

HEALING HANDS



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Dealing with Disability: Cognitive Impairments & Homelessness

Homeless people with cognitive impairments affecting thought, memory, speech, and/or psychosocial competence present some of the toughest challenges that clinicians face. Indeed, too many choose to avoid these difficult clients altogether — an option that experienced homeless assistance providers find unacceptable. The following articles describe the complex tapestry of cognitive disabilities and homelessness, and specify practical strategies to assure that these extremely vulnerable people receive the assistance they need to achieve stability, minimize dysfunction, and maximize competency.

Fundamental to our ability to function in the world is the capacity to process information, communicate clearly, and interact fruitfully with others. Impairment of these cognitive skills presents serious obstacles that become virtually insurmountable for individuals without stable housing, social supports, and assistance from knowledgeable and compassionate caregivers. Cognitive disabilities are functional impairments associated with disorders of the brain, resulting from trauma, mental illness, chronic substance abuse, developmental disabilities, diseases, or toxic agents that affect the central nervous system.

People with cognitive disorders often feel misunderstood or misinterpreted. Deficits in perception, thought, memory, and speech frequently trigger psychosocial problems, aberrant behaviors, withdrawal, and isolation that can precipitate and prolong homelessness. Cognitive deficits can also interfere with service access, accurate diagnosis, and effective health care. It is not unusual for cognitively impaired homeless people to be “banned” by service providers for unpleasant behavior or failure to comply with prescribed treatment. Many such clients fall through the cracks of fragmented health and social service systems in which no particular agency or individual takes responsibility for them. As one brain-injured client reported, “I can’t help myself, and no one else will help me.”

Experienced Health Care for the Homeless providers maintain that successful interventions and outcomes are possible, even for homeless individuals with significant levels of impairment. Flexible service systems, integrated health and psychosocial services provided by a multidisciplinary team, and client-centered care are among the prerequisites for success. Engagement in a therapeutic relationship based on trust and development of a plan of care influenced, where possible, by the client’s own perception of what constitutes well-being and quality of life, are essential to this process.²

WHAT IS COGNITIVE DISABILITY?

- A direct result of brain disease or injury, involving perception, information processing, and formulation of a verbal or motor response.
- Can affect attention, memory, language, recognition, visual/spatial functioning, ability to perform unfamiliar tasks, awareness, organization, and regulation of behavior.
- May involve impairment of memory [amnesia] or language [aphasia] or a combination of deficits, as in mental retardation and dementia.
- Except in cases of traumatic brain injury, stroke, and some developmental disabilities, etiology is not well understood.

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ETIOLOGY Cognitive deficits have multiple causes, some of them not well understood. Among the most serious cognitive disabilities seen in homeless people are those resulting from *traumatic brain injury* (TBI), frequently seen in males under age 40. Vehicular accidents (being hit by cars), falls, assaults, gunshot wounds and violent shaking are common causes.

There is evidence that homeless individuals bear a disproportionate risk for severe head injury, which increases with prolonged homelessness. Of more than 2,000 homeless people surveyed during hospital visits in Broward County, Florida, 24% reported severe head injuries, compared to 1% of the general population, according to occupational therapist **Georgiana Herzberg, PhD**, a professor at Nova Southeastern University in Ft. Lauderdale.

“There is a positive correlation between time spent homeless, usually two-to-five years, and severe head injury,” says Herzberg. “The functional implications of severe head trauma are greater, however, if injury occurs in childhood and impacts the achievement of developmental milestones.” The kind and extent of functional impairment also depends on which areas of the brain are damaged, as well as the person’s abilities and personality traits prior to injury.

Other cognitive impairments often seen in homeless patients are associated with *acquired brain injury* (ABI) secondary to mental illness, chronic substance abuse, infection, strokes, tumors, poisoning,

or near drowning; or with *developmental disabilities*, including mental retardation and progressive neurological disorders such as multiple sclerosis and Alzheimer’s disease.

DIAGNOSTIC CHALLENGES Multiple co-morbidities, which are characteristic of homeless patients, complicate diagnosis of the underlying cause(s) of disability. For example, cognitive impairment in a homeless patient with HIV may be indicative of AIDS-related dementia, depression, opportunistic infection, or a side effect of medication, including chronic “self-medication” with psychoactive substances.

Symptoms of some diseases mimic organic brain disorders — e.g., confusion, incoherence, and distorted speech caused by very low blood sugar levels in patients with uncontrolled diabetes. Clients whose disabilities impede communication can be under-diagnosed or diagnosed incorrectly. People with mental retardation or pre-lingual deafness are sometimes diagnosed with psychosis, resulting in inappropriate treatment.

COGNITIVE COMPETENCIES “The main issue is whether the client is competent to participate in treatment decisions,” stresses **Fred Osher, MD**, Director of the Center for Behavioral Health, Justice, and Public Policy and Associate Professor of Psychiatry at the University of Maryland School of Medicine. “Clinicians need to test for specific competencies: Can the client understand directions? Make competent decisions? Organize time well? Diagnosing disability determines treatment strategy.” Competency can change, warns Osher. Case managers should reassess plans of care periodically and make changes, if necessary, in collaboration with the client or, if determined legally incompetent, with the client’s appointed guardian.

Reliable tests to assess cognitive competencies can be used by screeners who are not mental health professionals. The most popular tool, says Osher, is the **Mini-Mental Status Examination (MMSE)** — a 25 item questionnaire that can be answered in 10 minutes, testing orientation, attention, immediate and short-term recall, language, and the ability to follow simple verbal and written commands. Scores fall within thresholds indicating levels of cognitive function. “This exam, which screeners can be easily taught to administer, allows for individualized treatment plans and should probably be given to every homeless person with a suspected cognitive disorder,” advises Osher. [For more information, see www.minimental.com/.]

Case managers should evaluate the “whole person,” not just cognitive disabilities and competencies, adds **Yvonne Perret**, Executive Director of the Advocacy and Training Center in Cumberland, Maryland. “For clients who are able to communicate coherently, it’s important to focus initially on meeting basic needs,” she says. “Search for the underlying meaning in client communications, even if they seem unclear, and provide help as needed. Do what you say you will do; don’t over-promise and under-deliver. Remember that people need choices to have a sense of control over their lives.” ■

LEVELS OF COGNITIVE DISABILITY

- **Mild impairment** — often seen in clients with attention deficit hyperactivity disorder (ADHD) or learning disabilities. Service priorities are meeting basic needs for food and shelter, medication management, vocational assessment, and counseling. Standard interventions include cognitive therapy, life skills training, and assistance with schedules; more specialized assistance is not required. Once stabilized in transitional housing, mildly impaired individuals can usually find and maintain employment and become self-sufficient.
- **Profound impairment** — a consequence of [untreated], serious and persistent mental illness (e.g., schizophrenia, schizoaffective disorder, bipolar disorder). Homeless individuals with these disorders require assistance in applying for disability benefits and related health insurance coverage (Medicare/Medicaid) to assure their access to specialty care and medications. Advocacy to help them meet basic needs and a representative payee are usually necessary. These clients are difficult to keep engaged, and may be committed to psychiatric hospitals or incarcerated for violent and aggressive behaviors or even minor offenses such as trespassing.
- **Temporary impairment** — frequently occurs as a result of alcohol or drug abuse, dependence or withdrawal. It can also be induced by acute medical conditions (i.e., delirium) as a result of infection or medication. Optimal care includes medical evaluation and treatment, detoxification, substance abuse counseling, and transitional housing. Most of these clients can be self-sufficient in time.
- **Permanent impairment** — can result from “huffing” (inhaling glue, aerosol, paint, freon and other toxic substances), traumatic brain injuries, AIDS, or other degenerative health problems. These clients usually need assistance in applying for disability benefits (SSI/SSDI), food stamps, supportive housing, transportation to medical appointments, and other social services. Shelter is essential to stabilize these individuals and keep them engaged in treatment.

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Effective Case Management Strategies

Successful case management for cognitively impaired homeless individuals rests on four principles — intensity, longevity, repetition, and support — observes veteran HCH provider and community psychiatrist **Fred Osher, MD**.

INTENSITY Reduce case loads, spend significant amounts of time with each client, and engage the client in a nurturing, caring, trusting relationship, advises Osher. These things are critical to development and implementation of an effective plan of care for homeless persons with cognitive disabilities.

“Use reflective listening to better understand what your client is saying. Mirror the client’s comments with your own; reflect what you are hearing, and probe further. Convey respect for the individual, and use motivational interviewing³ to explore and resolve ambivalence about setting self-imposed goals. Essential to this process is the development of a partnership based on mutual trust.”

Many homeless health care clinics use intensive case management approaches that resemble *Assertive Community Treatment (ACT)*, an evidence-based model that has been successfully adapted to meet the needs of homeless clients with severe cognitive and co-occurring disorders.⁴ Clinics using this approach design intensive, specialized packages of client-directed services. The client is actively engaged in treatment, from the initial screening and identification of disability to remission or control of symptoms. Stable housing, satisfying work, and caring relationships are ultimate goals of case management.

LONGEVITY Since cognitive impairment is a chronic condition for most patients, short-term interventions are unlikely to be as effective as long-term strategies. For ambulatory clients without fixed addresses or dependable transportation, follow-up by telephone or through outreach to shelters and other sites is crucial to maintaining continuity of care.

Severely impaired clients may reject staff intervention, warns **Janet Caughlan, LCSW-C**, coordinator of mental health and case management services for Health Care for the Homeless, Baltimore, Maryland. There are many starts and stops with clients who have fixed and sometimes-inaccurate ideas about the health care system, she says. For some individuals, the best clinicians can do is to keep them from getting worse. “Sometimes it’s more important to focus on process than outcomes. Case management is like a patchwork quilt; every client’s square is unique.”

Access is the major issue, HCH clinicians agree. “A case management team can help a vulnerable client complete Social Security benefits and housing applications, but most agencies offer such a narrow range of services that many clients, especially active substance users, are screened out,” says Caughlan.

“Most service systems deny access to clients who don’t fit their paradigm, instead of trying to work with them by building relationships. That’s where these systems fail.”

*Jan Caughlan, LCSW-C,
Baltimore, Maryland*

Follow-up strategies She recommends four useful interventions to facilitate follow-up:

- *Payee program* – a place for clients to receive benefits payments and follow-up letters from case managers.
- *Adherence program* – to set up appointments, track no-shows, monitor medications, and arrange transportation or travel partners.
- *Alternative sentencing team* – finds alternatives to incarceration for homeless people with mental disorders.
- *Central referral system* – to identify health care providers who will treat clients refused by other providers.

REPETITION Homeless persons with dementia or co-occurring mental illness and substance abuse require repetition of instructions and plans of care many times. Role-playing and portable reminder cards with distinctive colors, kept in a plastic sleeve, can help to reinforce this information between clinic visits. Case managers frequently provide printed information cards that include the clinic address and location, a 24-hour emergency telephone number, and space for the client’s personal information, including current medications. Pocket calendars help disorganized clients keep appointments and adhere to a routine. Clinicians are advised to schedule regular appointments for these clients on the same day, at the same time and place.

Simplicity and repetition are key, says Caughlan. “Pick and choose a single topic and stick with it. If you are discussing SSI benefits, for example, only deal with that issue. Extraneous information can confuse clients with cognitive deficits.”

SUPPORT Optimally, dealing with cognitive disability requires collaboration with neurologists, radiologists, psychiatrists, neuropsychologists, occupational therapists, and speech pathologists. But with limited budgets and facilities, many clinics can provide only basic care with periodic visits from or referrals to specialists. Skilled case managers are essential to keep doors to needed health and social services open for these clients.

Case management teams Many HCH clinics use multidisciplinary teams coordinated by a designated case manager, who may be a physician, nurse, or other health care worker. Teams usually include stable consumers as active support workers. Graduate students in psychology or social work interns can be used to assess clients’ cognitive competencies and help them complete applications for Social Security, Medicaid, and other benefits.

Deborah Field, MD, medical director of the Homeless Outreach and Advocacy Project in

Worcester, Massachusetts, strongly recommends a team approach to case management, particularly for clients with significant impairments. Essential elements of this strategy include:

- *Multidisciplinary case management teams* that meet regularly;
- *Easily learned case management systems and low case loads* for each case manager; [10:1 is optimal⁴]
- *Local service networks* including hospitals, shelters, mental health centers, and other public and nonprofit organizations;
- *Flexible, intensive, short-term interventions* during transition from homelessness to stable housing.

The *Dartmouth Assertive Fidelity Treatment Scale* is a useful tool to assess how well different aspects of a multidisciplinary case management team are functioning [available at: www.dartmouth.edu/dms/psychrc/pdf_files/IPS_FidelityScale.pdf].

Help with medications To facilitate treatment adherence, provide customized pillboxes or “bubble packs” containing a week’s supply of prescribed medications, recommends Field. Her clinic encloses a card listing a dedicated telephone number to call for refills or in emergencies. Callers reach a central location where all prescriptions written by clinicians at various sites are recorded. “Many clients don’t know who prescribed their medications and contact the wrong doctors for refills. Having all records in a central place eliminates this problem,” explains Field.

Clients with severe cognitive impairments are encouraged to visit the clinic daily for directly observed therapy or injections. These visits also provide opportunities for social support. If necessary, outreach teams deliver daily dosages to clients at shelters or subsidized housing, where they can observe medication use and re-educate clients who are not taking medications as prescribed. For

clients who are functionally illiterate, clinic staff use photographs or pictures from magazines, journals or manufacturer’s inserts to illustrate instructions.

Benefits assistance Homeless people with cognitive impairments need disability assistance (SSI/SSDI) and health insurance coverage linked to disability determination (Medicaid/Medicare) to achieve stable housing and access to appropriate care. But a two-year waiting period for SSI is typical in most states. The University of Maryland’s SSI Outreach Project helps clients expedite this process and links them to other community services. The outreach team serves clients referred by transitional

Yvonne Perret, who directed this project for ten years. “Find out if they can read, but don’t make them feel stupid for being illiterate. Involving clients in developing a plan of care and respecting individual differences helps to build trust and strengthen motivation. Coercion leads to failed treatment plans and rejected services.”

Protective services Clients determined incompetent to participate in treatment decisions are exceptions to this paradigm, notes **Rexine McKinley, RN**, of the Maricopa County Public Health Department’s HCH project in Phoenix, Arizona. “Elderly homeless people and persons with alcohol or TBI-related

dementias normally can’t make good decisions. We try to get them into a safe environment, sometimes utilizing Adult Protective Services or Safe Haven shelters.”

MULTIPLE DIAGNOSES

Cognitively disabled persons with co-occurring alcohol or drug use problems are frequently unable to access or benefit from traditional substance abuse treatment programs. Some programs are too rapidly paced, and counselors lack skills for dealing with these clients, who may be unaware of the effects of substance abuse. Therapists may interpret this as denial.

Mike Misgen, MA, LPC, PATH program manager at Stout Street Clinic in Denver, Colorado, recommends the Strengths Model of Case Management for dually and multiply diagnosed clients. This approach focuses on finding concrete solutions to daily challenges

related to alcohol or drug addiction, while taking the client’s goals and disabilities into consideration when developing a plan of care.

The goal of the Projects for Assistance in Transition from Homelessness (PATH) program is to provide community support services to individuals with severe mental illness, including those with co-occurring substance

PRACTICAL CASE MANAGEMENT TECHNIQUES FOR CLIENTS WITH COGNITIVE DISABILITIES

Emotional Support

- Speak clearly, using a calm and reassuring tone, in an adult voice.
- Use client’s name to get attention and maintain eye contact.
- Eliminate the impossible; do only what is realistic.
- Avoid confrontations and arguing.
- Encourage client to slow down; it’s all right to take one’s time.
- Use non-verbal expressions: nodding, smiling, and pointing.

Reducing Confusion

- Provide orientation. Use calendars, clocks/watches, signs.
- Avoid confrontation; don’t ask clients to justify their decisions.
- Redirect as necessary; model calm behavior.
- Keep environment structured and familiar.
- Assess level of stimulation needed.

Memory Aids

- Help clients keep a memory journal.
- Help maintain a regular, predictable, structured routine.
- Always write appointments down on client’s calendar.
- Help client set small goals; break complex tasks into simple steps.

Adapted from: AIDS Caregiver Education Program, Compass Cascade Women’s Program, Seattle, Washington

housing programs, shelters, drop-in centers, and state agencies. Clinical evaluations are conducted during several client encounters. A report specifying diagnoses and functional impairments is submitted with the SSI application to Disability Determination Services.

“Case managers must listen carefully to their clients and clarify what is unclear,” says

abuse disorders, who also are homeless or at risk of homelessness. PATH program staff in Denver build cooperative relationships with local law enforcement agencies, landlords, and mainstream health providers. The Shelter Plus Care program, nursing homes, and sympathetic landlords provide stable housing for PATH clients.

Misgen recalls a client with schizophrenia who spent his time collecting metal cans. "He thought he was a government employee. PATH staff gained his trust by talking with him, getting his laundry washed, and allowing him to make popcorn for people in the waiting room," says Misgen. "We let him collect our empties for a year and eventually moved him from the abandoned parking garage to an apartment. He had to be trained for apartment living — to leave his cart outside the door and store cans in closets. The landlord keeps an eye on him and notifies us if he seems to need help."

INAPPROPRIATE BEHAVIORS

Some cognitively disabled clients are habitually aggressive. Because of their threatening behaviors, they may burn all bridges to care. Such clients may be acting out, or may simply suffer severe vision or hearing problems, or are frustrated by linguistic barriers. Others are mistrustful and suspicious of health service providers. Intoxication frequently triggers hostility. Caring but overworked clinicians may find themselves reacting to these behaviors in frustration, anger, or concern for their own safety.

Judith L. Allen, DMD, Healthcare for the Homeless-Dental Program, Cincinnati, Ohio, recently treated such a client, who required multiple appointments to extract all 28 teeth. Allen happened to mention that her home was near the temporary shelter where the client was living. The man wandered into her neighborhood looking for her, usual-

ly intoxicated. When the client's dentures were discovered under the windshield wipers on her car, Allen alerted police and learned the client had been arrested 18 times for assault. Other cognitively impaired clients have attempted to extract their own teeth, leaving broken and abscessed roots. "Extreme pain can push these very fragile people to their emotional limits," notes Allen.

The best response to such situations is a graduated one, according to case managers. First, try to help the client identify the inappropriate behavior and the reasons behind it. Then ask the client to propose a solution that includes behavioral change. If that fails,

uations, advises **Yvonne Perret**. "Talk down escalating situations; speak softly if clients yell at you, and give them physical space. Don't try to handle the situation alone. Supportive case management teams can help find creative solutions," she says.

"Sometimes staff confronted by hostile clients just need to take a break," remarks **Margaret Hobbs, MSW**, clinical supervisor at Community Connections, an outreach program in Washington, D.C. that serves individuals with severe mental illness. Money disputes related to payee programs frequently trigger inappropriate behavior, she observes. In payee conflict cases, a mediator or someone trained in conflict resolution should be present.

Behavioral contracts

Constructive ways to respond to undesirable client behaviors include negotiating service goals (giving clients ownership of outcomes) and goal-attainment scaling (rating the degree to which goals are achieved). Validating a behavioral contract is an important step toward eliciting behavioral change, says Hobbs. Contracts should state which client behaviors are inappropriate and self-destructive. In return, health care workers provide treatment plans in writing.

These reciprocal contracts are positive rather than punitive agreements. They are sometimes linked to rewards (e.g., toiletries, food coupons, bus tokens, etc.) for cooperative clients, explains Hobbs. Contracts state realistic expectations for treatment. For

their part, staff agree to provide services consistently and avoid power struggles with clients. Trust is essential, and paternalism is disallowed, says Hobbs, to ensure that vulnerable clients with cognitive disabilities perceive clinics as "safe places."

COMMUNICATION Cognitive disabilities that affect speech, language, and vocal func-

EFFECTIVE COMMUNICATION PRACTICES

Simplify Language

- Use very clear and specific language. Avoid abstractions.
- Use short, concise instructions.
- Give verbal information slowly; pause for processing time.
- Repeat information as needed. Use different wording if necessary. Provide corrective feedback.
- Use open-ended questions.
- Use humor, but don't interpret unresponsiveness as rudeness. Sarcasm or subtleties may not be grasped.

Respect Clients

- Treat adults with cognitive disabilities as adults.
- Be patient and flexible with clients who respond slowly.
- Be alert to responses and adjust communication methods. Use diagrams or demonstrations.
- Eliminate or reduce background noise so clients with perceptual or sensory overload problems will not become disoriented.
- Ask inarticulate clients to repeat concerns or questions.
- Realize that some clients may have literacy problems.

Based on information produced by the Adaptive Environments Center, Boston, Massachusetts⁵

temporary sanctions can be invoked. Clinicians should refer clients they cannot manage to other health care providers who have the skills and willingness to treat them. Permanent banning of clients should be considered only when they jeopardize the safety of staff or other clients.

Teach staff how to de-escalate dangerous sit-

tions restrict social interactions and prevent clients from negotiating needed services or managing self-care. Such clients often have discerning but selective “street smarts,” but have trouble navigating complex benefits systems or the workplace.

Outreach staff can conduct exercises at clinics or shelters to help these clients develop communication and reasoning skills, suggests **Georgiana Herzberg**. “People with cognitive disabilities need concrete learning experiences to help them regain or maintain dignity and control. Communication is most effectively learned through active problem

solving and decision making,” she says.

Group meetings stimulate communication with and among clients, and enable them to exercise speech and thinking skills. Groups focused and supervised by stable consumers are particularly effective, often involving art or discussion of issues related to treatment.

One exercise involves stringing colored “power beads” on a chain — a process-oriented task that helps clients consider reasons for their choice of design and colors. In this exercise, clients demonstrate their skills rather than talking about them, explains

“Living with a cognitive disability is like negotiating life in a foreign country where the traveler does not know the language or cultural rules.”

Georgiana Herzberg, PhD,
Ft. Lauderdale, Florida

Herzberg. Working in groups helps clients to interact and learn to treat teammates with respect. After the exercise, group members critique the process, which reinforces their reasoning and communication skills. ■

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