



Examining the Health Status and Needs of Older Women with Intellectual and Developmental Disabilities Through National Health Interview Survey Data

DEBORAH ANDERSON, CHARLIE LAKIN, AND SHERYL LARSON

As women with intellectual and developmental disabilities (I/DD) become visible and empowered through policies that support greater community integration and longevity, they and their families, professionals and advocates need accurate information about their health concerns and options. They need to know, for example, expected health timelines (e.g., age of menopause), risks for secondary conditions (e.g., medication-related osteoporosis), health-enhancing behaviors (e.g., health screening tests), and utilization of and satisfaction with services. Such information is crucial in planning supports for successful community living and for decision-making on both the individual and public policy levels.

The findings from cross-sectional studies should be viewed as studies of “survivors” who are relatively healthy and who have good functional skills (Moss, 1991; Anderson, 1993), in contrast to large longitudinal studies, which more accurately show the rate of decline (Eyman & Widaman, 1987). In addition, some health conditions may be undiagnosed and underreported in survey research on people with cognitive impairments (Anderson et al., 1987). Finally, a host of other factors influence health conditions and mortality rates, including severity and type(s) of disability and residential versus community placement (Chaney, Eyman, Givens & Valdes, 1985; Strauss & Eyman, 1996; Strauss & Kastner, 1997).

A national study of adults living in residential facilities reported that women were significantly more likely than men to have malnutrition/obesity and to

have seen a nutritionist, but less likely to have had liver problems, brain damage and gum disease (Anderson, 1996). The National Medical Expenditure Survey’s (1987), which included only 19 older women with mental retardation (MR) living in the community, indicated that only 20% had received a pap smear within the past year, 26% had received one within two years but more than one year ago, 58% had received one more than two years ago, and 16% had never had one. One-quarter had never received a breast examination and only 15% had ever had a mammogram.

Studies also found that the age of onset for menopause may be younger in women with Down syndrome (DS) (Schupf, et al., 1997; Carr & Hollins, 1995). This finding is consistent with the notion of accelerated aging in people with DS. Although these findings are informative, systematic research is needed to investigate the health trajectories of noninstitutionalized aging women with ID and compare them to the trajectories of aging women with other disabilities, aging women in general, and aging men.

Study Purpose and Objectives

The central goal of this project was to fill the knowledge gap regarding the health status and needs of older women with ID by analyzing and disseminating relevant information from the 1994-1995 National Health Interview Survey core and disability supplement (NHIS-D). Specifically, the study developed a broad, national framework of information about the health care status of women with I/DD during their middle and

Living Arrangement

Women with I/DD were 4.3 times more likely to be living with relatives than were adults with only functional limitations.

older years. The study had the following research questions:

1. What is the prevalence of various types of health-related conditions, limitations, needs and services among older women with ID?
2. Do older men and women with ID differ from one another in health conditions or health service utilization?
3. How do women aging with ID differ from women aging with other disabilities and women in the general population?
4. How are education and employment related to health issues for older women with ID?
5. What factors are most strongly associated with good or poor health?

Sample Population and Methodology

The National Health Interview Survey (NHIS) is a household survey administered annually to a representative sample of over 40,000 households, and over 100,000 civilian, noninstitutionalized adults in the U.S. to elicit detailed health information about the U.S. population. In 1994 and again in 1995, a two-stage Disability Supplement (NHIS-D) was added to the Core Survey to provide policy-relevant information about persons with disabilities. The NHIS-D identified respondents with disabilities and elicited additional information about their health perceptions, their health care experiences, service usage, and other health-related concerns (National Center for Health Statistics (1997, 1998).

This study selected the sample of women age 30 and older with either developmental disabilities (DD), intellectual disability (ID) or both (ID/DD). The age range selected in this study reflects the differences in mortality and morbidity risks for adults with certain disabilities, permits study of women with a wider range of more severe disabilities, some of which are underrepresented in the older age ranges, and permits

observation of early age-related changes.

Data Analysis

Each person in the survey received an individualized weight factor, reflecting the fact that survey respondents were selected to be representative of geographical areas, age, sex, race, and ethnicity, necessitating analysis of weighted data in order for the correct proportions. The NHIS-D's complex design required special procedures for variance estimation for unbiased



estimates of national prevalence rates. Population estimates were developed using the Taylor linear variance estimation method, with weighted data from 1994-1995 combined. Statistical comparisons are based upon weighted data, using SUDAAN.

Findings

Delineating a sample of older women with ID/DD required refinement of the database to provide samples which optimally reflected both the survey's intent and the mandates governing the definitions of ID and DD. Respondents were identified as having ID but not a DD, a DD but not ID or both (ID/DD). Results have been obtained for population and demographic statistics. Additionally, analyses have been done on health indicators, including women's perceptions of their health status, activities of daily living (ADL) and instrumental activities of daily living (IADL) status, health care services utilized in the prior year, activity limitations due to health problems, and indicators of psychological functioning were used to provide a broad picture of health and health-related functioning. The impact of having a developmental disability was most



evident in the health area, whereas the impact of an intellectual disability, particularly when combined with a developmental disability, was most apparent in the area of daily living skills.

Proxies were the sole respondents for 16%, 22%, and 46% of respondents with DD, ID, and both, respectively, and another 9-16% were partial respondents.

The following results were obtained for the population, sample demographics, and the health and related issues affecting women aging with ID/DD.

- Women with DD and/or ID comprise an increasingly smaller proportion of the non-institutionalized population living in the community as they age (1% of the population of civilian, non-institutionalized females under the age of 30, but only 0.2% over the age of 30).
- The majority of women (62%) age 30 and older with ID alone had married at some point, although only one in four were still living with their spouse. In contrast, 70% of women with both ID/DD had never married. The impact of having a developmental disability as well as ID was considerable – women with both ID/DD were likely to have never married, were more likely to be living with relatives (69% versus 51% respectively), and were more likely to report having had no formal education (54% versus 40%).
- One in five (21%) women with ID were working. Reported family incomes were typically quite low, with 60% of women with ID reporting 1994-95 family incomes of less than \$20,000, and slightly

over one-quarter reporting family incomes of less than \$10,000. One in four (26%) women with ID lived below the poverty level, which was about 2.5 times the percentage of women in general age 30 and older below the poverty threshold (10%).

The high rate of poverty was one of the more troubling findings. Extremely low incomes are likely to cause multiple strains that may affect health, including difficulty in paying for uncovered health care services and goods, in transportation for medical care, in having sufficient income for a healthful diet, supplements,

medications, preventive care, medical devices, etc., and for allied medical services that may be needed. Poverty may be a disincentive to living independently. In addition, numerous research findings attest to the adverse health effects of poverty, although the aspects of poverty involved and how these

effects are translated into health outcomes are not clear. Relative affluence may be protective for genetic risk factors by early nutritional enhancement of brain development. Poverty may also contribute to stress, which, if prolonged, is associated through cortical steroids with adverse health outcomes.

The findings regarding marital status reflect some important differences between women who remain in the community, who are likely to have more freedom in their life (and health) choices, and women living in licensed residential facilities. Although marriage is often viewed as social support, which can be a buffer to stress and an aid in encouraging appropriate health care, it is less clear that this is the case with women with ID, both because of traditional caretaking roles being assigned to women and the high rate of disrupted marriages among this group, suggesting that there may be considerable stresses on such relationships.

ADLs/IADLs

Women with both ID and DD were seldom independent in IADLs (17%), and the areas in which they were most likely to report difficulty were in “managing money” and “shopping.”

Health indicators. Most women (84%) in general age 30 and older without ID or DD rated their overall health as good to excellent. Fewer (64%) women with ID indicated this, and women with DD alone were most negative about their health, only 38% so indicating.

ADLs and IADLs. Women in the general population (without ID or DD) were almost always (96%) independent in ADLs, whereas about 2 in 3 with ID reported independence in all ADLs (69%). An examination of specific ADL areas found that 90% or more of women with ID reported no problems eating, getting in and out of a chair, getting around inside, and using the toilet. The most difficult tasks were dressing and bathing (about 1 in 3 women with ID needed help). IADLs (e.g., meal preparation, shopping, managing money, using the telephone, doing heavy work around the house and doing light work) were problematic for many respondents and group differences were much larger than for ADLs. Just over half (55%) of women with ID alone were independent in all IADL areas. Women with both ID and DD were seldom independent in IADLs (17%), and the areas in which they were most likely to report difficulty were in “managing money” and “shopping,” both of which involve fairly complex cognitive skills. Women without either of these disabilities were by far the most independent, almost 9 in 10 reporting independence in all IADLs (89%). In women between 18 and 34 years old with ID/DD, the most common limitation was in learning limitations (87.3%), closely followed by limitations in economic self-sufficiency (85.5%). Over half (51.3%) reported difficulties in IADLs and 45% reported substantial limitations in self-direction.

Mobility and activity limitation. Slightly more than one-quarter of women with ID reported difficulty walking and going up steps, and about 13% used some type of mobility aid. Lifting was difficult for 23%, bending for 16%, standing for 19%, and reaching,

using fingers, or writing with a pen were difficult for 9-10%. Over three quarters of the estimated population of women in general of this age, but very few women with ID, reported no activity limitations (78% and 13% respectively). Most commonly, “activity limitations” meant being unable to perform a major activity (e.g.,

work, student, housewife). Secondly, about one quarter of women with ID and 8% of women without disabilities indicated that they were limited in engaging in the kind or amount of activity.

Prior studies have demonstrated that disability, inactivity, and weak muscle strength serve to reinforce each other in a spiral of further disability, and adults with ID living at home are particularly likely to be physically inactive. Greater attention needs to be paid to the issues of obesity and fitness.

Communication and sensory concerns. Among adult women with ID/DD, 36.3% reported problems in understanding others and 25.2% reported difficulty in communication with persons outside their immediate family. Although nearly one in four women with ID had trouble communicating with others outside the family, and 20% had difficulty understanding others, only 12% reported communication difficulties within the family.

Mental Health. Psychological distress was much more widespread among women with ID than among women in general. The extent of reported psychological and social difficulties suggests that this is an extraordinarily distressed group, in contrast to women without ID. A substantial minority (27%) of women with ID reported serious difficulty coping with day to day stresses, but this was rare for women in general (3%). Women with ID had somewhat greater success in the social sphere, including making and keeping friends and in getting along in social settings, but they still had a great deal more difficulty than women without such disabilities (15% of women with

Social Relationships

Fifteen percent of women with ID, compared with less than 1% of women in general, indicated serious difficulties with friendships.

ID, compared with less than 1% of women in general indicated serious difficulties with friendships; 13% and .5% respectively had social difficulties).

Health insurance coverage. Health insurance coverage is an area in which little information has been available on “non-institutionalized” people with I/DD. Topics covered in this report include type of insurance, items covered by insurance plans, overall satisfaction with care, and the impact of insurance coverage on four health-related outcomes. Thirty-two percent of women with no functional limitations were HMO only users compared to 18% of women with ID, 18.2% of women with DD, and 10.8% of women with I/DD. Fifty-three percent of women with no functional limitations, 25.8% of women with ID, 24.9% of women with DD, and 21.3% of women with I/DD reported using fee for service or mixed plan. Only 15.2% of women with no functional limitations used other public health care services compared to 56.2% of women with ID, 56.9% of women with DD, and 67.9% of women with I/DD.

Implications for Research and Practice

In comparison with women in general, women with ID/DD have considerable vulnerability – a combination of very poor financial and educational resources, physical limitations, and psychological distress, particularly depression and anxiety, but also marked confusion or forgetfulness, difficulty concentrating, difficulty coping with life’s stresses, and social difficulties. These findings present a picture of women with few coping skills, whose sense of well-being and ability to plan and implement strategies to deal with challenges is often poor, and who may not have adequate financial, emotional and practical support (the majority had no case coordinator; many were not living with their families; and few worked). High levels of depression and stress have been shown in many studies to be a risk factor for disease and disability. The markedly elevated rates of several risk

factors for disease and disability strongly suggest that more attention needs to be paid to the social context, and in particular to psychological health. However, there were also differences among the three disability groups.

Having a developmental disability had less impact on educational attainment than ID or both, and women with DD were most likely to be self-respondents, to live apart from their family, and to have married. They were also most likely to be below the poverty index, to have negative perceptions of their health, to be limited in major activities, and to experience ADL difficulties, along with substantial IADL difficulties. Women with ID alone were almost as likely to have married as women with DD, although they did not share their relatively high educational levels, they were much more likely to be independent in IADLs than women with either ID or DD, and they were the least likely to indicate limitations in major activities.



Women with both disabilities (ID/DD) appeared in most respects to be more severely affected, having some of the impairments of both intellectual and physical disabilities. They were most likely to have a proxy respond for them, they declined precipitously from the community in the age 30 and over group, and they were also least likely to be represented in the 60 and 70 age group. A large percentage had no education, they tended to live with their families, and most had never married. Very few were independent in IADLs, similar to individuals with DD, but the tasks they had the most difficulty with tended to be tasks in which both cognitive skills and physical skills were needed, such as shopping, whereas women with DD more

typically had difficulty with IADLs with more demanding physical requirements, such as lifting. A large percentage indicated that their disability had impacted major life activities. However, they were similar to the less severely affected women with MR on ADL's, they had the most positive assessment of their health status, and they were the least likely to be living below the poverty level of the three disability groups.

The study demonstrates a high level of certain types of limitations, some of which are affected by both cognitive and physical factors, including many of the IADLs, and suggests that the needs of these groups of women are multiple in nature, involving economic resources, work-related disability, education, and social and family supports, in addition to rehabilitative supports more directly linked to specific disabilities.

Products and Publications

Doljanac, R., Larson, S., & Lakin, C. (Eds.). (Jan. 2004). *DD Data Brief: Gender, Age, and Disability Differences in Functional Limitations for Non-Institutionalized Adults in the NHIS-D*, (Vol. 6, No.1), Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. URL: www.rtc.umn.edu/nhis/databrief9/dddb.html.

Larson, S., Lakin, C., & Huang, J. (Eds.). (Dec. 2003). *DD Data Brief: Service Use by and Needs of Adults with Functional Limitations or ID/DD in the NHIS-D: Difference by Age, Gender, and Disability*, (Vol. 5, No.2), Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. URL: www.rtc.umn.edu/nhis/databrief8/dddb.html.

Anderson, L., Larson, S., Lakin, C., & Kwak, N. (Eds.). (May 2003). *DD Data Brief: Health insurance coverage and health care experiences of persons with disabilities in the NHIS-D*, (Vol. 5, No.1), Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. URL: www.rtc.umn.edu/nhis/databrief7/dddb.html.

Anderson, D.J. (2003). Women Aging with Intellectual Disabilities: What are the Health Risks? In P.N. Walsh & T. Heller, (Eds.), *Health of women with intellectual disabilities*. Oxford, UK: Blackwell Science.

Anderson, D.J. (2002). Health, Age, and Gender: How do women with intellectual disabilities fare? *Journal of Gerontological Social Work*, 38(1/2), 137-160.

Larson, S.A., Lakin, C.K., Anderson, L., Kwak, N., Lee, J.H., & Anderson, D. (2001). The prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal of Mental Retardation*, 106 (3), 231-52.
