Centers for Independent Living in Support of Transition
By Kristi E. Wilson

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Centers for Independent Living (CILs) have long been in the business of providing a variety of communitybased support services to people with disabilities. The provision of transition services to youth and young adults, however, has, for the most part been the responsibility of regional school systems and, to some extent, of other state rehabilitative service agencies. In the last few years, CILs have played an increasing role in the provision of transition services through the development and implementation of CIL-specific programs and services and as part of collaborative, multidisciplinary, community-based transition teams. Because of their unique administrative and operational organization, CILs have begun to play an integral role in the support of youth and young adults in transition. As a result, local, state, and federal agencies are continuing to determine the short- and long-term role of CILs in support of transition.

Almost everyone today knows of, or is acquainted with, a person who has a disability. We are becoming accustomed to interacting with people with disabilities through work, school, or community activities. However, with the evolving increase in the level of awareness, interaction, and understanding of the disability community, society at large probably rarely thinks about the range of people to whom the term disabled applies, or the extent to which people are affected socially, emotionally, and economically by this label (Burgdorf, 1980).

People with disabilities represent an extremely diverse group. Some have mobility impairments and are unable to get around without the aid of crutches, walkers, and wheelchairs; some have developmental disabilities such as cerebral palsy and autism; some have visual or hearing impairments; some have missing or malformed limbs; some are dyslexic or hyperactive; and some have conditions such as arthritis, diabetes, HIV, or mental illness.

It is nearly impossible to identify any single distinguishing characteristic or unifying trait in this unmistakably heterogeneous group of people; yet decades ago and to a great extent today, people with disabilities continue to be perceived as a singular, distinct class of people (Hull, 1979). Regardless of whether the impairments are manifest as cognitive, physical, or a combination thereof, the sheer presence of disability, more often than not, is assumed to correlate with limited life-long performance and gross underachievement by societal standards. As a result of this type of thinking, individuals with disabilities are often rendered "exempt" from the opportunity to participate successfully in society, and society is thereby relieved of the burden of providing elaborate accommodations and extraordinary assistance (Gilson, 1998).

Still today, American society is without question operating under a flawed set of assumptions and beliefs regarding people with disabilities and the lives they lead. People without disabilities continue to consider a person's disability as an essential and core component of that person's being. Individuals with disabilities are treated quite differently, and the expectation in many instances is that they behave as deviants, menaces, or poor unfortunates to the detriment of the larger society (Mason, Williams-Murphy, & Brennan, 1996).

In the past, this flawed school of thought led to the overt, widespread oppression and maltreatment of people with disabilities. Ultimately, it became the impetus for the emergence of the independent living movement, whose collective voice contended that the only common denominator among people with disabilities was
having one’s capabilities ignored and being underestimated and undervalued as a contributor to society (Drieger, 1989).

This article (a) provides an overview of the independent living movement, (b) describes the structure and scope of services of Centers for Independent Living (CILs), and (c) discusses the potential role of CILs in the provision of transition services.

The Movement

The independent living movement is characterized as the civil rights movement of people with disabilities. It was initiated by individuals, and quickly became a national, informal network of community organizations and individuals, including not only people with disabilities but also human rights advocates, political lobbyists, and the like (Mathews, 1990). Persons involved in the independent living movement were painfully aware of the stigma and prejudice associated with the socially devalued status of those with disabilities. Individually and collectively, they began to voice their concerns, lobbying socially and politically, in an effort to alleviate generalized discrimination and promote full acceptance as typical members of society (Bogdan & Taylor, 1976).

It has been documented in the United States and abroad that the population of persons with disabilities lags behind almost all other segments of society in terms of education, jobs, income and earning potential, housing, and social and political opportunities. For this reason, advocates of the independent living movement continue to support anti-discrimination legislation and services that will guarantee those with disabilities equal opportunity and access (Nosek, Zhu, & Howard, 1992).

The philosophy of the independent living movement or disability rights movement, as it is also referred to, is based on the principles of self-determination, choice, and consumer control (Nosek et al., 1992).

Self-determination refers to an individual’s ability to express preferences and desires, make decisions, and initiate actions based on these decisions. Simply, self-determination refers to choice. It stresses goal setting and active follow-through to achieve the goals. Control expands the principles of self-determination. Control focuses on the extent to which individuals are independent, self-sufficient, and capable of gaining access to the resources necessary to freely act on their choices and decisions. Whereas self-determination emphasizes goal setting and follow-through action, control addresses the extent to which the decision-making process is carried out, free from excessive external influence (Kregel, 1992). Regardless of whether the decision-making scenarios involve employment, vocational training, academic pursuits, personal care, or housing, the extent to which self-determination, choice, and control are exercised defines the overall quality of life for individuals with disabilities.

The Medical Model vs. Independent Living Model

An initial goal of the movement was to enhance and strengthen the public perception of the community of persons with disabilities. The success of this ongoing task depended, to a large extent, on dispelling myths regarding disability that were perpetuated for decades by the early "medical model" of disability. Medical personnel saw the root of the problems that people with disabilities faced as a result of a clinical condition. The medical model labeled people with disabilities as helpless, passive, dependent, unable, and perhaps disinterested in gaining or maintaining employment. This model sought to assess functional capacity, assign a clinical diagnosis, prescribe appropriate medical intervention, and provide minimal, short-term rehabilitation effort in support of the patient (Racino, Walker, O'Connor, & Taylor, 1993).
In contrast, those that support the independent living movement asserted that the predicament that those with disabilities face resulted from sociopolitical issues rather than medical ones (see Table 1). The systemic nature of inequality that existed could, however, be remedied by consideration of the uniqueness and individuality of people with disabilities, provision of reasonable accommodations and appropriate services, facilitation of life-long independence, and freedom of choice (Nosek et al., 1992). If provided with equal opportunity, people with disabilities can and will take responsibility for their own lives and the choices that they make, as opposed to remaining eternally dependent on family, the health care community, and society at large (Mathews, 1990).

**An Issue of Control**

Through the course of the independent living movement, there has been a slow yet deliberate shift of control to the consumer. At one time, almost all disability organizations and disability specific services were controlled by and tailored to meet the needs and standards of the service providers. As a result, the disability community was forced to accept uniform, generalized services that did not meet their differing needs (Melvin & DiPeppe, 1996). Organizations were established by disability category along medical or diagnostic lines, thereby facilitating division among the community of persons with disabilities. The framework of such a paradigm denied uniqueness and deprived individuals of personal choice. Further, disability organizations were often administered by medical personnel whose relatively narrow clinical focus often hampered the progress of the independent living movement toward self-determination, self-help, and consumer control (Jones, 1986).

The success of the independent living movement is reflected in many pieces of legislation instituted since the 1970s. Legislation such as the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) of 1990 serves to facilitate appropriate consumer input and, to some extent, control the administrative organization and scope of services offered by both federally funded and privately owned disability service organizations and programs.

One landmark piece of legislation, the Rehabilitation Act of 1973 (P.L. 93-112) and ensuing amendments, serves as the framework for the federally funded independent living program that supports what has become a national network of CILs. At least one CIL is located in each state, the District of Columbia, the U.S. Virgin Islands, Puerto Rico, and American Samoa. The CIL program annually provides hundreds of thousands of individuals who have severe disabilities with direct services that include, but are not limited to, information and referral, independent living skills training, peer counseling and mentorship, and consumer advocacy. Numerous other individuals benefit from the results of successful systems advocacy to increase the availability and quality of community options for independent living and to increase the capacity of local communities to meet the needs of individuals with significant disabilities (Frieden, Richards, Cole, & Bailey, 1979).

<table>
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<tr>
<th>Table 1</th>
<th>Comparison of a &quot;Medical Model&quot; and &quot;Independent Living Model&quot; of Disability</th>
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<tr>
<td><strong>Issue</strong></td>
<td><strong>Medical model</strong></td>
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<tr>
<td>What is the problem?</td>
<td>Clinical condition resulting in dependence and apathy</td>
</tr>
<tr>
<td>What is the solution?</td>
<td>Diagnose, prescribe, and support</td>
</tr>
<tr>
<td>Who is in control?</td>
<td>Physicians and allied health care professionals</td>
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Source: Kregel, 1992

**What CILs Have to Offer**

Each CIL is mandated to provide a well-defined group of core services. However, the CILs are allowed the flexibility to provide additional expanded services as appropriate. The quality and quantity of both core and expanded services vary extensively from one region to another. Most CILs strive to design programs and deliver services that generally meet the needs of most disability groups, while attempting to address the specific demographic and geographic characters of its region.

For example, interpreter or reader services could be provided to an individual with a significant sensory or cognitive disability, assistance with locating accessible and affordable housing and transportation may be offered to a consumer with a spinal cord injury or other mobility impairments, and life skills training and personal assistance services may be extended to an individual with cerebral palsy or some other developmental disability.

Collectively, CILs are making meaningful contributions to the communities in which they are located. Although the CILs operate under a federally mandated framework, those that are most successful at meeting the needs of their respective communities demonstrate innovation and creativity in their program design and service delivery. Some characteristics that distinguish high-quality CILs are (a) strong community connected leadership; (b) diverse, resourceful staff and volunteer corps; (c) flexibility in the provision of extended services; (d) sound understanding and consideration of community-specific needs; and (e) demonstrated appreciation for strong collaborative partnerships, with community stakeholders.

**CILs Defined in Legislation**

The Rehabilitation Act of 1973 and the Rehabilitation Act Amendments of 1992 (P.L. 102-569) are the current authorizing legislation for independent living services. Provisions are made for both the state programs of independent living services, and CILs. CILs are legislatively defined as consumer-controlled, community-based, cross-disability, nonresidential, and private nonprofit agencies. They are designed and operated within local communities, primarily by individuals with disabilities, and provide an array of independent living services (the Rehabilitation Act of 1973). Through adherence to a stringent set of standards and assurances (see Table 2), CILs promote strong leadership, empowerment, independence, and productivity of individuals with disabilities (the Rehabilitation Act of 1973 and its 1992 amendments).

In contrast to many community-based organizations that develop programs and provide support services to people with disabilities, CILs model consumer control. That is, they have delegated power and authority within their organizational structure, for the most part, to individuals with disabilities. People with disabilities hold leadership and decision-making positions, get intricately involved in the program planning process, and are the primary providers of training, counseling, and all other direct services offered by CILs. By design, CILs are service organizations that encourage people who themselves have been successful at establishing independent, self-sufficient lives to assist others with severe disabilities to do the same. Most of the staff have relevant training and personal experience, know exactly what is required to live independently, and have a true commitment to sharing their knowledge and experience with others.
For those in need of disability-specific information, centers maintain comprehensive information on the availability of accessible housing, transportation, employment opportunities, rosters of persons available to serve as personal assistants, interpreters for the sensory impaired, and resource information regarding assistive technology of all types. Centers can provide training courses to help people gain the tools necessary to live more independently. Courses may include utilization of local public transportation systems, establishing a budget and managing personal finances, or dealing with discriminatory behavior and practices.

Because many of the staff members of the CILs are individuals with disabilities, they can serve as role models and mentors. Further, they can offer emotional support and suggest coping strategies to family members and caregivers. Awareness and sensitivity training are often offered to the public at large. The recipients of the peer counseling and mentoring services are afforded the opportunity to express their individual issues, explore options, and solve problems with the support and encouragement of those who have been through similar situations. Issues commonly dealt with include making adjustments to a newly acquired disability, coping with changes in living accommodations, and accessing appropriate community services.

For most individuals and family members, dealing with disability is difficult and overwhelming. Especially early on, the advocacy services offered by CILs can be invaluable. Centers provide both consumer advocacy, which involves the staff working with individuals to obtain necessary support services from other community agencies, and community advocacy in which center staff, board members, and volunteers make a concerted effort to initiate activities in the community that facilitate widespread changes that have an impact on all persons with disabilities.

Traditionally, CILs serve the adult population. Recently however, they have moved into serving transition-age youth and building strong partnerships with schools. CILs have realized that not only is their administrative structure and community-based posture conducive to the provision of transition support services, but also many of the services that they currently provide are apropos for youth in transition.

<p>| TABLE 2 | Assurances and Standards for Centers for Independent Living |
| Assurances | Standards |
| Promote and practice the independent living philosophy of consumer control, self-help, and self-advocacy; develop peer relationships and peer role models; provide equal access of individuals with severe disabilities | Be designed and operated within local communities by individuals with disabilities, including an assurance that the center will have a board that is the principal governing body of the center and a majority of which shall be composed of individuals with severe disabilities |
| Provide services to individuals with a range of severe disabilities on a cross-disability basis; eligibility for services may not be based on the presence of any one or more specific severe disabilities | Use sound organizational and personnel assignment practices, including taking affirmative action to employ and advance in employment qualified individuals with severe disabilities on the same terms and conditions required for able-bodied employees |</p>
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<tr>
<th>Facilitate the development and achievement of independent living goals selected by individuals with severe disabilities</th>
<th>Practice sound fiscal management, including making arrangements for an annual fiscal audit</th>
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<tr>
<td>Increase the availability and improve the quality of community options for independent living to facilitate the development and achievement of independent living goals by individuals with severe disabilities</td>
<td>Ensure that the majority of the staff and individuals in decision-making positions are individuals with disabilities</td>
</tr>
<tr>
<td>Provide independent living core services and, as appropriate, a combination of any other independent living services.</td>
<td>Ensure that individuals with severe disabilities who are seeking or receiving services at the center will be notified by the center of the existence of the client assistance program</td>
</tr>
<tr>
<td>Conduct resource development activities to obtain funding from sources other than Chapter 1 of Title VII of the Rehabilitation Act of 1973</td>
<td>Conduct annual self-evaluations, prepare an annual report, and maintain records adequate to measure performance with respect to the standards</td>
</tr>
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**A Historical Perspective of the Transition Initiative**

During the 1970s, in addition to the Rehabilitation Act, several pieces of landmark legislation were implemented that have an impact on the lives of all persons with disabilities and lead to the emergence of the current transition initiative. Significant changes were implemented to facilitate the recruitment, training, and promotion of persons with disabilities (Rusch & Chadsey, 1998).

The Education of All Handicapped Children Act of 1975 (P.L. 94-142) was implemented to address the disparity in educational opportunity among students with disabilities and other students. In 1976, the Vocational Education Act Amendments of 1967 (P.L. 90-99) and 1968 (P.L. 90-391) were revised, which resulted in increased funding for vocational education (Rusch & Chadsey, 1998).

During the 1980s, previously enacted legislation was refined to target the needs of youth with disabilities to prepare for the transition from the educational environment to the workplace. In 1984, the Carl D. Perkins Vocational and Technical Educational Act (P.L. 98-524) was passed, which mandated vocational assessment, counseling, support, and transitional services for disadvantaged youth and youth with disabilities. Further, this legislation mandated planning and coordination with other federally funded programs and agencies.

In 1983, the Education of All Handicapped Children Act was amended with Section 626, entitled Secondary Education and Transition Services for Handicapped Youth. This section authorized federal funds for grants to
demonstrate support and coordination among the educational and adult service arenas, ultimately modeling smooth transition from school to employment to community service as appropriate (Kochlar & West, 1995). This legislation was to foster the development of innovative programs and improve existing programs for school-age youth with disabilities and fortify the links between schools, specialized training entities, employers, and related service providers. The 1980s legislation provided a sense of clarity and definition to the transition initiative, which could guide further policy development in the 1990s (Will, 1983).

**Transition Services Defined in Legislation**

The 1990s saw continued advancements in legislation that provided clarity and definition to transition services. In July 1990, the Americans with Disabilities Act (ADA) of 1990 (P.L. 101-336), was enacted. It was hailed by many as the civil rights law for all people with disabilities (West, 1992). This law was followed by a comprehensive set of regulations that provided for accessibility, nondiscrimination, and enhanced opportunities in the workplace, community facilities, and public transportation. The ADA affirms that people with disabilities are willing and able to make valuable contributions to the economic life of their localities. It is founded on the belief that people are not burdens to business and industry. The barriers to employment they face are most often around them, not within them (Blanck, 1994).

Also in 1990, the reauthorization of the Individuals with Disabilities Education Act (IDEA; P.L. 101-476) brought to focus long-term life management. Transition planning was to incorporate participation of adult service agencies and other community services as deemed applicable. It was mandated that Individualized Educational Programs (IEPs) include a statement of need for transition services, identify specific services, and assign responsibility to various agencies (Rusch & Chadsey, 1998).

IDEA (34 CFR, Section 300.18) defined transition services as

> A coordinated set of activities for students, designed with an outcome based process, which promotes movement from school to post school activities, including postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living or community participation. The coordinated activities must: (1) be based on the individual student's needs, (2) take into account student's preferences and interests and (3) include instruction, community experiences, the development of employment and other post-sCHOOL adult living skills and functional vocational evaluation. (§ 1401 [a][191).

By defining transition services and requiring the inclusion of such services in the IEP, the 1990 reauthorization of IDEA was extremely important in terms of facilitating educational programs that focused on post-school goals and emphasized the need for involvement of community-based agencies in the transition process.

The Rehabilitation Act Amendments of 1992 are significant primarily because they emphasized the provision for consumer choice. Consumers were no longer at the mercy of others to determine what was in their best interests with regard to vocational options and the provision of key services. These amendments mandated that consumers must be provided with all available information regarding options for services and the providers of services of interest, including information regarding quality, accessibility, and consumer satisfaction.
This is the primary legislation that encourages access to disability support services and vocational rehabilitation for individuals with disabilities after school. The 1992 amendments were far-reaching and facilitated the combination of federal and state funds in each state to increase the capacity to provide vocational and independent living services (Wehman, 1996). Table 3 illustrates the major features of the Rehabilitation Act Amendments of 1992.

The Technology-Related Assistance Act for Individuals with Disabilities (Tech Act) Amendments (P.L. 103-218) were signed into law in 1994. These amendments provided individuals with disabilities of all ages access to assistive technology services and devices. They also acknowledged the powerful role that assistive technology plays in maximizing the potential for independence of individuals with disabilities. Because this act emphasized being responsive to the needs of consumers, CILs played an important role in its implementation from a community-based perspective. CILs initially provided community awareness and demonstration activities, information and referral, technical consultation, and technology-specific training in support of individuals with disabilities and their families. Through the Tech Act, funds are provided to support systems change and advocacy activities that will increase funding for and access to assistive technology and related services.

Although these laws do not guarantee change, they certainly do provide a framework for the current-day continuum of services and the assignment of accountability and responsibility among pertinent stakeholders (i.e., special and vocational education teachers, transitional specialists, counselors, community agencies, parents).

**What Role Can the CILs Play in Transition Services?**

For several reasons, CILs are collectively in a unique position to play an integral role in the provision of community-based, transition support services. First, they have the administrative structure, personnel, and expertise already in place to incorporate transition planning and support services as fundamental components of their core program. Second, they currently possess significant ties to the community and have developed extensive collaborative relationships with other federal and state agencies, private service providers, and other relevant stakeholders. Finally, the CIL network collectively holds a wealth of interdisciplinary subject-matter expertise that would be invaluable to the consumers and other professionals involved in the transition process (Frieden et al., 1979).

Except for the focus on the school-age population, independent living centers are already providing the same types of services to relatively the same population as those eligible for transition services, that is, consumers with disabilities of varying types and severity levels. Some service areas in which CILs are currently focused that are applicable in transition support are assistive technology, independent living skills, information and referral, transportation support, vocational planning and assessment, and employment skills training.

An example of an exemplary CIL program is one offered in metropolitan Detroit. Termed the Career and Leadership Development Series (CLADS), this program provides leadership, job-readiness training, and paid and volunteer job experiences for transition-age youth and young adults. The CLADS provides a systematic, hands-on process by which transition-age students can become involved in individualized career exploration, skills training seminars and workshops, and an opportunity to participate in organized community service projects and formal summer internships with the support of CIL staff. In addition, community and business leaders are involved in facilitating the training and students are afforded the opportunity to network and build rapport with the community leaders and potential employers.
A second dynamic program is offered a CIL in central Virginia and includes statewide network of mentors and peer counselors. In this instance, spinal cord-injured consumers are matched in both group and individual settings with consumers, CIL staff, and other volunteers who have personal experience with disability and are committed to assisting others with similar disabilities to deal with their experiences. This CIL offers numerous disability-specific and cross-ability self-help and support group settings whose working premise is that group members can help each other by sharing experiences and predicaments, being exposed to successful peers, expanding their social networks, and working through the problem-solving process (Melvin & DiPeppe, 1996).

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<thead>
<tr>
<th>Feature</th>
<th>Legislative language</th>
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<tr>
<td>Eligibility</td>
<td>Requires a presumption that the person can benefit from vocational rehabilitation, unless there is &quot;clear and convincing evidence&quot; otherwise</td>
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<tr>
<td>Making informed choices</td>
<td>Each individual must be provided a list identifying all of his or her options for services and the providers of services of interest</td>
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<tr>
<td>Employment Outcome</td>
<td>&quot;Must be consistent with the abilities, capabilities, and interests&quot; of the individual</td>
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<tr>
<td>Helping students make transition</td>
<td>State plan must contain policies designed to facilitate the transfer of responsibilities for helping students to make school-to-work transition</td>
</tr>
<tr>
<td>Competitive Employment</td>
<td>&quot;Compensation at or above minimum wage is required&quot;</td>
</tr>
<tr>
<td>Extended Employment</td>
<td>Replaces the term sheltered employment with &quot;work in a non-integrated setting with a compensation at or above the minimum wage, unless a lower wage based on productivity is permitted.&quot;</td>
</tr>
<tr>
<td>Supported employment plan</td>
<td>Requires each state to have an acceptable plan for providing supported employment services</td>
</tr>
<tr>
<td>Movement to more integrated employment</td>
<td>States must make a &quot;maximum effort&quot; to provide services to promote movement from extended employment to integrated employment</td>
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**Conclusions**

There are many different types of organizations that serve people with disabilities, such as state vocational rehabilitation agencies, group homes, rehabilitation centers, sheltered workshops, and nursing homes. Undoubtedly, each of these entities provides a valuable service and serves as an important link in the network of services that help people with disabilities maintain choice, control, and independence.
CILs, however, are different from these other organizations in terms of the degree of exposure to and expertise in working with people with disabilities of all types and the capability to draw from their first-hand knowledge and experience as individuals with disabilities. CILs have expended a great deal of time and energy in establishing strong community ties and significant collaborative networks. They are invested in meeting the needs of the individuals with disabilities in their communities. Undoubtedly, CILs are in a perfect position to provide support services for youth in transition that will foster self-awareness and self-esteem, develop advocacy, leadership, and self-empowerment skills that will ultimately enhance their long-term achievement and overall quality of life.

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REFERENCES


