Practitioners' Guide To Primary Care for Women with Physical Disabilities

Berkeley Policy Associates and
Alta Bates Summit Medical Center,
Rehabilitation Department

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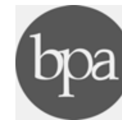

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Introduction

The Practitioner's Guide to Primary Care for Women with Physical Disabilities is a series of articles authored over the last several years by physicians and other health care professionals with specific expertise in delivering care to women with physical disabilities.

Berkeley Policy Associates and **the Rehabilitation Department of Alta Bates Summit Medical Center** have coordinated the development of these articles and put together this introductory booklet to provide basic information about the health care needs of women with physical disabilities highlighting some of the unique challenges and issues they face, and some general strategies for addressing the most common barriers.

The rest of the articles in this series address specific issues in much more detail. They are of two types: 1) articles that provide detailed treatment recommendations for specific clinical conditions and issues such as spasticity, immobility concerns, pressure ulcers, bowel and bladder management, pain management and reproductive health considerations; and 2) articles that address the women's health issues associated with specific neurological diagnoses including arthritis, stroke, cerebral palsy, multiple sclerosis, polio, spinal cord injury, and traumatic brain injury.

This series of articles will be available soon on the Berkeley Policy Associates website at berkeleypolicyassociates.com/practitionersguide at no charge. Please credit the article's author and cite the website if you wish to use any of the material. An index of the articles is included at the end of this booklet.

PRIMARY CARE FOR WOMEN WITH PHYSICAL DISABILITIES

Advances in medical science, and an emerging disability civil rights movement have contributed to a trend toward community-based living rather than institutional care. This trend has led to a significant increase in the number of women with physical disabilities who seek primary care from practitioners who wish to increase their knowledge of the ways that disabling conditions affect the delivery of care.

At least 10% of women in the general population, or over 13 million American women have physical disabilities (Census). Yet even with these large numbers, people with disabilities, and women with disabilities in particular, have been historically overlooked in medical research. Therefore research-based knowledge about their primary care and health promotion requirements is still limited (Stuifbergen and Becker, 1994). For example, crucial knowledge is lacking about how being both female and disabled affects the physiological processes associated with diseases, illness and aging (Nosek, 1992; Gill *et al*., 1994).

Fortunately, this situation is beginning to change, and researchers – sponsored by funders such as the National Institutes of Health – are now addressing the health care needs of people with a variety of physical disabilities, and are looking for ways to prevent or lessen secondary conditions or related health problems.

While current research is limited in some areas, practitioners who specialize in serving individuals with specific physical disabilities can offer tremendously valuable clinical experience that can be very useful to their colleagues whose practice has included few women with physical disabilities. In this guide we have made an effort to pull together the best and most practical information from both current research and clinical practice.

This information is especially timely as new consciousness is emerging among women with disabilities as well. The growing trend among members of the disability community is to approach the health care system with an attitude of "knowledgeable consumerism" rather than as patients, as individuals entitled to quality health care, rather than as passive receivers of services. This trend reflects the shift in the political climate within the disability community that began in the 1960s with the emergence of the disability civil rights movement (Peters, 1978).

A growing body of literature provides glimpses into the lives of women with disabilities as they struggle to be heard and understood, literature that is based on the true stories of women with disabilities as they encounter frustrations, prejudices, and “the joys of womanhood” (e.g., Fine and Asch, 1988; Browne *et al*., 1985; Finger, 1990, Panzarino, 1994). The emergence of the disability civil rights movement has led women with disabilities to increasingly use the Americans with Disabilities Act (ADA) to get their disability needs met in doctors' offices and health facilities (Gill, 1993; Saxton, 1994), and to expect to have their health concerns addressed from a health promotion philosophy rather than from a reactive medical approach.

Although much research is yet to be conducted, a great amount of information is already available about health promotion strategies

for women with disabilities. It is important for health care providers to be aware of prevention strategies and specific medical or clinical issues associated with specific disabilities. They need to understand the physiology underlying primary and secondary conditions to better select the most appropriate treatment management course. Women with disabilities also need to be aware about the possible clinical consequences of their own disability because secondary conditions (such as contractures, pressure sores, and urinary tract infections) are often preventable.

This guide is aimed at the primary care practitioners including physicians, nurse practitioners and physician assistants who play an essential role in caring for the general health of their patients who are women with disabilities. Further, in today's era of managed care, primary care practitioners are often the "gatekeepers" to the rest of the health care system, who must recognize medical and health care issues that indicate the need for specialists, therapies, adaptive equipment, personal assistance or other types of appropriate referrals.

THE HEALTH CARE NEEDS OF WOMEN WITH PHYSICAL DISABILITIES – AN OVERVIEW

Women with disabilities and chronic health problems are among the highest users of medical services (Saxton, 1996). Like other health care consumers, they need a variety of safe and appropriate medical services as well as access to medical technology and information. Too often, however, health care practitioners lack adequate information about the health care needs of women with disabilities. In some cases this may be due to the fact that the information doesn't yet exist. More often, however, the information is there, but not readily available to the busy practitioner. Sometimes, much of this information finds its way only to specialists rather than getting into the hands of primary care providers.

What Is Disability and How Is it Measured?

The current legal definition of disability is based on the Americans with Disabilities Act (ADA), which defines a person with a disability as an individual with "a physical or mental condition that substantially limits a major life activity, such as walking, seeing, hearing, learning, breathing, caring for oneself, etc." (DOJ, 1993). The more specific term "work disability" refers to a degree of compromise that significantly impacts a person's occupation. It is dependent on the interaction of her job demands and her condition. Accordingly, there is much interest in being able to predict present or future job disability accurately.

Being able to assess disability meaningfully, and recognize when interventions should be implemented, are two essential skills for the astute clinician. In an effort to quantify disability, many scales and mechanisms have been proposed. The activities of daily living (ADL) www.hartfordign.org/publications/trythis/issue02.pdf and instrumental activities of daily living (IADL) www.abramsoncenter.org/PRI/documents/IADL.pdf are simple assessments currently used to gauge the most basic aspects of daily function such as dressing, self-hygiene, toileting and grooming (Goldman, 2000). Quality of life questionnaires, such as the Short Form Health Survey (SF-36) http://www.swin.edu.au/victims/resources/assessment/health/sf36.html, may provide further insight into the burdens

associated with disabling conditions (Neumann). Under most circumstances, a simple classification system is most useful; one such system in use for rheumatoid arthritis, and applicable to other conditions, is as follows:

Class I: *No restriction of ability to perform normal activities.*

Class II: *Moderate restriction, but with an ability to perform most activities of daily living.*

Class III: *Marked restriction, with an inability to perform most activities of daily living and occupation.*

Class IV: *Incapacitation with confinement to bed or a wheelchair (Goldman,2000).*

Another example is the Stanford Health Assessment Questionnaire http://aramis.stanford.edu/HAQ.html. In addition to charting the course of illness and determining appropriate interventions, the classification of disease severity can have greater implications for patients. For example, financial resources (e.g. long-term disability insurance and Supplemental Security Income) may only be available when documentation of a certain degree of disability is documented.

Disability frequently has a psychological component. A study of patients with knee pain, for example, found that those with marked pain were more likely to suffer a diminished quality of life as measured by the SF-36, psychiatry co-morbidity, and a perception of overall poorer health (O'Reilly *et al*, 1998). Another study suggested that patients with osteoarthritis of the knee or hip often develop a cascade of cause-and-effect type changes leading to muscle weakness and negative effect (Dekker, 1993). It is rare for the disability resulting from even "minor" physical condition to be limited to the involved joint; usually many aspects of a patient's life are affected.

Being able to choose effective tools to measure disability and provide some insight into future patient livelihood are essential skills for the clinician to develop. With advances in medical research, as more effective treatments become available, the importance of early intervention and longitudinal measurement of disability are amplified.

Women with Disabilities Have Unique and Unmet Health Care Needs

In any discussion of the unique health care needs of women with disabilities, it is important to remember that to a large extent, their needs are those common to all women. All women share medical concerns such as obstetrics, gynecological and breast health issues, access to appropriate technology and information, and the need for their medical concerns to be included in research, regardless of whether they have a long-term disability. For many women with disabilities, however, services need to be adapted to respond to their disability-related needs. Women need clinicians to understand contra-indications and interactions between medications related to their disability and medications taken for

> ***"Doctors need to know to look for information if they don't have the answers. It's not possible for every doctor to have comprehensive information about women with disabilities, but they need to know where to get the information."***
>
> ***~ A Physician***

other reasons. For example, oral contraceptives may increase the risk of DVT especially in women with decreased mobility. SSRI's used for depression may increase spasticity complaints. Women with spinal cord injuries and neurogenic bowels and bladders may have increased spasticity due to urinary tract infections so it would be necessary to rule out this etiology or other underlying factor prior to increasing anti-spasticity medication treatment. Women with disabilities are still sexually active and seek information about reproductive health and sexuality. They need to work with clinicians who understand the ways that these matters may be affected by their disability.[1]

Many women with disabilities themselves also lack information about their own bodies (Nosek, 1992). Adequate counseling on birth control, sexuality, breast health, reproduction issues and childbirth is generally not available from either gynecologists or rehabilitation professionals due to the limited number of informed practitioners and the physical inaccessibility of health care facilities (Haseltine *et al.*, 1993). Some practitioners do not realize that many women, particularly those who did not benefit from mainstream health education classes or who have not received comprehensive rehabilitation, have not learned good nutritional and preventive behavior (Nosek, 1992). It is therefore important that primary care providers be very thorough in interviewing women with disabilities and aware of their potential need for basic health education.

Primary care practitioners also need to be familiar with a woman's need for personal assistance services (i.e., assistance with dressing, bathing, personal care, etc.), and the primary care clinician's (especially physician's) role in authorizing such services. The physician needs to be aware of whether the patient is receiving the needed care and if the care provider is well informed about personal care routines. Limitations in quality personal assistance services can be a major contributor to an individual's poor health (Nosek, 1992).

"Practitioners need to see disability not as a misfortune, but in social, political, and economic terms. If they do, this shifts their understanding of what providers have to do to provide good quality care. For example, instead of saying that a woman can't transfer onto a table, say, 'that table isn't accessible to that woman."

~ A Disabled Woman

[1] Statements from physicians and women with disabilities sprinkled throughout this guide are quotes from focus group discussions conducted as part of the research involved in developing the guide.

Access to Services

"We are disabled more by barriers of access than from the specific limitations of our bodies" (Browne *et al.*, 1985). While lack of physical access is the most obvious of barriers, access issues go well beyond stairs and doorways (Nosek, 1992; Gill *et al.*, 1994). In particular, access issues extend into practitioners' exam rooms, treatment rooms, and bathrooms. Equipment such as exam tables, scales, x-ray machines and mammography equipment must also be accessible. Access must also include the availability of staff to assist in the exam room, and to assist with dressing and/or transferring as necessary (Ferreyra *et al.*, 1982; Gill, 1993; Waxman Fiduccia, 1997). In addition, for some women with disabilities health providers may need to schedule extra time for medical appointments and procedures. (See the attached ***Accessibility Matters*** for hints and tips on making medical appointments and procedures accessible to women with disabilities.)

The Americans with Disabilities Act (ADA) has created federal, state, and local access requirements for all public facilities, whether or not they receive federal assistance. The ADA, which went into effect in January 1992, stipulates that all facilities providing services to the public be made accessible to the extent that it is readily achievable. This means that all privately-operated medical and health care facilities, including outpatient facilities, are covered under Title III of the ADA and their operations may not prevent any individual with a disability from full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations the facility offers (DOJ, 1993).

In addition to physical barriers to accessing health care services, many women with disabilities face financial barriers. Women with disabilities are among the poorest in this country (Berkeley Planning Associates, 1997; Gill, *et al.*, 1994). The unemployment rate among women with disabilities is estimated to be over twice that of women who do not have disabilities (76% vs. 36%) (Nosek, 1992). Women with disabilities who are employed often hold low salaried jobs that do not offer benefits, and thus lack health insurance. The combination of poverty and increased health-related needs means that many people with disabilities must spend a higher proportion of their resources on health services and health-related needs than people who do not have disabilities. Some of the reasons why women with disabilities put off seeing physicians, and thus lack preventive health care, include lack of, or limits to, health insurance (including Medicaid); need for accessible transportation; and lack of financial resources. Even preparing nutritious foods or getting exercise can be a challenge if one needs to pay for a personal assistant to accomplish it (Nosek, 1992).

"Treat me as a person, not a disease or research subject.

~ A Disabled Woman

Attitudinal Barriers

If health care providers do not see people with disabilities outside of the medical setting, they only see them as "patients" when they are ill (Saxton, 1996). Even without an acute medical condition, people with disabilities are often seen as ill. From this viewpoint, they are sometimes dismissed from usual responsibilities and social roles, and may be seen primarily as victims of disease (Nosek, 1996). As a result, some health care providers may hold some misguided beliefs about the lives of people with physical disabilities and about their need for the types of health promotion activities which might be prescribed for patients who do not have disabilities. Some common misconceptions are:

> ***"Many doctors don't believe that disabled women should get pregnant. They don't think we can be good mothers."***
>
> ***~ A Disabled Woman***

- People with physical disabilities can't or shouldn't exercise.
- Individuals with physical disabilities should expect to develop secondary conditions or health problems.
- People with physical disabilities should expect their conditions to get worse.
- People who are physically disabled are asexual or incapable of being sexual partners.
- People with physical disabilities are not able to be parents

Beliefs of this sort have a direct effect upon the type of health care services provided to women with physical disabilities. For example, if a woman is not perceived as being sexual, her health care provider may believe that she has no need for reproductive health care services (Nosek, 1996).

Women with disabilities sometimes encounter discrimination in the health care system both as women, and as individuals with disabilities. Being both female and disabled, they may find their health concerns disregarded and ignored by the research, policy-making and service delivery systems (Gill, 1992). In addition, some medical professionals may feel uncomfortable with women with disabilities if they cannot be "cured," rather than viewing disability "as an integral part of life" (Gill *et al.*, 1994). In a recent national study of women with physical disabilities 31% of respondents reported feeling that they had been refused care by physicians because of their disability (Nosek *et al.*, 1997).

> ***"I worry that if I were in a crisis situation, doctors might let me die because of perceptions about the quality of a disabled person's life, especially since I am single and without family or children."***
>
> ***~ A Disabled Woman***

Many individuals without disabilities, including physicians and other health care providers, may have difficulty imagining that a person with a disability might have a good quality of life. Disabled people may feel that others, even physicians, "devalue" their lives, as evidenced by very public "right to die" cases involving people with disabilities over the last few years (Shapiro, 1993). Recently, disability advocates have raised concern that people with disabilities have been sacrificed to the "right to die" movement because well meaning physicians believe their quality of life isn't worth saving (Gwin and Olin, 1996).

Some physicians may let their own views of disability affect how they deliver reproductive health care to women with disabilities (Odette, 1994). For example, while women without disabilities feel societal pressure to have children, women with disabilities are pressured not to have children (Haseltine *et al.*, 1993; Waxman Fiduccia, 1997). In some cases, women with spinal cord injury, for example, continue to be discouraged from becoming pregnant in spite of reports of good outcomes with appropriate medical attention (Baker *et al.*,1992).

Explicit or not, practitioner attitudes can affect the quality of care that women with disabilities receive, and many disabled women report avoiding general medical care because of their own mistrust of the medical profession. Specific complaints include:

- Physicians are not sensitive to their specific gynecological needs;
- Physicians are untrained in alternative approaches to performing pelvic exams; and
- Doctors frequently give the woman's disability the greatest attention (even when it is not warranted), such that primary health care services and preventive screening are often never completed (Peters, 1978).

Such attitudes can result in women with disabilities feeling "dehumanized" and being seen only in terms of their disabilities and not as individuals (Waxman Fiduccia, 1997).

Varying Needs Among Women with Disabilities

It is important to keep in mind that not all women with disabilities have the same needs. Both age and type of disability can have an impact on her health care needs.

Women with different disabilities have varying medical and access needs throughout their life cycle. Some needs overlap, but others are specific to their disabilities and ages. For example, women with tetraplegia resulting from spinal cord injuries need medical practitioners to understand bowel and bladder management, dysreflexia, osteoporosis, and the prevention and treatment of pressure sores. Some younger women may want practitioners to answer questions about pregnancy and childbearing.

Many women with physical disabilities are susceptible to decreased function or secondary conditions as they age (Berkeley Planning Associates, 1997). For instance, women who have had polio will need clinicians to understand the ways that aging and the possibility of post-polio atrophy syndrome may affect their functioning the need for adaptations to activities of daily living. Women with orthopedic disabilities that limit or prevent weight-bearing may have special concern about preventing osteoporosis and the risk for bone fractures. Women with

> ***"If a woman with a disability wants to improve her physical performance she is often asked, 'Why? You're disabled and you're doing well,' or told 'You're just getting older.'"***
>
> ***~ A Doctor***

episodic or progressive neuromuscular conditions, such as multiple sclerosis or lupus, may need help with adapting to their changing functioning. Those with spasticity associated with spinal cord injury, post stroke and post traumatic brain injury may worry about preventing contractures.

Summary

These needs may be seen as barriers, or they may be seen as opportunities for primary health care providers to improve the quality of the care for women with physical disabilities. With improvements in medical science, the general population generally benefits from high quality care, and our goal is for women with disabilities to receive that same high quality. Our goal is to support primary care practitioners in providing high-quality care to women with disabilities through compiling the best available information and current knowledge in research and clinical practice. It is our hope that primary care practitioners find the information and resources provided in this guide to be useful in their practice with women with disabilities.

Attachment

ACCESSIBILITY MATTERS: EXAM ROOM TIPS AND HINTS FOR ACCOMMODATING DISABLED WOMEN IN MEDICAL APPOINTMENTS AND PROCEDURES

Scheduling Issues

Schedule Extra Time for Medical Appointments

- It often takes more time for a woman with a physical disability to undress and to transfer on and off an exam table.
- A woman with a disability may have a more complex medical history requiring a longer than usual interview, especially at her first appointment.

Consider the Scheduling Needs of Women with Disabilities

- Office staff can ask disabled women who have poor endurance or weakness, and/or those on pain medications for the best appointment times for them. These factors may result in time preference needs. For example, a woman with multiple sclerosis may require an earlier appointment time if she fatigues by the afternoon.
- Transportation needs may also affect appointment times. Some women may have to depend on others or a county paratransit system for people with disabilities for rides. This can cause them to have less appointment time flexibility.

The Medical Interview

- It is important that health care providers always directly address the woman with the disability rather than the person who may accompany her. Women with speech impairments in particular frequently complain that health care providers erroneously assume that they have cognitive impairments and ask questions of those that may accompany her. If you do not understand a patient with a speech impairment, it is important that you ask her to repeat herself, apologizing for not understanding. It is often helpful to repeat or state the parts of the conversation you did understand. Never pretend that you understand when you don't. Patients with speech impairments may also choose to bring a friend or attendant to help interpret for her.
- Acknowledge the fact that people with disabilities frequently know a lot about their medical condition and their own needs. They may also have already tried a variety of treatments health care providers may recommend.
- Many women with chronic illnesses or disabilities may have developed techniques or methods for management of symptoms that may appear to providers to be unorthodox or misguided but are working for them. Even if providers don't understand the reasoning behind methods used, it is important to respect the experience and background that may have led to the decision to use these methods. Unless they appear to be definitely harmful, it is often best to just accept that this is what works for this particular woman. If it does seem to be harmful or to be having negative consequences, it is important to point this out in a respectful way. For example, you might say, "I find it interesting that method X works for you. In my experience, I find that method Y works better for these reasons."

Transfers

- It is best to use an adjustable height exam table – one that can be electrically lowered to about 19" from the floor for easier transfers for wheelchair users, and then raised up to an appropriate height for the examiner. An accessible exam table makes it much easier for patients to transfer and for staff to assist people with transfers. Many people with significant disabilities can transfer themselves with minimal or no assistance using an accessible table. Using an accessible table also allows a person with a disability to maintain their dignity, as well as prevent injury to themselves and to office staff. Accessible tables can also be well utilized for other patients who have difficulty getting on conventional exam tables, such as patients who are very frail, heavy or pregnant.
- If your office does not have an adjustable exam table, staff should be trained in safe lifting technique. The Americans with Disabilities Act "requires that medical and health care facilities must provide assistance to help lift patients onto the high tables, including lifting them if necessary."[2] However, lifting presents a safety risk to both patient and staff, and may feel very uncomfortable for patients so we highly encourage the use of accessible tables.
- There may be financial incentives for purchasing accessible exam tables: physicians or practices that do not have non-profit status may be able to use this purchase as a tax deduction. Congress has also amended the Internal Revenue Code to include tax incentives for businesses that incur expenses in removing architectural barriers or increasing accessibility for people with disabilities[3]
- Always ask the woman with a disability how she wants to be assisted in a transfer. Have her guide you in every step of the way.
- Health care providers need to be aware of sensation issues when transferring women with sensory impairments such as spinal cord injuries. Having paralysis may not indicate total lack of sensation. Being bumped in a transfer can still be very painful and can cause significant skin injury in women without good sensation. A transfer or moving patients on the table for an exam can trigger spasticity. Patients can have extensor spasms in the trunk or legs, or sustained clonus, especially in lower extremities with changes in position. As stated above, the patient should be asked to provide guidance on the best way to transfer or position her.
- Patients should never be left unattended on exam tables without side rails.

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[2] Council of Better Business Bureaus' Foundation (1992). *Medical Offices: Access Equals Opportunity - Your Guide to the Americans with Disabilities Act*, Publication No. 24-280.

[3] Council of Better Business Bureaus' Foundation (1992). Medical Offices: Access Equals Opportunity- Your Guide to the Americans with Disabilities Act, Publication No. 24-280.

Bowel and Bladder Issues

- For some patients with disabilities such as spinal cord injuries or multiple sclerosis, an exam or transfer may instigate an episode of bowel and bladder incontinence. This has to be dealt with in a way that maintains the patients' self-respect. If this is an ongoing problem for a patient, she may need to intermittingly wear Depends.
- Some women might have leg bags that may have to be emptied prior to a transfer.

Exam Techniques

- Loss of sensation may be very patchy. Some women may have sensation to deep touch. Different tracks of the spinal cord may be intact, resulting in selected preservation of different types of sensation, deep pressure, heat, or temperature. It is also important to note that some women may also be hyper-sensitive to touch.
- People with disabilities such as spinal cord injury may have pain even if sensation is not preserved below the level of injury. Dysesthesia, neuropathic pain, or deafferentation pain are just some types of pain that can affect patients with altered sensation.
- Any invasive procedure, such as a pelvic exam, urethral catherization, skin biopsy, or toenail removal can trigger dysreflexia in women who are susceptible. (See also the article on Autonomic Dysreflexia in Spinal Cord Injury.)
- When examining a person with spasticity, move slowly. Jerky movements can result in spasticity in legs and arms.

Making Lab Procedures Easier

- Enabling a patient to bring a urine sample to the office rather than have to provide a sample during the office visit may be much easier.
- For those on anti-spasmatic medications, ask the patient what times are best for them to be examined or have blood drawn.
- For patients who are susceptible to dysreflexia, certain lab procedures can trigger dysreflexia. (See also the article on Autonomic Dysreflexia in Spinal Cord Injury.)

Having an awareness of specific appointment and laboratory scheduling issues, interview considerations, and transfer and exam techniques useful for many women with physical disabilities will help make medical appointments more productive and satisfying for both the provider and the patient.

SUGGESTED READING

Removing Barriers to Health Care: A Guide for Health Professionals, The Center for Universal Design at North Carolina State University and the North Carolina Office on Disability and Health. For a free copy, call the North Carolina Office on Disability and Health at (919) 966-2932 or email bogues@mail.fgp.unc.edu. The guide may also be downloaded in either PDF or HTML formal or ordered from the NCODH (North Carolina Office on Disability and Health) web site at www.fpg.unc.edu/~ncodh

Welner, Sandra. (1999), *A Provider's Guide for the Care of Women with Physical Disabilities and Chronic Medical Conditions*. For a free copy, call the North Carolina Office on Disability and Health at (919) 966-2932 or email bogues@mail.fgp.unc.edu. The guide may also be downloaded in either PDF or HTML formal or ordered from the NCODH (North Carolina Office on Disability and Health) web site at http://www.fpg.unc.edu/~ncodh/Provider.pdf

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