

# A PROVIDER'S GUIDE FOR THE CARE OF WOMEN WITH PHYSICAL DISABILITIES AND CHRONIC HEALTH CONDITIONS



DEVELOPED BY THE  
NORTH CAROLINA  
OFFICE ON DISABILITY  
AND HEALTH

IN COLLABORATION WITH  
VILLANOVA UNIVERSITY  
COLLEGE OF NURSING

SUZANNE C. SMELTZER,  
RN, EDD, FAAN

NANCY C. SHARTS-HOPKO,  
RN, PHD, FAAN

## **A PROVIDER'S GUIDE FOR THE CARE OF WOMEN WITH PHYSICAL DISABILITIES AND CHRONIC HEALTH CONDITIONS**

### **Authors**

Suzanne C. Smeltzer, RN, EdD, FAAN  
Professor & Director, Nursing Research  
Director, Health Promotion for Women with Disabilities Project  
Villanova University College of Nursing  
800 Lancaster Avenue  
Villanova, PA 19085  
Phone: 610-519-6828  
Fax: 610-519-7650  
E-mail: [suzanne.smeltzer@villanova.edu](mailto:suzanne.smeltzer@villanova.edu)

Nancy C. Sharts-Hopko, RN, PhD, FAAN  
Professor & Director, Doctoral Program  
Villanova University College of Nursing  
800 Lancaster Avenue  
Villanova, PA 19085  
Phone: 610-519-4906  
Fax: 610-519-7650  
E-mail: [nancy.sharts-hopko@villanova.edu](mailto:nancy.sharts-hopko@villanova.edu)

Developed by the North Carolina Office on Disability and Health, a partnership between the North Carolina Division of Public Health of the Department of Health and Human Services and the FPG Child Development Institute at the University of North Carolina at Chapel Hill in collaboration with Villanova University College of Nursing.

**2005**

The information provided in this material was supported by Grant/Cooperative Agreement Number U59/CCU419404 from the Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities. The contents are solely the responsibility of the authors and do not necessarily represent the official views of CDC.

# DEDICATION

---

This revision of *A Provider's Guide for the Care of Women with Physical Disabilities and Chronic Health Conditions* is dedicated to Sandra L. Welner M.D. for her tireless efforts to improve the health care of women with disabilities. Dr. Welner's genteel advocacy explored and explained unique problems facing women with disabilities from contraception, infections, bleeding and/or estrogen replacement to those seeking enjoyable sexuality, those suffering sexually transmitted diseases, or cervical / breast malignancy. She was a master of idealistic problem solving, with an incredible eye for detail. Welner contributed to women's health on a much broader scale through her committee work with various agencies, from the US Department of Health and Human Services and the Centers for Disease Control, to states' health departments and health care institutions such as the American College of Obstetrics and Gynecology. These organizations' policies for caring for those with disabilities were shaped directly by Dr. Welner. She lectured all over the world at university grand rounds and conferences, and invited special sessions at venues as notable as the United Nations. Recognizing that women with disabilities may skip important medical follow-up because mobility problems can make doctors' appointments an ordeal, Dr. Welner designed the first universally accessible examination table for women with disabilities. The Welner Table is found in facilities around the world. It reflects the necessary sensitivity to accessible care at the level of the examination room beyond mere ramps and wide elevators. Her legacy endures in the medical centers she inspired and in the patients she cared for. (Welner Enabled; [http: www.welnerenabled.com/legacy.html](http://www.welnerenabled.com/legacy.html))

This guide is also dedicated to women with disabilities who have taught us in numerous ways the importance of recognition, sensitivity, and dignity in all their health care encounters.

# ACKNOWLEDGEMENTS

---

The authors of this guide would like to acknowledge the reviewers who provided excellent comments and feedback to us. Their feedback enabled us to make the content contained in the Provider's Guide relevant to clinicians and to the health care needs of women with disabilities.

Alicia Conill, MD  
CEO and Medical Director  
Conill Institute for Chronic Illness  
Clinical Associate Professor of Medicine  
University of Pennsylvania

Pam Dickens, MPH  
Women's Health Coordinator  
NC Office on Disability and Health  
University of North Carolina at Chapel Hill

Cathy Kluttz-Hile, BSN, CDDN, MA  
Specialized Services Unit Manager  
Division of Public Health  
NC Department of Health and Human Services

Sefi Knoble, MD  
Medical Director  
Inglis House/Inglis Innovative Services  
Clinical Assistant Professor of Medicine  
Drexel School of Medicine

Karen Luken, MS, CTRS  
Project Director  
NC Office on Disability and Health  
University of North Carolina at Chapel Hill

Lori L. Rowlett, PhD  
Associate Professor of Religious Studies  
University of Wisconsin at Eau Claire

# C ONTENTS

---

1	INTRODUCTION
2	BARRIERS TO ACCESS
3	HEALTH PROMOTION AND WELLNESS
	• Screening Tests and Immunizations Guidelines
	• Immunizations
6	PELVIC EXAMINATION
8	CANCER SCREENING
10	SEXUALITY
11	MENSTRUAL SELF CARE
12	CONTRACEPTION
14	PREGNANCY
	• Preconception Care
	• Prenatal Care
	• Labor and Delivery
	• Breastfeeding
	• Unique Considerations
18	INFERTILITY
19	INFECTION
	• Urinary Tract Infections
	• Vaginitis
	• Sexually Transmitted Diseases
	• Pressure Ulcers
22	MENOPAUSE
24	BLADDER AND BOWEL DYSFUNCTION
25	OSTEOPOROSIS
26	VIOLENCE AND ABUSE
29	PSYCHOLOGICAL / MENTAL HEALTH ISSUES
30	AGING WITH A DISABILITY
31	CONCLUSION
32	REFERENCES
39	APPENDICES
	• A: Organizations
	• B: Interacting with Persons with Disabilities
	• C: Ten Behaviors to Good Health
	• D: CDC Adult Immunization Guidelines

# INTRODUCTION

---

Over 30 million women, or more than 20% of women, in the United States have a disability. These disabilities range from relatively mild limitations requiring little or no need for assistive aides or devices to significant disabilities necessitating substantial care and advanced technology to enable mobility, self-care and breathing. Disabilities may be physical, sensory, developmental, intellectual, or psychiatric in nature or a combination of these. While there are many definitions of disability, there is general agreement that disability is a limitation in a major activity, caused by a chronic health condition (Jans & Stoddard, 1999). Despite even significant disabilities, most women who have a disability are expected to have a normal or near-normal life span (Vandenakker & Glass, 2001). Thus, health care, including preventive health screening, is essential to enable them to live with the highest quality of life within the limitations related to their disability or chronic health condition. Women with disabilities have the same needs for health care and preventive health screening as all women.

This guide is designed for clinicians to improve their knowledge and practice in providing care to women with physical disabilities and chronic health conditions. The guide reviews strategies for management as well as specialized approaches. While the first sections focus on access to general medical care and removing common barriers, other sections cover the pelvic exam, cancer screening, contraception, pregnancy, menopause, aging, health promotion, as well as other critical components of comprehensive reproductive health care. Viewing the woman with a disability as a woman first, who happens to have physical differences, will give us a better understanding of how her disability affects her health and how her health affects her disability. Recognizing that she is the person most knowledgeable about her own disability will foster effective provider-patient relationships and more active participation in self-care and health promotion.

Although the American with Disabilities Act (ADA) of 1990 was enacted more than 15 years ago to assure equal access to persons with disabilities, women with disabilities continue to encounter and report multiple barriers to health care services and providers (Nosek, 2004). These barriers can be environmental (absence of ramps, inaccessible health care facilities), informational (lack of alternate formats, high reading level), communication (lack of TTY, video relay services, sign language interpreters), or attitudinal (negative perceptions and stereotyping of persons with disabilities). Other barriers to health care and preventive screening encountered by women with disabilities include transportation difficulties, inability to pay because of limited income, difficulty finding a health care provider knowledgeable about care for people with their particular disability, previous negative experiences, reliance on caretakers, and the demands of coping with the disability itself (Nosek et al., 1997). Lack of emotional support from significant others and lack of attention to general health among women living in institutions (Better Health Channel, 2004) are also significant concerns.

Women with disabilities do not differ from other women in their need for pelvic examinations and other health screenings. The National Study of Women with Physical Disabilities (Nosek et al., 1997) revealed that women with disabilities are significantly less likely to receive pelvic exams at least every two years than women who do not have disabilities. In addition, the more severe their physical disabilities, the less likely women were to have regular pelvic exams. Minority women with disabilities were also less likely to have regular pelvic exams. The most frequent reasons women gave for not having regular pelvic exams included difficulty getting onto the exam table, being too busy, and inability to find a physician who suited them. Additional reasons included the belief that they did not need pelvic exams because of their disability, inability to find a health care provider knowledgeable about their disability, difficulty in accessing the office or clinic, and finding transportation. These findings have been corroborated in other studies (Coyle et al., 2002; Odette et al., 2003; Schopp et al., 2002; Veltman et al., 2001). Iezzoni and associates (2001) have observed that while women with disabilities, in general, receive screening and preventive services at rates comparable to all women, those with mobility limitations had much lower rates of having gynecological exams. Data from the Centers for Disease Control and Prevention (CDC) have also indicated that women 65 years of age and older with functional limitations are significantly less likely to have Pap tests and mammograms than younger women (Thierry, 2000).

Because of the persistence of barriers to accessing services, it is essential that health care providers take steps to ensure that their offices and other health care facilities used by those with disabilities are accessible. Ensuring access includes removal of structural barriers by the addition of ramps, designation of accessible parking spaces, and modification of restrooms to make them usable by women with disabilities. Alternate communication methods (e.g., sign language interpreters, TTY text telephones, assistive listening devices) and alternate formats of patient education (e.g., audiotapes, large print, Braille) are essential to provide appropriate health-related information to women with disabilities. These reasonable accommodations fall within the guidelines of the Americans with Disabilities Act (ADA), which requires their provision without cost to the patient.

In addition, health care providers may underestimate the effect of a woman's physical disability on her ability to access health care, including health screening and health promotion. Further, health care providers may focus on the woman's disability while ignoring her general health issues and concerns (Nosek et al., 1997).

General health screening recommendations for all women apply to women with disabilities. Although physical limitations resulting from a disability and barriers in health care facilities may make it difficult for some women to obtain health care and preventive health screenings, the presence of a disability should not be used as a reason to defer or neglect recommended screening. Rather, the presence of a disability may increase the need for screening and follow up. Various federal and state agencies have established general health promotion guidelines, and these guidelines may vary slightly. One federal agency, the National Women's Health Information Center (2004), has developed recommendations for health screening for all women (Table 1); these include specific issues that pertain to all women, including women with disabilities. However, based on a woman's health and her disability, some screenings may be recommended sooner, more often, or not at all. Each woman should be considered individually.

TABLE 1

Screening Tests	Ages 18-39	Ages 40-49	Ages 50-64	Ages 65+
General Health: full checkup including weight and height	Discuss with health care provider	Discuss with health care provider	Discuss with health care provider	Discuss with health care provider
Thyroid test	Start at age 35, then every 5 years	Every 5 years	Every 5 years	Every 5 years
Heart Health: Blood pressure test	Start at age 21, then once every 1-2 years if normal.	Every 1-2 years	Every 1-2 years	Every 1-2 years
Cholesterol test	Discuss with health care provider.	Start at age 45, then every 5 years	Every 5 years	Every 5 years
Bone Health: Bone mineral density test		Discuss with health care provider.	Discuss with health care provider.	Get a bone density test at least once. Talk to health care provider about repeat testing.
Diabetes: Blood sugar test	Discuss with health care provider.	Start at age 45, then every 3 years.	Every 3 years	Every 3 years
Oral Health: Dental exam	One to two times every year	One to two times every year	One to two times every year	One to two times every year
Reproductive Health: Pap test and pelvic exam	Every 1-3 years if woman is sexually active or is older than 21	Every 1-3 years	Every 1-3 years	Discuss with health care provider
Chlamydia test	If sexually active, yearly until age 25	If woman is at high risk for chlamydia or other STDs may need this test.	If woman is at high risk for chlamydia or other STDs, may need this test.	If woman is at high risk for chlamydia or other STDs, may need this test.



TABLE 1 CONTINUED

Screening Tests	Ages 18-39	Ages 40-49	Ages 50-64	Ages 65+
Sexually Transmitted Disease (STD) tests	Talk to health care provider if woman or partner has had sexual contact with another person or persons or if either has had a STD.	Talk to health care provider if woman or partner has had sexual contact with another person or persons or if either has had a STD.	Talk to health care provider if woman or partner has had sexual contact with another person or persons or if either has had a STD.	Talk to health care provider if woman or partner has had sexual contact with another person or persons or if either has had a STD.
Breast Health: Mammogram (and annual clinical breast exam)		Every 1-2 years. Discuss with health care provider.	Every 1-2 years. Discuss with health care provider.	Every 1-2 years. Discuss with health care provider.
Colorectal Health: Fecal occult blood test			Yearly	Yearly
Flexible sigmoidoscopy (with fecal occult blood test) is preferred			Every 5 years	Every 5 years
Double contrast barium enema (DCBE)			Every 5-10 years (if not having colonoscopy or sigmoidoscopy)	Every 5-10 years (if not having colonoscopy or sigmoidoscopy)
Colonoscopy			Every 10 years or sooner if abnormalities warrant more frequent monitoring.	Every 10 years or sooner if abnormalities warrant more frequent monitoring.
Rectal exam	Discuss with health care provider.	Discuss with health care provider.	Every 5-10 years along with screening (sigmoidoscopy, colonoscopy, or DCBE)	Every 5-10 years along with screening (sigmoidoscopy, colonoscopy, or DCBE)
Eye and Ear Health: Vision exam with eye care provider	Once initially between age 20 and 39	Every 2-4 years	Every 2-4 years	Every 1-2 years
Hearing test	Starting at age 18, then every 10 years	Every 10 years	Discuss with health care provider.	Discuss with health care provider.
Skin Health: Mole exam	Monthly mole self-exam; by a health care provider every 3 years, starting at age 20.	Monthly mole self-exam; by a health care provider every year.	Monthly mole self-exam; by a health care provider every year.	Monthly mole self-exam; by a health care provider every year.
Mental Health Screening	Discuss with health care provider.	Discuss with health care provider.	Yearly	Yearly

Recommendations for immunizations for women with disabilities are typically the same as those for all women. CDC/ACIP recommendations are provided in Table 2 (See Appendix D). Despite these recommendations, questions have been raised about the safety of immunization in immune-mediated conditions. The available evidence suggests that immunizations do not cause immune-mediated disorders, such as MS, or exacerbations or relapses. Further, immunizations, such as influenza vaccine, may decrease the likelihood of serious consequences of influenza. People with chronic health problems and disabilities and the elderly are more likely to experience complications associated with influenza than others. Therefore, the CDC (2004) has recommended that all people who are 50 years of age or older, all persons with medical problems, persons with immunosuppression (including medication-induced) and all persons with any condition that compromises respiratory function or the handling of secretions be immunized against influenza.

Evidence-based recommendations developed for persons with MS (Multiple Sclerosis Council for Clinical Practice Guidelines, 2001) can serve as a guide for those with other chronic illnesses and disabling conditions. While these recommendations advise that immunizations be administered when patients are not experiencing a relapse of MS, the rationale is that vaccination may result in fever, which could worsen the symptoms of relapse. Further, if relapse is treated with corticosteroids, their administration might decrease the vaccine's effectiveness. To avoid these problems, it is recommended that immunizations be postponed and not administered during febrile episodes associated with infections or for 4 weeks after completion of a regimen of corticosteroids.

For individuals with disabilities who are living in congregate housing (e.g., nursing homes, group homes), influenza, hepatitis B and pneumococcal vaccines are recommended. Although data are limited, there is no conclusive evidence that these immunizations are unsafe for persons with immune-mediated disorders, such as MS. One recent case-control study has suggested that immunization with recombinant hepatitis B vaccine is associated with an increased risk of MS (Hernán, Jick, Olek & Jick, 2004). However 93% of persons with MS in this study had not received hepatitis B vaccine, and other studies have not supported this finding. The researchers were not able to establish a causal relationship.

The United States Preventive Services Task Force recommends that all women ages 18 to 65 years should have a gynecological exam every one to three years (AHRQ, 2003). If currently sexually active, they should be screened before age 18 and beyond age 65.

An appropriate examination table is essential to the safe care of women with disabilities. Ideally, the table can be raised and lowered. Additional personnel may be needed to assist the woman to transfer onto the table and to stabilize her lower extremities during the examination. Assistance by clinic or office personnel is a reasonable accommodation under the Americans with Disabilities Act (ADA). Assistance by clinic staff or office personnel is a recommended way to make the exam accessible to all women. Expecting women to bring their own assistants to scheduled visits is not in compliance with the Americans with Disabilities Act.

It is important to ask the woman with a disability what would make the exam easier and more comfortable for her. Ask her if she needs help and if so, how others can assist her. With some disabilities (e.g., stroke, spina bifida, multiple sclerosis, cerebral palsy, some orthopedic injuries), spasticity may result in pain and limit range of motion of the legs. Rapid positioning can increase spasticity and pain. Spasticity can be managed by gentle stretching of the legs during positioning, as well as application of 2% lidocaine to the perineum to eliminate discomfort that can exacerbate the spasticity. Adverse responses to lidocaine could include allergic or sensitivity responses and skin rashes. (MedlinePlus 2001). Using padded, soft, adjustable boot-type stirrups can make positioning more comfortable and easier. Other women may need to be examined on a regular examining table or bed, positioning their legs in the diamond-shaped position. Another alternative position for women for whom abduction is difficult or impossible is side-lying. One nurse practitioner has described performing pelvic examinations on women in the seated position, by crouching beneath them.

Autonomic dysreflexia is a potential complication of pelvic examination among women with a spinal cord injury above the T-6 level. It is the reaction of the autonomic nervous system to manipulation of visceral organs such as the cervix, uterus, bladder and rectum. Autonomic dysreflexia has a rapid onset and can result in seizures, intracranial hemorrhage, coma and death; therefore a physiatrist or anesthesiologist should be present during the examination. Ask the woman if she has a history of autonomic dysreflexia associated with urinary tract infection, a full bladder, menstrual abnormalities, sexually transmitted diseases, decubiti, appendicitis, ovarian cysts, ectopic pregnancy or constipation. Signs and symptoms of autonomic dysreflexia include headache, sweating and piloerection above the level of the lesion, nasal stuffiness, facial flushing, papillary dilatation, rapid heart rate, arrhythmias, and labile hypertension among other findings.

Another population with a known need for special consideration is women with spina bifida (SB). Up to 73% of individuals with SB are sensitive to latex. Consider all patients with SB to be at high risk for an allergic reaction to latex. The reaction can range from watery or itchy eyes, sneezing and coughing to hives, laryngeal edema, and anaphylactic shock. Patients with SB should avoid exposure to latex gloves, catheters, condoms, balloons, or any product that contains, or is contaminated with, latex. Office management staff should be alerted to this when making appointments, and providers should make provisions for a latex-free environment when examining women with spina bifida.

**Breast and cervical cancer.** Breast cancer is one of the obesity-linked cancers. Because women with mobility limitations have difficulty maintaining normal weight, this can place them at increased risk. Shootman and Jeffe (2003) have observed that long-term limitations in activities of daily living are associated with reduced likelihood of being screened for breast cancer among women from age 40 to older than 70. They may have difficulty getting to the office or clinic, undressing for the exam, using a traditional examination table, standing or positioning for their mammograms or positioning for a clinical breast exam.

Women with disabilities should have clinical breast examinations and mammography on the same schedule recommended for all women their age. Both the National Women's Health Information Center (2004) and the Agency for Health Care Research and Quality (2002) recommend a mammogram every one to two years for women age 40 and older. Women at particular risk for breast cancer may be advised to be screened earlier. Factors to consider are a woman's personal or family history of breast or gynecologic malignancy. Women who cannot be positioned for a mammogram may be assessed using ultrasound, but they may need more frequent clinical breast examinations. Both the American Cancer Society (2004) and the Agency for Health Care Research and Quality (2002) have stopped recommending breast self examination because no evidence supports its effectiveness in promoting improved patient outcomes.

When women with disabilities are treated for breast cancer, they are less likely than other women to be offered breast conservation surgery at comparable stages of cancer (Caban et al., 2002). This suggests bias on the part of health care providers that body image is less important for women with disabilities. While women who have had repeated x-ray exposure in relation to managing their disability may be concerned about further exposure from mammograms or other health screening, the National Cancer Institute (2002) maintains that the benefits of health screening outweigh the risks. Still, health care providers should take steps to minimize exposure when possible.

Women with disabilities are as likely as women in the general population to have cervical cancer, but health care providers, believing that they are less sexually active, may inappropriately minimize their risk for cervical cancer and their need for recommended screening. Some sexually transmitted diseases, including human papilloma virus (HPV), herpes simplex virus (HSV), human immunodeficiency virus (HIV) and chlamydia, have been associated with increased risk for cervical cancer (Hatcher, 2004). Women with viral STDs, particularly HPV and HIV, may warrant cervical cancer screening more frequently than once per year. Treatment with immunosuppressive drugs can be associated with increased risk for cervical dysplasia.

**Endometrial cancer.** Endometrial cancer is another one of the obesity-linked cancers (Schottenfeld & Beebe-Dimmer, 2004). While there is no evidence that women with disabilities are at increased risk for endometrial cancer, they are more inclined than the general population to be overweight or obese (Sharts-Hopko & Sullivan, 2003; Weil et al., 2002). Some chronic health conditions or disabilities are specifically associated with dysfunctional uterine bleeding and oligo-ovulation, including multiple sclerosis

(MS), myasthenia gravis (MG) and Sjögren's syndrome. Thus, such women may be at increased risk for developing endometrial cancer. Irregular vaginal bleeding needs to be evaluated promptly.

**Ovarian cancer.** Women with disabilities are not at increased risk for ovarian cancer per se, but they are more likely to have predisposing characteristics including nulliparity and less frequent use of oral contraception. Ovarian cancer can be a silent disease until late in its progression. Annual pelvic examinations are important for identification of an adnexal mass as early as possible (Johns Hopkins Pathology, 2004).

**Colon cancer.** Colon cancer is the fourth most common cause of cancer in women (American Cancer Society [ACS], 2004). There is no evidence that this differs in women with disabilities. Recommendations for colon cancer screening are described in Table 1. While cancer screening techniques range from fecal occult blood testing (FOBT) to colonoscopy, women with disabilities report undergoing such screening infrequently (Smeltzer & Zimmerman, unpublished data). Fecal occult blood testing should be carried out yearly from age 50 on (National Women's Health Information Center, 2004); however, women with mobility limitations may have difficulty with the procedure. Therefore, testing of stool for blood during a rectal exam should be part of every gynecologic exam. Because many women with disabilities are less likely than women without disabilities to have gynecologic exams and FOBT on a yearly basis, colonoscopy is recommended. See recommendations in Table 1.

**Skin cancer.** The National Women's Health Information Center (2004) recommends that women conduct monthly self-assessment of their skin with assessment by a health professional every three years from 20 to 40 years of age, and annually beginning at age 40. Because of physical limitations, many women with disabilities are unable to perform a self-assessment of their skin without assistance. Thus, an assessment should be performed whenever women have physical examinations and referral made to a dermatologist for any suspicious skin lesions. Because women with disabilities and other health issues are not likely to see this as a priority, extra emphasis should be given in discussion of the importance of assessment for skin cancer.

Women with disabilities have reported that their health care providers often assume that they are asexual, sexually inactive, or uninterested in issues related to sexual function, reproduction and childbearing. As a result, they are often not asked about sexuality, sexual function and dysfunction, menstrual changes, contraception, sexual practices, pregnancy and menopause.

Women with disabilities are sexual beings and like all women, they should be asked about sexual function / dysfunction and sexual practices by their primary health care provider. Women with disabilities that have been present from birth or from early childhood have reported that they have often been excluded from health education classes in school in which sexuality and reproductive issues were discussed. Further, they report that it is often assumed that no one would want to have a sexual relationship with someone who has a disability. Thus, they may have many basic, but unanswered, questions about sexual function and unmet needs related to sexuality. Health care providers need to provide women with disabilities the opportunity to discuss issues of interest and importance to them. They should be encouraged to ask questions about sexuality, the effects their disability has on sexual function, and strategies to address changes in sexual function that may occur with the specific disability (Sipski & Alexander, 1997).

Instead of the spontaneity usually associated with sexual relationships, women with disabilities may have to plan ahead to make sure that they are well rested, alter their bowel and bladder management, modify their medication schedule to minimize spasticity and arrange to have a personal assistant nearby. These issues and those associated with sexual function related to specific types of disabilities should be discussed sensitively in a private setting, without negative or biased responses on the part of the health care provider.

Often simple solutions can be suggested to women with disabilities who experience vaginal dryness secondary to their disability or medications used in its management. Written and pictorial materials illustrating modifications in positions for sexual intercourse can be helpful to some women with disabilities and their partners. At times, referral to a sexual counselor may be appropriate. Even if the health care provider has the misconception that sexual relationships are impossible or that no remedy to sexual challenges exists when a disability is present (Sipski & Alexander, 1997), the issues of sexuality should not be overlooked.

Questions related to possible sexual exploitation are an important part of the assessment of sexuality in women with disabilities, particularly those with intellectual or developmental disabilities, as studies have shown that these women have a higher incidence of sexual assault (Disabled Women's Network Ontario, 2002).

Management of menstrual flow can be a significant challenge for many women with physical limitations. Among women who catheterize for bladder management, sterile technique during menses is nearly impossible, particularly in settings outside the home. Tampon use requires manual dexterity and balance. Some women who are away from their homes during the day have reported using multiple tampons and pads together so they can get through their work days without having to change them; however, toxic shock is a potential risk associated with this practice. For reasons such as these, over the past several decades women with disabilities have elected to undergo hysterectomy at a greater rate than the general population, and at younger ages (Nosek et al., 1997). Reports from the Center for Research on Women with Disabilities note that rehabilitation centers do not prepare women with disabilities to manage menstruation.

In recent years women have been provided the options of continuous or three-month continuous oral contraception to decrease the hassle of menstrual hygiene. The Food and Drug Administration has approved menstrual suppression particularly among women with specific health-related needs (Andrist et al., 2004). Health care providers need to discuss with women who have limited mobility the benefits of hormonal reduction of menstruation frequency versus the risk of a slightly increased risk of deep vein thrombosis (DVT) or stroke. Hypercoagulability assays can be obtained to investigate a woman's risk for DVT particularly if there is a history of transient ischemic attacks or DVT.

Some neurological conditions are associated with irregular menses. Women with MS and other neurological diseases may experience an increase in disease-related symptoms during the premenstrual or menstrual phases (Sandyk, 1995; Weppner & Brownscheidle, 1998).

If it is suspected that a woman has menorrhagia, periodic hematocrits will be valuable in diagnosing anemia. Irregularity or excess bleeding can be managed with progesterone or Provera regimens, or with use of nonsteroidal anti-inflammatory agents in the absence of contraindications. Oral contraceptives may be considered for regulation of menstruation. Pre- or peri-menopausal women who become anemic can take iron supplements or daily multivitamins with iron. Women with dysfunctional uterine bleeding should be evaluated for pregnancy or cervical or endometrial abnormalities including polyps, fibroids and cancer (Welner et al., 2002).



Contraception is a topic that is often neglected by health care providers working with women with disabilities (Society of Obstetricians and Gynecologists of Canada, 2004). Health care professionals often assume that disability (limitations of mobility, sensory loss, reduced dexterity, intellectual disability, or altered sensation) precludes sexuality. Moreover, barriers to accessing health information and care create a potential disadvantage for women with disabilities in obtaining contraception. Nosek and associates (1998) found in a national survey that women with disabilities were more likely to use permanent contraception or no contraception at all than the general population of women.

Many women with disabilities are able and would like to have children and may prefer temporary contraception. Others may decide that they will not bear children, so permanent or long-acting contraceptive methods may be appropriate for them. Permanent modes of contraception include hysterectomy or tubal ligation/obstruction. When women with disabilities consider their contraceptive options, factors that need to be addressed include the quality of circulation in the lower extremities, clotting abnormalities associated with their condition, degree of physical sensation, manual dexterity, the stability of their condition, the interaction of various contraceptives with their disabling condition or their medications, presence of depression, and any problem the woman has with menstrual hygiene (Family Health International, 1999). In addition, women with disabilities have reported that while the weight gain that is associated with hormonal contraception may be a minor issue for most women, for women with mobility limitations this can be a significant disadvantage (Weil et al., 2002). All women need to be managed individually.

Women with disabilities who smoke should be informed about health risks associated with tobacco use including those associated with oral contraceptives if they continue to smoke, particularly deep vein thrombosis (DVT). Efforts to stop smoking should be encouraged and reinforced.

As noted above in the discussion of menstrual suppression, if a woman is considering hormonal contraception, risk of DVT needs to be assessed by history (for immobility, or history of DVT or transient ischemic attack [TIA]) and hypercoagulability assay before estrogen-based products are used. Transdermal contraceptive patches may be an option for women for whom oral contraceptives are contraindicated. Injectable depot-medroxyprogesterone acetate (DMPA) or the progestin-only pill could be considered. Diminished effectiveness of the progestin-only pill may mandate simultaneous use of barrier contraception (Hatcher, 2005). DMPA offers the advantage of reducing menstrual flow, even causing amenorrhea, which can be a benefit for women for whom menstrual hygiene is difficult. DMPA may help stabilize seizure activity among women with seizure disorders. However, it does contribute to bone loss, which is a particular concern with women with mobility limitations. Norplant is another progestin-only option, though the issue of irregular break-through bleeding may be particularly stressful for women for whom menstrual hygiene is a challenge.

Anticonvulsant medications may reduce the efficacy of hormonal contraceptives (International Planned Parenthood Federation, 1999). It remains unresolved whether hormonal contraceptives exacerbate MS (Family Health International 1999); it appears that they confer some protection against rheumatoid arthritis. Contraceptives with high doses of synthetic estrogens have been associated with exacerbation of lupus symptoms; progesterone-only products, barrier contraception or intrauterine devices (IUDs) are alternatives for women with lupus (Society of Obstetricians & Gynecologists of Canada, 2004).

Intrauterine devices (IUDs) may increase menstrual flow. In addition, women who have diminished pelvic sensation may be unable to detect IUD-associated pelvic inflammatory disease (PID) or ectopic pregnancy should they occur. Spasticity of the lower extremities can increase the difficulty of insertion of an IUD. Women or their partners must be able to assess the presence of the IUD string weekly. Women with cardiac valvular disease need to be aware that IUD insertion is associated with transient, minimal bacteremia (Welner, 1999).

Barrier contraception requires intact balance, physical dexterity and hand coordination or the willingness of the woman's sexual partner to assume responsibility for its use. Women at risk for latex allergies need to be cautioned to select products accordingly.

While women with disabilities are less likely to become pregnant and bear children than women in general (Nosek et al., 1997), many women with disabilities and chronic health or conditions share the same desire to bear and parent children as other women. Specific pregnancy-related concerns vary by type of disability, and specific recommendations for women with disability may be obtained from advocacy groups particular to their condition. (See Appendix A.) Health care providers' nonjudgmental acceptance of a woman's choice is an essential component to quality health care. Some health care providers may assume that risks of poor outcomes among women with disabilities are greater than they actually are. Ideally, when informing a woman that she is pregnant, the health care provider can ask the woman whether or not the pregnancy is intended or desired. If it is not, then discussing implications of a positive pregnancy test outcome will be a priority. Women with disabilities have frequently been discouraged from becoming pregnant or continuing a pregnancy, or turned away by health care providers who lack experience in managing pregnancy among women with their specific disability. These are discouraging and frightening messages at a time when all women need knowledgeable support and assistance. Some women receive care that does not meet standards of practice. For example, Nosek and her colleagues (1997) have reported that while most women are weighed frequently during pregnancy to ensure appropriate growth of their babies and monitor for pregnancy-induced hypertension, women who are not able to stand may never be weighed throughout their pregnancies due to lack of accessible scales.

Women with disabilities and their babies occasionally will need the resources of a collaborative team approach that might include disability specialists. Their expertise and anticipatory guidance can ensure that the woman is properly supported through her pregnancy and postpartum, that contingencies are planned for and addressed, and that the woman's feelings of comfort and security are enhanced. In turn, this will optimize her self-confidence to begin parenting.

Some of the ways that pregnancy may affect women with disabilities include decreased mobility, fluid retention, bladder dysfunction, and increased incidence of vaginal and urinary tract infections. Pregnancy causes a shift in the center of gravity, and women may be at increased risk for loss of balance and falling. Women with disabilities that affect gait may find that they require greater use of assistive devices such as canes or walkers, or of a wheelchair some or all of the time during the last trimester of pregnancy because of increased fatigue and a change in their center of gravity. They may be more likely to fall if they experience changes in balance or gait. In addition, potential new pressure points may develop as the woman's body changes. Common symptoms of pregnancy may be more severe than among women without disabilities; in addition, pregnancy may alter the course of the disability, temporarily or even permanently. Because of the potential impact of having a disability on pregnancy, women with physical disabilities and chronic health conditions require care from the preconception period throughout pregnancy and the postpartum period.

### **Preconception Care**

Preconception care is recommended for couples considering pregnancy. For women with disabilities and chronic health conditions, the support of a partner and/or other family members or friends is a priority in ensuring positive outcomes for the woman and her child. Preconception care and counseling, ideally involving both the physician and the woman herself, as well as the obstetrician, nurse midwife or nurse practitioner, focuses on assessing the woman's health status prior to pregnancy and anticipating particular risks that she and her baby may encounter. The provider who manages health care for the woman with a disability may be able to recommend an obstetrician or other health care provider who has experience working with women with a particular type of disability. Ideally, all women have one or more obstetrical-gynecological visits in the months before conception.

Of particular importance is the woman's nutritional status. All women of child-bearing age should consume 400 micrograms of folic acid daily to prevent neural tube defects (CDC, 2003). Women who have already had a pregnancy affected by neural tube defect as well as women who have spina bifida may discuss with their health care provider the option of increasing their intake of folic acid to 4 milligrams (4000 micrograms) for one month prior to attempting pregnancy and during the first three months of pregnancy (March of Dimes, 2001). All women's risks associated with childbearing and neonatal outcomes are lower when they are within their normal weight range at the time of conception. The woman's drug regimen should be reviewed for safety during pregnancy; some medications may be discontinued at least during the first trimester and in other cases, substitutions may be made. Preconception care can also entail genetic testing and counseling for both partners, when indicated.

### **Prenatal Care**

All pregnant women require prenatal care. The general population of women at low risk should have monthly visits during the first two trimesters, visits every two weeks during the seventh and eighth month, and weekly visits beginning in the ninth month until delivery. Women with a disability may require more frequent visits throughout their pregnancy.

Prenatal visits involve monitoring the health status of the woman and her fetus, including intrauterine growth; monitoring and managing symptoms related to pregnancy or to the woman's disability; assessing the woman and her partner's ability to adapt to changes associated with pregnancy and to anticipate needs after delivery; preparing the woman for labor and delivery, postpartum and parenting; and providing the woman and her partner with the opportunity to discuss any issues related to pregnancy, labor and delivery and postpartum (Smeltzer, 2002; Rogers & Matsumura, 2005).

Nutrition continues to be important throughout pregnancy. It is more important for women with mobility limitations than for the general population to avoid excess weight gain during pregnancy as the weight can impede their balance or ability to transfer, make it more difficult for caregivers or partners to provide assistance and increase the potential for skin breakdown and infection. Prenatal vitamins are recommended for all pregnant women. Of particular importance are folic acid, iron, calcium and phosphorus. Constipation may be a greater issue during pregnancy for women with disabilities or chronic health conditions. A diet high in fiber, particularly fruits and vegetables, and high fluid intake is recommended and stool softeners may be necessary.

Pregnant women with disabilities are encouraged to continue to exercise to the extent that they are able. Some women with disabilities are more prone to muscle spasms during pregnancy. A regular exercise program within the woman's abilities can reduce spasms and spasticity. Range of motion exercises may be helpful. Setting up an exercise plan with a physical therapist or other knowledgeable health professional may be helpful.

Monitoring the woman's weight and identification of excess weight gain or loss is important. Therefore, strategies to weigh women who are unable to stand on a traditional medical scale should be identified and implemented to assure periodic weighing during pregnancy. These might involve purchase of an accessible wheelchair scale that permits a wheelchair, scooter or walker to be moved onto a scale or use of an accessible scale at a nearby hospital.

Fatigue is a common concern during pregnancy for all women. Rest during the day is helpful, in addition to regularly getting seven to eight hours of sleep at night. Stress management methods such as meditation may help with sleep disruption, as does regular exercise. For some women with heat-sensitive disabilities, such as MS, increased body temperature associated with pregnancy is particularly bothersome. They may benefit by limiting their exercise to earlier parts of the day, exercising in air-conditioned settings during warmer seasons, or taking cool baths.

### **Labor and Delivery**

Most disabilities do not interfere with a woman's ability to have a normal labor and delivery. The need for a cesarean delivery should be based on each woman's overall health status, the progress of labor, and the well-being of her fetus, rather than on the fact that she has a disability. Some women may not feel uterine contractions and they should be instructed to watch their abdomen for muscular activity. Some women in late pregnancy may wear a uterine monitor.

Women should plan with their obstetricians how labor and delivery will be managed. Alternative positioning for delivery, for example side-lying, may be required if spasticity is a problem. In addition, women can plan with their obstetricians and anesthesiologists in advance about the need and desirability of having an epidural anesthesia or other types of pain management strategies.

### **Breastfeeding**

Women with disabilities are able to breastfeed as often as other women. Some women may benefit from the use of adaptive parenting equipment such as baby slings (See Appendix A) . In fact, breastfeeding eliminates the need for preparation of formula and clean-up, and so is easier for these women. Some may choose to have their partner supplement the feedings with a bottle during the night. If women have altered sensation in their breasts, they will need to be taught how to detect mastitis by appearance and palpation if possible. Women who are taking medications or using nutritional supplements should discuss these matters with their health care providers, as metabolites of some medications and supplements pass into the breast milk and may be harmful to the baby.

### **Unique Considerations or Concerns**

Some disabilities are associated with particular concerns or risks. For example, women with spinal cord injury are more likely to experience pregnancy-induced hypertension and autonomic dysreflexia than the general population. Women with MS may experience an exacerbation of their disease within one to three months postpartum, although, it usually abates within a few months. Women with systemic lupus erythematosus (SLE) are at increased risk for thrombotic events (e.g., DVT, pulmonary embolus, cerebrovascular attack [CVA]) throughout their pregnancies. In addition, women with SLE are at greater risk for fetal loss throughout pregnancy, intrauterine growth retardation, premature placental aging with thrombosis, and pregnancy-induced hypertension (i.e., preeclampsia). Any woman with a disability and her health care providers are well-advised to contact the national advocacy group associated with that condition for information on particular issues related to pregnancy. See list of selected groups in Appendix.

If there are concerns about the safety of a woman with a disability becoming pregnant and delivering a healthy baby, the woman should be referred to a women's health care specialist knowledgeable about her particular disability or chronic health condition for comprehensive discussion of her pregnancy options.

Women with disabilities have fewer children than the general population, but in general they are at no greater risk for infertility. If a couple experiences infertility they need not assume that it is related to the woman's disability. When infertility becomes a concern for a couple in which the woman has a disability, counseling and guidance should include consideration of the interaction of the woman's disabling condition with infertility treatment, childbearing and childrearing, as well as the commitment of her partner to the pursuit of infertility treatment.

Women with possible ovulatory dysfunction can be evaluated and offered treatment options. Women with SCI who undergo evaluation for ovulatory dysfunction may require monitoring and preparation for treatment of autonomic dysreflexia. Women with degenerative hips or contractures may not tolerate positioning for dye injection to assess tubal patency.

**Urinary tract infection**

Urinary tract infections (UTI) are more common among women with disabilities than among the general population. While all UTIs must be individually managed, there are some general recommendations for the treatment of UTIs and for bladder management. All women with frequent or chronic urinary tract difficulties should undergo baseline urodynamic evaluation to determine appropriate bladder management. Women with significant urinary tract dysfunction will need to be collaboratively managed by a urologist in collaboration with their other health care providers.

Neurological conditions, including MS and brain or spinal cord injury, are often associated with alteration in bladder control. Retention as well as incontinence may result. Loss of urinary control can be managed by the following methods singly or in combination: bladder training regimens such as intermittent self-catheterization, anticholinergic agents, indwelling catheters, or urostomy pouches. Women with a neurogenic bladder diagnosis require renal ultrasounds to rule out the development of hydro-nephrosis and nephrolithiasis, as determined by the urologist.

Asymptomatic bacteriuria or bladder bacterial colonization need not be aggressively managed. Urine is not considered infected in the absence of pyuria, and home dipsticks can be used to monitor this (NIDDK, 2003). When a woman is pregnant, UTIs are more likely to ascend to the kidneys (National Women's Health Information Center, 2002). Taking vitamin C or drinking cranberry juice and adequate fluids will discourage the development of UTIs by reducing the urinary pH level (National Women's Health Information Center, 2002). Cranberry extract tablets are an alternative to reduce urinary pH. Probiotic management with *Lactobacillus* (e.g. in live culture yogurt or in tablets) helps restore normal vaginal flora and may prevent urinary tract infection (Stapleton, 2003). Women who are prone to UTIs may want to avoid use of a diaphragm for contraception; it can impede complete bladder emptying (National Women's Health Information Center, 2002). If a UTI does develop, the least aggressive antimicrobial agent to which the pathogen responds should be used. Periodic bladder cystoscopy may be indicated for women with an indwelling catheter to rule out bladder stones.

**Vaginitis**

Common non-sexually transmitted types of vaginitis include candida or "yeast" vaginitis, bacterial vaginosis, and noninfectious vaginitis. Candida is normal vaginal flora, but infection may fulminate when pH level changes or when the normal flora are otherwise disrupted by metabolic or disease-related change, including pregnancy and the onset of diabetes. As with candida vaginitis, bacterial vaginosis also emerges when the normal flora are disrupted, and is even more prevalent than candida vaginitis. Non-infectious vaginitis may result from allergic reaction or irritation from vaginal sprays, douches, spermicides, perfumed soaps, detergents or fabric softeners; from atrophic changes associated with menopause; or from irritation by vaginal secretions that build up (NICHD, 2004).



Women who use wheelchairs are at especially increased risk for vaginitis because of chronic moisture and irritation of the labial area related to prolonged sitting. Women who are on chronic corticosteroid therapy or have disabilities related to diabetes are also predisposed to recurrent candida vaginitis. Candida can be treated by topical and oral antifungal medications. Antifungal powder, which also absorbs moisture, can be applied prophylactically to the perineum. Bacterial vaginosis will require antibacterial medications. Recurrent vaginitis should be assessed prior to treatment. In addition to noninfectious causes, vaginitis can be caused by various sexually transmitted organisms. Noninfectious vaginitis is managed by removal of the cause. If it is associated with menopause, topical or oral estrogen may alleviate symptoms.

The National Vaginitis Association (2003) recommends the following prevention strategies: avoid douching, careful and immediate drying after washing or bathing, exclusive use of cotton underwear and pantyhose with a cotton crotch, front to back wiping after bowel movement, and avoidance of all scented bath or perineal products.

### **Sexually Transmitted Diseases**

When access to reproductive health services and sexual health information is limited, women are at increased risk of sexually transmitted diseases (STDs). Women with disabilities are often presumed by health care providers not to be sexually active, and they may experience barriers to sexual health care. It is as important for women with disabilities to be assessed for sexually transmitted diseases as for all other women. Moreover, health care providers need to be alert to the possibility that STDs may be contracted through nonconsensual or forced sexual activity, especially among women with developmental or intellectual disabilities.

Some STDs, such as chlamydia, are “silent” in most women. Women with pelvic sensory impairments or neuropathy may not report pain, burning or other discomforts. They may experience less specific symptoms such as increased spasticity or malaise (Welner, 1999). Women with vision loss may not be aware of lesions or discharge; they are dependent on a partner or caregiver to notice and describe any abnormalities to them.

Health care providers need to be attentive to altered manifestations of STDs in women with disabilities, such as increased spasticity or fatigue in women with spinal cord injury. Health care providers should consider the possibility that pelvic scarring and adhesions may be related to an STD. Women with disabilities have the same risks for blood-borne viral infections as all other women; they may be infected by sexual contact, contact with blood or body fluids, trauma, shared needles or transfusion.

### **Pressure Ulcers**

Women who are at risk for skin breakdown, including women whose ability to change positions is extremely limited or those with loss of sensation, are prone to pressure ulcer formation and infections. These infections can lead to life-threatening sepsis. Further, pressure ulcers may affect women's ability to use a wheelchair and severe pressure ulcers may require surgical treatment and skin grafts. Women and their health care providers need to be aware of early signs of skin breakdown and preventive strategies including changing positions, use of cushions, proper fitting of prosthetics or orthotics, and good nutrition. Women, their partners, caregivers, or family members need to inspect the woman's skin daily. Women at risk for pressure ulcers should have their skin inspected thoroughly at each health care encounter. Because pressure ulcers are costly as well as difficult to heal, referral to a wound care specialist may be warranted to prevent and treat pressure ulcers.

In the last twenty years, women have become more aware of options for enhancing the quality of life and promoting health during perimenopause and menopause. Women need general information about health promotion during menopause as well as specific information about symptom management and the potential effect of menopause on their disabilities (Morrow, 2002).

Women with a number of disabilities or chronic health conditions may experience menopause earlier than the average age of 51. Depending on the specific disability or chronic health condition, menopause may be triggered by circulatory, endocrine, immunological or neurological alterations (Welner, Simon & Welner, 2002). Aging affects changes in cardiovascular, respiratory, metabolic, muscular, skeletal, skin and connective tissue, endocrine, and sexual function. Estrogen, which declines throughout perimenopause, affects all body systems. These changes may be more significant among women with disabilities than the general population (Welner, Simon & Welner, 2002).

Women with mobility limitations face increased risks for conditions that are associated with menopause, including heart disease and osteoporosis. Women with multiple sclerosis (MS) may find hot flashes more debilitating than other women because of their sensitivity to thermal fluctuation and because MS is estrogen-sensitive. Women with conditions that affect their bowel and bladder may have an increase in genitourinary problems including urinary tract infections, kidney and bladder stones and poorer renal function. Women with autoimmune diseases have complex and varied responses to changes in their estrogen levels. Women for whom skin integrity is an issue, such as women with SB, SCI, or MS, may have increased difficulty with decubiti after menopause. In addition, women with MS, SCI and seizure disorders may be more sensitive than other women to thermal and vasomotor changes (Welner, Simon & Welner, 2002), and may report an increase in symptoms (fatigue, muscle weakness). Women with cognitive and mood changes associated with their disabilities, including those with MS and brain injury, may find the increased mood, sleep and memory changes associated with menopause to be particularly troublesome.

Practice in regard to hormone replacement therapy (HRT) has undergone a major change since 2003. Current recommendations include using HRT in the lowest doses possible for the shortest time possible to manage disruptive menopausal symptoms (National Women's Health Information Center, 2003). Concerns that were formerly regarded as potential indications for HRT, such as prevention of heart disease or osteoporosis, can be managed more effectively by other means. Women with menstrual irregularities may choose to use supplemental hormonal agents or low-dose oral contraceptives for cycle control and regulation of fluctuating estrogen levels. Women with alterations in mobility may use transdermal estrogen with cyclic progestin withdrawal, to avoid the increased risk for DVT associated with oral contraceptives (Welner, Simon & Welner, 2002). As noted in the discussion of contraceptive options above, the weight gain associated with hormonal therapies may be of greater significance for women with mobility limitations than for other women (Weil et al., 2002).

Women may have specific concerns about the interactions among the medications they use to manage their disability or chronic health condition and medications available for menopause-related problems. Some absolute contraindications to hormone therapy include acute TIA, acute stroke, pulmonary embolism, SLE, and recent DVT. HRT use has been linked to increased seizure activity among women with seizure disorders although the results of research on this topic are mixed (Welner, Simon & Welner, 2002). When women with rheumatoid arthritis use HRT, menopausal symptoms and disease activity may be reduced. HRT appears to slow progression of osteoarthritis. MS may respond positively to estrogen and negatively to dropping estrogen levels, and women may experience improvement in MS-related symptoms when they use HRT.

Alternatives to HRT include medications that target estrogen receptors, such as selective estrogen receptor modulators (SERMS), which benefit the lipid profile as well as bone health. Phytoestrogens and isoflavonoids, substances derived from plant sources such as soy products, have a variety of estrogen-like properties and act on estrogen receptors in a manner similar to SERMS. Red clover derivatives also act on estrogen receptors and may improve vasomotor instability. There is little information on the safety of other products such as black cohosh, or on the interaction of various alternative products with underlying disabilities or with the medications used to manage them. Women who are interested in alternative products or nutritional supplementation are advised to work with health care providers who are knowledgeable in the field of complementary and alternative medicine (Welner, Simon & Welner, 2002). The National Institutes of Health National Center for Complementary and Alternative Medicine (NCCAM) is a valuable resource, and is listed in the Appendix.

Lifestyle recommendations that may benefit women with disabilities include performing Kegel exercises if they are able; establishment of a regular exercise regimen to the extent possible; attention to sleep alterations; participation in a support group; engagement in regular recommended screening examinations; attention to dental health; eating a healthy diet with emphasis on fruits, vegetables and fiber; stress management; smoking cessation; and maintenance of body mass index between 19 and 25 (Vandenaeker & Glass, 2001).

Women with disabilities that can potentially impair bowel and bladder function, resulting in incontinence or constipation, require attention to dietary and other factors that can affect elimination. Health care providers need to ask women about their elimination patterns and the routines that help them regulate elimination patterns. It should not be assumed that bowel and bladder dysfunction is inevitable and that treatment is futile because of the presence of a disability. Women may benefit from referral to specialists who can help them with bowel or bladder regimens to maximize control and predictability in their lives.

It is important to address prevention of osteoporosis, osteoporotic fractures and secondary disabilities with women with disabilities and chronic health conditions.. Osteoporosis is characterized by low bone mineral density (BMD) and compromised bone strength predisposing to bone fragility and increased risk of fracture. It is widely recognized that the risk for loss of bone mass and osteoporotic fracture increases in post-menopausal women (NIH, 2001; U.S Department of Health and Human Services [USDHHS], 2004). BMD testing is recommended for all women 65 years of age and older and for post-menopausal women younger than 65 years of age who have one or more risk factors in addition to gender and menopause as soon as the risk factors are identified (U.S. Preventive Services Task Force, 2002; National Osteoporosis Foundation, 2003). Although a growing body of research suggests that many women with disabilities develop low bone mass at a younger age than other women and have more osteoporosis risk factors (Smeltzer, Zimmerman & Capriotti, 2005), BMD testing is often not made available (Shabas & Weinrub, 2000; Smeltzer, Zimmerman, Capriotti & Fernandes, 2002). Studies of the usefulness of clinical indices developed to predict bone loss have largely excluded women with disabilities. Thus, health care providers and women with disabilities themselves need to carefully assess the risks for each woman based on her own risk profile and obtain baseline and periodic BMD testing to monitor bone health.

Women with long-standing disability, particularly disabilities with onset at birth or early in life (e.g., spina bifida, cerebral palsy), are unable to achieve an adequate peak bone mass if they have been unable to bear weight on their extremities or if their disability limits their ability to participate in weight-bearing exercise. Thus, they are likely to have low BMD at a very early age. As with all women, bone loss in women with disabilities dramatically increases as they approach menopause. If they have not undergone BMD testing before, they should have BMD testing at the time of menopause to establish a baseline and to permit informed decision making about treatment. Women with significant mobility limitations or who are unable to participate in weight-bearing activities and women who have had prolonged exposure to corticosteroids or anticonvulsant therapy should be tested before menopause as soon as their osteoporosis risk is identified to enable initiation of strategies to prevent or slow bone loss along with strategies to reduce risk for falls. Treatment should be provided for women with disabilities with low BMD to prevent or slow bone loss; follow-up BMD testing is needed to monitor the progression of bone loss and effectiveness of treatment. In the absence of specific recommendations for treatment to prevent, slow or treat osteoporosis, prevention and treatment strategies for women with disabilities parallel those for women without disabilities. Most women in the U.S. have an inadequate dietary intake of calcium (USDHHS, 2004) and may receive less vitamin D due to lack of exposure to sunlight secondary to their disability. Thus, an increase in calcium along with vitamin D is indicated. Although there is some concern among clinicians about the increased risk of renal calculi with an increased calcium intake in sedentary women, this risk can be substantially reduced if women take steps to remain adequately hydrated. Periodic monitoring of a woman's serum and urinary calcium levels may alleviate clinicians' concerns about increased risk for formation of renal stones.

Medications (e.g., bisphosphonates [Fosamax, Actonel], raloxifene [Evista], calcitonin) designed to reverse or slow bone loss are currently available. The bisphosphonates must be used with caution because of the significant gastrointestinal effects that can occur if instructions in their use are not followed. Women whose disability keeps them from sitting up for at least 30 minutes (preferably 60 minutes) after taking a bisphosphonate are not good candidates for its use. Zoledronic acid (Zometa), the most potent bisphosphonate, may be useful in women with disabilities because it is administered intravenously once a year, avoiding the gastrointestinal side effects of daily or weekly oral bisphosphonates (Reid et al., 2002). Clinical studies are needed to determine its effectiveness in women with disabilities. Zoledronic acid should not be used if there is a possibility of pregnancy. Another new alternative is ibandronate (Boniva), a recently approved oral bisphosphonate with a once-a-month dose. (MedlinePlus 2005). Lifestyle changes (smoking cessation, reduced caffeine and alcohol intake) are other osteoporosis preventive strategies worth discussing with women with disabilities. Exercise within the woman's physical abilities is an important strategy to maintain bone loss; however, many women with disabilities, including those who are ambulatory, tend not to participate in weight-bearing exercise. Identification of a safe program of exercise and discussion about its importance in maintaining bone mass may increase women's willingness to participate in some weight-bearing exercise, when possible.

Women with disabilities are more vulnerable than other women to physical assault, sexual assault, verbal and emotional abuse and are at risk for abuse by intimate partners, family members, paid caregivers, health care workers, and strangers. Sixty-two percent of a national sample of women with physical disabilities reported emotional, physical, or sexual abuse (Nosek, Howland, & Young, 1997). It has been estimated that women with disabilities are abused 3 to 10 times more often than their peers without disabilities (Sobsey & Doe, 1991). They endure abuse longer and experience types of violence that women without disabilities are unlikely to experience such as: removal/destruction of assistive devices (e.g. walker, TTY text telephone, cane), withholding of medications, and denial of access to transportation and health care (Nosek, Howland, & Young, 1997). Women with disabilities, who are dependent on others, including their abusers, are often unable to extricate themselves from abusive relationships and situations.

Women with developmental disabilities, including those with intellectual disabilities and those with hearing or vision loss, are at particularly high risk for violence and abuse. These women experience physical or sexual assault at a rate estimated to be 4-10 times higher than other women, and are more likely to be victims of emotional or sexual abuse from personal care attendants and health care workers than women without disabilities (Sobsey & Doe, 1991).

Complicating the issue of violence against women with disabilities is the lack of domestic violence/sexual assault (DV/SA) services that consider the unique needs of women with disabilities. Shelters and other facilities are often inaccessible and lack the accommodations (e.g., sign language interpreters, barrier-free facility, alternate formats for written materials) essential for women with disabilities to obtain services and support. It is essential to ask women about abuse in a safe private setting without family members or caregivers present. To assess women with disabilities for abuse, it is important to ask not only about physical or sexual abuse, but also types of abuse that are specific to women with various disabilities. Positive responses to any questions on the Abuse Assessment Screen-Disability (AAS-D) indicate the need for further assessment. In addition, the health care provider must determine if the woman is able to leave an abusive relationship and knows how to obtain assistance. Providers should be knowledgeable about mandatory reporting laws. Health care providers also need to be knowledgeable about community DV/SA services and share this information with women, as appropriate. Moreover, health care providers need to be aware of state laws dictating their reporting requirements.



### ABUSE ASSESSMENT SCREEN-DISABILITY (AAS-D)

1. Within the last year, have you been hit, slapped, kicked, pushed, shoved or otherwise physically hurt by someone?
2. Within the last year, has anyone forced you to have sexual activities?
3. Within the last year, has anyone prevented you from using a wheelchair, cane, respiratory, or other assistive devices?
4. Within the last year, has anyone you depend on refused to help you with an important personal need, such as taking your medicine, getting to the bathroom, getting out of bed, bathing, getting dressed, or getting food or drink?

Center for Research on Women with Disabilities. Abuse Assessment Screen-Disability. <http://www.bcm.edu/crowd/?PMID=1325m>, Accessed September 2, 2005.

Women with disabilities are at risk for depression and mental health disorders because of the isolation, dependence, low self-esteem and lack of intimate relationships with others that often occur with disability (Nosek, Hughes, Swedlund, Taylor & Swank, 2002). However, clinical depression and other mental health disorders should not be considered a normal response to having a disability. Women with disabilities should be assessed for depression during each health care visit. Changes in women’s medications, home situation, support systems, and stress level should be assessed. Their usual coping strategies should be identified and unhealthy methods of coping (e.g., alcohol use, substance abuse, smoking) identified and addressed. Pharmacologic and non-pharmacologic methods of addressing depression and other mental health issues should be offered to women with disabilities just as they would be to other women. The presence of a disability should not preclude use of medication, counseling and psychotherapy, if warranted.

The CAGEAID (see below) is a brief screening tool to identify individuals at risk for substance abuse, in particular alcohol abuse. If the individual answers yes, the woman is asked if each incidence has occurred in the past year. If there are 1-2 positive responses, alcohol-related problems may be present. With 3-4 positive responses, alcohol dependence may be an issue, necessitating intervention.

**CAGEAID**

The CAGEAID screening tool’s name is derived from Cutting down, Annoyance by criticism, Guilty feelings, and Eye-openers) Adapted to Include Drugs

C: Have you ever felt that you should CUT DOWN on your drinking (or drug use)?

A: Have people ANNOYED you by criticizing your drinking (or drug use)?

G: Have you ever felt bad or GUILTY about your drinking (or drug use)?

E: Have you ever had a drink (or used drugs) first thing in the morning to steady your nerves or get rid of a hangover (or to get the day started)? (EYE-OPENER)

Brown, R.L. (1992). Identification and office management of alcohol and drug disorders. In: Fleming, M.F., and Barry, K.L., eds. Addictive Disorders. St. Louis: Mosby Yearbook.

Many women with disabilities identify aging with a disability along with concern about further disabilities or progression of their disability to be among their greatest worries or concerns (Smeltzer & Zimmerman, 2005). Today, the typical life span of women with disabilities is close to that of women without disabilities. In previous generations, many people with long-term disabilities did not survive into older adulthood due to complications of secondary conditions associated with their disabilities. As women with disabilities age, they may experience the onset of new health problems and changes in functional status (Campbell, Sheets & Strong, 1999). Thus, women with disabilities often have a smaller margin of safety and lower level of function because of aging combined with the limitations of their pre-existing disability.

The interaction of aging and disability on health and access to care must be considered. For example, people with spinal cord injuries or polio survivors can begin to show the signs of aging earlier than those without disabilities. Some people with cerebral palsy report increased spasticity as well as musculoskeletal, urinary and gastrointestinal problems as they get older. Some women report increasing muscle and joint pain, discomfort and dysfunction with aging due to the life-long wear and tear resulting from an altered gait or use of the upper extremities with crutch walking or propelling themselves in a manual wheelchair.

Psychosocial issues may occur with aging related to concerns about the continued availability of care and services (Nosek, 2000). There may be concerns about decreasing availability of supportive friends and family as they, too, age and develop chronic illnesses that may limit the support and assistance that they are able to provide. Women with disabilities should be actively involved with life planning as they age, and develop specific plans about housing, finances, and health-related arrangements. Health care providers can be helpful in encouraging women with disabilities who are aging to consider developing life plans to minimize their anxiety and concern about these issues.

## CONCLUSION

---

We guide will assist you in providing high quality care to women with physical disabilities and chronic health conditions. In line with “The Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities”, this guide will help meet the four goals of this “Call to Action” (The Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities. 2005.

<http://www.surgeongeneral.gov/library/disabilities/calltoaction/factsheetwhatwho.html>

1. Increase understanding nationwide that people with disabilities can lead long, healthy and productive lives.
2. Increase knowledge among health care professionals and provide them with tools to screen, diagnose, and treat the whole person with a disability with dignity.
3. Increase awareness among people with disabilities of the steps they can take to develop and maintain a healthy lifestyle.
4. Increase accessible health care and support services to promote independence for people with disabilities.

The information needed by clinicians to provide high quality care to women with physical disabilities and chronic health conditions can be summarized simply: most women with disabilities have the same health care needs as women without disabilities, but may also have additional unique health needs. In addition, women with disabilities often face barriers that make it difficult or impossible for them to receive even basic health care. An appreciation for these similarities and the differences goes a long way in providing the sensitive and dignified health care that all women want and deserve.

# REFERENCES

---

Agency for Health Care Research and Quality (2002). U.S. Preventive Services Task Force. Screening for breast cancer. AHRQ, Rockville MD. <http://www.ahrq.gov/clinic/uspstf/uspstfbrca.htm> Accessed April 15, 2005.

Agency for Health Care Research and Quality (2003). U.S. Preventive Services Task Force. Screening for Cervical Cancer. AHRQ, Rockville MD. <http://www.ahrq.gov/clinic/uspstf/uspstfcerv.htm>. Accessed April 15, 2005.

American Cancer Society (2004). Colon and rectal cancer. [www.nci.nih.gov/cancertopics/types/wyntk/colon-and-rectal](http://www.nci.nih.gov/cancertopics/types/wyntk/colon-and-rectal) Updated March 10, 2004. Accessed November 11, 2004.

American Cancer Society (2004). Role of breast self-examination changes in guidelines. [www.cancer.org/docroot/NWS/content/NWS\\_1\\_1x\\_Role\\_of\\_Breast\\_Self-Examination](http://www.cancer.org/docroot/NWS/content/NWS_1_1x_Role_of_Breast_Self-Examination)

Andrist LC, Arias RD, Nucatola D, Kaunitz AM, Musselman BL, Reiter S, Boulanger J, Dominguez L, Emmert S. (2004). Women's and providers' attitudes toward menstrual suppression on extended use of oral contraceptives. *Contraception* 70(5):359-63.

Berkman, L. & Breslow, L. (1983). *Health and ways of living: The Alameda County study*. New York: Oxford University Press.

Better Health Channel (2004). Pap tests and women with disabilities. [www.better-health.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Pap tests and\\_women with disabilities](http://www.better-health.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Pap_tests_and_women_with_disabilities) Accessed November 20, 2004

Brown, R. L. (1992). Identification and office management of alcohol and drug disorders. In: Fleming, M.F., & Barry, K.L., eds. *Addictive Disorders*. St. Louis: Mosby Yearbook.

Caban, M.E., Nosek, M.A., Graves, D., Esteva, F.J. & McNeese, M. (2002). Breast carcinoma treatment received by women with disabilities compared with women without disabilities. *Cancer*, 94(5), 1391-1396.

Campbell, M. L., Sheets, D., & Strong, P. S. (1999). Secondary health conditions among middle-aged individuals with chronic physical disabilities: Implications for unmet needs for services. *Assistive Technology*. 11: 105-122.

Center for Research on Women with Disabilities. Abuse Assessment Screen-Disability. [www.bcm.edu/crowd/?PMID=1325m](http://www.bcm.edu/crowd/?PMID=1325m) Accessed September 2, 2005.

Centers for Disease Control and Prevention (2004). Adult immunization schedule. [www.cdc.gov/nip/recs/adult-schedule.htm](http://www.cdc.gov/nip/recs/adult-schedule.htm) Accessed October 27, 2004.

# REFERENCES

---

Centers for Disease Control and Prevention (2003). Folic acid. Frequently asked questions. [www.cdc.gov/doc.do/id/0900f3ec8000d558](http://www.cdc.gov/doc.do/id/0900f3ec8000d558) Accessed November 3, 2004.

Centers for Disease Control and Prevention (1997). Morbidity and Mortality Weekly Report, 46(RR-08), 1-24.

Coyle, P.C. & Santiago, M.C. (2002). Health care utilization among women with physical disabilities. *Medscape General Medicine*, 4(3). [www.medscape.com/viewarticle/433156](http://www.medscape.com/viewarticle/433156)

Disabled Women's Network Ontario (2002). Sexual assault and women with disabilities. [http://dawn.thot.net/sexual\\_assault.htm](http://dawn.thot.net/sexual_assault.htm) Accessed April 15, 2005.

Family Health International (1999). Disabled have many needs for contraception. *Network*, 19(2). [www.fhi.org/en/RH/Pubs/Network/v19\\_2/disablneeds.htm](http://www.fhi.org/en/RH/Pubs/Network/v19_2/disablneeds.htm)

Hatcher, R.A. (2005). *Contraceptive technology*, 18th ed. Easthamptom, MA: Ardent Media Inc.

Hernán, M. A., Jick, S. S., Olek, M. J. & Jick, H. (2004). Recombinant hepatitis B vaccine and the risk of multiple sclerosis. A prospective study. *Neurology*, 63:838-842.

Iezzoni, L., McCarthy, E. P., Davis, R. B., Harris-David, L., & O'Day, B. (2001). Use of screening and preventive services among women with disabilities. *American Journal of Medical Quality*. 16(4):135- 144.

International Planned Parenthood Federation (1999). Statement on contraception for women with medical disorders. [www.ippf.org/medical/imap/statements/eng/1999\\_06a.htm](http://www.ippf.org/medical/imap/statements/eng/1999_06a.htm) Accessed July 26, 2004.

Jans, L., & Stoddard, S. (1999). *Chartbook on Women and Disability in the United States. An InfoUse Report*. Washington, D.C.: U.S. National Institute on Disability and Rehabilitation Research.

Johns Hopkins Pathology (2004). Ovarian cancer. [www.ovariancancer.jhmi.edu](http://www.ovariancancer.jhmi.edu) Accessed November 10, 2004.

Kopac, C.A., Fritz, J. & Holtz, R.A. (1998). Gynecologic and reproductive services for women with developmental disabilities. *Clinical Excellence for Nurse Practitioners*, 2(2), 88-95.

Lanig, I.S., Chase, T.M., Butt, L.M., Hulse, K.L., & Johnson, K.M.M. (1996). *A practical guide to health promotion after spinal cord injury*. Gaithersburg, MD: Aspen Publishers, Inc.

# REFERENCES

---

- March of Dimes (2001). Spina bifida. <http://search.marchofdimes.com/msmres.asp?query=folic+acid+and+women+with+spina+bifida>. Accessed April 15, 2005.
- McFarlane, J., Hughes, R. B., Nosek, M. A., Grof, JY., Swedlend, N. & Dolan Mullen, P. (2001). Abuse assessment screen-disability (AAS-D): measuring frequency, type, and perpetrator of abuse toward women with physical disabilities. *Journal of Women's Health & Gender-Based Medicine*. 10(9):861-6.
- MedlinePlus (2001). Lidocaine (Topical). National Library of Medicine. [www.nlm.nih.gov/medlineplus/druginfo/uspdi/500058.html](http://www.nlm.nih.gov/medlineplus/druginfo/uspdi/500058.html). Accessed September 1, 2005.
- MedlinePlus (2005). Ibandronate (Systemic). National Library of Medicine. [www.nlm.nih.gov/medlineplus/druginfo/uspdi/500499.html](http://www.nlm.nih.gov/medlineplus/druginfo/uspdi/500499.html). Accessed September 1, 2005.
- Morrow, M. (2002). Challenges of change: midlife, menopause and disability. The Canadian Women's Health Network. [www.cwhn.ca/resources/afi/disability.html](http://www.cwhn.ca/resources/afi/disability.html). Accessed July 26, 2004.
- Multiple Sclerosis Council for Clinical Practice Guidelines (2001). Immunizations and multiple sclerosis. Evidence-based management strategies for immunizations in multiple sclerosis. Washington, DC: Paralyzed Veterans of America.
- National Cancer Institute (2002). Radiation risks and pediatric computed tomography (CT): A guide to health care providers. [www.cancer.gov/cancertopics/causes/radiation-risks-pediatric-CT/print](http://www.cancer.gov/cancertopics/causes/radiation-risks-pediatric-CT/print). Accessed September 17, 2004.
- National Institute of Child Health & Human Development (2004). Vaginitis. <http://www/nichd.nih.gov/publications/pubs/vag3.htm>
- National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) (2003). Urinary tract infections in adults. <http://kidney.niddk.nih.gov/kudiseases/pubs/utiadult/index.htm>
- National Institutes of Health Consensus Development Panel on Osteoporosis, Prevention, Diagnosis and Therapy. (2001). Osteoporosis prevention, diagnosis, and therapy. *JAMA*. 285: 785-795.
- National Institute on Alcohol Abuse and Alcoholism (2004). Helping patients with alcohol problems: A health practitioner's guide. [www.niaaa.nih.gov/publication/practitioner/HelpingPatients.htm#step1b](http://www.niaaa.nih.gov/publication/practitioner/HelpingPatients.htm#step1b). Accessed October 28, 2004.
- National Osteoporosis Foundation (2003). Physician's guide to prevention and treatment of osteoporosis. Washington, DC: National Osteoporosis Foundation.

# REFERENCES

---

National Osteoporosis Foundation (2002). America's bone health: The state of osteoporosis and low bone mass in our nation. Accessed online on November 4, 2002 ([www.nof.org/advocacy/prevlance/index.htm](http://www.nof.org/advocacy/prevlance/index.htm))

National Vaginitis Association (2003). Prevention. [www.vaginalinfections.com/pdas-nva/cons\\_prevention.html](http://www.vaginalinfections.com/pdas-nva/cons_prevention.html). Accessed November 20, 2004.

National Women's Health Information Center (2003). Menopause & hormone therapy. [www.4women.gov/menopause/index2.htm](http://www.4women.gov/menopause/index2.htm). Accessed November 20, 2004

National Women's Health Information Center (2003). Women with disabilities: breast health access. [www.4women.gov/wwd/wwd.cfm?page=36](http://www.4women.gov/wwd/wwd.cfm?page=36). Accessed November 20, 2004

National Women's Health Information Center (2003). Urinary tract infections. [www.4women.gov/faq/uti.htm](http://www.4women.gov/faq/uti.htm). Accessed November 20, 2004

National Women's Health Information Center (2004). Screening Tests and Immunizations Guidelines for Women (Part 1 and 2). [www.4women.gov/screeningcharts.htm](http://www.4women.gov/screeningcharts.htm). Accessed November 20, 2004

Nosek, M.A., Wuermsler, L. & Walter, L.J. (1998). Differences in contraceptive methods used by women with physical disabilities compared to women without disabilities. *Primary Care Update for Obstetricians & Gynecologists*, 5(4), 172-173.

Nosek, M. A. (2000). Overcoming the odds: The health of women with physical disabilities in the United States. *Archives of Physical Medicine and Rehabilitation*. 81: 135-138.

Nosek, M. A., Howland, C. A., Rintala, D. H., Young, M. E. & Chanpong, G. F. (1997). National Study of Women with Physical Disabilities. Final Report. Houston: Center for Research on Women with Disabilities.

Nosek, M. A. & Howland, C. A. (1997). Breast and cervical cancer screening among women with physical disabilities. *Archives of Physical Medicine and Rehabilitation*. 78 (Suppl 5): S-39 – S 44.

Nosek M. A., Howland, C. A. & Young, M. E. (1997). Abuse of women with physical disabilities: Policy implications. *Journal of Disability Studies*. 8 (1-2), 157-176.

Nosek, M. A., Hughes, R. B., Swedlund, N. Taylor, H. B. & Swank, P. (2002). Self-esteem and women with disabilities. *Social Science & Medicine*. 56: 1737-1747.

Nosek, M. A., Hughes, R. B., Howland, C. A., Young, M. E., Mullen, P. D. & Shelton, M. L. (2004). The meaning of health for women with physical disabilities: a qualitative analysis. *Family & Community Health*. 27(1):6-21.



# REFERENCES

---

Odette, F., Yoshida, K.K., Israel, P., Li, A., Ullman, D., Colantonio, A., Maclean, H. & Locker, D. (2003). Barriers to wellness activities for Canadian women with physical disabilities. *Health Care for Women International*, 24, 125-134.

Reid, I. R., Brown, J. P., Burckhardt, P., Horowitz, Z., Richardson, P., Trechsel, U. et al. (2002). Intravenous zoledronic acid in postmenopausal women with low bone mineral density. *New England Journal of Medicine*. 346(9):653-661

Rogers, J. & Matsumura, M. (2005). *Mother-to-be: A guide to pregnancy and birth for women with disabilities*. New York: Demos Publications.

Sandyk, R. (1995). Premenstrual exacerbation of symptoms in multiple sclerosis is attenuated by treatment with weak electromagnetic fields. *International Journal of Neuroscience*, 83(3-4), 187-198.

Schopp, L.H., Sanford, T.C., Hagglund, K.J., Gay, J.W. & Coatney, M.A. (2002). Removing service barriers for women with physical disabilities: promoting accessibility in the gynecologic care setting. *Journal of Midwifery & Women's Health*, 47(2), 74-79.

Schottenfeld, D. & Beebe-Dimmer, J.L. (2004). Advances in cancer epidemiology: understanding causal mechanisms and the evidence for implementing interventions. *Annual Review of Public Health*, Oct. 25, 2004 (Epub ahead of print).

Shabas, D., & Weinreb, H. (2000). Preventive health care in women with multiple sclerosis. *Journal of Women's Health and Gender-Based Medicine*. 2000, 9(4): 389-395.

Sharts-Hopko, N.C., & Sullivan, M. (2002) Beliefs, perceptions and practices related to osteoporosis risk reduction among women with multiple sclerosis. *Research in Nursing and Health*. 27(6): 232-236.

Sharts-Hopko, N. & Sullivan, M. (2003). Obesity as a confounding health factor among women with mobility impairment. *Journal of the American Academy of Nurse Practitioners*. 15(10):438-443.

Shootman, M. & Jeffe, D.B.(2003). Identifying factors associated with disability-related differences in breast cancer screening (United States). *Cancer Causes Control*, 14(2), 97-107.

Sipski, M. & Alexander, C. (1997). *Sexual function in people with disability and chronic illness. A Health professional's guide*. Gaithersburg, MD: Aspen

Smeltzer, S. C., Zimmerman, V., Capriotti, T. & Fernandes, L. (2002). Osteoporosis risk factors and bone mineral density in women with multiple sclerosis. *International Journal of MS Care*. 4(1): 17-23, 29.

# REFERENCES

---

Smeltzer, S. C., Zimmerman, V., & Capriotti, T. (2005). Osteoporosis risk and low bone mineral density in women with disabilities. *Archives of Physical Medicine and Rehabilitation*.

Smeltzer, S. C., & Zimmerman, V. (2005). Health promotion interests of women with disabilities. *Journal of Neuroscience Nursing*. 37(2), 80-86.

Smeltzer, S.C. (2002). Reproductive decision making in women with multiple sclerosis. *Journal of Neuroscience Nursing*. 34(3): 145-157.

Sobsey, D. & Doe, T. (1991) Patterns of sexual abuse and assault. *Sexuality and Disability*. 9(3): 243-259.

Society of Obstetricians and Gynaecologists of Canada (2003). Disabled have many needs for contraception. *Network*, 19(2). [www.reproline.jhu.edu/English/6read/6issues/6network/v19-2/nt1924.html](http://www.reproline.jhu.edu/English/6read/6issues/6network/v19-2/nt1924.html). Accessed July 26, 2004

Society of Obstetricians and Gynaecologists of Canada (2004). Contraception, disability and illness. [www.sexualityandu.ca/eng/health/DC/](http://www.sexualityandu.ca/eng/health/DC/). Accessed July 26, 2004.

Stapleton, A. (2003). Novel approaches to prevention of urinary tract infections. *Infectious Disease Clinics of North America*, 17(2), 457-471.

The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities. <http://www.surgeongeneral.gov/library/disabilities/calltoaction/factsheetwhatwho.html>. 2005.

Thierry, J. M. (2000). Increasing breast and cervical cancer screening among women with disabilities. Observations from the CDC. *Journal of Women's Health & Gender-Based Medicine*. 9(1):12.

U.S. Department of Health and Human Services (2000). *Healthy People 2010*. U.S. Department of Health and Human Services. Washington, D.C.

U.S. Department of Health and Human Services (2004). *Bone Health and Osteoporosis: A report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services. Washington, D.C.

U.S. Department of Health and Human Services. (2004). *Bone Health and Osteoporosis: A report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services. Washington, D.C.

# REFERENCES

---

Veltman, A., Stewart, D.E., Tardif, G.S. & Branigan, M. (2001). Perceptions of primary health care services among people with physical disabilities. Part 1: Access issues. *Medscape General Medicine*, 3(2). [www.medscape.com/viewarticle/408122](http://www.medscape.com/viewarticle/408122)

Vandenakker, C. B. & Glass, D. D. (2001). Menopause and aging with disability. *Physical Medicine and Rehabilitation Clinics of North America*. 12(1): 133-151.

Weil, E., Wachterman, M., McCarthy, E. P., Cavis, R. B., O'Day, B., Iezzoni, L. I. et al. (2002). Obesity among adults with disabling conditions. *Journal of the American Medical Association*, 288(10), 1265-1268.

Welner, S. (1999). A provider's guide for the care of women with physical disabilities & chronic medical conditions. North Carolina Office on Disability & Health. Chapel Hill, NC.

Welner, S. L., Simon, J. A., Welner, B. (2002). Maximizing health in menopausal women with disabilities. *Menopause: The Journal of the American Menopause Society*, 9(3), 208-219.

Weppner, D. M. & Brownschidle, C. M. (1995). The evaluation of the health care needs of women with disabilities. *Primary Care Update for Obstetricians & Gynecologists*, 5(4), 210.

# APPENDICES

---

## APPENDIX A

### Organizations

(This abbreviated list of organizations is offered as a service only.)

#### General Women's Health

American College of Obstetricians and Gynecologists - <http://www.acog.com>

FDA Office of Women's Health - <http://www.fda.gov/womens>

National Center for Complementary and Alternative Medicine - <http://nccam.nih.gov>

National Women's Health Information Center - <http://www.4women.gov>

Women with Disability and Health

Breast Health Access for Women with Disabilities (BHAWD) – <http://bhawd.org>

Center on Research for Women with Disabilities (CROWD) - <http://www.bcm.tmc.edu/crowd/>

Disabled Woman's Network (DAWN) Ontario - <http://dawn.thot.net/index.html>

Health Promotion for Women with Disabilities -

<http://www.nursing.villanova.edu/WomenWithDisabilities/welcome.htm>

Mammacare - <http://www.mammacare.com/>

North Carolina Office on Disability and Health – <http://www.fpg.unc.edu/~ncodh>

SafePlace - <http://www.austin-safeplace.org/>

Through the Looking Glass - <http://lookingglass.org/index.php>

#### Disability-Specific

Arthritis Foundation - <http://www.arthritis.org>

American Foundation for the Blind - <http://www.afb.org/>

Brain Injury Society - <http://www.bisociety.org>

Epilepsy Foundation - <http://www.epilepsyfoundation.org>

Lupus Foundation of America - <http://www.lupus.org>

Myasthenia Gravis Foundation of America - <http://www.myasthenia.org>

National Institute of Health Consensus Conference on Osteoporosis - March, 2000

[http://opd.od.nih.gov/consensus/cons/111/111\\_intro.htm](http://opd.od.nih.gov/consensus/cons/111/111_intro.htm)

National Institutes of Health, Osteoporosis and Related Bone Diseases - National Resource Center - <http://www.osteoporosis.org/osteoporosis.html>

National Multiple Sclerosis Society - <http://www.nmss.org>

National Osteoporosis Foundation - <http://www.nof.org>

National Spinal Cord Injury Association - <http://www.spinalcord.org>

Parents with Disabilities online - <http://www.disabledparents.net/adaptive.html>

Post-Polio Health International - <http://www.post-polio.org>

Spina Bifida Association of America - <http://www.sbaa.org>

The Sjogren's Syndrome Foundation - <http://www.sjogrens.org>

UCP National (a.k.a. United Cerebral Palsy) - <http://www.ucp.org>

# APPENDICES

---

## APPENDIX A

### Equipment Resources

(We do not formally recommend or endorse the equipment or products listed.)

#### Accessible Exam Tables

- Accessible Examination Tables in Physicians' Offices - <http://www.members.aol.com/criptrip/accessible-exam-tables.htm>
- The Importance of Accessible Examination Tables - <http://www.cdihp.org/briefs/brief1-exam-tables.html>
- Hausmann Industries, Inc. - <http://www.hausmann.com>
- Chatanooga Group - <http://www.chattgroup.com/>
- Keitzer Manufacturing USA - <http://www.keitzer.com/>
- Hill Laboratories - <http://www.hilllabs.com>

#### Wheelchair Scales

- Medical Wheelchair Scales from Seca, Detecto and Tanita- [http://www.healthchecksystems.com/wheelchair\\_compare.htm](http://www.healthchecksystems.com/wheelchair_compare.htm)

#### Assistive Listening Devices

- Harris Communications - <http://www.hearinglossweb.com/res/gen/harris.htm>
- United TTY Sales and Service (UTSS) - <http://www.hearinglossweb.com/res/gen/united.htm>
- Sound Clarity, Inc.- <http://www.soundclarity.com>
- Pure Direct Sound - <http://www.puredirectsound.com>

### Books

*Enabling Romance: A Guide to Love, Sex and Relationships for People with Disabilities (and the People who Care About Them)*. Kroll, K. and Klein, E.L. Klein and Kroll, Inc., No Limits Communication, 1992

*Mother to Be: A Guide to Pregnancy and Birth for Women with Disabilities*. Rogers, J, Matsumura, M. Demos Publications, 386 Park Avenue South, New York, NY 10016, 1991.

*The Parenting Book for Persons with a Disability*. Centre for Independent Living in Toronto (CILT), Inc. 205 Richmond Street West, Suite 605, Toronto, Ontario, M5V 1V3, 1999.

*Women with Physical Disabilities: Achieving and Maintaining Health and Well-Being*. Krotsky D, Nosek MA, Turk MA (eds.) Brookes Publishing, 1996.

*You May Be Able to Adopt! A Guide to the Adoption Option for Prospective Mothers with Disabilities and Their Partners*. Barker, L.T. and Kirshbaum, M. Berkeley Planning Associates, 440 Grand Avenue, Suite 500, Oakland, California 94610-5085, 1997

# A PPENDICES

---

## APPENDIX B

### Interacting and Communicating with Women with Disabilities

Women with physical disabilities and chronic health conditions will feel most comfortable receiving health care if you consider the following suggestions.

#### General Considerations

Do not be afraid to make a mistake when interacting and communicating with someone with a disability or chronic medical condition. Keep in mind that a person with a disability is a person first, and, like you, is entitled to the dignity, consideration, respect, and rights you expect for yourself.

- Treat adults as adults. Address people with disabilities by their first names only when extending the same familiarity to all others present. Never patronize people by patting them on the head or shoulder.
- Relax. If you don't know what to do, allow the person who has a disability to identify how you may be of assistance and to put you at ease.
- If you offer assistance and the person declines, do not insist. If your offer is accepted, ask how you can best help, and follow directions. Do not take over.
- If someone with a disability is accompanied by another individual, address the person with a disability directly rather than speaking through the accompanying companion.
- Be considerate of the extra time it might take for a person with a disability to get things done or said. Let the person set the pace.
- Don't be embarrassed to use common expressions such as "See you later" or "Got to be running" that seem to relate to the person's disability.

#### People First Language

- Place the person before the disability. Say "person with a disability" rather than "disabled person." Since "disability" and "disabled" have separate and different definitions and meanings, the latter usage is not only a violation of people first language-- it is also incorrect in most cases.
- Avoid referring to people by the disability they have (for example, "an epileptic" or "blind people"). A person is not a condition. Rather, refer to "a person with epilepsy" or "people who are blind."
- People are not "bound" or "confined" to wheelchairs. They use them to increase their mobility and enhance their freedom. As assistive technology provides increased mobility, it is preferred to say a "person who uses a wheelchair." When asked the question, "How long have you been in that chair?" a person who uses a wheelchair replied, "Since this morning."

# A PPENDICES

---

## APPENDIX B cont.

### Mobility Limitations

- Do not make assumptions about what a person can and cannot do.
- Do not push a person's wheelchair or grab the arm of someone walking with difficulty without first asking if you can be of assistance and how you can assist. Personal space includes a person's wheelchair, scooter, crutches, walker, cane, or other mobility aid.
- Never move someone's wheelchair, scooter, crutches, walker, cane, or other mobility aid without permission.
- When speaking to a person seated in a wheelchair for more than a few minutes, try to find a seat for yourself so the two of you are at eye level.
- When giving directions to people with mobility limitations, consider distance, weather conditions, and physical obstacles such as stairs, curbs and steep hills.
- It is appropriate to shake hands when introduced to a person with a disability. People with limited hand use or who wear an artificial limb do shake hands.

### Vision Loss (Low Vision and Blindness)

- Identify yourself when you approach a person who has low vision or blindness. If a new person approaches, introduce him or her.
- It is appropriate to touch the person's arm lightly when you speak so that he or she knows to whom you are speaking before you begin.
- Face the person and speak directly to him or her. Use a normal tone of voice.
- Don't leave without saying you are leaving.
- If you are offering directions, be as specific as possible, and point out obstacles in the path of travel. Use specifics such as "Left about twenty feet" or "right two yards." Use clock cues ("The door is at 10 o'clock.").
- When you offer to assist someone with vision loss, allow the person to take your arm. This will help you to guide rather than propel or lead this person. When offering seating, place the person's hand on the back or arm of the seat.
- Alert people with low vision or blindness to posted information.
- Never pet or otherwise distract a canine companion or service animal unless the owner has given you permission.

# APPENDICES

---

## APPENDIX B cont.

### **Hearing Loss (Hard of Hearing, Deaf, Deaf-Blind)**

- Ask the person how he or she prefers to communicate.
- If you are speaking through a sign-language interpreter, remember that the interpreter may lag a few words behind—especially if there are names or technical terms to be fingerspelled—so pause occasionally to allow the interpreter time to translate completely and accurately.
- Talk directly to the person who has hearing loss, not to the interpreter. However, although it may seem awkward to you, the person who has hearing loss will look at the interpreter and may not make eye contact with you during the conversation.
- Before you start to speak, make sure you have the attention of the person you are addressing. A wave, a light touch on the arm or shoulder, or other visual or tactile signals are appropriate ways of getting the person's attention.
- Speak in a clear, expressive manner. Do not over-enunciate or exaggerate words. Unless you are specifically requested to do so, do not raise your voice. Speak in a normal tone; do not shout.
- To facilitate lip reading, face the person and keep your hands and other objects away from your mouth. Maintain eye contact. Don't turn your back or walk around while talking. If you look away, the person might assume the conversation is over.
- While you are writing a message for someone with hearing loss, don't talk, since the person cannot read your note and your lips at the same time.
- Try to eliminate background noise.
- Encourage feedback to assess clear understanding.
- If you do not understand something that is said, ask the person to repeat it or to write it down. The goal is communication; do not pretend to understand if you do not.
- If you know any sign language, try using it. It may help you communicate, and it will at least demonstrate your interest in communicating and your willingness to try.

### **Speech Disabilities or Speech Difficulties**

- Talk to people with speech disabilities as you would talk to anyone else.
- Be friendly; start up a conversation.
- Be patient; it may take the person a while to answer. Allow extra time for communication. Do not speak for the person.
- Give the person your undivided attention.



# A PPENDICES

---

## APPENDIX B cont.

- Ask the person for help in communicating with him or her. If the person uses a communication device such as a manual or electronic communication board, ask the person how best to use it.
- Speak in your regular tone of voice.
- Tell the person if you do not understand what he or she is trying to say. Ask the person to repeat the message, spell it, tell you in a different way, or write it down. Use hand gestures and notes.
- Repeat what you understand. The person's reactions will clue you in and guide you to understanding.
- To obtain information quickly, ask short questions that require brief answers or a head nod. However, try not to insult the person's intelligence with over-simplification.
- Keep your manner encouraging rather than correcting.

## Intellectual Disabilities

- Treat adults with intellectual disabilities as adults.
- When speaking to someone who has an intellectual disability, try to be alert to his or her responses so that you can adjust your method of communication if necessary. For example, some people may benefit from simple, direct sentences or from supplementary visual forms of communication, such as gestures, diagrams, or demonstrations.
- Use language that is concrete rather than abstract. Be specific, without being too simplistic. When possible, use words that relate to things you both can see. Avoid using directional terms like right-left or east-west.
- Be prepared to give the person the same information more than once in different ways.
- When asking questions, phrase them to elicit accurate information. People with intellectual disabilities may be eager to please and may tell you what they think you want to hear. Verify responses by repeating a question in a different way.
- Give exact instructions. For example, "Be back for lab work at 4:30," not "Be back in 15 minutes."
- Too many directions at one time may be confusing.
- Depending on the disability, the person may prefer information provided in written or verbal form. Ask the person how you can best relay the information.
- Using humor is fine, but do not interpret a lack of response as rudeness. Some people may not grasp the meaning of sarcasm or other subtleties of language.
- People with brain injuries may have short-term memory deficits and may repeat themselves or require information to be repeated.
- People with auditory perceptual problems may need to have directions repeated, and may take notes to help them remember directions or the sequence of tasks. They may benefit from watching a task demonstrated.

# APPENDICES

---

## APPENDIX B cont.

- People with perceptual or “sensory overload” problems may become disoriented or confused if there is too much to absorb at once. Provide information gradually and clearly. Reduce background noise if possible.
- Repeat information using different wording or a different communication approach if necessary. Allow time for the information to be fully understood.
- Don’t pretend to understand if you do not. Ask the person to repeat what was said. Be patient, flexible, and supportive.
- Some people who have an intellectual disability may be easily distracted. Try not to interpret distraction as rudeness.
- Do not expect all people to be able to read well. Some people may not read at all.

## Psychiatric Disabilities

- Speak directly to the person. Use clear, simple communication.
- Offer to shake hands when introduced. Use the same good manners in interacting with a person who has a psychiatric disability that you would anyone else.
- Make eye contact and be aware of your own body language. Like others, persons with psychiatric disabilities will sense your discomfort.
- Listen attentively and wait for them to finish speaking. If needed, clarify what they have said. Never pretend to understand.
- Treat adults as adults. Do not patronize, condescend, or threaten. Do not make decisions for the person, or assume their preferences.
- Do not give unsolicited advice or assistance. Do not panic or summon an ambulance or the police if a person appears to be experiencing a mental health crisis. Calmly ask the person how you can help.
- Do not blame the person. A person with a psychiatric disability has a complex, bio-medical condition that is sometimes difficult to control. They cannot just ‘shape up’. It is rude, insensitive, and ineffective to tell, or expect, a person to do so.
- Question the accuracy of media stereotypes of psychiatric disabilities. The movies and media sensationalize psychiatric disabilities. Most people never experience symptoms that include violent behavior.
- Relax. Be yourself. Do not be embarrassed if you happen to use common expressions that seem to relate to a psychiatric disability.
- See the Person. Beneath all the symptoms and behaviors of psychiatric disabilities is a person who has many of the same wants, needs, dreams, and desires as anyone else. If you are afraid, learn more about psychiatric disabilities.

Please note: *This material is adapted and based in part on Achieving Physical and Communication Accessibility, a publication of the National Center for Access Unlimited, and Community Access Facts, an Adaptive Environments Center publication and The Ten Commandments of Interacting with People with Mental Health Disabilities, a publication of The Ability Center of Greater Toledo.*

# A PPENDICES

---

## APPENDIX C

### Ten behaviors related to good health

1. Avoid smoking
2. Get 7-8 hours of sleep per night
3. Maintain weight within recommended limits for height
4. Get regular exercise
5. Consume little or no alcohol (1-2 drinks per day)
6. Eat breakfast daily
7. Avoid between-meal snacks
8. Being married is associated with improved health and longevity
9. Maintain contacts with friends and relatives with whom one feels emotionally close
10. Belong to a community group, e.g. a faith-based organization or service club

(Adapted from Berkman, L. & Breslow, L. Health and ways of living: The Alameda County study. New York: Oxford University Press, 1983.)

## APPENDIX D

(TABLE 2: Recommended Adult Immunization Schedule by Vaccine and Age Group)

### Recommended Adult Immunization Schedule by Vaccine and Age Group UNITED STATES · OCTOBER 2004 – SEPTEMBER 2005

Vaccine ▼	Age group (yrs) ▶	19–49	50–64	≥65
Tetanus, Diphtheria (Td)*		1 dose annually <sup>2</sup>	1 dose booster every 10 years <sup>1</sup>	1 dose annually <sup>2</sup>
Influenza		1 dose annually <sup>2</sup>	1 dose annually <sup>2</sup>	1 dose annually <sup>2</sup>
Pneumococcal (polysaccharide)		1 dose <sup>3,4</sup>	1 dose <sup>3,4</sup>	1 dose <sup>3,4</sup>
Hepatitis B*		3 doses (0, 1–2, 4–6 months) <sup>5</sup>	3 doses (0, 1–2, 4–6 months) <sup>5</sup>	3 doses (0, 1–2, 4–6 months) <sup>5</sup>
Hepatitis A*		2 doses (0, 6–12 months) <sup>6</sup>	2 doses (0, 6–12 months) <sup>6</sup>	2 doses (0, 6–12 months) <sup>6</sup>
Measles, Mumps, Rubella (MMR)*		1 or 2 doses <sup>7</sup>	1 or 2 doses <sup>7</sup>	1 or 2 doses <sup>7</sup>
Varicella*		2 doses (0, 4–8 weeks) <sup>8</sup>	2 doses (0, 4–8 weeks) <sup>8</sup>	2 doses (0, 4–8 weeks) <sup>8</sup>
Meningococcal (polysaccharide)		1 dose <sup>9</sup>	1 dose <sup>9</sup>	1 dose <sup>9</sup>

\*Covered by the Vaccine Injury Compensation Program. See Footnotes for Recommended Adult Immunization Schedule on back cover.

For all persons in this group
  For persons lacking documentation of vaccination or evidence of disease
  For persons at risk (i.e., with medical/exposure indications)

**The Recommended Adult Immunization Schedule is Approved by the Advisory Committee on Immunization Practices (ACIP), the American College of Obstetricians and Gynecologists (ACOG), and the American Academy of Family Physicians (AAFP)**

This schedule indicates the recommended age groups for routine administration of currently licensed vaccines for persons aged ≥19 years. Licensed combination vaccines may be used whenever any components of the combination are indicated and when the vaccine's other components are not contraindicated. Providers should consult manufacturers' package inserts for detailed recommendations.

Report all clinically significant postvaccination reactions to the Vaccine Adverse Event Reporting System (VAERS). Reporting forms and instructions on filing a VAERS report are available by telephone, 800-822-7967, or from the VAERS website at <http://www.vaers.org>.

Information on how to file a Vaccine Injury Compensation claim is available at <http://www.hrsa.gov/osp/vicp> or by telephone, 800-338-2382. To file a claim for vaccine injury, contact the U.S. Court of Federal Claims, 717 Madison Place, N.W., Washington, DC 20005, telephone 202-219-9657.

Additional information about the vaccines listed above and contraindications for immunization is available at <http://www.cdc.gov/hnp> or 800-CDC-INFO [800-232-4636] (English and Spanish).

# OTHER NCODH PUBLICATIONS \_\_\_\_\_.

## **Removing Barriers to Health Care: A Guide for Health Professionals**

A booklet, developed by NCODH and the Center for Universal Design at N.C. State University, that walks the health care provider through the process of making a medical facility physically accessible. It is complete with specific ADA requirements, picture illustrations, and some helpful tips on creating accessible environments and services.

## **Removing Barriers: Tips and Strategies to Promote Accessible Communication**

This booklet is an easy-to-read, quick reference guide that addresses the basics on ways to effectively communicate and interact with people with disabilities. Provides information and tips that can be incorporated in the workplace as well as in daily community living.

## **Partners in Health Care: People with Disabilities & Their Health Care Providers**

A brochure filled with tips for health care providers in promoting the health of people with cognitive and physical disabilities. Suggestions are given for people with disabilities on ways to help build positive partnerships with their medical care providers.

## **Orchid**

A special issue health and wellness magazine for women with disabilities that focuses on achieving wellness, not removing disability. Articles in Orchid include topics such as relationships, recreation and leisure, travel, and gardening. Orchid also offers an abundance of resource listings.