

Aging Families of Adults with Mental Retardation: The Impact of Lifelong Caregiving

UNANTICIPATED LIVES

AN UPDATE ON NEW STUDY FINDINGS

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Introduction

From 1988 to 2000, we studied 461 families who had an adult son or daughter with mental retardation. When the study began, all of these adults lived at home. Their parents faced an atypical and unstudied dual challenge: continuing to provide care for an adult child with a disability and the personal challenge of adjusting to the manifestations and consequences of their own aging.

The overall purpose of the research was to investigate the factors contributing to the well-being of parent caregivers, the residential transitions for adults with mental retardation, the consequences of such decisions for families, and changes in the well-being of adults with mental retardation who continue to live at home as compared to those who have moved to a different residential setting.

The study addressed these issues with the largest existing sample in the U.S. of older mothers and fathers and their adult sons and daughters with mental retardation, about one-third of whom had Down syndrome. Data were collected from multiple members of the family a total of eight times over the 12 year study period.

In 1988, the mothers of these families averaged 66 years of age, and their son or daughter averaged 33 years. Today, these mothers would average 85 years and their son or daughter would average 52 years of age.

Update

The last update we sent to your family in the year 2000 summarized our findings up until that point. We have continued to analyze the data that we collected from your family and the other families in the sample. In this report, we present some of the new findings from our study based on analyses we have conducted since our last contact with your family. We learned a great deal from our visits with the families during those twelve years, and we would like to share with you these additional findings as another thank you for your family's participation.

If you would like to read previous project updates, papers we have published, or learn more about our research and other ongoing projects, you can find us on the web at <http://www.waisman.wisc.edu/family>.

New Findings

Regarding Mothers

1. Behavior problems in adults with mental retardation take a toll on their mothers' psychological well-being, and reciprocally, the mother's level of psychological well-being has an influence on the son or daughter's degree of behavior problems. Adults with mental retardation who had fewer behavior problems had mothers who, over a six-year period, showed improvements in their psychological well-being. In addition, mothers who had better psychological well-being to begin with had adult children who showed decreasing behavior problems over time.

2. The son or daughter's specific diagnosis is associated with differences in maternal well-being. Mothers of adults with Down syndrome have better relationships with their son or daughter than do mothers of adults with autism or schizophrenia. Similarly, mothers of adolescents with Down syndrome tend to have better psychological well-being as compared to mothers of adolescents or young adults with fragile X syndrome or autism. We have learned that these differences between mothers of adolescents with Down syndrome and fragile X syndrome are due to differences among the mothers in how they cope with their child's problems and the degree to which the son or daughter has behavior problems that are difficult to manage.

3. Certain coping strategies are more productive in maintaining mothers' psychological well-being. Mothers who use "problem-focused" coping show a reduction in distress and an improvement in the quality of the relationship with their adult child. Problem-focused coping involves trying to deal with the cause of the problem. For example, finding out more information about the disability, learning new skills to manage associated health and behavior problems, and rearranging family routines to best meet the son or daughter's needs are all productive ways of coping. On the other hand, mothers who use "emotion-focused" coping had declining levels of well-being. Emotion-focused coping involves focusing on the emotional consequences of the problem, for example, releasing pent-up emotions, denying the problem, or distracting oneself, and these coping strategies tend to be less helpful.

4. The ethnic group of a family is a factor in determining parental well-being. For example, Puerto Rican mothers of adults with mental retardation are less advantaged than Caucasian mothers of adults with mental retardation, in part because they are more likely to have financial constraints and poorer physical health than Caucasian mothers. Moreover, Puerto Rican mothers with more family problems are more likely to have depressive symptoms as compared to both Puerto Rican mothers with fewer family problems and also compared to Caucasian mothers. Puerto Rican mothers with poor health are also more likely to have depressive symptoms as compared to Puerto Rican mothers with good health and compared to Caucasian mothers.

Regarding Siblings

5. Siblings of adults with mental retardation maintain strong ties with their brother or sister across the life course. Findings from our research indicate that siblings constitute a major source of social support for adults with mental retardation. These siblings provide more emotional support to the adult with mental retardation when compared to siblings of adults with mental illness and are twice as likely to expect to assume primary caregiving responsibility in the future. Indeed, two-thirds of siblings of adults with mental retardation expect to be the legal guardian in the future. Further, when the non-disabled sons and daughters have a high degree of involvement with their brother or sister with mental retardation, these mothers tended to have better psychological well-being than mothers with less involved siblings.

6. The brother or sister's specific diagnosis is associated with differences in the quality of the sibling relationship. Siblings of adults with Down syndrome spend more time with and have a closer relationship with their brother or sister than do siblings of adults with autism. They are also more optimistic about their brother or sister's future than the siblings of adults with autism. These differences are likely due to the difficulties in the behavior problems of the adult with the disability.

7. Coping strategies used by siblings affects the quality of the relationship with their brother or sister with mental retardation. Siblings of adults with mental retardation who use "problem-focused" coping have a closer relationship with their brother or sister. Further, use of specific coping strategies differs by the gender of the non-disabled sibling. Non-disabled sisters of sisters with Down syndrome are more likely than non-disabled brothers of sisters to use "emotion-focused" coping, but no differences are seen among non-disabled sisters and non-disabled brothers of brothers with Down syndrome.

Regarding Adults with Mental Retardation

8. Midlife adults with Down syndrome are comparable to adults with mental retardation due to other causes in regards to their health, adaptive abilities and behavior problems. We tracked changes over a 10 year period in adults with Down syndrome and adults with mental retardation due to other causes. Prior to age 40, the two groups show similar patterns of change over the 10 year period. Their health remains relatively stable, and although functional abilities tend to get somewhat worse, their behavior problems become less frequent. Although older adults with Down syndrome are at increased risk of earlier onset of dementia than adults with mental retardation due to other causes, this risk is not evident in midlife.

9. Residential placement often follows declines in the health of adults with

mental retardation, and is associated with increases in behavior problems. About a third of the sample moved away from the parental home during the study period. Health declines in the adults with mental retardation preceded and were perhaps contributing to the decision-making leading to these residential relocations. Following a move, increases in behavior problems have been observed. However, this increase in behavior problems tends to lessen with time.

10. Few adults with mental retardation experience symptoms of depression, but this is a problem for some. We interviewed those adults with mental retardation in our sample who were able to tell us about their mood and feelings related to depression. Of these individuals, most did not experience symptoms of depression, or only experienced mild symptoms. However, about a third reported severe depressive symptoms. This rate of depressive symptoms is greater than reported by the average population, so there are grounds for concern.

Final Thoughts....

Since our study began nearly 20 years ago, in 1988, we have learned a great deal about the dual challenge faced by parents who are caring for an adult child with mental retardation and, at the same time, adjusting to the consequences of their own aging. We have learned about the many ways families cope with challenges of caregiving. We have also examined differences among these parents and those caring for individuals with a variety of other types of disabilities (such as autism or schizophrenia) and belonging to different ethnic groups. And we have extended our focus beyond the well-being of the parents and siblings and addressed the impact of residential changes on the individual with mental retardation.

While our research has answered many questions about the process of caregiving for an adult child with mental retardation, it has also generated potential questions for further research. We are eager to continue to track more recent changes experienced by individuals with mental retardation and by the family to learn how individuals with mental retardation cope with later-life transitions. We look forward to catching up with you and your family to try to answer these new research questions.

Project Publications

New Articles in Professional Journals

Esbensen, A. J., Seltzer, M. M., & Krauss, M. W. (in press). Stability and Change in Health, Functional Abilities and Behavior Problems among Adults with and without Down Syndrome. *American Journal of Mental Retardation*.

Esbensen, A. J., Seltzer, M. M., & Greenberg, J. S. (in press). Factors predicting mortality in midlife adults with and without Down syndrome living with family. *Journal of Intellectual Disability Research*.

Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism or Down syndrome: Effect on adult lives. *Journal of Intellectual Disability Research*, 51, 382-396.

Esbensen, A. J., Seltzer, M. M., & Greenberg, J. S. (2006). Depressive symptoms of adults with mild to moderate intellectual disability and their relation to maternal well-being. *Journal of Policy and Practice in Intellectual Disabilities*, 3, 229-237.

Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., & Lounds, J. (2005). Life course studies of siblings of individuals with developmental disabilities. *Mental Retardation*, 43, 354-359.

Esbensen, A. J., Seltzer, M. M., Greenberg, J. S., & Benson, B. A. (2005). Psychometric evaluation of a self-report measure of depression for individuals with mental retardation. *American Journal on Mental Retardation*, 110, 469-481.

Seltzer, M. M., Abbeduto, L., Krauss, M. W., Greenberg, J., & Swe, A. (2004). Comparison groups in autism family research: Down syndrome, fragile X syndrome, and schizophrenia. *Journal of Autism and Developmental Disorders*, 34, 41-48.

Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal of Mental Retardation*, 109, 237-254.

Greenberg, J. S., Seltzer, M. M., Krauss, M. W., Chou, R., & Hong, J. (2004). The effect of quality of the relationship between mothers and adult children with schizophrenia, autism, or Down syndrome on maternal well-being: The mediating role of optimism. *American Journal of Orthopsychiatry*, 74, 14-25.

Magaña, S., Seltzer, M., & Krauss, W. (2004). The cultural context of caregiving: Differences in depression between Puerto Rican and non-Latina White mothers of adults with mental retardation. *Mental Retardation*, 42, 1-11.

Kim, H., Greenberg, J. S., Seltzer, M. M., & Krauss, M. W. (2003). The role of coping in maintaining the psychological well-being of mothers of adults with mental retardation and mental illness. *Journal of Intellectual Disability Research*, 47, 313-327.

Orsmond, G. I., Seltzer, M. M., Krauss, M. W., & Hong, J. (2003). Behavior problems in adults with mental retardation and maternal well-being: Examination of the direction of effects. *American Journal of Mental Retardation*, 108, 257-271.

Magaña, S., Seltzer, M.M., Krauss, M.W., Rubert, M., & Szapocznik, J. (2002). Well-being and family role strains among Cuban American and Puerto Rican mothers of adults with mental retardation. *Journal of Human Behavior and the Social Environment*, 5, 31-55.

Previous Articles in Professional Journals

Magaña, S., Seltzer, M., & Krauss, W. (2002). Service utilization patterns of adults with intellectual disabilities: A Comparison of Puerto Rican and non-Latino white families. *Journal of Gerontological Social Work*, 37, 65-68.

Seltzer, M.M. & Krauss, M.W. (2001). Quality of life of adults with mental retardation/developmental disabilities who live with family. *Mental Retardation and Developmental Disabilities Research Reviews*, 7, 105-114.

Seltzer, M.M., Krauss, M.W., Hong, J., Orsmond, G.I. (2001). Continuity or discontinuity of family involvement following residential transitions of adults with mental retardation. *Mental Retardation*, 39, 181-194.

Seltzer, M.M., Greenberg, J.S., Floyd, F.J., Pettee, Y., Hong, J. (2001). Life course impacts of parenting a child with a disability. *American Journal on Mental Retardation*, 106, 282-303.

Hong, J., Seltzer, M.M., & Krauss, M.W. (2001). Change in social support and psychological well-being: A longitudinal study of aging mothers of adults with mental retardation. *Family Relations*, 50, 154-163.

Orsmond, G.I., & Seltzer, M.M. (2000). Brothers and sisters of adults with mental retardation: The gendered nature of the sibling relationship. *American Journal on Mental Retardation*, 105, 486-508.

Magaña, S. (1999). Puerto Rican families caring for an adult with mental retardation: The role of familism. *American Journal on Mental Retardation*, *104*, 466-482.

Essex, E.L., Seltzer, M.M., & Krauss, M.W. (1999). Differences in coping effectiveness and well-being among aging mothers and fathers of adults with mental retardation. *American Journal on Mental Retardation*, *104*, 545-563.

Greenberg, J.S., Seltzer, M.M., Orsmond, G.I., & Krauss, M.W. (1999). Siblings of adults with mental illness or mental retardation: Influences on current involvement and the expectations of future caregiving responsibility. *Psychiatric Services*, *50*, 1214-1219

Freedman, R. I., Griffiths, D., Krauss, M. W., & Seltzer, M. M. (1999). Patterns of respite use by aging parents of adults with mental retardation. *Mental Retardation*, *37*, 93-103.

Seltzer, M. M., Heller, T. (1997). Families and caregiving across the life course: Research advances on the influence of context. *Family Relations*, *46*, 321-323.

Seltzer, M.M., Greenberg, J.S., Krauss, M.W., Gordon, R.M., & Judge, K. (1997). Siblings of adults with mental retardation or mental illness: Effects on lifestyle and on psychological well-being. *Family Relations*, *46*, 395-406.

Greenberg, J.S., Seltzer, M.M., Krauss, M.W., & Kim, H. (1997). The differential effects of social support on the psychological well-being of aging mothers of adults with mental illness or mental retardation. *Family Relations*, *46*, 383-395.

Kling, C.K., Seltzer, M.M., & Ryff, C.D. (1997). Distinctive late-life challenges: Implications for coping and well-being. *Psychology and Aging*, *12*, 288-295.

Seltzer, M.M., Greenberg, J.S., Krauss, M.W., & Hong, J. (1997). Predictors and outcomes of the end of co-resident caregiving in aging families of adults with mental retardation or mental illness. *Family Relations*, *46*, 13-22.

Essex, E.L., Seltzer, M.M., Krauss, M.W. (1997). Residential transitions of adults with mental retardation: Predictors of waiting list use and placement. *American Journal on Mental Retardation*, *101*, 613-629.

Freedman, R.I., Krauss, M.W., & Seltzer, M.M. (1997). Aging parents' residential plans for adult children with mental retardation. *Mental Retardation*, *35*, 114-123.

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

Hong, J. & Seltzer, M.M. (1995). The psychological consequences of multiple roles. *Journal of Health and Social Behavior*, 36, 386-398.

Seltzer, M.M., Krauss, M.W., Walsh, P., Conliffe, C., Larson, B., Birkbeck, G., Hong, J., & Choi, S.C. (1995). Cross-national comparisons of ageing mothers of adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 39, 408-418.

Seltzer, M.M., Greenberg, J.S., & Krauss, M.W. (1995). A comparison of coping strategies of aging mothers of adults with mental illness or mental retardation. *Psychology and Aging*, 10, 64-75.

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

Krauss, M.W., & Seltzer, M.M. (1993). Current well-being and future plans of older caregiving mothers. *Irish Journal of Psychology*, 14, 47-64.

Seltzer, M.M., Krauss, M.W., & Tsunematsu, N. (1993). Adults with Down syndrome and their aging mothers: Diagnostic group differences. *American Journal on Mental Retardation*, 97, 464-508.

Krauss, M.W., Seltzer, M.M., & Goodman, S.J. (1992). Social support networks of adults with retardation who live at home. *American Journal on Mental Retardation*, 96, 432-441.

Seltzer, G.B., Begun, A., Seltzer, M.M., & Krauss, M.W. (1991). The impacts of siblings on adults with mental retardation and their aging mothers. *Family Relations*, 40, 310-317.

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

New Book Chapters

Esbensen, A.J., Seltzer, M.M., & Abbeduto, L. (in press). Family well-being in Down syndrome and fragile X syndrome. In J. E. Roberts, R. Chapman, & S. Warren (Eds.), *Speech and language development and intervention in Down syndrome and fragile X syndrome*. Baltimore, MD: Brookes.

Lounds, J. J., & Seltzer, M. M. (2007). Family impact in adulthood. In S. L. Odom, R. H. Horner, M. E. Snell, & J. Blancher (Eds.), *Handbook on developmental disabilities*. (pp. 552-569). New York: Guilford.

Greenberg, J.S., Seltzer, M.M., & Brewer, E. (2006). Caregivers to older adults. In B. Berkman (Ed.) *Handbook of social work in health and aging*. (pp. 339-354). New York: Oxford University Press.

Seltzer, M.M., Floyd, F.J., & Hindes, A.R. (2004). Research methods in intellectual disabilities: The family context. In E. Emerson, C. Hatton, T. Parmenter, & T. Thompson (Eds.). *Handbook of methods for research and evaluation in intellectual disabilities*. (pp. 237-260). NY: John Wiley.

Ryff, C.D., Singer, B. H., & Seltzer, M.M. (2002). Pathways through challenge: Implications for well-being and health. In L. Pulkkinen & A. Caspi (Eds.), *Pathways to successful development: Personality in the life course*. Cambridge, UK: Cambridge University Press.

Previous Book Chapters

Essex, E.L., Seltzer, M.M., & Krauss, M.W. (2001). Fathers as caregivers for adult children with mental retardation. In B. J. Kramer & E. H. Thompson (Eds.), *Men as caregivers: Theory, research, and service implications*. New York: Springer.

Robison, D., Krauss, M.W., & Seltzer, M.M. (2001). Does parenting ever end? Experiences of parents of adults with Down syndrome. In S. Pueschel (Ed.), *A parent's guide to Down syndrome: Toward a brighter future*. Baltimore, MD Paul H. Brookes.

Krauss, M. W., Greenberg, J. S., & Seltzer, M. M. (1999). Aging in adults with developmental disabilities and severe and persistent mental illness. In J. J. Gallo, & J. Busby-Whitehead, P. V. Rabins, R. A. Silliman, & J. B. Murphy, (Eds.), *Reichel's care of the elderly: Clinical aspects of aging* (fifth edition). Baltimore: Williams & Wilkins.

Krauss, M. W., & Seltzer, M. M. (1999). An unanticipated life: The impact of lifelong caregiving. In H. Bersani (Ed.), *Responding to the challenge: International trends and current issues in developmental disabilities*. Brookline, MA: Brookline Books.

Seltzer, M.M. & Greenberg, J.S. (1999). The caregiving context: The intersection of contextual and individual influences in the experience of family caregiving. In C.D. Ryff & V. Marshall (eds.) *The self and society in aging processes* (pp. 241-251). New York: Springer.

Seltzer, M.M. (1998). Service utilization patterns and organization of the service delivery system for persons with mental retardation and other developmental disabilities. In S. Allen & V. Mor (Eds.), *Living in the community with disability: A cross-group perspective*. New York: Springer.

Seltzer, M.M., & Krauss, M.W. (1998). Families of adults with Down syndrome. In J. F. Miller, L. A. Leavitt, & M. Leddy (Eds.), *Communication development in young children with Down syndrome*. Baltimore: Paul H. Brookes.

Gordon, R.M., Seltzer, M.M., & Krauss, M.W. (1997). The aftermath of parental death: Changes in the context and quality of life. In R. L. Schalock (Ed.), *Quality of life: Its application to persons with disabilities*. Washington, DC: American Association on Mental Retardation.

Krauss, M.W., & Seltzer, M.M. (1997). Life course perspectives on mental retardation research: The case of family caregiving. In J.A. Burack, R.M. Hodapp, & E. Zigler (Eds.), *Handbook on mental retardation and development*. NY: Cambridge University Press.

Seltzer, M.M., (1997). Later life parenting by older mothers of adults with disabilities. In E. Bleckman (Ed.), *Behavioral Medicine for women: A comprehensive handbook*. NY: Guilford Publications.

Ryff, C.D., & Seltzer, M.M. (1996). The uncharted years of midlife parenting. In C.D. Ryff & M.M. Seltzer (Eds.), *The parental experience at midlife*. Chicago: University of Chicago Press.

Seltzer, M.M., Krauss, M.W., Choi, S.C., Hong, J. (1996). Midlife and later life parenting of adult children with mental retardation. In C.D. Ryff & M. M. Seltzer (Eds.), *The parental experience at midlife*. Chicago: University of Chicago Press.

Krauss, M.W., & Seltzer, M.M. (1995). Long-term caring: Family experience over the life course. In D. Rosenthal & L. Nadel (Eds.), *Down syndrome: Living and learning in the community*. New York: John Wiley.

Krauss, M.W., & Seltzer, M.M. (1994). Taking stock: Expected gains from a lifespan perspective on mental retardation. In M.M. Seltzer, M.W. Krauss, & M.P. Janicki (Eds.), *Life course perspectives on adulthood and aging*. Washington, DC: American Association on Mental Retardation.

Seltzer, M.M., & Krauss, M.W. (1994). Aging parents with co-resident adult children: The impact of lifelong caregiving. In M.M. Seltzer, M.W. Krauss, & M.P. Janicki (Eds.), *Life course perspectives on adulthood and old age*. Washington, DC: American Association on Mental Retardation.

Krauss, M.W., & Seltzer, M.M. (1993). Coping strategies among older mothers of adults with retardation: A life span developmental perspective. In A.P. Turnbull, J.M. Patterson, S.K. Behr, D.L. Murphy, J.G. Marquis, & M.J. Blue-Banning (Eds.), *Cognitive coping, families, and disability: Participatory research in action*. Baltimore: Paul H. Brookes.

Seltzer, M. M., & Krauss, M. W. (1993). Adult sibling relationships of persons with mental retardation. In Z. Stoneman & P. Berman (Eds.), *Siblings of individuals with mental retardation, physical disabilities, and chronic illness*. Baltimore: Paul H. Brookes.

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

Seltzer, M.M. (1992). Aging in persons with developmental disabilities. In J. E. Birren, R. B. Sloane, & G. D. Cohen (Eds.), *Handbook of mental health and aging*. New York: Academic Press.

Seltzer, M.M., Krauss, M.W., & Heller, T. (1991). Family caregiving over the life course. In M.P. Janicki, & M. M. Seltzer (Eds.), *Aging and developmental disabilities: Challenges for the 1990s*. Washington, DC: Special Interest Group on Aging, AAMR.