

AGING FAMILY CAREGIVERS: POLICIES AND PRACTICES

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This review examines later life family support for adults with developmental disabilities from a life course perspective that takes into account social trends and changes in service patterns and in attitudes of families. Key issues addressed include: (1) trends affecting family caregiving, (2) health and social outcomes of life-long caregiving, (3) support needs of families, (4) family support policies and practices, and (5) recommendations for a research and policy agenda. Research examining outcomes of life-long caregiving has shown that most families adapt well to having a family member with disabilities. However, some families are at risk for poorer physical and mental health outcomes. These include cultural minorities and families of adults with behavioral challenges. Caregiving does seem to have a negative impact on maternal employment and family income as mothers often give up or cut back on employment to care for a child with developmental disabilities, who is more likely to continue living in the family home throughout adulthood than other adult children. Federal and state initiatives are addressing issues of family support through both the developmental disabilities and aging service systems.

MRDD Research Reviews 2007;13:136–142.

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Key Words: aging; families; family support

Families have always been the main care providers for individuals with developmental disabilities throughout their lives. Over 75% of adults with developmental disabilities live with their families [Fujiura, 1998; Braddock, 1999]. Yet little attention has focused on assessing and promoting the health and well-being of these families. With longer life expectancies and growing governmental fiscal constraints, reliance on family caregivers for adults with disabilities will likely grow. In 1994, Fujiura, Roccoforte, and Braddock predicted that the demand for family support will outweigh the supply. A decade later this imbalance continues to increase.

This review examines later life family support for adults with developmental disabilities from a life course perspective that takes into account social trends and changes in service patterns. While the term “family caregiving” primarily refers to support provided to the adult with disabilities, it is also common for adults with disabilities to provide support to other family members. Key issues addressed include: (1) trends affecting family caregiving, (2) health and social outcomes of life-long caregiving, (3) support needs of families, (4) family support policies and practices, and (5) recommendations for a research and policy agenda.

TRENDS AFFECTING FAMILY CAREGIVING

The demographic trends over the last 50 years in the US of increased life expectancy, lower fertility rates, and more dual income families, impact the ability of families to provide care for individuals with developmental disabilities. The percentage of individuals aged 65 years and over has risen from 8.1% to 12.4% and is expected to rise to 20.7% by 2050 [U.S. Bureau of the Census, 2004 Current Population Reports Series P25-1104; 2004 American Community Survey]. Between 1950 and 2000, life expectancy has risen from 66 to 74 years for men and from 70 to 79 years for women [Martin et al., 2002]. The life expectancy for adults with developmental disabilities has also risen during this period. Reports show that mean age at death now ranges from the late fifties (for those with more severe disabilities or Down syndrome) to 71 years for adults with mild to moderate intellectual disabilities [Patja et al., 2000; Bittles et al., 2002]. This is compared with an average life expectancy of 15 years for males and 22 years for females with intellectual disabilities in 1931 [Carter and Jancar, 1983]. This aging trend in combination with the low fertility rate of 1.9 children in 2004 in comparison with 3.6 children in the 1950s [Dye, 2005] results in both an extended period of caregiving for adults with developmental disabilities and fewer family members from which to draw support.

Increases in dual careers and single parents contribute to the caregiving demands faced by parents. From 1993 to 2005 the percentage of women employed in the labor force rose from 57.9% to 59.3% [U.S. Department of Labor, 2005]. Having dual careers affects not only the parents but also other family members, such as female siblings who can be sources of support to parents and to their sibling with a disability. Increased economic pressures can further stress families. The number of families living below the poverty line has risen

Grant sponsor: Rehabilitation Research and Training Center on Aging with Developmental Disabilities, National Institute on Disability and Rehabilitation Research; Grant number: H133B031134.

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Received 19 December 2006; Accepted 20 December 2006

Published online in Wiley InterScience (www.interscience.wiley.com).

DOI: 10.1002/mrdd.20138

from 25 to 37 million from 1975 to 2004 and poor families now comprise nearly 13% of US families [U.S. Bureau of the Census, 2004]. Families of individuals with developmental disabilities face higher rates of poverty than other families [Fujiura, 1998] and spend considerable out of pocket costs for the care of their relative with disabilities [Caldwell, in press; Fujiura et al., 1994].

Another demographic trend is the increase in the minority population in the US. The percentage of non-Hispanic Caucasians is projected to decrease from 75.6% in 2004 to 54% of the population in 2050 [U.S. Bureau of the Census, Current Population Reports, American Community Survey, 2004]. Immigration has contributed to the growing diversity in the U.S; from 1990 to 2000 the immigrant population grew by about 50% [U.S. Immigration and Naturalization Service, 2002]. These minority and immigrant groups often have greater challenges in accessing services. In the National Survey of Children with Special Health Care Needs Hispanic and Black families of children with special health care needs were more likely than White Non-Hispanic families to spend more than 5 hours a week providing care and Hispanic families were more likely to report having financial problems because of their child's health [Data Resource Center for Child and Adolescent Health, 2005].

Minority group families are often less likely than other families to apply for and to receive formal services for their relative [Heller and Factor, 1988; Heller et al., 1999]. The lower formal service use by cultural minorities could be attributed to a greater reliance on extended family supports, suspicion of formal services, and cultural beliefs that families should take care of their own. Hence, with the changes in demography, the service system has to increasingly shape services in culturally and linguistically competent ways.

HEALTH AND SOCIAL OUTCOMES FOR FAMILIES

Life-long caregiving for an adult with disabilities can have long-term effects on the economic, health, and social well-being of families. The economic impact has been noted for both parents caring for children and for adults with disabilities. According to the National Health Interview Disability Supplement of 1994/1995, families of children with developmental disabilities were less likely to take a job, worked fewer hours, were more likely to quit working, and had

more severe financial problems than families of other children with disabilities and families of nondisabled children [Anderson et al., 2002]. Other studies of nonelderly family caregivers of disabled or ill family members have found lower employment and more missed days of work [Ho et al., 2005] and fewer hours of maternal employment [e.g., Eiman and Cuskelly, 2002]. The lower economic participation of these mothers could be attributed to their greater time demands and lack of child care. As children move into adulthood the time demands of caregiving are likely to be reduced [Heller et al., 1997a]. However, these families are also more likely to have their adult child living at home than do other families, as the "launching" phase is likely delayed [Seltzer and Krauss, 1994].

Studies of mothers of adults with developmental disabilities have also indicated lower rates of employment [Parish et al., 2004; Seltzer et al., 2001]. Using

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the Wisconsin Longitudinal Study, Seltzer et al. [2001] found that in middle age these mothers (but not the fathers) had lower rates of employment and when employed reported more work/family role strain. Parish et al. [2004] found lower rates of maternal employment in a job for over 5 years, lower savings and lower income in these families. Mothers may delay their employment as their child with a disability is less likely to move out of the family home in adulthood. Little data, however, exists on the relative economic impact of severity of the disability, the time demands of caring for the child with disabilities, or the differential impact on minority families.

In addition to the economic impact of caregiving, families also experience health and social impacts. A Commonwealth Fund Biennial Health Insurance Survey [Ho et al., 2005] found that caregivers of a disabled or ill

family member are more likely to report health problems of their own, including nearly twice the number of chronic conditions as noncaregivers. The gerontological literature is replete with studies of the health consequences of caregiving for ill or disabled family members, including greater heart disease, higher blood pressure, poorer immune function, and lower perceived health status [reviewed in Feinberg et al., 2006].

Yet, several studies examining the health status of parents of adults with developmental disabilities report that their physical and mental health status is similar to that of the general population [Chen et al., 2001; Seltzer et al., 2001]. A study conducted in the UK showed that having a child with intellectual disabilities had no significant impact on mortality [Hill-Smith and Hollins, 2002]. They suggested that the additional caregiving challenges faced by these parents may have prolonged their motivation to stay healthy.

Singer's [2006] meta-analysis of studies examining depression in mothers of children with developmental disabilities indicated that these mothers had higher levels of depression than other mothers. However, in the one reported study of mothers caring for adult children [Seltzer et al., 1988], depression was not significantly higher for these mothers. One explanatory theory is the "adaptational" theory [Townsend et al., 1989] that predicts that caregiving becomes less stressful over time, because of increasing stability in routines, a reduction in behavioral problems, greater acceptance of the family member and greater reciprocity in caregiving with the child with disabilities. Heller et al.'s [1997b] study found that children with developmental disabilities living at home provided companionship support to their parents and help with household chores. This support could be particularly important as parents experience greater frailty and or widowhood. Additionally, mothers of adults with developmental disabilities are also more likely than other mothers to experience low rates of social participation [Seltzer et al., 2001].

Context of Care

Various contextual factors influence the health and well-being of families of adults with developmental disabilities, including child characteristics, socio-economic status, minority cultural context, and extent of social support networks [Greenberg et al., 1997;

Heller et al., 2000; Hong et al., 2001; Orsmond et al., 2003; Magana et al., 2004; Orsmond et al., 2006]. In addition, access to and use of formal services can influence family outcomes [e.g., Heller and Factor, 1993; Heller and Caldwell, 2006; Caldwell, 2006].

Child characteristics associated with lower levels of maternal psychological well-being include the diagnosis of autism [Abbeduto et al., 2004; Blacher and McIntyre, 2006; Singer, 2006] and the presence of challenging behaviors [Heller and Factor, 1993; Pruchno et al., 1996; Magana, 1999; Orsmond et al., 2006]. Blacher and McIntyre [2006] found that young adults with autism had more behavior problems than those with cerebral palsy (CP) or Down syndrome and their mothers had higher stress and depression. The diagnosis, however, did not account for variance in maternal well-being after controlling for behavioral problems.

Social resources of the family can serve as protective factors. Mothers who have more social support, family cohesion, and active coping tend to have lower burden [Seltzer and Krauss, 1989; Heller and Factor, 1993; Heller et al., 1994; Greenberg et al., 1997; Heller et al., 1997a; Magana, 1999] and depression [Blacher et al., 1997; Greenberg et al., 1997; Magana, 1999]. Within the family, supports from other siblings to the adult with disabilities [Seltzer et al., 1991] and to the mother [Pruchno, 2003] have been associated with higher maternal well-being. Support from the adult with disabilities can also contribute to maternal caregiving satisfaction [Heller et al., 1997b].

Cultural minorities may have differential responses to lifelong caregiving for members with developmental disabilities, as they are more prone to experience daily hardships, including racism, discrimination, poor English literacy, adaptation to immigration, and poverty. Several studies found poorer physical and mental health outcomes for Latina [Blacher et al., 1997; Magana et al., 2002; Magana et al., 2004; Blacher and McIntyre, 2006; Magana and Smith, 2006] and Black [Magana and Smith, 2006] mothers of offspring with developmental disabilities. On the other hand, other studies [Pruchno et al., 1996; Valentine et al., 1998] did not find poorer socio-emotional outcomes for Black mothers after controlling for socio-economic variables. Blacher and McIntyre [2006] found that Latina mothers of young adults

with developmental disabilities reported higher depression and lower morale, but also a higher positive impact from their child than did White mothers. Using the National Health Interview Survey, Magana and Smith [2006] found that in comparison with other older Black and Latina mothers, those caring for a child with developmental disabilities had higher rates of arthritis. Also, the Latina caregivers had more heart disease while the Black caregivers had more diabetes. Among mid-life Latinas, depressive symptoms were higher. The impact of daily caregiving on the health of minority women warrants greater attention.

Roles Within Families: Fathers, Siblings, and Grandparents

Most of the literature has focused on mothers with only a few studies examining the roles of fathers, siblings or grandparents of adults with developmental disabilities. Yet these other members play important roles in the lives of family members with developmental disabilities.

Minority families or families of adults with behavioral challenges are at risk for poorer physical and mental health outcomes.

Fathers

A consistent finding is that fathers are less likely to be primary caregivers across the lifespan than mothers. Several studies have found higher caregiving burden for mothers versus fathers of children [Kazak, 1987; Beckman, 1991] and of young adults with a disability [Hallum and Krumboltz, 1993]; whereas some found little differences in burden [Essex et al., 1992; Bruce and Schulz, 1994]. Heller et al. [1997a] found that fathers of children and adults with intellectual disabilities spend less time in caregiving tasks, offer fewer types of supports, perceive less burden than mothers and are less affected by behavioral challenges of the child. Essex et al. [1999] study of older mothers and fathers found that mothers faced more problem, which focused coping and were less pessimistic about the future. Having a son versus a daughter with developmental disabilities was more

stressful for older fathers but not for mothers. Although family caregiving is predominately a woman's task, fathers play a significant role in providing support, particularly financial support [Heller et al., 1997a]. Often fathers assume more responsibility after their wife becomes incapacitated or dies, often choosing to continue caregiving [Gordon et al., 1996]. Yet the fathers are mostly neglected in research on families and on family support services.

Siblings

Siblings provide the most long-lasting relationships for adults with developmental disabilities and provide considerable social support to them [Krauss et al., 1992]. Research focused on the impact of having a sibling with developmental disabilities on other siblings has found mixed results with some noting more behavior problems and depression and others failing to find such differences or finding positive impacts [Rossiter and Sharpe, 2001; Stoneman, 2005]. Adult siblings tend to maintain high levels of involvement with their sibling with disabilities across the life course [Zetlin, 1986; Seltzer et al., 1991]. When parents are no longer able to provide care for their child with disabilities or die, siblings are likely to assume responsibility (including coresiding with them) [Krauss et al., 1996; Pruchno et al., 1996; Freedman et al., 1997; Greenberg et al., 1999; Heller and Kramer, 2006]. Yet most siblings are not included in family discussions of future plans for their siblings with disabilities [Krauss et al., 1996; Heller and Kramer, 2006]. No research has examined the perspectives of adults with disabilities toward their siblings.

Grandparents

A growing number of children live with grandparent caregivers and many of these children have developmental disabilities. In 2000, 5.8 million children lived with grandparents, and 39% of grandparent caregivers had cared for their grandchildren for more than 5 years [U.S. Bureau of the Census, 2000]. Grandparents caring for children with disabilities face heightened needs compared with other grandparent headed families. In studies conducted in New York City these grandparents reported receiving less social support, higher levels of depression, role strain, financial strain, and life disruption than other grandparent caregivers [Burnette, 2000; McCallion et al., 2000]. In addition to demands because of the child's

disability, and fewer formal supports available to them [Kolomer, 2000], these grandparents had to deal with specialty educational, medical, and social service agencies, which were difficult to negotiate. This research needs to be expanded to include other locales and populations to better understand needs of these families and ways to support them.

Families have unmet needs for supports to maintain caregiving

Among family caregivers of adults with developmental disabilities, 711,478 (25%) are over the age of 60 years and another 984,207 (35%) are aged 41–59 years, the boomer generation [Fujiura, 1998; Braddock et al., 2005]. Many of these families receive few formal services and face long waiting lists for family support and residential services. An estimate of 73,828 families waiting for residential services [Prouty et al., 2006] is an underestimate as many states do not have waiting lists. Thompson [2004] found that 78% of adults aged 18 years and older in the US who receive long-term care at home get all their care exclusively from unpaid family and friends.

Families caring for adults with developmental disabilities have reported high unmet needs for respite services, case coordination, transportation, recreational services, and information regarding housing, financial plans, and guardianship [Heller and Factor, 1993; Heller et al., 1999; Pruchno and McMullen, 2004]. Feinberg et al. [2006] warns of greater pressure on the health care system if families' needs for medical and psychological support are unmet.

POLICIES AND PRACTICES

While most adults with developmental disabilities live with families, family support policy has not emerged as a national priority in the United States. Only about 5% of developmental disabilities funding is allocated for family support though it has increased in the past decade [Rizzolo et al., 2006]. Aging populations and increasing demands for long-term services are influencing policymakers to consider policies that support families to avoid more costly institutional placements. A broad policy agenda is suggested below, from developing supports within the developmental disabilities service system to forging coalitions with other aging and disability groups to advance legislation for family caregivers.

Consumer-Directed Supports

Early family support programs within the developmental disabilities system emerged in the late 1970s and early 1980s. This movement embraced ideals of maximizing flexibility and meeting the needs of the family as a whole [Agosta and Bradley, 1985]. Many states developed consumer-directed family support programs, which provided families with cash subsidies or individualized budgets. Currently, these types of programs exist in 22 states [Rizzolo et al., 2006]. Research from several programs has indicated that families in consumer-directed programs are more satisfied with services, have fewer unmet needs, and fewer out-of-pocket expenses for disability services [Heller et al., 1999; Caldwell, 2005]. Caregivers report reduced feelings of stress and burden, greater self-efficacy, better access to healthcare, more opportunities for employment, and improved social and leisure opportunities [Zimmerman, 1984; Meyers and Marcenko, 1989; Herman, 1991, 1994; Heller et al., 1999; Caldwell and Heller, 2003; Caldwell, 2005]. Individuals with disabilities experience benefits in community participation and employment [Heller et al., 1999]. Among lower income families benefits include better mental health of caregivers and self-determination of individuals with disabilities [Caldwell, 2005]. Furthermore, Heller and Caldwell [2005] found that consumer-directed supports decreased institutional placements over a period of 8 years.

The Medicaid Home and Community-Based Services (HCBS) waiver has been increasingly used to finance family support. Currently, approximately 57% of family support in developmental disabilities services uses the HCBS waiver [Rizzolo et al., 2006]. Ideological and structural barriers within the Medicaid program pose difficulty in providing flexible supports that target the joint needs of individuals with disabilities and families [Caldwell, 2005]. Instead of focusing on families, the trend within the recent consumer-directed supports has been to target individuals with disabilities but allow family caregivers to become paid employees. One extensive survey of consumer-directed programs in the United States identified 139 programs of which 80% permitted hiring family [Doty and Flanagan, 2002]. Research from the Cash and Counseling demonstrations found that the ability to pay family members was one of the most desirable

features of consumer direction [Simon-Rusinowitz et al., 2001; Mahoney et al., 2002]. Nearly half of employees in the Cash and Counseling demonstrations and consumer-directed programs nationally, have been family members [Benjamin et al., 1999; Dale et al., 2005]. Furthermore, positive benefits of hiring family members include increased service satisfaction and greater community participation [Benjamin et al., 1999; Caldwell and Heller, 2003; Foster et al., 2005]. While these programs targeted individuals, capped amounts of cash strengthened the financial stability of families [Simon-Rusinowitz et al., 2005].

Federal Family Support Initiatives: Collaboration Across Aging and Disability

Growing recognition of the need for collaboration across the aging and developmental disabilities service systems has led to the development of joint efforts rather than solely creating a parallel network of services. Beginning in 1987, amendments to both the DD Assistance and Bill of Rights Act (P.L. 100-142) and the Older Americans Act (P.L. 89-73) and formal joint agreements at the national and state levels created an infrastructure jointly addressing the needs of older adults with developmental disabilities and their families. The 1987 amendments to the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 100-142) required state developmental disabilities planning councils to review and comment on the annual plan prepared by the state aging agency and to include the state aging agency as a member of the council. It also fostered capacity building through collaboration between University Affiliated Programs in Developmental Disabilities and university-based gerontology centers.

The 1987 amendments to the Older Americans Act (P.L. 100-175) and subsequent reauthorizations expanded access to aging network services for older adults with developmental disabilities and their family by: (1) targeting older adults with severe disabilities, (2) allowing disabled dependent adults under age 60 to be served at congregate meal sites, and (3) encouraging outreach to older families caring for adults with developmental disabilities at home.

In 1989, the Administration on Developmental Disabilities (ADD) initiated an agreement with the Administration on Aging (AoA) to: (1) promote

training on aging and developmental disabilities, (2) allocate funds for demonstrations, and (3) encourage state aging and developmental disabilities agencies to establish memoranda of understanding. The AoA's family support program, The National Family Caregiver Support Program (NFCSP), enacted under Title III-E of the Older Americans Act Amendments of 2000, has funded states to serve caregivers of adults age 60 and older and grandparent caregivers of minor children. While the initial NFCSP neglected to cover aging caregivers of adults with developmental disabilities, language included in the 2005 reauthorization will hopefully expand coverage to this population. In addition to the NFCS program, AoA and the Centers for Medicare and Medicaid (CMS), in 2003, jointly developed the Aging and Disabilities Resource Centers (ADRCs), coordinated, "one-stop" informational centers. Currently there are 43 ADRCs (AoA, 2005) of which at least 14 specifically target families and individuals with developmental disabilities.

Future Planning Supports

Concern over the future security of their relative with developmental disabilities when they are no longer able to provide care is a source of anxiety for aging caregivers. Informational, psycho-social, and service system barriers prevent more than half of families from making concrete plans for the future [Heller and Factor, 1993; Freedman et al., 1997]. Key aspects of planning typically include financial and legal planning, future living arrangements, and vocational and recreational supports. Several initiatives have been developed to assist aging families in planning for the future [Susa and Clark, 1996; Etmanski, 1997; Botsford and Rule, 2004; Heller and Caldwell, 2006]. One intervention, which adopted a peer support model and included adults with developmental disabilities in the planning process was successful in assisting families to complete letters of intent, take actions on residential planning, and develop a special needs trusts [Heller and Caldwell, 2006]. This intervention also led to decreased caregiving burden and increased opportunities for daily choice-making of individuals with disabilities. New interventions are recognizing the importance of including siblings in the planning process, as in the future they are likely to assume caregiving responsibilities.

Towards a National Family Caregiver Support Agenda

Over 30 pieces of legislation have been introduced in the 109th Congress that would address needs of family caregivers [National Family Caregiver Association, 2006]. One area of proposed legislation concerns caregiver tax credits of up to \$3,000 tax credit for qualified caregivers. These proposals were contained in the Long-Term Care and Retirement Security Act (S. 1244 and H.R. 2682), Improving Long-Term Care Choices Act (S. 1602), and the Ronald Reagan Alzheimer's Breakthrough Act (S. 602 and H.R. 1262). A second concentration of legislative activity includes enhancement of the Family and Medical Leave Act (FMLA). Enacted in 1993, the FMLA provides covered employees up to 12 weeks of unpaid leave a year for the birth of a child, adoption of a child, personal medical leave, or to care for an immediate family member with a "serious

Federal and state initiatives are addressing issues of family support through both developmental disabilities and aging services.

health condition." One likely barrier for many families is that the leave is currently unpaid. Several bills have been introduced to provide partial or full wage replacement through payroll taxes or state grants or to expand the qualifications for leave and definitions of family. The Healthy Families Act (S. 1085 and H.R. 1902) has also been proposed, which would mandate employers with fifteen or more employees to provide 7 days of paid sick leave per year for employees to use for themselves or to care for a family member. The US lags behind other industrialized countries in paid leave policies. More than 96 other countries mandate annual paid leave and over 139 countries provide paid sick leave [Pandya et al., 2006]. Finally, a third recently passed legislation is the Lifespan Respite Care Act (S. 1283 and H.R. 3248), which authorizes funding for state grants to develop coordinated systems of respite. Respite illustrates another common area where caregiver needs transcend age and disability groups.

SUMMARY

With the increasing number and longer life span of older adults with developmental disabilities, families are facing longer periods of caregiving. Support for these families is small relative to support for adults living in out of home settings. Most families adapt well to having a family member with disabilities. However, some families, such as minority families or families of adults with behavioral challenges are at risk for poorer physical and mental health outcomes. Caregiving does seem to have a negative impact on maternal employment. Federal and state initiatives are addressing issues of family support through both disabilities and aging services.

CHALLENGES FOR THE FUTURE

A broad agenda is suggested to advance support for families of adult relatives with developmental disabilities. Continued efforts need to expand flexible, consumer-directed supports. Special attention will need to focus on the health and social needs of aging caregivers, particularly those living in poverty and also who are from minority cultural backgrounds. This includes efforts to assess needs of family caregivers, improve access to services, and increase sensitivity to cultural and linguistic competence. More research is needed to address the efficacy and effectiveness of various policies and practices including consumer directed family supports, psycho-educational supports, and respite programs on the well-being of families and adults with developmental disabilities. Finally we need to expand our research to incorporate the perspectives of people with disabilities regarding their families and the type of support they want to receive for themselves and their families. ■

REFERENCES

- Abbeduto L, Seltzer MM, Shattuck P, et al. 2004. Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile x syndrome. *Am J Ment Retard* 109:237-254.
- Agosta J, Bradley V. 1985. Family care for persons with developmental disabilities: a growing commitment. Cambridge, MA: Human Service Research Institute.
- Anderson L, Larson S, Lakin KC, et al. 2002. Children with disabilities: social roles and family impacts in the NHIS-D, DD Data Brief, Vol 4. Minneapolis, MN: Rehabilitation Research and Training Center on Community Living, University of Minnesota.

- Beckman PJ. 1991. Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. *Am J Ment Retard* 95:585-595.
- Benjamin AE, Franke TM, Matthias RE, et al. 1999. Consumer direction and in-home services: recipient perspectives on family and non-family service provision. *J Rehab Adm* 22:233-247.
- Bittles A, Petterson B, Sullivan S, et al. 2002. The influence of intellectual disability on life expectancy. *J Gerontol A Biol Sci Med Sci* 57:470-472.
- Blacher J, McIntyre LL. 2006. Syndrome specificity and behavioural disorders in young adults with intellectual disability: cultural differences in family impact. *J Intellect Disabil Res* 50:184-198.
- Blacher J, Shapiro J, Lopez S, et al. 1997. Depression in Latina mothers of children with mental retardation: a neglected concern. *Am J Ment Retard* 101:483-496.
- Botsford AL, Rule D. 2004. Evaluation of a group intervention to assist aging parents with permanency planning for an adult offspring with special needs. *Soc Work* 49:423-431.
- Burnette D. 2000. Latino grandparents rearing grandchildren with special needs effect on depressive symptomatology. *J Gerontol Soc Work* 33:1-16.
- Braddock D. 1999. Aging and developmental disabilities: demographic and policy issues affecting American families. *Ment Retard* 37:155-161.
- Braddock D, Hemp R, Rizzolo MC, et al. 2005. The state of the States in developmental disabilities. Boulder, CO: Coleman Institute for Cognitive Disabilities, University of Colorado.
- Bruce EJ, Schultz CL. 1994. A cross-sectional study of parenting perceptions: caring for children with intellectual disability. Special issue: family caregiving. *Australian J Marriage Fam* 15:56-65.
- Caldwell J. 2005. Consumer-directed family support: Experiences of families with adult relatives with developmental disabilities. Doctoral Dissertation (Unpublished), University of Illinois at Chicago.
- Caldwell, J. 2006. Consumer-directed supports: Economic, health, and social outcomes for families. *Ment Retard* 44:405-417.
- Caldwell J, Heller T. 2003. Management of respite and personal assistance services in a consumer-directed family support programme. *J Intellect Disabil Res* 47:352-366.
- Carter G, Jancar J. 1983. Mortality in the mentally handicapped: a 50 year study at the Stokes Park group of hospitals. *J Mental Deficiency Res* 27:143-156.
- Chen SC, Ryan-Henry S, Heller T, et al. 2001. Health status of mothers of adults with intellectual disability. *J Intellect Disabil Res* 45:439-449.
- Dale S, Brown R, Phillips B, et al. 2005. Experiences of workers hired under cash and counseling: findings from Arkansas, Florida and New Jersey. Washington, DC: Office of Disability, Aging, and Long-Term Policy, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services.
- Data Resource Center for Child and Adolescent Health. 2005. Available at www.cshcddata.org
- Doty P, Flanagan S. 2002. Highlights: Inventory of consumer-directed support programs. Washington, DC: Office of Disability, Aging and Long-Term Care Policy, U.S. Department of Health and Human Services.
- Dye JL. 2005. Fertility of American women: June 2004, Current Population Reports P20-555. Washington, DC: U.S. Census Bureau.
- Eiman M, Cuskelly M. 2002. Paid employment of mothers and fathers of adults with multiple disabilities. *J Intellect Disabil Res* 46:158-167.
- Essex EL, Seltzer MM, Krauss MW. 1992. Aging fathers as caregivers for adult children with developmental disabilities. Presented at the National Institute on Aging Seminar on Men's Caregiving Roles in an Aging Society, Washington, DC.
- Essex EL, Seltzer MM, Krauss, MW. 1999. Differences in coping effectiveness and well-being among aging mothers and fathers of adults with mental retardation. *Am J Ment Retard* 104:545-563.
- Etmanski A. 1997. Safe and secure: six steps to creating a personal future plan for people with disabilities. Burnaby, British Columbia: Planned Lifetime Advocacy Network.
- Feinberg LF, Wolkowitz K, Goldstein C. 2006. Ahead of the curve: emerging trends and practices in family caregiver support. National Center on Caregiving Family Caregiver Alliance. AARP.
- Foster L, Brown R, Phillips B, et al. 2005. Easing the burden of caregiving: the impact of consumer direction on primary informal caregivers in Arkansas. *Gerontologist* 45:474-485.
- Freedman R, Krauss M, Seltzer M. 1997. Aging parents' residential plans for adults with mental retardation. *Ment Retard* 35:114-123.
- Fujiura GT. 1998. Demography of family households. *Am J Ment Retard* 103:225-235.
- Fujiura GT, Roccorfote JA, Braddock D. 1994. Costs of family care for adults with mental retardation and related developmental disabilities. *Am J Ment Retard* 99:250-261.
- Gordon RM, Seltzer MM, Krauss MW. 1996. The aftermath of parental death: changes in the context and quality of life. In: Schalock RL, editor. Quality of life: its applications to persons with disabilities. Washington, DC: American Association on Mental Retardation. p 23-40.
- Greenberg JS, Seltzer MM, Krauss MW, et al. 1997. The differential effects of social support on the psychological well-being of aging mothers of adults with mental illness or mental retardation. *Fam Relat* 46:383-394.
- Greenberg JS, Seltzer MM, Orsmond GI, et al. 1999. Siblings of adults with mental illness or mental retardation: current involvement and expectation of future caregiving. *Psychiatr Serv* 50:1214-1219.
- Hallum A, Krumboltz JD. 1993. Parents caring for young adults with severe physical disabilities: psychological issues. *Dev Med Child Neurol* 35:24-32.
- Heller T, Caldwell J. 2005. Impact of a consumer-directed family support program on reduced out-of-home institutional placement. *J Pol Pract Intellect Disabil* 2:63-65.
- Heller T, Caldwell J. 2006. Supporting aging caregivers and adults with developmental disabilities in future planning. *Ment Retard* 44:189-202.
- Heller T, Factor A. 1988. Permanency planning among black and white family caregivers of older adults with mental retardation. *Ment Retard* 26:201-208.
- Heller T, Factor A. 1993. Aging family caregivers: support resources and changes in burden and placement desire. *Am J Ment Retard* 98:417-426.
- Heller T, Hsieh K, Rowitz L. 1997a. Maternal and paternal caregiving of persons with mental retardation across the life-span. *Fam Relat* 46:407-416.
- Heller T, Hsieh K, Rowitz L. 2000. Grandparents as supports to mothers of persons with intellectual disability. *J Gerontol Soc Work* 33:23-34.
- Heller T, Kramer J. 2006. Involvement of adult siblings of people with disabilities in future planning. Chicago: University of Illinois at Chicago.
- Heller T, Markward R, Rowitz L, et al. 1994. Adaptation of Hispanic families to a member with mental retardation. *Am J Ment Retard* 99:289-300.
- Heller T, Miller AB, Factor A. 1997b. Adults with mental retardation as supports to their parents: effects on parental caregiving appraisal. *Ment Retard* 35:338-346.
- Heller T, Miller AB, Hsieh K. 1999. Impact of a consumer-directed family support program on adults with disabilities. *Fam Relat* 48:419-427.
- Herman SE. 1991. Use and impact of a cash subsidy program. *Ment Retard* 29:253-258.
- Herman SE. 1994. Cash subsidy program: family satisfaction and need. *Ment Retard* 32:416-421.
- Hill-Smith AJ, Hollins SC. 2002. Mortality of parents of people with intellectual disabilities. *J Appl Res Intellect Disabil* 15:18-27.
- Ho A, Collins S, Davis K, et al. 2005. A look at working-age caregivers' roles, health concerns, and need for support. New York, NY: The Commonwealth Fund.
- Hong J, Seltzer MM, Krauss MW. 2001. Change in social support and psychological well-being: a longitudinal study of aging adults with mental retardation. *Fam Relat* 50:154-163.
- Kazak AE. 1987. Families with disabled children: stress and social networks in three samples. *J Abnorm Child Psychol* 15:137-146.
- Kolomer S. 2000. Kinship foster care and its impact on grandmother caregivers. *J Gerontol Soc Work* 33:85-102.
- Krauss MW, Seltzer MM, Goodman SJ. 1992. Social support networks of adults with retardation who live at home. *Am J Ment Retard* 96:432-441.
- Krauss MW, Seltzer MM, Gordon R, et al. 1996. Binding ties: the roles of adult siblings of persons with mental retardation. *Ment Retard* 34:83-93.
- Magana SM. 1999. Puerto Rican families caring for an adult with mental retardation: Role of familism. *Am J Ment Retard* 104:466-482.
- Magana S, Seltzer MM, Krauss MW. 2004. Cultural context of caregiving: differences in depression between Puerto Rican and non-Latina White mothers of adults with mental retardation. *Ment Retard* 42:1-11.
- Magana S, Seltzer MM, Krauss MW, et al. 2002. Well-being and family role strains among Cuban American and Puerto Rican mothers of adults with mental retardation. *J Hum Behav Soc Environ* 5:31-55.
- Magana S, Smith, MJ. 2006. Health outcomes of midlife and older Latina and Black American mothers of children with developmental disabilities. *Ment Retard* 44:224-234.
- Mahoney KJ, Desmond SM, Simon-Rusinowitz L, et al. 2002. Consumer-preferences for a cash option versus traditional services: telephone survey results from New Jersey elders and adults. *J Disabil Pol Stud* 13:74-86.

- Martin JA, Hamilton BE, Ventura SJ, et al. 2002. Births: Final Data 2000. National Vital Statistics Report, Vol. 50. Hyatsville, MD: National Center for Health Statistics.
- McCallion P, Janicki MP, Grant-Griffin L, et al. 2000. Grandparent caregivers II: service needs and service provision issues. *J Gerontol Soc Work* 33:63–90.
- Meyers JC, Marcenko MO. 1989. Impact of a cash subsidy program for families of children with severe developmental disabilities. *Ment Retard* 27:383–387.
- National Family Caregiver Association. 2006. Pending legislation relating to family caregivers and their loved ones. Washington, DC: National Family Caregiver Association.
- Orsmond GI, Selzer MM, Greenberg JS, et al. 2006. Mother-child relationship quality among adolescents and adults with autism. *Am J Ment Retard* 111:121–137.
- Orsmond GI, Seltzer MM, Krauss MW, et al. 2003. Behavior problems in adults with mental retardation and maternal well-being: examination of the direction of effects. *Am J Ment Retard* 108:257–271.
- Pandya SM, Wolkwitz K, Feinberg LF. 2006. Support for working family caregivers: paid leave policies in California and beyond. San Francisco, CA: Family Caregiver Alliance.
- Parish S, Seltzer MM, Greenberg JS, et al. 2004. Economic implications of caregiving at mid-life: comparing parents with and without children who have developmental disabilities. *Ment Retard* 42:413–426.
- Patja K, Iivanainen M, Vesala H, et al. 2000. Life expectancy of people with intellectual disability: a 35-year follow-up study. *J Intellect Disabil Res* 44:591–599.
- Prouty RW, Smith G, Lakin KC. 2006. Residential services for persons with developmental disabilities: status and trends through 2005. Minneapolis: Research and Training Center on Community Living, University of Minnesota.
- Pruchno RA. 2003. Enmeshed lives: adult children with developmental disabilities and their aging mothers. *Psychol Aging* 18:851–857.
- Pruchno RA, McMullen WF. 2004. Patterns of service utilization by adults with a developmental disability: type of service makes a difference. *Am J Ment Retard* 109:362–361.
- Pruchno RA, Patrick JH, Burant CJ. 1996. Aging women and their children with chronic disabilities: perceptions of sibling involvement and effects on well-being. *Fam Relat* 45:318–326.
- Rizzolo M, Hemp R, Braddock D. 2006. Family support services in the United States. *Pol Res Brief* 17:1–11.
- Rossiter L, Sharpe D. 2001. The siblings of individuals with mental retardation: a quantitative integration of the literature. *J Child Fam Stud* 10:65–84.
- Seltzer GB, Begun A, Seltzer MM, et al. 1991. Adults with mental retardation and their aging mothers: impacts on siblings. *Fam Relat* 40:310–317.
- Seltzer MM, Greenberg JS, Floyd F, Pettee Y, Hong J. 1998. Life course impacts of parenting a child with a disability. Presented at the Annual Scientific Meeting of the Gerontological Society of America, Philadelphia, PA.
- Seltzer MM, Greenberg JS, Floyd FJ, et al. 2001. Life course perspectives of parenting a child with a disability. *Am J Ment Retard* 106:265–286.
- Seltzer MM, Krauss MW. 1989. Aging parents with adult mentally retarded children: family risk factors and sources of support. *Am J Ment Retard* 94:303–312.
- Seltzer MM, Krauss MW. 1994. Aging parents with co-resident adult children: the impact of lifelong caregiving. In: Seltzer MM, Krauss MW, Janicki MP, editors. *Life-course perspectives on adulthood and old age*. Washington, DC: American Association on Mental Retardation. p. 3–18.
- Simon-Rusinowitz L, Mahoney KJ, Loughlin DM, et al. 2005. Paying family caregivers: an effective option in the Arkansas cash and counseling demonstration and evaluation. In: Caputo RK, editor. *Challenges of aging on U.S. families: policy and practice implications*. Binghamton, NY: Haworth. p. 83–105.
- Simon-Rusinowitz L, Mahoney KJ, Shoop DM, et al. 2001. Consumer and surrogate preferences for a cash option versus traditional services: Florida adults with developmental disabilities. *Ment Retard* 39:87–103.
- Singer GHS. 2006. Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *Am J Ment Retard* 11:155–169.
- Stoneman Z. 2005. Siblings of children with disabilities: research themes. *Ment Retard* 43:339–350.
- Susa C, Clark P. 1996. Drafting a blueprint for change: coordinator's manual. Kingston, RI: University of Rhode Island.
- Thompson L. 2004. Long-term care: support for family caregivers (Issue Brief). Washington, DC: Long-Term Care Financing Project, Georgetown University.
- Townsend A, Noelker L, Deimling G, et al. 1989. Longitudinal impact of interhousehold caregiving on adult children's mental health. *Psychol Aging* 4:393–401.
- U.S. Bureau of the Census. 2000. Summary File 3. Washington, DC: U.S. Department of Commerce.
- U.S. Bureau of the Census. 2004. American Community Survey 2004. Washington, DC: U.S. Department of Commerce.
- U.S. Bureau of the Census. 2004. Current Population Reports. American Community Survey, 2004. Washington, DC: U.S. Department of Commerce.
- U.S. Bureau of the Census. 2004. Current Population Reports, Series P25–1104, Population projections of the United States by age, sex, race, and Hispanic origin, 1993 to 2050. Washington, DC: U.S. Department of Commerce.
- U.S. Bureau of the Census. 2004. Current Population Reports Series P25–1104, American Community Survey 2004. Washington, DC: U.S. Department of Commerce.
- U.S. Department of Labor. 2005. Women in the Labor Force: A Data Book. Washington, DC: Bureau of Labor Statistics, U.S. Department of Labor.
- U.S. Immigration and Naturalization Service. 2002. Yearbook of Immigration Statistics. Washington, DC: Office of Immigration Statistics.
- Valentine DP, McDermott S, Anderson D. 1998. Mothers of adults with mental retardation: is race a factor in perceptions of burdens and gratifications? *Fam Soc* 79:577–584.
- Zetlin AG. 1986. Mentally retarded adults and their siblings. *Am J Ment Defic* 91:217–225.
- Zimmerman SL. 1984. The mental retardation family subsidy program: its effect on families with a mentally handicapped child. *Fam Relat* 33:105–118.

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