

Women with Developmental Disabilities: Health and Aging

Allison A. Brown, BA* and Carol J. Gill, PhD

Address

*Department of Disability and Human Development (MC626), University of Illinois at Chicago, 1640 West Roosevelt Road, Chicago, IL 60608, USA. Email: lisab@uic.edu

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Major shifts have occurred in the world of disability that have profound implications for health-service provision. Although health researchers and clinicians have begun to address the health needs of women with disabilities, representation of older women with intellectual disabilities in health research and health-care practice remains inadequate. As the visibility of this group continues to grow through policies that support greater community integration and longevity, they and their families, professionals, and advocates will require more information about their health concerns, and appropriate health services and options. This article provides an overview of major issues of women with developmental disabilities within the areas of primary health care, aging, access to health services, and future directions in research and practice.

Introduction

Two major shifts have occurred in the world of disability that have had profound implications for health care in this area. First, disability scholars have begun to illuminate the true complexity of disability as a category of human difference. They have exposed the instability of the category over time and place, suggesting that, like gender, disability is defined as much by cultural views and social practices as it is by biology [1]. Second, people with disabilities have begun to speak and act for themselves. Taking inspiration from other minority group movements, they have cultivated a group identity and have lobbied forcefully for laws to protect their rights to education, jobs, services, transportation, and access to the existing environment [2]. The two shifts have resulted in a new generation of people with disabilities who seek accommodation in the social mainstream, and who feel entitled to choices, including health-care options. The growing presence and empowerment of people with disabilities mean that they are less likely to be institutionalized or restricted to specialized services, and more likely than ever before to be part of any health

professional's practice. A related development is an increased focus on disability in health research. As more Americans live long enough to acquire disabilities and as more people navigate their communities with functional limitations, researchers are learning more about their health issues. Consequently, health professionals have a new knowledge base to master.

As women and other marginalized groups continue to raise public awareness of their under-representation in the nation's health agenda, women with physical disabilities—many of them professionally trained and working in the health disciplines—have been organizing vigorously for inclusion in health research and services [3]. The health issues of women with developmental disabilities affecting cognition (that is, an ongoing intellectual disability, or combination of intellectual and physical disabilities, beginning before adulthood and affecting a person's level of functioning in multiple areas of major life activity), however, have received little attention until recently. Hampered by a long history of institutionalization and neglect, compounded by society's devaluation of "mental retardation," females with developmental disabilities have been among the most silenced and forgotten of all women. Fortunately, this picture is changing. The health needs of women with developmental disabilities have generated a productive new stream of research and health-service models. Although many information gaps remain, much of this recent work is guided by promising approaches that support health-related self-determination in women that, too often, have been deemed incompetent in every sense.

General Health

People with developmental disabilities are now living longer than previously expected [4•]. Adults with developmental disabilities have common age-related health problems comparable to the general population, however, they are at higher risk for several specific medical conditions, such as gastrointestinal and esophageal disorders [5], hypothyroidism, nonischemic heart problems, and visual impairment [6]. Persons with developmental disabilities are also more likely to have epilepsy, particularly if they have multiple or more severe impairments [7•]. Adults with Down's syndrome generally have a higher frequency of thyroid dysfunction, cardiac disorders, and sensory impairments [8,9,10] compared with their peers who do not have Down's

syndrome. Although individuals with low levels of impairment are aging at a rate that appears to be equal to that of the general population, the presence of Down's syndrome is associated with premature aging, in that geriatric health problems may begin up to 20 years earlier than would be expected in the general population [5,6].

Little systematic data are available that document the prevalence or incidence of age-related health problems in older women with developmental disabilities, as compared with other women with disabilities, or with women in general [5,11•,12–14]. Many women with developmental disabilities are now living longer than before, but without ever having given birth and are, therefore, at increased risk of developing breast cancer [15•,16••]. Down's syndrome and Rett's syndrome are common causes of intellectual disability in girls. Unlike Down's syndrome, Rett's syndrome affects primarily females, and usually involves significantly greater needs for health-related supports and services [17], yet comparatively little empirical data exist on the health of women with Rett's syndrome as compared with those who have other developmental disabilities. Furthermore, it is unclear to what extent differences exist between women and men with developmental disabilities in types and rates of common age-related health problems. Although cardiovascular disease is a leading cause of death among persons with developmental disabilities [4•], findings comparing cardiovascular health of women and men with developmental disabilities have been mixed. Whereas Rimmer, Braddock, and Marks [18] found that women had a lower probability of heart disease than men, Janicki *et al.* [19] reported that the women in their sample had a higher rate of mortality-associated heart disease than their male peers. They also reported that women with developmental disabilities have higher rates of cancer but lower rates of respiratory disease than men with developmental disabilities [19].

Residential setting may influence whether women with developmental disabilities are at increased risk for developing heart disease. Women with developmental disabilities who live at home with a family member may have higher levels of cholesterol and obesity, and lower cardiovascular fitness than the general population, placing them at greater risk for heart problems [18]. In addition, women with Down's syndrome have a higher rate of congenital heart disease, and have a higher risk than other women of developing heart murmurs as they age [6].

Data from multiple sources suggest that women with developmental disabilities, particularly those with Down's syndrome, have much higher rates of obesity and related nutritional disorders than do other women, or their male counterparts [13,18,20]. Increased activity can help counteract the harmful effects of unhealthy diet and sedentary lifestyle; however, designing health interventions for this population presents several challenges. Education on nutrition must be conveyed in simple, interesting, and varied formats when comprehension or communication gaps present barriers to how the information is received or

processed. The potential for earlier onset and heightened risks for health problems in many women with developmental disabilities suggests taking a cautious approach to designing and implementing exercise programs and other fitness activities.

Effects of medication

Women with disabilities are frequently prescribed long-term and/or multiple medications for psychiatric and medical conditions. Unfortunately, little formal research has systematically examined the effects of such medications on health and aging. Generally, persons with developmental disabilities have limited awareness of the purpose and side effects of the medications they take. They usually are not given adequate information regarding alternatives to medication and possible interaction effects between the different medications or substances they may be taking [21•]. They also may be limited in how they can verbally or nonverbally communicate the presence of side effects, placing them at higher risk for having unrecognized adverse events or clinical manifestations from under- or over-dosing. The prolonged use of anti-epileptic medications can affect menstrual functioning and lead to other age-related health issues in women with developmental disabilities [22]. Furthermore, psychotropic medications can interfere with a number of hormonal and metabolic functions. The long-term use of neuroleptics can cause hyperprolactinemia, resulting in a greater likelihood of menstrual disorders, impaired fertility, or sexual dysfunction [23].

Sexuality and Reproductive Health

Like other women, those with disabilities have a long tradition of advocating for their sexual rights and reproductive health options. Historically, they have been subjected to denial of services and treatment without consent, including involuntary and concealed contraception, sterilization, and abortion [3,24]. Even today, women with developmental disabilities do not have adequate access to information on sexual health, reproduction, pregnancy, or parenting, routinely offered to women with primarily physical disabilities, or to nondisabled women [11•,25]. Likewise, when care providers, family, or attendants are comfortable supporting women in expressing their sexuality and reproductive choices, few receive training to do so effectively [26].

Menstruation, fertility, and contraception

Although a small percentage of women with Down's syndrome do not menstruate, the vast majority of women with developmental disabilities have regular menstrual cycles, comparable to women in the general population [27]. Sadly, women with developmental disabilities have endured a long history of medical coercion around issues of contraception for pregnancy prevention or menstrual hygiene [24,28]. Although the frequency and type of contraception used by women with developmental disabilities remains

unknown, its use may be influenced more by social and parental control factors than by medical necessity or personal choice. For example, Servais *et al.* [29•] recently reported a greater likelihood of sterilization and use of long-term contraceptive injections (*ie*, Depo-Provera) in women with intellectual disabilities as compared with other women, instead of receiving appropriate education in menstrual self-care and alternative approaches to contraception.

Although it is a controversial topic, many women with developmental disabilities have successfully managed wanted pregnancies and subsequent child rearing. Furthermore, forced contraception fails to protect them from the dangers of sexual exploitation or sexually transmitted disease. Given how little empirical information exists on the long-term health consequences of early sterilization of women with disabilities, care providers and health professionals have a responsibility to consider the full range of present and future hazards confronting women with developmental disabilities when deciding on the best forms of contraception, including none at all.

Menopause

It is unclear how different hormone levels change with the natural aging process for women with developmental disabilities. Conversely, for some women with epilepsy, menopause may precipitate changes in seizure activity that are not adequately recognized or addressed by health-care providers [7•,30]. However, within the last 5 years, a considerable amount of attention has begun to focus on issues related to menopause and the effects of decreasing estrogen levels in women with Down's syndrome and dementia [14,16••,32]. Recent studies on women with Down's syndrome show hormonal changes indicative of primary gonadal dysfunction [14]. Consistent with the hypothesis of accelerated aging in people with Down's syndrome, several studies have shown that the onset of menopause averages 4 to 5 years earlier in women with Down's syndrome than in the general population [14,16••,32,33].

The earlier-than-expected age at onset of menopause may put women with Down's syndrome at increased risk for post-menopausal health problems, such as heart disease, depression, breast cancer, osteoporosis, dementia [16••], and glaucoma [34]. Studies among women in the general population show that despite the health risks, the quality of women's lives can increase after menopause, but there are no known comparative studies that examine whether women with developmental disabilities experience this change in similar ways [11•,12,14].

Osteoporosis

Preliminary reports on women with developmental disabilities suggest that bone loss may occur at a faster and earlier rate than in the nondisabled population [35,36], leading to an increased risk of osteoporosis and fractures. One risk factor is activity restriction. Women with cerebral palsy, for example, may experience reduced mobility at an

earlier age than the general population, and women with Down's syndrome are more likely to have musculoskeletal problems that limit their physical movements and activities. As previously mentioned, another risk factor may be the long-term effects of medication. Although the long-term use of anticonvulsant medication is a known risk factor for osteoporosis in both sexes, women with developmental disabilities and epilepsy are at higher risk for fractures than their male counterparts [37]. The use of hormone replacement therapy as a primary prevention for osteoporosis has not been studied systematically in this group, but evidence of the potential benefits for nondisabled women warrants further investigation of its use in women with developmental disabilities.

Mental Health

The mental health needs of women with developmental disabilities remain under-investigated. Although these women have a greater number of risk factors associated with mental health problems, such as isolation, lesser education, poverty, and lack of social supports, they generally have not been included in research on depression, suicide, and other emotional problems. However, existing research focusing on either women with disabilities or persons with developmental disabilities report both groups are at increased risk for mental health problems compared with the general population [9,31,38•], although direct comparisons between these groups are lacking. Mental health needs may be overlooked because emotional problems in individuals with developmental disabilities often are not diagnosed, or misdiagnosed. Because self-report is often very limited, it may be difficult to determine when women in this group are experiencing distress that might otherwise be treated with supportive counseling, group therapy, or medication.

Dementia

It is estimated that there are some 140,000 adults with intellectual disabilities who are affected by dementia, and that this number will grow threefold over the next 20 years [39]. Preliminary reports regarding dementia and developmental disability have been mixed. Whereas dementia has been reported to occur at four times the rate found in the age-matched general population of older persons with developmental disabilities [31], Janicki and Dalton [39] found that the rate of dementia paralleled that of adults in the general population, except for persons with Down's syndrome, who had a higher rate and earlier age of onset. Large population studies indicate that, in general, the rate of occurrence of Alzheimer's disease among persons with developmental disabilities appears to be about the same as in the general population (about 6% of persons aged 60 and older). The rate among adults with Down's syndrome, however, is significantly higher: about 25% for adults aged 40 and older, and about 65% for adults aged 60 and older. Schupf *et al.* [14] reported that postmenopausal women

with Down's syndrome appear to be significantly less likely to acquire Alzheimer's disease than their male counterparts, and that the higher risk of Alzheimer's disease in men may be related to differences in hormonal function between men and women with Down's syndrome that are distinct from those in the general population.

Abuse

Abuse and violence are primary issues for all women with disabilities, in that they are at significantly higher risk than their male peers and nondisabled women [38•,40,41]. Women with developmental disabilities experience alarmingly high rates of sexual, physical, and emotional abuse, and homicides [38,41]. According to the Department of Justice's Office for Victims of Crime Bulletin from September 1998, "research has found that 68% to 83% of women with developmental disabilities will be sexually assaulted in their lifetime, which represents a 50% higher rate than the rest of the population" [42]. Violence is generally perpetrated by persons in the disabled woman's immediate environment: care providers, family, peers, intimate partners, and casual acquaintances. Abuse of women with disabilities usually is chronic, and involves physical, financial, or emotional dependence on the perpetrator, which allows the abused women little or no opportunity for escape or support [38•,40,42].

Because of such barriers as communication difficulties, the fear of harmful consequences to themselves or others, and a lack of accessible resources or education, women with developmental disabilities often do not report abuse or violence. The ones who do report it are often not believed. These issues are compounded by a lack of recognition from care providers that these women are indeed at high risk [41,43], and the fact that the vast majority of domestic violence shelters in the US still are inaccessible to women with mobility, sensory, and cognitive disabilities. Overall, little progress has been made by health-care providers or community agencies to establish accessibility for women with developmental disabilities in abuse prevention or treatment programs.

Emotional disorders

In the general population, depression is more likely to affect women than men, and women with disabilities are more likely to report depression and stress than are nondisabled women [3]. Persons with developmental disabilities are frequently treated for behavior-related problems. Although studies on behavior interventions and the use of psychotropic medication in this population have been documented [44], the underlying causes or manifestations of mental health problems are not well understood. In part, communication issues can preclude the accurate diagnosis or assessment of emotional problems, which often can be related to any number of potential causes. Issues such as hormonal changes, medication side effects, grief and reactions to sudden changes or loss, effects of violence and abuse, depres-

sion, anxiety, psychoses, and inadequate pain management pose potential or undetected mental health risks [31].

Access and Barriers to Health Services

Many women with developmental disabilities are still not receiving basic routine health care. Reasons range from health professionals' lack of knowledge about and willingness to treat this population, perceived difficulty in obtaining informed consent, lack of perceived need by family or primary caregivers, insufficient financial resources or insurance coverage, and the women's own fears of examinations and other medical procedures [11•,43,45]. Limited data on access to health services for persons with developmental disabilities suggest that women with developmental disabilities are receiving less than adequate preventive health services [46], including breast examinations, mammograms, or Pap smears [15•,43,45,47].

Health-service providers often overlook breast-screening opportunities for women with developmental disabilities [15•], and often fail to provide these women and their care providers with training and resources to improve breast-health promotion. Case studies have been reported in which women who had developed breast or uterine cancer were never given preventive screenings related to their cancers. In research, women with developmental disabilities express their fears of medical procedures, and report that they often endure encounters with health professionals who handle their bodies without asking permission or offering any explanation of the procedures themselves [11•,12,25,45]. Many who have had pelvic exams and Pap smears report experiencing pain and extreme difficulty with the procedures [45], and as a result are often given sedating medications, which can further compound difficulties they may be having with comprehension, communication, sense of control, and self-determination.

The attitudes of health professionals, family, personal assistants, and other care providers are critical in ensuring equitable services and access to health care for women with developmental disabilities. Health-service providers who view disabled women as asexual will continue to overlook signs of significant women's health problems, including cancer, pelvic disorders, sexual dysfunction, sexually transmitted diseases, or sexual abuse [3]. Other barriers to adequate health care are physically inaccessible health-service settings (including wheelchair-unfriendly restrooms and nonadaptable mammography or exam tables) that fail to accommodate women with mobility impairments. Further barriers include the lack of alternate communication formats (such as sign language interpreters, and information in Braille or via audiotape) for women with sensory or communication limitations, problems with transportation, and lack of programmatic supports to assist women in making medical appointments and having comfortable exams [11•]. The pressures of managed care funding may severely compromise the time needed for sensitive and respectful procedures.

Training issues are also critical. Few physicians and other health-care professionals receive adequate training regarding the health issues of women with developmental disabilities, including ways to facilitate medical examinations [43,45,46]. Additionally, access to the resources of the community is a significant factor in a disabled woman's ability to choose the kind of health services she needs. As women with developmental disabilities reach older ages, they are more likely to be living in nursing homes, which can affect their level of access to quality health care and quality of life.

Gaining New Ground

The good news is that health-care professionals, researchers, and advocates who share concerns about the health needs of aging women with developmental disabilities are pioneering new approaches that emphasize self-determination and consumer participation. The recent literature describes innovative strategies and models for the provision of health care, particularly reproductive health services, to women with developmental disabilities [28,43,48]. Researchers around the world are creating a new agenda on health and aging issues for women with developmental disabilities, and producing collaborative international publications [49]. Most research instruments can be made accessible to women with cognitive limitations, allowing for their subjective views, personal experiences, and choices to be included as primary sources of information. Qualitative researchers in several countries have begun to design studies that ask women with developmental disabilities directly for their viewpoints and experiences regarding their own health needs [11•,25,49].

In recent years, a few health-care professionals and clinic teams have taken the initiative to begin designing programs that offer information and options in a milieu of respect and care. Exemplary approaches include longer and multiple appointments to allow for orientation sessions before exams, use of peer and family support groups, and desensitization training films, discussion, and demonstration of medical procedures and equipment [28]. A unique online gender violence prevention training program for women with developmental disabilities has been developed in Maryland, with a curriculum co-taught by women with and without disabilities (<http://www.thearcmd.org/Programs/Gender-Violence/final.pdf>). The University of Texas Southwestern Medical Center at Dallas has developed a continuing education program (*The Patient With Mental Retardation: Issues in Gynecologic Care*) [50] designed to give medical professionals an overview of issues pertaining to gynecologic services for these women. The disability and women's health communities have urged health policymakers to prioritize making accessible health centers and programs to include women with developmental disabilities and their families,

and to provide them with professionals who can fully address their health needs [17].

With respect to policy, the US Senate passed legislation reauthorizing the Violence Against Women Act in October, 2000. This legislation specifically calls attention to the needs of older and disabled women who are victims of domestic violence or sexual assault, and expands resources to develop and strengthen programs addressing abuse and violence through risk prevention, training, and education. In February, 2002, the US Public Health Service released the Surgeon General's conference report, "A National Blueprint to Improve the Health of Persons with Mental Retardation" [46]. This report draws national attention to the health disparities affecting persons with developmental disabilities, and outlines priority goals and action steps toward closing the gap between health needs and services for this group.

Conclusions

The right of women with developmental and intellectual disabilities to informed, responsive health services is increasingly acknowledged by their families, guardians, health-service providers, researchers, and the women themselves. Along with this acknowledgment comes increasing support for the women to make their own choices throughout their lives, and to participate in the health services that affect them. As community integration becomes a reality for a population that was once routinely institutionalized, women with developmental disabilities are joining their nondisabled "sisters" in seeking equal access to community health services and resources.

Many health-service professionals are now familiar with the requirements of the 1990 Americans with Disabilities Act (ADA), which mandates the removal of discriminatory barriers to public services, including those in buildings, communication systems, and transportation. The ADA has been a tremendous force in allowing women with disabilities to achieve access to health-service programs that were once unavailable to them. However, there is not yet an adequate, systematic body of data documenting the health-service experiences of women with developmental disabilities as they grow older. We need to gather more data on the kinds of health services these women receive or lack, where they can go to access better services, and what types of model approaches can be made available through existing health-care systems. There are some promising directions in research and practice. but inevitably, as health-care professionals increasingly meet these women in professional health-care offices, more information will be needed. It will take a continuing collaborative effort and a pioneer spirit on the part of all stakeholders—women with developmental disabilities, families and supporters, researchers, and practicing health-care professionals—to build the health knowledge base that these women deserve.

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