

# HEALING HANDS



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## Dealing with Disability: Physical Impairments & Homelessness

*This issue of Healing Hands focuses on the special challenges that physical impairments present for homeless individuals and their caregivers. A future issue will address challenges in case management for homeless clients with cognitive and emotional impairments secondary to trauma, mental illness, and/or substance abuse. The following articles sketch the etiology and scope of physically disabling conditions frequently seen in homeless people, specify major obstacles they encounter, suggest what HCH providers can do to prevent or remove these barriers, and highlight special sensitivities that clinicians need to serve disabled clients effectively.*

To work in a Health Care for the Homeless project is to encounter a daily cavalcade of disabilities. Persistent physical and mental health problems commonly result in poverty and homelessness, and are only aggravated by life on the streets.

### DISABILITY DEFINED

"... a physical or mental impairment that substantially limits one or more of the major life activities."

*Americans with Disabilities Act of 1990*

One-fifth of surveyed homeless adults residing in New York City shelters reported a disease or disability that restricted their functioning.<sup>2</sup> In a national survey of homeless service users, 46 percent reported one or more chronic, debilitating conditions including arthritis, rheumatism, or joint problems (24%); high blood pressure (15%); and problems walking, a lost limb, or other handicap (14%). Over two-thirds (66%) reported mental or emotional problems, alcohol use, and/or use of illegal drugs during the past month.<sup>3</sup>

Risks of developing a disability while homeless are substantial. Exposure to the elements or to communicable disease in shelters, victimiza-

tion, nutritional deficiencies, co-morbidities, and limited access to health care increase the likelihood that minor disabilities in homeless individuals will become serious functional impairments.

People without homes are also at high risk for trauma, which may either cause or exacerbate physical disabilities. Twenty-two percent of surveyed homeless clients report being physically assaulted while homeless.<sup>3</sup> Disabled persons on crutches or in wheelchairs are especially easy targets for perpetrators. Underlying substance abuse or mental illness may increase their vulnerability to trauma and interfere with adherence to treatment of concurrent illnesses.

Occupational injuries, especially to the back and spine, are common sources of impairment among homeless people, many of whom are engaged in manual labor. The day labor available to homeless people is mostly construction work, which can cause and aggravate musculoskeletal disorders such as osteoarthritis.

"We see many day laborers aged 50 or older, whose bodies are worn out from the constant stress of construction work and manual labor," says **Ed Farrell, MD**, medical director of the Stout Street Clinic in Denver. "They are too

disabled to work at their trade, and too under-educated to be retrained in service or computer jobs that pay living wages."

**Sandra McMahan, MSSW, CMSW**, social services director at Metropolitan Nashville General Hospital in Tennessee, notes that carnival workers are an overlooked population that frequently incurs job-related injuries. "These laborers are highly transient. If disabled by accidents or a musculoskeletal disorder, they are left behind when the carnival moves on, and many become homeless."

Homelessness is so debilitating that the health and functional problems of homeless adults ages 45-64 are said to "resemble those of geriatric persons in the general population."<sup>4</sup> Although persons age 65 and over represent only two percent of surveyed homeless service users,<sup>3</sup> their numbers are increasing, according to HCH providers.

Health Care for the Homeless program coordinator **Karen Fields, RN**, Columbus, Ohio, reports that clinics in her city are treating more elderly homeless people than in past years. She is especially alarmed that some families living at the poverty level have deliberately abandoned disabled seniors to the shelters.

Half of all people 65 and over are currently disabled.<sup>5</sup>

Ed Farrell is also concerned about the aging homeless population. "All factors are in place

for the middle-aged working poor to be ensnared in a downward spiral leading to homelessness. Injuries frequently result in job loss. Next to go is living space, when folks can't pay the rent. After that, many become

clinically depressed or dependent on alcohol or drugs. That situation deteriorates into further joblessness and chronic homelessness," he explains. ■

## Overcoming Barriers for Disabled Clients

Coping with disabilities is hard enough for people with stable housing; for those who are homeless, it can be a Herculean task. Health Care for the Homeless providers recognize the challenges faced by disabled clients, and recommend the following approaches to assist them:

- Improve the accessibility of clinical and other facilities;
- Help clients apply for federal disability assistance, SSI-related Medicaid, and other entitlements;
- Provide holistic care and enhanced case management;
- Help clients obtain and store discounted assistive devices;
- Provide recuperative care services.

**ACCESSIBLE FACILITIES** Disabled people are entitled to accessible facilities. It's the law. The Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability in access to public accommodations, transportation, employment, commercial facilities, and telecommunications. ADA Title III protects equal access to doctors' offices, homeless shelters, transportation depots and day care centers, and permits private lawsuits as well as governmental remedies if ADA regulations are violated. The Architectural Barriers Act (ABA) requires buildings and facilities designed, constructed or altered with federal funds to meet federal physical accessibility standards.<sup>1</sup>

What do clinics that are accessible to physically disabled people look like?

- Reserved parking spaces and passenger-loading zones for vehicles carrying disabled homeless clients are ample and well marked.
- Entrances are protected from the weather by a canopy or roof overhang.
- Buildings with stairwells have elevators, ramps or lifts, automatic door openers, and lowered counters for nonambulatory persons.
- Barriers to entrances, hallways, restrooms, waiting areas and examination rooms are removed.
- Rooms are large enough to accommodate persons in wheelchairs and other assistive devices.
- Corridors are at least 36 inches wide for wheelchair mobility.

**Sandra McMahan** suggests that health centers create an advocacy and ethics committee to monitor compliance with government regulations, investigate patient complaints, and mediate disputes.

Sometimes clinics are inaccessible to disabled homeless persons because of rigid appointment scheduling, she adds, citing a shortage of after-hours clinics that treat homeless day laborers injured on the job. "These workers can't take time off for clinic appointments during the day, so they go to emergency rooms at night," she explains. Health

Inside the soup kitchen, I sit across from a scruffy, dirty white male with a broken arm. I ask him whether his arm hurts. He snarls at me that he broke it at the elbow, is taking lots of painkillers, and hasn't been able to work at his construction job for at least eight weeks. He struggles with the shrink-wrap that covers our junk food feast. I ask him if he needs help. First, he refuses and barks at me. After repeated failures to unwrap his food, he throws the plastic packages at me and demands that I open them. I do so and hand them back. He does not acknowledge my help, and starts complaining loudly about inaccessible hospital care, doctors in general, the free clinic, and his lack of medical insurance. He then demands that I return his used tray to the front of the dining room with the other used trays. He disappears before I return to the table.<sup>6</sup>

centers should schedule appointments on occasional evenings or weekends, she advises, or provide drop-in clinics with extended hours that do not require appointments.

"Many homeless people with disabilities are living on the land," observes **Karen Fields**. "The real problem is a shortage of affordable, accessible housing. Most of our homeless clients are employed, but at minimum wage or sporadically. Lease agreements are restrictive and expensive. Apartments are unavailable to persons with felony records, bad credit or no work histories." Even where housing is affordable, it may not be easily accessible to individuals with physical impairments.

### SSA DEFINITION OF DISABILITY

"... the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can last for a continuous period of not less than 12 months.

*Disability Evaluation under Social Security (The Blue Book)*<sup>7</sup>

**DISABILITY ASSISTANCE** About 10 million disabled persons depend on Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) to meet daily needs.<sup>8</sup> In most states, SSI is linked to Medicaid eligibility. To qualify for SSI, a person must satisfy the statutory definition of disability under the Social Security Act. SSI covers only functional impairments that preclude gainful employment for at least 12 months. Claimants must have income and countable assets below federally defined levels, and drug or alcohol abuse cannot be a major determining factor of their disability.<sup>7,9</sup>

A middle-aged man lives in his wheelchair. He ambulates with it and sleeps in it. The man is a double amputee and incontinent. He can't control his bladder. He never wears pants; the lower half of his body is covered only by rumpled, stained sheets. Although he habitually stays at a local shelter, he is barely tolerated, since he publicly relieves himself in jars or cans he carries, whenever and wherever. Thieves routinely steal his medications, assault him, and tip over his wheelchair. A health care worker insists that he belongs in a nursing home, but he has no documented mental disability. He has been unable to qualify for SSA benefits.<sup>6</sup>

Helping clients negotiate the SSA system is frustrating for many homeless service providers, who say the disability determination process is unnecessarily complex and time-consuming. Although it takes only seven days for Social Security Administration (SSA) field offices to complete necessary paperwork for a disability claim, it can take as long as 1,150 days to process a disability application, according to SSA Commissioner Jo Anne Barnhart, who is endeavoring to expedite this process. Hundreds of days are lost to application backlogs, incomplete applications, legal appeals, and other procedural delays. Disabled persons in households often wait two to three years to start receiving their checks.<sup>8</sup>

The situation for homeless people is far worse. Only 11 percent of surveyed homeless people receive SSI benefits, although 40 percent may be eligible.<sup>3</sup> SSI and related Medicaid benefits are frequently denied if a claimant has no fixed address. Homeless health care providers in several states report that most SSI applications are initially denied. Allowance rates for initial applications vary widely from state to state. In Oklahoma, the denial rate is reported to be as high as 95%. Massachusetts approves a higher percentage of disability claims than most states, but denial rates are twice as high for homeless claimants as for all disability claimants.<sup>9</sup> For those who eventually qualify, benefits are usually insufficient to cover the cost of housing.

Homeless advocates have petitioned SSA to simplify its eligibility process. In Berkeley, California, they filed a class action lawsuit charging state and Federal SSA agencies with systematically denying benefits to disabled homeless people. The suit alleges that federal regulations governing the evaluation and approval of SSDI and SSI are routinely violated, denying entitlements to thousands of the neediest applicants.<sup>10</sup>

"The majority of our clients in San Antonio have multiple disabling conditions including mental health problems," says **Marian Santillan Rabe, RN, FNP**, El Centro Del Barrio, San Antonio, Texas, echoing assessments by clinicians in other localities. "Entitlements are rarely approved based exclusively on physical impairments. But you can't force a client to get a psychological examination. Many clients deny having a mental disability, despite evidence to the contrary."

Unlike many other states, Colorado provides a supplemental old age pension/ health and medical care fund separate from Social Security to serve growing numbers of elderly, indigent people ineligible for federal entitlements. "But a person must be 60 years old to receive the state benefit," **Ed Farrell** says. "Working, middle-aged indigents or undocumented immigrants who are injured in day labor jobs aren't covered."

Inadequate documentation of impairments by a claimant's physician is one reason why Federal disability claims are denied. To meet the strict Federal definition of disability, clinicians must document the severity of a client's *functional* impairments and his or her work history. Providing a diagnosis alone is not sufficient.

In *Determining Disability: Simple Strategies for Clinicians* **James O'Connell, MD**, Boston Health Care for the Homeless Program, explains how clinicians can simplify this process.<sup>11</sup> O'Connell divides SSA's disability determination process into five steps, listing criteria for successfully completing each step plus shortcuts. He also offers letter-writing guidelines and documentation examples. By following these steps, clinicians can expedite approval of their clients' disability claims.

Another way in which HCH clinicians can facilitate SSI applications is through aggressive outreach to chronically homeless persons who shy away from clinics and SSA offices. **Jan Caughlan, MSW, HCH**, Baltimore, reports success using skilled social workers with expertise in disability outreach to help clients fill out SSI applications and carefully document functional impairments.

**HOLISTIC CARE** There is no one-size-fits-all treatment for disabled homeless persons. A multidisciplinary approach is optimal, according to Health Care for the Homeless providers. **Njide Udochi, MD, MPH**, medical director of the HCH project in Baltimore, Maryland, advises a holistic strategy for treating persons with disabilities. Dr. Udochi and her colleagues routinely conduct multidisciplinary conferences to integrate care for clients with injuries or disabling morbidities. "Our goal is to build a relationship with each client," she says. Medical care which "treats the whole person" is essential, she contends, together with health insurance coverage to make such care financially feasible. "SSI-related Medicaid benefits should be comprehensive and cover specialty care for physically disabled persons," says Udochi. "Universal health care is the ideal."

New York City's Department of Homeless Services is linked to a coalition of public and private agencies offering comprehensive health and social services — primary care, substance abuse treatment, mental health counseling, housing and employment assistance. Saint Vincents Medical Centers, one of the original McKinney Act grantees, are among more than 100 locations with on-site triage units that direct severely disabled homeless clients to appropriate, accessible facilities. St. Vincent's Manhattan is affiliated with shelters that specialize in clients who have trouble ambulating or are in wheelchairs, explains Homeless Health Care director **Barbara Conanan, MS, RN**. "Most of these shelters have a clinical component. Medical teams including case managers are

available five or six days a week to give special attention to disabled clients and develop appropriate care plans.”

Holistic health care also has a psychological dimension. It's important to remember that disabled individuals, especially those who are homeless, often crave attention and being touched, says **Suprenia Bond, RN**, manager of the Downtown Clinic in Nashville, Tennessee. “We used to give regular foot baths to homeless clients with foot lesions. The word on the street was we gave free foot massages. The clinic was inundated.”

**ASSISTIVE DEVICES** Touching can also be perceived as inappropriate. Clinicians may inadvertently offend disabled individuals by trespassing on their personal space. For example, leaning on a wheelchair, pushing it or resting one's feet on it without permission violates a person's integrity. An assistive device should be considered an extension of a person's body. Playing with a client's crutches or cane and patting a person in a wheelchair on the back, shoulder or head can be offensive. Most disabled people want good Samaritans to offer assistance before providing it.<sup>12</sup>

Canes, back braces, artificial limbs, wheelchairs, and technology for the visually or hearing impaired can be extremely expensive. To complicate matters further, assistive devices and medications are commonly misplaced or stolen from disabled persons in shelters or on the street, where they are frequently exchanged for cash. The cost of replacing them can be prohibitive.

Clinics serving homeless people must often rely on equipment donations and/or voluntary discounts from pharmacies or manufacturers, which may be unreliable. Health Care for the Homeless providers express the need for national or regional clearinghouses where federally qualified health centers can obtain discounted equipment.

**RESPITE CARE** The nationwide shortage of “respite” or “recuperative” care facilities presents another barrier for physically disabled homeless people. After inpatient or outpatient surgery, a homeless person may be discharged to the streets with no safe place to recuperate. Most shelters do not provide beds for respite care, or medically trained staffs to monitor the use of oxygen tanks or catheters.

“Someone who is exposed to weather, subjected to communicable diseases, poor nutrition, and no place to change dressings or store medications can't heal properly,” says Suprenia Bond. “Without a safe place to recover from surgery or serious health problems, even minor disabilities become extreme emergencies.”

**Karen Fields** has documented several cases of poorly managed hospital discharges in Columbus, Ohio: “One person was discharged from a city hospital to a shelter with chest tubes still in place, draining bodily fluids onto the shelter floor. Another man, blind in one eye, was sent to a shelter following a colostomy without extra colostomy bags or supplies. An indigent woman was discharged to the street during daylight hours, wearing only a hospital gown. A homeless worker was discharged following an above-knee amputation with only 800 milligrams of ibuprofen for pain, and no crutches or wheelchair.”

In another case, a homeless man with lung cancer needed his right lung lobe removed. Since there was no proper respite care available, he refused surgery and died in a shelter. Many homeless people with chronic medical conditions lack convalescent facilities, reports Fields. Especially worrisome are those with TB or other infectious diseases who are excluded from shelters.

One solution is pre-admittance workshops for homeless people scheduled for surgery, says Fields, where social workers assess the client's living situation, inquire about possible care partners, help clients complete insurance applications or disability claims, and negotiate with hospital administrators for longer recovery periods.

A distinguished, elderly gentleman with a woolly silver mane, intelligent piercing eyes, and a cavernous *basso profundo* lives full-time in a shelter. Both feet were amputated as a result of diabetes complications. For the first six decades of his life, he had home and family. He boasted a distinguished career as an award-winning editorial cartoonist for the longest, continuously published African-American newspaper. But ten years ago, he lost his wife to cancer and the newspaper to a libel suit. In his grief, he drank excessively and neglected his health. Now he makes himself useful by preparing food for the soup kitchen. Peeling oranges, he points to a young man who wears his baseball cap backwards. “That's our world today. They wear their caps the way they think,” the elderly cartoonist mutters.<sup>6</sup>

Another solution is the provision of respite care services. There are a variety of respite care models. Some HCH projects collaborate with shelters that set aside beds for post-surgery clients who can ambulate unassisted. Others have voucher agreements with motels and nursing homes.

The Barbara M. McInnis and Betty Snead houses, operated by the Boston Health Care for the Homeless Program, are prototypes of recuperative care. Their clients are admitted 24 hours a day, seven days a week from hospitals, shelters, emergency rooms and outpatient clinics. Medical care is provided daily. Pharmacy, dental and rehabilitation services are available on-site.<sup>13</sup> Respite patients receive free transportation to specialized care, detoxification, and behavioral health programs, if needed. Case management and social services are also provided. Clients are given three prepared meals a day, and can recuperate in private or multi-bed rooms. This model program is now at risk due to threatened cutbacks in Massachusetts' Medicaid program, which provides reimbursement for medical respite care.

Other respite centers limit the range and scope of services. Some HCH projects offer recuperative care for women with complications of pregnancy such as preeclampsia and gestational diabetes. Another specialized facility, MedRest in Seattle, serves disabled homeless youth.<sup>13</sup> ■

# Raising Clinicians' Disability Consciousness

What can practitioners of the healing arts do to help their disabled patients further? Most people with chronic disabilities do not expect miracles, asserts **Alicia Conill, MD**, founder of the Conill Institute for Chronic Illness in Philadelphia. Disabled people know there is no cure for multiple sclerosis, polio, or a missing limb. Besides alleviating discomfort and helping them hold onto the abilities they have left, people with disabilities expect health care providers to “understand their experience of illness and empathize with their emotional response to impairment.”

This is hardly news to experienced Health Care for the Homeless providers, for whom health and care are equally important goals. But even clinicians whose empathy quotient is high may not understand the practical impediments their disabled patients face. Walking a mile in another's shoes — experiencing first-hand the frustrations of coping with limbs or organs that do not function properly — is an experience not easily forgotten by clinicians.

And that is Conill's mission. She has challenged more than 350 new physicians and nurses to an ordeal that makes “reality TV” contestants on such shows as “Fear Factor” or “Survivor” look like wimps. For several harrowing hours, normally able-bodied medical and nursing students live with severe physical disabilities that are “assigned” to them. “They are horrified and astonished by what they have experienced, and sadder but wiser,” says Conill. “It's a far more comprehensive experience than sensitivity training.”

A general internist, Conill knows the “disability experience” first-hand. She closed her

practice in 1995 after being diagnosed with multiple sclerosis seven years earlier. Through her institute, new physicians and nurses focus on “collaborative, integrated care, including aspects such as communication and technological skills, ethics, diversity, pain control,

But the disabled community wants its worldview understood,” says Conill.

No bones are broken or limbs sawed off, nor is anyone deliberately exposed to infectious diseases. Instead, students first meet for a dinner, where they are given the

ground rules and such assistive devices as walkers, canes, wheelchairs, braces and crutches. Participants are divided into pairs of caregivers and receivers, and swap roles during the immersion experience.

“We teach students how to initiate a transfer from bed to chair and how to assist in a transfer without injuring themselves,” Conill explains. “Each pair receives a medical diagnosis, and we explain the relationship between patient and caregiver. They are given a list of observations to record and an itinerary which includes shopping at local stores.”

After this immersion experience, the frustrated and bleary-eyed students attend debriefings. Their major complaint? That basic, everyday tasks take “way too long.” The students find that allegedly accessible restrooms are inaccessible. Outside, curbs and sidewalks are unfriendly to wheelchairs and crutches. Worse, the students are objectified — stared at or

condescended to by insensitive people. This amounts to insult compounding injury — an experience that chronically disabled individuals know well.

To combat the isolation imposed by disabilities, Conill suggests that clinicians provide social centers apart from shelters or clinics for disabled clients. “There are groups for veterans to network, and numerous self-help groups which meet regularly for emotional

## TIPS FOR CLINICIANS SERVING CLIENTS WITH PHYSICAL DISABILITIES

- **Speak at eye level** to create rapport with clients in wheelchairs.
- **Talk directly to clients.** Look directly at disabled clients when addressing their needs.
- **Encourage the use of care partners.** If a care partner is available and the client is willing, invite him/her to accompany the client to health care visits.
- **Don't turn disabilities into handicaps.** Redesign office entrances for wheelchair ramps, add devices to raise toilet seats, use “sling” scales to weigh disabled clients.
- **Specify physical therapy goals.** When referring to a physical therapist, specify desired outcomes and conditions that cause discomfort or exacerbate symptoms.
- **Allow extra time** to care for clients with impaired mobility. Don't ask disabled clients to undress and sit on the exam table at every visit. When an exam is necessary, allow clients to undress at their own speed.
- **Evaluate the whole client.** Clients have other health issues that are unrelated to their disabilities.
- **Care, even if you can't cure.** Address symptoms and improve clients' quality of life by understanding the barriers they face and helping them to overcome them.

*Alicia Conill, MD, Philadelphia, Pennsylvania<sup>15</sup>*

nutrition, complementary therapies, spirituality, and improved educational models.”<sup>14</sup>

Starting with 14 voluntary participants in 1998, the “Disability Experience” program has been mandatory for medical students at the University of Pennsylvania since 2000. Nursing students at Villanova University followed suit one year later. “Some students were concerned that they were being disrespectful because they faked their disabilities.

support. Disabled homeless people can be empowered in this way too," she explains, citing her involvement with the National Multiple Sclerosis Society.

Regardless of the facilities or services available, the need for compassionate care remains — for all homeless people, not just those with obvious disabilities. Such barriers as inaccessible facilities, entitlement restrictions, assis-

sive device shortages, and inadequate respite care can be perceived as stumbling blocks or challenges. Whatever a clinician's response, empathy is paramount. ■

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