QUALITY OF LIFE OF ADULTS WITH MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES WHO LIVE WITH FAMILY

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In this paper, we review the literature related to the quality of life of adults with mental retardation/developmental disabilities (MR/DD) who live at home with their families. We examine the nature of the relationships between adults with MR/DD and their parents and siblings, the social worlds of adults with MR/DD, age-related functional and health issues that affect their quality of life, the range of services and supports provided to them, and familial efforts to plan for their continued well-being when parental care is no longer viable. Individual characteristics associated with these dimensions and/or more compromised quality of life profiles are identified. The paper concludes with recommendations for expanded research on the quality of life of adults with MR/DD who live in the parental home, a topic which has received markedly less attention than the quality of life of adults who live in publicly supported residential settings.

INTRODUCTION

Surprisingly little research has been conducted about the quality of life of adults with mental retardation/developmental disabilities (MR/DD) who live at home with their parents, even though living with family is the dominant residential arrangement for people with MR/DD in the US. Recent estimates indicate that about 60% of Americans with MR/DD live with their family [Fujiura, 1998; Braddock, 1999; Seltzer et al., 2001]. In contrast, fewer than 15% live in a publicly funded residential setting, with the remaining adults living in their own household with or without a spouse [Fujiura, 1998]. The quality of life of adults who live with their families has been largely ignored by researchers, policy makers, and service providers, whose attention has been focused instead on the quality of life of the much smaller group of adults who live in publicly funded residential settings [Campo et al., 1997; Dagnon et al., 1998; Hatton, 1998].

One reason for this lack of attention to the quality of life of adults with MR/DD who live with their parents is that public expenditures for services are targeted overwhelmingly to adults who live in out-of-home residential settings. Although individuals who live with their families often receive publicly supported services, family support programs account for only 3% of the public expenditures for persons with MR/DD [Braddock, 1999]. Thus, families have the responsibility to shape and support their son’s or daughter’s lifestyle with little guidance from the formal service system and virtually no financial resources. Indeed, Fujiura et al. [1994] estimated that, on average, parents of adults with MR/DD spend more than $6,000 per year in out-of-pocket expenditures for their son or daughter with the disability, although the range was between $1,400 and $28,000 in the year preceding the study (in 1990 U.S. dollars). As Fujiura et al. [1994] noted, expenditures made by families for their son or daughter with MR/DD can be viewed as “demands not placed on public resources” (p. 258).

A second reason for the lack of attention to the quality of life of adults who live with their family concerns the privacy of family life. It is not surprising that the quality of family life is more unexamined than the quality of life of similar individuals living in publicly funded settings. Yet interest in the quality of life of adults who live at home is warranted from a research perspective, as it will serve to fill a gap in our knowledge about the life course of a very large percentage of adults with MR/DD. We know very little about whether the quality of life of individuals who live with their families differs from that of adults living in publicly funded residential settings, and given the prevalence and stability of family living, the life course profile of these adults is of social scientific interest.

Three theoretical perspectives informed our review of the literature on the quality of life of adults who live with their families. First, there has been an active interest during the last decade in defining what “quality of life” means for persons with MR/DD [Felce and Perry, 1996; Schalock, 1996; Felce, 1997]. As noted by Hatton [1998], there is a developing consensus that the following dimensions need to be included in a definition of quality of life: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. To a large ex-
tent, efforts to define and operationalize quality of life have been fueled by reform movements aimed at changing the evaluation of publicly and privately funded services. In many states, quality of life is now the preferred standard for evaluating residential services. To our knowledge, however, no research has been focused explicitly on assessing the quality of life of adults with MR/DD living in family settings, although research on related topics is informative. In this review, we use some of the common dimensions articulated in the quality of life literature as a framework for discussing multiple aspects of the personal, familial, and social context of adults with MR/DD who live with their family.

The second theoretical perspective on which our review is based is family life course theory [Aldous, 1996], which posits that families, like individuals, follow a predictable life course that governs their growth, development, and functioning. Common to most family life course models are the following stages: marriage, the birth and rearing of children, the launching or departure of family members from the household, and retirement from the work force. During later stages of the family life course, the functions and roles of parents and the relationships between adult children and their parents differ from earlier stages, primarily as a result of the functional, financial, and social independence of the adult children and consequent cessation of parental activities in their daily care and nurturance. For families of adults with MR/DD who continue to live at home, however, there may well be alterations in the stages of the family life course with respect to the role that parents and other adult siblings have vis-à-vis the family member with a disability [Turnbull et al., 1986; Seltzer and Krauss, 1994; Todd and Shearn, 1996a]. In this paper, we examine the literature on the interpersonal relationships among family members, the roles that parents and adult siblings assume for their family member with MR/DD, and the unique tasks they face regarding future planning.

The third perspective that informs this review is the literature on formal and informal social support as a factor in the functioning of the family and the quality of life of persons with MR/DD. Social support refers to interpersonal transactions involving aid, affect, or affirmation [Antonucci, 1985], and thus includes both informal (i.e., unpaid, voluntary) support and formal (i.e., purchased) services and supports. The literature on the effects of social support on the general population is large, suggesting the vital importance of friends and family members for the maintenance of health, social functioning, and psychological well-being [Dean and Lin, 1977; House et al., 1988; Thoits, 1982]. There is a parallel emphasis in the literature on the importance of appropriate services, such as employment or other day activity programs, social and recreational programs, health services, etc. for the well-being of adults with MR/DD [Schalock, 1996, 1997]. There is ample evidence that formal services and supports are more readily provided to persons with MR/DD who live in licensed residential settings compared to those who live with their families [Gordon et al., 1997]. Further, the social lives and sources of emotional and interpersonal support for persons with MR/DD living with their families are much less researched than for persons living in residential programs [Krauss et al., 1992]. Our review includes a consideration of the literature on the informal and formal social supports of persons with MR/DD living with their families, a dimension of their lives that, as will be seen, is less well known than for persons with MR/DD who live in the “other” residential system.

To accomplish these goals, we have structured our review around five domains that shape the quality of life of adults with MR/DD who live at home. We begin with a focus on family relationships, as these form the core and context for the individual’s quality of life. We then turn to an examination of friends and social activities apart from the family. Third, we take stock of what is known about the health and functional abilities of adults who live with their families. Then, we consider the services received from the formal service system while the adult is co-resident with the family. Last, we review the literature on planning for the future care of the son or daughter, when the parents can no longer be the primary caregivers. We end this paper with a discussion of the state of knowledge about quality of life of adults with live with their families, and set an agenda for future research.

DOMAINS OF QUALITY OF LIFE

Family Relationships

Naturally, family relationships form a central core of the quality of life of adults with MR/DD who live in the parental home and figure prominently in most theoretical frameworks of quality of life [Borthwick-Duffy, 1992]. One measure of the closeness of family relationships which has been used in research on families of adults with MR/DD is the Positive Affect Scale [Bengtson and Black, 1973], a measure of the extent to which the relationship between two members of a family is characterized by mutual trust, affection, understanding, respect, and the perception of fairness. The scale ranges from 10 to 60, with higher scores indicating greater closeness. Greenberg et al. [1993] used this measure in their study of the quality of the relationship between aging mothers and their adult son or daughter with a disability (mental retardation or mental illness) who lived at home with the parent. Among the mothers of adults with mental retardation, the average Positive Affect Scale score was 50.0 on the 60-point scale, whereas the mothers of adults with mental illness rated their relationship with their son or daughter as considerably less close (an average of 40.2). As a point of comparison, in the general population, Li [2000] used this measure to assess the closeness between nondisabled adult daughters and their aging parents, with scores averaging 48.8—virtually identical to the scores of the relationships between parents and their adult son or daughter with mental retardation. Thus, there is some indication that the mother–adult child relationship among adults with MR/DD who live with their parents is similar to the norm in closeness, and considerably closer than the mother–child relationship when the son or daughter has mental illness.

Using data from the same study as Greenberg et al. [1993], Essex [1998] investigated feelings of closeness (measured by the Positive Affect Scale) among 132 married mothers and fathers of adults with mental retardation who lived at home. Mothers had significantly higher scores on the Positive Affect Scale than fathers. For mothers, a close relationship with the adult son or daughter was more likely when the adult had better functional abilities, fewer behavior problems, and when the mother scored higher in expressivity (defined as being caring, warm, sympathetic, etc.). For fathers, a close relationship with the adult son or daughter was more likely when the adult had better functional abilities, fewer behavior problems, and when the mother scored higher in expressivity, (defined as being caring, warm, sympathetic, etc.).

A different indicator of the quality of the relationship between adults with MR/DD who live at home and their aging parents was offered by Heller et al. [1997] who surveyed 80 families in which the mean age of the primary care-
giving parent was 68 and the mean age of the adult with mental retardation was 42. The focus of this study was on support provided by the adult son or daughter with mental retardation to the parent. The most common types of support provided were preventing the parent from feeling lonely (in 41% of the families), helping with household chores (39%), sharing mutually enjoyable activities (33%), and providing support when the parent is feeling upset (23%). Furthermore, Heller et al. [1997] found that parental burden was lower and caregiving satisfaction was higher when the adult son or daughter was perceived by the parent to be a source of support. This study highlights the fact that although the parent may be the primary caregiver for an adult son or daughter with mental retardation, the relationship often is not unidirectional, as these adults also provide support to as well as receive support from their parents.

Another component of the quality of family life for adults with MR/DD is the sibling relationship. Pruchno et al. [1996] studied 838 families in which the mother was age 50 or older and had an adult child with either a developmental disability ($n = 487$) or schizophrenia ($n = 351$). Data on the two sub-samples were combined in the analysis. Although relatively few of the adults with disabilities (18%) received instrumental assistance from a sibling, the majority (85%) had an excellent or good affective relationship with a sibling. Instrumental assistance was most likely to be provided by a sibling to an adult with disabilities when the adult had poorer functional abilities, when the siblings both lived in the family home, when the family was larger (i.e., had more siblings), and when the adult with disabilities was a sister. The affective quality of the sibling relationship was stronger when the adult with disabilities had DD rather than schizophrenia, when he or she had fewer behavior problems, and in larger families. Mothers experienced less caregiving burden, greater caregiving satisfaction, and less worry about the future care of their adult child with disabilities when the quality of the sibling relationship was rated highly and when the adult with disabilities had DD rather than schizophrenia.

Seltzer et al. [1991] studied 461 aging mothers of adults with mental retardation; 93% of the adults had a living sibling. Similar to the findings reported by Pruchno et al. [1996], Seltzer et al. [1991] found that while only 20% of the adults with MR/DD received instru-

mental support from a sibling, fully 80% received affective support from a sibling. The affective support exchanged between siblings was not balanced, with nondisabled siblings providing significantly more support to their brother or sister with retardation than the reverse. Interestingly, as in the Pruchno et al. [1996] findings, sibling involvement in the Seltzer et al. [1991] study was a predictor of maternal well-being, with mothers whose nondisabled siblings were involved with the adult with mental retardation feeling less burdened and less stressed than mothers whose other children were not involved.

...the available literature suggests that adults with MR/DD who live with their parents tend to have close family relationships, characterized by the exchange of support and emotional involvement. This is an intergenerational pattern, extending to adult siblings as well as mothers and fathers, and is particularly notable among sisters of persons with MR/DD.

Krauss et al. [1996] extended this study with data collected directly from the siblings in these families. They found that there was a fairly high level of contact between siblings with and without disabilities, with 30% reporting phone contact once a week or more often, 41% reporting in-person visits once a week or more, and 58% living within a 30-minute drive of each other’s residence. Fully 44% of the adults with mental retardation had an overnight visit with a sibling in the previous year. Among the most common shared activities were going to a restaurant (63%), shopping together (56%), and going to movies (44%).

A number of factors were found to foster emotional involvement of nondisabled siblings with their brother or sister with mental retardation [Greenberg et al., 1999]. Sisters were more involved than brothers. In addition, involvement was more likely when the nondisabled sibling did not have a minor child at home and when he or she lived in close proximity to the brother or sister with the disability. Not surprisingly, behavior problems in the sibling with mental retardation were a barrier to emotional involvement. Involvement was higher among siblings who had been close to their brother or sister with mental retardation during adolescence and who currently have a close relationship with their mother.

Finally, Orsmund and Seltzer [2000], again using data from the same study, examined changes in the sibling relationship over a three-year period. Involvement and closeness among siblings and their brother or sister with mental retardation increased over time when the nondisabled sibling was a sister. For brothers, however, the general pattern of increasing closeness was interrupted when the mother’s health was in decline, with brothers perceiving that their sibling with mental retardation became more emotionally distant during this time. The data also suggest that prior patterns of sibling intimacy may be re-established after parental death. In general, nondisabled sisters provided more care and companionship to their sibling with mental retardation than nondisabled brothers, and sisters felt a closer sibling bond than brothers. Brothers’ emotional responses to the sibling relationship were conditioned by the gender of the sibling with mental retardation, with brothers of nondisabled siblings having the most favorable emotional response and brothers of sisters having the least favorable.

To summarize, the available literature suggests that adults with MR/DD who live with their parents tend to have close family relationships, characterized by the exchange of support and emotional involvement. This is an intergenerational pattern, extending to adult siblings as well as mothers and fathers, and is particularly notable among sisters of persons with MR/DD. A close relationship between the nondisabled sibling and the mother appears to be an impetus to sibling involvement. There also is an indication of a ripple effect of sibling involvement, as there was an association between sibling involvement with their brother or sister with MR/DD and ma-
ternal well-being. Clearly, close family relationships are at the core of a high quality of life for adults with MR/DD, their parents, and their siblings.

**FRIENDSHIPS AND SOCIAL ACTIVITIES**

Hughes et al. [1995] note that social relationships and interaction are a critical aspect within most conceptualizations of quality of life and, indeed, found that this dimension has the largest number of empirical measures of all the dimensions they analyzed. Measures typically focus on the number of friends (with and without disabilities), having a best friend, having a girlfriend/boyfriend, frequency of interactions, and types of social activities in which people participate. Given the prominence of friendships and social activities as an indicator of quality of life, it is surprising, if not shocking, that so little research attention has focused on the social relationships of adults with MR/DD who live with their families. On the basis of the limited available literature, there is ample reason to be concerned about the social worlds of adults with MR/DD who live with family.

For example, Krauss and Erickson [1988] studied the size, composition, and functional roles of the informal support networks of adults with MR/DD who live with their family in comparison to those in licensed residential settings. Persasive differences were found between the two groups, with those living with their families having smaller social support networks that were composed primarily of family members, spending most of their leisure time with family members, and receiving significantly less support from paid professionals.

Krauss et al. [1992] studied the social support networks of 418 adults with mental retardation, whose average age was 33.6 years, all of whom lived at their families' residence. They examined the characteristics of the adult's support networks (based on maternal report) and the influence of level of mental retardation and gender on these networks. Within their sample, a fifth had severe/profound retardation, 41% had moderate retardation, and 38% had mild retardation. Slightly over half (53%) were male. They found that the average size of the social support networks (which included both family and nonfamily members) was 7.1 persons. However, about a quarter of the sample had more than 10 persons identified, while almost a fifth had less than three persons. Further, on average, almost three-quarters of the network members were either parents, siblings, or other relatives. Almost half of the sample had no friends (i.e., nonfamily members) enumerated in their support network. Interestingly, on average, half of the members of the support networks of the adult with mental retardation were also members of their mothers’ support network. This was not surprising given the high percentage of the adult’s network who were family members (and thus also associated with the mother). But it was also found that 40% of the friends in the support network of the adult with mental retardation were also listed as friends in their mother’s network. These friends, based on their age, gender, and duration of the relationship, were most likely the mother’s friends who were also considered to be important sources of social support to their son or daughter with mental retardation. Only a quarter of the sample of adults with mental retardation was described as having even one friend who was completely independent of their mothers’ friendship networks.

With respect to differences in social support networks based on gender and level retardation, two particular risk groups were identified: men and persons with more severe mental retardation. Men had a lower percentage of friends in their networks and fewer same-sex friends than did women. Adults with more severe retardation had the smallest networks and were the most likely to have no friends.

The authors concluded that there were both strengths and weaknesses characteristic of the social lives of adults with retardation who live with their parents. Among the strengths is the high degree of embeddedness of the adults with their families and the stability and duration of their sources of support. The weakness of these social support networks is the limited number of friendships with age-peers.

Lusnky and Benson [1999] interviewed parents or staff caregivers to obtain data about the social support networks of 121 adults with mental retardation who lived in a variety of types of settings, including 18 who lived with their parents. The authors commented that although adults who lived with their parents were found to have fewer friends than those who lived in other types of settings, it is possible that the parent respondents did not know about all of the friends that their son or daughter had. Therefore, the restricted number of friends among adults with MR/DD who live at home might be an artifact.

With respect to participation in social activities, adults with MR/DD who live with their parents often engage in many of the social and recreational activities of their parents. They may also be eligible to participate in more structured social and recreational activities available in community-based organizations, as well as generic community programs as the YMCA/YWCA and local health clubs. While empirical studies of the participation rates in these types of programs by adults with MR/DD who live with their parents are not available, limited data have been reported about participation in formal “social-recreational programs” broadly defined. Griffiths et al. [1997] reported that over 60% of their sample of adults with MR/DD living with their parents were involved in social-recreational programs during the preceding year. Smith et al. [1994] studied 235 families of adults with MR/DD in New York State and reported that 61% of the adults who participated in day programs also participated in formal social-recreational programs. Among those not participating in day programs (i.e., who were at home during the day), only 14% were reported to participate in formal social-recreational programs. Thus, involvement with the service system via a day program may provide a context for inclusion in social-recreational programs by adults who live with their family.

**HEALTH AND FUNCTIONAL ABILITIES**

As Borthwick-Duffy [1992] notes, most quality of life schemas include personal well-being as a core dimension. Within the construct of personal well-being, issues such as health status and functional independence are typically considered. Because of the increased life expectancy of adults with MR/DD, there has been an active program of research in age-related changes in health status, cognitive functioning, adaptive behavior skills, and mental health status [Seltzer and Luchterhand, 1994; Zigman et al., 1994; Callacot and Cooper, 1997; World Health Organization, 2000]. The results of this emerging body of research are beginning to provide a more comprehensive perspective on developmental trajectories characteristic of individuals with MR/DD across the life course. For the purposes of the present review, however, it is important to note that most of the published literature does not differentiate between adults with MR/DD who live with their families compared to...
those who live in other types of residential settings. This is understandable, given the increased probability of out-of-home residence with advancing age among this population, although, as noted earlier, home-based care is still very common among persons with MR/DD at all ages. Whether there are differential age-related developmental and physical health status changes based on type of residence has not yet received necessary attention, although there is an obvious confound between living in some types of residential settings (such as nursing homes and/or medically supported community residential programs) and individual health and developmental needs.

There is considerable concern worldwide about the quality of health care available to adults and elders with mental retardation [Beange et al., 1995; World Health Organization, 2000] regardless of their residential setting. Beange et al. [1995] conducted a comprehensive study of 202 randomly selected adults with mental retardation in Sydney, Australia (40% of whom lived with relatives or independently) and found that the study group had an increased prevalence of factors associated with poor health outcomes and an increased number of chronic diseases that were frequently not recognized, or when diagnosed, not treated appropriately. Indeed, even having a regular source of medical care has been reported to be a considerable problem for adults with MR/DD, particularly among those living with their family or independently [Minihan and Dean, 1990].

With respect to the overall health status of adults with MR/DD living with their families, Seltzer et al. [1995] compared maternal ratings of their co-resident adult child’s health status among mothers in the United States, the Republic of Ireland, and Northern Ireland. Over three-quarters of the U.S. mothers described their son or daughter’s health as excellent or good (average age, 34 years). Mothers in the Republic of Ireland made similar judgments (84% of the adult children were in excellent or good health; average age, 30 years). In contrast, fully one-third of the mothers in Northern Ireland rated their adult child’s health to be only fair (average age, 35 years).

Gordon et al. [1997] reported that the health of adults with mental retardation who lived with their family declined over a six-year period, although their daily living skills remained stable or even improved. Todd et al. [1993] also reported improved skills over time in adults who live at home. Thus, the trajectory of age-related changes might be different for different domains of functioning.

With respect to other health issues, Pary [1993] studied the use of medications among adults with mental retardation and found that there is increasing use of psychoactive drugs by middle-aged individuals with MR/DD. He also noted, based on chart review, that there was a significant increase in the use of neuroleptics among elderly individuals (those age 55 and above) living with their families. He speculated that families may be reluctant to taper the use of neuroleptics among their adult offspring with MR/DD because of fears of behavioral disintegration, even if in some instances these are unfounded fears.

Rubin et al. [1998] studied the prevalence of being overweight among adults with Down syndrome and found a higher rate than in the general population. They also noted that both males and females with Down syndrome who live with their families had a higher chance of being overweight than did those living in group homes.

Some data are available regarding the prevalence of behavior problems among adults with MR/DD who live with their parents. Seltzer et al. [1997] found that about one-quarter of their sample of aging families of adults with mental retardation reported their son or daughter had no behavior problems. Another 44% of the adults were said to have some behavior problems, but none that would be classified as clinically significant. However, about 30% of families in their sample had adult children with clinically significant behavior problems. They also found that there was stability in behavior problems over a six-year period among those adults with MR/DD who continued to live with their families.

SERVICES RECEIVED

While families of adults with MR/DD who live at home are undoubtedly the primary provider of day-to-day supports, many of these adults are also recipients of publicly supported community-based services, most commonly day activity programs. Thus, there is an important public/private partnership in the provision of supports that help to maintain the quality of life of the adult with MR/DD [Todd and Shearn, 1996b]. The empirical literature, however, is sparse with respect to documenting the range of formal services in which adults with MR/DD who live at home participate.

Some insights into the utilization of formal services by adults with MR/DD who live with their family are provided by the Krauss and Seltzer [1999] longitudinal study, with a focus on changes over time in the number of services received by these adults [Gordon et al., 1997; Griffiths et al., 1997], unmet service needs [Griffiths et al., 1997], vocational services received [Conyers et al., 1997], and maternal satisfaction with services [Conyers et al., 1997; Griffiths et al., 1997].

Gordon et al. [1997] compared the number of services received by adults who lived at home to those who were subsequently relocated to a community residential program. Whereas the number of services received by those who lived at home throughout the six-year study period averaged slightly less than four, the average number of services received following relocation jumped to almost six (not including the residential program). In a related analysis, Griffiths et al. [1997] reported stability over an eight-year period in the number of services used by adults with MR/DD who lived at home, but an increase in the number of unmet service needs during this period. Not surprisingly in light of the increased levels of unmet service needs over time, there was a decrease in maternal satisfaction with the services their son or daughter received.

Conyers et al. [1997] examined changes in the pattern of vocational services utilized by adults with mental retardation who lived at home. The longitudinal study spanned a six-year period. A substantial minority (12%) received no vocational services and had no formal day activity. In addition, about 70% of the adults participated in segregated vocational services (e.g., sheltered workshops), just over 10% were in integrated settings in the community, and about 5% spent part of the week in a segregated setting and part of the week in an integrated setting. During the study period, there was a 7% decrease in the number of adults who were in segregated vocational placements and a 6% increase in the number who were in integrated placements among those who lived with their parents. The average work week was 30 hours for those adults who worked in segregated settings and 25 hours for those in integrated settings. Mothers of adults who worked in integrated settings were significantly more satisfied than mothers of adults who worked in segregated settings with the type of work in which the adult was engaged, the supervision received, and the work demands of the job. However, they were significantly less satisfied with the son’s or daughter’s work.
schedule and transportation to and from work. It is possible that their dissatisfaction with the work schedule stemmed from the shorter work week of the adults in integrated settings. It is also possible that transportation to integrated settings in the community was more difficult for parents to arrange than transportation to agency-operated sheltered workshops, which often provide transportation.

As noted earlier, Smith et al. [1994] found that adults with MR/DD who live at home and who participate in a day program have access to a wider range of additional services than those who are not involved in a formal day program, such as case management, specialized therapies, transportation, and recreational activities. They also noted the variability in the types of day programs in which their sample participated, including day treatment, sheltered workshops, and competitive employment, reflecting a similar array of day programs as are commonly accessed by those living in publicly funded residential programs. Further, they found that families of adults who were in day programs had a much greater familiarity with the service system than families of adults who stayed home during the day, and perceived a greater need for services for their son or daughter. Smith [1997], using data from the same study, analyzed the predictors of service utilization among those who participated in day programs and those who remained at home during the day. He found that adults who used more services were more likely to be female, younger, from lower SES households, and received higher levels of care from mothers who reported greater levels of subjective caregiving burden. Families reported more unmet service needs when the mothers were married, received less caregiving assistance from the nondisabled siblings in the family, and had higher levels of caregiving burden.

Heller et al. [1999] reported on the impact of a family support intervention for family caregivers of 78 adults with developmental disabilities, who were compared with a control group (n = 146). Following the intervention, the adults with disabilities in the experimental group had fewer unmet needs and used more services than those in the control group, and the family participants in the experimental group were less likely to desire an out-of-home placement. There is clearly a need for innovative family support interventions such as this one to increase the likelihood that families can advocate for and obtain the services needed by their family member with MR/DD.

PLANNING FOR THE FUTURE

One unique aspect of the quality of life of adults with MR/DD who live at home with their parents is the impermanence of this caregiving arrangement and the concomitant need for planning for future care and quality of life after the parent is no longer the primary caregiver. Hence, future plans are needed to avoid a crisis in care and to maintain the adult’s quality of life when the parents die. A number of studies have investigated the prevalence and content of future plans made on behalf of adults with MR/DD who live at home, with a range of definitions of what constitutes a future plan. Smith et al. [1995] conceptualized future planning as a continuum, ranging from no discussion of this topic to making a definite plan. In their sample of 235 mothers (age 58 to 96 years) of adults with mental retardation who lived at home, 20% had not yet discussed the future care of their adult son or daughter, 35% were in some stage of discussion, 35% wanting more information about residential programs, 35% wanting more information about guardianship, and 35% wanting more information about financial planning. One of the most prominent findings of this study is that European-Americans were more likely to have made plans than African-Americans, and that African-Americans were more likely than European-Americans to prefer family living.

Providing an international perspective, Walsh et al. [1993] contrasted aging mothers in the Republic of Ireland and their counterparts in Northern Ireland with respect to the extent and type of future planning they had conducted on behalf of their son or daughter with intellectual disability. Whereas the mothers in the Republic of Ireland were more likely to have placed their son’s or daughter’s name on a waiting list for residential placement than mothers in Northern Ireland (29% versus 10%), the reverse pattern was evident in the extent to which mothers had identified a “successor caregiver” to take over responsibility after maternal caregiving was no longer a viable option (33% versus 48%).
Thus, the reliance of older mothers on the formal versus the informal support system for future caregiving may vary by cultural context. However, when informal and formal options were combined, just over half of the mothers in both samples had made some type of future plan—59% in the Republic of Ireland and 55% in Northern Ireland.

Krauss and Seltzer [1999] examined this issue from a number of different perspectives, including whether a successor caregiver had been identified [Krauss and Seltzer, 1993], whether parents had made a specific plan for where the son or daughter would live in the future [Freedman et al., 1997], whether the son’s or daughter’s name was placed on a formal waiting list for residential placement [Krauss and Seltzer, 1993; Essex et al., 1997], whether siblings expected to assume caregiving responsibility in the future [Greenberg et al., 1999], and quality of life after parental death [Gordon et al., 1997].

Krauss and Seltzer [1993] contrasted families who preferred continuation of family-based care to those who preferred that the formal service system would take over responsibility. Similar to the findings of Heller and Factor [1991], about half of the families in this study (51%) preferred the former, having designated a successor caregiver (most often a close relative) and not having added their son’s or daughter’s name to a waiting list for residential placement. Only 9% preferred residential placement, having added their son’s or daughter’s name to a waiting list but not designating a successor caregiver. Fully 23% of the families had done both types of future planning, and 18% had made no plans whatsoever.

Mothers who had designated a successor caregiver tended to feel less caregiving stress, more satisfaction with life, and had larger social support networks. In contrast, those using a waiting list felt more caregiving stress, more burden, less satisfaction with life, had smaller networks, and used more formal services. These findings suggest that the formal service system is seen as a preferred option when caregiving is difficult, perhaps because the mother does not want to burden a relative under such circumstances, whereas the family is seen as the preferred option when caregiving is not stressful and when the mother has a large network of family and friends on whom to depend.

Analyzing data from the same study, Essex et al. [1997] examined the dynamics of waiting list use for residential placement. This analysis was based on longitudinal data, spanning a four and one-half year period in the lives of the older families. The majority of the sample (64%) did not have their son’s or daughter’s name on a waiting list at any point in the study period. However, 16% of the families had added their son’s or daughter’s name to a waiting list during the study period, and 17% were on a waiting list from the outset of the study. Interestingly, 4% of the families whose son’s or daughter’s name was initially on a waiting list had changed their minds during the study period and no longer used this mechanism for future planning. Thus, waiting list use is not a static method of future planning.

Extending this study in yet a different direction, Freedman et al. [1997] examined the factors associated with families having made a plan for the future care of the son or daughter with mental retardation, with planning defined as either living with a relative or being on a waiting list. One of the key factors differentiating those who made a plan from those who did not was the marital status of the mother, with widows more likely to have made a plan than currently married mothers.

Finally, Greenberg et al. [1999] examined planning from the perspective of the nondisabled siblings, asking the “most involved” sibling about expectations of future caregiving responsibility. Fully 58% of these most involved siblings expected to inherit primary responsibility for their brother or sister with mental retardation, including such tasks as providing or arranging housing, providing financial oversight, and obtaining legal guardianship. By way of contrast, only 36% of the siblings of adults with mental illness who also were included in this analysis shared these expectations. Two factors predicted whether siblings of adults with mental retardation were likely to expect to assume caregiving responsibility: whether the nondisabled sibling was a sister and whether the siblings had been close emotionally during adolescence. However, the intergenerational transmission of caregiving responsibility is not an uncomplicated aspect of family life. Griffiths and Unger [1994] reported that although almost half of the 41 nondisabled siblings they studied were willing to assume caregiving responsibility for their brother or sister with mental retardation, their parents were often reluctant to have them take on this role.

Several studies examined factors that predicted the likelihood that a sibling would be willing to assume responsibility for care of their brother or sister with MR/DD after the period of parental care ended. Krauss et al. [1996] reported that siblings were more likely to plan to co-reside with their brother or sister with mental retardation when their mother was in poorer health (perhaps suggestive that there was a more acute need for such planning), when the sibling with mental retardation was a sister who had mild or moderate retardation, and when there was a high level of current involvement between the siblings. Pruchno et al. [1996] found that mothers were more likely to expect that a nondisabled sibling would become the primary caregiver when their brother or sister with disabilities had better functional abilities and less severe maladaptive behaviors, when the quality of the sibling relationship was better, and when the sibling with the disability had DD rather than schizophrenia. Finally, Griffiths and Unger [1994], reporting somewhat similar results, found that siblings were more likely to expect to become the caregiver when the brother or sister had better cognitive abilities, when they rated their families low in family problems, and when they did not feel pessimistic about the brother’s or sister’s future.

Heller et al. [2000] reported on an intervention in which adults with mental retardation were taught about later-life planning. Of the 60 participants, 37% were still living at home with their parents. Although the data were not presented separately for this group, several findings warrant attention. First, the intervention was judged to be effective, with those in the experimental group making more choices about their future as a result of the intervention than the controls (who did not receive the intervention). Support from family was viewed by participants to be a key ingredient for meeting the goals they set for themselves. Supportive families gave time to the participant, accompanied him or her to activities or appointments, and gave financial support to help him or her meet goals. In contrast, inadequate family support was perceived to be a barrier to the likelihood that the adult would meet his or her goals. Although this study’s sample was small and only partly consisting of individuals who still lived at home with their parents, it is suggestive of the importance of including the individual with MR/DD in the future planning process.

Some insight about the effect of future planning on the quality of life of adults with MR/DD after parental death is provided by Gordon et al. [1997]. In
general, the adults whose mother had died during the study were more likely to experience a change in their place of residence, vocational or day placement, and social activities than a comparison group whose parents were still alive. However, in fully 16 of the 18 families in which the mother had made a plan prior to her death or incapacitation, the plan was either completely or partially implemented according to the mother’s wishes. For example, as noted in Gordon et al. [1997], one mother named her daughter as the successor caregiver and also indicated that she hoped her son with retardation would eventually move to a group home. Following the mother’s death, the sister took over responsibility for supervising her brother’s care and the brother moved to a placement fitting the mother’s description. Thus, there is preliminary evidence that permanency planning has an influence on the quality of life of adults with MR/DD after parental death.

SUMMARY AND AGENDA FOR FUTURE RESEARCH

Although the “quality of life” lens has not been explicitly focused on family-based care, there is emerging evidence from a variety of studies that begins to draw a portrait of the lives of adults with MR/DD who live at home. The most extensively researched area relates to family relationships, which is fortunate given the central role that the family occupies as the daily context in which the adult with MR/DD lives. There is considerable research on the types of instrumental and functional roles that siblings without disabilities play for their brother or sister with MR/DD, with most of the research indicating continued involvement of siblings, and the spillover effects of strong sibling relationships on other members of the family, particularly mothers. There is also a body of research on familial planning efforts for the continued well-being of the adult with MR/DD after parental care is no longer a viable option. There is a convergence of findings regarding the positive influence of family relationships and the value of planning for the future. Thus, strong and close family bonds are a boon to the quality of life of adults who live at home, and explicit plans for the future increase the likelihood that the current quality of life will be maintained after the period of parental caregiving is over.

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There are other important issues about the quality of life of adults with MR/DD who live outside the formal residential system for which we have no information. Particularly glaring is the absence of research literature on the degree of choice, personal autonomy, and self-determination of adults at home. These are the driving issues that have galvanized the quality of life debate for those adults who live in the formal ser-
vice sector. The extension of this focus to the lives of adults who live with their families is a promising avenue for future research. We suspect that these issues will be complex for adults with MR/DD who live at home, because these are not just individual issues, but family issues, as each member living in the household balances and negotiates how their personal choices are expressed and respected and how their own goals and aspirations are meshed with or compete with those of other family members. While the family is not formally “accountable” for the quality of life provided to their son or daughter with MR/DD as are publicly funded residential settings (other than for issues such as abuse and neglect), research that provides comparative data on the core dimensions of quality of life among adults living in different types of settings would be extremely useful in advancing our understanding of the consequences of public funding and private family decisions.

Research on the quality of life of adults who move in with their siblings after parental death is also needed, given the prevalence of this expectation among those families which have made future plans. No empirical study has examined the effects of this form of family co-residence on the quality of life of the individual with MR/DD, the sibling, or the sibling’s family and yet it is the most frequently preferred option of families. As the field begins to acknowledge the prevalence of family-based care, it is important to extend this acknowledgment to the wide variety of “family” situations that are implicated—including siblings and other relatives.

Families of color warrant a special examination, as quality of life may vary across cultural and ethnic groups, both in definition and in the factors that promote a desired lifestyle [Heller and Factor, 1991; Heller et al., 1994; Keith, 1996; Pruchno et al., 1997; Magana, 1999]. There is evidence that families of color prefer family co-residence, but the supports that would enhance this living arrangement for all family members remain unknown. It is also important to encourage studies of families of greater economic diversity. While the extent literature includes studies with low- and high-income families, most of the analyses control for income, rather than examine the effect of differing economic (both low and high) circumstances. Further, given the documented disparity in income between families who have a member with MR/DD versus the population at large [Fujirua, 1999], it is important to examine more explicitly the role that both material and social resources exert on the quality of life of adults with MR/DD.

Although this list of needed research topics is long, the current state of the literature on the quality of life of adults with MR/DD who live at home provides a foundation on which to pursue these more elaborated research questions. By grounding these studies from the perspective of well-formulated conceptual models of the domains of quality of life, the gap in the quality of life literature between adults who live in residential placements and adults who live with their families may be narrowed.

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