

Health Status and Needs of Women with Intellectual Disabilities (ID)

CAROL GILL AND ALLISON BROWN

Women's health initiatives of the 1990's address the historic neglect of women's complex health issues in our nation's research agenda. A number of recent conferences, articles and research efforts have underscored the particular neglect of women with disabilities (Krotoski, Nosek & Turk, 1996). In contrast to women in the general population, health research on women with disabilities is still sparse, most of it focusing on working-age women with physical disabilities. Additionally, existing studies of women with ID focus on women living in residential facilities rather than in natural settings.

Limited data on persons with physical and specific developmental disabilities suggests that disability status and related treatments can significantly affect the process of aging for women. For example, preliminary reports suggest that osteoporosis may occur earlier in women with disabilities than in the nondisabled population (Turk et al., 1995). This may be associated with longtime use of anticonvulsives, which is a known risk factor for osteoporosis in men and women. Women with cerebral palsy may be at increased risk of complications from cervical spinal stenosis and inadequate pain management, which may affect their functional mobility (Turk et al., 1995). A study by Gill (1996) found that the majority of women she interviewed with physical disabilities who were middle age or older expressed concern about weight gain and reported that their doctors

had not discussed aging issues with them, such as physical fitness or treatment for osteoporosis. Although most received routine health screening tests, such as pap smears and mammograms, a substantial minority had such tests infrequently because of access problems (Gill, 1996).

This study responds to two trends: 1) women with intellectual disabilities are living longer and 2) they are increasingly integrated into the community rather than being placed in institutions. These trends indicate that this group of women is becoming more socially active and independent. Consequently, they and their families, caregivers, and health professionals need better information about health and aging to support healthier futures for women with ID as they age. Little research documents how these women understand their health

needs or the implication of the aging process, yet such information is critical for developing health education programs and clinical services. This information is critical for counseling families on how to support the health and well-being of the women with I/DD and for training health service professionals.



Study Purpose and Objectives

The purpose of this project was to conduct a study in which the health status, needs, and experiences of older women with ID are examined qualitatively. The findings would allow women with ID to convey information about their health needs and concerns.

The specific objectives of this research project were to: 1) use focus group methodology to explore and document the views and experiences of women with ID, age 30 and above, regarding health concerns,

health status, access to health information, aging, health services, health practices, women's health issues, psychological well-being, and the experience of disability; 2) analyze and interpret these data in the context of quantitative research findings about this population; 3) incorporate the resulting information in the design and evaluation of professional training to address documented deficiencies in health provider knowledge regarding women with intellectual disabilities, and; 4) plan and implement a comprehensive dissemination effort to convey critical information about health and aging to women with ID, their families, advocates, service providers and policymakers.

Sample Population and Methodology

Six focus groups were conducted with women with ID regarding their perceptions of health and aging. The results of these groups were analyzed to determine how women with ID frame their own health and aging issues. This project is an exploratory qualitative research project, utilizing a semi-structured focus group format designed to collect, summarize, analyze, and interpret information as provided by the participants' verbal responses to open-ended questions. The study conceptualized disability as a complex social category determined by the interaction of social, cultural, political, and physiological phenomena. Consistent with a grounded theory approach to qualitative research, the investigators allowed the perspectives of the participants, rather than a pre-selected theory, to shape the research discussions and guide the interpretations.

Recruitment and enrollment ended with a total of 34 women with ID having participated in the study. Subjects were recruited through agencies providing services for persons with developmental disabilities in a metropolitan area. Eligible study participants were women age 30 or older, currently receiving services through a developmental disability service agency. Participants had diverse disability types and cultural backgrounds and were able to respond to simply stated open-ended questions. Each focus group was composed of 4 to 8 participants, and project research staff (facilitators). The RRTCADD consumer and

Health Care Needs

Women with I/DD want explanations about health care procedures and need information that empowers them to express their personal rights and manage their own health.

professional advisors participated in developing the focus group questions and interpreting the results.

Data Collection and Measures

Prior to joining the focus group, each participant (and guardian, if applicable) was asked to read (or have read to her/him), and sign a consent form describing the nature of the research and study procedure. All participants and legal guardians who were contacted gave assent and consent to participate.

Participants were asked questions by facilitators about their health, aging, disability, life experiences, and views of health services and health professionals. They were also asked questions about work and home, the people in their lives, the choices they make and overall well-being. Each focus group lasted approximately 90 - 120 minutes. Discussions were audiotaped by project staff. The women had opportunities to express their ideas, opinions, and feelings related to each topic.

Data Analysis

Audiotaped responses were converted to printed transcripts and analyzed according to the constant comparative method. This analysis method is characterized by a process of categorizing responses into meaningful segments, assigning descriptive code words to the segments, comparing coded segments within and across transcripts to develop a set of major themes, and noting relationships between themes that have potential theoretical importance. Focus group participants were also asked to keep the discussion private and were informed that they were free to withdraw from the study at any time.



Findings

The major themes that emerged from the data analysis included the following:

- ◆ issues of aging in general
- ◆ knowledge of women's health
- ◆ health promotion
- ◆ concerns about health care services and health professionals
- ◆ perception of disability
- ◆ vulnerability and abuse
- ◆ protection and empowerment issues

The results suggested that women held mostly negative perceptions of aging, had misconceptions and limited knowledge regarding age-related physical and psychosocial changes (both in general and for women). They also expressed a desire for more information about their bodies and wanted explanations of health service procedures. Also, participants tended not to identify as having a disability, and lacked information on health promoting behaviors.

Women discussed engaging in high-risk behaviors without a clear understanding of potential consequences. Lastly, participants lacked information and autonomy regarding personal rights and empowerment in managing their own health.

Implications for Research and Practice

The results of our work can be used to plan consumer/professional collaborative women's health programs. Our findings can also be used to guide health service for women with ID (e.g., using more peer support in health services, making health information more accessible, and training family members to support health promotion).

Presentations to consumers, family members, and professionals aim to improve health education and

health care services for women with ID. The responses from consumers, family members, and professionals have been enthusiastic. Information regarding these presentations is also available through the RRTCADD *Aging & DD/MR Women's Health Forum* (Womhlthaging-dd@listserv.uic.edu), which disseminates information and expands the network of consumers, researchers and professionals interested in the health of women with developmental disabilities. This list currently has between 100 and 150 subscribed members who are people with disabilities, researchers, students, advocates, families, agency staff, and other interested members of the general public.

Women's Perceptions and Knowledge

Women with I/DD had negative perceptions of aging, along with limited knowledge about age-related physical and psychosocial changes, health promoting behaviors, and high-risk behaviors.

Publications and Products

Gill, C. J. & Brown, A. A. (2002). Health and aging issues for women with intellectual disabilities in their own voices. In P. N. Walsh & T. Heller (Eds.). *Health of Women with Intellectual Disabilities*. Oxford, England: Blackwell Science.

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J. Hammel & S.M. Nochajski (Eds.). (2000). *Aging and Developmental Disability: Current Research Programming and Practice Implications*. Binghamton, NY: Haworth Press.

Brown, A. A. & Murphy, L. (1999). *Aging with developmental disabilities: Women's health issues*. Arlington, TX: The Arc of the United States and the RRTC on Aging with Mental Retardation.

Brown, A. (1998). *Aging & DD/MR Women's Health Forum* (Womhlthaging-dd@listserv.uic.edu). To subscribe, email Allison Brown at lisab@uic.edu.
