

Module III. Independent Living & Working with People who have Disabilities

Independent Living

The term “independent living” stems from the philosophy that people with all types of disabilities should have the same civil rights, options, and control over choices in their own lives as do people without disabilities. The philosophy of independent living involves shifting attitudes away from dependency, pity, and charity to advocacy, integration, and removal of architectural and other barriers. The “Independent Living Movement,” which began in the U.S. in the late 1960’s, brought this philosophy into the realm of contemporary thinking and thus aided in the changes that have been made and continue to be made in the provision of services to people with disabilities.

The first Center for Independent Living (CIL) was organized in Berkeley, California by a group of students with disabilities. Ed Roberts, who is considered the “father” of independent living was one of those individuals. Based largely on Ed Robert’s testimony, the U.S. Congress gave the Commissioner of the Rehabilitation Services Administration the power to fund states to operate CILs in 1978.

Implementing the independent living philosophy when providing TLS training means that the consumer’s choices come first, whether or not the person providing the service agrees with them or not. Every individual, with or without a disability, has the right to decide how they live. In the past, people with disabilities have been treated like children—told what to do, when to do it, and how to do it. Today, we recognize the importance of giving every adult the dignity of taking risks and making their own choices. As long as the consumer understands the consequences of their choice, it is their’s to make. It is also important to remember that along with the right to make choices comes accepting responsibility for them and their outcomes.

From Medical Model to Independent Living

Service Delivery

People who experience brain injuries have traditionally been treated in medical and rehabilitation programs for extended lengths of time. The stay in rehabilitation depends on funding as much or more than the extent of a person’s brain injury. If a person has unlimited funds, he or she often receives unlimited services in institutional settings (Williams, 1990).

Typically the medical community does all it can, within funding limits, to restore someone to his or her former capacity. Then the person is sent to a nursing home, a group home, or lives with relatives.

Recently there has been a shift in practice and policy away from defining life after medical intervention in terms of institutions, care-giving and residential facilities and towards more flexible consumer-responsive approaches. This controversial shift has been, in part, due to the influence of the independent living movement.

There has been some disagreement between caregivers and disability advocates about the most appropriate form of service provision. Professional caregivers tend to favor an “expert” model; whereas disability advocates tend to favor self-direction and self-help approaches. Conflicting philosophies surrounding the service needs of persons with brain injury will likely continue to be debated for some time. The combined effects of increasing numbers of persons with brain injuries, the questioning of previously held assumptions about persons with brain injuries, and the move toward shorter hospital stays has resulted in many people struggling to design services that meet the lifetime needs of persons with brain injuries who want to live in the community.

Following hospitalization, there are three existing community-based systems that persons with brain injuries often look to for services. These are Centers for Independent Living (CILs), home care agencies, and community-based programs for persons with developmental disabilities.

The medical model differs from the independent living philosophy on various aspects of life with a disability (Shapiro, 1993). For example, the medical model views the problem as residing in the individual. Therefore, the person must be “fixed” to fit into society. Disability itself is viewed as a problem that needs to be eradicated. The independent living movement on the other hand, views society as the problem, calling upon society to find a place for all people regardless of disability.

Most people are willing to be “fixed” as much as possible (Oxford, personal communications, 1996), a task in which the medical model specializes. The dichotomy begins when acute issues stabilize. With brain injury, stabilization can come very slowly, but come it eventually does. One of the greatest sources of tension is disagreement concerning when a person is considered to be stabilized and when they need to continue to be fixed.

The Medical Model and Service Delivery

Application of the medical model to service delivery often results in the perception that persons with disabilities need to be controlled by others; most notably providers and family members. Problems are generally defined in terms of inadequate performance in activities of daily life or in terms of inadequate preparation for gainful employment (DeJong, 1979). The underlying frame of reference is a role expectation. That is, the person with a brain injury is expected to assume his or her role of “patient” or “client.” While the goal of rehabilitation is supposed to be gainful employment or some other person-oriented accomplishment, success is to a large degree thought to be determined by whether the patient or client complies with the prescribed therapeutic regime (DeJong, 1979).

Even outside of rehabilitation society keeps people with disabilities in the client role, making many aspects of their lives subject to professional authority (Biklen, 1998). Because of their

disability-related needs, people who are at risk for social processing and social control become the captives of a treatment model; they and their lives become medicalized (Bogdan and Taylor, 1982; Gould, 1981). The common tendency is to view a person with disability as (a) victimized by a disabling condition and (b) in need of treatment– not rights (Biklen, 1988).

Service Delivery: Medical or Independent Living Model?

A comparison between the medical model and the independent living model for persons with brain injuries show that these models disagree on several fronts. There are pros and cons to each position which depend largely on the needs and wants of a person at a particular time.

Diagnosis

The medical model and independent living models disagree even before services are provided. The medical model classifies people in discrete categories and uses a variety of medical tests and assessments to assign further subgroups within a diagnosis. For example, persons with traumatic brain injuries are often classified as mild, moderate and severe depending on the length of coma.

By contrast, the independent living movement opposes labeling and categories, let alone subgroups. Thus, many CILs do not classify or label the people they serve and do not know how many people fall into each category. Recently, some CILs have complied with requests to categorize the people they serve, only because their future funding has been tied to reporting different categories.

It can be important, however, for someone to know that they have a brain injury. If someone is misdiagnosed or has substantial life problems without a diagnosis, his or her ability to access services can be misdirected or not allowed. For example, if someone experiences an injury that causes organic changes in the brain but is misdiagnosed as having schizophrenia, this can lead to an inappropriate journey through the mental health system or the prescription of inappropriate medications that may cause further harm. The treatment for someone with a brain injury is quite different from treatment for someone with schizophrenia.

Further, if the person is not diagnosed at all, he or she may experience significant problems in many functional areas and be blamed for behavior that is not under his or her control, but part of the disability. For example, the person may be judged as lazy (when experiencing the fatigue that is common to many people with brain injuries) or unmotivated (when problems with initiation of activities is common to persons with brain injuries). Many other problems can be misinterpreted without an accurate diagnosis.

The independent living movement strives for a service delivery system that is not based on diagnosis, but on universal needs. Therefore, services are often provided along those lines without regard to disability. Independent living is not the business of rehabilitation or acute treatment (Oxford, personal communication, 1996). The movement does not like labels because they objectify people into stereotypical beings. Also, such labeling is seen as pointless, since labels do not make a difference in terms of functioning. It is considered

more important to know what people need than to know the name of their disability. Regardless of disability category, a big part of understanding these needs is investigating what people can and cannot accomplish with or without which kinds of assistance.

On the other hand, when challenges posed by a particular disability are not known, the delivery of services can be fragmented or nonexistent. For example, if Tom has a memory problem and calls an agency for an appointment to get housing, he is likely to miss the appointment unless he writes it down or has some other way of knowing when and where the appointment is. The agency might interpret such a missed appointment as an indication that Tom is not longer interested or has found other resources. They may also deem Tom inconsiderate for not calling to cancel, and become less willing to reschedule when he calls in for another appointment. Furthermore, Tom may not even remember that he called to make an appointment, let alone missed it.

Assessment

The medical model tends to assess and test for deficits and problems. Assessed at frequent intervals, persons with brain injuries may be found to be different at each testing. Further, a person may obtain dramatically different test results even if the same test is given at different times on the same day.

The independent living model would argue that testing costs money that could be better utilized for a tutor to help someone try to learn math on their own, thereby questioning the accuracy of any test. They may also argue that testing exclusively points out problems and deficits without focusing on abilities. Everyone, they say, deserves a chance to try. CILs assess people to look at strengths, and as mentioned previously, to find out what a person can and cannot accomplish with or without which kinds of assistance. The assessment is done by talking to people not testing them. People are not seen as test subjects.

The medical model and the independent living model also define the problem and its potential solutions, social roles, locus of control, and outcome quite differently. Persons with brain injuries may agree or disagree with each of the distinctions.

Definition of the Problem

In the medical model the problem is defined as the individual's physical or cognitive impairment. In the independent living model the definition of the problem is a dependence on professionals, relatives and others, as well as inadequate support services and architectural and economic barriers.

For persons with a physical disability who subscribe to the independent living philosophy, physical change may not be ongoing. For example, someone with a spinal cord injury may come to the realization soon after the injury that his or her physical status is not going to change. However, people with brain injuries may experience ongoing changes (i.e. improvement) in relation to the medial community. They may thus take longer to move away from dependence on professionals, families, and the service delivery system, and come to the

realization that the disability is a real part of them, and that it is okay to have it.

Some persons with brain injuries may never move away from the definition of the disability as the problem. Disability pride is still a minority position for many people with disabilities.

Social Role

The social role of a person with a disability in the medical model is that of patient. *The American Heritage Dictionary* defines patient as someone who “endures pain or difficulty with calmness” and “receives medical treatment”. In the independent living philosophy, the social role of a person with a disability is a person with civil rights. CILs are committed to civil rights and to consumers rather than patients. Again, according to *The American Heritage Dictionary*, a consumer is someone who “buys goods or services”.

At differing times, persons with brain injuries find themselves in both the passive role of patient receiving medical treatment and the more active role of the consumer who buys services and participates in making decisions. The social role preferred or accepted by the person may depend on the urgency of the individual’s need, which philosophy he or she subscribes to, outside influences from family and friends, or any combination of variables. This is also sometimes the case with persons with physical disabilities who are determined to find a cure for a spinal cord injury, or some other physical disability.

People with brain injuries may choose to remain within the medical mode or may be enticed back into it more frequently than people with physical disabilities, because the consequences of their injuries are more varied and overlapping. Additionally, new experimental treatments continue to come along for consequences such as memory loss, epilepsy, visual loss and vestibular (balance) challenges.

Solution to the Problem

Within the medical model, the solution to the problem is a cure, or more therapy. Within the independent living model, the solution is removal of barriers. For persons with brain injuries, the solution may be to accommodate lasting disabilities as change occurs, or to continue ongoing cognitive therapy to improve memory while learning to accommodate the disability by writing things down. As their memory improves, they may need to write down fewer and fewer things. The medical model may provide the ongoing therapy for total recall, while the independent living movement may provide creative accommodation techniques for cognitive disabilities. The person with a brain injury decides, or funding dictates, when enough therapy is enough and how much memory loss to live with over time.

Locus of Control

In the medical model the locus of control is the professional; in the independent living model it is the consumer. However, persons with brain injuries may be unconscious or confused, necessitating that someone else control decisions. Someone who is unconscious is not making any decisions, nor in all likelihood, is someone who is seriously confused. People like this usually have someone appointed to make the decisions for them. Unfortunately,

many people who are fully conscious and not confused are forced to have guardians and are not allowed to make their decisions. The medical model tends to be more cautious in this regard, taking into account issues like liability to the provider in allowing risks and overall deficit approach. By comparison, the independent living model tends to be less cautious, reasoning that a person has the right to make their own decisions (and mistakes).

Each stance could cause difficulty for a person with a brain injury. An overly cautious approach may limit a person's abilities and hinder achievement of their potential. On the other hand, a laissez-faire approach without regard for reasoning, problem-solving or judgment disabilities could lead to great harm.

An additional factor related to locus of control is who is considered an "expert". The medical model views professionals as experts who give advice with which persons with disabilities are expected to comply. This is especially true in the field of brain injury. In a field so new, "experts" are often those who have tried out the latest interventions or treatment, often before outcomes are proven (Jacobs, personal communication, 1995). The independent living model considers those with similar life experiences and disabilities to be the experts. Thus, peer counseling is a core service at CILs, which mandate that at least 50% of the staff and board members be persons with disabilities (DeJong, 1979).

Outcome

For the medical model the outcome is complete cure or compliance with continued treatment. For the independent living model, the outcome is quality of life. It is easy to understand how a person with a brain injury could go back and forth if the scientific community is uncertain about the most appropriate treatment for memory loss, right-sided weakness, loss of vision or any other effect of the brain injury. At one point in time, a person may be comfortable knowing they might not walk; and at other times, they may want to walk more than anything else in the world.

Funding

An additional factor in the tension between the medical model and the independent living movement is the issue of funding. The medical model is funded by private health insurance, workers' compensation, private funds, Medicare and Medicaid. As a result, the type of funding a person has often dictates access to the medical system.

CILs, on the other hand, are non-profit organizations governed by a board of directors. Some CILs receive funds from the Rehabilitation Services Administration for basic operating expenses. They may also receive funding from grants or fund raisers. Medicaid and private insurance are designed to pay for professional, acute and rehabilitative type care. Thus, many people with disabilities look to CILs only after their private insurance has run out, the homecare agency has completed its visits, or the hospital has ended their stay due to "lack of progress."

Services to persons with brain injuries will continue to necessitate some degree of medical

intervention along the lines of the medical model as well as to incorporate the independent living philosophy as soon as possible. There are no clear answers or time lines for the most appropriate perspective. Awareness of the range of services available through each perspective enables persons with brain injuries to make the most appropriate choices possible.

CILs are a logical choice for service delivery to persons with brain injury because they are not time-limited, they believe all people with disabilities deserve human rights, and they understand how to access benefits from a variety of systems such as Social Security and vocational rehabilitation. Additionally, CILs receive funding to serve all people with disabilities and cannot turn people away who need services based on disability or income. The challenge for CILs is to expand their philosophy about persons with physical disabilities to creatively develop accommodations for people with cognitive disabilities.

Interacting with People who have Disabilities

In general...

- See the person who has the disability as a person—like anyone else.
- Understand that, although a disability may be caused by a disease, the disability is not the disease itself and cannot be contagious.
- Appreciate what the person can do. Remember that difficulties may stem more from society’s attitudes and environmental barriers than from the disability.
- Be neither patronizing nor reverential. Understand that the life of a person who has a disability can be interesting. Avoid appealing to others to respond to person with disabilities out of “gratefulness” for not having a disability themselves.
- Speak directly to the person who has a disability rather than through a third party. Help draw the person into the group. If the subject of the disability comes up, discuss it with the person rather than with others who may be present.
- Treat adults as adults. Call the person by his or her first name only when extending that familiarity to all others present.
- Be considerate of the extra time it might take for the person with a disability to get things said or done. Let the person set the pace in walking or talking.

People who use wheelchairs or crutches...

- Allow a person who uses a wheelchair or crutches to keep them within reach.
- Push a wheelchair only after asking the occupant if you may do so.
- Stand or sit next to a person’s wheelchair rather than lean or hold onto it.
- If conversation proceeds more than a few minutes, sit down in order to share eye level. It is uncomfortable for a person who is seated to look straight up for a long period of time.

People with speech difficulties...

- Give whole, unhurried attention to the person who has difficulty speaking.
- Keep your manner encouraging rather than correcting.

- Rather than speak for the person, allow extra time and give help when needed.
- When necessary, ask questions that require short answers or a nod or shake of the head.
- If you have difficulty understanding, don't pretend. Repeat as much as you do understand. The person's reactions will guide you and clue you in.

Persons with hearing losses...

Hearing losses range from mild to severe and can influence the way a person communicates or responds to sounds and to speech of others.

- If necessary, get the person's attention with a wave of the hand, a tap on the shoulder, or other signal. Move away from background noises.
- Speak clearly and slowly, but without exaggerating your lip movements or shouting.
- Be flexible in your language. If the person experiences difficulty understanding what you are saying, switch the words around and rephrase your statement rather than keep repeating. If difficulty persists, write.
- Place yourself facing the light source and keep hands, cigarettes, and food away from your mouth when talking in order to provide a clear view of your face. Speaking directly into a person's ear won't help, but could be harmful.
- Look directly at the person and speak expressively. The person who has a severe hearing loss will rely on your facial expressions, gestures, and body movements for help in understanding. Use sign language if you— and the person—are both familiar with it. Ask what the person prefers.
- When an interpreter accompanies a person, direct your remarks to the person rather than to the interpreter.

Persons with Vision Losses...

Losses of vision also vary in degree. Persons with this disability may be able to see one thing but not another.

- When greeting a person with severe loss of vision, always identify yourself and any others who may be with you. Say, for example, "On my right is John Jones."
- Use the person's name when starting conversation as a clue to whom you are talking. Speak directly to the person, using a normal tone of voice. Let the person know when you move away from or need to end a conversation.
- When offering a handshake, say something like, "Shall we shake hands?" If the person extends a hand first, be sure to take it or to explain why if you can't.
- Ask the person if he or she wants help in getting about. When providing assistance, allow the person to take your arm (which enabled you to guide). Warn the person of any steps or changes in level. Use specifics such as "left" and "right" rather than mention visual landmarks.
- When offering seating, place the person's hand on the back or arm of the seat.
- In handling money, separate the bills into denominations. Hand the person all the ones, the fives, the tens, etc. together, saying they are the ones, fives, tens, etc.

Using “Person First” Language

It's the person you speak of first, then the disability. For example:

Say...a person who has...	Instead of...afflicted, suffers from, victim
Say...nonverbal	Instead of...mute or dumb
Say...developmental delay	Instead of...slow
Say...emotional disorder	Instead of...crazy or insane
Say...uses a wheelchair	Instead of...confined to a wheelchair
Say...person with epilepsy	Instead of...epileptic
Say...non-disabled	Instead of...normal or healthy
Say...has quadriplegia	Instead of...is quadriplegic
Say...has a physical disability	Instead of...crippled