

Introduction to Special Issue

Independent Living Management

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The first Center for Independent Living (CIL) was established in 1972 in Berkeley, California. A group of dedicated Berkeley University students with disabilities, led by Ed Roberts, formed a group called the Rolling Quads, which aimed to make wheelchairs commonplace on the Berkeley streets. They succeeded in their mission by securing curb cuts (the first in the entire country), and went on to create the first Center for Independent Living (CIL). This center has gained national – and international – prominence.

The Rehabilitation Act 725 Standards define what constitutes as a center for independent living; more than 50% of the staff and board of directors have to be people with disabilities and the following four core services must be provided: peer counseling, independent living skills training, individual and systems advocacy, and information and referral. Additional services may be provided based on community need but a center for independent living may not provide residential services. For example, one of the first services offered by the Berkeley CIL, beyond the four core services, was wheelchair repair.

The independent living philosophy is rooted in deeply held values and beliefs of how people with disabilities can acquire and maintain their personal independence. While once people with disabilities were

“patients” or “clients” in the role of sick or “impaired” for whom care must be given, they now saw themselves as consumers of services they chose and managed.

Across the United States, a simultaneous flow of innovative concepts and leaders developed, leading to the growth of more CILs. As some State Vocational Rehabilitation systems became increasingly aware of CILs’ growth, they began showing their support through Innovation and Expansion grants, supporting the growth of a small number of additional CILs.

In 1978, the Rehabilitation Act of 1973 was amended. This allowed for the allocation of funding to CILs, contributing to CIL growth. Today, there are over 600 CILs. In the Rehab Act, a CIL became defined as a “consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agency that (a.) is designed and operated within a local community by individuals with disabilities; and (b.) provides an array of independent living services. (Title VII Rehab Act Sec. 702; Rehabilitation Services Administration. Rehabilitation Act of 1973 as Amended by the Rehabilitation Act of 1992 (P.L. 102–569). Washington DC: US Department of Education)

With the availability of federal and state funding, CILs evolved from grassroots community organizations serving people with severe specific disabilities,

to fairly sophisticated, community-based, not-for-profit organizations controlled by the people with disabilities they served and representing all major disability groups in their specific service area. One result of this increased funding was more CILs emerging than there were trained staff to manage them. Under-trained and understaffed CILs were being placed in situations where they needed to secure funding and develop administrative processes retroactively. At times, the original base financial support of CILs could not keep up with the cost of living causing CILs to lose staff to more profitable careers. Some CIL administrators had little experience with hiring staff, paying bills, or dealing with program funding issues. They found themselves in the role of community change agent, service provider and small business manager, subject to the same rules, regulations, and personnel issues as the business next door. CILs needed to define their programs, recruit competent staff with disabilities, recruit consumers, network with other organizations, develop funding and revenue streams, and administer sound and reliable services and programs. To complicate the situation, there were no schools or courses on how to set up and run a multi-mission program like a CIL, while maintaining the independent living philosophy.

In 1992, amendments to the Rehabilitation Act established Statewide Independent Living Councils (SILCs). SILCs had the responsibility of developing three-year plans directing the use of independent living funds. They were responsible for monitoring and evaluating plans for future development. SILCs were created in order to give states more control over independent living issues and to help with the promotion and monitoring of the IL philosophy. A SILC is defined as a state appointed Council, which coordinates the functions related to the planning, monitoring and evaluation of independent living services while serving to promote the philosophy of independent living and empower individuals with significant disabilities.

Also contained in the re-authorization of the Rehabilitation Act in 1992 was a self-performance report (the Section 704 Annual Performance Report for Centers for Independent Living) that required CILs to report on activities, services, and the demographics of people served in a uniform document to demonstrate the work of centers nationally.

Incorporated into CILs are RRTC-ILMs, who are featured in this special issue. Rehabilitation Research & Training Centers on Independent Living Management identify and replicate suitable management models from CILs (and other organizations) which will

assist CILs in achieving a greater degree of economic self-reliance and excellence in management. Various RRTCs and CILs have contributed articles to this journal to show how they are able to carry out this mission with the intent of seeing other RRTCs and CILs attain similar success. One such article focuses on the aforementioned 704 report (Usiak, Tomita and Tung, this issue) and examines the feasibility of using the 704 Annual Performance Report as a planning tool to enhance CILs' management capacity. The article presents state-by-state comparisons to reflect the services provided by CILs and begins a discussion about the impact and contributions of CILs to their communities and to the country.

In another article Tomita, Usiak, Moffat and Moffat (this issue) present the results of a national survey of centers for independent living and their organizational structure. 255 main centers for independent living responded to a survey (called the Independent Living Organizational Survey), which was used to develop a comprehensive National CIL Management Database. The Independent Living Organizational Survey identified important CIL management patterns.

Usiak, Stone, House, and Montgomery (this issue) have prepared an article where they discuss a study representing an initial phase of a larger RRTC-ILM project which seeks to identify CIL management practices in an effort to help the centers identify training needs. The article identifies the profile and elements of a successful CIL and the level of consumer (stakeholder) involvement resulting in this data. Next, Wehmeyer and Gragoudas (this issue) address CILs' role in transition services for youth with disabilities, particularly in promoting self-determination and empowerment. CILs serve an important role in supporting young people with disabilities transitioning from secondary education to adulthood.

Stoddard and Premo (this issue) present information regarding the collaboration between CILs and vocational rehabilitation (VR) agencies based on survey data from 136 CILs collected to determine how successful this collaboration is at expanding employment opportunities.

Moffat and Tung (this issue) then address the issue of increasing CIL service and outreach effectiveness to foreign-born consumers. Their article presents the culture brokering model and explains how it is being implemented. Nary, White, Budde, and Vo (this issue) conducted a survey to identify the employment and vocational rehabilitation concerns of people with traditional and emerging disabilities. Through the sur-

vey, key issues of concern, as well as areas of progress, were identified in an effort to prioritize the concerns of people with disabilities across the US regarding their ability to fully participate in their communities and in society.

An article by O'Day, Wilson, Killeen and Ficke, to be included in the next issue of the JVR (Volume 20, Number 2), will present findings from a comprehensive two-year evaluation of the CIL program. The article reports the areas of service examined and the outcomes related to consumers served, data gathered from interviews of 569 consumers. A description of the survey methodology is contained in the article. Also in the next issue of the JVR, the final article addressing Independent Living Management by Kim and Fox asks the questions: "How do Centers for Independent Living

(CILs) provide services to people with emerging disabilities," and, "What more can be done with them by these centers". This is an attempt to understand the obstacles and benefits of greater integration of people with emerging disabilities with information gathered through telephone interviews and focus groups involving 102 people with disabilities. The characteristics of emerging disability groups as well as the difficulties faced by groups receiving services (such as Medicaid Waivers) will be discussed.

Articles in this journal issue, and the O'Day et al. and the Kim and Fox articles in the journal issue to follow, showcase the cooperation among CILs as well as between CILs and vocational rehabilitation services and school systems (among others). They present positive outcomes and identify areas of further study.