

Introduction

A-1 Description and Use of the Manual

The Home and Community-Based Services (HCBS) Waiver for Persons who have sustained a traumatic brain injury (HCBS/TBI) Policy and Procedure manual contains the official policies and procedures to be used when providing services to those on the HCBS/TBI waiver as well as those who are eligible for TBI Targeted Case Management. The information in this manual was developed through a policy and procedure review process conducted by Community Supports and Services (CSS), a unit of the Kansas Department of Social and Rehabilitation Services (SRS)/Division of Health Care Policy (HCP). It is consistent with the Medicaid waiver criteria set forth by the federal Centers for Medicare and Medicaid Services (CMS). Providers are encouraged to become familiar with the contents of the manual and refer to it as the first course of action when questions arise.

A-2 Maintenance of the Manual

The manual will be revised and updated as policies change. The holder of the manual is responsible for adding updates to the manual as they become available. Updates can only be made by CSS. When revisions are made to the manual, instructions for filing the revised material will be distributed to all service providers.

A-3 Medicaid and Home and Community-Based Services

Medicaid

Title XIX (Medicaid) of the federal Social Security Act is a public assistance medical care program administered by states and financed jointly through federal and state funds. The purpose of the program is to help states meet the costs of necessary health care for low-income and medically needy populations. States qualify to receive federal matching funds to help finance these costs by filing a state Medicaid plan document with the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services. States have substantial flexibility in designing their own programs as long as they stay within the parameters of federal requirements related to eligibility, services, program administration, and provider compensation.

1915 (C) Waivers

In 1981, Congress authorized the waiver of certain Title XIX requirements to enable states to provide home and community-based services to individuals who would otherwise require institutional care. The waiver programs are called 1915 (C) waivers after the section of the Social Security Act that authorized them.

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- Medicaid home and community-based service waivers afford states the flexibility to develop and implement creative alternatives to placing Medicaid-eligible individuals in hospitals, nursing facilities or intermediate care facilities for persons with mental retardation. The HCBS waiver program recognizes that many individuals at risk of being placed in these facilities can be cared for in their homes and communities, preserving their independence and ties to family and friends at a cost no higher than that of institutional care.
- Under section 1915 (C) of the Social Security Act (the Act), States may request waivers of certain federal requirements in order to develop Medicaid-financed community-based treatment alternatives. The three requirements that may be waived are in section 1902 of the Act and deal with statewideness, comparability of services and community income and resource rules for the medically needy.
- The Act specifically lists seven services which may be provided in HCBS waiver programs: case management, homemaker/home health aide services, personal care services, adult day health, habilitation, and respite care. Other services, requested by the state because they are needed by waiver participants to avoid being placed in a medical facility (such as non-medical transportation, in-home support services, special communication services, minor home modifications, and adult day care) may also be provided, subject to CMS approval. The law further permits day treatment or other partial hospitalization services, psycho-social rehabilitation services, and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness. Room and board is excluded from coverage except for certain limited circumstances.
- States have the flexibility to design each waiver program and select the mix of waiver services that best meets the needs of the population they wish to serve. HCBS waiver services may be provided statewide or may be limited to specific geographic subdivisions.
- Federal regulations permit HCBS waiver programs to serve the elderly, persons with physical disabilities, developmental disabilities, mental retardation or mental illness. States may also target 1915 (C) waiver programs by specific illness or condition, such as technology-dependent children or individuals with AIDS. States can make home and community-based services available to individuals who would otherwise qualify for Medicaid only if they were in an institutional setting.

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- To receive approval to implement HCBS waiver programs, state Medicaid agencies (in Kansas—the Department of Social and Rehabilitation Services [SRS]) must assure CMS that, on an average per capita basis, the cost of providing home and community-based services will not exceed the cost of care for the identical population in an institution. The Medicaid agency must also document that there are safeguards in place to protect the health and welfare of beneficiaries.
- HCBS waiver programs are initially approved for 3 years and may be renewed at 5-year intervals.
- The first home and community-based waiver program was established in 1981. All states except Arizona have at least one such program. Arizona is a technical exception, though, because it runs the equivalent of an HCBS waiver program under section 1115 demonstration waiver authority.
- Kansas currently has six HCBS waivers: 1) Physically Disabled-PD, 2) Frail Elderly-FE, 3) Traumatic Brain Injury-TBI, 4) Mental Retardation/Developmental Disability-MR/DD, 5) Severe Emotional Disturbance-SED, and 6) Technology Assisted-TA.
- Section 1915 (C) of the SSA is also outlined in the U.S. Code of Federal Regulations [42 U.S.C. 1396n].

Financial Eligibility

Some of the rules for determining financial eligibility are different for individuals receiving HCBS. For example, the amount of money a consumer can receive each month and not have to contribute to the cost of HCBS services (called Protected Income Level-PIL) is greater for the HCBS programs than for other Medicaid programs. Since consumers who are eligible for HCBS are also eligible for Medicaid State Plan Services and because of the different eligibility rules for HCBS, some consumers would not be eligible for Medicaid if they were not also eligible for HCBS services.

The Institutional Model & Cost Effectiveness

CMS does not specifically define special populations that may be served by a waiver, but allows states latitude in identifying groups of individuals with similar health care needs. Once a special population has been identified (in this case, people who have had traumatic brain injuries), the state must be able to demonstrate an institutional model eligible for reimbursement from Title XIX from which cost-effectiveness can be determined. For the HCBS/TBI program, the institutional comparison model is the TBI Rehabilitation Facility

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(TBIRF). Therefore, the total cost to serve persons receiving HCBS/TBI services must be equal to or less than the total cost in a TBI rehabilitation facility. If HCBS/TBI waiver program costs are greater, on average, than the cost to serve all persons in a TBIRF, Kansas loses the authority to provide services under the HCBS/TBI program.

In addition to determining cost-effectiveness, the institutional comparison model is also the basis for many HCBS rules and regulations. CMS will not allow states to develop policies or procedures for HCBS programs that would not be allowed in the institutional model. For example, CMS prohibits families from financially supplementing needed services on the HCBS Plan of Care because families are also prohibited from financially supplementing costs in a nursing facility. However, per the adoption of a 2002 regulation by the Kansas Legislature, families *may* pay for services that are *beyond* what is found to be needed on the Plan of Care. Families are encouraged, when appropriate, to also remain a part of the person's informal support system. Families who remain actively involved in providing care tend to help ensure quality services and cost-efficiency in HCBS.

A-4 History of HCBS and the TBI waiver in Kansas

In 1984, the Kansas Department of Social and Rehabilitation Services (SRS) established its first HCBS waiver program which was called HCBS/Nursing Facility (HCBS/NF). This waiver was later discontinued and rewritten as two separate waivers: the HCBS/Physically Disabled waiver and a waiver for elders called HCBS/Frail Elderly (HCBS/FE). They became effective on January 1, 1997, replacing the HCBS/NF program.

The HCBS/TBI Waiver

The HCBS waiver for individuals who have Head Injuries began in 1991. It was the first waiver of its kind in the United States. The Kansas HCBS/Hi waiver was a “model” waiver as opposed to a “regular approved” waiver (a/k/a 1915 (c) waiver), which meant that by law, the waiver could not serve more than 200 people. When the waiver was renewed on July 1, 2004, it became a regular 1915 (C) waiver, thus removing the cap on the number of individuals the waiver can serve, should more funds be allocated in the future. It was also renamed at that time to the HCBS/TBI waiver. The name was changed simply to better explain the population the waiver had always served (*traumatic* vs. other types of brain injuries).

The program serves individuals that are 16 to 65 years of age who meet the criteria for placement in a brain injury rehabilitation hospital and who have an external, traumatically acquired non-degenerative structural brain injury. (The TBI waiver served those ages 18-55

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until it was amended in 1998 to serve those as young as 16 years of age. It was amended on July 1, 2004 to serve individuals through age 65.) The individual must also be financially eligible for Medicaid. Those who are on the waiver at age 65 and continue to progress in their rehabilitation may continue to stay on the waiver with approval of the program manager.

Self-Directed Care

In 1989, the Kansas Legislature passed House Bill 2012 which allowed individuals on the HCBS Medicaid waivers to arrange for and direct their own personal attendant care. Now K.S.A. 65-6201, the law requires that consumers age 16 years of age and older be allowed to self-direct their own personal in-home care. Consumers who choose this option are responsible for recruiting, training, and managing their attendants. Some tasks, termed 'Health Maintenance Activities,' do require delegation from a nurse or physician. A large percentage of HCBS consumers in Kansas choose to self-direct their attendants.

Following the passage of K.S.A. 65-6201, the Nurse Practice Act of 2001 (K.S.A. 65-1124) included language that referred to the statute, and allowed for the performance of a nursing procedure by a person when that procedure is delegated by a licensed nurse, within the reasonable exercise of independent nursing judgment and is performed with reasonable skill and safety by that person under the supervision of a registered professional nurse or a licensed practical nurse.

The statute on self-direction (65-6201) can be found in its entirety in Section H of this manual, as well as more detailed information in the provision of self-directed care.

A-5 HCBS/TBI Program Administration and Operation

The Kansas HCBS/TBI waiver program is administered by Community Supports and Services (CSS), which is a department of Social and Rehabilitation Services/Division of Health Care Policy. CSS is responsible for formulating HCBS/TBI policies and procedures within the framework of state and federal laws and regulations. CSS is also responsible for overseeing the waiver program to ensure that it is effectively and efficiently implemented throughout the state.

Four of the state's six waivers are administered by CSS (TBI, PD, MR/DD, and TA). The SED waiver is administered by the SRS Division of Health Care Policy/ Mental Health. The FE waiver is administered by the Kansas Department on Aging (KDOA).

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Centers for Independent Living (CILs) and Home Health Agencies (HHAs) who are enrolled to provide TBI waiver services assess the level of functional impairment of potential consumers. Financial eligibility is determined by Economic Employment Support (EES) Specialists in local SRS offices. Because a portion of eligibility determination is completed by different agencies, communication among these agencies is crucial.

In addition to determining functional eligibility, provider agencies are responsible for developing individual Plans of Care. The HCBS waiver requires that each individual receiving HCBS services has a plan of care that identifies, at a minimum: 1) medical and other services, regardless of funding sources, to be furnished (e.g., informal supports such as support groups); 2) the frequency, scope, and duration of the services; and 3) the provider who will furnish each service, and 4) the cost of each service. The Plan of Care must be entered into the Medicaid Management Information System (MMIS) so that claims for authorized services will be reimbursed to the providers who delivered the authorized service. The MMIS is a prior authorization system in which Plans of Care must be electronically referred to the HCBS/TBI Program Manager for the necessary approval.

To keep abreast of current information, TBI providers are encouraged to visit the SRS/HCP/CSS web site regularly. The section devoted to HCBS/TBI services can be found on-line at: <http://www.srskansas.org/hcp/css/HCBS.html>.

A-6 Independent Living Movement & Philosophy

The HCBS/TBI waiver was developed on the foundation of the independent living philosophy. For this reason, it is important to know and understand the civil rights of people with disabilities, as well as the discrimination they have historically faced.

The history of 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 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. A person with quadriplegia, Roberts had to fight the California Department of Rehabilitation for his right to attend college. Due to a lack of

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accessibility and structural issues (the weight of his iron lung), Roberts lived in the campus hospital when he first arrived at Berkeley. Because of his tenacity, by 1967 there were 12 individuals with severe disabilities following his example and attending Berkeley. All of the individuals were forced to live on the same wing of the hospital, and eventually formed a group focusing on the civil rights of people with disabilities, calling themselves “The Rolling Quads.” This vehicle of empowerment led to the formation of the Physically Disabled Students’ Program, which branched into the service of non-students and the creation of the first CIL.

Another independent living policy framer was Judy Heumann who served both on the Board of Directors and as Chief Deputy Director of the CIL in Berkeley. She later served as Assistant Secretary of the Office of Special Education and Rehabilitative Services, a division of the U.S. Department of Education, during the Clinton Administration.

In 1973, Congress enacted the Rehabilitation Act which prohibits discrimination on the basis of disability in programs conducted by Federal agencies, in programs receiving Federal financial assistance, in Federal employment, and in the employment practices of Federal contractors. The standards for determining employment discrimination under the Rehabilitation Act are the same as those used in title I of the Americans with Disabilities Act.

The U.S. Department of Education’s Office of Special Education and Rehabilitative Services (OSERS) administrates the Rehabilitation Services Administration (RSA) which oversees formula and discretionary grant programs that help individuals with physical or mental disabilities to obtain employment and live more independently through the provision of such supports as counseling, medical and psychological services, job training and other individualized services. 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.

Some sections of interest in the Rehabilitation Act are:

Section 501 - requires affirmative action and nondiscrimination in employment by Federal agencies of the executive branch.

Section 503 - requires affirmative action and prohibits employment discrimination by Federal government contractors and subcontractors with contracts of more than \$10,000.

Section 504 - states that "no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under" any

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program or activity that either receives Federal financial assistance or is conducted by any Executive agency or the United States Postal Service.

Section 508 - establishes requirements for electronic and information technology developed, maintained, procured, or used by the Federal government. Section 508 requires Federal electronic and information technology to be accessible to people with disabilities, including employees and members of the public.

Section 702 - Defines Centers for Independent Living

Section 704 - Establishes a State Plan for Independent Living including the creation of a Statewide Independent Living Council (in Kansas, the Statewide Independent Living Council of Kansas, or SILCK)

Section 721 (Part C) - Centers for Independent Living

The Rehabilitation Act can be found in its entirety on the RSA web site at:

<http://www.ed.gov/policy/speced/reg/narrative.html>

Information on RSA's Independent Living State Grant Program can be found at:

<http://www.ed.gov/programs/rsailstate/index.html>

For more information on the Independent Living Movement, see the *History of Independent Living* by Mike Oxford and Gina McDonald online at: <http://www.kacil.org/history.htm>

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.

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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

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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

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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

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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.

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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.

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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

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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.