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## The impact of family and other social involvement on overall client satisfaction for individuals with developmental disabilities

Sean Timothy Carey  
*University of Nevada, Las Vegas*

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THE IMPACT OF FAMILY AND OTHER SOCIAL INVOLVEMENT  
ON OVERALL CLIENT SATISFACTION FOR INDIVIDUALS  
WITH DEVELOPMENTAL DISABILITIES

by

Sean T. Carey

Bachelor of Business Administration  
University of Wisconsin, Milwaukee  
1983

Master of Science  
University of Wisconsin, Milwaukee  
1993

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

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**in**

**Psychology**

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The Graduate College  
University of Nevada, Las Vegas

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The Thesis prepared by

Sean T. Carey

**Entitled**

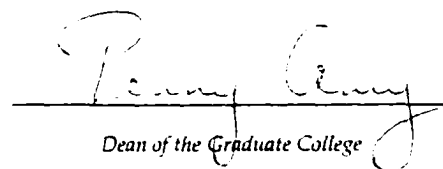
The Impact of Family and Other Social Involvement on Overall

Client Satisfaction for Individuals with Developmental Disabilities

is approved in partial fulfillment of the requirements for the degree of

Master of Psychology

  
Examination Committee Chair

  
Dean of the Graduate College

  
Examination Committee Member

  
Examination Committee Member

  
Graduate College Faculty Representative

## ABSTRACT

This study investigated the impact of family and other social involvement on overall client satisfaction for individuals with developmental disabilities. The family-related outcome measures reviewed included social-role fulfillment, the existence of a natural support network, and the existence of intimate relationships. The other social outcome measures investigated included the impact of having friends, community involvement, and community interaction. This study found that there was a relationship between the life satisfaction level of individual's with mental retardation and their level of social involvement. Also discussed were various variables that impact family involvement such as parenting styles, family characteristics, reasons for out-of-home placements, siblings' role, and specific problems related to unique transitional periods during the individuals' lifetime. Quality of life issues and their relation to family and social involvement are discussed. Recommendations to enhance family involvement for service providers were made.

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## CHAPTER 1

### INTRODUCTION

During the past five to ten years there has been a transformation in the manner services are being delivered to the developmentally disabled. The focus of services is driven by a desire to provide the individual with services that improve his or her quality of life. One potential way to improve an individual's quality of life is to ensure that the amount of social interaction he or she experiences is satisfactory (Hawkins, Kim, & Eklund, 1995). This study investigates the impact of family and other social involvement on overall client satisfaction for individuals with developmental disabilities.

A variety of services are provided to individuals with mental retardation, with the objective being "support" that assists individuals in achieving goals that are significant on a individual-by-individual basis (Goode, 1994). This is a departure from past practices which normally forced an individual to adapt to existing services, rather than tailoring the services towards the individual (Racino, 1994). It has been suggested that the extent an individual engages in preferred activities is one of the many important measures of the quality of his or her life (Newton, Ard, Horner, 1996). This suggests that past practices that utilized an "organizational process" without taking into account individual preferences did not serve the individual in the most productive manner.

One way to increase an individual's level of satisfaction is to inquire on an individual-by-individual basis to determine each individual's preferences. Each individual's preferences would then dictate methods of increasing the components of quality of life. Quality of life would be improved since the individual is now participating in more events that have importance to that individual. The variables that improve quality of life have

been extensively debated (e.g., Goode, 1994; Knoll, 1990; Schalock, 1990). Hughes, Hwang, Kim, and Eisenman (1995) conducted research to determine the number of different definitions for quality of life that appeared in the literature. He found that from 1970 through 1993 there were over 1200 unique measures that attempted to assess the variable. It is clear then that there is no one accepted definition that encompasses all facets that are considered to be part of the definition of quality of life.

### A State's Attempt to Improve Lifestyle Outcomes

One study (Newton, Ard, Horner, & Toews, 1996) focused on quality of life issues addressed by one state's attempt to improve lifestyle outcomes for individuals within the state system. In 1990, Oregon's Office of Developmental Disability Services outlined a process that provided a clarification of the values, principles, and outcomes that the state's service system was expected to produce for individuals with mental retardation and their families. Quality of life was defined for the program as the individual's satisfaction with his or her residential services (as revealed in the survey process), and by the valued outcomes the person experiences. Some of the outcomes identified by the program were as follows: physical integration, social integration, independence, and progress on instructional objectives from an Individualized Support Plan (frequency, variety, and preference of desired activities). Reviews of the program found that residential programs were constantly maintaining the continuous quality improvements identified by the process, and the program managers found the new programs important and useful to the individuals (Newton, Ard, Horner, & Toews, 1996).

A number of life satisfaction indices designed for individuals with mental retardation have noted the significance of family and social involvement to the individual. The Five Dimensional Life Satisfaction Index (Hawkins, Kim, & Eklund, 1995) as well as the Life Satisfaction Scale-Modified (Hawkins & Eklund, 1994), focus on close social interaction as a determinant of life satisfaction, and have been identified as critical areas of

life functioning of adults with mild to moderate mental retardation (Hawkins et al., 1995). Family (hereafter family is defined to also include "close personal friends") involvement not only adds to the individual's direct satisfaction, but may also indirectly increase satisfaction by granting the individual improved confidence to experience additional activities without the family.

Siblings, as well as parents, can play a significant role in the individual's satisfaction level. Krauss, Seltzer, Gordon, and Friedman (1996) found that siblings that maintain regular and personal contact can provide emotional support, and were also knowledgeable about the varied needs of their brother or sister. They further found that the adult siblings' current involvement with their brother or sister with mental retardation was a good predictor for future involvement. Involvement was defined as frequency of their visits and telephone contacts, as well as the number of shared activities. The ability to predict future involvement is especially significant with those individuals who remained with their parents, as the knowledge of the sibling to act as a future caregiver constitutes an important agenda on which future policy development could be based (Griffiths & Unger, 1994).

### Significance of Social Interaction

The significance of social interaction has been displayed in a number of studies (Alloway & Bebbington, 1987; Cohen & Wills, 1985; Thoits, 1982; Leavy, 1983) in the form of improved mental and physical health. These and other studies have shown an inverse relationship between poor health attributes, such as higher levels of stress, and the amount of social interaction. Generally, as the amount of social interaction increases, the amount of stress experienced by the individual is reduced. In fact, Berkman and Syme (1979) conducted an important 9-year study on the relation between social ties and mortality of Alameda County, California residents. They looked at four specific types of social relationships: 1) marriage, 2) contacts with close friends and family, 3) church

membership, and 4) formal group associations. Without exception, those residents who had relationships in each of the four categories had lower mortality rates than those who lacked such connections. Subsequent studies have supported these results (House, Robbins, & Metzner, 1982). Further, social support is recognized as being good in itself, even in the absence of any mental or physical health benefits (Newton, Horner, Ard, LeBaron, & Sappington, 1994).

With the significance of social interaction rather clear, it is surprising to note that there has not been a great deal of direct research regarding individuals with mental retardation. There are few studies that review an individual's perception of the availability of social support, or satisfaction with the level or amount of specific socially supportive services received (Newton et. al., 1994). Rosen and Burchard (1990) compared the social networks of individuals without disabilities to those of individuals with mental retardation and found that those without disabilities had networks equal to twice the size of those with disabilities. Additionally, the individuals with disabilities reported that 38% of their social network were comprised of paid staff members. Also, when asked who provided their most frequent source of companionship and support, over 50% of the participants with disabilities responded that it was a staff member (Rosen & Burchard, 1990).

#### Staff as Major Component of Social Support Network

Researchers have explored possible causes to determine why paid staff plays such a significant role in social support networks. Results have suggested that participants in community-based residential programs have difficulty finding friends and enjoyable social activities (Sullivan, Vitello, & Foster, 1988), as well as dealing with loneliness (Edgerton, 1988). Other research has found that when an individual with mental retardation is able to establish a friendship with someone other than family or long-time established close friends, the new relationship seldom endures over time (Kennedy, Horner, & Newton, 1989). In attempting to identify possible problem areas for this isolation-type behavior, an

individual's social skill abilities has been suggested as a possible solution (Haring, 1991; Mcfall, 1982). If the individual lacks basic social skills that prohibit him from interacting with another individual, the new relationship clearly has little potential for growth.

Researchers have taught individuals behaviors or skills that are meant to increase or expand social interactions. Such behaviors include the sharing of a hand-held video game (Gaylord-Ross, Haring, Breen, & Pitts, 1984), as well as making and offering coffee during work breaks (Breen, Haring, Pitts, & Ross, 1985). As discussed above, individuals with mental retardation often have difficulty meeting new people and making new friends. When a new friend is made, the friendship often does not last. Out of loneliness the individual will turn to family, and if family is not available, he or she will often be reliant on staff to fulfill social interaction needs.

#### Out-of-Home Placement: General Factors

As a way to better understand a parent's interaction with a child with mental retardation, it may be beneficial to investigate parental reasons for out-of-home placements. Past research has focused on three areas: child characteristics, family characteristics, and lack of supportive services. Sherman (1988) found that a major reason for placement included the child's problem behaviors, and Cole and Meyer (1989) identified that individuals with more severe levels of retardation were placed at a higher proportion. Sherman's research supported that of Cole and Meyer, finding that children with severe and profound levels of mental retardation are more likely to be placed than those children with mild or moderate retardation. Dunlap, Robbins, and Darrow (1994) found that challenging behaviors exhibited by a child with disabilities often interfere with the establishment and maintenance of family routines and interactions, as well as the family's quality of life. Recognizing this as a significant problem, Dunlap and Robbins (1991) suggested that each family's strengths, needs, and circumstances be reviewed on an individual basis to determine the best course of action for each family. Bristol (1984) has

suggested that possible interventions may include: skill training for the family members, respite care, or support groups.

### Out-of-Home Placement: Parental Factors

Dunlap, Robbins, and Darrow (1994) discovered that skill building with either the child or the parents was one of the most requested services by the parent. Parents also requested a greater involvement from professionals, such as social workers and psychologists, to help them deal with the child's problem behavior. When asked which services were providing the most help, parents responded that published materials, teachers, and other family members were providing the most useful support. It was not clear to the researchers whether teachers were identified as very useful because they provided emotional support, understanding, and friendship; or because school provided the parents with a break from the children. Parents also identified contingency management as one of the most useful behavior control method.

Other researchers have suggested that parenting styles need to be different for children with and without mental retardation (Harris & Fong, 1985). Overprotection of children, especially those with mild retardation, can have an extremely negative impact on the child's development. Herman and Shantz (1983) compared parents who were highly directive and protective of their children with mild retardation to parents who allowed their children to make many decisions on their own. The children who were overprotected tended to have low problem-solving skills, whereas the other children were more mature, and had more developed strategies for problem solving that resembled those used by children without mental retardation. The researchers concluded that more conventional parenting styles result in the most adaptive results in children with mild retardation. Nihira, Mink, and Meyers (1984) found that a more stimulating environment at home also resulted in the child having better adaptive functioning skills.

### Out-of-Home Placement: Family Factors

Family characteristics that were identified as significant for out-of-home placement decisions included: daily stress, family size, marital status, and parental age and health (Bromley & Blacher, 1991). Generally, if parents tended to be elderly or in failing health (Tausig, 1985), or if the individual came from a single-parent home (German & Maisto, 1982), the probability of placement increased. Sherman (1988) also found that children which came from larger households also had a higher possibility of placement. Other factors include the status of the family prior to the birth, availability of financial supports, and social support. Social support of the parents (or parent) is often recognized as one of the best predictors of how well the family is going to cope and adjust (O'Connor, 1983, Rowitz, 1985). Friedrich (1979) conducted a study in which the greatest predictor of coping with stress was marital satisfaction. This conclusion has been supported by other research that suggests the existence of an intimate relationship (spouse or significant other), has acted to reduce the amount of stress within the family (Blacher & Baker, 1987). Blacher and Baker (1987), reported that mothers of children with mental retardation often identified their spouse as the greatest source of social support. On the other side of the coin, Faber (1959) found that parents of children with severe mental retardation generally experience a higher level of marital conflict.

### Out-of-Home Placement: Social Support Factors

German and Maisto's (1982) research also investigated the impact of the presence and quality of supportive services as an important variable. They noted each family's level of support as reflected in the presence of services such as help at home, respite care, and baby-sitting. They found that as the level of support at home went down, the probability of placement went up. Further, Bromley and Blacher (1989) found that the availability of appropriate schooling often delayed the placement decision. It seemed that the availability of having a period during the day when the individual was away from home acted as a



form of respite care for the parents. Support groups themselves have been found to greatly aid in coping with stress (Dunst, Trivette, & Deal, 1988). Felton and Barry (1992) found that informal support groups buffer stress and promote health. This has been found to also hold true for parents of children with mental retardation (Flynt, Wood, & Scott, 1992). Even for families that have a strong support system already in place, support groups often help with providing needed information, as well as providing a psychological gap to help the parents understand that they are not alone in dealing with the stress of the situation (Rosenberg, 1984).

Despite the fact that families often recognize that they are in need of outside support services and they are aware of the existence of the services, some individuals and families are unwilling to request such services. Gross and McMullen (1983) found a reluctance to seek out help because the individuals felt that seeking such services would make them feel inferior and dependent. The same research has shown that if the involved individual seeking services has not accepted his or her disability, they have a much more difficult time requesting services. For the person who has not accepted his disability, the disability is said to be at the center of his self-concept. Nadler, Sheinberg, and Jaffe (1981) conducted research with individuals who were paraplegic, and found that those who had accepted their disability were much more likely to seek out help to resolve problems related to their disability. In the same way, parents may view their child with mental retardation as a reflection of their own shortcomings, and this may cause the parent to feel inadequate. They may feel that seeking help draws attention to their inadequacy (Wolfensberger & Menolascino, 1970). Research has shown that parents of children with mental retardation are likely to feel shame because their children are stigmatized, and because of this the parents often feel a threat to their own self worth (Margalit, 1979).

Parents who experience the birth of a child with mental retardation generally experience a much higher level of stress than couples whose child is not disabled (Scott, Sexton, & Wood, 1986). One interesting factor from Bromley and Blacher's (1991) work

was that no "one" significant factor was identified as a variable which controlled placement. In 94 percent of the cases, parents identified at least three items as a strong or very strong influence on the placement decision. The first five reasons stated by parents for placement were: 1) day-to-day stress within the family related to the child, 2) the child's low-level of functioning, 3) the child's problem behaviors, 4) feelings of siblings without disabilities, and 5) the spouse's attitude towards placement. Lack of respite care (identified as item 7), and lack of baby-sitting services (item 8), were identified as significant items by approximately half of the parents.

### Transitional Periods

Another period of time when the individual with mental retardation may cause stress for parents is the transition period when the "child" completes high school and embarks on adulthood. This period is normally marked by heightened expectations and concerns for the future of the child (Stark, 1992). For parents of nondisabled children this is a period normally marked by a reduction of parental involvement in the life of their children; whereas, parents of children with mental retardation often must become more involved (Nisbet, Covert, & Schuh, 1992). McNair and Rusch (1991) found that although parents are called upon more often to aid in the transition, they are not aware of the fact that they may actually become part of the transition team that shapes the future of their child. The transition team may be comprised of the individual's state social worker, a representative from one or more potential work sites, and other state and professional personnel. While conducting the survey, McNair and Rusch found that many parents desired to be part of the transition team, but were not aware of its existence.

Another transition period that is often difficult for parents is when the parents become too old to properly care for their retarded children. Older parents often experience stress because they feel as though they are in a state of perpetual parenthood, caused by their child's constant and unending reliance on the parents (Jennings, 1987). Parents also

feel sorrow related to the realization that their children have not experienced a typical life, and usually have concerns for the financial future of their children, as well as feeling socially isolated and unable to find formal resources to relieve their burden (Jennings, 1987).

Since the majority of parents will not survive their children, they usually are faced with the responsibility of making plans for their offspring's well-being once they are no longer able to care for him or her (Heller & Factor, 1993). Unfortunately, researchers have found that a majority of parents are not formalizing definite permanency plans for their children once they are no longer capable of caring for them (Heller & Factor, 1991). If plans are made, it provides for a smoother transition for the offspring, avoiding possible emergency placement (Wood, 1993). Smith and Tobin (1993) found that professionals such as case managers could help in this area by providing specialized assistance directed at elderly parents. They also suggested the possibility of identifying specific case managers that could be assigned to cases involving older parents. This would allow these case managers to develop special skills in assisting elderly parents.

### Family Involvement

The maintenance of family involvement throughout the disabled individual's lifetime is considered central to the well-being of the son or daughter. Brotherson, Backus, Summers, and Turnbull (1986) found that family members are virtually the only constant figures in the developmentally disabled person's life, and that only a family has a broad enough perspective to take in the total picture of service needs.

For child-age offsprings, family involvement often assures some type of stability in the child's life (Knitzer, Allen, & McGowan, 1978). For adult-age offsprings, the extent and type of family involvement changes over the years. But parental involvement in the form of guidance, relationships, and expectations provides an enormous positive benefit with how the adult offspring views themselves (Zetlin & Turner, 1984). Parents also

provide sources of assistance including financial, emotional, and in the role of advocacy (Winik, Zetlin, & Kaufman, 1985). Family involvement has also been shown to increase the individual's quality of life (Schalock & Lilley, 1986), and improve his or her social integration (Hill & Lakin, 1986). For individuals who are part of a small setting placement, visits to the individual's parents home can provide the care-giving staff a brief respite. Stoneman and Crapps (1990) found a correlation between reduced staff stress, and a high level of involvement on the part of the family. The reduced staff stress was a result of the families taking the children which provided for a respite for the care providers.

Hill, Rotegard, and Bruininks (1984), investigated the amount of family involvement of 965 residents from 161 different community residences, and found that of every 5 residents, 1 had no personal contact at all with any relative, 3 were visited by relatives (usually parents) an average of three times a year, and the remaining individual was visited in a more frequent manner. In another study Hill et al. (1989) found that about half of the residents interviewed desired more contact with family, and virtually none of those interviewed wanted less family contact. Willer and Intagliata (1982) reported that of their sample in New York facilities, 41% of residents in foster-family care and 43% in group homes had no family visitation. Conroy and Bradley (1985) found that 75 percent of the parents they interviewed felt that their institutionalized son or daughter had no potential for future development. This type of belief by parents may precede detachment, or may be a form of rationalization for it.

The current study is concerned with investigating the relationship between family and other social involvement, and overall client satisfaction for individuals with developmental disabilities. Specifically, this research was concerned with examining the level of activity in six separate social involvement areas. The six social involvement outcome areas were: 1) community involvement, 2) interaction with community members, 3) social-role fulfillment, 4) existence of friends, 5) existence of a social support network,

and 6) the existence of intimate relationship(s). This paper refers to all six areas collectively as social interaction items.

This report contends that individuals with greater family and social involvement, as measured by the six interaction items referred to above, will rate higher in overall life satisfaction.

## CHAPTER 2

### METHOD

#### Participants

There were 357 participants in the study. Table 1 contains information on the demographics of the participants; it gives a breakdown by gender, disability level, and living arrangement. Potential participants included all individuals that: 1) met the State of Nevada certification as mentally retarded, 2) lived outside of their natural parental home, and 3) were receiving financial and/or service support from state agencies. From the potential participants, individuals who elected for any reason not to participate in the study were automatically exempted. The interview process is in its second year. Therefore, two measurements were available for all participants. This study used the second evaluation because the raters were more experienced and reliable during the second year. However, if the second interview information was incomplete, then the information from the first interview (if complete), was used instead.

Table 1

Participant Demographic Information Broken-down by Gender, Disability Level, and Living Arrangement.

<u>Disability Level</u>	<u>Male</u>	<u>Female</u>	<u>Total</u>
Mild	85	92	177
Moderate	50	39	89
Severe	29	13	42
Profound	<u>33</u>	<u>16</u>	<u>49</u>
	197	160	357

<u>Living Arrangement</u>	
State residential	113
Group home and supported living	<u>244</u>
	357

Participants were from one of three regions: southern, northern, or rural. The southern region consisted mostly of individuals in Las Vegas and the immediately surrounding area. The northern region mainly consisted of Reno and its surrounding area. The final area was the rural area which was mostly in the northern section of Nevada, but in a somewhat isolated area. Of the 357 participants, 227 were from the south, and 130 were from the north and rural areas.

The participants included individuals that were living in one of three possible living arrangements. Certain participants lived in state residential settings. There are two state facilities in Nevada, Desert Regional Center in Las Vegas, and Sierra Regional Center in Reno. Within these state facilities there are individual units housing anywhere from six to

fifteen residents. The second type of living arrangement was the group home. The group homes generally house six residents and were either owned by private parties, or by the state. The final living arrangement was supported living, and this was generally supported in association with a non-profit organization. In the supported living arrangement the individual usually is living on his own, or with a roommate, and a worker from the non-profit agency assists the individual on a weekly basis. The agency person may help with shopping, or financial matters, or other areas where the individual needs assistance.

All participants were volunteers, receiving no remuneration for taking part in the study other than the surveyors' attempting to solicit certain information that could potentially aid the individual during their annual state meeting. During the annual state meeting all state personnel involved with the individual meet to address the individual's needs, and to devise an annual plan for the individual.

Approval to analyze the research was obtained on August 22, 1997, and was granted by the Office of Sponsored Programs at the University of Nevada - Las Vegas.

### Instrumentation

To gather information, the interviewer followed a supplied written semi-structured interview. The interview was designed and field tested by "The Accreditation Council on Services for people with Disabilities"; hereafter, referred to as Council. The Council describes itself as a "...national quality enhancement organization representing national consumer and professional organizations and service providers dedicated to providing leadership and improving the quality of services for people with disabilities ...". The interview form was developed by the Council from input from individuals who took part in the Community Integrated Living Arrangement program in the state of Illinois. The results of the initial study were provided to various care-providers, state and federal agencies, and professionals. The revised interview format was then field tested at ten sites in the United States and Canada. The instrument was then, and is still, being improved



based on feedback to the Council. It has tested well for inter-rater reliability, content validity, and construct validity.

The first part of the interview gathers demographic information including: state I.D. number, name, age, gender, disability level, communication level, mobility level, case manager, employer, and living service provider. This part of the interview was designed by University of Nevada, Reno personnel. The actual interview instrument is concerned with collecting data on whether the participant: 1) has chosen personal goals; 2) has realized personal goals; 3) has chosen where he lives; 4) has chosen where to work; 5) selects how to use his free time; 6) sets his own daily routine; 7) can exercise all rights afforded him; 8) is afforded due process if his rights are limited; 9) in the past few years has not been physically or mentally abused or neglected; 10) is respected by the people around him; 11) has the availability of privacy if desired; 12) decides when to share personal information with others; 13) has health care services; 14) is in best possible health; 15) is physically safe from danger; 16) lives in a non-restricted environment; 17) interacts with individuals without disabilities; 18) has economic resources to purchase desired goods; 19) has insurance to protect his resources; 20) experiences continuity in home and work life; 21) is satisfied with services provided him; 22) participates in the community; 23) interacts with members of the community; 24) performs different social roles; 25) has friends; 26) remains connected to a support network; 27) has intimate relationships; 28) is allowed to choose services; 29) is allowed to retain physical possessions of which he owns; and 30) is satisfied with his personal life situation.

The interview form is written to gather information on whether or not the individual has met the outcome for each of the content items. For example, various questions are concerned with whether the individual participates in the community. If the relevant questions are answered in the affirmative, then the individual is said to have met the requirements and the outcome is said to be present. There are thirty content areas and

for each area it must be determined whether the individual has met the outcome requirements.

This study is only concerned with the six social interaction outcomes. In the above community involvement example, the outcome would be present if it can be established that the individual had actually participated in the community. To do this, the interviewer questions to determine what type of activities the individual does in the community, i.e., shopping, banking, or recreation. Next, the individual would be questioned to see if there is anything that he wants to do in the community but cannot. Finally, the individual is asked whether the current amount of community involvement is satisfactory. The interviewer then must make the final determination, based upon the interviewee's responses, as to whether or not the outcome is present.

The next of the six items is whether the individual has interacted with other members of the community. Here the interviewer is looking for interaction with individuals outside of the service or support organization. Does the individual have the ability to meet new people, and spend time with people other than staff or other people with disabilities. The final question is whether or not the amount of time and frequency of interaction is satisfactory to the individual.

To determine whether the individual performs a variety of social roles the interviewer directs questions to see if the person is involved with his family, in a club or group, is on some type of team, volunteers, or associates with fellow-workers outside of the work environment. To meet this outcome the individual must be satisfied with the number and type of social roles. One of the outcome areas somewhat related to this is whether the individual has remained connected to a natural support network. Generally the network is comprised of family, e.g., parents or sibling(s) who are close to the individual. The interviewer would want to see the existence of a very close personal relationship that involves the sharing of private moments, and that the network is satisfactory to the individual.

To determine whether the individual has friends, the question may be asked to identify by name any friends the person has. If the person identifies friends, then he will be asked what type of activities they do together. In the same way, an individual would be asked to identify any intimate relationships they are involved in. Intimate relationship can be defined in terms of having intellectual, social, emotional, and sexual aspects. For example, a family member may be very close and provide emotional support, and the individual may therefore share personal confidential information with this family member. The sharing of the personal information illustrates the existence of a close and intimate relationship. The last question would be whether the individual sees and interacts with his friends, and those people who represent intimate relationships, as much as he or she would like to. Paid staff members are excluded when making the determination with regard to friends and intimate relationships.

The final outcome area, and the first of two life satisfaction measures, is the determination of the individual's overall satisfaction with his or her personal life situation. The individual is questioned about what they like about their personal life situation, and what they do not like. The person is also questioned about whether they would prefer to do something other than what they are doing. Since this is the last question in the interview, the interviewer also can reflect on answers the participant has given to this point, and perhaps remind the individual about an item that they were really not that happy with. The interviewer also inquires of care providers of whether the interviewee is happy more than not happy, and asked if they can think of any situations the participant is not happy with. The interviewer must make the ultimate judgment based upon the above information whether the outcome is present.

The second life satisfaction measure is a "happy-face" measure. The interviewee is presented with a paper with five happy faces representing: 1) very unhappy; 2) unhappy; 3) neither happy nor unhappy; 4) happy; and 5) very happy. The participant is then asked to select the face that best represents how he normally feels.

### Procedure

The Accreditation Council sent personnel to Nevada to train interviewers in proper interviewing techniques. The training was extensive and has been followed-up with a number of re-training and inter-rater reliability sessions. The individuals conducting the actual interviewing were graduate psychology students at the University of Nevada - Las Vegas (UNLV), and the University of Nevada - Reno (UNR). The three UNLV students conducted the interviews in the Las Vegas area, and the two UNR students conducted interviews in the north and rural areas.

Each interviewer contacted the individual to be interviewed, or contacted the persons' care-provider and scheduled appointments making any necessary arrangements to aid in communication with the individual. For example, certain interviews required that a translator was present who knew sign language. The interviewer interviewed the individual, and possibly the care-provider, family, and social worker. Follow-up with other persons was necessary when it was not possible to ascertain the information directly from the individual or care-provider. As part of the review process the interviewer also reviewed the individual's file, and observed the individual in his or her home and/or work environment. The demographic information was completed first followed by the content information.

Approximately every three weeks the interviewers in Las Vegas met together along with their supervisor on the project, in this case, Dr. Jeffrey Kern. At that time, if the interviewers had any difficulty determining the existence of an outcome, it was discussed and feedback was provided to the interviewer. Also, any relevant new topics or processes related to the project were fully discussed. Completed interview forms were submitted to Dr. Kern, who supplied information on the next group of interviewees. The information was then routed to Reno where it was inputted into a computer format and summarized.

Approximately every three months, an individual came from the Accreditation Council and tested all interviewers for inter-rater reliability. Interviewers from each region also performed inter-rater reliability on the other region, by traveling to that region and performing tests. Inter-rater reliability, assessed via a percentage agreement measure, in all of these situations was in the 82 to 90 percent range.

## CHAPTER 3

### RESULTS

To compute Chi-square tests, participant responses were segregated into two separate groups. The two groups were determined and formed based on whether the overall life satisfaction outcome was found to be present or absent. Six independent chi-square tests were conducted to compare the two groups within each of the six social interaction outcome areas, see Table 2. Alpha levels for significance were set at .01 to control for Type I error. Analyses of the results supported the hypothesis that social interaction affects an individual's overall satisfaction with his or her life situation, since statistical significance was found for each of the six areas: 1) community involvement, 2) interaction with community members, 3) social-role fulfillment, 4) existence of friends, 5) existence of a social support network, and 6) the existence of intimate relationship(s). Means and standard deviations for the Chi-square calculations are presented in Table 3.

Table 2

Comparison of Participants Who Met, or Did Not Meet, Social Inclusion and Relationship Outcomes.

<u>Social Inclusion Items</u>	<u>Outcome present</u>	<u>Satisfied with life situation</u>	
		<u>yes</u>	<u>no</u>
Community involvement <sup>(1)</sup>	yes	239	44
	no	51	23
Interact with community <sup>(2)</sup>	yes	148	19
	no	143	47
Social role fulfillment <sup>(3)</sup>	yes	180	22
	no	112	43

<u>Relationship Items</u>	<u>Outcome present</u>	<u>Satisfied with life situation</u>	
		<u>yes</u>	<u>no</u>
Has friends <sup>(4)</sup>	yes	236	31
	no	55	35
Has support network <sup>(5)</sup>	yes	199	27
	no	92	39
Has intimate relationship <sup>(6)</sup>	yes	179	27
	no	112	39

$$(1) \chi^2_{\text{com invol}} = 9.28, df=1, p < .01$$

$$(2) \chi^2_{\text{int w/com}} = 10.57, df=1, p < .01$$

$$(3) \chi^2_{\text{social role}} = 16.72, df=1, p < .01$$

$$(4) \chi^2_{\text{friends}} = 33.23, df=1, p < .01$$

$$(5) \chi^2_{\text{supp net}} = 17.48, df=1, p < .01$$

$$(6) \chi^2_{\text{intimate}} = 9.34, df=1, p < .01$$

Table 3

Mean and Standard Deviation Scores for each Social Interaction Outcome Based on Chi-square Results.

	<u>Life Satisfaction Outcome</u>				
	<u>Present</u>		<u>Absent</u>		
<u>Social Interaction Outcomes</u>	<u>Mean</u>	<u>SDV</u>	<u>Mean</u>	<u>SDV</u>	
Community involvement	.848	.360	.689	.467	*
Interact with community	.887	.319	.751	.433	*
Social role fulfillment	.886	.312	.712	.451	*
Friends	.880	.326	.618	.489	*
Support network	.881	.328	.702	.459	*
Existence of intimate relationship	.870	.334	.740	.440	*

\*  $p < .01$

Participants who were involved in the life of the community expressed a higher level of satisfaction with their life than participants who were not involved,  $\chi^2_{(com\ invol)}=9.28$ ,  $df=1$ ,  $p < .01$ . The next item, interaction with members of the community, was also found to be significant,  $\chi^2_{(into w/com)}=10.52$ ,  $df=1$ ,  $p < .01$ , reflecting that participants who interacted with members of the community expressed a higher-level of satisfaction with their life. Social-role fulfillment was found to be significant,  $\chi^2_{(social)}=16.72$ ,  $df=1$ ,  $p < .01$ . People who performed a variety of social roles such as being a member of a family, or a club or team, or interacting with fellow workers, or being a volunteer, experienced greater satisfaction with their personal situation than those who did not fulfill a variety of social roles. Having a natural support network in place was found to significantly impact ( $\chi^2_{(sup net)} = 17.48$ ,  $df=1$ ,  $p < .01$ ) overall life satisfaction. With



regard to relationships, the existence of friends ( $\chi^2_{(\text{friends})} = 32.33$ ,  $df=1$ ,  $p < .01$ ), along with the existence of intimate relationships ( $\chi^2_{(\text{intimate})} = 9.34$ ,  $df=1$ ,  $p < .01$ ) improved the overall satisfaction level of the participant.

Six independent (between-subject 2x2) analyses of variance (ANOVAS) were conducted to compare mean participant responses for each of the six social interaction measures. The two independent variables were: 1) the one outcome area measure being tested, and 2) level of mental retardation (mild, moderate, severe, and profound). The five-scale Likert-type life "happiness" (happy faces) measure was the dependent variable. Because multiple ANOVAS were computed, the significance level was set at the .01 level. Means and standard deviations are presented in Table 4.

Table 4

Mean and Standard Deviation Scores for each Social Interaction Outcome, and for the Likert-type Happiness Rating.

<u>Social Interaction Outcome</u>	<u>Mean</u>	<u>SDV</u>	
Community involvement	.794	.405	
Interact with community	.469	.499	*
Social role fulfillment	.570	.496	*
Friends	.747	.432	*
Support network	.632	.483	
Existence of intimate relationship	.579	.494	
<u>Dependent Measure</u>			
Happiness rating	4.330	1.016	

\*  $p < .01$

Significant main effects results were obtained for: 1) community interaction ( $F = 7.10$ ,  $df=1,35$ ,  $p < .01$ ); 2) social roles ( $F = 8.27$ ,  $df=1,35$ ,  $p < .01$ ); and 3) friends ( $F = 12.16$ ,  $df=1,35$ ,  $p < .01$ ). This means that participants who met the outcomes for: community interaction, social roles, and friends were more satisfied than those participants who had not met the outcomes. Non-significant results were obtained for: 1) community involvement ( $F = 4.09$ ,  $df=1,35$ ,  $p = .044$ ); 2) support network ( $F = 1.66$ ,  $df=1,35$ ,  $p = .199$ ); and 3) intimate relationships ( $F = 4.72$ ,  $df=1,35$ ,  $p > .0304$ ) (see table 4). However, the data does illustrate a definite trend toward significance, i.e., community involvement and intimate relationships are significant at the .05 level.

The second independent variable, level of mental retardation, was significant at the .01 level for all six tests; none of the interactions between the two independent variables were significant. Subsequent testing was completed to determine if there were significant differences between the four levels of mental retardation. Tukey Studentized Range Method revealed that at the .01 level, and for all six of the outcome areas, the only significant differences were between the profound level, and the remaining three levels. Those participants who were profoundly retarded had lower life satisfaction scores as a group, than the participants in the other three mental retardation levels. This was true for all six outcomes, which suggests individuals with profound mental retardation experience lower levels of life satisfaction than other individuals with mental retardation. Tables 5 through 10 contain means and standard deviations for each level of retardation, and for each of the six outcomes.

Table 5

Mean and Standard Deviation Score Broken-down by Mental Retardation Level, for  
Community Involvement Outcome.

<u>Disability Level</u>	<u>Outcome Present</u>		<u>Outcome Absent</u>	
	<u>Mean</u>	<u>SDV</u>	<u>Mean</u>	<u>SDV</u>
Mild	4.570	0.856	4.464	0.576
Moderate	4.403	1.091	4.167	1.030
Severe	4.424	0.614	3.857	1.464
Profound	<u>3.609</u>	1.196	<u>3.308</u>	1.258
Mean	4.429		3.892	

Table 6

Mean and Standard Deviation Score Broken-down by Mental Retardation Level, for  
Community Interaction Outcome.

<u>Disability Level</u>	<u>Outcome Present</u>		<u>Outcome Absent</u>	
	<u>Mean</u>	<u>SDV</u>	<u>Mean</u>	<u>SDV</u>
Mild	4.652	0.768	4.385	0.878
Moderate	4.781	0.608	4.140	1.217
Severe	4.400	0.737	4.280	0.891
Profound	<u>3.875</u>	1.356	<u>3.381</u>	1.188
Mean	4.617		4.074	

Table 7

Mean and Standard Deviation Score Broken-down by Mental Retardation Level, for Social Role Fulfillment Outcome.

<u>Disability Level</u>	<u>Outcome Present</u>		<u>Outcome Absent</u>	
	<u>Mean</u>	<u>SDV</u>	<u>Mean</u>	<u>SDV</u>
Mild	4.641	0.740	4.327	0.966
Moderate	4.652	0.875	4.070	1.203
Severe	4.550	0.510	4.100	1.021
Profound	<u>3.667</u>	1.204	<u>3.415</u>	1.204
Mean	4.591		3.981	

Table 8

Mean and Standard Deviation Score Broken-down by Mental Retardation Level, for Friends Outcome.

<u>Disability Level</u>	<u>Outcome Present</u>		<u>Outcome Absent</u>	
	<u>Mean</u>	<u>SDV</u>	<u>Mean</u>	<u>SDV</u>
Mild	4.564	0.841	4.500	0.694
Moderate	4.486	0.989	3.947	1.311
Severe	4.444	0.641	4.077	1.115
Profound	<u>3.850</u>	1.089	<u>3.200</u>	1.243
Mean	4.478		4.031	

Table 9

Mean and Standard Deviation Score Broken-down by Mental Retardation Level, for Social Support Network Outcome.

<u>Disability Level</u>	<u>Outcome Present</u>		<u>Outcome Absent</u>	
	<u>Mean</u>	<u>SDV</u>	<u>Mean</u>	<u>SDV</u>
Mild	4.593	0.813	4.405	0.832
Moderate	4.490	1.120	4.211	1.018
Severe	4.389	0.698	4.273	0.935
Profound	<u>3.500</u>	1.265	<u>3.441</u>	1.211
Mean	4.472		4.233	

Table 10

Mean and Standard Deviation Score Broken-down by Mental Retardation Level, for Intimate Relationship Outcome.

<u>Disability Level</u>	<u>Outcome Present</u>		<u>Outcome Absent</u>	
	<u>Mean</u>	<u>SDV</u>	<u>Mean</u>	<u>SDV</u>
Mild	4.535	0.833	4.587	0.796
Moderate	4.635	0.929	4.000	1.179
Severe	4.350	0.671	4.300	0.979
Profound	<u>3.700</u>	1.342	<u>3.300</u>	1.119
Mean	4.461		4.097	

Both the overall life satisfaction outcome measure, as well as the five-scale Likert-type life happiness measure, attempt to determine the participant's overall life satisfaction. Since the overall life satisfaction outcome measure has only two responses, satisfied or not satisfied, a categorical test had to be used. The Chi-square test was utilized because there are few other tests available when testing categorical data. However, the Chi-square test is viewed as a weak statistical test. The two-way ANOVA test does not have these limitations. A correlation matrix between the two dependent variables is presented in Table 11. The correlation between the two measures is significant at the .01 level.

Table 11

Amount of Correlation Between Individual Outcomes and each Outcome Measure, and Correlation Between the Life Satisfaction Outcome Measure and Likert-type Scale of Happiness.

<u>Outcome Area</u>	<u>Satisfaction</u>	<u>Happiness</u>
	<u>Outcome</u>	<u>Scale</u>
Involvement in community	.1516	.1919
Interaction with community members	.1734	.2669
Social-role fulfillment	.2137	.2980
Existence of friends	.2880	.2521
Social support network	.2206	.1897
Existence of intimate relationships	.1638	.1530
Overall correlation between the two measures	.6745 *	

\*  $p < .01$ .

A final ANOVA was calculated to determine if there was a relationship between where a participant resided (state residential compared to group homes and supported living), and overall life satisfaction. Significant results were obtained,  $F = 11.00$ ,  $df=1$ ,  $p < .01$ . Participants who resided in private facilities were more satisfied than participants who resided at state facilities. See Table 12 for relevant means and standard deviations.

Table 12

Mean and Standard Deviation Score Broken-down by Mental Retardation Level, and on whether Participant Resided in a State or Private home.

<u>Disability Level</u>	<u>State Home</u>		<u>Private Home</u>		<u>Mean</u>
	<u>Mean</u>	<u>SDV</u>	<u>Mean</u>	<u>SDV</u>	
Mild	4.439	0.808	4.588	0.821	4.553
Moderate	3.950	1.356	4.493	0.964	4.371
Severe	4.067	1.100	4.480	0.586	4.325
Profound	<u>3.297</u>	1.127	<u>3.923</u>	1.382	3.460
Mean	3.929		4.514		

## CHAPTER 4

### DISCUSSION

The results clearly demonstrate that there were significant differences between the participants who took part in social interaction activities, and those who did not. Those who met the social interaction outcome measures were more satisfied with their life situation than those who did not meet the outcomes. This was true for both the Chi-square tests as well as the ANOVA tests. However, the Chi-square calculations had two distinct disadvantages: 1) the range of response was restricted to either satisfied or not satisfied; and 2) the Chi-square test is considered a weak statistical test since it is non-parametric. Further, the data used to complete the Chi-square test is gathered by simply asking the subject to point at a picture without any further explanation. On the other hand, the data used to calculate the ANOVA test is gathered by asking a number of questions in a probing manner. This would suggest that the ANOVA test results should be more precise. For these reasons the discussion will mainly focus on the ANOVA test results.

The participants that interacted with community members demonstrated that distinct differences do exist with this outcome measure as it impacts the overall satisfaction of the individual. Specifically, participants who actively interacted with members of their community experienced a higher level of life satisfaction. This outcome is directed at interaction with members of the community who are not staff, nor other individuals with disabilities.

The group of participants who were satisfied with the social roles they fulfilled were more satisfied with their life situation than those who did not perform different social roles. The type of social roles included being a son or daughter or other family



relationship, being a member of a team, i.e., a bowling-team, or involved in activities as part of a group from the work or home environment. The other significant result was for individuals who had friends compared to those who did not. The participants who had friends were happier as a group than the group of participants who did not have friends. This supports the notion that one of the more serious problems facing individuals with mental retardation is isolation.

The three outcome areas which did not differentiate the two groups were: community involvement, the existence of a support network, and the existence of an intimate relationship(s). However, all three of these outcome areas are trending towards significance, and the community involvement and intimate relationship areas were significant at the .05 level. Each of these areas can clearly have a significant impact on an individual's contentedness with his or her life. If an individual seldom went into the community, had no support network, and lacked any intimacy in his or her life, this would normally be expected to negatively impact the individual's satisfaction. This may suggest that other factors may be influencing the results. Perhaps, what may be happening is the two groups are very similar with regard to these three outcome areas. For example, almost all care-providers in our sample recognize the importance of having individuals go out into the community. Since this is a very recognized and clear objective, care-providers focus on tracking how many times each individual goes into the community, and whether this frequency is satisfactory to the individual. By doing this, almost all of the participants go into the community a satisfactory amount, and therefore it is not possible to differentiate the two groups on this outcome item. A review of the means of the two groups suggest this may be one possible explanation, although there does appear to be more variance within the scores of the group where the outcome is absent.

The non-significant result related to the existence of a intimate relationship may not be as easy to explain. As defined in this context, an intimate relationship can be defined in terms of having - intellectual, social, emotional, and sexual aspects. For

example, a family member may be very close and provide emotional support, and the individual may therefore share personal confidential information with this family member. Clearly this relationship could be described as a intimate relationship. However, what may confound this category is how individuals with mental retardation rather loosely define a "girlfriend" or "boyfriend". From an investigator's perspective it may be difficult to determine the extent of the girlfriend / boyfriend relationship. Sometimes the definition encompasses an acquaintance at work who would not otherwise qualify as an intimate relationship since a close personal sharing is absent. Generally, it becomes difficult for the investigator to make the relationship determination despite a battery of relevant questions. The questioned individual remains firm to his or her conviction, and the outcome is therefore judged met. Again, as in the above instance, a distinction between the two groups may not be possible based upon their similarity with regard to this outcome issue. A review of the group means and standard deviations suggest somewhat similar results. The non-significant result for natural support network may overlap with the intimate relationship issue. If a determination is made that an individual has an intimate relationship, to a certain extent, this relationship fulfills some or even most of the requirements for support network. Therefore, a distinction between the two groups is not possible, and a non-significant result would be rendered.

Of the six outcome areas, at least four of them can be defined or met in terms of family involvement. The four such outcomes are: social-role fulfillment, friends, a natural support network, and the existence of an intimate relationship. Of the four items, two were significant at the .01 level (social-role fulfillment and friends), and one was significant at the .05 level (intimate relationships), supporting the contention of the significance of family and social interaction. Clearly, the family plays a very significant role with regard to the social integration of an individual with mental retardation. The family has proven to be a powerful resource for guidance, social support and as an

advocacy agent for the individual. Family involvement benefits the individual with mental retardation, the family itself, and the care-provider.

The role of paid staff was investigated to determine current interaction patterns, as well as isolate areas that an increased amount of social interaction may resolve.

Approximately half of individuals with disabilities have identified staff as the most important person in their life. The difficulties that clients have making friends and the lack of involvement on part of families, has caused staff to take on this additional role. Efforts must be directed at increasing family involvement to reduce the problems experienced by individuals with mental retardation.

A family places an individual in outplacement for a variety of reasons. By understanding these reasons it is possible to increase an individual's level of satisfaction with his life by amending programs to address needs. Problem behavior of the individual is recognized as a significant reason for placement. By knowing this, programs can be designed that aid the family in controlling the individual's negative behavior. If the problem behavior is brought under control it is more likely that the family will remain involved. One of the key items is that state and federal programs need to focus on the family as if it were the client. By taking each family individually, the agency will be able to recognize the unique strengths and weaknesses of each family. Professionals can also help parents realize that their parenting style is creating the very attributes in the individual that they are trying to eliminate. By over-protecting the child they are reducing independent thought and behavior, and instead creating a dependent needy individual. The child will not be able to make independent decisions nor become adaptive in his or her environment. Proper parenting classes can rectify this situation and encourage family unity.

Another significant area to the family is support services. The current perspective needs to be amended to redirect services. For example, couples often experience a good deal of marital conflict due to the stresses associated with the child. A progressive agency may focus on this fact and provide marriage counseling as part of its services. The

counseling services may also help all parties to accept the disability and thereby encourage the family to seek help when problems arise. Other key items to the family include the provision of baby-sitting or respite care, as well as help with transition planning. A state agency could identify specific social workers to specialize in helping aging parents, and permanency placement.

Additional ways to enhance family involvement should start with the facility's rules and regulations. Right from the initial move-in of the client, families should be included in making decisions including the transition process itself. The organization also needs to establish policies that are family orientated, including directives to staff that set out the policy that family involvement is to be a desired outcome. The staff needs to be aware that it is part of their job responsibility to aid involvement of the family. The policy should be in writing and should be distributed to families to make the families aware that their involvement is desired. The organization can also sponsor events that bring together the staff, the families, and the clients. Simple events such as bi-monthly picnics of this nature will do much to foster the desired relationships. The family, or more specifically the parents, should also be encouraged to participate in the case management or decision-making process of the client by attending quarterly or annual status meetings.

One of the more significant limitations of this study involved having care providing staff respond for those participants who were unable to communicate. The bias of the staff could easily be introduced under this method. However, there appeared to be no alternative method available for gathering information for these individuals. Another limitation of the study was collecting categorical data that could only be analyzed using less than desirable statistical testing, Chi-square. The dependent measure had a restriction in range of only two responses, either satisfied or not satisfied with life situation. However, this limitation was rectified partially through the first year of testing, allowing for a more diverse response measure, and hence more precise statistical testing.

The results of this study support a number of conclusions reached in other studies. Hawkins, Kim, and Eklund (1995) had found, as this study has found, that social interaction can increase the overall level of life satisfaction for individuals. Krauss, Seltzer, Gordon, and Friedman (1996) found that the amount of involvement with siblings (social role fulfillment) was related to the level of satisfaction experienced by an individual with mental retardation. This study also supports the conclusion that Hill and Lakin (1996) reached, that social and family involvement increase the amount of social integration (community interaction). In summary, the overall results of this study support the findings of Hawkins and Eklund (1994) that close social interaction are crucial to life satisfaction of individuals with mental retardation.

A potential area for future research may be to review the role that stress plays in social involvement. In other words, if the individuals involved: parents, siblings, care providers, are under different degrees of stress, how would it impact social involvement and interaction. For example, this study has reviewed a number of areas where stress was discussed, i.e., parents and other care providers experienced reduced stress when they were allowed a respite period from the individual with mental retardation. This area may be further investigated to determine the overall role that stress plays.

The results of the Chi-square comparisons (all six social interaction areas found to be significant), and the ANOVA results (three significant at .01 level and two significant at .05 level) demonstrates the significance of social interaction within the life of an individual with mental retardation. It is the duty of all in this field to improve the life of those served, this may very well be one of the most significant and efficient manners to accomplish that goal.

## REFERENCES

Alloway, R., & Bebbington, P. (1987). The buffer theory of social support - A review of the literature. Psychological Medicine, 17, 91-108.

Berkman, L. F., & Syme, L. (1979). Social networks, host resistance, and mortality: A nine-year follow-up study of Alameda County residents. American Journal of Epidemiology, 109, 186-204.

Blacher, J., & Baker, B. L. (1992). Toward meaningful family involvement in out-of-home placement settings. Mental Retardation, 30, 35-43.

Breen, C., Haring, T. G., Pitts-Conway, V., & Gaylord-Ross, R. (1985). The training and generalization of social interaction during breakfast at two job sites in the natural environment. Journal of the Association for Persons with Severe Handicaps, 10, 41-50.

Bristol, M. M. (1984). Family resources and successful adaptation to autistic children. In E. Schopler & G. Mesibov (Eds.), *The effects of autism on the family* (pp. 289-310). New York: Plenum.

Bromley, B., & Blacher, J. (1989). Factors delaying out-of-home placement of children with severe handicaps. American Journal on Mental Retardation, 94, 284-291.

Bromley, B. E., & Blacher, J. (1991). Parental reasons for out-of-home placement of children with severe handicaps. Mental Retardation, 29, 275-280.

Brotherson, M. J., Backus, L. H., Summers, J. A., & Turnbull, A. P. (1986). Transition to adulthood. In J. A. Summers (Eds.), The right to grow up. Baltimore: Brookes.

Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. Psychological Bulletin, 98, 310-357.

Cole, D. A., & Meyer, L. H. (1989). Impact of needs and resources on family plans to seek out-of-home placement. American Journal on Mental Retardation, 93, 380-387.

Conroy, J. W., & Bradley, V. J. (1985). The Pennhurst longitudinal study: A report of five years of research and analysis. Philadelphia: Temple University Developmental Disabilities Center. Boston: Human Services Research Institute.

Dunlap, G., & Robbins, F. R. (1991). Current perspectives in service delivery for young children with autism. Comprehensive Mental Health Care, 1, 177-194.

Dunlap, G., Robbins, F. R., & Darrow, M. A. (1994). Parents' report of their children's behaviors: Results of a statewide survey. Mental Retardation, 32, 206-212.

Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). Enabling and empowering families (pp. 1-32). Cambridge: Brookline Books.

Edgerton, R. B. (1988). Aging in the community- A matter of choice. American Journal on Mental Retardation, 92, 331-335.

Faber, B. (1959). Effects of a severely retarded child on family integration. Monographs of the Society for Research in Child Development, 24(2).

Felton, B. J., & Berry, C. (1992). Groups as social network members: Overlooked sources of social support. American Journal of Community Psychology, 20, 253-260.

Flynt, S. W., Wood, T. A., & Scott, R. L. (1992). Social Support of mothers with mental retardation. Mental Retardation, 4, 233-236.

Friedrich, W. N. (1979). Predictors of the coping behavior of mothers of handicapped children. Journal of Consulting and Clinical Psychology, 47, 1140-1141.

Gaylord-Ross, R. J., Haring, T. G., Breen, C., & Pitts-Conway, V. (1984). The training and generalization of social initiation skills with autistic youth. Journal of Applied Behavior Analysis, 17, 229-247.

German, M. L., & Maisto, A. A. (1982). The relationship of perceived family support system to the institutional placement of mentally retarded children. Education and Training of the Mentally Retarded, 17, 17-23.

Goode, D. (Ed.). (1994). Quality of life for persons with disabilities: International perspectives and issues. Cambridge, MA: Brookline Books.

Griffiths, D. L., & Unger, D. G. (1994). Views about planning for the future among parents and siblings of adults with mental retardation. Family Relations, 43, 1-8.

Gross, A. E., & McMullen, P. A. (1983). Models of help seeking. In B. M. DePaulo, A. Nadler, & J. D. Fisher (Eds.) New directions in helping (Vol. 2): Help seeking (pp. 47-73). New York: Academic Press.

Haring, T. (1991). Social relationships. In L. H. Meyer, C. A. Peck, & L. Brown (Eds.), Critical issues in the lives of people with severe disabilities (pp. 195-217). Baltimore: Brookes.

Harris, S. L., & Fong, P. L. (1985). Developmental disabilities: The family and the school. School Psychology Review, 14(2), 162-165.

Hawkins, B. A., Kim, K., & Eklund, S.J. (1995). Validity and reliability of a five dimensional life satisfaction index. Mental Retardation, 5, 295-303.

Hawkins, B. A. (1993). An exploratory analysis of leisure and life satisfaction of aging adults with mental retardation. Therapeutic Recreation Journal, 27(2), 98-109.

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

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. R. Factor, B. A. Hawkins, T. Heller, & G. B. Seltzer (Eds.), Older adults with developmental disabilities. Optimizing choice and change (pp. 107-122). Baltimore: Brookes.



Herman, M. S., & Shantz, C. U. (1983). Social problem solving and mother-child interactions of educable mentally retarded children. Journal of Applied Developmental Psychology, 4, 217-226.

Hill, B. K., & Lakin, K. C. (1986). Classification of residential facilities for individuals with mental retardation. Mental Retardation, 24, 107-115.

Hill, B. K., Rotegard, L. L., & Bruininks, R. H. (1984). The quality of life of mentally retarded people in residential care. Social Work, 29, 275-280.

House, J. S., Robbins, C., & Metzner, H. (1982). The association of social relationships and activities with mortality: Prospective evidence from the Tecumseh community health study. American Journal of Epidemiology, 116, 123-140.

Hughes, C., Hwang, B., Kim, J., Eisenman, L. T., & Killian, D. J. (1995). Quality of life in applied research: A review and analysis of empirical measures. American Journal on Mental Retardation, 99, 623-641.

Jennings, J. (1987). Elderly parents as caregivers for their adult dependent children. Social Work, 32, 430-433.

Kennedy, C. H., Horner, R. H., Newton, J. S. (1989). Social contacts of adults with severe disabilities living in the community: A descriptive analysis of relationship patterns. Journal of the Association for Persons with Severe Handicaps, 14, 190-196.

Knitzer, J., Allen, M. L., & McGowan, B. (1978). Children without homes: An examination of public responsibility to children in out-of-home care. Washington, DC: Children's Defense Fund.

Knoll, J. A. (1990). Defining quality in residential services. In V. J. Bradley & H. A. Bersani (Eds.), Quality assurance for individuals with developmental disabilities: It's everybody's business, 235-261. Baltimore: Brookes.

Krause, M. W., Seltzer, M. M., Gordon, R., & Friedman, D. H. (1996). Binding ties: The roles of adult siblings of persons with mental retardation. Mental Retardation, 34, 83-93.

- Leavy, R. L. (1983). Social support and psychological disorder: A review. Journal of Community Psychology, 11, 3-21.
- Margalit, M. (1979). Ethnic differences in expressions of shame feeling by mothers of severely handicapped children, The International Journal of Social Psychiatry, 25, 79-91.
- McFall, R. M. (1982). A review and reformulation of the concept of social skills. Behavioral Assessment, 4, 1-33.
- McNair, J., & Rusch, F. R. (1991). Parent involvement in transition programs. Mental Retardation, 29, 93-101.
- Nadler, A., Sheinberg, L., & Jaffe, Y. (1981). Coping with stress by help seeking: Help seeking and receiving behavior in male paraplegics. In C. Spielberger, I. Sarason & N. Milgram (Eds.), Stress and anxiety (Vol. 8, pp. 375-386). Washington, DC: Hemisphere.
- Newton, J. S., Ard, W. R., Jr., Horner, R. H., & Toews, J. D. (1996). Focusing on Values and Lifestyle Outcomes in an Effort to Improve the Quality of Residential Services in Oregon. Mental Retardation, 34, 1-11.
- Newton, J. S., Horner, R. H., Ard, W. R., Jr., LeBaron, N., & Sappington, G. (1994). A Conceptual Model for Improving the Social Life of Individuals With Mental Retardation. Mental Retardation, 32, 393-402.
- Nihira, L., Mink, I. T., & Meyers, C. E. (1984). Salient dimensions of home environment relevant to child development. International Review of Research in Mental Retardation, 12, 149-175.
- Nisbet, J., Covert, S., & Schuh, M. (1992). Family involvement in the transition from school to adult life. In F. R. Rusch, L. DeStefano, J. Chadsey-Rusch, L. A. Phelps, & E. Szymanski (Eds.), Transition from school to adult life: Models, linkages, and policy (pp. 407-424). Sycamore, IL: Sycamore.

O'Connor, G. (1983). Social support of mentally retarded persons. Mental Retardation, 21, 187-196.

Racino, J. A. (1994). Creating change in states, agencies, and communities. In V. J. Bradley, J. W. Ashbaugh, & B. C. Blaney (Eds.), Creating individuals supports for people with developmental disabilities (pp. 171-196). Baltimore: Brookes.

Rosen, J. W., & Burchard, S. N. (1990). Community activities and social support networks: A social comparison of adults with and without mental retardation. Education and Training in Mental Retardation, 25, 193-204.

Rosenberg, P. P. (1984). Support groups: A special therapeutic entity. Small Group Behavior, 15, 173-186.

Rowitz, L. (1985). Social support: The issue for the 1980s. Mental Retardation, 23, 165-167.

Schalock, R. L. (1990). Quality of life: Perspectives and issues. Washington, DC: American Association on Mental Retardation.

Schalock, R. L., & Lilley, M. A. (1986). Placement from community-based mental retardation programs: How well do clients do after 8 to 10 years? American Journal of Mental Deficiency, 90, 669-676.

Scott, R. L., Sexton, D., Thompson, B., & Wood, T. A. (1986). Measurement characteristics of a short form of the Questionnaire on Resources and Stress. American Journal on Mental Retardation, 94, 331-339.

Sherman, B. R. (1988). Predictors of the decision to place developmentally disabled family members in residential care. American Journal on Mental Retardation, 92, 344-351.

Smith, G. C., & Tobin, S. S. (1993). Practice with older parents of developmentally disabled adults. Clinical Gerontologist, 14, 59-77.

Stark, J. (1992). A professional and person perspective on families. Mental Retardation, 30, 247-254.

Stoneman, Z., & Crapps, J. (1990). Mentally retarded individuals in family care homes: Relationships with the family-of-origin. American Journal on Mental Retardation, 94, 420-430.

Sullivan, C. A. C., Vitello, S. J., & Foster, W. (1988). Adaptive behavior of adults with mental retardation in a group home: An intensive case study. Education and Training in Mental Retardation, 23, 76-81.

Tausig, M. (1985). Factors in family decision-making about placement for developmentally disabled individuals. American Journal of Mental Deficiency, 89, 352-361.

Thoits, P. A. (1982). Conceptual, methodological, and theoretical problems in studying social support as a buffer against life stress. Journal of Health and Social Behavior, 23, 145-159.

Willer, B., & Intagliata, J. (1982). Comparison of family care and group homes as alternatives to institutions. American Journal of Mental Deficiency, 86, 588-595.

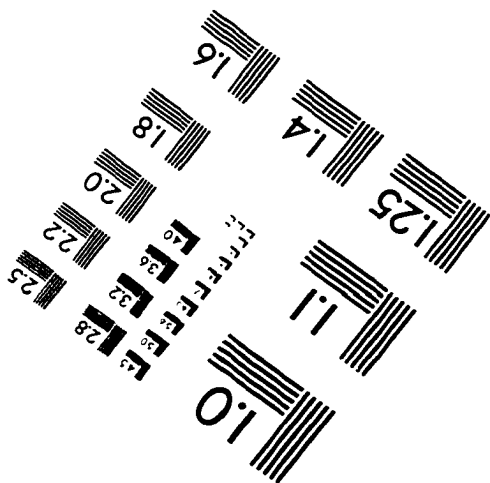
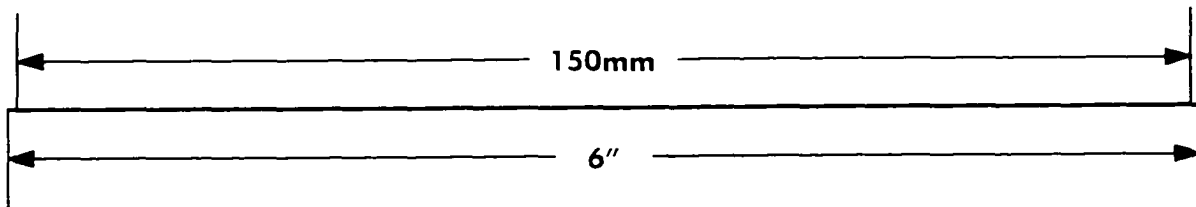
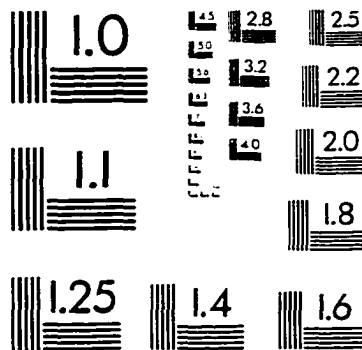
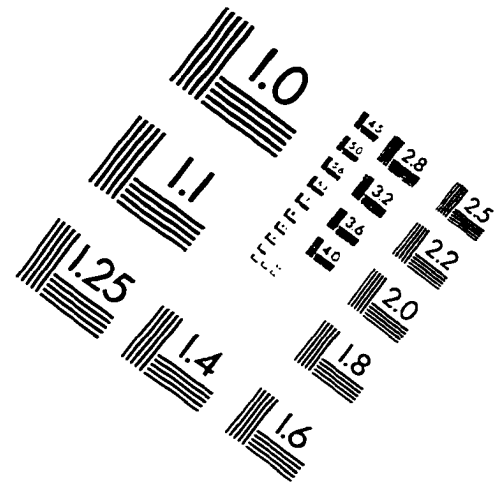
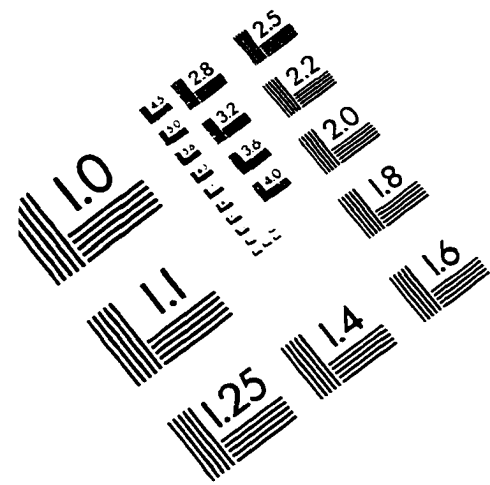
Winik, L., Zetlin, A. G., & Kaufman, S. Z. (1985). Adult mildly mentally retarded persons and their parents. Applied Research in Mental Retardation, 6, 409-419.

Wolfensberger, W., & Menolascino, F. J. (1970). A theoretical framework for the management of parents of the mentally retarded. In F. Menolascino (Ed.), Psychiatric approaches to mental retardation (pp. 475-493). New York: Basic Books.

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

Zetlin, A. G., & Turner, J. L. (1984). Self-perspectives on being handicapped: Stigma and adjustment. In R. B. Edgerton (Ed.), Lives in progress: Mildly retarded adults in a large city (pp. 93-120). Washington, DC: American Association on Mental Deficiency.

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