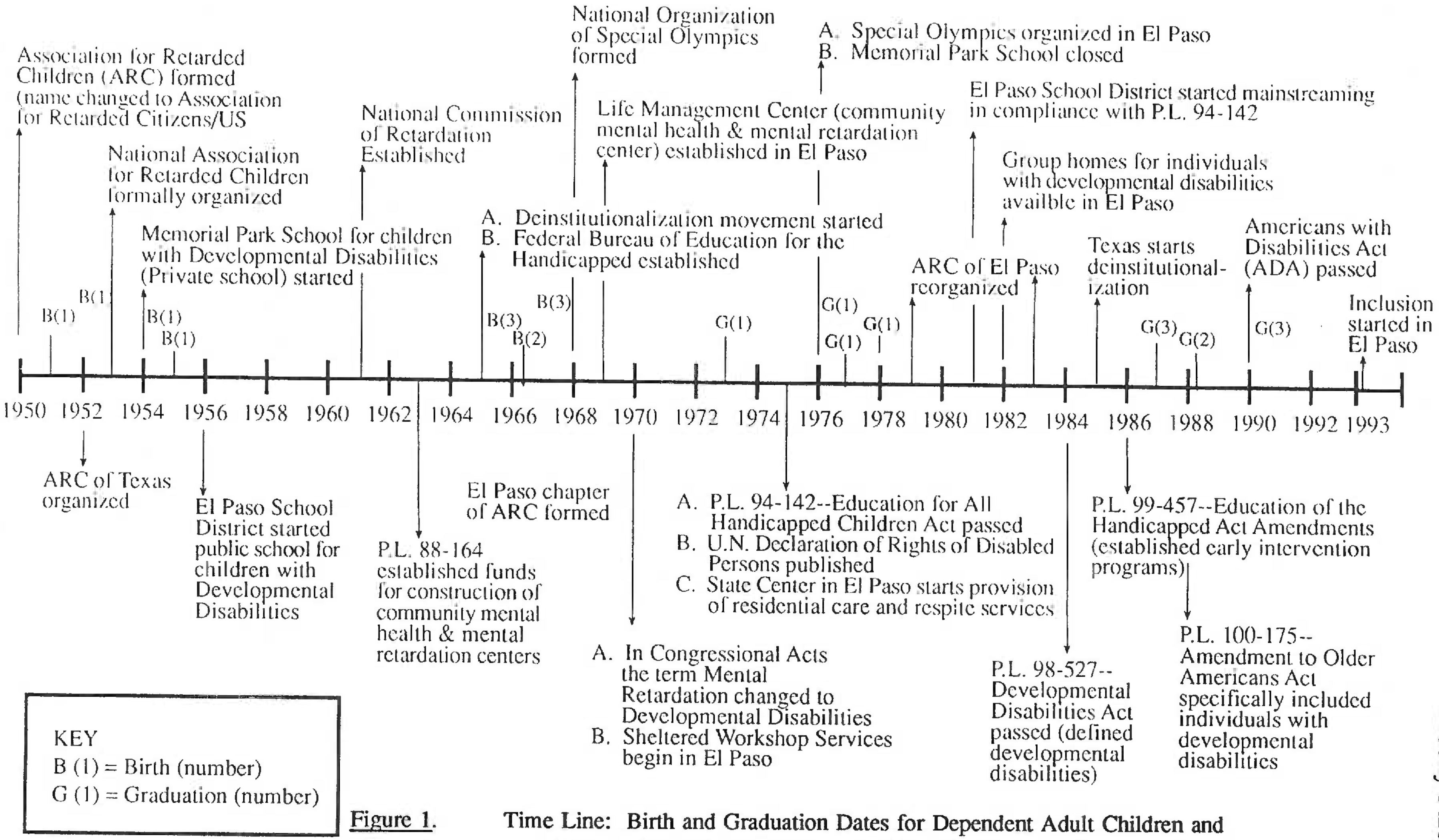


Figure 1. **Time Line: Birth and Graduation Dates for Dependent Adult Children and Significant Services and Organizations Started and Legislation Passed**

developmental disabilities to be educated with nonhandicapped children whenever possible. Segregated special education classes in neighborhood schools were to be used for children only when the severity of their disabilities did not allow integration (Education for All Handicapped Children Act of 1975, 1975). When this act was passed, the age of the dependent adult children in this study ranged from six to 23 years.

In addition to changes occurring at the national level in education, the 1960s experienced a variety of changes. These included the allocation of funds for the construction of community mental health and mental retardation centers (1963), the start of the deinstitutionalization movement (1965), and the formation of the Special Olympics national organization (1968).

Advancements in the form of new legislation or amendments to previous legislation were significant during the 1970s and 1980s. In 1970 Congress changed services from individuals with mental retardation to individuals with developmental disabilities. In 1984 Congress defined the concept of developmental disabilities. In 1986 Congress provided monies for the development of early intervention programs for young children with developmental disabilities (Lippman & Loberg, 1985). (By this time the age of dependent adult children in this study ranged from 16 to 35 years).

In 1988 and 1990, significant legislation was passed that potentially had the greatest impact on all participants in this study. In 1988 amendments to the Older Americans Act included a special provision for individuals with developmental disabilities. The intent of these amendments was to include persons with developmental disabilities within the scope of services for elders (Janicki, 1992). Prior to these amendments, there was disagreement among programs that provided services to elders and programs that provided services to individuals with developmental disabilities about responsibility for services to older individuals who were also developmentally disabled. In 1990 the Americans with Disabilities Act was passed. This act was expected to protect the civil rights of individuals with developmental disabilities and prohibit employment discrimination (Lakin, Bruininkis, & Larson, 1992).

In the last 40 years the U.S government has initiated legislation that has deinstitutionalized individuals with developmental disabilities in order to include them in U.S. society. Large institutions for individuals with developmental disabilities are being closed and replaced by small group homes in the community. Children are being moved from segregated schools and classrooms for those with developmental disabilities into regular classrooms with other children.

State. In the early 1900s, Texas established large institutions for the care of individuals with developmental disabilities. While deinstitutionalization of individuals with developmental disabilities began in 1965, the state of Texas began deinstitutionalization 20 years later in 1985. However, in 1975 the state of Texas built a State Center for individuals with mental illness and mental retardation in El Paso. This program continues to provide services in the community by offering residential facilities to individuals age six and over. Respite services are also available to individuals three years and over. There are two beds available on a first come first serve availability, there is no waiting list.

In 1988, Texas spent 28.1% (national ranking of 48 out of 51) of its funding for individuals with developmental disabilities for non-residential services such as sheltered workshops. Additionally, Texas had allocated only 17.6% (national ranking of 50 out of 51) of its funding for individuals with developmental disabilities for small aggregate housing (homes for less than 15 people). In 1988 the largest portion of funding in Texas went to support large conjugate institutions for individuals with developmental disabilities (Fujiura & Braddock, 1992). Currently, a judicial inquiry is being held to determine why the state of Texas spends significantly less per capita on services to individuals with mental illness and mental retardation in El Paso County than in other Texas counties. Finally, on the state level, ARC was organized in Texas in 1952. The national headquarters for ARC currently is in Arlington, Texas.

Local. Most of the funding for services to individuals with developmental disabilities in the El Paso area comes from state and federal governments. However, from 1954 until 1976 there was a private, community supported school (Memorial Park) for children with developmental disabilities. From 1954 until 1956 this was the only school available for children with mental retardation. The public school districts aided the Memorial Park school until it closed. In 1956 El Paso School district started one of the first public schools dedicated to children with developmental disabilities. The school begun at the request of parents who appealed to the school district and the state Department of Education. After the school district began special education classes, Memorial Park provided early intervention to children from ages of three to six years. In 1981, after a threatened law suit by parents, schools in El Paso implemented the Education of All Handicapped Children Act of 1975.

In 1966 ARC was first organized in El Paso; however it has had a rocky history. The organization was reorganized 1979, and 1983. Special Olympics of El Paso was organized in 1976 and has continued to be very active.

In 1969, six years after federal funds became available, Life Management Center (a community mental health and mental retardation center) was opened. During the following year the first sheltered workshop opened for young adults with developmental disabilities opened. Not until 1982 did the first group home for individuals with developmental disabilities open in El Paso.

Sampling Plan

Participants for this study were parents who perceived themselves as being in long-term parenting roles with dependent adult children. Families in this sample represent a group that preceded the availability of such services as educational and habilitation programs for developmentally disabled young children. Although these parents have endeavored to procure a wide range of services, their children have not had the life long benefit of these services. Some of the adult children have only recently found placement in day programs, such as sheltered workshops.

Criteria for Participation

Criteria for selection of the participants for this study included the following:

participants were parental primary care providers of a dependent adult child, had a dependent adult child living with them in their homes, were 60 years of age or older, had English as the primary language, were non-Hispanic, were able to tolerate a one to two hour interview, and were willing to participate in more than one interview.

Sampling Procedures

Purposeful sampling was utilized to select participants who represent diversity of the aggregate non-Hispanic population experiencing the phenomenon studied (Miles & Huberman, 1984; Morse, 1991). With purposeful sampling, key informants were identified who were knowledgeable about, able to provide detail of, and live the phenomenon in question (Fetterman, 1989).

Sample diversity is essential in order to achieve a broad description of the phenomenon (Robertson & Boyle, 1984). Typically, caregivers of any dependent individual are women. Therefore to achieve adequate diversity of gender and a sample representing the multiplicity of experiences, snowball sampling technique was used to supplement purposeful sampling.

Sample Characteristics

Parents. Parents from 15 families were contacted; parents from 12 families met the criteria for participation. Nineteen parents from 13 families participated in the study. However, data from only 18 parents and 12 families were analyzed. It was discovered after the interview began that one parent did not meet the criteria for participation as the dependent adult child was living in a group home. This parent continued to perceive herself as "caring for" her adult child. Three fathers who were eligible to participate did not because of illness (2 fathers), and conflict of scheduling (1 father). One family did not participate in the second interview because of a prolonged life threatening illness of one of these parents.

Twelve mothers and six fathers participated in the study; their age range was 60 to 74 years with a mean of 63.39 years. Sixteen of the parents were of European descent and two were of non-Hispanic other minority heritage. All parents had at least a high school education. Three parents obtained college degrees and worked in special education after the birth of their dependent adult child. Three parents were employed in full time positions, while three parents were employed until the birth of their dependent adult child and have since stayed home to care for the dependent adult child. Most parents perceived their present, past, and future health as good to excellent. However, there was a downward trend over time. Whereas 50% of the parents perceived their health as excellent 10 years ago, only 18% predicted their health would remain as excellent over the next 5 years. Parents reported a variety of health problems including Parkinson's disease, cardiovascular diseases, hypertension, hypercholesterolemia, migraine headaches, strokes, emphysema, arthritis, and diabetes. Two parents denied the presence of any health problem. A summary of demographic data regarding the parents is presented in Table 2. Figure 2 presents the self-reported health status of parents currently, in the past, and in their predictions for the future.

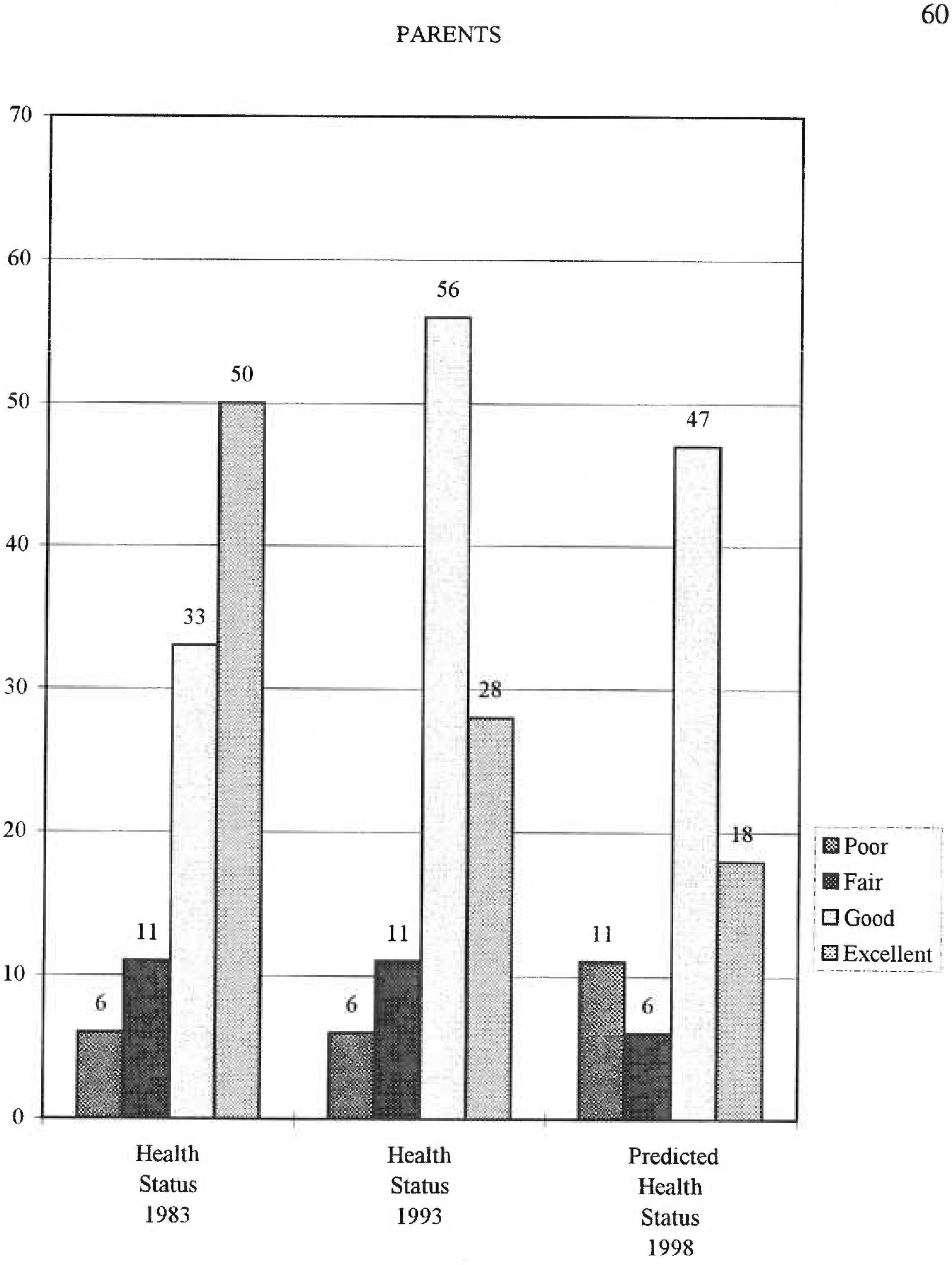
Dependent adult children. Participants in the study were providing care to six female and six male adult children with developmental disabilities. Disabilities

Table 2

Demographic Data: Parents (N=18)

Characteristics of Parents	Total (%) n=18	Mothers (%) n=12	Fathers (%) n=6
Age			
60-64 years	14 (78%)	9 (75%)	5 (83%)
65-69 years	2 (11%)	1 (8%)	1 (17%)
70-74 years	2 (11%)	2 (17%)	
mean	63.68 yr	64.08 yr	62 yr
Gender			
Female	12 (66%)	12 (100%)	
Male	6 (33%)		6 (100%)
Education			
high school diploma	7 (39%)	5 (42%)	2 (33%)
some college	4 (22%)	3 (25%)	1 (17%)
college degree	7 (39%)	4 (33%)	3 (50%)
Employment			
full time	3 (17%)	2 (17%)	1 (17%)
retired	8 (44%)	3 (25%)	5 (83%)
never employed	4 (22%)	4 (33%)	
not employed after birth of dependent adult child	3 (17%)	3 (25%)	
Current number of health problems reported			
None	5 (28%)	3 (25%)	2 (33%)
One	6 (33%)	5 (42%)	1 (17%)
Two	6 (33%)	3 (25%)	3 (50%)
Three	1 (6%)	1 (8%)	

*total may equal more or less than 100% as the result of rounding



values are in percent (N=18)

Figure 2. Self-reported health status: Parents.

included Down's syndrome, cerebral palsy, and mental retardation. Two individuals had comorbidity of cerebral palsy and mental retardation. The average age of the dependent adult child was 30.75 years with a range from 25 to 42 years. Ten of the 12 dependent adult children were of European descent; two were of non-Hispanic minority heritage. Six of the dependent adult children (3 males and 3 females) were not involved in regular daytime activities, while the other six (3 males and 3 females) were involved in sheltered workshops or educational programs. All but three parents reported that their dependent adult child's health was good to excellent currently, in the past, and projected it to be similar in the future. However, as with the parents there was a shift from the good to excellent health range to the fair to poor health range. Dependent adult children also had health problems such as hypothyroidism, congenital heart defects (corrected and non-corrected), cancer, blood disorders, gastric ulcers, and dental problems. Table 3 summarizes the demographic data regarding dependent adult children. Figure 3 illustrates the parents reported health status of dependent adult child currently, in the past, and predicted for the future.

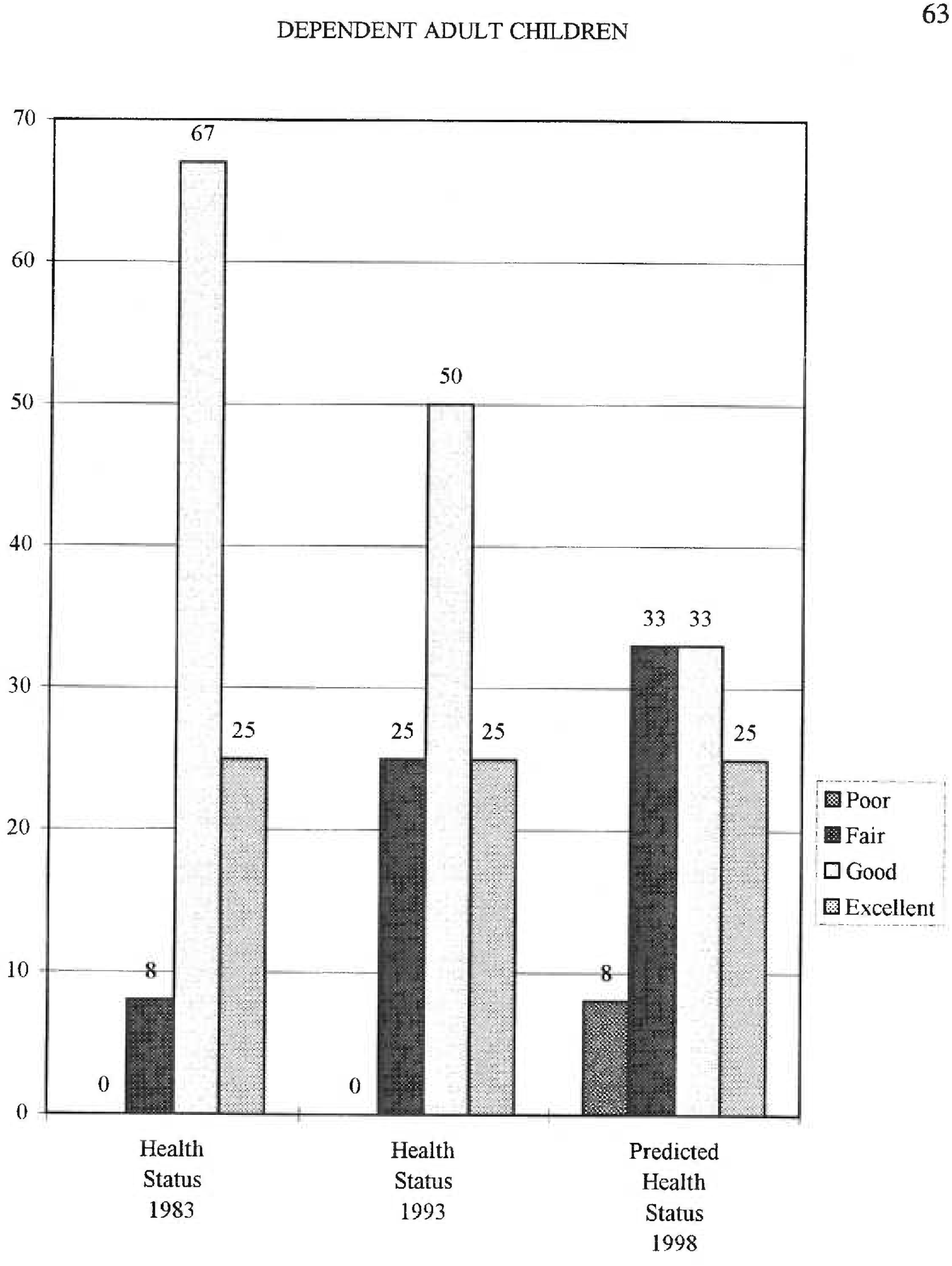
Parental perceptions of care. Parents were asked for their perceptions regarding the amount and type of care provided to their dependent adult child. Thirteen of the 18 parents rated their dependent adult child need for help with every day activities as "a little." However, when asked about the amount of supervision required in daily activities, ratings of parents were fairly evenly distributed over the range of "a little" to "all the time." Fifteen of the 18 parents reported that the overall difficulty in providing care was "none" to "a little." When asked to determine the

Table 3

Demographic Data: Dependent Adult Children (N=12)

Characteristics of Dependent Adult Children	n	%
Age		
25-29 years	8	67%
35-39 years	3	25%
40-45 years	1	8%
mean age 30.75 years		
Gender		
male	6	50%
female	6	50%
Developmental Disability		
Down's Syndrome	8	67%
Mental Retardation	2	17%
Mental Retardation & Cerebral Palsy	2	17%
Number of current health problems not including developmental disability		
None	3	25%
One	2	17%
Two	5	42%
Four or more	2	17%

*total may equal more or less than 100% as the result of rounding



values are in percent (N=12)

Figure 3. Parents report of health status: Dependent adult children.

balance between the negative aspects of having a dependent adult child at home with the positive aspects, 13 parents reported that positives outweighed negatives. The one parent who reported that negatives outweighed positives was actively searching for out-of-home placement for the dependent adult child. Table 4 summarizes the parent's perceptions of type and amount of care they provide.

Families. Nine of the 12 families that participated consisted of both parents and the dependent adult child living in the same house. All dependent adult children lived the majority of their lives in two parent households. At the time of the interview, in three families there was only one parent. All dependent adult children were the natural children of both parents except for one. In two families another adult child and their offspring (1 child and 3 children) resided with the parents. The annual income for the families ranged from $15,000 to over $50,000. Two-thirds of the families had incomes less than $40,000 per year. In four families at least one parent was providing care to another adult family member. Two other mothers provided child care for their grandchildren on a daily basis. Table 5 summarizes the family demographic data.

Refusals. All families who were contacted by the investigator and met eligibility criteria participated in the study. The investigator does not know if any families refused to participate after talking with the agency/organization or church representative about the study and prior to the investigator getting potential participant's names. Two eligible families asked to have the investigator call back in three weeks because relatives were visiting during the summer. After the three week

Table 4

Perceptions of Parents Regarding Type and Amount of Care Provided (N=18)

Parental Care to Dependent Adult Children	Total (%) n=18	Mothers (%) n=12	Fathers (%) n=6
Amount of supervision required			
None	0 (0%)	0 (0%)	0 (0%)
A little	5 (28%)	4 (33%)	1 (17%)
Moderate amount	5 (28%)	4 (33%)	1 (17%)
Quite a bit	6 (33%)	3 (25%)	3 (50%)
All the time	2 (11%)	1 (8%)	1 (17%)
Amount of help required in every day activities			
None	1 (6%)	1 (8%)	0 (0%)
A little	12 (67%)	9 (75%)	3 (50%)
Moderate amount	4 (22%)	2 (17%)	2 (33%)
Quite a bit	1 (6%)	0 (0%)	1 (17%)
A lot	0 (0%)	0 (0%)	0 (0%)
Degree of difficulty in providing care to dependent adult child			
None	6 (33%)	4 (33%)	2 (33%)
A little	9 (50%)	6 (50%)	3 (50%)
Moderate amount	2 (11%)	2 (17%)	0 (0%)
Quite a bit	1 (6%)	0 (0%)	1 (17%)
A lot	0 (0%)	0 (0%)	0 (0%)
Balance between positives and negatives aspects of having dependent adult child in home			
Negatives outweigh	1 (6%)	0 (0%)	1 (17%)
Positives outweigh	13 (72%)	9 (75%)	4 (67%)
Equal	4 (22%)	3 (25%)	1 (17%)

*total may equal more or less than 100% as the result of rounding

Table 5

Family Demographic Data (N=12)

Family Attributes	n	%
Number of parents in home		
One	3	25%
Two	9	75%
Number of persons in the home		
Two	2	17%
Three	8	67%
Five	1	08%
Seven	1	08%
Provision of care by parents to family members other than dependent adult child		
No one	6	50%
Another adult	4	33%
Grandchildren	2	17%
Annual family income		
$15,000-19,000	2	17%
20,000-29,000	4	33%
30,000-39,000	2	17%
40,000-49,000	3	25%
50,000 & over	1	08%

*total may equal more or less than 100% as the result of rounding

period both families participated in the study. Three eligible fathers did not participate in the study. Wives of two fathers reported that their husband's health was poor and could not participate. The third father was always out of town during the data collection periods and a meeting time could not be established because of other obligations.

Once the study was explained by the investigator, parents were very open and eager to participate. In scheduling interviews parents often asked to make an appointment at the researcher's convenience. When scheduling the second interview all families agreed to participate. However, after discussion with one parent, and at the investigator's suggestion, it was mutually agreed that the family would not participate in the second interview. The other parent of this family had been in the hospital several times recently, and was hospitalized again at the time when the second interview. Overall, parents were most helpful in the research process.

Instrumentation

Intensive Interview

The purpose of intensive interviewing is the collection of in-depth data regarding the phenomenon of study. Interviews were composed of questions that allowed the researcher to elicit, describe, organize, and identify units of social settings. This type of interview elicits information that addresses the purpose of this research, specifically to identify the meaning elderly parents attribute to their life-long parenting of and caregiving to their dependent adult children. The interview guide used open-minded questions, beginning with a few broad questions. Additional questioning was used to expand responses and provide in-depth, rich descriptions. Questions were repeated and rephrased to get as complete a description of the phenomenon as possible. The interview guide was developed to be administered in a one to two hour time period.

The interview guide was developed based upon a previous pilot study of elderly parents of adult children with developmental disabilities (See Appendix A) (Schaller-Ayers, 1991). The interview guide served as a guide for the interview; it was not a questionnaire that was meant to be followed in a particular order or used verbatim (Lofland & Lofland 1984). Consistent with the method of intensive interviewing additional questions emerged as relevant during the interviews, and questions also arose from the data analysis. For example, in the guide there were no questions regarding formal agencies and informal networks. By the third interview it became evident that this was an important topic to parents. Therefore, questions were included regarding the parents perceptions of formal agencies and informal networks. The investigator sought to have parents "speak freely in their own terms about a set of concerns . . . plus whatever else they might introduce" (Lofland & Lofland, 1984, p. 59) to more fully describe their perceptions.

Demographics

A questionnaire was developed using standard items to elicit demographic information such as age, gender, marital status, income and educational status (See Appendix B). The questionnaire contained items regarding the parent as well as the dependent adult child. Because elderly parents may be providing care to other family members, an item regarding caregiving activities was included. Additional items were used to obtain a parental rating of how difficult it was to provide care, and how much potential care and supervision their dependent adult child needed. These along with health items were similar to data collected by Seltzer and Krauss (1991). The item regarding the rating of negatives to positives of having a dependent adult child in the home was included because during the pilot study (Schaller-Ayers, 1991), elderly parents identified 19 difficulties but only four good aspects of parenting dependent adult children. Intrigued with these numbers, the investigator wanted to detect how the parents would qualitatively balance the difficulties with the benefits. This item came from a family caregiving study by Stewart and Archbold (1989).

Procedures

Recruitment Through Agencies

The investigator talked with directors of government and nongovernment agencies, organizations, and churches who were aware of elderly parents who provide care to adult a child with developmental disabilities. The intent of the research project was explained and assistance with recruitment was requested from the directors. Directors were given a copy of the consent form for the study. Directors were asked to identify elderly parents who met the sample criteria. The directors then communicated with potential participants to inquire about their willingness to learn more about participation in the study. Although directors from both governmental and nongovernment agencies and organizations were contacted, only the nongovernmentally sponsored agencies and organizations and churches identified and contacted potential participants for this study.

Once initial approval was obtained from potential participants by the agency contact person, the investigator contacted the parent by telephone to explain the study and to seek verbal consent to participate. An appointment was arranged with those individuals who agreed to participate. Before the interview began, the researcher reviewed the study and its risk and benefits using the consent form (Appendix C). The consent form was typed in "18pi" font; a font of "14pi" or higher is recommended for reading ease for elders. The consent form was signed and the participant retained a copy of the consent form. The consent form was reviewed and verbally reaffirmed at all subsequent interviews agreed to by the participant.

Demographic information for both the elderly parent and the dependent adult child were collected from the parent at the end of the first interview. During the initial telephone contact, parents were advised that a desirable time for the interview was one in which the dependent adult child was not present. If the dependent adult child was present in the home, the interview took place in a room not occupied by the dependent adult child. The investigator was able to meet and interact with 10 of the 12 dependent adult children; six during the first interview and four additional dependent adult children during the second interview.

Data Collection

Data were collected through in-home interviews lasting one to four hours each. All interviews were tape recorded. Family caregiving is largely a maternal role (Ascher-Svanum & Sobel, 1989). Therefore, fathers rarely have participated in parental caregiving research. In this study, when both parents were willing to participate, parents were interviewed separately except when it created an inconvenience for one family. This provided an opportunity for fathers and mothers to have separate input.

The interview guide (see Appendix A) was derived from the purpose and specific aims for this study. For example the items "Would you describe what it was like taking care of (name) when he/she was younger?" and "Has taking care of (name) changed over time?" are related to the research aim of describing how the parents' perceptions regarding the meaning of parenting to dependent developmentally disabled children has changed over time. The item regarding parents' concerns about their children and the types of concerns is related to the specific aim of describing current parenting and caregiving concerns identified by these parents.

Open ended questions were used to obtain participant responses. After initial interviews and data analysis, an additional interview with both mother and father present, when agreeable, was arranged with participants to validate preliminary findings and to identify and expand missing and preliminary developed areas of the emerging themes. Because intensive interviewing is an emergent process, the beginning interview guide was revised as data were analyzed and needs for particular information become apparent. Specifically, an item regarding beliefs about agencies was added to the interview guide, after this topic repeatedly came up in early interviews. Fifteen parents were interviewed twice, three parents were interviewed once. Those parents who were interviewed once participated in at least a two hour interview.

Ethical Considerations

Protection of Human Subjects

The study was reviewed and approved (Appendix D) by the Oregon Health Sciences University institutional review board. Participants were given sufficient time to read the consent form and ask questions regarding the study prior to signing (See Appendix C). All participants were given a copy of the signed consent form before the first interview. At subsequent interview times, consent forms were reviewed with the participants. To maintain the confidential nature of the interviews, true names were not transcribed. All identifying information was removed from the transcripts. All mothers in the study were referred to as "M"; all fathers as "F"; all dependent male children as "S"; and all dependent female children as "D". All identifying data collected during interviews were kept separate from the transcripts. Information obtained during the interviews was not shared with the referring agencies.

Potential Risks and Benefits

Participants were advised at the time of the informal consent that the identification of suspected caregiving neglect or abuse must be reported to the state adult protective services division. No reports were made. Elderly parents often found discussing concerns about caregiving and future options to be emotionally stressful. When a participant became upset or distressed, the participant was asked if he or she desired to continue, reschedule, or temporarily stop the interview. If the researcher believed continuation of the interview was not in the best interest of the participant the researcher planned to terminate the interview. No interviews were terminated early. However, with one father and one mother the topic of discussion was changed because of participant distress, primarily crying and long pauses during the interviews. All fathers in the study had tears at some point in the interview process. The researcher provided emotional support as necessary to seven parents. Emotional support consisted of affirming their feelings, offering tissue, and touching. If the participant desired additional support, the researcher had planned to refer the participants to an appropriate service. No referrals were made, although possible options were discussed with participants.

Benefits included an opportunity to discuss with an interested individual the lived experience of being a life long caregiver. These elderly parental caregivers had never participated in research and desired to tell their story. Additionally, the discussion regarding their parenting did provide insight into problems experienced, possible options, and decisions that needed to be made. Parents who participated in the study asked the researcher to return, often reported that they enjoyed the visit, and frequently asked if the information provided by them was useful or helpful.

Data Analysis

Analysis of Interviews

All interview tapes were transcribed. The investigator transcribed three interviews; the others were transcribed by an experienced research transcriber. All transcribed interviews were verified by listening to the tape recordings and reading the transcripts at the same time. Corrections were made to the transcripts to correspond to audio tapes. Transcripts were also scrutinized to assure that identifying information, such as names, was deleted. Copies of the transcripts were stored on computer diskettes, one copy on an investigator-only access computer hard drive, and in print form. There were a total of four copies of the computer diskettes that were stored in four different secured locations. Original audio tapes were stored in a locked drawer and destroyed at the end of the study.

A computer program, Ethnograph (Seidel, Kjolseth, & Seymour, 1988), which allows printing, coding, and sorting of data into analytic categories was briefly used in data management. Data management consistently used included note cards, computer generated copies of interviews, poster boards, and highlighting meaningful data. The analysis process involved identifying units of social settings as described by Lofland and Lofland (1984).

Transcribed interviews and observations were used for data analysis. To protect the veracity of the participants' ideas, data remained in the language of the participants. Analysis began after transcription of the first interview. The major method of data analysis was Lofland and Lofland's (1984) conceptualization of units of social settings. This strategy was selected to allow consideration of the consequences of the experiences of parenting adult dependent children upon the parents and adult children. The method of analysis also preserved the context of the parent's descriptions.

Lofland and Lofland (1984) have identified eleven units of social settings that they describe as most basic. These units are meanings, practices, episodes, encounters, roles, relationships, groups, organizations, settlements, social worlds, and lifestyles. An additional unit, entitled sources of support by the researcher, was also identified as being most useful for the analysis. Lofland and Lofland (1984) state that there is no definitive list of units, therefore the addition of this unit is consistent with this method of analysis.

The units of social settings utilized in this study were meanings, practices, episodes, encounters, roles, relationships, lifestyle and sources of support. Three of these units, meanings, relationships and sources of support were analyzed thoroughly. The consequences of these units upon other units were explored. For example, the unit "meaning of being a parent" was explored for its consequences on the units of practices, and lifestyle. Social units are not conceived of being separate entities but units that build upon one another, so that data are not mutually exclusive (Lofland & Lofland, 1984).

Meanings. Meanings are "linguistic categories that make up the participants' view of reality and with which they define their own and other actions" (Lofland & Lofland, 1984, p. 71). Meanings are present at all levels of social settings.

Practices. Practices are normal, ordinary traits of every day life. Practices are noted to be exceptional by the researcher only after analyzing the data (Lofland & Lofland).

Episodes. By definition episodes are "remarkable and dramatic to the participants" (Lofland & Lofland, 1984, p. 76).

Encounters. Lofland and Lofland (1984) describe encounters as the interaction of two or more people that tends to be bounded by social systems and generally lasts for only a brief period of time.

Roles. Roles are ascribed (such as child, parent, and girl) and achieved (such as nurse, banker, and president). Roles are used to organize one's behavior and to make sense of other's behaviors (Lofland & Lofland, 1984).

Relationships. Relationships are described as the interactions of two or more people who interact over time and consider themselves to be connected to each other (Lofland & Lofland, 1984).

Lifestyle. Lofland and Lofland (1984) describe lifestyles as "adjustments to life by a large number of similarly situated persons" (p. 91). Although influenced by economic status, lifestyle is also affected by other variables such as values.

Sources of support. For the purpose of this study, sources of support was defined as means by which parents received physical, emotional, and financial assistance in provision of care to their dependent adult child.

Once useful social units of analysis were identified, the social units were subjected to a series of questions as suggested by Lofland and Lofland (1984). "Social analysts commonly pose seven basic questions about units of social life. These questions should be thought about conjointly with the units of social organization" (Lofland & Lofland, 1984), p. 93). The seven questions asked of each social unit of analysis were (a) What type is it?, (b) What is its structure?, (c) How frequent is it?, (d) What are the causes?, (e) What are the processes?, (f) What are the consequences?, and (g) What are the strategies? (Lofland & Lofland, 1984, p. 94). Of all these questions, the question regarding consequences is unique. Not only are the consequences within the unit explored but so are the consequences of the social unit upon other social units. For example, the social unit of meaning can be explored for its consequences on the social units of encounters and practices.

In order to identify those units that contained the greatest number of descriptors, the greatest number of relationships, and exhibited the most interest to the parents who participated, the initial data analysis used was ethnography as described by Spradley (1978). Initial analysis involved domain analysis and was guided by semantic relationships as described in Spradley's (1978) text. The basic elements of domain analysis are concept identification, descriptive terms for the concept, the semantic relationship between the domain concepts (cover terms) and descriptive terms, and what is excluded from the domain concept. Transcripts were scrutinized for all possible descriptive terms which fit the semantic relationship of the domain concepts.

When the domains were adequately saturated, taxonomy analysis was then undertaken by relating similar descriptive terms and domain concepts that were described by the same semantic relationship. The domains were then shared with participants (See Appendix E). Few descriptors were added to the domains; by the participating parents. The Taxonomy analysis are found in Appendix F. The descriptors and cover terms from the domains and taxonomies were then subjected to analysis as suggested by Lofland and Lofland (1984).

Analysis of Demographic Data

Demographic data were analyzed using the CRUNCH 4 computer statistical program. Descriptive statistics such as frequencies, means, and percentages were the only statistics calculated.

Validity and Reliability

Just as qualitative and quantitative designs utilize different approaches to data collection and analysis, different approaches are used to attend to the issues of scientific rigor for qualitative research. Lincoln and Guba (1985) propose that validity and reliability of qualitative research are based upon the issue of trustworthiness of the findings. They have operationalized trustworthiness as credibility (analogous to internal validity in quantitative studies), transferability (analogous to external validity), dependability (reliability), and confirmability (neutrality). Other qualitative methodologists, such as LeCompte and Goetz (1982), describe reliability and validity in different ways. Because there is no agreement among methodological authors regarding validity and reliability issues for qualitative research, the general approach suggested by Lincoln and Guba (1985) for these issues, utilizing terminology commonly applied by researchers, was used for this study.

Validity: Credibility and transferability. Validity is based upon the accuracy of research findings. To establish validity, findings are evaluated to judge the extent to which they accurately represent empirical reality and whether constructs devised represent categories of human experiences that naturally occur (Bernard, 1988; LeCompte & Goetz, 1982). Credibility of research findings is enhanced by prolonged engagement with the study population that allows testing for misinformation, and persistent observation that allows the researcher to identify contextual factors most relevant to the phenomenon and to sort out irrelevant factors (Lincoln & Guba, 1985).

Validity of findings is considered a strength of qualitative research methods. Validity is enhanced through data collection and analysis techniques that include taking findings back to the participants for confirmation during the analysis phase of the study, a prolonged data collection period, and the use of both interview and observational methods of data collection. Interviews, the major source of data, are informant-driven and done in the language of the participants to reflect empirical reality. Intensive interviewing reflects self-monitoring and exposure of all phases of the study to questioning and verification of findings from participants (LeCompte & Goetz, 1982).

Threats to validity occur when analysis is prematurely ended, findings are not questioned for fit or considered as alternative explanations, and participants are not asked about appropriateness of findings. The researcher also must assess the probable impact of the researcher on the interview and observational data collected.

For this study, issues of creditability were addressed through the use of multiple interviews with participants over time and by asking participants to verify findings. All participants were mailed a list of descriptors for categories that emerged from the data; these included difficult things, good things, concerns, sources of support, characteristics of parents, changes that occur with age (See Appendix E). During the analysis phase the researcher sought alternative explanations for findings, and asked participants to verify conclusions. Tentative findings were shared with participants and their comments regarding the veracity of the findings was sought.

Transferability or generalizability of the findings is not the responsibility of the researcher; Lincoln and Guba (1985) state that it is the responsibility of the researcher to "provide the data base that makes transferability judgements possible on the part of potential appliers" (p. 316). Further, transferability is reached through a "thick" description of the data. Data should provide a "sufficient base to permit a person contemplating application in another. . . setting to make the needed comparisons of similarity" (Lincoln & Guba, 1985, p. 359-360). Detailed report of data collection and analysis strategies should allow readers of ethnographic research to make some judgements regarding validity and transferability.

Marshall and Rossman (1989) report that transferability is enhanced through triangulation of multiple sources of data and repeated sampling. For this study, all but three parents were interviewed twice. Also the efforts used to ensure credibility enhance transferability. Additionally, a record of data collection and analysis strategies used can be helpful to others in making judgements regarding the appropriateness of transferability. A brief record of strategies and decisions regarding analysis was kept for this study.

Reliability: Dependability

Qualitative research occurs in natural settings that do not allow for the replication of research. However, generation, refinement, and validation of constructs do not require replication of situations (LeCompte & Goetz, 1982). Reliability or dependability can be enhanced through informant selection, description of the context for data collection, and use of techniques that enhance believability (Lincoln & Guba, 1985). Dependability is further enhanced by asking repeated questions (i.e., asking the same question in a different manner several times) and asking for detailed descriptions of the phenomenon of study. Validation of descriptions by other informants supports reliability (Spradley, 1978).

Reliability is considered to be adequate when previous informants and new informants provide redundant information, and when no new properties of existing domains are generated by the interview process. For this study, all participants except three were interviewed two times, interviews lasted from one to four hours each. During the interview process questions were repeated, rephrased and detailed descriptions were requested. Verification of descriptors was asked across participants. As in the preliminary study, participants frequently verified statements of other parents.

Confirmability

Confirmability refers to the ability to establish the degree to which the findings of a study are determined by the participants and not by the perspective of the researcher (Lincoln & Guba, 1985). The intensive interviewing method enhances confirmability through sharing of findings with participants for confirmation of the accuracy of the analysis. Participants were asked to confirm findings and verify appropriateness of analysis throughout the analysis process. These efforts enhanced the opportunity to establish trustworthiness of the findings.

CHAPTER IV

RESULTS: MEANINGS AND RELATIONSHIPS

The results of this study reflect the data collected on the perceptions of the 18 participants. Lofland and Lofland's (1984) conceptualization of units of social settings was used to analyze systematically the data. The major data units analyzed and described for this study were meanings, relationships, and sources of support. The units of meanings and relationships are presented in this chapter. From a synthesis of social units of meanings and relationships the theme "lack of developmental closure" emerged. This synthesis is presented in this chapter. The unit of social support is presented in Chapter 5.

The social units of meanings and relationships were subjected to the seven questions posed by Lofland and Lofland (1984) and described in Chapter 3. Of the questions posed the questions most useful for the social unit of meanings and relationships were type, process, and consequences. Figures 4 and 5 identify the questions used for analysis of social units of meanings and relationship and the corresponding subheadings used in this section.

As themes emerged from the data, they were defined in terms of the perspectives of the participants. When participants' quotes were used each participant was identified by family number and role; for example, Mother 8 indicates family number eight and mother, Father 5 denotes family number five and father. Dependent adult children as described earlier are identified as "S" for son and "D" for daughter. All names and initials utilized are fictitious.

Meaning of being a parent

- Type
  - Labeling
  - "A different kind of parenting"
- Process
  - Changes over time
- Consequences
  - Social Unit of Role
    - Hopes and plans for the future
    - Traits of successful parenting
  - Social Unit of Practices
    - Parental practices and strategies
  - Social Unit of Life Style
    - Day to day life

Meaning of being a dependent adult child

- Type
  - Functionally a child
- Consequences
  - Social Unit of Episodes
    - Significant life event
  - Social Unit of Life Style
    - Quality of life
  - Social Unit of Encounters
    - Encounters with the health system and health professionals

Figure 4. Analysis for Unit of Meanings

Relationship of parent and dependent adult child

- Types
  - Type of relationships
- Consequences
  - Advantages and disadvantages

Relationship of other children and dependent adult child

- Process
  - Process of relationship between dependent adult child and other children
- Consequences
  - Consequences of the relationship for other children

Figure 5. Analysis for Unit of Relationships

Lofland and Lofland (1984) state that while participants in naturalistic studies can identify descriptions of themselves, they are unlikely to identify anyone else. However, when social groups are small and have unique identifying characteristics, others may easily identify participants. The uniqueness of these families increased the probability that service providers and others in the community could identify families who participated in the study merely by vague descriptions. To provide and embellish description of their experiences, participants often discussed other parents and families. Without using names, the investigator could identify the other parents and families being discussed. Therefore, detailed descriptions of families are not presented in the report, as one effort to protect the confidentiality of the participants and their families.

Meanings

Lofland and Lofland (1984) describe meanings as those devices by which people defend and legitimize their circumstances; meanings are not inherent in reality but are associated with reality by the individuals experiencing a phenomenon. Meanings are associated with

> culture, norms, understandings, social reality, definitions of the situation, typification, ideology, beliefs, world view, perspective or stereotypes . . . Meanings are transbehavioral in the sense that they do more than describe behavior - they define, justify and otherwise interpret behavior as well. (Lofland & Lofland, 1984, pp. 71-72).

Two meanings emerged from the interviews with elderly parents of a dependent adult child with developmental disabilities: The meaning of being a parent of a dependent adult child and the parents' perception of the meaning of being a dependent adult child. Because meanings traverse units, other meanings that are appropriate to other units also emerged. These meanings will be addressed in those units.

The Meaning of Being a Parent

The meaning of being a parent of a dependent adult child with developmental disabilities was richly described by the participants. Participants included descriptors regarding labeling, how parenting differs between dependent adult children and other children, changes that occur over time, hopes and plans for the future, tactics used in successful parenting, and day to day life associated with the meaning of parent.

Labeling

Labels are words that are used to symbolize concepts, objects, actions, activities and complex social situations. Cultural meaning is established by using symbols (Spradley, 1978). In the literature, elderly parents who provide care to a dependent adult child are labeled as "caregivers," while agencies often label parents or anyone providing care to a dependent adult child as "providers." When given a choice of using the labels "caregiver" or "provider" to describe what they did, the participants always chose "parent/parenting" over "caregiver/caregiving" or "provider." Father 7 had this to say about which label to use:

> I consider myself . . . to be a parent. . . . but to be a caregiver means that I can go out and slop the pigs and cows. . . . [being a parent] is a lot different

> than being a caregiver, there's no question about it.

Another participant (Mother 5), who repeatedly had been called a "provider" by agencies, had this to say:

> They don't call [it] . . . [parents] anymore; they call it "providers." We're not his parents; we're his "providers" . . . I think it's gross. I think it undermines the position of being parents. I'm not a "provider", I'm a parent. . . . He's my son, I'm his mother, I'm his parent, that's what I'm doing.

In distinguishing differences between the labels "provider," "caregiver" and "parent," participants often found little difference between "caregiver" and "provider" but did note differences between "parent" and either "caregiver" or "provider." Participants believed that the concept "parent" not only encompassed "caregiving" and "provider" roles but included also love, protecting, teaching, nurturing, and disciplining. They expressed the belief that "caregiver" and "provider" did not necessarily include such attributes as love and discipline, and one could even be thought of as receiving monies for "caregiver" or "provider" activities. While parents provided care for their own child, to be a "caregiver" or "provider" one does not have to give care for one's own child. Several participants remarked that the term "provider" was a "cold" characterization for someone who cares of a dependent adult child. (After learning of the parents preferred label, the investigator chose to refer to participants as parents for the remainder of the study.)

"A Different Kind of Parenting"

Parents used the phrase a "different kind of parenting" to differentiate their parenting activities with their dependent adult child from their activities with their other children. Lofland and Lofland (1984) state that it is helpful to classify how people distinguish variations in meanings. As suggested by Lofland and Lofland (1984) this was done by identifying what specific "type" of parenting parents believed the meaning of being a parent of a dependent adult child signified.

Although parents stated that parenting their dependent adult child was different than parenting their "normal" children (parents often said "normal, whatever that means"), parents believed their parenting activities performed with their dependent adult child were no different than what they had done in parenting their other children. The differences between parenting normal children and a dependent adult child were described in relationship to the duration of parenting. Parents maintained that their caregiving and provider responsibilities ceased in their other children when they gained independence. The caregiving and providing responsibilities continued with their dependent adult child. In describing this difference, Mother 1 said

> For instance, my son [a normal adult child] was 45 yesterday . . . and I told him . . . "L, you know, I feel my job of parenting is over. You have a stable marriage and you've graduated from college. . . I think you're on your own." But . . . with S, I think its ongoing . . . the same as for a small child and parenting, never, it never ceases. I don't have to do any caregiving with my older child but I was still parenting because I helped him. . . . But with these kids, your parenting is never done and your caregiving is never done because you are still responsible for them.

Parents related that the major difference between parenting their dependent adult child and other children was that their other children became independent, could fend for themselves, and could live unsupervised. None of the parents believed their dependent adult child, regardless of functional level, could ever live without some supervision. However, all of their other children did live independently. Father 7 related that

> I think . . . if there was a need, if two of my children needed something at the same time and D was one of them. I would probably help D because the other children could really fend for themselves. Where she cannot do that.

Mother 12 had this to say about the difference between parenting her other child and her dependent adult child

> Our daughter who is studying at college, you know that's different. We're still her parents and she's still our daughter but it's a totally different situation. We always will be responsible for him [meaning dependent adult child]; he will always be dependent. . . . But she has achieved an independence that he never will. But we don't dwell on it; that's the way things are.

Whereas the parents perceived an end in caring responsibilities for their other children, there was no end in caring for their dependent adult children. The perceived life long caring responsibility of parenting a dependent adult child was realized by parents at different times in the life of the child. The parents reported the realization that the child was the responsibility of the parent until either the parent's or dependent child's death, occurred shortly after birth of the child, during adolescence, or after graduation from high school. Father 10 stated "You see in the beginning we said we accept the responsibility." However, Mother 8 stated that

> He was only 14 then and . . . I was living in that Mary Poppins world where everything was going to turn out right. But, God, reality smacked me in the face 10 years ago when I realized he was probably going to be with me until I die. So that's when I started doing, and saying, and feeling, and acting with him a little bit different than I did. And now I've reached the point where if he does something wrong I just [say] "S for God's sake you know better than that." . . . But just like I say, he is a perpetual teenager so . . . I have to be a perpetual mother of a teenager.

Graduation from high school was a significant event in the lives of dependent adult children and their parents. For parents the dependent adult child's graduation signaled a deviation from parenting typified by their other children. Other children got jobs, went to college, moved away from home, and married. The dependent adult child stayed home. The inability to perform developmental tasks of young adulthood brought into focus the realities of life long dependence of the dependent adult child.

With graduation the services available through schools were no longer available and parents needed to look elsewhere for services. Four parents reported that lack of services and the inability of group homes to provide the type of environment desired for the dependent adult child made them realize that it was their responsibility to continue to provide care to their dependent adult child. After talking with agency staff about future possibilities for his daughter, Father 7 asserted, "I have made up my mind that we're going to accept the situation as it is. We're going to continue on . . . . And she's going to be our responsibility until the end." Two parents related that to place a child in a group home was to "give up" and to "give away" one's responsibility.

There were multiple reasons why parents continued to accept the responsibility of continuing to care for their dependent adult child. Four mothers reported they thought they were the only ones who could best take care of their dependent adult child. Mother 12 reported

> We've made arrangements for him in the event that something happens to us. . . .I don't know, I've often said that I would have no qualms in giving him up in death, but I don't know that I could give him up now. . . . what we have chosen for him is beyond our [financial] reach for now. . . . But right now [placement out-of-the-home], it's not an option.

These parents perceived that being a parent to a dependent adult child meant that they would continue to provide care until either the dependent adult child's death or their own.

Parenting a dependent adult child was different than other children and included the need for more patience with the dependent adult child. The need for patience and other qualities is discussed in more detail in the subsection "Traits for Successful Parenting." Four parents stated a wish for the dependent adult child to die prior to their own death. Mother 8 said, "It's a sad thing to have to wish that a child of yours would die before you would. . . . I mean not soon, but you know, that I would still be around when she goes." Wishing for the death of a child, regardless of age, prior to a parent's death is not a usual expectation of parenting. These four parents did not express a similar wish for their other children.

Parents' descriptions of "a different kind of parenting" have similarities to the literature. Birenbaum (1971) proposed that "mothers of young retarded children are able to create a normal-appearing . . . life because they can engage in activities similar to those of parents of young normal children" (p. 64). Birenbaum (1971) further states that only when children with retardation were older and the mothers activities did not change were mothers' roles inconsistent from mothers of similarly aged normal children. A central premise of normal parenting is that there is a consistent change toward increased independence of children and a change in parental activities to reflect that increasing independence (Birenbaum, 1971). The fact that dependent adult children are unable to reach the same level of independence as their siblings result in premature freezing of parental activities at childhood levels and makes this type of parenting different. Furthermore, as children with developmental disabilities "move from childhood into adulthood, the life long dependence becomes a reality rather than a prognosis" (Gliddeen & Zetlin, 1992, p. 102).

Krauss (1990) identified five reasons why parents continue to accept parenting responsibilities for their dependent adult child. These include (a) willing acceptance of family responsibility, (b) resignation to one's fate, (c) unacceptable alternatives, (d) mutual benefits, and (e) children's preferences. As Krauss (1990) found, reasons to continue parenting are complex. For example, Mother 2 cited lack of acceptable alternatives, family responsibility, and what her children (both her dependent adult child and her other children) preferred as reasons not to place her dependent adult child out of the home.

Changes Over Time

Change over time was perceived as a process. Lofland and Lofland (1984) define processes as a "continuing operation or development marked by a series of gradual changes that succeed one another in a relatively fixed way" (p. 105). Although parents maintained that what they did was a continuation of what they have always done, the realities of being a parent did change over time. The changes over time can be associated with the developmental changes that occurred in the dependent adult child and the parents. Changes parents noted included a change in the activities of parenting, the need to consider guardianship, and concerns about reproduction and marriage. Furthermore, parents noted a change in their own expectations, hopes and willingness to fight for services.

When the dependent adult child was under 21 years, parents reported that taking care of a dependent adult child was just like taking care of the other children except for extra time spent with the dependent adult child. As the dependent adult child aged, parents reported that with slight supervision or reminders most of their dependent adult children were independent in activities of daily living, such as bathing, personal hygiene, and dressing. However, in instrumental activities of daily living (e.g. shopping, cooking, and laundry), all dependent adult children continued to be either partially or completely dependent upon parents. Over time, parenting switched from providing direct care for activities of daily living to supervision of those activities. For example, Father 7 reported that he no longer had to "constantly keep looking after. . . [his daughter] to see if she's got her shoes on the right feet. . . Occasionally, she still gets her shoes on the wrong feet . . . there was a period of time where, for many years, where she couldn't [get her shoes on correctly]." With the parents' other children such direct supervisory activities ceased a long time ago.

As the dependent adult children aged, new parenting concerns and activities emerged. Upon reaching the age of 21, dependent adult children were viewed as capable adults legally (Glidden & Zetlin, 1992) while not responsibility a functional adult. Because of the change in legal status, parents debated the issue of guardianship, complete and limited, and legal guardianship versus natural guardianship. Four parents had legal guardianship of their dependent adult child. Three parents believed that because they were the parents of a dependent adult child there was no need for legal guardianship. Parents believed they were the children's natural guardians. Father 5 expressed this view with

> I believe that if a child is born to the parents, then his blood makes him a child for the rest of his life of those two parents. It shouldn't take a judge to sit up there to give you guardianship of your own child. That's . . . our role, there are children that are 50 years old, . . . they're not the maturity of 50; they're the maturity of 15. So that makes the child still . . . your child because it's a blood relative.

As dependent adult children physically matured, parents became concerned about reproduction and marriage. Parents of daughters sought means to protect their dependent adult child from pregnancy by considering tubal ligations, use of oral contraceptives, and avoiding situations that would place the daughter at risk. Mother 10 stated that since her daughter had become an adult it had been harder to have her daughter understand that she (daughter) cannot marry and that she (daughter) needs help with daily activities. One of her biggest concerns was "what if she [the daughter] decided to just leave this house one day and just go to the courthouse and get married or just, you know, I worry about her being out and somebody [might kidnap her]."

Concerns of pregnancy and marriage were not just the concerns of parents of females. The parents in family 3 expressed a concern that their son could be accused of fathering a child. They debated sterilization, with the mother in favor and the father opposed.

As parents aged they reported that their expectations, hopes, and willingness to fight for services had changed. Mother 9 had this to say about becoming more realistic in expectations regarding her child: "In the beginning, . . . I really thought that S and I were going to conquer the world, so to speak, and you can't do it. We got brought down." Parents reported that over time they became less optimistic about the future and the availability of agencies to assist them. Father 3 had stated "when he was younger, we were optimistic that he might be self sufficient; that he would receive services that would help him live in a sheltered environment. That's not going to happen. There's no optimism anymore." Although hope continued, parents no longer looked for a "miracle cure" or "miracle pill." They reported that in the beginning you "hope for a cure, melioration [sic], improvement, growth, [but] after about 20 years, you say 'this is it'" (Father 3), and "you reach the point where this is the way it is and you've got to make the best of it" (Mother 7). All parents reported that as they aged they became tired of "fighting" the agencies for the services they desired for their dependent adult child. "You just give up faster after awhile. You say 'that's the way it's going to be'" (Father 10).

> As you get older, you get frustrated at having to fight the same battles with new providers, new service systems, it's a cycle. . . . [And after] you see you're fighting the same battles over and over, you take a different view and say "I'll take care of my kid." (Father 3)

Parents described that as they aged they had become more selective in what they fought for, selecting things that were either important or had a chance for success "instead of trying to get them all" (Father 3).

While parents reported that as both parents and their dependent adult child aged some things changed, and some things became harder. They also reported that some things became easier. Mother 11 said "She's a lot easier. I don't think of the every day problems like we did when she was younger." Mother 7 echoed this with,

> I think it's gotten easier, but it's much easier, either that or I'm getting used to it. . . . But it's not as intense as it use to be.

Heller (1993) provides three reasons for a reduction in the perceived burden parents feel in parenting their dependent adult children. First, parent find it easier to adjust to the demands of parenting; echoing the views of Mother 7. Second, parents know better how to help dependent adult children, having a better understanding of their capabilities. And third, parents learn to love and appreciate their dependent adult child.

Heller (1993) also states that parents of dependent adult children over 21 years report less difficulty in finding services for their dependent adult children than do parents of adolescents with developmental disabilities. Engelhardt, Lutzer, and Brubaker (1987), Gold (1987), and Holmes and Carr (1991) reported that elderly parents of dependent adult children do not tend to use available formal services. Services available for adults with developmental disabilities and their families are extremely limited (Lehmann & Roberto, 1993). This all seems paradoxical but may be explained by the parents' decreased optimism in appropriate services being available, their being less willing to fight for better or new services, and their being comfortable in their abilities to meet their dependent adult child's needs.

Ability to Continue Parenting

Lofland and Lofland (1984) state that social systems strive to maintain themselves. The effects of these efforts have consequences. Because these parents believed they had a responsibility to care for their dependent adult children, they were concerned about their future ability to provide care and continue their parenting role in the future. Of primary concern was their own physical and emotional health status. When asked about concerns for themselves, all parents reported that their major concern was for their continued good health, to be able to provide care for their dependent adult children for as long as possible. For example, Father 3 stated "Staying healthy so we can do it. . . . Being physical or mentally unable to do it is always in the back of your mind." Mother 2 said, "I'm always praying for good health for S's sake, that's all. That I would be able, and to tell you the truth, I pray to God, that God will find a way of, of asking for him before He does us." Four fathers expressed concern regarding their wives continued health status. (These four mothers all reported their current health status as good to excellent.) Father 10 told of a family with a dependent adult child in which the mother had Alzheimer's disease and was in a nursing home and the father of this family was in failing health at home with the dependent adult child. With tears in his eyes, Father 10 expressed his worry that something similar could happen to him. He stated that he became "demoralized" whenever his wife became ill. His wife, however, reported her health status as good and expected it to remain good for the next five years.

Parents also were concerned about their health status in relationship to needing to depend on others in the future. They realized that if their health failed and they needed the assistance of their other children, these children would need to provide services to not only the parent but also to the dependent adult child. One mother and her dependent adult son were receiving instrumental activities of daily living assistance from an adult child and friends.

Gold (1987) and Roberto (1993b) discussed parents' concerns about their own health in relationship to parents' abilities to continue caring for their dependent adult children. Roberto (1993b) reported that parents perceived that negative changes in their health status over the last 10 years negatively affected their ability to care for their dependent adult children. However, Roberto (1993) discovered that the dependent adult children's health status was a better predictor than parents' health status for predicting increased stress and caregiving burden among parents. Parents in this study worried about the impact of poor health of both parent and dependent adult child on their continued ability to parent. Gold (1987) found that increased caregiving burden occurred when both the parents' and dependent adult children's health status were perceived as less than good. In one of the few studies to report findings from fathers, Brubaker and Brubaker (1993) found that fathers expressed more concern over their abilities to provide care than did mothers.

Hopes and Plans for the Future

Parents reported that everyone has hopes and "without hopes you would die" (Mother 3). The hopes of these parents were focused on their dependent and adult children. One of the consequences for parents of dependent adult children was the necessity to plan for the future needs of their dependent adult children. Because they realized a life-long responsibility for the care of their dependent adult child, parents perceived a responsibility for planning for continued care of their dependent adult child after their death. Parents hoped to develop a plan for their dependent adult child to be "well taken care of" and "happy" when parents were no longer available to provide care. However intentions and hopes do not necessarily achieve the desired results. Several factors interfered with parents' ability to develop adequate plans for their dependent adult child.

In discussing their own death in relationship to future plans, only two parents said the word "die" (Father 3 and Mother 4); other parents used euphemisms such as "when I pass" (Mother 10), "when we're gone" (Mother 7), "if anything happens" (Mother 6), and "leaving her" (Mother 8). Only one family had made definitive plans for the dependent adult child. That plan was for the dependent adult child to live in a group home near a sibling after the death of the parents. One family was hoping that the dependent child would get into some sort of supervised living situation; this individual was on a waiting list for such a placement. None of the other 10 dependent adult children was on any list for out-of-home placement. Eight families were hoping plans for the dependent adult child to live with other family members (primarily other children) would work out. Only three of these families had plans regarding with whom the dependent adult children would reside with, and all hoped that the normal child's life situation did not change to negatively affect those plans. One parent did not want the dependent adult child to live in a group home or to live with the other sibling, but this parent did not know what to do. She did not like group homes and did not wish to "ruin another life" (Mother 4) by having the dependent adult child live with her normal adult child. The last family was hoping for some new type of semi-supervised living arrangement.

Parents had attempted to make arrangements for their dependent adult child by making wills, naming guardians, arranging for survivor benefits of their pensions to be continued for the dependent adult child, qualifying their dependent adult child for

Supplemental Security Income (SSI), and talking with their other children and family members. However, this has not been successful in mitigating their concerns for their dependent adult children and their concerns about burdening their other children.

Six of the 12 parents had named a specific guardian for their dependent adult children. Two parents had made provisions for their pensions to be continued as survivor benefits to support the dependent adult child, and all of the dependent adult children were receiving SSI from the Social Security Administration. One mother expressed concern regarding the appropriateness of her will, because if too much money was left to the dependent adult child, the child would no longer qualify for SSI. Services are often tied to SSI eligibility. In this pilot study (Schaller-Ayers, 1991) elderly parents in Oregon expressed a major concern about the appropriateness of wills and trust funds for dependent adult children. Trust funds were not discussed by parents in this study. The difference may be explained by a different social environment. In 1990 Oregon pass a family support law to assist families with dependent children while a voter referendum threatens social services to family and individuals with disabilities. Also the Oregon Association for Retarded Citizens had a meeting about wills and trust funds just prior to data collection.

When parents attempted to talk with other children about the future, other children often advised the parents "not to worry, that they will take care of" the dependent adult child. Although this made the parents feel better, Father 10 reported that "to me, it's something you mention but you don't discuss." Plans that parents had for the dependent adult children were vague. For example, Mother 8 had named a guardian and hoped her dependent adult child would either live in the mother's home with a companion hired by the guardian or live with the guardian. She worried how this would affect the guardian's spouse and her grandchildren. Mother 4 and her normal child (who lives out of state) were discussing the possibility of maintaining her dependent adult child in the home with other dependent adult children by hiring a caretaker.

Even though parents named guardians, that did not imply that the adult children would live with any of the designated guardians. Mother 1 named a guardian, but talked of her dependent adult child possibly living with one of two grandchildren, an adult child out of state, or another adult child in town. Parents in Family 3 stated that they have provided as best they could for their dependent adult child and hoped that one of their two children would provide care for their dependent adult child. However, Father 3 believed that it was "a hell of a thing to ask your children to take care of their handicapped brother or sister. That's a hell of an imposition and that's a moral question."

A major concern that all parents worried about was providing for the dependent adult child after their parents' death. However, no strategies for successfully reducing this concern were identified by the parents. Father 3 said there "never will be [a way to reduce the concern]. . . .I'm certainly not going to be able to safeguard S. It's more important to try to safeguard S. because he can't make it on his own like his brothers." In planning for the future, the needs of dependent adult children took precedence over other children. Mother 12 said "Our daughter understands that he [meaning her brother] comes first as far as whatever we leave. It will go to his care." In thinking of the future, Mother 11 found that "If I think in the future too much, I get myself so emotionally upset, that . . . I can't handle that day, so I don't do that. And that may be wrong."

In making plans for the future all parents worried about how a dependent adult child would cope without the parents. For example Mother 2 said

> I'll get very melancholy and I'll start crying and just wondering what's going to happen to him [meaning dependent adult child] you know. And . . . if I was to go before my husband, I don't think that my husband would have the patience to care for him; I don't know. . . . He [meaning the husband] says I'm just a worrier. But they get along just fine. But I don't know, he just doesn't have the patience.

The literature consistently reports that parents do not plan adequately for the transfer of responsibility of their dependent adult child upon the parents' death. Wood (1993) has proposed four factors to explain why parents do not make adequate plans. First, parents expect to outlive their dependent adult child. When these dependent adult children were born, the life expectancy of children with developmental disabilities was short and parents were consistently advised of their child's limited life expectancy. Wood (1993), Grant (1990), and Krauss (1990) also reported that a few parents expressed that the desire for the dependent adult child to die prior to the parents. The death of the dependent adult child would relieve other family members of future caregiving responsibilities and the parents' need to plan for the future of the dependent adult child.

The second factor identified by Wood (1993) was that the stigma attached to developmental disabilities. When the dependent adult child was born stigma may have caused parents to be overprotective. This circumstance may have led parents to experience ambivalence about entrusting the care of their dependent adult child to others, especially if not known to the parents.

Third, over time parents and dependent adult children had developed mutual dependencies, each providing care to the other. Finally, the fourth factor identified by Wood (1993) was the parents' perceptions of the lack of acceptable alternatives for the dependent adult child. Additionally, Gold (1987) suggested that future planning meant "facing final separation" (p. 20) from the dependent adult child.

Heller and Factor (1991) found it surprising that parents did not discuss future plans for a dependent adult child with their other children, especially when those other children were presumed by parents to assume care. The question arises if the lack of discussion was the result of unwillingness by the parents, or other children, or a combination of both? Parents in this study discussed both the difficulty of discussing plans and their other children stopping the discussion of future plans. When the discussion of future plans came up, a daughter of Mother 11 told her mother that she couldn't "handle" the discussion at the moment. Gold (1987) has suggested that just as parents have difficulty planning because of the implications of final separation, other children may have difficulty discussing plans that revolve around their parents demise.

Traits Used for Successful Parenting

When asked what one needed to care for a dependent adult child, parents identified traits of the parenting role. Roles are used to organize one's behavior and each role has a set of traits or characteristics to distinguish one role from another (Lofland & Lofland, 1984). Once roles are defined by traits, tactics are necessary to maintain the role. The meaning that parents give to the label of parent of dependent adult children had consequences for role tactics. Role tactics are identified by Lofland and Lofland (1984) as the dynamics of performing the role. "Once a role is occupied, there are tactics for rising in it . . . for maintaining a position in it or defending against difficulties encountered" (Lofland & Lofland, 1984, p. 82). Parents identified 26 traits needed in their role of parent. The first trait identified by every parent was that of patience. Other major traits identified by parents included determination, perseverance, understanding, flexibility, and love. Parents also stated that they had to teach, to have acceptance, to find activities for the dependent children, and had to protect the dependent adult children.

Patience was considered a learned trait, and parents perceived that they had more patience with their dependent adult children than they did with their other children. Parents reported that it took more time for a dependent adult child to learn new skills so the parents needed to have the patience to repeat things over and over again. Fathers frequently stated that mothers had more patience than did they. Although the parents learned patience was an important quality to be expressed, they continued to find that being patient was difficult. For example, Father 5 said

"Sometimes you would like to murder them. But that's the way you feel sometimes. [It's] extremely frustrating sometimes." Mother 5 puts into perspective the loss of patience "I lose patience with S. But that doesn't say I don't understand and don't love him." Mother 9 believes that one would "go nuts if you don't have patience."

Parents believed they also needed determination (defined as a mind set to reach a particular goal) and perseverance (the ability to physically continue until a goal was reached). While determination and perseverance were requisites for coping with their dependent adult child, they also were requisites for obtaining social services. Parents discussed the necessity of fighting for services, pressing for implementation of laws and regulations, and, if necessary, using the judicial system to force provision of services. (This is discussed in greater detail in Chapter 5.)

Flexibility frequently was mentioned by parents as a necessary trait. Father 7 reported that flexibility was important: "with a handicapped child, I think you have to be flexible no matter what. There's no way you can have it one, two, three, four, because sometimes it gets jumbled in the process." Often, flexibility was mentioned along with patience, perseverance, and determination.

Parents stated that they had to understand the needs of dependent adult child and the dependent adult child's perspectives regarding what was happening. Understanding was important because "It's not an easy life for a child, you know,. . . especially if they are borderline" (Mother 8). Three of the mothers with daughters found it very difficult to explain to their daughters why they could not marry. Parents had an understanding of their child's desire to marry but could not perceive it as an viable option for the dependent adult child. The effect of a dependent adult child's potential marriage was perceived by Mother 10 as:

> She doesn't know the responsibility of marriage, like how much money it costs for an apartment, and taking care, how they can get to the store, and getting groceries, and it would just be like us having two children all over again.

Parents said it was necessary to get information or knowledge to adequately understand the needs of the dependent adult child. Mothers talked of reading all they could find, picking up information when ever available. Three parents went to college and received degrees in special education in an effort to learn more about their child and how to help the child.

Love for the dependent adult child was recognized as important by parents. "Love is a part of the caring, too. In spite of all else, we love him" (Mother 12). Parents acknowledged that not only did parents "have to have a lot of love for the child" (Mother 11), but the dependent adult child needed "a lot of love" (Father 7).

Acceptance was a trait that was learned over time. For Father 10 acceptance was not based on knowing, "We never get the answer . . . 'Why me?' We never have. So we go on accepting something we don't have answers [for] . . . Unconditional, acceptance instead of knowing." Parents disclosed that there were two basic types of acceptance, acceptance of a life-time responsibility and acceptance of the "way things are." Mother 8 said that "I feel very sorry for people who can't accept, you have to be able to accept this." Additionally, Mother 7 said, "This is the way it is, and you just have to make the best of it."

Because parents attempted to balance independence of the dependent adult child with protection, the trait of protector was both important and vexing. Parents desired that their dependent adult child do what he or she was capable of, however, they wanted to avoid potential harm. Parents worried about people who might manipulate, molest, or injure their dependent adult child. Father 7's perspective was that "I would imagine that D could be a lot more independent if we were to go ahead and turn her lose and let her learn from hard knocks, but I would just as soon not have to put her through that." Father 3 believed that

> I'm sure we tend to be overprotective. We don't think it's overprotective. Others may view it that way; we just think it's being prudent. That's the way the world is. We don't dwell on it but we pay attention to where he is and what he's doing and who he's with. And he's never with people we don't know or trust. In fact, most of the time he's just with us.

Teaching their dependent adult child and finding meaningful activities for the dependent adult child were additional tactics used by parents. Teaching was not considered the learning of new knowledge or skills but maintaining and reinforcing the currents level of knowledge and skills. Father 10 found that "it's [a] constant renewal of training." With her daughter, Mother 7 was "continually thinking 'she's still in the learning process' and that 'we want to help her as much as possible.'" Maintaining current levels of capabilities was perceived to include finding meaningful activities for the dependent adult children.

Inactivity was associated with regression in dependent adult children. Parents believed it was important for their dependent adult child to have something to do. Mother 10 stated, "our children need something to do every day, especially something with education." Mother 11 supported this view when she said "I find that when these kids sit at home, that they regress terribly. . . . I want her to be kept mentally active and physically active so that she doesn't regress." Because activities were not readily available, parents needed to find appropriate activities for their dependent adult children.

Parental Practices and Strategies

Lofland and Lofland (1984) define practices as activities that "participants regard as unremarkable, as a normal and undramatic feature of ongoing life. It is only the analyst who, by collecting instances of it . . . singles it out as something remarkable." (p. 75). To maintain practices, strategies were developed. The meaning of being a parent of a dependent adult child affects the practices of parents. Parents have a variety of practices that they perform regularly. The practices related to the meaning of parenting a dependent adult child were classified as protecting, nurturing/caring, enhancing development, and networking with other parents of dependent adult children. Associated with each of these practice themes were strategies parents used on a daily basis.

Protecting practices.

Protecting practices were defined as those strategies parents used to shield a dependent adult child from real or potential harm. Harm was perceived as physical, sexual, or emotional abuse; manipulation by others; unintentional injury; and getting lost. Protecting strategies of parents included knowing where the dependent adult child was suppose to be at all times, being able to observe the dependent adult child, having security doors with key locks and window guards (present in 10 of the 12 homes), leaving dependent adult child home alone for only short time periods during the day time (never overnight), discouraging the dependent adult child from answering the door without permission or telling telephone callers that the parent was not at home, and allowing only one mishap in an independent activity. For example, Mother 2 allowed her son to take the bus to and from the sheltered workshop after an extensive training period. Upon missing the bus one day, he accepted a ride from an unknown person who delivered him safely to his home. The same bus stop, however, was also used by the Juarez, Mexico bus company. One day when he did not return home on time, his mother feared that her son had either boarded the Juarez bus or had gone with someone with the intent to harm him. The son no longer is allowed to ride the bus.

Nurturing/caring practices. Nurturing/caring practices were defined as those activities parents undertook to provide care and love to their dependent adult child. Nurturing/caring practice strategies parents identified were fixing meals, taking dependent adult children to activities, reminding their dependent adult child to bathe and wash hair, doing laundry, seeing that the dependent adult child was dressed nicely, buying clothes, taking care of the child when he or she was ill, and loving the dependent adult child. Parents provided the primary transportation for their dependent adult child, taking them to activities such as sheltered workshops, Special Olympics activities (sometimes two to three activities every week), monthly Friday night dances, and getting together with friends. Parents feared losing the ability to drive and the impact that would have upon them and their dependent adult child. Parents also reported that, except for sheltered workshop activities, they were involved in the activities of their child. They attended practices and sport meets, volunteered as coaches, and chaperoned at the dances.

Enhancing development practices. Enhancing development practices were defined as those activities parents engaged in either to improve or more likely to maintain the capabilities of the dependent adult child. Although parents believed their dependent adult child had progressed about as far as he or she would, the parents continued to use strategies that could potentially enhance or maintain their child's current level of functioning. Mother 10 continued with her daughter to

> try to teach her, you know, how to count money . . . so she won't forget everything. Because they do forget, if you don't keep on, you have to go over and over and over and over. . . . She still doesn't know how to count big money; just little money. And sometimes you know during the day I sit down with her, just like you do in kindergarten. I sit and try to, so she won't exactly forget.

Parents talked of finding activities that were appropriate for the child to do around the house such as taking out the garbage, weeding the yard, and cleaning the house. Parents found volunteer activities for their dependent adult child when sheltered workshop positions were not available. While parents also encouraged their dependent adult child to complete tasks, the parents also attempted to have realistic expectation about their dependent adult child's capabilities. There was an expressed desire to keep the dependent adult child busy to prevent regression and because the dependent adult child wanted something to do. The fear of regression was real for these parents. Father 5 stated that his son had

> "gone backwards now. You notice it. . . . you can see in his handwriting [of] different words that he misspells or something like that. He didn't use to do that. He regresses so much now that I'm afraid what he'll be like in 4 or 5 more years.

Parents of children with Down's Syndrome discussed their concerns regarding the risks of Alzheimer's disease. Two parents' concerns were aggravated by the fact that there was a positive family history of Alzheimer's disease, a spouse and an older sister of the parents.

Nurturing practices. Nurturing practices were evident from the interviews and, also, from observation of parent child interactions. Parents and dependent adult children would often hug, hold hands, kiss, and sit near each other. Parents who identified their dependent adult child as being between the developmental ages of five and ten tended to speak to the dependent adult child in a diminutive form, using terms of endearments. Praise for drawings and finished tasks was also evident. Parents reported getting "thrilled" over the little things in their dependent adult child's lives and making them into events. For example, Father 7 related that "anything that she does, even if it is not astounding, we make it into something to build her up, most definitely."

The practice of networking with other parents. The practice of networking with other parents was defined as activities parents engaged in to maintain contact with other parents who were sources of information and support to the parents themselves. Parents identified strategies for maintaining their networks, such as meeting at sport practices, telephoning, and becoming friends. Parents reported that maintaining a network with other parents of dependent adult children was an important activity for them. Other parents were a significant source of information in terms of new services, solutions to problems, and verification of rumors. Parents reported hearing of changes, services, and other important information via the "grapevine," which was identified as being very effective. Other parents as sources of support and the parent network, as a social unit are discussed more fully in Chapter 5.

Day-to-Day Life

A person's day-to-day life included philosophy and lifestyle. Lofland and Lofland (1984) define lifestyle as the "global adjustments to life . . . of similarly situated persons" (p. 91). Having a dependent adult child live with parents affects the day-to-day life of the parents. When discussing their present lives, four themes emerged regarding parents' daily lives. Parents reported that they "take one-day-at-a-time philosophy," they were always a threesome if both parents were in the home (or a twosome if one parent was in the home); they were restricted in what they could do; and they were content with the way their lives were. Parents also reported that they were "more accepting of the situation than when we were younger" (Mother 12).

"One day at a time philosophy. A philosophy expressed by parents was the need to take one-day-at-a-time. All mothers agreed with the one-day-at-a-time philosophy. Four of the six fathers also agreed with this philosophy, the other two fathers stated they liked to plan. Mother 11 disclosed that "I learned to live one day at a time; it was the only way I could exist." Mother 12 echoed Mother 11 with a different twist: "You just have to take one day at a time. And it never gets better, things get worse, wish that were different but it isn't." Parents found planning for the future was somewhat difficult; however parents were evenly divided about the ability to make plans. Some parents stopped making plans. Mother 5 said "I don't make plans anymore. It's, . . . because then I don't feel let down when the plans don't pan out." Mother 4 said "you just have to live one day at time and do the best you can." Mother 1 related that a reason to take one-day-at-a-time was because "you need to manage it [meaning a problem] as it comes along. You can't worry about it . . . you can't tell what you are going to do till the problem arises. When the problem arises you take care of them." Interestingly two fathers, who said they were definitely planners and planned their daily activity, had no definite plans for their dependent adult child's future.

Daily life style. In their day to day life parents felt some restriction on their lives because they rarely were able to go anywhere without their dependent adult child. Parents whose child attended a day program had from 7:00 AM until about 3:00 PM when they could schedule activities that did not involve the dependent adult child. The parents had to ensure they were at home when the dependent adult child arrived. Dependent adult children who did not attend day programs were with the parents almost 24 hours per day. Parents reported going to the store for short periods of time (less than one to two hours) without the dependent adult child. Nevertheless, when leaving the dependent adult child home alone, parents were concerned the entire time they were away. Mother 3 stated that when she left her dependent adult child at home alone for short periods of time she "prays a lot." Parents reported scheduling their activities around the dependent adult child's activities such as Special Olympics practices and summer camp activities.

Parents described never, or infrequently, having the opportunity to celebrate a night out without the dependent adult child. Parents indicated that their lives were restricted or there was a loss of freedom. Mothers often felt that there was "no time for me." While parents wished for an opportunity to be alone, they reported that "it's been so long since we've done it, it's not a problem, I guess we adapted" (Father 3). When parents did go out without the dependent adult child, friends and family always asked where the dependent adult child was prior to greeting the parents. Mother 2 referred to her dependent adult child as her "shadow" and "guardian angel", and Mother 3 described her dependent adult child and herself as "joined at the hip." Two other mother's agreed with Mother 3's description.

Always having dependent adult children with parents was not only a physical experience but also a mental phenomenon. Whenever dependent adult child was not physically present they were mentally present for the parents. Mother 11 described this situation

> Because you can't . . . . think of yourself; you have someone else that you have to think of 24 hours a day. . . . They have to be with you in, not physically, but they have to be with you in mind practically all of the time.

Although parents felt restricted, they also expressed contentment with their lives and a sense of completeness. Overall, parents were satisfied with the way their lives were. Mother 9 commented that "We are relatively happy with what life is doing now . . . and I'm content." Only one family discussed a desire to have the dependent adult child out of the home now. Mother 5 said "I mean it started out the two of us and I'd like to end up the two of us. . . . [but] there's nothing I can do about it so accept it , I live with it." Parents (including Mother 5) also stated that they would not know what they would do without their dependent adult child. Mother 5 said "Without him my life would be a whole lot less than it is." Mother 6 said

> I don't consider D. a cross, I guess. I used to, I don't know, I guess I consider her, in a way, our greatest blessing. . . it's one of the most difficult things we've ever done. I can't tell you, it's (sigh), it's so mixed; it's just so mixed. But it's just so much a part of my life. I can't even imagine it without [her]. . . I can't.

Even though parents had struggled in the past and may continue to do so in the future, Mother 1's perspective of "just relax and go from day to day. And really, when you read about all the problems of the world, it's pretty simple. . . I really enjoy S" was similar to that voiced by other parents regarding their lives.

Roberto (1993) suggested that as dependent adult children reach adulthood parents experienced stability in their parenting situation. After 20 to 40 or more years of parenting, parents had learned to cope with responsibilities and knew the capabilities of their dependent adult child. Wood (1991) indicated that parents' satisfaction with their lives was related to their adjustments to life's difficulties. Brubaker and Brubaker (1993) proposed that with the life long development of skills to handle crises, elderly parents might have found that the stressors of old age did not result in higher levels of stress but continued levels of satisfaction.

Summary. The label parent's preferred and which symbolized roles they performed in caring for their dependent adult child was "parent." Parents did not perceive that the labels "caregiver" or "provider" adequately represented what they did. In fact, parents believed that the label "parent" of dependent adult children included caregiving and providing responsibilities in addition to other parental tasks, such as love and discipline. This was in opposition to the literature that refers to these parents as caregivers, and to the agencies that refer to them as providers.

Although parents perceived that parenting their dependent adult child was not different than caring for other young children, they did not see an end to their parenting responsibilities with their dependent adult child as they did with their other children. Parents believed the dependent adult child would be their responsibility until the death of the parent or the death of the dependent adult child. Parents also observed that the parenting activities they were doing were no different for their dependent adult child now than they had been for years. Reasons given for the difference in duration and the continuation of the same parenting activities for several years were based on the perception of the dependent adult child's inability to independently perform activities of daily living and instrumental activities of daily living.

Parents' abilities to continue parenting were taxed by developmental issues of both the dependent adult child and the parent. Some aspects of parenting became easier: for example, parenting activities switched from direct provision of activities of daily living to supervision of those activities. Conversely, some things became more difficult such as handling sexuality issues, and contending with the dependent adult child's adult legal status though functionally a child. As parents aged they noted that they became more realistic in their expectations, less hopeful, less willing to fight for services, and less optimistic that agencies would be able to assist them and their dependent adult child. Parents also found that the parenting activities had become less intense for them.

Parents' concern for the future revolved around the care of the dependent adult child. Parents hoped for good health, not for their own benefit but for the benefit of their dependent adult child. Parents wanted to remain healthy at least until the dependent adult child died so the parents could continue to provide the care needed. Plans for their dependent adult child's future were full of hopes and lacked concrete plans. Parents found making adequate plans difficult and something they worried about constantly but did not discuss with other family members. Parents perceived that other family members did not wish to discuss plans.

The meaning of being a parent of a dependent adult child affected the enactment of the parental role. Parents believed that role tactics for successful parenting practices included patience, determination, perseverance, understanding, flexibility, loving, teaching, accepting, protecting, and to finding activities for the dependent adult child. Patience was the first role trait identified by all parents. Parents identified strategies for all of the role trait activities.

Several practices were affected by the meaning of being a parent of a dependent adult child. The practices of protecting, nurturing/caring, enhancing development, and networking with other parents of dependent adult children were identified. Associated with each of these practice themes were strategies parents used on a daily basis.

Parents identified four themes related to the effect on their life of having a dependent adult child in the home. These were to have a take one-day-at-a-time philosophy, they were restricted in activities, the dependent adult child was always with them, contentment with their lives. Having a dependent adult child in the home presented a dichotomy: it was the most difficult thing parents had done while also being their greatest blessing.

Parent's Perspective of the Meaning of Being a Dependent Adult Child

The meaning of being a dependent adult child in need of parenting is complementary to the meaning of being a parent of a dependent adult child. The parents' perceptions of what it meant to be a dependent adult child influenced their role of parent. Four themes emerged from the data regarding the parents' perspective of being a dependent adult child. These were functionally a child, high school graduation as a significant life event, parents' concerns for quality of life, and encounters with the health care system and health professionals. Parents' assessment of their children was not based upon medical diagnoses, causes of mental retardation, or professional prognosis of capabilities, but upon the parents' perception of the dependent adult child's functional capabilities. Parents frequently talked about what their dependent adult child was capable of doing instead of what he or she could not do. For example, Mother 2 said that she "could leave her son alone for two hours," and not that she could not leave him alone for more than two hours.

Functionally a Child

Even though parents knew that their dependent adult children were adults, parents classified their dependent adult children as children. For example Mother 5 said that "as far as I'm concerned he'll be a kid until I die." When describing the dependent adult child, parents often assigned dependent adult child to functional ages. Parents said their dependent adult child was "like a little four or five year old" (Father 7), "just like having a 9 or 10 year old child for 37 years" (Mother 12), and "like a 12 or 13 year old" (Father 5). Parents also perceived that their dependent adult child sometime thought of self as an adult in wanting to do the same things their siblings were doing, such as driving, living independently, being married and having children. However, some dependent adult children continued to believe in Santa Claus and the Easter Bunny. Mother 9 related an incident at church when the minister said

> "Come on children." Boy he was right up there. . . . And he's going to be in the [children's] Christmas program. And he's going to be the biggest angel in the batch. . . . He's just very happy with more his social age groups than his chronological [age group].

Primary reasons given by parents for their adult child's dependency was the adult child's inability to be independent. By independent, parents implied that dependent adult child should be able to shop and pay for items, get to destinations by themselves, perform activities of daily living and instrumental activities of daily living without supervision and or direct care, and reason or make appropriate judgments. To some degree the dependent adult child's dependency was increased by the parents' perceptions of today's world. For example, Mother 1 said that you "can't be too protective of him. . . . This is a funny world nowadays . . . there are weird people [out there]. . . a lot more weird than these kids. . . .things today, you just don't know what's going to happen."

Parents expressed concern for their dependent adult child's vulnerability to potential manipulation and molestation because of his or her lack of judgment. Mother 1 explained that dependent adult children were handicapped because "they don't have the reasoning that others do." Because of this concern, parents tended to avoid situations where the dependent adult child could be manipulated. For example, Mother 11 reported that

> I hesitate, lots of times letting her do things that she wants to do, I think she's capable of it, I think she would do all right, but you never know what

> someone else is going to talk her into and do. Uh, she doesn't manipulate that easy, but she still can be manipulated.

Mother 2 reported that her concern about manipulation was "the reason why I'm always with him . . . to see who he's talking to, and what he's talking about, and to see that they don't manipulate him."

Parents also perceived that their dependent adult child was not able to survive without help. Nonhandicapped children "will succeed because they're a human beings with all their [faculties]. . . . [Our children] with disabilities cannot succeed without our help. . . . [They] certainly can't succeed without somebody's help so it's more important, it's more critical" (Father 3).

Another factor interfering with the dependent adult child's ability to be independent was the inability to handle financial matters. Mother 10 illustrated this by stating that her daughter

> couldn't go to the store and get her own groceries and count the money and things like that. She wouldn't know what change she should get back or what she should pay. . . . I don't think she knows the value of money. . . . She needs help.

Even Mother 6 whose dependent adult child was in an adult educational program and has a checking account, believed that her child would need continuous supervision regarding financial matters and never will be independent.

Additionally, parents perceived that their dependent adult children could never be financially able to provide for their own needs. Although dependent adult children with sheltered workshop placements were paid, they were paid by the piece, a practice resulting in far less than minimum wage. Reported income ranged from $10 to $40 per month for a 30-40 hour work week. Even with the addition of SSI, parents did not believe that dependent adult children would be able to afford independent living.

In addition to financial dependency, parents believed that their dependent adult child could not safely cross busy streets. Parents said at times their dependent adult child was oblivious to the traffic on the roads. Besides busy streets, parents were concerned about their dependent adult child being unable to find their way home or to another destination and possibly getting hurt when out alone. Because of these concerns, parents did not allow their dependent adult child to walk to sheltered workshops, to stores, or to visit with friends that were within walking distance.

Wood (1993) suggests that parents may keep their dependent adult child as functionally a child by their interactions with the dependent adult child. Wood (1993) reported that family caregivers "infantilized" the dependent adult child and he or she was "often referred to by 'pet' names or in diminutive terms and spoken to in a patronizing tone" (p. 103). Parents in this study had "pet" names and talked in diminutive terms to their dependent adult child. However, this was perceived as a nurturing practice of parents (Refer to parenting practices section). In addressing the dependent adult child, parents used language appropriate for the perceived functional age of their dependent adult child. Parents also used parenting activities that would be appropriate for children without disabilities at the same age as that perceived for their dependent adult child. For example, parents would not allow a four or five year old to cross an unmarked four lane busy road unaccompanied. These parents did not allow their dependent adult child who was viewed to be functionally four or five years old to cross that same street alone.

Significant Life Event

All parents whose dependent adult children were mainstreamed reported that graduation from high school was a significant life event for themselves and their dependent adult children. Lofland and Lofland (1984) define significant and remarkable events as "episodes." Episodes may represent turning points or rites of passage in an individual's life. The meaning of being a dependent adult child had an unique affect on the implications of high school graduation.

Mother 5 summed up the high school graduation experience this way:

> You know the most special time of S's life I think was on his graduation night and . . . three, four, five hundred people graduated that night and they . . . walk across the stage to get their diploma. When S got up, and I'm crying even thinking about it, when he got up to go across [the stage] . . . every kid in that graduating class stood up and clapped and hollered. He was so proud you know. And he turned around and looked up at us and shook his diploma. . . . it really made me feel great when they all stood up and clapped and yelled his name. I think that was the biggest night of his life I don't think he'll ever have anything to match it. I think . . . it was one of the most important, if not the most important thing, that's ever going to happen to him.

Graduation meant different things for the dependent adult children and their parents. Mother 10 saw graduation as retirement--her child had nothing to do and she had to find activities for her child. Mother 9 found that graduation meant that her son understood that "it was the end of his schooling. And he never asked again 'Where was school? Where was the bus?'" However, Mother 11 found that graduation also bought about disappointments for her dependent adult child "because her brothers and sisters all graduated from high school. They went to college and then got married. . . . And I think that was a disappointment for her."

For parents their dependent adult child's graduation was a significant rite of passage for their child. Parents discussed the excitement surrounding the graduation ceremony, their dependent adult child graduating from a regular school and receiving a regular diploma. However, for the parents graduation meant that the dependent adult child would be home with them every day until an appropriate day program became available. Graduation also signaled a sharp reduction in the amount of services available to their dependent adult children. This is discussed further in Chapter 5.

Quality of Life

Quality of life was defined as the adequacy of adjustments to life and the ability to provide for tangible and intangible needs. Because parents perceived their adult child was dependent, they were concerned about their ability to maintain an adequate quality of life. Their concerns for the present and future quality of life for their dependent adult child was perceived by the researcher to be a consequence of parents' meaning about being a dependent adult child. Of the six parents asked, all six agreed that their concerns for their dependent adult child's quality of life were in part because of their belief that their dependent adult child was incapable of surviving on his or her own. Lofland and Lofland (1984) state that identification of "causes" in qualitative research explains the occurrence of behaviors in situations in social realms. Questions asked to identify causes include "what facilitates its occurrence? [and] . . .in the presence of what conditions is it likely to be an outcome?" (Lofland & Lofland, 1984, p. 100).

Parents perceived that they were responsible for enhancing, maintaining, and protecting the physical, social, and emotional environment of their dependent adult child. Parents attempted to create a good quality of life for their child, one without hurt while promoting functionality. Mother 6 described her attempts and her dilemmas:

> should I screen her from everything? Should I expect her to be perfect in everything? A normal child isn't. A normal child isn't screened from hurt or perfect in every way. And yet do you try to create that kind of environment for the handicapped child? Yeah, you do.

Father 3's perspective on quality of life was

> Quality of life is important; more than life. Maybe that's age. . . I'm more interested in living, depending on the quality of my life. The best of quality for your child is, I think a major concern. You think you go through all of this thinking what is the child's quality of life. . . . I just provided the best

> quality of life that I could. . . . That's why you take the time to do the Special Olympics and worry about not being able to drive.

Parents hoped for two outcomes: first, that the dependent adult child would be happy and well taken care of, and second, that the dependent adult child would remain healthy and not become more disabled. Fear of increased disability was based upon the effect a disability would have on the dependent adult child and upon the parents. Mother 2 related her concerns for her dependent adult child being hurt during Special Olympic activities because of advanced aging of his skeleton. She expressed her concerns as "lets hope he doesn't get hurt or completely handicapped, and I would have to, and at our age, take care of a paralyzed child." Mother 10 echoed her concern with

> Sometimes I think about what if D. gets disabled. You know, what if I have to take care of her. What am I going to do if I can't take care of her? You know, you don't know what's going to happen to any of us, but I especially worry about her.

The future quality of life for their dependent adult child was especially worrisome for parents. As parents worried about their dependent adult child, they also worried about their other children and the burden parents would leave these children. Mother 5 stated that she wanted to find a place where her son would be "happy, comfortable and safe." Mother 1 wanted her son "to be with people he knows and trusts." Whereas Mother 11 stated

> One of my big hopes and dreams [for her daughter's future] is to find

> something for her . . .[that will continue her life style], we don't have a fancy lifestyle as you can see, we don't live fancy, but she has her things, her own items like her TV and her stereo and stuff; and, I know . . . [group homes] have to be careful, but the kids can't have those in their dorms and it makes it bad because . . . it's taking part of them away.

With their concern for the dependent adult child, parents worry what effect group homes might have on their child. Mother 10 questioned

> if none of her sisters or my relatives take her, you know I think about her being in one of those homes. Would she still be the girl she is now, and how would she get on.

Father and Mother 3 worried about institutionalization, in fact they feared "institutionalization. . . . Institution sucks. I visited several of them. It's no way for a human being to live."

With the concerns about the quality of life of the dependent adult child, and the general apprehension about group homes, parents turned to their other adult children to oversee the quality of life of the dependent adult child when the parents were no longer able. Parents expressed a concern about burdening their other children and impacting their other children's quality of life. Mother 4 voiced a concern of "ruining" her other child's life by placing this burden upon her. Mother 6 expressed her concern by saying

> My boys are really good and they say "Don't worry about it; we'll take care of her", but I hate to burden them with it. I don't know what's going to

> happen. That's my biggest nightmare.

The relationship between other children and dependent adult children is more fully discussed in the Relationship section.

Encounters with the health system and health professionals. Lofland and Lofland define encounters as "a tiny social system formed when two or more persons are in one another's immediate physical presence and strive to maintain a single . . . focus of mutual involvement" (p. 78). Most encounters last only for brief periods of time. Many individuals with developmental disabilities also have other health problems. The number of health problems dependent adult children in this study had was reported to be from zero (two individuals) to five (one individual) with an average of approximately two health problems per dependent adult child. Because of delayed development, congenital health problems, and usual childhood illnesses, dependent adult children and their parents have had frequent encounters with the health system and health care providers. Being an individual with developmental disabilities had unique affects on the health care encounters parents experienced with their dependent adult child.

Because all dependent adult children in this study received SSI, they were all eligible for Medicaid. Five of the dependent adult children were also eligible for military health care benefits. A problem encountered with Medicaid was finding a physician who would accept Medicaid clients. A problem encountered with the military health care system was the transfer of physicians in the normal course of military assignments. These parents frequently had to adjust to new physicians.

Receiving appropriate care was considered a problem. Up until the age of 21 most dependent adult children received care from pediatricians. After the age of 21 dependent adult children received care from other specialists such as internists and family practitioners for routine health care. Mother 8 related her experience in seeking health care for her daughter as

> She was 21 when they [meaning the clinic] no longer had specialized clinics for her . . . the last three or four years I haven't been satisfied with the doctors that have taken care of her, and I don't like to do it but, I've gone from one doctor to another, I've gone to, lets see, one, two, three doctors. . . . They all seem about the same. [They say] "We don't know what this is and we don't know that [is]". . . . It's difficult to have a physician who would be helpful because they can't treat the whole person, . . . so they would kind of scuff off [problems].

Parents also believed that health providers were not interested in providing care to their dependent adult child. Mother 6 found that health providers had an "attitude [of] . . let's get this funny child out of my office. . . . [And] oh well, let's not spend too much time with her." This has been a long term problem for Mother 6 although she believed it was a "little better" now. Mother 9 reported a similar problem with the health clinic her son used when she stated "I felt very much like they were . . . trying to throw us out; trying to not help us when we needed it."

Children with developmental disabilities, especially those with Down's syndrome, are often difficult to understand because of their inability to clearly enunciate words. Individuals with mental retardation may not be able to clearly describe symptoms they experience. Mother 8 found it difficult "communicating to a doctor what is wrong with D from her complaints to me . . . because it is very hard to interpret what she's telling me in order for a doctor to know what is really wrong with her."

Summary. Parents perceived their dependent adult child as functionally children with numerous capabilities. The capabilities or the strengths of the dependent adult children were emphasized by the parents, they did not dwell on what the dependent adult children could not do, but what they could. Parents' perceptions of the dependent adult children's functional level determined how they were treated by parents. Parents balanced protection and independence in a way they perceived as safe.

High school graduation symbolized many things; for example, adulthood, retirement, loss of services, and the highest expected achievement. High school graduation was a rite of passage that for many parents seemed like a "dead end" as the dependent adult children went on waiting lists for sheltered workshop positions and other formal supports ceased. High school also symbolized that these children were different than other children. Other children went off to college and joined the work force; dependent adult children did not.

Maintaining a quality of life for their dependent adult child that was acceptable to the parents was a major concern for parents. Parents' efforts to engage their dependent adult child in meaningful activities was related to maintaining a desired quality of life. Parents hoped for two results for their dependent adult child, that he or she would be happy and taken care of and that he or she would remain healthy. However, parents grappled with their wish for their dependent adult child to remain healthy and at the same time wished dependent adult child would die prior to the parents.

All but two parents believed that group homes could not provide the quality of life for their dependent adult children that was desired. The parents' other children were deemed more able than group homes to provide what was needed by a dependent adult child. However, with other children caring for a dependent adult child, parents were then additionally concerned about the quality of life for their other children.

Parents perceived that because their dependent adult child had developmental disabilities, health care providers did not always take the necessary time to provide care. Parents discovered that health care providers who provide services to adults had insufficient information regarding developmental disabilities. This caused a dissatisfaction with the level of service provided to dependent adult children.

Additionally, parents had difficulty communicating with health care providers what problems were being experienced by the dependent adult children. Because their dependent adult child could not precisely describe what was wrong and because of problems with enunciation, parents had difficulty interpreting to health care providers information needed for care decisions.

Relationships

Lofland and Lofland (1984) define relationships as "two parties who interact with some regularity over a relatively extended period of time, and who view themselves as 'connected' to one another" (p. 83). The major relationship that emerged from the data was the relationship between the parents and their dependent adult children. Additionally, the perceptions parents had about the relationship between their other children and their dependent adult children also emerged from the data.

Relationship of Parent and Dependent Adult Child

Parents perceived that they were connected with their dependent adult child. Mother 3 said that she and her dependent adult child were "joined at the hip." Other mothers agreed with her statement. In describing their relationship with their dependent adult child, parents discussed different types of relationships and the consequences of the relationship.

Types of Relationships

Lofland and Lofland (1984) state there are many types of relationships, that relationships change over time, and that relationships have different qualities. Parents identified two different types of relationships that they maintained with their dependent adult child. These relationships were parent-child, parent-adult child. The parent-child relationship was a continuation of the type of relationship parents and dependent adult children had established shortly after the child's birth. The parent-adult child was perceived as the relationship parents and dependent adult child were attempting to establish sometimes. A mutual help or reciprocity quality of the relationships between parents and dependent adult child was also identified.

Parent-child relationship. The parent-child relationship was defined as a vertical relationship, with the parents being the authority figures and dependent adult child being dependent. The parent-child relationship was the dominate type of relationship that parents and their dependent adult child maintained. This relationship possibly continued and remained the predominant type of relationship because both parents and dependent adult children perceived the dependent adult children as children and not as adults. When talking about their dependent adult child parents frequently referred to them as "children" and "kids." Mother 9 referred to her almost 30 year old dependent adult child as my "little child. . .[my] little sweetheart." Parents' other children were often referred to as "my daughter" or "my son." Dependent adult children often called their parents "mommy" and "daddy."

Dependent adult children asked parents for permission to engage in activities, to spend money, and for parents to transport them to activities. Mother 8 reported that she finds her "self treating her [dependent adult child] as a child . . . you know it's like trying to talk to her, you know, to correct her."

Both mothers and fathers observed that their dependent adult child had a stronger bond with their mothers than with their fathers. The mothers' stronger bond with the dependent adult child was seen as a result of their long term, everyday interaction. Mother 2 referred to her dependent adult son as a "Mamma's boy." Father 8 verbalized that

> there's such a strong bond between you [mother] and S., that I hope the boy is never separated. Extremely strong bond. Mine is more supportive role, it's not as strong a bond.

Additionally, both mothers and fathers reported that fathers' involvement with the dependent adult child had increased since the fathers' retirement. Father 10 said that he has more opportunity to observe "her activities, I get a chance to see her more, . . . than when I was working." His wife reported that "since my husband has retired, I think he has more patience with D."

Parent-adult child relationship. Parent-adult child relationship was defined as the relationship between parents and adult children. The relationship become more horizontal when both parents and adult children have similar status in the relationship. This was the type of relationship parents had with their other children. With their dependent adult child parents perceived that because their child was an adult and "have the right to make choices" (Mother 6), these parents attempted to develop a parent-adult child relationship with their dependent adult child. All parents, except one, reported that they tried to treat their dependent adult child more like an adult. The one mother who did not, stated that she "should."

In attempting to treat their dependent adult child as an adult, parents stated they attempted to give the dependent adult child choices when possible in clothing selection, purchasing items, and decisions about self. Attempts to treat their dependent adult child as an adult, allowing them to make own decisions generally only occurred in situations of minimal risk to the dependent adult child. Attempting to treat their dependent adult child as an adult was not easy for parents and was "something you've got to work at." Mother 6 related this incident about trying to treat her 24 year old daughter as an adult:

> I have to force myself to do it [treat dependent adult child as an adult], sometimes. Like the other night, I got up in the middle of the night . . . and I heard the TV on, it was 20 to four in the morning. And I went up, I said " What are you doing up at this hour?" You know, and then I thought to myself, now wait a minute, she wants to be up, and she has to get up in the morning and she can't get up, alright, so she has to face the consequence; leave her alone. I did yell at her, you know, and then I thought about it, I shouldn't have.

In the attempt to treat the dependent adult child more as adults, parents have also noted that they perceived their dependent adult child to be more of a friend, a buddy, and in some cases a best friend.

Mutual help. Reciprocity within relationships refers to the mutual exchange of tangible or intangible assistance. Parents expressed that in their relationship with their dependent adult children, their child was a help to parents. Mother 3 said that "I don't do much for him [dependent adult child]. He does chores for me." Parents reported that their dependent adult child did activities to help parents such as vacuum, fold clothes, take out the garbage, set and clean the table, wash dishes, weed the yard, iron, fix simple meals, and dust. Mother 10 reported that when her dependent adult child comes home and if there were dishes in the sink, the daughter would "say 'sit down and relax, I'll do the dishes' or 'I'll help.' I've never really given her special things because she'll just volunteer."

Parents also reported that their dependent adult child helped when parents were not feeling well. The daughter in family 10 had helped her father to stop smoking. Two mothers whose husbands had recently been in the hospital and three other mothers who were not presently married reported that their dependent adult child provided them companionship that they otherwise would not have. Mother 1 summed up the mutual quality of the relationship with "he helps me a lot too, he's a gofer boy. We work well together. . . . So even though you have to give to them . . . you get a lot back."

The dependent adult child also provided for the parents a continued role in life. A role the parents considered to be important. Mother 7 stated that she did not experience the "empty nest syndrome." More importantly, Mother 11 stated that

> I went through a very hard period right after the divorce, an extremely hard period, and I think if I hadn't of had her, I would probably have killed myself. . . .but with having her, it has given me a reason to live.

Parenting a dependent adult child is not a one way street. Parents did receive as well as give in the parent-dependent adult relationship. Seltzer, Krauss, and Heller (1991) proposed that parenting dependent adult children provides an important emotional and psychological benefit to mothers. Heller and Factor (1988) also reported that dependent adult children gave meaning to the lives of parents. In fact, according to Mother 11, dependent adult children give parents a reason to live.

Types of assistance provided by dependent adult children included household chores, companionship, helping parents with personal care when ill, emotional support, sharing enjoyable activities, and helping financially (Grant, 1986; Heller & Factor, 1991; Wood, 1993). Parents in this study reported receiving assistance from children in all the above areas. Mother 11 was the only parent who reported a financial benefit from having her dependent adult child living with her. In the following statement Mother 11 identified three ways her dependent adult child provides assistance, "with her Social Security and with what I have coming in, we can live very comfortably. . . .then, again, . . . I don't know if I could stand it [living] alone . . . we enjoy going places [together]."

Consequences of the Relationship Between Parent and Dependent Adult Child

Lofland and Lofland (1984) defined consequences as the effects of a particular meaning or practice. Consequences explain what happens. As a result of the relationship with their dependent adult child, parents reported that there were benefits and disadvantages.

Benefits. Parents identified several aspects they believed were good about having a dependent adult child live with them. These included making holidays special; showing love; helping; enjoying the dependent adult child; keeping active; having companionship; and, knowing that without dependent adult children, parents' lives would have gaps.

Parents said that their dependent adult child lives from holiday to holiday. Parents and dependent adult children decorate the house for most holidays. Christmas and Easter were special because dependent adult children continued to believe in Santa Claus and the Easter Bunny. Parents described some friends without children at home who do not decorate or do special activities at holidays. Mother 5 said that

> The best thing about S is the fact I don't think I'm ever going to grow up quite as fast as I would have if I didn't have him here. Because I don't . . . ever plan on growing up, growing old yes, but never growing up. And S helps keep me young. Especially at holiday time. Cause Christmas time and Easter and Thanksgiving is kids time, and I'll always have a kid. So that makes it special for me.

Every family had a Christmas tree up shortly after Thanksgiving day. It was not only the decorations and the celebration but also the excitement for the holiday shown by their dependent adult child that the parents enjoyed. Mother 7 declared

> Santa Claus is always here. . . . you still have a child in the home. I mean Christmas is always fantastic, because it's all wide eyed and fun things, and the excitement of getting ready for the holidays. And D has a problem with keeping secrets, so D and I still have to shop Christmas Eve, . . . It's always just like a little child . . . holidays are great.

Even though holidays were special times, it was the every day things that parents enjoyed with their dependent adult child. Parents said their dependent adult child was a joy to be around, he or she was such a loving child. Mother 4 said "well, we enjoy being together, we have fun, we laugh, the girls are always saying something funny, you know, those are the good things." Parents reported that "she's a joy . . . we're very lucky to have her" (Mother 7), "he just emanates love and joy" (Mother 9); "I enjoy her a lot, I enjoy her activities" (Mother 8); and "He's fun be around, he makes you laugh" (Mother 1).

Besides enjoying the dependent adult children, parents asserted that their activities and presence helped keep parents active. The dependent adult child's participation in Special Olympics not only got the parents out because of transportation needs of the dependent adult children, but many parents were volunteer coaches. One parent related learning how to swim with her dependent adult daughter. Mother 8 said of her dependent adult child "because of her I'm doing more than I would be doing if she wasn't [with me], you know." Father 7 believed that his daughter "has kept M [wife] and I young because of the way she acts about certain things."

The companionship of the dependent adult children was frequently discussed by parents with and without spouses. Parents reported missing the dependent adult child when ever the child was away, whether it was only for several hours or several days. Mother 10 said that a good thing about her dependent adult child was "we're here alone now, me and my husband, and D is here. . . . I don't know what I'd do if she wasn't here." Mother 12 related that "when his dad was in the hospital . . . I was very glad he was here." Mother 11 said

> I have never [been alone] I don't know if I could handle it . I enjoy being alone but not all the time. . . . [I don't know] whether . . . we're the type of personality that needs that companionship or because we become that way,

> because we do have each other.

Finally, Mother 2 replied that "I know I always have someone here with me. Yeah, I can always count on him."

Along with companionship many parents said they would be "lost", or "not know what to do" if they did not have their dependent adult child living at home. The dependent adult child's needs and activities had become an integral part of the parents lives. Parental activities revolved around when the dependent adult child needed to be transported, supervised, and involved in an activity. Many parents had difficulty imagining their lives without their dependent adult child living with them. Mother 8 said that

> I don't know where my life would have lead if I didn't have D, what I would have done after my youngest child left home. I really don't know but I sometimes think, well maybe, I just [would] have sat home and vegetated. . . . I often say I'm thankful that I have D.

Disadvantages. Parents said there were more disadvantages than benefits of their relationship with their dependent adult child. However, there was less description of the disadvantages when compared to the benefits. Parents often said "that's the way things are." Father 3 stated that "nothing's hard anymore. Hard is the future; the present isn't hard. And the only thing that's hard is not knowing what's going to happen." Disadvantages of the relationship between parent and dependent adult child identified by parents included a restrictions on their freedom, and trying to find mutually satisfactory activities.

Because parents perceived that their dependent adult child could not be left alone except for short periods of time during the day, parents often expressed a lack of freedom. Every plan parents made had to consider their dependent adult child's needs whether it was to go out of town for a weekend or to go the store for an hour. Parents needed to consider if they would be back from an outing prior to a dependent adult child's return; if the child was left at home what would he or she do; and if going away for the evening who could watch the dependent adult child. Parents whose dependent adult child was not in day programs expressed a new found freedom of not having to be home at a particular time when the dependent adult child graduated from high school. Even when the dependent adult child was left at home alone during the day or at night with another adult to supervise, parents expressed a lingering concern about what their dependent adult child might be doing. For example Mother 2 reported that "if I don't take him, well, I'm always worried about him anyway." Additionally, Mother 5 said

> I know that when we go into town for a couple of hours I'm always kind of leery about coming home because you know in the back of my mind there is always that thought what did he do?, What kind of trouble is he into? and it, it's going to be there for the rest of my life.

Restrictions parents felt included not being able to celebrate anniversaries alone, not having an opportunity to do anything by themselves ("a twosome becomes a threesome" [Father 10]), not being able to go anywhere they want, not having time to call their own, and considering the dependent adult child's feelings about being left alone. Mother 8 related an incident where she had the opportunity to go out one night without her daughter, however her daughter wanted to go. Mother 8's feelings about this opportunity were "I would have liked to have gone by myself but I felt bad because of D's feelings."

Because activity interests differed between parents and their dependent adult child, parents talked of foregoing particular vacation trips and seeing certain movies. Parents reported trying to find activities both they and the dependent adult child enjoyed. Parents recognized that the dependent adult child did not always enjoy the activities of the parents. Mother 5 stated that it was "kind of hard for us to find something that we all can do, that he enjoys and that we enjoy, and last longer than 30 or 40 minutes."

Summary

Parents maintained that the primary type of relationship they had with their dependent adult child was a parent-child relationship. This was a continuation of the relationship parents had always had with their dependent adult child. Possibly because of more prolonged interaction with the dependent adult child, he or she was perceived to have a stronger bond with the mothers than with the fathers. Since retiring most fathers had more opportunity to be involved in their dependent adult child's activities.

Parents struggled to treat their dependent adult child as an adult and to establish a parent-adult child relationship. Parents attempted, when it was considered "safe," to allow their dependent adult child to make own decisions. Parents remained "the key decision-makers in orchestrating the affairs" (Grant, 1986, p.338) of their dependent adult child in deciding when it was safe to initiate the parent-adult child relationship and when the parent-dependent adult child relationship was most appropriate.

A reciprocity existed in the relationships parents shared with their dependent adult child. Dependent adult children help parents with instrumental activities of daily living as well as providing emotional support. The dependent adult child also provided parents with an important continuing role, giving parents a purpose in life and a reason to live.

Although fewer in number, the benefits of having a dependent adult child live with parents outweighed the disadvantages for all but one parent. Holidays and everyday events brought enjoyment to parents. Accomplishments of the dependent adult child were important to parents and made into important events. Parents felt loved and needed by their dependent adult child.

The limited discussion of disadvantages may represent an acceptance or adjustment to those difficulties. As Father 7 stated, "we've adapted." Disadvantages were not considered difficult, but represented the "way things are." Parents considered benefits as "good things," but infrequently referred to disadvantages as "hard things."

Parents' Perceptions of Other Children's Relationship with Dependent Adult Children

Overall, most parents perceived that their dependent adult child had good relationships with their other children. Only the family that was currently seeking an out of home placement discussed their other children being uncomfortable with the dependent adult child. In exploring the parents' perceptions of the relationships of their dependent adult child with their other children two main themes developed, the process of the relationship and consequences for the other children because of their relationship.

Process of the Relationship Between Dependent Adult Children and Their Siblings

Lofland and Lofland (1984) describe processes as "time ordered series of steps or phases" (p.108). Phases in a process have "several periods whose beginning and ends are usually marked by some important change" (Lofland & Lofland, 1984, p. 84). Three steps of the relationship between the dependent adult child and their other children were identified by the parents as past, current, and the predicted future.

Past relationship. Parents perceived that the past relationship began with the dependent adult child's birth and ended when the other children leaving home. If the dependent adult child was born first then the past relationship began with the birth of the other children and ended when the other children left home. Four dependent adult children had younger siblings.

Except for one family, parents reported that other children were accepting of the dependent adult child and actively involved in enhancing the dependent adult child's development. Other children taught skills to and helped to take care of the dependent adult child. For example, other children "put themselves into helping him learn things" (Mother 9), my daughter "used to train him," (Mother 2) and "our kids were involved because we went through X [name of a program] and all" (Father 3). If other people (primarily children) made fun of or antagonized the dependent adult child, the other children "stood up" for them.

In growing up together, the dependent adult child participated with other children in family activities and had "fights" as all siblings do. Mother 8 stated that her dependent adult child was "a part of everything that we did [as a family]." Mother 2 stated that everyone in her family was "devoted" to the dependent adult child. In four families dependent adult children participated in the same sports activities as older children. All children in these families competed in swimming events.

Current Relationship

The phase of this relationship began when the other children moved out of the house and would end with the parents' death. Other children's involvement with the dependent adult child declined sharply when the other children moved away from home. Those other children who lived out of the area had less contact with the dependent adult child than did those children who lived in the area. In all the families, parents talked about the dependent adult child visiting other children and other children visiting the dependent adult child. Spouses and significant friends of other children also seemed to interact positively with dependent adult sibling. For example Mother 6 reported that

> My son . . . and his girl friend, they would invite her [dependent adult child] for the weekend and she'd go there and she'd stay with his girl friend in her

dorm or she took her home to her parents.

In other situations, other children included the dependent adult sibling in their family outings such as swimming, and ball game activities. Other children also had the dependent adult child come stay with them for a few hours or days to provide a respite for their parents.

Parents perceived that their other children enjoyed being with the dependent adult child and "have fun" together. However, not all was positive, parents stated that other children were embarrassed sometimes by the behavior of the dependent adult children. Mother 6 said her other children "get uptight" when her dependent adult child talks to herself in public because people stare. In the one family wherein other children have never established a good relationship with the dependent adult son, the father believed that his other children did not want anyone to know "that he's [meaning the dependent adult child] their brother and he's the way he is" (Father 5).

<u>Predicted future relationship</u>. This phase of the relationship begins with the death of the parents and ends with the death of the dependent adult children. When parents die, parents believed that other children would assume responsibility for the dependent adult child. In all families except one, at least one other child has agreed to be a guardian for the dependent adult child. Parents perceived the possibility of the dependent adult child living with other children. Even if the dependent adult child did not live with the other children, parents believed that other children would manage financial affairs, find something meaningful for the dependent adult child to do, and see that the dependent adult child have what they need.

Consequences of the Relationship for Other Children

Just as parents perceived consequences of their own relationship with the dependent adult child, parents perceived that other children had benefits and disadvantages in their relationship with the dependent adult child. Parents believed that their other children's involvement with the dependent adult child was beneficial to all children. Mother 6 found that her other children were "real compassionate; they've grown up being a little bit more aware, little bit more compassionate than the average young person is today." The influence of the dependent adult child on other children was viewed positively.

However, parents identified more disadvantages than benefits for their other children. Compared to their own descriptions where benefits were thicker and richer than disadvantages, parents' descriptions of disadvantages for their other children were greater than descriptions of benefits. Parents perceived that their other children may have been neglected after the birth of the dependent adult child. A great deal of the family's energy was focused upon the dependent adult child in the child's early life and during this time other children may have felt "left out." However, the disadvantage parents worried about most was their other children's potential burden of providing care to the dependent adult child.

Parents perceived that their other children who had agreed to take care of the dependent adult child were not realistic about how much of a burden it might really be. Parent believed the predicted burden other children perceived was based on the present relationship with the dependent adult child. Mother 10 expressed her concern this way

> They don't know how they can handle D without me because I'm always handling, . . .I take care of her, but they have fun with her or something like that. . . . they just have fun with her, but I live with her. But they tell me they'll take care of her.

Mother 11 feared that her other children did not "know the heartaches and . . . being tied down [by] taking care of her." Mother 4 feared having her dependent adult child live with her other child would "ruin" her other child's live. Parents also worried how their working children could manage both work and the dependent adult children. Parents feared the burden might become too great, especially if their other children were not provided respite by other brothers and sisters. Other children brushed off parents concerns and told their parents "not to worry."

Summary

The parents' reported perceptions of the relationship between their dependent adult child and their other children were constrained by the limited amount of data collected about the other children. Nevertheless, themes did emerge from the interviews. Overall, parents perceived that the relationships between their dependent adult child and other children were good. The relationship had three basic stages, past, current, and future. The past relationship was similar to any sibling relationship, other children attempted to enhance the development of their developmentally disabled sibling and they were involved with one another. The current relationship between dependent adult children and other children was marked by a reduction in the interaction between siblings, although other children did visit and had the dependent adult child visit. The future relationship caused the most concern for parents. Parents perceived that interaction would increase between other children and the dependent adult child as the other children assumed responsibility for the dependent adult child. Parents worried about the burden this would place on their other children.

Parents reported more disadvantages for their other children in the relationship with the dependent adult child. The disadvantages all focused around the future caregiving responsibilities of the other children. Although some other children had agreed to assume this responsibility, parents believed that other children did not understand the ramifications of caring for a dependent adult child on a full time basis.

Lack of Developmental Closure

From a synthesis of the units of meanings and relationships the theme lack of developmental closure emerged. This synthesis is in accordance with Lofland and Lofland (1984) who suggest that one can go further with the data analysis and ask "'of what more abstract and social analytic category are these data an instance?' The goal is to translate the specific material under study into instances of widely relevant and basic human types, process, or whatever" (p. 124). Parents of dependent adult children experienced a lack of developmental closure at both the family and individual level. This lack of developmental closure contributed to parents concerns of who could take care of the dependent adult children and resulted in long term parenting that provided parents with both benefits and disadvantages.

Family Development

Duvall (1957) identified eight stages of family development, starting with beginning families and ending with aging families. The stage of family development is tied to the oldest child's developmental stage until the last two stages of family development when children are no longer expected to be at home. The "launching" stage (stage VI) begins when the first child leaves home and ends when the last child leaves home. Seltzer (1992) suggests that families with dependent adult children remain fixed in the "launching" stage. However, because parents are also aging, experiencing deteriorations in health, and are either planning retirement or are retired, the family developmental stage has also moved on to the "aging family" stage, constituting two concurrent developmental stages. The family's placement in dual stages would be dependent upon the parent's developmental stage and the dependent adult child's developmental stage as perceived by the parents. Families from this study were considered to be in the stages of aging/school-aged children stage and aging/adolescent stage.

Off-cycle. Seltzer (1992) and Birenbaum (1971) have referred to families with dependent adult children as being "off cycle" in family development. The "off cycle" is because dependent adult children are "never fully launched to independent adulthood" (Seltzer, 1992, p. 93). However, parents in this study did not plan to launch their dependent adult children. Parents planned on keeping their dependent adult child at home until the parents either die or were no longer able to care for the dependent adult child. This is contrary to normative family life cycle stage expectations. Dependent adult children remain at home with parents for reasons other than economic. Parents in this study alluded to reasons such as the need for protection, the inability to handle finances, poor decision making, and the need for supervision in activities of daily living.

Duvall (1957) identified a unique set of tasks for each stage of family development. Parents of dependent adult children have two sets of family developmental tasks that potentially compete with one another. Each stage of development and tasks generally is time limited to only a few years. Yet, the final stage, "aging family" potentially is substantially longer than any of the other stages. Families with dependent adult children become fixed in either the "school-aged" or "adolescent" stage for 20 or more years.

Parents are generally responsible for overseeing, initiating, and completing the family developmental tasks in families with dependent children. Parental roles are partially formulated by the tasks associated with family developmental stages. "Managing a retarded [young] child in the home is considered to be made routine by emulating conventional parenthood" (Birenbaum, 1971, p. 55). Conventional parenthood is characterized by regular changes in the relationship with children as they pass through different developmental stages. While parents of dependent adult children do perceive of changes in the parent-child relationship; relationships do become "forever-crystallized" (Birenbaum, 1971, p. 64). Whereas parents of normal children are required to devote less energy to the parenting roles, parents of dependent adult children continue to devote the same amount of time as in earlier years. Mothers in this study reported that their parenting activities today were no different than when the dependent adult child was younger, 10 to 15 plus years ago. This is consistent with Roberto is (1993) findings that elderly caregiving to dependent adults tends to be fairly stable over time. Essentially, for parents in this study, parenting activities froze at the level parents perceived their dependent adult child's functional ability demanded. (Mother 12 taking care of S is "like having a 9 or 10 year old child that's around all the time," and Mother 5, "I'm a perpetual mother of a perpetual teenager.") The difference between parenting normal and dependent adult children noted by parents was that the parenting role with dependent adult children was without an end in sight.

Developmental tasks. Developmental tasks of the middle-aged family and aging family include sustaining satisfying relationships with other family members, including grandchildren, and adapting to declining health and possible loss of a spouse (Friedman, 1992). Parents in this study had no hopes of grandparenting their dependent adult child's children or anticipating being somewhat dependent in old age on any of their children. In fact, parents feared such possibilities. To depend on their other adult children meant that these children would have some responsibility for both the parent(s) and the dependent adult child. Parents feared such a responsibility might be too great of a burden for their other children.

Parents of a dependent adult female were fearful of the possibility of their daughters becoming pregnant. Parents' believed their dependent adult daughter's would be unable to care for an infant. Not only were the parents concerned about their daughters' inabilities to care for infants, they were concerned about also being potentially responsible as grandparents to care for more children, ones with potential developmental disabilities.

The potential loss of a spouse was especially troublesome to parents. Mothers worried about their husbands' ability to care for the dependent adult child after their own death. Primarily, mothers did not believe fathers had the patience to carry on the parenting responsibilities. Fathers also worried about something happening to the mothers because of the strong bond between the mother and their dependent adult child. The death of a father generally meant that the economic stability of the family would be disrupted. Most believed that the mother could continue parenting alone better than could the fathers.

Related to the loss of a spouse was the fear of institutionalization of the dependent adult child. Parents related that often after the death or incapacitation of one parent, the dependent adult child was placed out of the home. The lack of identified plans after their own death for the continuation of care for the dependent adult child caused the most concern for parents. This is discussed in greater detail later in this section.

Summary. Because parents could not launch their dependent adult child into fully independent living situations, the usual closure to family development was not possible with these families. Mother 12 appraised her family's life as "never will we ever have a normal life with him." Families are "off cycle" and at dual stages. Duvall (1957) stated that the family developmental stages ends with the death of the last parent. With these families, the family development stage possibly ends with the death of all three family members father, mother, and dependent adult child.

Physical Growth and Development and Chronological Age of Dependent Adult Child

Although a dependent adult child's cognitive and psychosocial development might be arrested, physical growth and biological development may be quite normal. Two of the dependent adult males in this study were over six feet tall. Dependent adult children and their parents lived with the paradox that the dependent adult children were physically, biologically, and legally adults while functioning as children.

Legal status. Beginning in the 1970s, the rights of individuals with disabilities was recognized. The Education for All Handicapped Children Act of 1975 established the rights of children with disabilities to attend public schools. In 1975 the United Nations adopted the Declaration on the Rights of Disabled Persons. In 1990 the United States passed the Americans with Disability Act (ADA). ADA is considered supportive of the civil rights of all individuals with disabilities including dependent adult children (Herr, 1992).

Legally, the dependent adult children acquire full adult status upon reaching age 21 years. Unless parents go to court and have the dependent adult children adjudicated incompetent and receive guardianship of dependent adult child, the dependent adult child can legally make decisions regarding his or her life.

Although dependent adult children over 21 years of age are adults, parents continued to perceive them as children in need of protection and guidance. This belief pitted parents against agencies that sought to enforce the concepts of "least restrictive environment" while asserting the civil rights and rights of self-determination of dependent adult children (Herr, 1985, 1992).

Parents were not able to bring closure to childhood in their dependent adult children because of the adult child's diminished cognitive abilities. Parents, therefore, believed that they had some rights and responsibilities in determining the best interests of their dependent adult child. In fact, parents believed that they had the right to invoke the concept of "natural parent" in providing care, and making decisions for their dependent adult child. Parents perceived that agencies, primarily group homes and sheltered workshops, allowed dependent adult children to make decisions and engage in activities that parents did not permit.

Because dependent adult children are functionally children and legally adults they are "off cycle" in their development. While still legally considered children, they were much like any other school age child attending neighborhood schools. Dependent adult children graduate from high school like other children. However, unlike other children receiving high school diplomas, the dependent adult child had not met the requirements for graduation but rather had attained his or her twenty-first birthday and legally did not qualify for continued educational services. An incongruence existed for parents, dependent adult children were perceived as children but legally ineligible for school. These dependent adult children were still in need of protected services while other "normal" adult children of the same age were either attending college or joining the labor force.

Minimizing "off cycle" effects. Birenbaum (1971) found that parents attempted to treat the dependent adult child as normally as possible and have him or her participate in normal activities. Promoting the dependent adult child as being similar to others while having an awareness of differences throughout the dependent adult child's life was the job of the parent. Parents did this to maximize potential development and to protect the dependent adult child against loss of capacity. Finding activities similar to other people of the same age for dependent adult children was difficult for parents. Waiting lists for sheltered workshops were long and available openings were few. Two parents, who sought employment for their dependent adult children in the public sector, said positions were not available because of the cost of insurance to the company. It is possible that the American with Disabilities Act (ADA) of 1990 will assist dependent adult children to find employment. However, parents said that it would take fighting to fully benefit their children and probably a court case using ADA.

Employment, regardless of salary, for the dependent adult child was considered important by parents. Employment and a pay check made the dependent adult child feel good about self. Employment allowed him or her to be like other adults the same age while providing something to do five days a week. Inactivity, or not having something meaningful for the dependent adult child caused parents to fear their dependent adult child would regress or loose capabilities.

Physical aging. As with any person, individuals with developmental disabilities continue physical development into old age; however, individuals with developmental disabilities begin physical aging at an earlier age than do others, especially those with Down's syndrome (Hawkins, Eklund, & Martz, 1993). Parents noted what they considered to be physical signs of aging in their dependent adult child included graying of hair, increasing facial wrinkles, and slowing down. Because Alzheimer's disease is highly correlated with Down's syndrome, parents of dependent adult children with Down's syndrome expressed concern about their child being afflicted. With their dependent adult child's advancing age, parents were concerned about having to provide care to their dependent adult child should their child become more physically disabled. The dependent adult child's aging occurred concurrently with parents' aging.

Summary. Dependent adult children were in a unique position for they were both adults and dependent children. Their right to self-determination was buffered by their judgement abilities and parents' desire to protect their child. With the enactment and enforcement of civil rights legislation for individuals with disabilities, parents were left without guidelines as to what were their parental rights. Parents were often at odds with agencies in determining what was in the best interest of the dependent adult child.

As parents faced their own old age they also had to deal with an individual who was functionally a child and potentially an old person at the same time. The physical maladies associated with aging also affected dependent adult children, but at an earlier age. Dependent adult children were "off cycle" as illustrated by several paradoxes: legally an adult while functionally a child, similar to others but different, functionally a child while becoming physically old.

Who Will Take Care of Dependent Adult Child

Because parents could not successfully launch dependent adult children into independence and independent living, the major concern of parents was what might happen to their dependent adult child when the parents would be unable to provide care. When asked about their concerns, parents always referred first to the future of their dependent adult children. Their concerns were multifaceted; for example, "where will the dependent adult children live," "will there be enough money," "will they be happy," "will it be too burdensome on other children," and "will my health remain stable." These concerns were with parents everyday. Although parents did not "dwell" on these concerns, the concerns were always "in the back of their mind." Concerns parents had about who would care for their dependent adult children revolved around their own abilities, their other children, and out-of-home placement. The uncertainty as to where the dependent adult children would live was expressed as the major concern.

Parents.

The concern parents had for themselves was their ability to remain healthy for as long as possible so they could continue caring for their dependent adult child. Parents believed that their caring for the dependent adult child was preferable to anyone else providing that care. Mothers believed that they were the ones who could provide the best care. Mother 2 expressed her beliefs with "He really needs someone, because nobody is going to care for him, nobody is going to love him the way Mother does. Not even the sisters or the dad either." Mothers prayed for their own good health for the sake of their children. A major hope parents had was their own good health.

Parental preference for continuing to care for and parenting the dependent adult child for as long as possible was discussed by Krauss (1990), and Heller and Factor (1991). Seltzer, Krauss, and Heller (1991) believe that the continuation of parenting, especially for mothers, provides parents with role in which they feel needed--giving them a purpose in life. Parents in this study reported that their dependent adult child gave them a reason to live, gave them something to do, and unlike other parents they did not experience the "empty nest" syndrome. One mother reported that the responsibilities of parenting prevented her from committing suicide during a stressful time in her life.

In discussing the death of a spouse, parents talked of the effect death would have on the dependent adult children. Fathers and mothers worried more about how the mother's death would impact the dependent adult child more than would the father's death. This was due to the parents' perception that a stronger bond existed between mothers and the dependent adult child than between fathers and the dependent adult child. Both parents perceived that fathers had less patience and would need assistance to adequately perform the mother-role responsibilities. One father, in particular, worried about his wife's health, although she rated her current health status as good and expected her health to remain so in five years.

In referring to their own death, parents used words such as "pass," "happen," "gone," and "leave." Frequently, parents prefaced their comments about their own death with "if" and not "when." For example, "if anything happens to my husband and I" (Mother 6), and "I think if it came to the point that something would happen to us" (Mother 9). This was quite different from parents' thoughts on losing their ability to drive. When discussing driving, parents would say "when" I can no longer drive and not "if." The parents wish to out live their dependent adult child may have made losing one's ability to drive more real than the possibility of the parents dying first.

Other children. Except for three families, parents perceived the next best place for their dependent adult child to live was with their other children in a family setting. However, plans for the dependent adult child to live with other children were incomplete, full of hopes, and included many uncertainties. Incomplete or lack of plans for the dependent adult child after the death of parents has been well documented in the literature. Parents overwhelming do not adequately plan for transition from parental care (Gold, 1987; Heller & Factor, 1991; Lehmann & Roberto, 1993; Wood, 1993).

Plans for the dependent adult child to live with their siblings were incomplete and vague in identifying with whom the dependent adult child would live. Although parents did identify a sibling guardian for the dependent adult child, plans were sufficiently incomplete to allow other children to make decisions regarding living placement. Mother 1 reported that in her plans she "didn't want to make any stipulations because if you make it too detailed, nobody will follow it then you get into legal entanglements and I don't want any legal problems. . . .so if the Lord takes care of that."

The parents' concerns about burdening their other children with the care of the dependent adult child also added to the incompleteness of plans. Parents desired to reduce the burden as much as possible by suggesting respites, sharing of caregiving, and placing the dependent adult child in a group home, if the burden became too great. Parents suggested that several of their other children might be involved in the caring of the dependent adult child if the burden became too much for one child. While parents desired for their dependent adult child to continue with the activities they enjoyed, parents also believed that transporting the dependent adult child to activities might be too great a burden for their other children. Mother 10 said that "nobody will do this except a parent."

Parents hoped that their other children's lives would not significantly change so that the other children would be able to provide care to the dependent adult child. Concerns parents had about the other children's ability to provide care were multifaceted. New husbands might not wish to have a dependent adult child living with them. Working daughters might not be able to provide the supervision needed by the dependent adult child. Parents also hoped that their dependent adult child would "get along with" the children of their other children.

Uncertainties associated with the dependent adult child living with the other children centered on the inability to discuss plans with other children. Parents related attempting to talk with other children about future plans, yet other children did not wish to discuss plans with parents. One parent attempted to discuss his concerns twice, once "too early and once too late" (Father 10). Another parent said in her attempts to talk with another child about plans for the future, "she really turns it off quick like, . . . it's just like 'I don't want to talk about it, mother' and that was that." Other parents reported that other children ended conversations early about the future with "don't worry, I'll take care of her or him." The lack of adequate planning for the dependent adult child's transition from the parents' home to a sibling's home may be the result of the inability of both parents and their other children to discuss future plans.

Out-of-home placement. Placement out-of-home was the option of last resort for all except two parents. Wood (1993) found the failure to make adequate plans for transfer of care was tied to the parents' perceptions of lack of acceptable alternatives. Heller and Factor (1991) also found that parents did not like non-family residences because of sexual permissiveness in those residences. Parents in this study did not like group homes or institutions for dependent adult children. Except for the parents who planned or hoped for an out-of-home placement, parents had no positive comments about group homes. Comments about group homes included: the unkept appearance of residents, theft of possessions, and abuse by co-residents. Residents of group homes were allowed to engage in sexual activity that was not acceptable to all parents. Parents also worried how their dependent adult child could adjust to sharing a bedroom, not being able to bring all his or her belongings and pets, and sharing possessions. Additionally, parents were concerned about how the dependent adult child would handle the increased independence offered, and who would love and take care of the dependent adult child when ill.

While all parents believed that the dependent adult child needed some supervision, some parents believed that their dependent adult child could live with minimal supervision. For these parents, group homes were considered too restrictive, however, supervised housing other than group homes does not currently exist in El Paso region. To meet alternative out-of-home placement needs of their dependent adult child, three families independently discussed developing their own living arrangements through the conversion of their homes into a family supervised group home.

Parents perceived that group homes and institutions were the least desirable options available to them and their dependent adult child. There was a desire by most parents to avoid out-of-home placement. Parents also perceived that their other children desired the dependent adult child to remain at home with the parents for as long as possible and that the other children would do what they could to keep the dependent adult child out of a group home.

Lack of predictability of service system. Parents in this study had seen numerous changes in services available to them and their dependent adult child over the course of their parenting. Services available to parents and their dependent adult child was not predictable. Questions arose such as "would a place be available when needed"? Parents could not count on service being available or the desired quality of the services. The lack of predictability caused parents to live with uncertainty. The uncertainty of the future was also based upon the certainty of the parents death.

Mishel (1992) has defined uncertainty as the inability to determine the meaning of "situations where the decision maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes" (p. 256).

Parents were not able to predict the outcome of their dependent adult child's placement, happiness, or well-being after the parent's death. Parents did try to provide for their dependent adult child, safeguard his or her well-being, and ensure happiness; nevertheless, they could never be satisfied that their efforts would have the desired outcomes. For these parents the future is uncertain. In Birenbaum's (1971) study "the future was most ambiguous" (p. 61), and he referred to the future as the uncertain future.

The only way for parents to be relieved of the uncertain future was for the dependent adult child to die prior to the parents' death. Wood (1993), Krauss (1990), and Grant (1990) reported several parents hoping for such an outcome. Four parents in this study verbalized that they hoped that their dependent adult child would die prior to their own death. Parents would preface their statements with "it's a sad thing to have to wish," "to tell you the truth," and "my doctor said . . . 'S is at a greater risk than you are.'" Parents also related that other parents they knew felt a release when their dependent adult child died.

Summary. Making plans for the future of the dependent adult child and deciding where the dependent adult child would live was not easily accomplished by parents. Parents first preferred that their dependent adult child live with parents. Non-family placement was undesirable because of perceived lack of supervision, lack of appropriateness, and the possibility of allowed sexual activity. This left parents with few options other than other children. Parents were unable to communicate effectively with other children about future care plans for the dependent adult children. Few parents had adequate plans. An additional reason for inadequate planning may be explained by Grant (1986), Seltzer, Krauss, and Heller (1991), and Heller and Factor (1993), who reported that in families where the caregiving role was satisfactory, and dependent adult children provided companionship and assistance with house hold chores, planning for the future was inadequate. This issue emerged in this study. Parents in this study were generally content with their lives and believed that the positives of the dependent adult child living with them were at least equal to or greater than the negatives.

Benefits As Well As Disadvantages

Although parenting and living with a dependent adult child was not easy, it was not without its benefits. In identifying descriptors for difficult and beneficial factors, parents could identify 34 difficult descriptors and only 17 benefit factors. When describing the difficulties, however, parents were rather blunt and often ended the description with "that's the way it is." Yet, descriptions for benefits were thick, rich, and told with a lot of positive affect and body language.

In the pilot study (Schaller-Ayers, 1991), a similar finding surfaced. For this study, parents were asked to quantify benefits and difficulties. The positives outweighed the negatives for 13 parents, the negatives and positives were equal for 4 parents, and the negatives outweighed the positives for only one parent. Also in this study two additional parents (one mother who was interviewed but did not meet criteria participation and another mother who had two dependent adult children and only one residing at home with her) with a child in out of home placements reported that for that particular dependent adult child the negatives of them living at home outweighed the positives.

The identification of difficulties with limited description of those difficulties, and reporting that the difficulties really were not hard, may represent the utilization of acceptance as a coping mechanism. Acceptance is an adaptation to "an unexpected and negatively perceived event including the importance of coming to terms with the event or of accepting it as real and as something with which to contend" (Seltzer & Krauss, in press, p. 7). Parents reported greater acceptance of their life situation occurred as they aged. Acceptance sometimes was unconditional without answers as to why.

Seltzer and Krauss (in press) also identified the coping strategy of positive reinterpretation of non-normative events. They found that mothers reinterpreted the devastating event of the birth of a non-normal child into a positive event. Parents in this study identified benefits as other children being made more aware and compassionate. The child that began as the parent's greatest burden or cross over time became their greatest blessing. Parents identified their dependent adult child as a best friends and good company, without whom the parents' lives would be a lot less.

One of the most interesting benefits, and the one that received the most description, was the excitement that the dependent adult child created about holidays and birthdays. When talking of their dependent adult child's excitement, parents became quite animated, their voice quality changed, and they had more facial expressions than at any other point in the interviews. These families described living from holiday to holiday so they could enjoy the excitement that holidays hold, an excitement that tends to fade as children move out of the home and families age.

Summary. The literature on elderly parents has clearly documented burdens parents contend with in parenting dependent adult children. Only two reports (Heller & Factor, 1991; Seltzer & Krauss, 1989) discussed benefits of dependent adult children in the home. However, parents in this study discussed in greater detail the benefits of the dependent adult child living at home with parents as opposed to the disadvantages. In rating benefits and disadvantages, parents overwhelmingly reported that the benefits were greater than the disadvantages. After 20 or more years parents may have learned to cope with the disadvantages while the benefits kept them going.

Summary

Lofland and Lofland's (1984) units of social settings were utilized to analyze the interviews for this study. Parents of dependent adult children described what it meant for them to be parents of a dependent adult child, their perceptions regarding the meaning of being a dependent adult child, the relationship they had with their dependent adult child, and their perceptions about the relationship between their dependent adult child and their other children. From analysis of the units, the theme lack of developmental closure emerged. The lack of developmental closures was perceived as contributing to parents concerns about who could take care of the dependent adult child and resulted in long term parenting that provided parents with both benefits and disadvantages. Chapter 5 presents the results of sources of support as a social unit of analysis.

CHAPTER V

RESULTS: SOURCES OF SUPPORT

Sources of Support

Lofland and Lofland (1984) did not identify or define sources of support as a unit of social analysis. However, Lofland and Lofland (1984) state that "there is no definitive list" (p. 71) of units. Sources of support was defined for this study as the providers of assistance as well as the nature of assistance available to families with dependent adult children. Sources were either agencies, organizations, or individuals. Sources of support as a unit emerged from the data as parents described their experiences with agencies, organizations, family, and other parents of developmentally disabled children. Parents had used all of these sources, with varying degrees of success, in their efforts to seek assistance for their dependent adult children and themselves. Parents identified three major types of sources of support; these were formal agencies, formal agencies-informal mixture, and informal. Figure 6 identifies the questions posed by Lofland and Lofland (1984) that were most useful for analysis of the social unit of sources of support. Subheadings used in this section that correspond to the questions are also identified. The parents' perceptions of each of these are presented separately followed by a comparison of formal versus informal sources of support.

Formal Agencies

Formal agencies were defined as agencies that were associated with the federal, state, and local governments. Examples of these agencies are Social Security

- Types
  - Formal agencies
  - Formal agencies-Informal mix
  - Informal network
- Process
  - Contact with formal agencies
  - Contact with formal agency informal mix
  - Contact with informal network
- Structure
  - Characteristics of formal agencies
  - Characteristics of formal agency-informal mix
  - Characteristics of informal network
- Frequency
  - Frequency of contact with formal agencies
  - Frequency of contact with formal agency-informal mix
  - Frequency of contact with informal network
- Consequences
  - Social Unit of Meanings
    - Differences of opinions between parents and formal agencies
  - Social Unit of Practices
    - Practices of formal agencies
  - Social Unit of Encounters
    - Encounters parents have with formal agency personnel
    - Results of parents' encounters with formal agencies
    - Results of parents' interactions with formal agency-informal mix
    - Importance of informal sources of support

Figure 6. Analysis for Unit of Sources of Support

Administration, Texas State Department of Mental Health and Mental Retardation, Life Management, the city-county bus department, and public schools. The data for formal agencies are presented in terms of parents' contact with agencies, differences of opinions parents had with agencies, experiences parents had with agencies, practices of agencies, and results of interaction parents had with agencies.

Contact with Formal Agencies

The history of parents' contact with formal agencies was viewed as a process. In describing the process parents, said that contact with formal agencies was minimal after the birth of the dependent adult children, however, contact with formal agencies increased and then was maintained at a fairly consistent level during the school years only to spiral rapidly downward after the dependent adult child finished school. Lofland and Lofland (1984) identify this type of process as a spiral pattern, "a continuously spreading and accelerating increase or decrease" (p. 107). In addition to the spiral pattern, parents also described a cyclic pattern, "a recurrent sequence of events which occur in such order that the last precedes the recurrence of the first in a new series . . . a course . . . of events returning upon itself" (Lofland & Lofland, 1984, p. 106). In explaining this type of process, parents told of having to fight the same battles over, and over, and over again. With the need for any new service or new provider, parents found that they needed to start anew. These two types of processes, spiral and cycle, occurred concurrently over time.

Initial contact. Initial contact with agencies as sources of support occurred shortly after the birth of their dependent adult child (children in this study were born between 1951 and 1968), when according to the parents they were encouraged "not to bring their child home." This did not happen to all parents, but all parents knew of other parents their same age who were encouraged to do the same. During this time, the options provided to parents were either to institutionalize the infant or to take the infant home. One mother whose child has Down's syndrome was told she had given birth to a "creature," while another was told to just take the infant home because the physicians "could not do anything with" the infant. When the parents of infants with Down's syndrome took their infants home, they were given little assistance and advised their infants probably wouldn't live past two years of age. When these children reached age two, the parents were told the children could not live past age seven to 12 years, and then past 20 years.

Regular contact. Parents first came into regular contact with agencies as sources of support when the dependent adult child entered school. There was a community private school, Memorial Park, for children with developmental disabilities that children could attend beginning at age three (the public school contracted with this school to provide services to the children). This school existed from 1954 until 1976. Nine of the 12 dependent adult children attended this school. Public schools established exclusively for children with developmental disabilities were opened in El Paso in 1956. All of the dependent adult children attended these segregated schools with eligibility beginning at age six. In 1981, six years after Congress passed the Education for All Handicapped Children Act (P.L. 94-142), schools in El Paso started mainstreaming children with disabilities into neighborhood schools.

Parents reported that they made special efforts to get schooling for their dependent adult child. Mother 1 reported that she and another parent "went to the school superintendent for special education and got them to appeal to Austin for special education, and [the school in] El Paso was the first steady school in Texas to have special education programs in the public schools." Two mothers reported that their dependent adult children were in the first special education classes held in public schools. Mother 3 reported that her husband "got all the kids out of the segregated schools for the retarded . . . by taking the school district to court." While their dependent adult child was in school parents found that they had

> to fight the same battles with new providers, new service systems, it's a cycle. . . . In the public schools, you saw it. The two teachers didn't talk to each other. . . . When that teacher passed the child onto another teacher, you had to start over. There's no continuity. (Father 3)

Every parent talked of the lack of continuity, and the need to continually start over, deal with the same issues, and refight the same battles.

For some of the dependent adult children, changes and innovations were occurring just as they were ready to move on to the next level. For example, Mother 7 reported that

> It seems like with D, everything . . . the mainstreaming--there was some mainstreaming, but they always felt that it was just starting and she was a little

> lower [functionally, so it was best to wait].

Father 3 echoed this sentiment with the fact that his son "was always behind the curtain you know. He was fortunate that we got the public money for Law 94-142 [Education for All Handicapped Children Act]. . . . But he was unfortunate in that everybody was starting; it was new."

Eventually, two of the dependent adult children in this study were mainstreamed into regular classes for some courses. Six of the dependent adult children were mainstreamed into neighborhood schools wherein they remained in contained special education classes for all courses. Four of the 12 dependent adult children never attended neighborhood schools but did graduate from the segregated handicapped schools.

Although parents fought for these early services they believed that educational services were better and more comprehensive today than when their child started school. Mother 2 stated

> They [meaning dependent adult children] wasted their time really, because if they had, had the advantage of going to schools the way they do now, they might have learned a little bit more. . . . He didn't get a lot of other things [like] math or something like that or at least learn what 1 and 1 is and 2 plus 2 or whatever. But they didn't, they had good teachers, but I guess . . . [the teachers] didn't have the time or they didn't have the knowledge to realize that these kids could be trained. It wasn't until after that you'd find out that they can be trained if you start young. So he lost out in a lot.

Parents also reported that some services were started after the dependent adult child graduated from high school. For example, none of the dependent adult children were able to benefit from a recently initiated transition program that aids children with disabilities to go from a school environment to a work environment. Because of transitional services, dependent adult children who graduate from high school today are perceived by parents as having better opportunities for gaining employment and avoiding the long waiting list for sheltered workshops than did the children of families in this study.

Reduced contact. Schools were the predominant agencies with which parents had contact when their dependent adult child was young. All service needs and information were dispersed to parents through the school. As the dependent adult child finished school, parents had direct contact with other agencies, such as Life Management. However, information was not disseminated as well after the dependent adult child graduated from school. Parents found no central agency, like the school, to provide services and information. Parents continued to fight the same battles over and over for services but at the same time found that their contact with agencies "spiraled down" (Father and Mother 7) dramatically.

Characteristics of Formal Agencies

Parents described the structure of formal agencies in terms of characteristics of the agencies. Lofland and Lofland (1984) define structure as "the integrate and precise characteristics" (p. 97) of the components of what is being studied. The components identified by parents included type of individuals employed by the agency, recipients of services, decision making, rules and regulations, eligibility, legislative mandate, and payment for services.

Formal agencies always employed professional individuals to provide services. The dependent adult children were the recipients of services. Father 10 said of agencies

> They don't know anything at all about the parents. They just know about the cases [meaning dependent adult child], they just know what they read in the papers [meaning agency case records] and that's not enough.

The only influence parents perceived they had in the decision making process regarding services for dependent adult children was to either accept, reject, or legally challenge what the agencies offered. Rules, policies, and types of services offered were determined by the agency as mandated by administrative policy or by state or federal legislation. Father 3 successfully challenged the public bus company policy not to provide handicapped services to individuals with mental retardation because of the risk of seizures. He "had to file a federal complaint of discrimination to say you can't discriminate on the basis of a handicap when you're a handicap service provider." Parents in four families rejected all services from state agencies; their dependent adult children continued to receive Supplemental Security Income (SSI) and participated in nongovernmentally-sponsored activities.

Dependent adult children had to meet agency eligibility criteria to receive governmentally-sponsored services. Eligibility for most government-sponsored services was dependent in part upon eligibility for SSI. For dependent adult children to qualify for services, parents had to complete eligibility forms. Being qualified for services did not guarantee receiving services. Once qualified for sheltered workshop services, the dependent adult child's name was placed on a waiting list. Dependent adult children could not be placed on the waiting list until after they graduated from high school. Mother 10 reported that her daughter had been on the "list ever since she got out of school. She got out in '87. . . . The only way D would get on [at the workshop would be if] some of them are not able to handle the work." Parents reported a sheltered workshop waiting list of 800 dependent adult children, with at least a seven year wait. Once services began the dependent adult child must be requalified on a regular interval.

Services provided by formal agencies to dependent adult children were usually provided without a fee. Children in sheltered workshops were paid for work done by the piece while SSI provided a monthly stipend. Dependent adult children did pay for some services, such as some transportation services, summer camp programs (sliding scale fee), special classes at the community college, and monthly Friday night dances (donation).

Frequency of Contact with Formal Agencies

Frequency of contact with formal agencies for support by parents was fairly consistent and frequent when the dependent adult child was in school. Upon reaching age 22, however and graduating from high school, parents and their dependent adult child experienced a dramatic drop in services available. Father 7 found that

> There is not anything here in the State of Texas after they're 22 years of age.

> The only thing that they have is the multi-purpose facility over on Viscount [the dances are held here]. That's about the only thing that there is. As far as any programs . . . that she could go out and do volunteer work. There is not anything like that. If there is some private organization that will still take in handicapped children, the waiting list is so terrific, it's just unbelievable.

For the dependent adult children, parents found that the only formal services available were sheltered workshops, group homes, respite (2 beds available), Friday dances, summer day camp, and transportation.

For parents, who had dependent adult children (five of 12) in sheltered workshops, contact with formal agencies occurred only when required by policy or when the dependent adult child had a behavior problem. Four of the five mothers whose children were in sheltered workshops said that the only time the workshop contacted them was when something was wrong, never to tell them anything good.

Differences of Opinions Between Parents and Formal Agencies

Consequences can be used to examine the effects of one unit on another unit (Lofland & Lofland, 1984). Parents perceived that there were differences in the meanings agencies had for parents and dependent adult children than parents had. For example, parents said agencies refer to parents as providers, whereas parents referred to themselves as parents.

Parents perceived their dependent adult child as a child with diminished capabilities for making decisions, such as being able to decide to engage in sexual intercourse and when to cross a street. Parents related that agency personnel advised parents that dependent adult children were consenting adults with the right to engage in sexual activity if desired. When discussing sexual activity with agency personnel, Father 7 was told

> they're consenting adults. And I said "That's beside the point; as long as she doesn't have to, she's not going to be involved or put into any position like that at all." Then they started talking about sterilization and of course, my wife and I both just jumped straight up in the air. Why in the world put her through that? It's not necessary if we look after her the way we should.

The parents in family 3 objected to group homes and respite services in part because dependent adult children were allowed to engage in sexual activity.

Mother 2 had a disagreement with agency personnel regarding her son's activities during breaks and restricting his activity. She related this incident

> I told them . . . "I don't want him going to the restaurant [across the street] at all." "Well we can't stop him because he's of age and we can't tell him what to do. He's of age." And I said "He is not of age. He's a child, he's got a mind of a child. Do you mean to tell me you can't control the child? You're just going to let him go out and get himself in trouble? Then what are you doing here? I might as well keep him home." . . . that street over there; it's a busy street. And these are children; they're not going to stop to see whether there's a car coming.

Mother 2 also related that this same agency had contacted her frequently about obtaining legal guardianship for her dependent adult son. Because parents believed that agencies perceived circumstances and situations differently, parents often did not agree with suggestions of agency personnel. These differences affected the experiences parents had with agencies, which is presented in the next section.

Encounters Parents Have with Formal Agency Personnel

"An encounter is a tiny social system formed when two or more persons are in one another's immediate physical presence and strive to maintain a single (ordinarily spoken) focus of mutual involvement" (Lofland & Lofland, 1984, p. 78). Parents had encounters with personnel from formal agencies for a variety of reason; for example, to problem solve, seek services, and maintain services. Most contact with formal agency personnel was parent initiated, unless there was a problem. When her dependent adult child had a problem, Mother 4 believed that sometimes the agency personnel were "punishing" her by requiring her to pick up her daughter early. She did not remember being called about any good news. Only four parents reported ever having someone come to their house; most encounters occurred at the agency. Mother 12 reported not receiving much help from professionals, and Mother 11 said that "I don't know of any professional that has really helped us . . . that I know, I can think of."

Encounters with professionals were somewhat confrontational experiences for parents. Father 7 found agency personnel

> Not willing to accept anything that you say and they'll go ahead and they'll shove your child into a program that's not doing them any good and it'll go for several months until they can accumulate enough data. They'll never

> admit they were wrong, but . . . they end up like doing what you told them they should have done anyway.

Parents believed that because they did not have a special degree, the professionals did not accept their assessment of their own child. Parents also believed that no one knew their dependent adult child better than they. Parents believed that professionals needed to listen more to parents and rely less on "book learning." Parents stated that professionals who had experienced living with an individual with developmental disabilities were more realistic and understood better than those who were without such an experience. For the parents, education alone was not enough to understand the total experience of taking care of and knowing the needs of an individual with developmental disabilities regardless of age. Father 3, who returned to school after the birth of his developmentally disabled child, assessed the functioning of professionals in this way

> Professionals seem to have a Goddamn punch list that they were taught but didn't experience and most of it doesn't work. . . . I took all the special ed courses at (school) when I went there to see if I could help S. And the kids they described were my kid [sic] and the things they said that would work, I knew didn't. . . . they only know what somebody taught them.

Overall, parents had few good things to say about professionals who worked at formal agencies and their experiences with those professionals.

Practices of Formal Agencies

Lofland and Lofland (1984) have defined practices as "normal and undramatic features" (p. 75) of an entity. Parents easily described normal and undramatic features of formal agencies. The lack of services after the dependent adult child reached 22 was evident to all parents. Mother 6 found that the

> most difficult thing for us out there is that there's no help really. When they're little, yeah, there's the school, there's this agency and that agency but once they're out of school, you're pretty much on your own.

Father 10 said that when his dependent adult child reached 22, the agencies "just faded into infinity."

The agencies that were available had long waiting lists and the dependent adult child need to wait "eight years" (Mother 3) to receive services. Along with the long waiting lists, parents discovered that agencies had many forms and "red tape." Mother 5 found that "sometimes you need a pick and shovel to get through the red tape." Mother 11 blamed all the red tape on the agencies inability to "focus on getting these children into a program."

Overall, parents found agency services lacking both in number and scope of services. Although some services were available, parents maintained that many services were inappropriate and unsatisfactory for the needs of their dependent adult child. Father 10 said that services were not sufficient to meet the needs of dependent adult children "by a long shot." Parents believed that agencies did the best they could but "sometimes their best flat isn't good enough" (Mother 5). Even though parents regarded services as insufficient, they also believed that programs for individuals with handicaps were the first to be cut during economic down turns.

From observations of dependent adult children who lived in group homes, and from talking to parents with children in group homes, parents had formed beliefs regarding the practices of group homes. Parents asserted that group homes did not provide the quality of care desired by the parents.

Parents believed that the practices of agencies did not assist parents nor did the agencies provide the services needed by dependent adult children. The services offered were limited in number and scope and provided no mobility for dependent adult children. Father 3 summarized the scope of services as

> you don't get what the child [needs], the child doesn't get what the child needs. And there's no, once you're in there, that's it; that's the end of your upward mobility. Wherever they drop you in, that's where you stay. You know, they may think upward mobility is going from being at home to a sheltered workshop to being at a sheltered workshop and supervise living or whatever you choose to call it.

Results of Parents' Encounters with Formal Agencies

The long term result of parents' encounters with formal agencies was to "give up on agencies helping," finding other resources outside of formal agencies, and utilizing identified strategies to get services and to avoid hassles. Four parents said that they had given up hope that formal agencies could be of help to them and their dependent adult child. Father 3 said "we gave up on agencies helping, finally, but it took 23 years. That's a long time." Parents gave up because agencies were not offering desired services. Furthermore, they were frustrated in having to fight agencies over and over to get or maintain services. Also, they believed the benefits of the service did not outweigh the hassles, and the agencies did not demonstrate that they cared what happened to the dependent adult child: hence, it was easier to provide services to their own child than to get agencies to provide services.

Four families had explored the respite services offered by an agency. Two of the families used these services once, each for three days. One family did not use the services because there was "too much red tape" and the service was too expensive. Another family did not use respite services because there were only two beds dedicated to respite service, and the family needed both beds. The opportunity to get both beds at the same time when the service was desired did not occur. The two families who used respite service did not like it because activities were very limited, and the dependent adult child did not like being there. These two families never planned to use this service again.

Because agencies did not provide services that parents perceived as needed and adequate, parents looked elsewhere for needed and meaningful assistance. Parents and their dependent adult child became involved in such activities as Special Olympics. Parents also sought to find meaningful activities for their child in the home and in volunteer positions. Four dependent adult children had volunteer positions at schools, nursing homes, and hospitals that were obtained through the efforts of the parents.

Strategies parents identified for getting services from agencies included fighting, pushing, "making waves," "foot stomping," "camping on the door," keeping after agencies, writing letters, telephoning agencies, filling out forms, putting the dependent adult child's name on a list, waiting, going to the city council, and going to court. Fighting was the most frequently mentioned strategy. Parents said "if you don't fight, you lose it. So you're committed to fighting as long as you can" (Father 3), and "sometimes it's very depressing because you think no matter what, you have to fight for it, and if you don't, then your child is going to be left along the road" (Mother 7).

Fighting for services was difficult for parents, for as they aged they became frustrated and tired of fighting. Mother 11 found that "one reason I really don't get out there and fight for some of the other things is I just (sigh) don't have the energy." Mother 3 said she got tired of "banging against the brick wall and getting nowhere." In summarizing her efforts, Mother 4 said "my goodness, you've worked and worked and worked for years and years and years . . . we can't work forever you know." Finally, Mother 5 said

> you get tired, you get real tried and it's not so much physical tired, you get fed up, and sick and tired of the royal run around from those allegedly in change, and that's what you get more tired of than anything.

Parents found after many years they were fighting the same battles over and over. Father 3 said that "as you get older, you get frustrated at having to fight the same battles . . . Most of us thought we wouldn't have to fight so many battles. That didn't happen." Because parents had less energy and stamina to fight for services they desired for their dependent adult child, they became more selective in the services they sought. Parents found they "avoid the battles" (Mother 8) unless they thought there was a good chance of success.

Summary

Parents have a long history of mixed reactions in working with formal agencies. The general consensus of parents was that agencies have always been behind in meeting their needs and the needs of dependent adult children. As Father 3 said the dependent adult children have been "behind the curtain," or possibly in front of the wave. Programs were just being developed as these dependent adult children needed them and were implemented after their eligibility had expired.

Receiving assistance from formal agencies was a long process that was marked by increases in services when the dependent adult child started school and then a sharp decrease in services with graduation. Fighting had been a continuous cyclical process. When one fight was done there was another to begin. However, as parents aged, their stamina and willingness to fight these battles decreased. It became easier for them to attempt to do what they could without involving agencies.

Professionals employed by agencies were regarded as not being helpful. Disagreements between parents and professionals occurred when the best interests of the dependent adult child were examined. Parents thought some of the disagreements were a result of the professionals' unrealistic and impractical knowledge base. The parents held the opinion that professionals needed practical experience with dependent adult children, something more than "you learn in books."

Formal Agency-Informal Mix

Parents identified the formal agency-informal mix source of support as organizations that were a combination of paid and volunteer staff. Parents were frequently the volunteers in these organizations and often held elected offices in the organizations. Examples of formal agency-informal mix sources of support included Special Olympics, Association for Retarded Citizens (ARC), and churches. Parents maintained these were very different from formal agencies because these programs "worked" and were "fun."

Contact with Formal Agencies-Informal Mix

The process of contact with formal agencies-informal mix had been quite different for parents than the formal agency contact process. In describing the formal agency-informal agency mix contact, parents said that it was fairly constant, with little variation once started. In this process, organizations moved in and out, but the level of involvement in one or the other remained fairly constant. Parents contacts with ARC, churches, and Special Olympics are presented separately.

Association for Retarded Citizens. In 1966 the first El Paso chapter of ARC was organized, receiving some support from the Texas state ARC that was formed in 1952. Parents from five of the twelve families held offices with the El Paso chapter of ARC in the early years of the organization. Mother 3 said this organization started out as "sort of a just a rap session for parents to help one another. And it did." However, at some point in time during the late 1970s, ARC stopped being effective in assisting these parents. Many parents continued to belong to ARC; however, none were currently active in ARC or attended meetings.

Churches. Two of the dependent adult children attended Sunday school classes for adults with developmental disabilities. Other dependent adult children attended church services with parents. Parents infrequently discussed church and church programs in relationship to sources of support for themselves and their dependent adult children.

Special Olympics. The organization most frequently mentioned as very supportive was Special Olympics. Special Olympics was organized in El Paso in 1976. Parents found that this organization had been "a God-send as far as an activity is concerned" (Mother 12). All dependent adult children had participated in Special Olympics at some time. At the time of the interviews 10 of the 12 dependent adult children were participating in Special Olympic activities. These 10 dependent adult children had participated in Special Olympics for close to 20 years. Parents from three families were coaches for different sports.

Dependent adult children in this study participated in one to three different Special Olympics sports and attended from one to three practices weekly. Parents transported their dependent adult child to and from these activities. Parents discovered that for adults with developmental disabilities Special Olympics was the only activity readily available.

Characteristics of Formal Agency-Informal Mix

Parents identified characteristics of the formal agency-informal mix components as individuals who work with the organization, recipients of services, decision making, rules and regulations, and eligibility to participate. Organizations in this category had a mixture of paid professionals and volunteers who provided services to dependent adult children and their parents. Volunteers were parents and other relatives of children with developmental disabilities. Special education teachers and other interested people also were volunteers. Parents often were officers in the local organization and had some influence on the functioning of the local organization.

Parents could be as involved as they desired in the functioning of the organizations. In Special Olympics some parents were coaches for swimming, bowling, track, and basketball. Other parents attended practice sessions and rooted for the dependent adult children. Special Olympics and churches also provided family activities such as picnics and meetings.

Parents, other active family members, and the dependent adult children were known by these organizations. Although the exact ages of the parents were not generally known, people in the organization knew approximate ages of parents unlike formal agencies who did not know who provided care to dependent adult children.

Organizations had general rules regarding joining and participation. To join ARC all one had to do was to pay dues. To participate in Special Olympics, children with developmental disabilities must be eligible by national policy. However, local organizations had some flexibility in allowing dependent adult children to practice and attend local meets. To participate on the regional, state, and national levels, the dependent adult child must meet national eligibility requirements. For example, the dependent adult child in family 9 was unable to compete at any sport meet event because of health problems: nevertheless he practiced every week with the team. Although he was physically unable to participate in the sport meet event, at the end of the season last year he still received a T-shirt that all participating team members received.

Frequency of Contact with Formal Agency-Informal Mix

Parents reported that their frequency of contact with formal agency-informal mix increased slightly after the dependent adult child graduated from high school, and this contact stayed fairly consistent. The increase in frequency after graduation was attributed to the fact that Special Olympics was about the only thing for the dependent adult child to do on a regular basis. Dependent adult children attended practice for every sport on a weekly basis from September to May. Of those dependent adult children participating in Special Olympics, most participated in two to three different sports. Because parents transported dependent adult children to all activities, parents had contact with Special Olympics for one-to-two hours, at least two to three times per week.

Special Olympics was considered important by parents because it helped to fill in for the lack of services available from government-sponsored services. Mother 10 reported that "there is nothing outside of Special Olympics that they could participate in, except things at church." Parents believed that it was important for dependent adult children to be kept busy in something that gave them a feeling of accomplishment. Mother 8 was involved in Special Olympics because "I think it would be terrible, I don't think I would be able to cope if we didn't have something for D to do. That's why you know we got involved with Special Olympics."

The parents and the dependent adult children who did not participate in Special Olympics (two families) had very limited contact with formal agency-informal mix sources of support. Members of both families attended church regularly. Neither of these churches had special classes for adults with developmental disabilities, therefore, dependent adult children attended regular services. The families' involvement with church activities had been consistent since prior to the birth of the dependent adult children.

Results of Parents' Interactions with Formal Agency-Informal Mix Sources of Support

The benefits of parents' interaction with formal agency-informal mix proved to be significant for parents. Because parents transported dependent adult children to Special Olympic practices, there were usually several parents who watched practice sessions. Practice sessions allowed parents to meet and communicate with other parents of dependent adult children and provided a mechanism to support the informal sources of support. Mother 8 noted that at practices

> parents who do not get involved in the activity always sit in a group and exchange ideas and talk about different things. . . . I think because of the activities you know, and there's so many different age groups in those activities and the parents just talk to any parent that's there. . . . [You] see the older ones [meaning parents] can help the younger ones if they have problems similar to what they've been through.

Summary

The formal agency-informal mix allowed for dependent adult children to have meaningful activities which at the same time supported the need of parents to give and receive information and support. After graduation these services became more important to both the dependent adult children and the parents because the services provided by the schools were no longer available. These organizations were believed to be different than government-supported organizations because the voluntary organizations were viewed as productive and fun, whereas formal agencies were not.

Informal Sources of Support

Parents had received informal sources of support from their own parents, their siblings, their other children, friends, and other parents of adult children with developmental disabilities. Parents from two families said they had received the most help and support from their families while other families identified other families with dependent adult children as their biggest source of support. Regardless of who was identified as the biggest source of support, parents discussed their relationships and networking with other parents more than any other source of support.

Contacts With Informal Networks

As with the formal agency-informal mix, support from informal networks had been fairly consistent over time but was slowly decreasing. In the early years of the dependent adult children's lives, parents talked of their other children being active participants in the development of the dependent adult children. Sibling involvement decreased as siblings matured, became independent and moved out of the house.

Because many of the parents' other children lived in distant locations, they infrequently saw their parents and dependent adult sibling.

The ability of the parents' parents and siblings of parents to assist the parents of the dependent adult child had also decreased. The parents' had died or became recipients of care and siblings had also aged. Assistance from extended families had become limited over time.

Most parents identified a core group of other parents they had known since their children started school together. This core group had been consistent over time and generally consisted of three to four other parents. These parents went through various rites of passages together: starting school, mainstreaming, graduation, and life after graduation. For example Father 3 stated that

> the friends we have made, who have children with mental retardation, way back when he was little, we're still a group, but that's the shared experience of going through public school, and trying to find services and make Special Olympics work and all those things that--nonhandicapped people get together over Little League and band--high school band--and things like that.

The core group provided significant relationships for the parents. Mother 10 reported that

> I think, you know although you have your regular family . . . you feel like that's your other family. That's your other family. I think that's the feeling that most of us get.

Parents reported having contact with other parents outside of their core group but the contact was not as consistent. Parents stated that their core group of other parents had remained fairly constant as a source of support. However, changes did occur during their years of parenting. Parents whose child was mainstreamed into the neighborhood school experienced a drop in networking with other parents that occurred simultaneously with mainstreaming. Parent Teacher Associations (PTA) assisted parents in maintaining their networks. Parents discovered that PTAs in the neighborhood schools

> dealt with the children who were normal children, they were majority. And we lost the contacts, . . . [at the segregated school (H)] I found that . . . [at H] you see a lot of people in the same boat you're in and you discussed things, you find that there are people you know, they have the same problems . . . . I found that once they went into the classrooms in the regular school [there were very few other parents]. And . . . still the contacts that I have the most. . . are the ones that I first met at H. . . . And still, they remain one of the stronger contacts.

While mainstreaming was viewed as an incident that reduced their contacts, parents believed mainstreaming was good for their dependent adult child.

As parents aged they expected their informal sources of support to decrease in size. Parents based this belief upon observing parents who were older than they. Mother 8 stated that "When a person gets older and when they need more support is when they probably won't have that support." The need for increased support was based on the probability of being unable to drive, failing health, and death of a spouse. The decrease in informal sources of support was viewed as difficult because of limited formal sources of support. Observations of Father 3 were that

> We're at an age now, where some of our friends who have children that are mentally retarded; one of the spouses die and one of them is stuck. The children, for the most part, end up in institutions. Because there's nothing else.

Characteristics of Informal Sources of Support

As with the other two sources of support parents identified characteristics of the components of the informal sources of support in terms of individuals involved, recipients of services, and payment for services. Table 6 summarizes characteristic of formal agencies, formal agencies-informal mix, informal networks. In contrast to the other categories of sources of support, informal sources of support did not include professional individuals unless professionals were a member of the family, a friend, or another parent. No one received monetary compensation for services performed or received. Mother 10 stated

> The friends, the other children, they have families that would do the same thing [meaning help out]. And like, we don't charge money. . . if my friend wants to keep D or something, then I keep her [daughter next time]. No money changes, just friendship, stuff like that.

Parents of other dependent adult children were family friends. Father 3 reported

> You know, most of our social environment is with people that have children

> who are handicapped whether it's mental retardation or blindness or deafness or something--people that have family members that have a disability. I think that's a natural progression of life of a handicapped family. It could be a hell of a lot worse; it could be terminal cancer.

For parents, the relationships established with other parents were strong relationships that had lasted 20 to over 35 years. As compared with other sources of support, the informal source of support provided direct services to both the parents and the dependent adult children. In fact, the focus of the support was directed toward supporting the parents so that parenting was easier.

Importance of Informal Sources of Support for Parents

Parents frequently stated that they received the most help from other parents and that interaction with other parents was very important. These parents shared a common bond and life experiences. Mother 11 related that

> well it's just like when we go [to watch] bowling [practice]. There will be, oh four or five of us parents will get together. . . But it's just, you have that companionship, you have people that understand, and if that's the day you want to sit there and cry because something's happened, they understand. . . . You don't have to apologize if my child has been, you're upset with them and you're ready to pinch their heads off, you don't have to apologize because that's how you feel. If they've been sick and you're worried and you're crying about it, they understand where you're coming from. It's not like someone else that doesn't understand why you're so worried about your child

Table 6

Comparison of Component Characteristics of 3 Types of Sources of Support

Formal Agencies	Formal Agencies-Informal Mix	Informal Networks
Professional people always involved	Mixture of professional and non professional individuals	Professionals not involved unless family member, other parent, or friend is a professional person
Providers are paid for services	Some individuals are paid for providing services other volunteer	No money exchange, parents trade off and reciprocate services
Children are recipients of services	Children and parents are recipients of services	Children and Parents benefit from services
Parents are not involved in decision making process of services--can accept or reject what is offered	Parents can hold office in organization and be involved in decision making to a certain level	There are no officers, parents ultimately make all decisions regarding adult children
Parents are not involved in activities of agencies	Parents are involved in activities of agency if they desire	Parents maintain the level of involvement they desire
All services directed toward children not parents--agencies know age of children but not of parents, agencies may or may not know parents	Agencies know age of children but not always the parent, they do know the parents.	Parents know children and other parents --some quite well, friends
Have numerous rules and regulations that must be followed	Rules and regulations on the local level can be loosely interpreted	No regulations regarding eligibility to participate, informal rules may be established between members of support system

Table 6 (con't)

<u>Comparison of Component Characteristics of 3 Types of Sources of Support</u>

Eligibility to participate in services determined by state/agency	Local programs have some control over eligibility of services	
Most services mandated by legislation or state/federal regulations	No legislative mandate National goals and policies to participate at regional/state/ national activities must be followed	No legislative mandate
Parents do not pay for children to participate in services with a few exceptions (Friday dances, Some bus service, community college, summer programs	Parents pay dues and donate time Agencies may assist with participation at national events.	Members may donate time such as respite care.

or why you're so upset. . . . Because if they haven't gone through that direct thing, they've gone through something else a little bit different or they know someone who has a similar situation.

Parents also trusted the feedback and information other parents provided more than the information received from agencies. Parents knew what agencies other parents had tried and valued other parents opinions. For example, Father 7 said

> we hear a lot of feedback about other agencies from the parents. It seems like the parents with handicapped children are quite verbal in their positive and negative you know, talks on different agencies.

This information allowed parents to have a different perspective of the information provided by agencies and assisted in the decision to try or forego agency service. The opinions of other parents were considered to be more accurate than agencies because the other parents had

> experienced it. Or we have experienced it, you know, and so it's really more accurate and I find it very informative in what I need to do, or what they tell me that I should do, . . . and I find that I'm right, by talking to other people, that I'm right. (Mother 2)

Parents also got together to maintain services provided to their dependent adult children. They would make a group effort as opposed to individual effort. For example, Mother 2 related an incident where an agency threatened to cut services to

> 38 of them [meaning dependent adult children] and just, just drop them completely; leave them at home. 'We don't have anymore room for you.'

> Well that wasn't going to work with me. I says "No, no, this child is not a home person. He cannot stay at home." Not only my child, I know of several others and . . . we were all concerned so we called [the program] president . . . I started calling a lot of the families so that we could get all together to find out what we could because these kids could not stay home. They've been doing some kind of work and they need to get up . . . And so we went to the City Council and . . . it wasn't two weeks, they were back in the program again.

Parents believed they had an effective "grapevine" and could pass information quickly through this route. The grapevine was faster than waiting for agency announcements about changes in services. Mother 3 reported that when she discovered a new service she told other parents

> in the swimming program, we have about 14 kids that are . . . [eligible]. And I went in there and told them all about it and they all went up and registered. [The only way you really find out about new services available in a community is by] word of mouth.

Summary

The informal sources of support for parents consisted primarily of other family members and other parents of dependent adult children. Family members as sources of support has slowly decreased over time related to the death and or infirmity of the parents of parents, the aging of parents' siblings, and other children moving out of the house and often out of the area. Family members had always been a significant source of support and parents depended upon other children continuing the support of the dependent adult child after the parents' death.

The informal network with other parents of dependent adult children began when the child started school, decreased slightly with mainstreaming and again with graduation from high school. However, agencies such as Special Olympics allowed parents to meet new parents of children with disabilities; this contact did not become as meaningful as relationships established when the child started school but did prevent social isolation. The core group of other parents was one of the most stable and significant sources of support for parents.

Formal Versus Informal Sources of Support

Lofland and Lofland (1984) state that comparative analysis of small units is useful in apprehending the phenomenon of study. Sources of support with three different identified types lends well to comparative analysis. It seems important to perform this level of analysis as sources of support was a serendipitous finding. Parents wanted to talk about the assistance they received from other families with dependent adult children and the lack of assistance from formal agencies. The formal agency-informal mix source of support really was a special type of formal agency source of support. Organizations identified in the formal agency-informal mix differed from formal agencies mainly in that they were voluntary agencies that allowed for the development and maintenance of informal sources of support. Accordingly, for this analysis only formal agencies and informal networks were compared. Major differences between informal and formal sources of support included availability, consistent core, and trustworthiness of information.

Availability

Formal government agencies were perceived to be available to parents during the regular nine to five, five day work week, excluding holidays. However, actual services for dependent adult children were not readily available. Formal agencies had long waiting lists for sheltered workshops. One dependent adult child had been on the list for seven years. The average waiting time reported was eight years. The only available respite services provided two beds for the entire county. When space was both desired and available, neither parents nor their dependent adult child liked the services. Group homes were available but the waiting time for them varied from a year or more.

Parents found that both the availability and scope of services were insufficient. Parents with a higher functioning dependent adult child found the workshops were inappropriate for their child's needs, while parents of a lower functioning dependent adult child voiced the same complaint. Parents questioned the appropriateness of some of the workshop jobs, such as picking up trash along the highway.

Availability of services to dependent adult children sometimes depended upon the parents willingness to be persistent, fight, and consider filing a law suit or complaint to seek compliance with government legislation and regulations. The need to continue to fight for services came at a time when elderly parents were tired and frustrated in fighting the same battles again and again.

Informal sources of support for parents differed from formal sources in that other parents were always available via telephone 24 hours a day, seven days a week and on holidays. Other parents assisted with the little things, such as helping when transportation was a problem, sharing experiences, providing emotional support to the parent, providing a couple of hours of respite, and increasing socialization of parents and dependent adult children. Parents found that they did not have to explain things to other parents because of a shared understanding that was missing in other settings and relationships.

Consistent Core

The turnover of personnel in formal agencies was frequent. Parents reported that agency personnel knew little about them and what they knew about their dependent adult children was what was available in the records. After the dependent adult children reached 22 years, the service providers the parents knew when the dependent adult child was in school were no longer providing services. At a stressful time of transition, parents had to adjust to new service providers. Parents believed that there was no continuity of services between agencies and that it was necessary to begin anew with every agency.

However, with the informal sources of support, parents reported a consistent core of parents they had known and interacted with since their children began school. Other parents knew parents of children with developmental disabilities. They also knew the children. They had attended together PTA meetings, Special Olympics practices and meets, and other activities from 20 to over 30 years.

Although parents met new parents at their children's activities, the parents related that the core group they established when the dependent adult children started school was the same group they interacted with today. Activities, such as Special Olympics, allowed parents to meet and exchange information. PTA meetings used to perform the same function. However, with mainstreaming to neighborhood schools, parent reported that the contact with other parents decreased; yet the parents' core group remained intact.

One concern for the core group was as these parents aged, the core group also ages. A core group of parents may find with advancing age, deteriorating health, and death that the core group is unable to continue to provide support. Parents reported that older parents' sources of informal support decreased as the parents aged and their needs increased.

Trustworthiness of Information

Advice from professionals associated with formal agencies was not always considered to be realistic. Parents believed the professionals did not always have practical experience to complement their "book learning." Practical experience, preferably with a family member, increased the reliability of advise given. Parents also believed that professionals thought they knew what was best for the parents' dependent adult child. Much disagreement occurred between professionals and parents regarding the best interest of the dependent adult child.

Because parents knew each other, and each other's situation, parents believed they knew who provided accurate information and who did not. Parents shared information whenever they got together. Sharing information and seeking advice was easy as most parents had similar experiences, and they could relate what worked and what did not for a particular problem. Parents could provide evaluations on new services available that would allow other parents the opportunity to consider the appropriateness of the service for their dependent adult child. Other parents may not have had a lot of "book learning," but their practical knowledge was valued.

Overall, parents valued the support from other parents more than the support from formal agencies. Parents reported receiving more support from other parents. Several parents could not remember a professional person ever having helped them. The core group of parents in the parent network was a significant presence in the lives of the parents and the dependent adult children.

Summary

Lofland and Lofland's (1984) method of analysis of social settings was used to analyze the social unit of sources of support. Parents identified three major sources of support; these were formal agencies, formal agencies-informal mixture, and informal networks. Of all sources of support, parents believed the informal sources were the most available, consistent, and reliable. Over the course of their dependent adult child's lifetime, parents encountered numerous agencies and agency personnel. However, over this same time period, parents had the friendship and support of a core group of other parents of dependent adult children. Parents believed their biggest source of support was other parents. Parents had difficulty identifying a professional individual who had helped them with their dependent adult child. The biggest threat to the support core groups of other parents was the fact that they were all aging. With advanced age came the threat of inability to drive, failing health, and death. In the future, other parents as sources of support might not be as viable.

CHAPTER VI

DISCUSSION

This chapter includes a discussion of the following: lack of developmental closure, sources of support, comparison with other studies, methodological issues, implications for nursing, and suggestions for further research.

The parents of this study and other parents of the same era represent a unique group of people. They kept their dependent adult children home at a time when they were encouraged to institutionalize children with developmental disabilities. They sought services and created organizations to assist with the development of their children. Their needs were always at least one step ahead of services. Seltzer (1992) stated that

> Because persons born at different times--and because families formed at different times--are the products of different personal and societal circumstances, they cannot be expected to move through the life course in identical trajectories . . . [for parents at different times there] might be quite . . . a difference in their patterns of individual and family adaptation for reason other than the age of the child [with developmental disabilities]. (p.91)

The experiences of parents in this study were unique to them and their families because of the different social climate, the lack of services, the stigma attached to developmental disabilities, and small but sporadic incremental changes in social and health policies regarding developmental disabilities.

Rowitz (1992) stated that during the past 30 years major changes have occurred that alter the way we view developmental disabilities and the way we provide services to individuals with developmental disabilities. In referring to the role parents had in nurturing the changes, a parent in the pilot study (Schaller-Ayers, 1991) said that elderly parents were "trailblazers," who created a path for others to follow. It might be said that because these parents were unique their coping strategies and adaptions might not be of use for those parents following. The path is different because the social climate was different. However, some insights can be gained from their experiences; the 800 person waiting list for sheltered workshops in El Paso will not end anytime soon. As parents of young children continue to have new experiences they continue to be frustrated in getting services desired or having to cope with the implementation of new services. Most recently, parents in El Paso were experiencing the phenomenon of "inclusion," where children with moderate to severe disabilities were included in regular classrooms, not in special education classes.

Historically, much has changed in the social and policy climate surrounding the needs of parents and their children with developmental disabilities. The changes noted represent only a trend. Rowitz (1992) stated that there have been three basic trends with developmental disabilities: trends on "family and life course, trends on health and services, and finally major trends on service and policy issues" (p. 5). From these basic trends Rowitz (1992) has predicted 130 changes that will affect the lives of individuals with developmental disabilities and their families by or beginning in the year 2000.

Lack of Developmental Closure

The phenomenon of lack of developmental closure is atypical in the original formulation of developmental theories as proposed by Erikson (1963) and Duvall (1957). Their theories propose an orderly process of development, either from birth to senescence, or from marriage to the death of both married partners respectively. However, Erikson's theory has been reconceptualized (Erikson, E., Erikson, J., & Kivnick, 1986) so that individuals are believed to have the opportunity to redo earlier stages of development because of introspection and the repetitious nature of life cycles. Erikson et al.'s (1986) reconceptualization used data from elderly individuals from his original study who were able to move on to higher stages of development. Parents in this study should have the same opportunity to redo earlier stages of development as did the individuals in Erikson et al.'s study. However, because of mental retardation, the dependent adult children in this study might not have the opportunity to progress through the developmental stages, or to redo earlier developmental stages. Dependent adult children, parents and families experience a disruption in the process of development. Breinbaum (1971) and Seltzer (1992) referred to individuals and families being "off cycle" when expected advancements within the developmental process did not occur.

Dependent adult children. Because the dependent adult children were unable to complete developmental tasks at an earlier stage of development, they remain in that developmental stage. Dependent adult children in this study remained in either school age or adolescent stages of development. Dependent adult children exist in an interesting paradox for they are functionally children but are legally adults, children while approaching old age.

Dependent adult children who must rely on parents to meet their basic needs cannot be launched successfully to independent living (Seltzer, 1992). Dependent adult children cannot be launched for a variety of complex issues that include the inability of the dependent adult child to live independently, the parents' desires to continue parenting, the lack of perceived acceptable alternatives, and the mutual benefit derived from parents and dependent adult children living together (Heller & Factor, 1991; Seltzer, Krauss, & Heller, 1991; Wood, 1993). The inability of the dependent adult children to be launched has a ripple effect upon their parents and families. Individuals and families become permanently frozen in an adaptive structure that may or may not be helpful (Rolland, 1988).

Parents. The developmental stage of old age has been labeled by Erikson (1963) as Ego Integrity versus Despair. This stage of development allows for introspection of one's life. Butler (1963) refers to old age as a time when one goes through a life-review process. Reflections on successes of children and grandchildren allows parents to confirm their own parenting skills (Ebersole & Hess, 1994). Seeing adult children independent and successful in their own lives provides some comfort to parents. However, parents with dependent adult children are denied this comfort. The inability of parents to successfully launch dependent adult children in their lifetime possibly interferes with the parents' ability to complete developmental tasks of old age as identified by Erikson (1963). Because these parents will always have the unfinished business of worrying about the uncertainty of the future, they must seek some sort of assurances regarding the quality of life for their dependent adult child when they can no longer care for their dependent adult child. The assurances parents seek are elusive. Since parents may never receive these assurances all they have are their hopes.

Aging family. Aging families with dependent adult children present an intriguing situation. The family triad or dyad consists of mother, father, and dependent adult child, or a mother or a father and a dependent adult child. Because of the divergent needs of the family members, families with dependent adult children become frozen in an earlier family development stage while at the same time continuing to progress toward the aging family stage. Seltzer (1992) has stated these families become frozen in the launching stage identified by Duvall. However, launching may not occur until after the death of both parents when the dependent adult is launched into another protective environment.

For the family to meet adequately the needs of its members, the family must concurrently manage two different sets of family developmental tasks that may be competing. The tasks of the aging family are complicated by the needs of the dependent adult children. However, tasks can also be made easier. For example, after the death of a spouse, an individual needs to adjust to the loss and the loneliness associated with the loss. Yet, parents of dependent adult children are not alone. They have their child's companionship. Dependent adult children also help parents by doing household tasks and tending to their parents when they are ill. Seltzer (1992) has reported that although dependent adult children can be stressors in meeting family development tasks of aging families, dependent adult children can also enhance the family's abilities to meet developmental tasks.

Sources of Support

Elderly parents of dependent adult children receive support from two divergent sources: (a) government and voluntary agencies and (b) informal sources such as families and other parents of dependent adult children. Over time, parents came to believe that informal sources of support were of greater assistance to them than were the governmental agencies. This belief may or may not be accurate, however perceptions are important in understanding the parents conclusions. Parents may have low opinions of governmental agencies' assistance because of disagreements about the best interest of the dependent adult child, frequent staff turn over, long waiting lists to get services, and the belief that professionals at governmental agencies lacked practical experience. Conversely, parents may give greater value to the assistance provided by the informal network because of consistency of contact over the years, shared experiences, support readily available, practical experience, and becoming friends with parents.

Regardless of the possible influences on the evaluation of sources of support, parent considered the assistance of formal agencies provided to be lesser in quality. Grant (1986) proposed several factors that may explain the low ratings parents give to formal sources of support. First, older parents did not expect direct support from formal agencies but had learned to rely on the informal network for assistance.

Second, in times of crisis when all else had failed, agencies were contacted to deal with unrealistic expectations, and professionals had difficulties attempting to fit existing services with client needs. Third, although parents and dependent adult children in day programs have daily contact with those program personnel, parents were passive recipients of services, having experienced no intimate contact with personnel. Additional reasons identified by parents in this study included services not designed to assist individual dependent adult children with special problems and the agency personnel's lack knowledge about parents.

Problems with formal sources of support have been well documented in the literature. Waiting lists for group homes and sheltered workshop positions are national problems. Additionally, there has also been a shortage of qualified personnel. Rowitz (1992) predicts that to solve problems associated with formal agencies community organizations need to be built on partnership. A partnership model involving parents, individuals with disabilities and agencies will be needed for comprehensive service models to be implemented. Comprehensive services should be available to all family members.

Policy research and program demonstrations with rigorous evaluation for improving the effectiveness of formal agencies are necessary. Fujiura and Braddock (1992) conclude that

> No object of public policy is more central to the larger national portrait of services than the American family: The parents. . . and other relatives of persons with mental retardation . . . collectively represent the nations largest

> alternative "system" of care. . . . New policy directions focused on the family must be considered, and included among these should be further development and expansion of support programs. . . Family empowerment must be elevated to the level of a national priority. (p. 336)

The need for policy research regarding services to families with dependent adult children becomes more crucial, given the current constraints on public funding and the knowledge that the number of dependent adult children in need of services is increasing dramatically. Between 1977 and 1988 new community residential facilities have accommodated 83,000 additional individuals with developmental disabilities; the 1990 waiting list for residential placement was approximately 83,000 dependent adult children (Fujiura & Braddock, 1992). To adequately accommodate the needs of dependent adult children and their families, service programs will need to be innovative.

Comparison With Other Studies and Implications for Research

The themes identified from the review of the literature were parental planning, problems encountered, utilization of services, health status, and difference between elderly parents of dependent adult children and other caregivers of disabled individuals. The findings from this study were compared to quantitative findings from other studies by using the identified qualitative themes from the literature as a framework.

Parental Planning

The major concern of elderly parents was what would happen when they would be unable to provide care to their dependent adult children. Although this concern was consistently reported in the literature and parents in this study, parents do not have adequate plans for the transfer of care of their dependent adult children. As with the studies by Gold (1987), Heller and Factor (1988, 1991), Kaufman, Adams, and Campbell (1991) and Wood (1991, 1993), parents in this study had ambiguous arrangements that ranged from having fairly complete plans with a private group home; to having hopes that other children would take the dependent adult child in to hopes that a new kind of supervised living program would be developed; and to having no plans at all, just hopes.

The most common planning activity parents had was to talk with other family member about parental wishes for the future: yet, parents perceived the other adult children as not always wanting to discuss future plans. However, the lack of discussion about future plans may be explained by Gold (1987) who suggested that the lack of adequate plans may be related to the reluctance of parents to discuss their deaths. Other children may also be reluctant to discuss future plans with parents that are directly related to the parents' death.

Another reason suggested in the literature for inadequate planning was the desire for parents to maintain their dependent adult children in their home (Gold, 1987; Heller & Factor 1991, Wood 1993). Long term planning was further complicated for several factors, including the hope and possibility that the dependent adult child might die first; the benefits of continued involvement with the dependent adult child; the reluctance to give up parenting; and the belief that no other acceptable alternatives existed (Wood, 1993). Each of these reasons was discussed by parents in this study. Reasons given why other alternatives were not acceptable by parents in this study included: sexual permissiveness of group homes, warehousing atmosphere, frequent turnover of staff, and lack of caring persons to attend to the dependent adult child when ill.

Gold (1987) found that parents had an increasingly difficult time in maintaining dependent adult children at home. Although this was not the case in this study, parents in Gold's study were older than were the parents in this study. Parents in this study perceived that as they aged, parenting their dependent adult child might become more difficult, especially if their health or ability to drive deteriorated, or if their dependent adult child's health deteriorated. Heller and Factor (1991) proposed that as parents know more about alternative housing options, the preference for these options increased. However, what the parents in this study knew about alternative housing options decreased their preference for these options.

Parental planning for the future transfer of care of the dependent adult child is a complex issue that involves parents, dependent adult children, other children, and availability of alternative housing. It is difficult to assume an adequate understanding for lack of parental planning for transfer of care without knowing the perceptions of others involved in the planning process.

Research is needed to gain the perspectives of all parties involved in the planning process regarding preferences for types of services desired and assistance needed. A grounded theory approach identifying the factors and stages involved in the planning process and decision to place a dependent adult child in residential facilities or with other children would be useful in enabling parents to make transfer of care plans. Additionally, a longitudinal study examining factors that predict parental preference for placement and actual placement of the dependent adult child may be helpful.

Problems Encountered

Parents in this study reported similar problems in parenting as did parents in other studies. For example, restrictions on own lives, keeping the dependent adult child occupied, managing behavior, maintaining own health, maintaining health and self-help skills of the dependent adult child, and safety issues. Interestingly, parent concerns about their own health were related to their abilities to continue parenting, not necessarily for their benefit. Additionally, problems such as maintaining health and self-help skills of dependent adult child and keeping him or her busy were related to parents' concern about the dependent adult child's potential regression. The context of these factors have not been identified in other studies.

Although parents in this study stated that problems were encountered, they had learned to adjust to the restrictions on their lives and the everyday parenting activities. The felt difficulty reported by this study's parents varied from that reported in other studies. Wood (1991) reported that the level of felt burden in caring was mild to severe in 40% of the mothers. The degree of difficulty in providing care to dependent adult children in this study for response of "moderate" to "a lot" was only 17%. Most parents in this study found that providing care to their dependent adult child either "not difficult" or "a little difficult." The perceived level of care to the dependent adult children was also less in this study than what was reported by Wood (1991). The averaged age of caregivers (parents or other relatives) in Wood's (1991) study was nine years older than the parents's in this study. However, parents' age and health status have consistently not been associated with parents' perceptions of increased difficulty, while the deterioration of the dependent adult's functional ability as been associated with perceptions of increased difficulty (Gold, 1987; Roberto, 1993).

Gold (1987) reported that parents felt being overwhelmed, without hope, and having no peace of mind. Parents in this study reported a decrease in hope of the dependent adult child improving and that services would be available; still, overall, they had hope. While parents in this study did not speak of being overwhelmed, they did report a constant concern that they would put in the "back of their minds" or they would go "crazy" with worry about the future. Concern for the uncertain future was always present. Gold (1987) suggested that the uncertain future was related to the denial of comfort from the knowledge that their childcare tasks are complete: that is being able to see their children live independently. This lack of closure makes parents more vulnerable to despair and stress.

In coping with their life situations, parents in this study discussed two of the four strategies identified by Seltzer and Krauss (in press). The coping strategies of acceptance and positive reinterpretation were frequently mentioned. Effective planners were able to create new services and organize family needs. Most parents in this study, however, reported being tired of advocating for the creation of new services or attempting to form new organizations. Parents reported being "burned out," and that it was time for younger parents to take on this task. Whereas planning appeared to have been a significant coping strategy in their earlier years, elderly parents in this study found that they were less willing to continue the fight entailed in planning for the development of new services. Examples given by Seltzer and Krauss (in press) support planning as a coping strategy of parents when their children were young.

Over time parents who continued to provide parenting to their dependent adult child developed a repertoire of coping mechanism for various problems. A question exists regarding the continued success of these coping mechanisms as both parents and dependent adult child aged, experienced a decrease in health status, and had decreased mobility. To adequately answer this question longitudinal studies are needed that examine changes in the parenting experience as well as the necessary corresponding changes for both parents and dependent adult children.

Utilization of Services

Elderly parents tend not to utilize formal and informal assistance in providing care to their dependent adult children (Engelhardt, Lutzer & Brubaker, 1987; Gold, 1987; Holmes & Carr, 1991). Engelhardt et al. reported that the utilization of services was inversely related to the parents' perceived ability to provide care. Wood (1991), Lutzer and Brubaker (1988) surmised that parents' lack of service utilization may be tied to lack of knowledge about services and diminished interest in socializing outside the family. Parents in this study seemed to know of services available and as new services appeared news of the service spread rapidly through the parent grapevine. Parents reported different reasons for not using services: easier not to involve agencies, frustrated with past experiences with agencies, agencies not able to provide what is desired, services not appropriate for dependent adult child, giving up on agencies being any help, perception that individuals at agencies do not care, not liking service (respite), and a way to avoid battles or fighting for services.

The under use of services by elderly parents to assist themselves and their dependent adult child is not merely a lack of knowledge about service availability but a complex issue. For the parents in this study, accessing desired services seemed to be very difficult. Dissatisfaction with services resulted in parents ceasing to use those services. Studies should be undertaken to determine what parents desire in services for themselves and their dependent adult child.

Health Status of Elderly Parents

As with other studies (Engelhardt et al., 1988; Heller & Factor, 1988; Roberto, 1993; Seltzer and Krauss, 1989; Seltzer, 1991b) few parents perceived their health status to be poor. Additionally, as with Wood's (1991) study, parents in this study also reported a trend toward the perception of deterioration of health. In this study parents reported a consistent downward trend in health status from 10 years ago to a projected 5 years in the future.

The trend toward the perception of deterioration of health may be the result of beliefs regarding the aging process. It may also be based upon observations of older friends with dependent adult children. Regardless, the perception of poorer health status has been associated with the perception of increased stress and burden in parenting dependent adult children (Roberto, 1993). Longitudinal studies are needed to determine the impact of health status and the aging process on perceived ability to parent, perceived stress and burden, service utilization, and plans to transfer care.

Themes Identified in Pilot Study Not Identified in the Literature

Themes in the pilot study not addressed by the literature included lack of financial security, enhancing development, and benefits of the dependent adult child living at home. Financial security for the parents and dependent adult child was a frequent concern of parents in the pilot study (Schaller-Ayers, 1991). Financial security for the parents was mentioned only by one parent in the larger study. Although parents thought they were financially secure, parents believed that financial security was a problem for other parents. These parents often cited one parent as having financial security problems.

The concern for the financial security of their dependent adult child was evident with these parents. As in the pilot study (Schaller-Ayers, 1991), concern was expressed that there would be insufficient monies to support the dependent adult child, and not financially burden other children providing care, and yet for funds to be available in such a way not to make the dependent adult child ineligible for Supplemental Security Income (eligibility for governmental supported services often depend upon eligibility for Supplemental Security Income). Most of the adult children in the pilot study were in day programs, whereas only 50% of the dependent adult children in this study were in day programs. Parents in the pilot study were also concerned about possible cuts in services because of financial constraints at the state level in Oregon. Financial issues were more frequently discussed by the Oregon parents than the Texas parents.

As with the pilot study, parents in this study discussed a continuous effort of working with dependent adult children's developmental status. While parents in this study reported that the dependent adult child had probably reached peak level and parents' efforts were directed at maintaining current level of functioning, the parents in the pilot study strived to enhance the dependent adult child's developmental level. One parent in the pilot study had been trying for 30 years to teach her daughter to read.

The benefits of having a dependent adult child in the home were similar for parents in both studies. Parents identified companionship, doing things together, enjoying the dependent adult child, and receiving the love offered by dependent adult child. Parents in this study also identified additional benefits a dependent adult child provided, such as helping the parent, keeping the parent young and active, giving the parents reasons to live, having positive influences on other children, providing enjoyment, keeping holidays special, and providing a meaningful presence in the parents lives.

There is a dearth of research regarding the benefits of dependent adult children residing with parents. Most of the literature focuses on the disadvantages: burden and stress. The benefits parents receive and the reciprocity that exists between parents and dependent adult children have been suggested to increase well-being of parents (Heller & Factor, 1991). Parents may experience personal rewards in the parenting role with their dependent adult children. The entire phenomenon of rewards with parenting dependent adult children needs to be explored.

Methodological Issues

Methodological issues discussed in this section are issues regarding the participants, the analysis methods of Lofland and Lofland (1984) and ethnography (Spradley, 1978), and strengths and limitations of the study.

Participants

Qualitative research is well suited to the elders who have the "psychological needs . . . to review their lives, [and] to educate the young" (Rowles & Reinharz, 1988, p. 20). Qualitative research interviews may allow elders to explore and provide some meaning to their lives. Also, elderly research participants may find enjoyment in sharing past experiences (Rowles & Reinharz, 1988). Parents who participated in this study readily agreed to participate in the study even after only limited explanation about the purpose. On the initial contact with one mother, she said that she had been waiting for the telephone call and that the interview "sounded fun." Parents would often start talking about their experiences prior to fully reading the consent form and had to be reminded that the consent forms needed to be completed before the interview could technically begin.

Sharing their experiences was important to the parents. Interviews that had been scheduled to last one to two hours lasted two to four hours. Parents asked the researcher to come back anytime or to telephone if there were any questions. Even the family who had a member in the hospital with a life threatening problem asked the researcher if the second interview could be rescheduled for the following week (the researcher suggested that a second interview was not required). At the beginning of the second interview, all parents spontaneously provided information on what had happened in their lives since the first interview. There were numerous questions on the progress of the dissertation and when the project would be complete. When scheduling interviews, parents were most concerned about what was convenient for the researcher, not themselves.

Rowles and Reinharz (1988) contend that elders are especially vulnerable to exploitation as a result of the establishment of a rapport that enables the elders to reveal their innermost thoughts about their lives. A dilemma exists in deciding when a relationship becomes exploitation. Two dilemmas in this study emerged. First, parents agreed to participate without really understanding the purpose of the study. Prior to signing the consent form, time had to be allowed for participants to read the entire informed consent form and have the opportunity to ask questions about the study. Parents were also encouraged to ask questions about the study during the interviews. Second, it would have been easy to allow a parent experiencing the stress of a hospitalized, acutely ill spouse to participate in the second interview. It was necessary to recognize the difficulty of this situation and discuss with the parent the right to refuse to participate in the interview. Honesty with participants did reduce the risk for exploitation. Shared with the parents was the number of interviews anticipated and what would happen with the information collected. The parents' questions were honestly answered.

Cassel (1985) proposed that elders like to believe they can make a contribution to the future and to society. Consistent with Cassel, all the parents diligently read material mailed to them regarding data analysis (See Appendix E) and made comments regarding the analysis. When there was an attempt to discuss selected areas of analysis, the parents, however, wanted to discuss all the analysis in its entirety. Parents expressed uncertainty whether the information they provided was indeed what the researcher wanted. One mother, who was a very good informant, frequently apologized for "rambling" and wondered if anything she said was of help. The researcher frequently reassured parents the information they provided was helpful; that they, not the researcher, were the experts in the area of study.

Overall, parents enjoyed the interviews. Some said they learned something in the process. Other parents considered different activities they could pursue, such as teaching the dependent adult child to dial 9-1-1 for emergency situations. However, at times the interviews were emotionally stressful. Four of the six fathers and seven of the twelve mothers had tears at some point during the interview.

Anonymity and confidentiality. Rowles and Reinharz (1988) state that there is an increased responsibility for anonymity, "particularly in situations where respondents are part of small and strongly interrelated networks" (p. 25). The parents in this study had highly interrelated networks. Parents as a result of their own network would tell the researcher they knew who was being interviewed next or whom had been interviewed, and in some instances what was discussed. Parents would often relate experiences of other parents in the study when describing a particular concern or topic. Maintaining anonymity in qualitative research was especially difficult when it was desirable for data from one participant to be verified and elaborated upon by another participant. In such situations names were never used and the data were reduced to short phrases.

Another debated issue regarding anonymity was how to protect anonymity of participants when demographic data could identify families to service providers. Using pseudonyms and describing individual families was considered; however, families could still be identified. After much thought and discussion, a decision was made to report demographic data only in aggregate form. This option provided one means of protecting anonymity of the families.

Analysis Issues: Ethnography

The original research design for this study proposed using ethnography as described by Spradley (1978) as the sole method of analysis. Spradley's (1978) analysis is based upon semantic relationships in the building of domains and taxonomies using any particular semantic relationship, the domains and taxonomies are mutually exclusive. Upon completion of the data analysis of the first interviews, wholeness of an experience or meaning appeared to be lost in the taxonomies. Instead of the data coming together, the data appeared to become more and more fragmented.

Spradley's (1978) method of analysis did allow for the collection and clustering of numerous descriptors into a meaningful form. This collection of descriptors was mailed to participants for comment and discussion. Approximately one-third of the way through the series of second interview, when the descriptors were to be discussed, a decision was made to change the method of analysis. Lofland and Lofland's (1984) intensive analysis of social settings was selected as an appropriate method given the type of data collected and the purposes of the study for capturing the holistic character of elderly parenting.

Lofland and Lofland's (1984) method of analysis allowed for a holistic exploration of a concept. For example using ethnographic analysis, patience, which was identified as a characteristic of parenting, was separated from future planning, which was a type of concern. In using intensive analysis of social units, patience and concerns for future planning were both considered in the social unit of meaning of being a parent. Also, because social units build upon one another and are not mutually exclusive, one could explore the consequences of one unit for another. For example, the meaning of being a parent was examined for its consequences on parenting practices.

Modification of the method of analysis, although unusual, is not impossible. Janesick (1994) states that the plan of analysis for qualitative studies is elastic. Likewise, Huberman and Miles (1994) state that loose analytical designs "work well when the terrain is unfamiliar and/or excessively complex" (p.431). The phenomenon of this study was consistent with the descriptions of unfamiliar terrain and complexity. The ability to modify the method of analysis is a strength of the qualitative research paradigm.

Analysis Issues: Analysis of Units of Social Settings

The analysis of units of social settings as proposed by Lofland and Lofland (1984) was selected as the method of analysis because the research questions and data collected were appropriate to this type of analysis. Units of social settings described by Lofland and Lofland (1984) emerged from the data. However, the data regarding assistance from formal agencies and informal networks as a unit did not fit into any of the 11 basic units described by Lofland and Lofland (1984). Since the list of units is potentially unrestricted it would have been possible to look at sources of support as strategies parents used in parenting an example of the social unit of roles. Asking questions such as what strategies are used for every social setting unit, is one of the analytic techniques identified by Lofland and Lofland (1984).

Informal sources of support also could have been considered to be an example of the social unit "groups." Lofland and Lofland (1984) define groups as "people who interact with some regularity over an extended period of time and who conceive [of] themselves as a social entity" (p. 85). Although individuals in the informal network did perceive themselves as a group, they did not perceive themselves to be a part of the formal support services.

Analyzing part of sources of support as strategies and other parts as groups would have been possible. In doing so the concept of sources of support would have become fragmented throughout the units analyzed. One of the reasons for switching from ethnography to units of social settings method of analysis was to reduce the perceived fragmentation of data. After much thought and discussion, a decision was made to develop a unit entitled "sources of support" so that data could be looked at in it's entirety. Sources of support was analyzed as suggested by Lofland and Lofland (1984) for type, structure, frequency, causes, processes, consequences, and strategies to obtain support. Furthermore, sources of support was analyzed for it's consequences upon other units, primarily encounters, meanings, and practices. The development of different units of social settings was consistent with the method presented by Lofland and Lofland (1984) and the purposes of qualitative research design.

A primary benefit of a qualitative design is the holistic perspective provided through analysis. Qualitative design "looks at the larger picture, the whole picture . . . [and] is focused on understanding a given social setting" (Janesick, 1994, p. 212).

Ethnograph, (Seidel, Kjolseth, & Syemore, 1988) was briefly used but abandoned after a short period of time. The researcher had not previously used this computer program and found it cumbersome to learn a new program while attempting to analyze data. For most of the analysis method suggested by Spradley (1978) and off of the analysis method suggested by Lofland & Lofland (1984) analysis was done using word processing, handwritten data bits and poster board.

Strengths and Limitations

Strengths. The strengths of this study included: prolonged contact with the participants, honesty of participants, the richness and thickness of the data, and the fathers' participation. A strength of using both ethnographic and unit of social setting methods of analysis lies in the prolonged contact through repeated interviews and taking data analysis back to the participants. All parents had the opportunity to view the first round of data analysis for accuracy and completeness. Only two descriptors were added to an 11 page list of categories with descriptors (See Appendix E). Most parents said the list was "good" and "complete." However, parents did note that while not every descriptor applied to them, they knew of parents to whom the descriptor applied. Parents did not request any descriptor to be removed. This study utilized the techniques suggested by Marshall and Rossman (1989) to enhance accuracy of data analysis. These were triangulating multiple sources through repeated interviews, repetitious questions, affirmation of perceptions by several participants, and confirmation.

Accuracy of data is dependent upon the honesty of participants and the credibility of the data analysis. The honesty and willingness of parents to share their experiences and perceptions was enlightening. Parents did not easily discuss the wish for their children to die before them, or for their dependent adult daughters to have tubal ligations to prevent pregnancy. The data provided were rich with descriptive terms such as "wide eyed," "reality smacked me in the face," "God damn punch list" and "faded into infinity." Credibility was enhanced by taking the data back to the participants for confirmation and to have face to face contact with each participant for three to seven hours.

In most published studies of elderly parents of dependent adult children, only mothers participated in the study or the fathers' participation was so minimal that analysis has not been reported. The participation of fathers in this study added an important dimension to the findings that would have been lacking without their involvement. An interesting discussion by fathers revolved around their increased involvement in their dependent adult children's care and activities since retirement.

Weaknesses. The weaknesses addressed in this section are biases, sample issues, population representativeness, and ethnicity. Janesick (1994) has said, "There is no value-free or bias-free design" (p.). All research is biased because it reflects "the play of class, gender, race, ethnicity, and culture, suggesting that so-called objective interpretations are impossible" (Denzin, 1994, p. 507). The risk for bias is increased when only one person is active in the analysis of qualitative data. Because of distance, the researcher was the only person that scrutinized all interviews for data. Transcripts were made available to the committee chair; however, active discussion did not occur regarding the transcripts. All committee members reviewed data bits selected by the researcher that were used to support findings. Therefore, credibility of the findings could have been enhanced through investigator triangulation.

One of the purposes of this study was to explore how the meaning of parenting dependent adult children had changed over time. The method used allowed for only a retrospective look at the changes. Also, all information came from only the parents. Therefore, other children may have a different perspective than did the parents on their relationship with the dependent adult child and their involvement in future planning. Fathers have generally been neglected in the study of elderly parents' parenting dependent adult children. Although a third of the participants in this study were fathers, fathers from three families did not participate. One questions whether their input would have had a significant influence on the findings, especially since two of the nonparticipant fathers were in their late 70s.

Overall, parents who participated in this study were among the younger old individuals. No parent was over age 75 years and the average age was only approximately 63 years. Older parents with potentially more health and mobility problems and in an older cohort may have had different views of their experiences than did the parents in this study. Father 3 said, as he aged, the future became more immediate, and mother 11 said that as she aged, she worried more about the future. Perspectives on parenting, sources of support, and the uncertain future might also be different with an older group of parents.

Denzin (1994) states that ethnicity is a source of bias. All but two parents shared European ethnic heritage; the other two were of a non-hispanic minority heritage. In talking to parents about parents of Mexican heritage, parents said there were a lot of similarities but differences also existed. Older parents of different ethnic heritages also may have different perspectives on parenting, sources of support, and the uncertain future.

There is no way for the researcher to know if the participants are representative of other older non-Hispanic individuals who continue to parent dependent adult children. The participants' names came from three churches, two organizations, and by use of the snowball sampling technique. After two and one half months no new names were obtained. There is the possibility that the parents missed were using only government sponsored services that the researcher did not access.

Practice Implications

Implications for practice fall across the areas of specialization in nursing. Nurses will increasing come into contact with families of children with developmental disabilities of all ages. Since the mid 1960s institutionalization of individuals has dramatically decreased and deinstitutionalization has increased since the 1980s. Most individuals with developmental disabilities reside with other family members.

School and community nursing. Parents in this study discussed the importance of knowing a core of other parents on whom they have relied on for support since their dependent adult child started school. Parents also stated that when their children were mainstreamed into the neighborhood schools, their other parent network decreased as they received less support from school PTAs where membership included a greater proportion of parents with nondisabled children. With the current trend of inclusion, parents might find that their network decreases further, or have only limited opportunities to develop.

School and community nurses can play an important role in assisting families to meet other parents, establishing support groups within the school, and nurturing the development of networks between parents. The increasing trend in single parents and working mothers may cause parents today to have less time to establish the bonds and networks elderly parents have found so helpful.

Family nursing. The effect of young children with developmental disabilities on families has been documented since the 1950s (Schonell & Watts, 1956; Caldwell

& Guze, 1960). As children with developmental disabilities grow and age, they continue to have an impact on families and family members. When nurses and other service providers come in contact with families of dependent adult children, the need for holistic services directed toward the individual needing services and the family is paramount. When working with families, a primary responsibility is to identify positive strategies for meeting each individual member's needs and the family's needs (Summers, Behr, & Turnbull, 1989).

Services for adults with developmental disabilities are limited nationally (Davis, 1987). In 1988 less than 50% of the states provided more monies to support community services than large institutional services for adults with developmental disabilities (Fujiura & Braddock, 1993). Services available to individuals with developmental disabilities are not always well known (Brubaker & Brubaker, 1993). Community health nurses and other health professionals could perform community assessments to determine the services available and service needs of communities. Because the Americans with Disabilities Act applies to individuals with developmental disabilities, agencies that provide services to adults and elders may need assistance in complying with the intent of the legislation.

Case finding. Case finding is the responsibility of every nurse in every setting. Three of the families in this study received no services from formal agencies, and one of these families did not participate in activities of any voluntary agency. Often dependent adult children come to the attention of formal agencies, such as the Department of Mental Illness and Mental Retardation, when the only parent is hospitalized or dies. The initial nursing assessment of an elderly individual needing services for elders could reveal that a dependent adult child is in the home and not receiving services. An assessment of an adult with developmental disabilities may also reveal the nonuse of services. In both situations the hospital, clinic, or emergency room nurse could refer the family to appropriate sources. With discharge planning, knowing that a dependent adult child resides at home should make the nurse think twice before dismissing the need for a home health nursing referral to evaluate service needs.

Nursing support to parents. The major concern of elderly parents of dependent adult children was the future prospects for their children. The delay in adequate planning may be related to lack of knowledge about availability, misconceptions, hopes the child will die first, and the appraisal that the alternatives available are unacceptable. Whatever the reasons, nurses and other providers can support parents as they grapple with their concerns. Allowing parents to openly discuss their concerns may provide parents with an opportunity not previously taken. In this study Father 10 stated that concerns for the future was something that was not discussed by parents or their other children. Furthermore, Father 7 stated that it was his intent for his daughter to live with him and his wife until they died. After making this statement, he said that he did not know how his wife felt about his decision. Sample, Spencer and Bean (cited in Lehmann & Roberto, 1993) stated that formal planning should include living arrangements, work or retirement options, transportation needs, social and recreation needs, health needs, self-care needs, and support in successful transition from parents' home to other settings.

Changing role of the nurse. Proposed changes in national health care will necessitate some changes in the role of nurses. One of those changes might be a greater role in case management. Depending upon the needs of families with dependent adult children and individual family members, a nurse might be the best professional to provide case management services. In such situations, one individual should be responsible for the case management for the entire family as these families have complex needs and the health needs of one member affects the needs of all family members.

Nursing education. Nursing education regarding individuals with developmental disabilities is generally limited to children. As the number of young, middle-aged, and elderly individuals with developmental disabilities increases, nurses will need greater knowledge in order to provide appropriate nursing care to adults with developmental disabilities. Very few nursing texts (with the exception of texts about nursing of children) contain any information about individuals with developmental disabilities. In the course of this study, interesting facts previously unknown to the researcher were learned. These included the high correlation between Alzheimer's disease and Down's syndrome, premature aging (as much as five to 10 years earlier than other individuals), and a higher prevalence of mental illness than the general public (25-35% versus 18%) (Stark & Menolascino, 1994). Adequate assessment of health status, formulating nursing diagnoses, and developing an appropriate plan of care are impossible without adequate knowledge.

There is a current and future need for nurses to be actively involved in the provision of services to families of children with developmental disabilities. For a number of years nurses have been actively involved in the care of young children and their families. As America ages and parents and dependent adult children gray, there will be an increasing need for nurses to be involved in the provision of services to aging families with adult children with developmental disabilities.

Research Implications

More individuals with moderate and severe developmental disabilities are surviving to adulthood than at any other time in our history. This trend is expected to continue. Currently, there is a paucity of empirical evidence about the needs of dependent adults with developmental disabilities and their families. Research by nurses in this area is wanting. The results of this study indicate the need for additional research. Recommendations for research include: (a) a repeat of this study with different ethnic-cultural groups; (b) a repeat of this study with an older population (people 75 and over); (c) a longitudinal study of parents with dependent adult children, (d) a reanalysis of the data separating fathers' data and mothers' data; (e) a study of dependent adult children's perceptions; (f) a study measuring family functioning and chronic sorrow and (g) a study describing the perspectives of parents other children about their relationship with dependent adult siblings and the issue of transfer of care.

Different ethnic-cultural groups. A replication of this study in different ethnic-cultural groups would provide information regarding difference in perceptions and concerns. During the course of this study, parents talked of interacting with parents of different ethnic backgrounds. Their evaluation was that there were similarities and differences between individuals of Mexican heritage and those of European heritage.

Replication studies would allow the identification of a core set of variables among all parents of dependent adult children with developmental disabilities. Also, identification of variables that are culturally sensitive would be possible. It would be interesting to discover commonalities and differences among groups of long term parents.

<u>Older population (people 75 and over)</u>. As people age, health and functional abilities generally deteriorate. People age 75 and over have a shorter life expectancy than people age 60. The future become more imminent. It would be interesting to discover if these parents plans for the future are further developed when they become older; whether their concerns remains constant; how they view their parenting activities; and if they remain content with their lives. A comparison of this group with the study's participants might be difficult because of health and cohort effects. It is interesting to note, however, that in the pilot study a 90 year old blind mother in poor health continued to hope she could outlive her 49 year old healthy son who had Down's syndrome.

<u>Longitudinal study of elderly parents with dependent adult children</u>. This study explored the retrospective change in the meaning of being a parent. Many questions could be answered more adequately with a longitudinal study that would identify changes as they occurred. A qualitative and quantitative charting of the

changes that occur with aging could be helpful in more adequately meeting the needs of parents and their dependent adult children. Important changes of both parents and dependent adult children would include health status, functional abilities, mobility, need for services, and service utilization. Additionally, perceived parental burden and stress, benefits to parents, and plans for transfer of care would be important.

Separating fathers' data and mothers' data. Most studies of parents of dependent adult children only include mothers. Fathers have been neglected. It would be interesting to reanalyze the data to see what similarities and differences exist between mothers and fathers. If no differences exist, then conducting future studies that include both mothers and fathers would be logical. However, if differences do exist, then future studies should analyze data from fathers and mother separately. The degree and nature of differences would have to be evaluated.

In this study mothers and fathers did not seem different in their responses except in three areas; however, without a systematic analysis this is impossible to say with any certainty. The three areas of apparent differences were: the amount of involvement with dependent adult children, fear of the spouse becoming ill, and the quality of the bond between parent and child. Mothers reported their involvement to be consistent while fathers said their involvement increased after retirement. Fathers feared their wives would become ill and leave them to care for the dependent adult children alone (mothers also feared dying first and leaving the child with the father). Mothers were perceived to have a stronger bond with the dependent adult child than did the father. Since data from mothers and fathers were collected separately in the first interview, re-analyzing the data is not impossible.

Dependent adult children's perceptions. During data collection and analysis, questions often arose as to what the dependent adult children thought. Parents also raised this question. It would be interesting to design a study to collect data from both parents and their dependent adult children. The congruencies and differences would help to explain the nature of long term parenting and being a dependent adult child.

Such a study would be difficult for several reasons. First, obtaining approval from human subject review committees might be difficult because individuals with mental retardation are considered a vulnerable population. Second, dependent adult children who are restricted in their physical communication abilities may not be able to participate, although their parents could. Third, dependent adult children might not be able to understand the abstract nature of some of the questions.

Family functioning and chronic sorrow. Feetham (Roberts & Feetham, 1982) developed an instrument to measure family functioning in families of young children with developmental disabilities. This instrument was designed to assess family relationships between the family and social units, the family and subsystems within the family, and the family and individual family members. This instrument has been adapted for use with aging families composed of the married couple with no children in the home. It would be intriguing to use this instrument with aging families with dependent adult children to measure family functioning. It would be worthwhile to determine if aging families with dependent adult children function more like families with young developmentally disabled children or other aging families, or if they function very differently from both.

Chronic sorrow was conceptualized in 1962 by Olshansky. In 1981 Wikler, Wasow, and Hatfield, using the instrument developed in 1962, re-studied the concept of chronic sorrow. They found that parents experienced periodic crises with grieving (chronic sorrow) rather than time bound adjustment to the child's disabilities. In this study, parents said that as they aged they became more accepting of their situation or "lot in life." The question would be if elderly parents were able to come to a "time bound" adjustment or if chronic sorrow continued?

Perceptions of parents other children. Parents discussed the relationship their other children had with their dependent adult child. It would be interesting to note how the other children perceive their relationship with their dependent adult sibling. A longitudinal study that traces the processes of this relationship may be interesting in understanding the phenomenon of the relationship.

Another aspect of the other children that is in need of research is their views on the transfer of care of the dependent adult child from the parents to the other children. Parents believed that their other children did not wish to discuss these plans. The reasons for the limited discussion about transfer of care was lost in this study. An important study would be to explore the perceptions of parents, the dependent adult child and the other children about transfer of care.

Summary

The purpose of this study was to describe the meaning parents gave to their life long parenting of their dependent adult children, to describe retrospectively how those meanings had changed over time, to identify concern of parents, and to explore how those concern impacted the day to day lives of these parents. The goal was to gain a greater understanding of the phenomenon of long term parenting.

Eighteen parents from 12 families were asked to share their perceptions and concern about parenting. The stories of their experiences were at times amusing, emotionally painful, and always interesting. They desired to share not only the ordinary but also the very personal aspects of their experiences. Parents also provided the researcher with the opportunity to meet and share some time with each of the dependent adult children.

These parents had entered old age while continuing to parent a dependent adult child. They had moved from the point of being devastated (shortly after the children's birth) to being content with their lives. Although it is not easy to be parenting in old age, parents did find benefits such as companionship, remaining active, and receiving help in household tasks from the dependent adult child. Parents' concerns revolved around who would care for the dependent adult children, knowing that they were the best prepared to provide that care.

Nurses can play a vital role in assisting these families in coping with their concerns and health care needs. Families need health providers who can provide holistic services to the entire family not just to individuals, who will listen to their concerns and wants, and who will assist with needed sources of support. Nursing will continue to undergo changes as the result of technology, changes in the health care system, and the ever expanding practice of all nurses. However, since Florence Nightingale, nurses have expressed a holistic view of humankind and can play an important role in the provision of services to aging families with a dependent adult member.

References

Aldin, M. (1993). Health care issues. In E. Sutton, A. Factor, B. Hawkins, T. Heller, & G. Sletzer (Eds.), Older adults with developmental disabilities: Optimizing choice and change (pp. 49-60). Baltimore: Paul H. Brookes.

Anderson, D. (1993). Health issues. In E. Sutton, A. Factor, B. Hawkins, T. Heller, & G. Sletzer (Eds.), Older adults with developmental disabilities: Optimizing choice and change (pp. 29-48). Baltimore: Paul H. Brookes.

Archbold, P., & Stewart, B. (1986). Family caregiving inventory. Unpublished manuscript, Oregon Health Sciences University, Department of Family Nursing, School of Nursing, Portland, Oregon.

Ascher-Svanum, H. & Sobel, T. (1989). Caregivers of mentally ill adults: A women's agenda. Hospital and Community Psychiatry, 40, 843-845.

Belcher, J. (1988). Mothers alone and supporting chronically mentally ill adult children: A greater vulnerability to illness. Women & Health, 12(2), 61-80.

Bernard, H. (1988). Research methods in cultural anthropology. Newbury Park CA: Sage.

Birchwood, M. & Cochrane, R. (1990). Families coping with schizophrenia: Coping styles, their origins and correlates. Psychological Medicine, 20, 857-865.

Birenbaum, A. (1971). The mentally retarded child in the home and the family cycle. Journal of Health & Social Behavior, 12, 55-65.

Brubaker, E., & Brubaker, T. (1993). Caring for adult children with mental retardation: Concerns of elderly parents. In K. Roberto (Ed.), The elderly caregiver: Caring for adults with developmental disabilities. Newbury Park CA: Sage.

Butler, R. (1963). The life-review: an interpretation of reminiscence in the aged. Psychiatry, 26, 65-74.

Caldwell, B. & Guze, S. (1960). A study of the adjustment of parents and siblings of institutionalized and noninstitutionalized retarded children. American Journal of Mental Deficiency, 64, 845-861.

Carter, G., & Jancar, J. (1983). Mortality in the mentally handicapped: A 50 year survey at the State Park Group of Hospitals (1930-1980). Journal of Mental Deficiency Research, 27, 143-156.

Caserta, M., Connelly, J., Lund, D., & Poulton, J. (1987). Older Asult Caregivers of developmentally disabled household members: Service needs and fulfillment. Gerontological Social Work With Families, 10, 35-50.

Cassel C. (1985). Research in nursing homes: Ethical issues. Journal of the American Geriatrics Society, 33, 795-799.

Chesla, C. (1991). Parents' caring practices with schizophrenic offspring. Qualitative Health Research, 1, 446-468.

Davis, S. (1987). National status report on waiting lists of people with mental retardation for community-based services. Arlington TX: Association for Retarded Citizens.

Denzin, N. (1994). The art and politics of interpretation. In N. Denzin & Y. Lincoln (Eds.), <u>Handbook of qualitative research</u> (pp. 515). Thousand Oaks CA: Sage.

Developmental Disabilities Act of 1984 (P.L. 98-527). (1984). <u>United States Code: Congressional and administrative news: 98th Congress--First session: Vol. 2 Legistrative history, proclamations, executive orders, tables and index</u> (pp.). St Paul MN: West Publishing.

Duval, E. (1957). <u>Family development</u>. Philadelphia: Lippincott.

Ebersole, P., & Hess, P. (1990). <u>Toward healthy aging: Human needs and nursing response</u> (3rd ed.). St. Louis: Mosby

Education for All Handicapped Children Act (P.L. 94-142). (1975). <u>United States Code: Congressional and administrative news: 94th Congress--First session: Vol. 2 Legistrative history, proclamations, executive orders, tables and index</u> (pp. 1425-1508). St Paul MN: West Publishing.

Engelhardt J., Brubaker, T., & Lutzer, V. (1988). Older caregivers of adults with mental retardation: Service utilization. <u>Mental Retardation</u>, <u>26</u> (4), 191-195.

Engelhardt, J., Lutzer, V., & Brubaker, T. (1987). Parents of adults with developmental disabilities: Age and reasons for reluctance to use another caregiver. <u>Lifestyles: A Journal of Changing Patterns</u>, <u>8</u>, 47-54.

Erikson, E. (1963). <u>Childhood and society</u> (2nd ed.). New York: W.W. Norton.

Erikson, E., Erikson, J., & Kivnick, H. (1986). <u>Vital involvement in old age: The experience of old age in our time</u>. New York: Norton.

Farber, B. (1986). Historical contexts of research on families with mentally retarded members. In J. Gallagher, & P. Vietze (Eds.), Families of handicapped persons: Research, programs and policy issues. Baltimore: Brookes Publishing Co.

Fetterman, D. (1989). Ethnography: Step by step: Vol. 17. Applied social research methods series. Newbury Park CA: Sage Publications.

Francell, C., Conn, V., & Gray, D. (1988). Families' perceptions of burden of care for chronic mentally ill relatives. Hospital and Community Psychiatry, 39, 1296-1300.

Friedman, M. (1992). Family Nursing: Theory and Practice (3rd ed). Norwalk CT: Appleton & Lange.

Fujiura, G., & Braddock, D. (1992). Fiscal and demographic trends in mental retardation services: The emergence of the family. In L. Rowitz (Ed.), Mental retardation in the year 2000 (pp. 316-338). New York: Springer-Verlag.

Glidden, L., & Zeltin, A. (1992). Adolescence and community adjustment. In L. Rowitz (Ed.). Mental retardation in the year 2000(pp. 101-114). New York: Springer-Verlag.

Grant, G. (1986). Older care, interdependence and the care of mentally handicapped adults. Aging and Society, 6, 333-351.

Grant, G. (1990). Elderly parents with handicapped children: Anticipating the future. Journal of Aging Studies, 4, 359-374.

Grant, G. & McGrath, M. (1990). Need for respite-care services for caregivers of persons with mental retardation. American Journal on Mental Retardation, 95, 638-648.

Greenberg, J., Seltzer, M., Greenley, J. (1993). Aging parents of adults with disabilities: The gratifications and frustrations of later-live caregiving. The Gerontologist, 33, 542-550.

Geiser, R., Hoche, L., & King, J. (1988). Respite care for mentally ill patients and their families. Hospital and Community Psychiatry, 39, 291-295.

Gold, M. (1987). Parents of the adult developmentally disabled. (Final Report to the United Hospital Fund). New York: The Brookdale Center on Aging, Hunter College/CUNY.

Hawkins, B., Eklund, S., & Martz, B. (1993). Aging adults with Down syndrome: Biological and psychosocial considerations for caregivers. In K. Roberto (Ed.), The elderly caregiver: Caring for adults with developmental disabilities. Newburry Park CA: Sage.

Herr, S. (1985). Legan processes and the least restrictive alternative. In M. Janicki and H. Wisniewski (Eds.), Aging and developmental disabilities: Issues and approaches (pp. 77-90). Baltimore: Brookes Publishing.

Herr, S. (1992). Beyond benevolence: Legal protection for persons with special needs. In L. Rowitz (Ed.), Mental retardation in the year 2000 (pp. 279-298). New York: Springer-Verlag.

Heller, T. (1993). Aging caregivers of persons with developmental disabilities: Changes in burden and placement desire. In K. Roberto (Ed.), The elderly caregiver: Caring for adults with developmental disabilities. Newbury Park CA: Sage Publications.

Heller, T., & Factor, A. (1988). Permanency planning among black and white family caregivers of older adults with mental retardation. Mental Retardation, 26(4), 203-208.

Heller, T., & Factor, A. (1993). Support systems, well-being, and placement decision-making among older parents and their adult children with developmental disabilities. In E. Sutton, A. Factor, B. Hawkins, T. Heller, & G. Seltzer (Eds.) Older adults with developmental disabilities: Optimizing choice and change. Baltimore: Paul H Brookes Publishing Co.

Heller, T. & Factor, A. (1991). Permanency planning for adults with mental retardation living with family caregivers. American Journal on Mental Retardation, 96, 163-176.

Holmes, N. & Carr, J. (1991). The pattern of care in families of adults what a mental handicap: A comparison between families of autistic adults and Down syndrome adults. Journal of Autism and Developmental Disorders, 21, 159-176.

Huberman, A.M., & Miles, M. (1994). Data management and analysis methods. In N. Denzin & Y. Lincoln (Eds.), Handbook of qualitative research (pp. 428-444). Thousand Oaks CA: Sage.

Jacobson, J., Sutton, M., & Janicki, M. (1985). Demography and characteristics of aging and aged mentally retarded persons. In M. Janicki & H. Wisniewski (Eds.), Aging and developmental disabilities: Issues and approaches (pp. 115-142). Baltimore: Brookes Publishing Co.

Janesick, V. (1994). The dance of qualitative research design: Methaphor, methodolatry, and meaning. In N. Denzin & Y Lincoln (Eds). Handbook of qualitative research (pp. 209-219). Thousands Oaks CA: Sage.

Janicki, M. (1992). Lifelong disability and aging. In L. Rowitz (Ed). Mental retardation in the year 2000 (pp. 115-127). New York: Springer-Verlag

Janicki, M., Otis, J., Puccio, P., Rettig, J., & Jacobson, J. (1985). Service needs among older developmentally disabled persons. In M. Janicki & H. Wisniewski (Eds.), Aging and developmental disabilities: Issues and approaches (pp. 289-304). Baltimore: Brookes Publishing Co.

Kaufman, A., Adams, J., & Campbell, V. Permanency planning by older parents who care for adult children with mental retardation. Mental Retardation, 29, 293-300.

Krauss, M. (1990, May). Later life placements: Precipitating factors and family profiles. Paper presented at the 114 Annual Meeting of the American Association on Mental Retardation, Atlanta, Georgia.

Krauss, M., & Seltzer, M. (in press). Coping strategies among older mothers of adults with retardation: A life-span developmental perspective. In A. Turnbull, J. Patterson, S. Behr, D. Murphy, J. Marquis, & M. Blue-Banning (Eds.), Cognitive coping research in developmental disabilities. Baltimore: Paul H. Brookes.

Larkin, K., Bruininks, R., & Larson, S. (1992). The changing face for residential service. In L. Rowitz (Ed.), Mental retardation in the year 2000 (pp. 197-247). New York: Springer-Verlag.

Lehman, J., & Roberto, K. (1993). Current and future service needs of aging individuals with developmental disabilities living with relatives. In K. Roberto (Ed.), The elderly caregiver: Caring for adults with developmental disabilities. Newbury Park CA: Sage Publications.

LeCompte, M. & Goetz, J. (1982). Problems of reliability and validity in ethnographic research. Review of Educational Research, 52, 31-60.

Leininger, M. (1985). Qualitative research methods in nursing. New York: Grune & Stratton.

Lincoln, Y. & Guba, E. (1985). Establishing trustworthiness. In Y. Lincoln & E. Guba, Naturalistic inquiry, (pp. 289-331). Beverly Hills CA: Sage Publications.

Lippman, L., & Loberg, D. (1985). An overview of developmental disabilities. In M. Janicki & H. Wisniewski (Eds.), Aging and developmental disabilities: Issues and approaches (pp. 41-55). Baltimore: Brookes Publishing Co.

Lipson, J. The use of self in ethnographic research. In J. Morris (Ed.), Qualitative nursing research: A contemporary dialogue (pp. 73-89). Newbury Park CA: Sage Publications.

Lofland, J., & Lofland, L. (1984). Analyzing social settings: A guide to qualitative observations and analysis (2nd ed.). Belmont CA: Wadsworth Publishing Company.

Lubin, R., & Kiely. (1985). Epidemiology of aging in developmental disabilities. In M. Janicki & H. Wisniewski (Eds.), Aging and developmental disabilities: Issues and approaches (pp. 95-114). Baltimore: Brookes Publishing Co.

Lutzer, V. & Brubaker, T. (1988). Differential respite needs of aging parents of individuals with mental retardation. Mental Retardation, 26, 13-15.

Marshall, C., & Rossman, G. (1989). Designing qualitative research. Newbury Park CA: Sage.

Miles, M., & Huberman, A. (1984). Qualitative data analysis. Beverly Hills, Ca: Sage.

Mishel, M. (1992). Reconceptualization of the uncertainty in illness theory. Image: Journal of Nursing Scholarship, 22, 256-262.

Nehring, W. (1991). Historical look at nursing in the field of mental retardation in the United States. Mental Retardation, 29, 259-267.

Noh, S. & Turner, J. (1987). Living with psychiatric patients: Implications for the mental health of family members. Social Science Medicine, 25, 263-271

Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. Social Casework, 43, 190-193.

Piaget, J. (1969). The theory of stages in cognitive development. New York: McGraw-Hill.

Rinck, C., & Calkins, C. (1993). Family satisfaction with case management and service provision: Rural and urban perspectives for older families. In K. Roberto (Ed.), The elderly caregiver: Caring for adults with developmental disabilities. Newbury Park CA: Sage Publications.

Roberto, K. (1993a). Family caregivers of aging adults with disabilities: A review of the literature. In K. Roberto (Ed.), The elderly caregiver: Caring for adults with developmental disabilities. Newbury Park CA: Sage Publications.

Roberto, K. (1993b). Older caregivers of family members with developmental disabilities: Changes in roles and perceptions. In K. Roberto (Ed.), The elderly caregiver: Caring for adults with developmental disabilities. Newbury Park CA: Sage Publications.

Roberts, C., & Feetham, S. (1982). Assessing family functioning across three areas of relationships. Journal of Nursing Research, 31, 231-235.

Robertson, M., Boyle, J. (1984). Ethnography: Contributions to nursing research. Journal of Advanced Nursing, 9, 43-49.

Rolland, J. (1988). A conceptual model of chronic and life-threatening illness and its impact on families. In Chilman, C., Cox, F., & Nunnally, E. (Eds.), Chronic illness and disability pp. 17-68). Newbury Park CA: Sage

Rowitz, L. (1992). Mental retardation in the year 2000. In L. Rowitz (Ed.), Mental retardation in the year 2000 (pp.3-11). New York: Springer-Verlag.

Rowles, G., & Reinharz, S. (1988). Qualitative gerontology: Themes and challenges. In S. Reinharz & G. Rowles (Eds.). Qualitative gerontology. New York: Springer Publishing.

Schaller-Ayers, J. (1991). Preliminary study of elderly parents of developmentally disabled adults. (Unpublished report).

Schonell, F. & Watts, B. (1956). A first survey of the effects of a subnormal child on the family unit. American Journal of Mental Deficiency, 61, 210-219.

Spradley, J. (1978). The ethnographic interview. New York: Holt, Rinehart and Winston.

Seltzer, G., Begun, A., Seltzer, M., Krauss, M. (1991). Adults with mental retardation and their aging mothers: Impacts of siblings. Family Relations, 40, 310-317.

Seltzer, M. (1992). Family caregiving across the full life span. In L. Rowitz (Ed.), Mental retardation in the year 2000 (pp. 85-100). New York: Springer-Verlag.

Seltzer, M. (Speaker). (1991a). Aging and developmental disabilities (Video Cassette). Richmond VA: Virginia Geriatric Education Center, Virginia Commonwealth University.

Seltzer, M. (1991b, November). Age-related differences in the impact of lifelong caregiving on middle aged and older mothers. Paper presented at the 44th Annual Scientific Meeting of the Gerontological Society of America, San Francisco, CA.

Seltzer, M. & Krauss, M. (1987). Aging and mental retardation: Extending the continuum. Monographs of the American Association on Mental Retardation, 9.

Seltzer, M., Krauss, M. (1989). Aging parents with adult mentally retarded children: Family risk factors and sources of support. American Journal on Mental Retardation, 94, 303-312.

Seltzer, M., Krauss, M., & Heller, T. (1991). Family caregiving over the life course. In M. Janicki & M. Seltzer (Eds). Aging and developmental disabilities: Challenges for the 1990s (The proceedings of the Boston Roundtable on Research Issues and Applications in Aging and Developmental Disabilities) (pp. 3-51). Washington, DC: Special Interest Group on Aging, c/o American Association on Mental Retardation.

Seltzer, M., Krauss, M., & Tsunematsu. (1993). Adults with Down syndrome and their aging mothers: diagnostic group differences. American Journal on Mental Retardation, 97, 496-508.

Seidel, J., Kjolseth, R., & Seymour, J. (1988). The ethnograph (Version 3.0). Littleton CO: Qualis Research Associates.

Stone, R., Cafferata, G., & Sangl, J. (1987) Caregivers of frail elderly: A national profile. The Gerontologist, 27, 616-626.

Stone, R., Newcomer, R. (1985). Health and social services policy and the disabled who have become old. In M. Janicki & H. Wisniewski (Eds.), Aging and developmental disabilities: Issues and approaches, (pp. 27-40). Baltimore: Brookes Publishing Co.

Summers, J., Behr, S., & Turnbull, A. (1989). Positive adaptation and coping strengths of families who have children with disabilities. In G. Singer & L. Irvin (Eds.), Support for caregiving families (pp. 27-40). Baltimore MD: Paul H. Brookes.

Whittick, J. (1988). Dementia and mental handicap: Attitudes, emotional distress and caregiving. British Journal of Medical Psychology, 62, 181-189.

Whittick, J. (1989). Dementia and mental handicap: Emotional distress in carers. British Journal of Clinical Psychology, 27, 167-172.

Wikler, L., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: Parent vs. professional depiction of the adjustment of parents of mentally retarded children. American Journal of Orthopsychiatry, 51, 63-70.

Wisniewski, H. & Merz, G. (1985). Aging, Alzheimer's disease, and developmental disabilities. In M. Janicki & H. Wisniewski (Eds.), Aging and developmental disabilities: Issues and approaches, (pp. 177-184). Baltimore: Brookes Publishing Co.

Wood, J. (1991). The aged and aging developmentally disabled in Virginia: Project report. Richmond VA: Virginia Department for the Aging.

Wood, J. (1993). Planning for the transfer of care: Social and psychological issues. In K. Roberto (Ed.), The elderly caregiver: Caring for adults with developmental disabilities (pp. 95-107). Newbury Park CA: Sage.

APPENDIX

A

Interview Guide

Except for first questions questions are not to be asked in any particular order. Let the interview naturally flow.

1. First could you tell me a little bit about (name)

2. Would you describe what was it like taking care of (name) when he/she was younger?

   Probes: what are some of the things you did when (name) was younger that other parents did not have to do? What was that like?

3. Has taking care of (name) changed over time? Would you describe this for me.

4. Would you describe for me what it is like to be taking care of (name) today?

   Probes: What are some of the things you are doing now that your friends without children at home are not doing?, What are some of the things that you do not do that your friends without children at home do. What are some of the unpleasant aspects of taking care of (name) What are some of the pleasant aspects of taking care of (name)?

5. Would you describe for me your usual day.

6. What makes a good day for you.
   Are there many good days? What do you think made this day special?

7. What makes a bad day for you.
   Are there many bad days? What do you think made this day so unpleasant?

8. Are there other kinds of days other bad and good days?

8. Parents usually have concerns about their children, what type of concerns do you have?
   Are there other kinds of concerns for you?

9. If you could give some advise to a younger parent who is taking care of a child similar to yours, what would you tell them?

Added after initial interview

10. Tell me about different agencies who have been a help to you. How have these agencies been helpful, how have they not been helpful? Have you found other parents to be helpful--how.

APPENDIX

B

Demographic Data Interview Guide

1. Age______

2. Gender_______

3. Marital Status______
married, widowed, divorced
separated, never married

4. Educational level____
8th grade or less, 9-11,
high school diploma, some
college, college degree

5. Age of Dependent Adult_______

6. Gender of Dependent Adult_____

7. Ethnicity________
white, African-American,
Hispanic, Asian, Native
American

8. In day program:____
what type___________
workshop, regular job,
day care

9. Number of persons in home ______

10. Relationship and age:

11. Annual income_______ Which of the following categories best reflects your total annual household income.
under 3,000; 3,000-5,999; 6,000-9,999;
10,000-14,000; 15,000-19,000; 20,000-29,000
30,000-39,000; 40,000-49,000; 50,000 and over

12. What is your employment status________ employed, not employed, retired, never employed, not employed after birth of (name)

13. If employed or retired type of position ___________

12. Number of persons care is provided to _______ if more than to dependent adult

13. Identify:

Health status of Parent:

14. Now:
poor fair good excellent

15. 10 years ago:
poor fair good excellent

16. in 5 years:
poor fair good excellent

17. **Health problems of parent:**

Health status of Dependent Adult:

18. Now:
poor fair good excellent

19. 10 years ago
poor fair good excellent

20. in 5 years:
poor fair good excellent

21. **Health problems of______:**

22. **Overall how much help does (name) require in every day activities such as**

dressing, bathing, moving, and eating:
no help a little help moderate amount of help
quite a bit of help a lot of help

23. **Overall how much supervision does (name) require in every day activities such as**

dressing, hygiene, preparing meals, daily activities:
none a little a moderate amount
quite a bit all the time

23. **Overall how difficult is it for you to care for ________,**

not difficult a little difficult moderate amount of difficulty
quite a bit difficult very difficult

24. **Overall, when you think of providing care for_______, would you say the negatives outweigh the positives, the positives outweigh the negatives, or that the negatives and positives are equal?**

OBSERVATION:

25. Type of housing: Apt. House mobile home other

26. Handicapped-accessible yes no not necessary now

APPENDIX

C

Oregon Health Sciences University
Consent Form

TITLE: The Meaning Of Being An Elderly Parental Caregiver for Developmentally Disabled Adult Children

PRINCIPAL INVESTIGATOR: Jennifer Schaller-Ayers, MNSc., RN,C., telephone (915) 747-7259. Research Advisor: Sheila Kodadek, Ph.D., R.N., telephone (503) 494-8382.

PURPOSE

Jennifer Schaller-Ayers, a doctoral graduate student at Oregon Health Sciences University in the School of Nursing, is conducting a research study to understand the experience of elderly parents who provide care to their dependent developmentally disabled adult children. The purpose of this study is to describe what it is like to provide long-term care to a developmentally disabled adult child when the parent is older. Little is known by health professionals about older parents as caregivers. The information you provide may help health care professionals in assisting individuals with similar experiences.

PROCEDURES

In this kind of research people are usually interviewed two or three times. Interviews usually last one to two hours. If you choose to participate your participation is voluntary and will not affect your relationship with any agency or the Oregon Health Sciences University. You may stop the interview at any time, or ask to continue the interview at another time, or agree to only one interview, or decline to answer any question, or withdraw completely from the study.

RISKS AND DISCOMFORTS

Some of the questions may be upsetting to you, but you have to answer only those questions you want to answer. If any abuse or neglect is suspected, the investigator will be required to report such information.

BENEFITS

Your participation will have no direct benefit to you, however what you share may be helpful to others in a similar situation in the future. In the past parents have found the interview to be enjoyable.

CONFIDENTIALITY

Your name and identity will not be connected with any of the information collected. Neither your name nor your identity will be used for reports. If you agree to an audio taped recording of the interview, the audio tape recording will be destroyed at the end of the study. Audio tapes will be copied into a written format, but your name will not be on the transcript. Written records may be reviewed by federal agencies monitoring research at the university.

COSTS

There are no costs nor payments to you for your participation.

LIABILITY

The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have any questions, you may call Michael Baird, M.D., at (503) 494-8014.

The study described above (The Meaning Of Being An Elderly Parental Caregiver for Developmentally Disabled Adult Children) has been explained, and any additional questions have been answered by Jennifer Schaller-Ayers. If you have any other questions, you can contact Jennifer at (915) 747-7259.

Your initials in the following spaces provide for agreement or refusal for the interview to be audio tape recorded:

_________agree to have interview audio tape recorded,

_________refuse to have interview audio tape recorded.

Your signature below indicates that you have read, or have had read to you this consent form and agree to participate in this study.

____

Signature date

You will receive a copy of this consent form.

APPENDIX

D

OREGON
HEALTH SCIENCES UNIVERSITY
3181 S.W. Sam Jackson Park Road, Portland, OR 97201-3098
Mail Code L106, (503) 494-7887 Fax (503) 494-7787

Institutional Review Board/Committee on Human Research

DATE: June 29, 1992

TO: Jennifer Schaller-Ayers, SN-FN
c/o Sheila Kodadek, Ph.D.

FROM: Committee on Human Research

SUBJECT: ORS#: 2715
TITLE: Elderly Parental Caregivers of Developmentally Disabled Adults.

This confirms receipt of your memo and/or revised consent form received/dated 6/25/92 requesting approval for a change and/or addition to the above-entitled study.

It satisfactorily meets the requirements of the Committee on Human Research. This change and revised consent form are herewith approved. It is suggested that the date of this memo be placed on the top right corner of the first page of the consent form. This is the approval date of this revised consent form.

Thank you for your cooperation.

wp:rcf_chg11.89

APPENDIX

E

November 19, 1993

Dear Mr. & Mrs

I talked with you last summer about your experience in caring for and parenting an adult child with developmental disabilities. At the conclusion of the interview I told you that I would be developing lists of things parents told me in order to get a better understanding of your experiences. The most frequent topics parents discussed were Concerns, Hard Things, Good Things, Changes With Age, Traits or Characteristics Parents Need, and Experiences With Agencies/Organizations/Professionals. I have enclosed a copy of these topics with descriptions from the interviews.

I would appreciate it if you would look over the lists and see what is missing, and determine what headings are appropriate and which ones should be changed. For example is the list of "hard things" really things you and other parents find difficult? I would like to ask questions such as which of these concerns do you find to be major or minor concerns, and which of these characteristics are learned?

I will be contacting you by telephone after the Thanksgiving holiday to arrange for another visit. Again, I will be able to visit you at your home, or any other place you wish, at a time convenient for you. If possible, I would like to visit with both parents at that time, even if one parent did not participate in the first interview. I would be most appreciative for this second visit, however, your participation is voluntary. If you have any questions prior to my calling please do not hesitate to contact me at 747-7259 and leave a message if I am not there.

I do hope you have a very happy Thanksgiving.

Sincerely,

Jennifer M. Schaller-Ayers, RN,C

TYPES OF CONCERNS PARENTS HAVE

1. What happens when we are gone
2. A place for child to live
3. Finances for child after we're gone
4. Adult child getting lost
5. Adult child getting abused by others
6. Adult child being manipulated by others
7 Being overprotective
8. Getting medical care for adult child
9. Parents staying healthy
10. Burden placed on other children
11. Adult child becoming more disabled
12. Parents becoming incapable of driving
13. Leaving adult child home alone
14. Not knowing what adult child is doing
15. If adult child will know what to do in emergencies
16. Adult child hurting someone else
17. How to enhance self-esteem of adult child
18. The possibility that adult child might regress
19. The adult child's health
20. Female adult child becoming pregnant
21. Adult child does not have companionships "normal" person would
22. Adult child will get Alzheimer's disease
23. What if adult child gets married
24. Wife not feeling well
25. Growing older
26. Giving other parents advise that may not be correct
27. Unusual or "weird" people in public

CHARACTERISTIC PARENTS NEED

1. Patience
2. Understanding
3. Giving of self
4. Sense of humor
5. Realize when adult child is manipulating parents/others
6. Teacher
7. Determination
8. Stamina
9. Love
10. Accept life time job
11. Accept the way things are
12. Live on a day-to-day basis
13. Provide care
14. Flexible
15. Get knowledge
16. Perseverance
17. Advocate
18. Network with other families
19. Find things for adult child to do
20. Be thick skinned-not sensitive
21. Have faith
22. Fight guilt/depression
23. Balance independence with protection
24. All plans include adult child
25. Take time
26. Show appreciation
27. Honesty
28. Be involved in adult child's activities

THINGS THAT ARE HARD ABOUT HAVING A DEPENDENT ADULT CHILD AT HOME

1. Adult child's disappointments
2. Always have a child at home
3. Sometimes they get on your nerves
4. Thinking about the future
5. Not to compare adult child with other
6. Adult child's desire to marry
7. Adult child's desire to live independently
8. Telling adult child they cant do something
9. Dealing with attitudes of others
10. Being patient
11. Balancing beliefs with what's best
12. Making plans
13. Determining how much independence adult child can handle
14. If parents don't drive, transportation for adult child
15. That adult child does not have relationships like other adults
16. Wife being ill
17. Seeing adult child regress
18. Finding things for adult child to do
19 Putting adult child in group home
20 Reasoning with adult child
21. When they complete school there is nothing for adult children to do
22. Not knowing
23. Interpreting to others what the adult child means
24. To get good medical care
25. Seeing adult child's health deteriorate
26. Additional care to another family member
27. Attending functions at night
28. Trying to find mutually enjoyable activities
29. Lack of services available
30. Having to answer "why me" questions
31. Not being able to go anywhere you want
32. Restrictions-not being able to do anything alone with spouse
33. Lack of freedom
34. Lack of time for me

GOOD THINGS ABOUT HAVING A DEPENDENT ADULT CHILD AT HOME

1. Enjoy adult child
2. Enjoy adult child's achievements
3. Companionship
4. People I know because of adult child
5. Learned from adult child
6. Helps me
7. Brought family closer
8. Keeps us young
9. Holidays are special
10. Adult child shows love
11. Adult child is a friend
12. Reason to live
13. There would be a gap in life without adult child
14. Other children enjoy adult child
15. Keeps me active
16. Adult child's influence on others
17. Adult child tries to do things

THINGS THAT HAVE CHANGED AS I HAVE AGED

1. Loose energy to fight
2. Lower energy level
3. Adult child is more independent
4. Got use to being a threesome/twosome
5. Easier, some things
6. Harder, some things
7. Less discipline now
8. Change in own health status
9. Change in adult child's health status
10. More pessimistic
11. Don't hope anymore
12. More involved in activities now
13. Expectations changed
14. Don't go out a lot anymore
15. Content with live now
16. More selective of participation
17. Calendar no longer full
18. Frustrated with having to fight the same battles over & over
19. More realistic now
20. Loose optimism
21. Gave up on agencies helping
22. Worry more about the future
23. Greater acceptance now
24. Attitudes of others bother me less now
25. Try to relate to adult child as an adult
26. Less time for me since out of school
27. Time freer since out of school
28. Finding services is more difficult now
29. Life is calmer now

30 It use to be like taking care of the other kids

PLACES/PEOPLE WHOM YOU CAN GET HELP/SUPPORT/SERVICES

1. Life Management Services
2. State Center on Delta
3. Workshops
4. Special Olympics
5. Schools
6. Professionals
7. Doctors
8. Social Workers
9. Dentists
10. Teachers
11. Counselors
12. Other parents/families
13. My family
14. Friends
15. Military
16. Social Security
17. Medicaid
18. Summer Camp Program
19. Association for Retarded Citizens
20. Bus Company
21. Church
22. Institutions
23. Group homes
24. Foster homes
25. Private Sector jobs
26. Friday Dances
27. DSC
28. Handicapped Services

WAYS TO GET SERVICES

1. You have to push
2. Know somebody at Life Management
3. Put adult child's name on a list
4. You have to wait
5. Keep after agencies
6. Make waves
7. Fight for services
8. Go to city council
9. Write letters, talk with agencies
10. Have dramas and traumas
11. Fill out forms
12. Get adult child qualified
13. Find own jobs for adult child
14. Stomp your foot
15. Pay for services

REASONS NOT TO USE AGENCIES/SERVICES

1. Easier to do it yourself
2. Frustrated with services
3. Not going to get what you want
4. Try only those with chance of success
5. Gave up on agencies helping
6. People at agencies don't care
7. Adult child doesn't like services
8. Don't need services
9. Involved in other things
10. Don't want the services that are available
11. Avoid battles

CHARACTERISTICS OF AGENCIES

1. After school they forget you
2. More contact through the schools
3. Unsatisfactory
4. Long waiting lists
5. Don't tell adult children the truth
6. Do the best they can
7. Provide no transition from school to whatever
8. Kids from group homes don't dress nice
9. Insufficient in number and scope of services
10. They don't know anything about the parents
11. Too much bureaucracy
12. Too much red tape
13 Pass the buck
14. Overwhelmed with people needing services
15. Adult children like day programs
16. Satisfactory group homes are expensive
17. Better than they use to be
18. Day programs provide flexibility for parents
19. Day programs end at 3:00 requiring parents to be home
20 Always been a void of services
21 Don't help too much
22. Handicapped programs get cut first
23. They only call if something wrong
24. Designed to institutionalize adults
25. No continuity
26. Few programs after school
27. They don't allow a lot of things
28 Relabel individuals with disabilities
29 Can't help you immediately

CHARACTERISTICS OF PROFESSIONALS

1. Don't help
2. Unsatisfactory
3. Not enough
4. Don't trust
5. Provide support
6. Effective ones make home visits
7. Can do things parent's can't
8. Devout professionals have family members with developmental disabilities
9. Do it for their own glory

CHARACTERISTICS OF PARENT NETWORKS

1. Parents have always interacted with each other
2. Friends
3. Learn from other parents
4. Provide help
5. Provide support
6. Get together at adult children's activities
7. Some have greater problems than me
8. Has a grapevine
9. School are where you got to know other parents

CHARACTERISTICS OF FAMILY NETWORKS

1. Willing to take adult child
2. Tell parents not to worry
3. Children want adult child to stay with parents
4. Other children uptight about "non-normal" behavior
5. Other children enjoy adult child
6. Adult child visits other children
7. Siblings are compassionate
8. Siblings don't want friends to know adult child
9. Siblings have more confidence in adult child's abilities than parents
10. Other children understand need to provide for adult child
11. Other children accepting of adult child
12. Spouses of other children get to know adult child
13. Other children will attempt to find something for adult child
14. Provide respite
15. Provide support
16. Provide help
17. Other children have been involved with adult child's development.

APPENDIX

F

Taxonomy of
Types of Concerns

- Future Concerns
    - For dependent adult child
        - What happens when we are gone
        - Finances for child
        - A place for child to live
    - Other children
        - Will care/responsibility of dependent sibling be a burden
    - Parents
        - Loose ability to drive
        - Be dependent on others
- Health
    - Self
        - Staying healthy
        - Wife not feeling well
        - Adult child knowing what to do in emergencies
    - Adult child
        - Becoming more disabled
        - Health status
        - Getting Alzheimers
        - Getting medical care
        - Regression
- Other People
    - Abusing adult child
        - Physically
        - Emotionally
        - Sexually
    - Manipulating adult child
    - Weird people and cooks
    - Child hurting others
- Adult child now
    - Getting lost
    - Becoming pregnant
    - Running off and getting married
    - Not having companionships

Taxonomy of
Types of Concerns

Parents concerns about care to adult child
    Not knowing what child is doing
    Enhancing self-esteem
    Being over-protective
    Leaving child alone

Giving wrong advise

Taxonomy of Characteristics

Characteristics parents have to have
- Patience
- Understanding
- Sense of humor
- Determination
- Stamina
- Love
- Perseverance
- Faith

Things parents have to be
- Giving of self
- A teacher
- Flexible
- Thick skinned-not sensitive
- Honest
- Advocate

Things parents have to do
- Realize when child is manipulating
- Accept:
  - Life time job
  - The way things are
- Live on a day-to-day basis
- Provide care
- Get knowledge
- Network with other parents
- Find things for child to do
- Fight guilt/depression
- Include child in all plans
- Take time
- Show appreciation
- Be involved

Taxonomy of
Result of Aging

- Parents
  - Energy
    - Lose energy to fight
    - Lower energy level
  - Some things are easier
    - Taking adult child places
    - Not as intense
    - Don't have to think of every day problems
    - Adult child can take care of self
    - Can leave home alone for short periods
    - Have gotten use to it
    - Don't have to watch as carefully
  - Some things are harder
    - Adult child has boyfriend
    - Explaining why can't marry
    - Tell me what she wants
    - Arrange schedule around adult child's activities
    - Keeping child busy
    - In past could get people to watch child easier than now
    - To get away
  - Health status not as good
  - Things that have increased
    - Pessimism
    - Realistic about child
    - Worry about the future
    - Acceptance
    - Finding services more difficult
  - Things that have decreased
    - Going out
    - Optimism
    - Attitudes of others bother less
    - Hope
  - Life
    - Calmer now
    - Content with the way things are
  - Given up on agencies helping

Taxonomy of
Result of Aging

- Since child finished school
  - Less time for me
  - Time freer

Adult Child
- Requires less discipline
- Health status changing
- Relate to child as an adult
- More independent

Taxonomy of
Hard Things

- Lack
  - Services
  - Freedom
  - Time for me
  - Nothing for child to do after school

- Child's Desires
  - To marry
  - To live independently

- Health
  - Adult Child
    - Getting medical care for child
    - Seeing child's health deteriorate
    - Seeing child regress
  - Parents
    - Wife being ill
  - Others
    - Needing to care for other family members

- Restrictions
  - Not going everywhere you want
  - Not being able to do something with spouse

- Caring for child
  - Always have a child at home
  - Thinking about the future
  - Telling child he/she can't do something
  - Determining how much independence child can handel
  - Balancing own beliefs with what's best
  - Being patient
  - Get on nerves
  - Not knowing
  - Finding things for child to do
  - Trying to find mutually enjoyable activities

  - Having to answer "why me" questions
  - Adult child's disappointments
  - Adult child doesn't have relationships like others
  - Reasoning with adult child

- Attitudes of others

- Putting adult child in group home

Taxonomy of Hard Things

Not to compare child to others

Making plans

Transportation if don't drive

Attending functions at night

Good Things

- That are done by adult child
    - Helps me
    - Tries to do things
    - Shows love
    - Makes holidays special

- Adult child's effect others
    - Parents
        - Enjoys child
        - Enjoys achievements
        - Learned from adult child
        - Keeps us young
        - Keeps me active
        - Gap in my life without child
        - Reason to live
        - Adult child is a friend
    - Others
        - Positive influence on others
    - Family
        - Brought family closer together
        - Other children enjoy adult child

- People I know because of adult child

Taxonomy of Types of Support

- Formal
  - Agencies
    - State
      - Life Management Center
      - State Center
      - Workshops
      - DSC
    - Federal
      - Military
        - Health care
        - Financial support (survivor benefits)
      - Social Security
      - Medicaid
    - City
      - Summer camp
      - Friday Night Dances
      - Bus Services

  - Schools
    - Community College
      - Handicapped services
    - Programs prior to age 22

  - Organizations
    - ARC
    - Special Olympics

  - Professionals
    - Doctors
    - Social Workers
    - Dentists
    - Teachers
    - Counselors

  - Church
  - Institutions
    - Group homes
    - Foster homes

- Informal
  - Family
    - Other children
    - Siblings
  - Parents of other children
  - Friends

Taxonomy of
Characteristics of Agencies

- After graduated from school
  - Forget you
  - Less contact
  - No transition
  - Few programs

- Day programs
  - Provide flexibility for parents
  - End at 3 PM
  - Children enjoy
  - Call parents only if problem

- Group Homes
  - Better ones are expensive
  - Kids that live there don't dress nice

- Agencies in general
  - Have long waiting lists
  - Too much bureaucracy
  - Too much red tape
  - Pass the buck
  - Don't help too much
  - Insufficient in number and scope
  - Do the best they can
  - Overwhelmed by people needing services
  - Better than they use to be
  - Always a void of services
  - Designed to institutionalize child
  - Handicapped services cup first
  - No continuity
  - Don't allow a lot of things
  - Can't help immediately
  - Frequently relabel adult children

Taxonomy of
Reasons not to use agencies

- Too much trouble
  - Easier to do it your self
  - Not going to get what you want
  - Avoid battles
  - Frustrated in trying to get services

- Don't want services available
  - Don't need available services
  - Don't want available services
  - Involved in other things
  - Child doesn't like the service

- Agencies don't care about child

- Parents gave up on getting services

- Try only those with a chance of success

Taxonomy of
Ways To Get Services

- Forcefulness on part of parent
  - Push
  - Make waves
  - Fight
  - Keep after agencies
  - Stomp your foot
  - Go to city council
  - Write letters, talk with agencies

- Mechanics
  - Fill out forms
  - Put name on list
  - Get child qualified

- Pay for own services

- Know somebody

- Find your own services/help

Taxonomy of
Parent Network Attributes

- Assistance
  - Learn from other parents
  - Provide help
  - Provide support
  - Effective grapevine

- Interaction
  - Get together at child's activities
  - Schools are where networks started
  - Sense of not being alone

- Friends

- Problems
  - Some parents have greater problems than others
  - All parents experience similar problems

Taxonomy of
Attributes of Professionals

Negative
- Don't help
- Unsatisfactory
- Not enough
- Don't trust
- They do it for own glory

Positive
- Provide support
- Can do things parents can't with child

Individual Professionals
- Effective ones make home visits
- Devout ones have family member with developmental disability

Taxonomy of
Attributes of Family Networks

- Members
  - Parents
  - Adult child with DD
  - Parents' other children
  - Siblings of parents
  - Parents of parents
  - Grandchildren

- Other children
  - Adult child's future
    - Willing to take adult child
    - Attempt to find something for adult child
    - Tell parents not to worry
    - Understand need to provide for adult child
  - Current
    - Get uptight about "non-normal" behavior
    - Don't want friend to know adult child
    - Are compassionate
    - Enjoy adult child
    - Have adult child come for visit
    - Accepting of adult child
    - Want adult child to stay with parents
    - Have more confidence in adult child's abilities than parents
    - Their spouse get to know adult child
  - In the past
    - Involved with adult child's development

- Assistance
  - Provide help
  - Provide support
  - Provide respite