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Health Needs of Women With Disabilities Across the Lifespan

Karen Piotrowski and Linda Snell

Women with disabilities experience a variety of unique health needs from adolescence to older age. They require compassionate and comprehensive health care services to manage their physical disabilities and to prevent secondary conditions. Unfortunately, many women with disabilities encounter attitudinal, informational, environmental, and geographic barriers as they seek access to health care. A variety of measures can be implemented to overcome these barriers and to improve the quality of health care that women with disabilities receive. *JOGNN, 36,* 79-87; 2007. DOI: 10.1111/J.1552-6909.2006.00120.x

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According to Census 2000, over 49 million noninstitutionalized civilian Americans 5 years and older have some type of long-lasting condition or disability. Approximately 25 million American women (19% of the female population) have some type of disability. The percentage of women 16 to 64 years with a physical disability is 6.4%, or nearly 6 million women. For women 65 years and older, that percentage escalates to 30.7% (Waldrop & Stern, 2003).

In the most recent *Chartbook on Women and Disability in the United States,* Jans and Stoddard (1999) reported that women are more likely than men to experience activity limitations and are twice as likely to develop arthritis, the second leading cause of physical disability in women. Many other health conditions limit the ability of women to be physically active and perform essential activities of living. Spine or back problems, orthopedic impairment of the lower extremities, paralysis, and multiple sclerosis commonly limit physical activity. Medical disorders (e.g., heart disease, hypertension, respiratory problems, and diabetes) and mood disorders (e.g., depression and anxiety) are also responsible for activity limitations in women (Hughes, 2005).

This article presents an overview of current research evidence regarding women with physical disabilities. The impact of physical disability on a woman's health and lifestyle will be discussed in general terms and then from a developmental perspective. Throughout the article, activities designed to meet the health needs of women with disabilities (WWD) from adolescence to older age are suggested.

Financial Impact of Physical Disability

Functional limitations associated with physical disabilities can negatively affect every aspect of a woman's life and increase her level of stress (Hughes, Taylor, Robinson-Whelen, & Nosek, 2005). Women with disabilities are less likely to obtain a level of education that can lead to satisfying, well paying jobs. Only 45% of WWD are employed; this rate decreases as changes associated with aging combine with disability-related functional limitations. The average earned income of WWD is considerably less than for women without disabilities or even men with disabilities, possibly reflecting discrimination due to both disability and gender (Center for Research on Women with Physical Disabilities, 2006; Jans & Stoddard, 1999; Nosek & Hughes, 2003). Their lower earned income places more than 25% of WWD below the poverty level.

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Despite the substantial cost of health care to treat the condition responsible for their physical disability, to promote health, and to prevent secondary conditions, WWD often have difficulty obtaining adequate health insurance. Approximately half of WWD are not married, placing further restrictions on income and access to adequate health insurance. Single marital status also increases the likelihood that WWD will need to hire a caregiver or personal care assistant to help them with activities of daily living (Jans & Stoddard, 1999).

Barriers to Health Promotion and Disease Prevention

Healthy People 2010 (U.S. Department of Health and Human Services, 2000) emphasizes the importance of health promotion and disease prevention activities as critical components of the care management for WWD. Physical activities are designed to maintain a high level of wellness and function and prevent the development of secondary conditions, but physical disabilities that limit movement increase the risk for obesity and osteoporosis. As WWD age, obesity also can result in many medical problems, including heart disease, hypertension, and type II diabetes. The stress of living with a physical disability and the difficulties encountered in forming close friendships and intimate relationships also increase the risks for depression, isolation, and emotional, physical, and sexual abuse (Nosek & Hughes, 2003).

Screening to facilitate early detection of secondary conditions and cancer is critical, but in a landmark study, Nosek, Howland, Rintala, Young, and Chanpong (1999) found that many WWD faced barriers in accessing general health monitoring and screening. Health care providers (HCPs) may be uninformed about or reluctant to make the necessary adaptations in the office environment (e.g., adequate parking, elevators/lifts, wide hallways and doorways, accessible bathrooms) and equipment (e.g., adjustable mammography machines and examination tables, platform scales). Other accommodations further increase the cost and burden of care delivery to WWD. Women with disabilities may need longer appointment times and additional assistance during examinations. Health care providers also may be reluctant to take the time to increase their personal knowledge of physical disabilities and secondary conditions or involve WWD in decision making regarding their care.

Barriers may also arise from the woman herself and her caregivers. They may have deficient knowledge regarding importance of health-promoting activities, inadequate transportation and health insurance, or live in rural or suburban areas with few HCPs who are able to meet their needs. Women with disabilities must learn the importance of health promotion and disease prevention activities and demand these services.

Women with disabilities should be active partners in choosing activities to promote high-level wellness and optimal well-being. Wellness programs offered to WWD should include dental care, exercise and physical activity programs, nutritional guidance, stress management, and substance abuse treatment (Odette et al., 2003). Opportunities to participate in support groups with other WWD and in community and social activities also should be included in health promotion programs (Hughes, 2005; Hughes, Nosek, Howland, Groff, & Mullen, 2003; Nosek & Hughes, 2003). Positive encounters with compassionate and knowledgeable HCPs will increase the likelihood that WWD will fully participate in these essential health care activities (Mele, Archer, & Pusch, 2005; Wolski, 2003).

Health Needs of WWD Across the Lifespan

Adolescence

Defining Health and Wellness. Developmentally, adolescent WWD may not be interested in learning about the secondary conditions that occur with aging and how to prevent them. It is, however, critically important that they receive this information since osteoporosis, hypertension, and type II diabetes can occur at an earlier age for them than for women without disabilities (Smeltzer & Zimmerman, 2005).

Assisting adolescents to develop a personal definition of health and wellness and encouraging them to actively participate in health-promoting activities can have the beneficial effects of lowering their risk for developing secondary conditions and enhancing their ability to achieve satisfying, independent lives (Nosek et al., 2004). Hughes (2005) identified a high level of self-efficacy (i.e., a person's judgment of their ability to achieve expected outcomes) as a critical factor in successful participation in health-promoting activities.

Developing a Healthy Body Image and a Positive Sexual Identity. As young girls with physical disabilities reach adolescence, there is a growing awareness of just how different their bodies are when compared with the bodies of their peers. They also come to realize that society

values an image of youth, beauty, perfection, and being active and views physical disabilities as imperfections and unattractive (Taleporos & McCabe, 2002; Zitzelsberger, 2005). Nosek et al. (1999) found that the self-esteem of WWD was more profoundly affected by societal views and environmental barriers than by the disability itself. As they strive for sexual expression and equality, WWD must also overcome myths that they are asexual or incapable of handling sexual relationships.

With puberty, girls begin to develop a sense of themselves as sexual beings. While adolescent WWD may feel sexy and have an interest in becoming sexually active, they may worry that their physical appearance is not sexually desirable to potential partners. A caregiver or the prospective partner may be required to help with various aspects of sexual activity, such as dressing/undressing, assuming appropriate positions, or using a contraceptive (Mona, 2003).

Over time, positive feedback from supportive family members, friends, partners, and HCPs can help WWD develop an image of their bodies with which they are comfortable by integrating and accepting both the positive features and those features that to them are less attractive. Higher levels of sexual self-esteem can be attained through satisfying intimate relationships with caring partners and through education and support from parents and HCPs (Black, 2005; McCabe, & Taleporos, 2003).

Reproductive Health Guidance and Care

As WWD progress through adolescence, health promotion activities should begin to address reproductive health care issues. Providing WWD with comfortable, rewarding, and gentle reproductive care that takes into consideration the limitations of their physical disabilities will help to ensure that they will continue to use these services. HCPs must recognize that having a physical disability does not make a woman asexual or less likely to develop sexually transmitted infections (STIs), unplanned pregnancies, and breast and reproductive tract problems including cancer. Gynecologic examinations must not be deferred but rather facilitated through environmental and equipment modifications. The HCP should use an approach that fosters trust and encourages WWD to be active participants in their reproductive health care (Shah, Norlin, Logsdon, & Samson-Fang, 2005; Welner, Foley, Nosek, & Holmes, 1999).

Clinical breast examination (CBE) is an essential component of a thorough gynecologic examination for WWD. Altered sensation in fingers, muscular spasms, weakness, or rigidity in hands, and difficulty assuming required positions make performing breast self-examination (BSE) difficult if not impossible (Mele et al., 2005). All WWD more than 20 years old should have a monthly BSE and perform as much as they can by themselves. During the CBE, a woman's ability to perform BSE should be assessed and teaching provided as appropriate. Additionally, the woman may choose someone (e.g., family member, friend, partner, caregiver) to be taught the technique and assist her as needed. The organization for Breast Health Access for Women with Disabilities (2002) has created a brochure that uses illustrations and simple descriptions to describe how BSE can be adapted for WWD.

Pelvic examinations may create considerable difficulties for both WWD and their HCPs. The need for an assistant(s) to monitor responses to the examination and to help the woman maintain her position during the examination may cause embarrassment and distress if not approached in a respectful manner.

Helping a woman to relax, ensuring an empty bladder and bowel, and determining the best transfer techniques and examination positions for the individual (e.g., semi-supine, frog-leg, V-leg, and lateral) are essential components of the pelvic examination for WWD. These techniques will reduce muscle rigidity and spasticity, incontinence, discomfort, and the risk of autonomic dysreflexia. Along with a speculum examination, thorough inspection of the external genitalia and perineum is critical. A WWD may be unable to perform genital self-examination (GSE) independently or to sense the pain and discomfort that can accompany reproductive tract infections and lesions. Nevertheless, assessment of her ability to perform GSE adequately and instructing her (and a caregiver if appropriate) in the technique are important components of care.

Frank, open discussions with adolescents and their caregivers should take place regarding maturational changes that occur with puberty, self-care during menstruation, and sexual activity (including safer sex measures and sexual expression adaptations). Health care providers need to be alert for and teach their patients signs of vaginal infections, STIs, and sexual abuse (Schopp, Sanford, Hagglund, Gay, & Coatney, 2002; Welner et al., 1999).

Since WWD are at greater risk for abuse, counseling should be provided regarding what constitutes sexual abuse and how to be assertive regarding their sexual and reproductive rights (McCabe & Taleporos, 2003).

Presenting birth control options in an unbiased manner is critical to ensure that decisions are informed and freely made. Including the partners of WWD in decision making can enhance the safe and effective use of the method chosen. Contraceptive choice should take into consideration the risks WWD may face regarding the formation of blood clots (e.g., combined estrogen-progestin contraceptives), osteoporosis (e.g., progestin-only contraceptives), and infection (e.g., intrauterine devices (IUDs)). While hormone-based contraceptives can increase the risk for complications, they can also reduce menstrual flow and uterine cramping (Quint, 2003). The ability of WWD or their partners, or both to manipulate and insert barrier methods and open pill containers are additional considerations.

Young- and Middle-Aged Women

Infertility

Many WWD desire to bear and parent a child, and improved medical care has enabled more women with life-shortening conditions to reach childbearing age. Unfortunately, HCPs may have little or no knowledge or experience in providing maternity and infertility services to WWD (McKay-Moffat, 2003).

Treatment for infertility presents financial and emotional hurdles for any woman experiencing difficulty conceiving. These issues are magnified for WWD. Society, as a whole, has not supported the reproductive rights of persons with disabilities, clinging to the myth that reproduction should only be attempted by or be available to individuals without physical or developmental limitations. Nonetheless, there are many examples of WWD successfully bearing and parenting children, and many interdisciplinary support services are available to assist WWD to be mothers (Earle & Church, 2004).

Since WWD are often viewed as asexual, birth control and infertility services are either purposely withheld or simply not considered as necessary or appropriate by caregivers and HCPs (Earle & Church, 2004). For WWD who successfully overcome these hurdles, barriers such as inability to obtain reliable transportation, access or pay for clinic procedures, or participate in a comprehensive treatment plan may still prevent them from obtaining the infertility treatments available to women without disabilities.

Some HCPs withhold infertility treatment to WWD due to ethical concerns, fear of litigation associated with changes in maternal health, the potential for fetal congenital anomalies (Coleman, 2002). Nurses play an indispensable role in advocating for women dealing with these issues. Nurses must educate WWD about the risks and benefits of assisted reproductive technology (ART) in the context of their specific health needs and those of their anticipated child. Nurses may refer WWD to other HCPs with expertise in reproductive health for women with physical disability problems and who are able to advise on life-threatening or debilitating anomalies that can occur in the child.

When working with WWD and their partners who are seeking parenthood, nurses need to provide emotional support, listen to concerns expressed, respect their desire to become parents, and help them to understand how pregnancy and parenthood relate to the specific physical disability. Nurses should be politically active at state and national levels in an effort to improve and equalize access to ART. While social attitudes toward WWD have been slow to change, nurses need to emphasize the strengths and abilities these women bring to society and to parenting.

While some medical conditions may be adversely affected by pregnancy, many WWD can give birth safely and parent a child effectively when the proper medical and interdisciplinary support systems are in place. Every woman with a physical disability who desires motherhood should be fully assessed, in an unbiased manner, to determine whether pregnancy and parenthood would be safe options for her (Earle & Church, 2004; McKay-Moffat, 2003).

Prenatal Screening

Prenatal screening for fetal abnormalities has been integrated into mainstream prenatal care over the past several decades. The decision to accept or decline screening tests is difficult for many pregnant women and often even more difficult for WWD, who may face pressure from HCPs to consent to prenatal screening and to terminate their pregnancies if fetal anomalies are detected. Since their ability to parent has likely been questioned even before the pregnancy occurred, WWD may feel even more vulnerable and unable to even attempt to care for an infant with anticipated anomalies (Earle & Church, 2004).

Women with disabilities may have strong personal reservations about prenatal screening. Some WWD and disability rights activists think that the ultimate purpose of prenatal diagnosis is to eliminate persons with disabilities. Women with disabilities may think that many people, including their HCPs, would have recommended that they be aborted if the extent of their disability had been known before birth. This perception can lead to despair and anger. Women with disabilities may think that only the limitations of their lives are acknowledged, instead of the many joys and successes they have experienced (Earle & Church, 2004).

The majority of people with disabilities lead happy, satisfying lives. Women with disabilities need HCPs to advocate for them and support their decision if they decline prenatal screening. This need is also vital for the woman who participates in testing but refuses to terminate a pregnancy when fetal anomalies are diagnosed. Respecting each woman's decision and assisting her to obtain necessary support services is critical.

Abuse

Physical and emotional abuse has been identified by a significant number of WWD as the most important health issue they face (Hassouneh-Phillips, 2005). Nosek et al. (1999) found that WWD experienced abuse for a significantly longer period of time than women without disabilities and were more likely to experience physical or sexual abuse by their caregivers and HCPs. A more recent study of 177 WWD found that 56% reported a history of abuse (Milberger, Israel, LeRoy, Martin, Potter, & Patchak-Schuster, 2003).

A number of factors have been associated with the increased risk of abuse for WWD. The increased vulnerability of WWD magnifies the risks and consequences of abuse. Many women cannot leave their residence or

caregiver without significant physical assistance. Abused WWD have reported that caregivers and partners withhold or threaten to withhold assistive devices (e.g., canes, wheelchairs) as a method of punishment and control. Abuse can take many forms (e.g., withholding personal care, medications, food, water, and money; isolating the woman from friends and family; limiting access to telephones). Women with children are especially vulnerable since they fear losing custody of their children if they leave the abusive situation or ask their partner to leave.

Shelters for abused women may not be handicapped accessible or have staff members equipped to meet the complex needs of WWD. One woman reported that she could not go to a shelter because her caregiver was male, and males were not allowed in the facility. Some common shelter rules (e.g., leaving the shelter early in the morning) are not realistic for WWD (Hassouneh-Phillips, 2005).

Perhaps, the most frequent reason WWD endure prolonged periods of abuse is their belief that they are inherently defective and are "lucky" that someone, no matter how abusive, will put up with them. Women who are totally dependent on caregivers for virtually all activities of daily living often cannot quickly or easily obtain another caregiver. Some women have endured multiple abusive caregivers and may have little hope that their situation will improve even if their current caregiver is replaced (Chang et al., 2003; Hassouneh-Phillips, 2005). Caregivers and partners often remind women repeatedly how fortunate they are to have them. Women with disabilities are more likely to use alcohol or drugs to cope with an abusive relationship or to please their partners. Fear of losing their partners and being alone may cause WWD to consent to sexual activities or endure repeated abuse, which they would not otherwise tolerate (Milberger et al., 2003; Nosek & Walter, 1998).

HCPs can use specific strategies to identify WWD who are in abusive situations. McFarlane et al. (2001) adapted a standard abuse screening tool by adding items specific to WWD, including questions about being prevented from using an assistive device or being refused care for an important personal need within the past year. These screening tools can increase the ability of HCPs to identify WWD who are being abused.

Common Health Risks in WWD

WWD are more likely than physically mobile women to experience obesity, heart disease, hypertension, type II diabetes, osteoporosis, and depression. Fatigue, lack of mobility, joint pain and other chronic pain, spasticity, and isolation are also frequently cited as problems experienced by WWD (Coyle, Santiago, Shank, Ma, & Boyd, 2000; Kinne, Patrick, & Doyle, 2004). Jones and Bell (2004) found that WWD were more likely to smoke, use alcohol to excess, and be obese than a comparison group of women without functional limitations.

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Despite these challenges, health promotion interventions can be adapted and used successfully by WWD (Coyle et al., 2000). While each woman has different limitations, most are able to improve their diet, participate in some form of exercise or conditioning activities, and stop smoking and excessive use of alcohol. A key factor in improving the overall health of WWD and decreasing the number of secondary conditions is consistent emotional and physical support given by caregivers. Nurses can help women and their caregivers understand that weight loss and increased activity can decrease fatigue, joint pain, and depression. With realistic goals that enhance motivation and persistent use of positive health behaviors, development of secondary conditions can be prevented or decreased in severity.

Health Needs of Older Adult WWD

As WWD are increasingly likely to live into older adulthood, they require the same or more intensive screening protocols as women in the general population. Despite their increased risk for osteoporosis due to limited weight-bearing activity and use of medications that decrease bone health, bone density screening rates among WWD are often low. Access to screening procedures such as mammograms may be limited by environmental, attitudinal, equipment related, and geographic barriers. Women who use wheelchairs or who are unable to stand need access to special mammography equipment that is not universally available (Mele et al., 2005). Clinical indices have not been developed for WWD, further hampering the creation of an evidence-based treatment plan (Schrager, 2004; Smeltzer & Zimmerman, 2005; Smeltzer, Zimmerman, & Capriotti, 2005). Nursing research must focus on how to best assist WWD in maintaining optimal health as they age.

Women with disabilities can be expected to experience menopausal symptoms similar to those of women without disabilities. HCPs need to question all midlife women about menopausal symptoms and treat them appropriately. Decisions regarding hormone based or other therapies need to be made on an individual basis, depending on the specific risk-benefit profile of each woman.

Recommendations for Improving the Health Care Provided to WWD

Nurses have an ethical and professional responsibility to provide optimal care for all patients, including those with disabilities. While the "invisibility" of WWD (Zitzelsberger, 2005) has been a barrier to care, growing numbers of WWD will demand high-quality, comprehensive care that meets their diverse health care needs. As discussed throughout this article, there are a number of ways that nurses can positively respond to the needs of WWD (See Table 1).

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A combination of political action, clinical research, and educational changes is needed. In looking to the future,

TABLE 1
Suggested Approaches for Addressing Barriers to Health Care Access for WWD

Barriers	*Suggested Approaches*
Environment and Transportation	• Develop Centers of Excellence where WWD could receive comprehensive primary and specialty health care in a single visit • Provide mobile clinic services for rural or homebound WWD • Promote the accessibility of emergency shelters for WWD dealing with abusive living situations • Integrate diagnostic technologies (e.g., consultations via the Internet) into the health care services for rural or homebound WWD • Obtain community outreach and grant supported transportation • Ensure adequate handicapped parking spaces, wheelchair accessible hallways, waiting rooms, examination rooms, and restrooms • Install sufficient elevators or ramps
Equipment	• Modify examination tables for ease in transfers and positioning • Use mammography equipment and scales that accommodate women in wheelchairs • Ensure that adequate numbers of experienced professionals are available to assist during examinations and testing in ways that preserve the woman's comfort and dignity
Informational	• Be proactive in offering written and verbal explanations about health issues as appropriate to each woman's situation • Provide health education at the level of the woman's and her caregiver's understanding • Educate future and current HCPs regarding the health care needs of WWD • Conduct and promote research that will improve the health outcomes of WWD
Attitudinal	• Assume that WWD have an interest in sexual expression, contraception, and childbearing and may be at risk for STIs • Provide WWD with basic health care and screening as would be provided to women without disabilities • Screen WWD routinely for sexual, physical, and emotional abuse • Examine personal and societal attitudes toward WWD focusing on each woman's abilities rather than just on her disability • Provide future HCPs with experiences interacting with and caring for WWD

Note. WWD = women with disabilities; HCP = health care providers; STI = sexually transmitted infection.

TABLE 2
Resources for WWD

Title	*Description*	*Contact Information*
Center for Research on Women with Physical Disabilities	Provides access to multiple research studies on topics of interest to WWD, their caregivers, and HCPs	Baylor College of Medicine, Margaret A. Nosek, PhD, executive director, 1709 Dryden Road, Suite 725, Houston, TX 77030, (713) 798-5782 or (800) 44-CROWD, http://www.bcm.tmc.edu/crowd/
Health Promotion for Women with Disabilities	Provides information about health promotion to WWD. There are multiple links to other organizations of interest to WWD	Villanova University College of Nursing, Suzanne Smeltzer, RN, EdD, FAAN, 800 Lancaster Avenue, Villanova, PA 19085, (610) 519-6828, http://nurseweb.villanova.edu/womenwithdisabilities
Health Resource Center for Women with Disabilities at the Rehabilitation Institute of Chicago	Multiple links to sites of interest, research, and health care for WWD	Rehabilitation Institute of Chicago, Judy Panko Reis, administrator director, 345 East Superior Street, Chicago, IL 60611, (312) 238-1051, http://www.ric.org/community/womendc.php
Initiative for Women with Disabilities	Multidisciplinary center committed to providing respectful, high quality gynecologic, medical, and wellness services for women with physical disabilities	New York University (NYU) Hospital for Joint Diseases, Mount Sinai NYU Health, 301 East 17th Street, Suite 551, New York, NY 10003, (212) 598-2000, http://www.med.nyu.edu/hjd/iwd
National Center on Physical Activity and Disability	Comprehensive resource on how to maintain activity despite a disability. A wide variety of disabilities are addressed	University of Illinois at Chicago, Department of Disability and Human Development, College of Applied Health Sciences, (800) 900-8086, http://www.NCPAD.org
North Carolina Office on Disability and Health	Health service designed to promote health and wellness of persons with disabilities in North Carolina. Several publications can be accessed from this site including: Smeltzer and Sharts-Hopko (2005). *A provider's guide for the care of women with physical disabilities and chronic health conditions*	Division of Public Health, 1928 Mail Service Center, Raleigh, NC 27699-1928, Anna Johnston, program director, (919) 707-5672, http://www.fpg.unc.edu/~ncodh
National Women's Health Information Center Office on Women's Health	Excellent resource covering many topics related to the needs and concerns of WWD. Links to other relevant sites are provided	U.S. Department of Health and Human Services, 200 Independence Avenue SW, Room 730B, Washington, DC 20201, (202) 690-7650 or (800) 994-9662, http://www.4women.gov

Note. WWD = women with disabilities; HCP = health care providers.

nurse educators can set the stage for improved care for WWD. Students entering the health care professions need to interact with and care for persons with disabilities as part of their clinical education. There is some evidence that HCPs who have these types of clinical experiences as students demonstrate greater empathy and feel more comfortable when caring for persons with various disabilities (Bassett & Pickard, 2005; Wilson & Merrill, 2002).

Local, state, and national listings of resources designed to provide care to WWD should be developed and widely available to WWD, caregivers, and HCPs. Nurses and WWD can locate resources for WWD via the Internet (See Table 2). Unfortunately, WWD who do not have Internet access may lack this tool to identify facilities, and HCPs with the expertise to provide sensitive comprehensive primary and specialty care.

Women with disabilities deserve comprehensive, compassionate, evidence-based health care. A growing number of clinicians and researchers are dedicated to bringing holistic health care to this population of underserved women. Nurses can further develop a leadership role in research and program development to improve care of WWD. Nurses can break down many of the barriers to care and provide WWD with the care, support, and education needed to lead full and satisfying lives.

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Karen Piotrowski, MSN, RNC, is an associate professor in the Department of Nursing, at D'Youville College in Buffalo, NY.

Linda Snell, DNS, WHNP-C, is chairperson and an associate professor in the Department of Nursing at the State University of New York at Brockport.

Address for correspondence: Karen Piotrowski, MSN, RNC, D'Youville College, 320 Porter Avenue, Buffalo, NY 14201. E-mail: KarenP3216@aol.com.