



# RRTC-ILM

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newsletter

## Successful Collaborations: Independent Living Centers & Vocational Rehabilitation Agencies

Independent living centers (ILCs) and vocational rehabilitation (VR) agencies can use their collaborative partnerships to leverage resources to improve employment outcomes. Our survey on current ILC / VR partnerships reveals that successful collaborations have developed and what they have accomplished.

A new management training session, presented at the National Rehabilitation Association fall conference held in Nashville, TN (October 2 - 5, 2003), introduced collaboration strategies and skills with examples from the current practices we learned about from vocational rehabilitation agencies, independent living centers and state independent living councils. Trainees learned to:

- Identify essential elements for collaboration;
- Identify good examples of successful collaboration; and
- Analyze a situation to determine potential for collaboration.

Feedback from the session will be evaluated: first, with conference participants, and then, with the RRTC-ILM team of investigators. Final materials will be developed and available for use by independent living centers and others who are working in collaboration on local employment systems.

Susan Stoddard, PhD  
*InfoUse*

## CILs and Transition-Age Youth Activities Continue

RRTC-ILM's partners at the University of Kansas (KU) continue to engage in multiple activities to examine the benefits of centers for independent living (CILs) being involved in activities to promote the successful transition from school to adulthood for youth with disabilities. Public schools are required to provide transition services for students receiving special education services and supports beginning at age 14. Increasingly, public school programs have recognized the importance of promoting the self-determination of youth with disabilities if they are to achieve more positive outcomes as young adults. CILs have unique capacity with regard to enabling individuals with disabilities to achieve greater independence, productivity and an enhanced quality of life, and can play an important role in ensuring a successful transition from school to adulthood.

A report in a previous RRTC-ILM Newsletter described one such activity in which CILs could engage to support transition age youth. Project staff evaluated the efficacy of an "empowerment group" in which transition-age youth with disabilities met weekly at a CIL with several staff members and with peer mentors. The purpose of the weekly meeting was to support students to learn to set transition-related goals and to discuss ways in which students could assume greater responsibility for their transition planning. A description of that activity and the impact on students will appear in an upcoming issue of the *Journal of Vocational Rehabilitation*.

Two additional activities have engaged project staff over the past year. The first has been an evaluation of the role of CILs in a statewide Youth Leadership Forum (YLF). Youth Leadership Forum activities are held in most states across the country. The YLF program brings young people with disabilities (usually juniors and seniors in high school) together for a week of intensive leadership training. Adults with disabilities mentor these students throughout the week. CILs can become actively

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# Evaluation of an Approach to Increase CIL Service Use By Older Persons with Disabilities

In collaboration with the RRTC-ILM, the RERC on Technology for Successful Aging is exploring how centers for independent living (CILs) can play a major role in providing services for older consumers (age 60+). A survey, sent to 255 CILs, asked what services are currently being offered to older consumers and to identify best practices. Sixty-four returned surveys are being analyzed. According to these responses, few CILs offer services that specifically target the older consumer and few CILs have working relationships with their local area agency on aging. Most CILs report that the programs they offer are tailored to anyone with a disability, not specifically to the elderly. Funding, age restrictions or socioeconomic status dictate whether a specific program for the elderly is available such as respite or day-care, home modifications or low vision support.

Since we were not able to identify best practices, we redirected our focus to assisting and encouraging CILs to develop services for older persons with disabilities. We are developing an aging services manual designed to help CILs to understand the specific needs, problems, and solutions unique to the older population. This manual will also help CILs understand the aging network's organizational structure, mission, objectives, and funding sources. It will serve as a guide for centers to identify ways to become a community resource provider through the aging network, including funding for senior programs.

Various research studies indicate that our aging population will increase dramatically by 2030 as more baby boomers reach age 65. People over age 85 will be the fastest growing population segment. Medical technology has made it possible to live longer lives but quality of life issues remain. Elder consumers and their caregivers require services that meet their needs. In May, 2003, Josefina G. Carbonell, Assistant Secretary for Aging, testified before the Senate on behalf of the aging network that "we must update and re-energize old programs and comprehensively develop new ones that can better empower and serve older Americans in their communities and in settings that work best for them."<sup>1</sup> CILs are well situated to develop programs to meet older consumers' needs including fee-for-service programs funded by the Older American's Act.

According to the National Council on the Aging, "Most programs in the aging network are developed locally and meet local need and to coordinate with other local agencies so as to provide comprehensive but non-duplicative services throughout the community."<sup>2</sup> There are opportunities for CILs to collaborate with their local aging network in the new planning stages for senior

service programs as well as to become a known, local resource and provider for the aging population. The aging services manual will help to identify how CILs can be included in the community-based service providers network for the elderly.

Since the 1970s, the independent living philosophy of consumer choice, consumer driven or directed services has been the foundation of services successfully provided by CILs. This is common knowledge for CILs. What CILs may not know is that this philosophy is currently being studied for adoption by the aging network. The Robert Wood Johnson Foundation funded a \$3 million project in cooperation with the National Association of State Units on Aging called *Promoting Consumer Direction in Aging Services*. Its purpose is to develop an assessment guide to help states identify opportunities to support consumer choice and control in home and community-based services for older adults.<sup>3</sup>

In several studies conducted by AARP, consumers (ages 45+) indicated that, if given a choice, they would rather age in place, that is, stay in their homes and receive long-term services, rather than go to an institution.<sup>4</sup> Another AARP study found that three-quarters of those surveyed (ages 45+) believe they would be able to stay and live the rest of their lives in their current home with only half of them anticipating the need to make changes to their home as they age. In this same study, respondents (ages 50+) were asked whether or not certain community services (door-to-door transportation, outdoor maintenance, health monitoring, home delivered meals, etc.) were important to them and if they knew whether or not their community offered such services. A substantial number of respondents did not know if these services were offered in their community.<sup>5</sup> It was recommended that service information should be marketed to persons aged 50+ so they will know the type of services available when they need them for themselves as consumers or as caregivers.

With long-term care costs rising, there is increased interest in cutting costs. Some CILs are involved in deinstitutionalization programs. With a new focus on the money following the person instead of the institution, states are given incentives to develop and execute strategies that will be responsive to consumers' needs and preferences.<sup>6</sup> Consumers will be able to choose to use the money on services they want and need. CILs could play a major role in assisting their local area agency on aging by providing training and assistance to elderly consumers and their caregivers.

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## CILs and Transition-Age... Continued from page 1

involved in these activities in a number of ways, from sponsoring the YLF activities, to providing trained mentors, to providing financial assistance. Project staff at KU were involved with the Kansas YLF activity in June 2003 and are working with YLF staff to conduct an evaluation of the impact of the YLF activities on youth who participated. The Kansas YLF is organized and sponsored by the Kansas Association of Centers for Independent Living (KACIL). Currently, we are working with KACIL and YLF staff to collect data from youth who participated in the summer experience to examine the impact that had on their lives.

Mentoring activities form the core of the second activity in which project personnel at KU and the RRTC-ILM staff of the Western New York Independent Living Project, Inc. (WNYILP) are collaborating. The RRTC-ILM

staff at WNYILP have been engaged in a one-year project to evaluate the impact of peer mentoring activities on youth with disabilities. Peer mentors from the WNYILP CIL were trained by project staff at the University of Kansas to implement a model of support titled the "Self-Determined Career Development Model" which enables facilitators (in this case adult mentors from the CIL) to support youth to self-direct goal setting, action planning, and evaluation activities pertaining to transition outcomes. Project staff at KU have worked closely with the WNYILP staff to collect data on student self-determination and goal attainment and are currently analyzing data to examine the impact of these mentoring activities on youth self-determination and goal attainment.

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## Evaluation of an Approach... Continued from page 2

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# RRTC-ILM Computer-Based Tutorials



**Visit-ability**, the second in our series of computer-based tutorials, is an instructional program about making residential property accessible for visitors and friends with mobility impairments.

The purpose of this tutorial is to promote and educate independent living center staff, volunteers and participants on Visit-ability and community action projects that support the development of Visit-able housing.

Universal design at the community level permits full access to social participation in community affairs and interaction with neighbors. Visit-ability is an important step toward making universal access to community life a reality.

This tutorial provides a basic understanding of the concept of Visit-ability including examples of effective practices and cost estimates for Visit-able features. It describes strategies for developing Visit-ability advocacy projects in local communities and contact information for organizations that can assist in promoting those projects. Housing that is welcoming, convenient and usable by every community member is among those needs.

The **Visit-Ability** CD, released October 2003, is an adaptation of the booklet Visit-ability: An Approach to Universal Design in Housing created by the RERC on UD. This CD was produced under the direction of Edward Steinfeld, Arch.D, Director of the Rehabilitation Engineering Research Center on Universal Design and Director of the Center for Inclusive Design and Environmental Access and Douglas J. Usiak, Director of the Rehabilitation Research & Training Center on Independent Living Management and Executive Director, Western New York Independent Living Project, Inc.

**Independent Living Philosophy and History** is the latest computer-based tutorial to be released by the RRTC-ILM and the first in DVD-Rom format. A computer DVD format was chosen for this tutorial because of its capacity to include a variety of resources for the user.

**Independent Living Philosophy and History** examines the values and beliefs that powered the independent living movement and established the core philosophy of independent living centers. The DVD includes a 16 page tutorial and video clips of an actual workshop followed by an exam and certificate of completion. In addition, the tutorial contains a variety of resources for learning and presenting the philosophy and history of independent living. These include: a one hour video program titled My Country, five video role-play examples

## How To Obtain Copies of RRTC-ILM's Computer-Based Tutorials

One **free** copy of each of the following is available to executive directors of independent living centers and state independent living councils:

### **VISIT-ABILITY INDEPENDENT LIVING HISTORY and PHILOSOPHY**

Request your free copies by e-mail at: [info@ilm.wnyilp.org](mailto:info@ilm.wnyilp.org) OR contact Maureen Moffat, Information Dissemination Coordinator, (716) 836-0822 ext. 168.

CIRRIE, the RERC on UD and the RRTC-ILM are supported by grants from the National Institute on Disability and Rehabilitation Research and the Rehabilitation Services Administration of the U.S. Department of Education.

We welcome comments that will enable us to deepen our own understanding of ways to enhance people's lives.

For more information about the programs and services of:

CIRRIE - [www.cirrie.buffalo.edu](http://www.cirrie.buffalo.edu)  
RERC-UD - [www.ap.buffalo.edu/idea/](http://www.ap.buffalo.edu/idea/)  
RRTC-ILM - [www.rrtcilm.org](http://www.rrtcilm.org)

of the influence of I L philosophy on CIL decision making, a disability rights history timeline and a booklet titled Freedom of Movement: Independent Living History and Philosophy. The RRTC-ILM is grateful to Aquarius Home Health Care Video and **ilru** for permission to include their products in this tutorial.

One free copy of the tutorial is available to every independent living center and SILC executive director by request.



Our first tutorial CD **Successful Outreach to Foreign-Born Consumers through Culture Brokering** was mailed free of charge to every independent living center executive director and to every SILC in October 2002.

Since the early 1980s, about 850,000 people per year have come to the United States from other countries. Thirty years ago, about one in twenty Americans was foreign-born; today the ratio is approximately one in ten. Nearly everyone in the U.S. has a cross-cultural story to tell. Independent living personnel are no exception. Coping with the effects of a disability can be a challenge no matter where one is born. For a recent immigrant, the challenge is often magnified. In addition to difficulties with language, housing and employment, the person may also have difficulty understanding and accessing rehabilitation services. Independent living staff often experience frustration that arises from miscommunication and differing cultural perspectives. It is helpful to recognize obstacles that exist in the system for the foreign-born consumer as well as the means to overcome them. This recognition will enable one to design interventions to overcome these barriers.

This computer-based tutorial was developed as a joint project of the Center for International Rehabilitation Research Information and Exchange (CIRRIE) and the Rehabilitation Research & Training Center on

Independent Living Management (RRTC-ILM). This program is an adaptation of the monograph Culture Brokering: Providing Culturally Competent Rehabilitation Services to Foreign-Born Persons written by Mary Ann Jezewski, PhD and Paula Sotnik. The RRTC-ILM adapted the monograph to the context of independent living services for people with disabilities by incorporating terminology, examples and case studies relevant to independent living. The CD was produced under the direction of John H. Stone, PhD, Director, Center for International Rehabilitation Research Information & Exchange (CIRRIE) and Douglas J. Usiak, Director Rehabilitation Research & Training Center on Independent Living Management (RRTC-ILM) and Executive Director, Western New York Independent Living Project, Inc. (WNYILP).

The Culture Brokering CD was mailed to every CIL executive director and to all SILCs. Additional or replacement copies may be purchased by contacting: e-mail: [info@ilm.wnyilp.org](mailto:info@ilm.wnyilp.org) or Maureen Moffat, Information & Dissemination Coordinator, at 716-836-0822, ext. 168.



John Moffat  
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# Peer Mentoring to Promote More Positive Transition Outcomes for Youths With Disabilities

In September 2002, the Rehabilitation Services Administration (RSA) funded the RRTC-ILM to develop a model mentoring project called "Peer Mentoring to Promote More Positive Transition Outcomes for Youth with Disabilities." This project just concluded its one-year cycle with very positive outcomes.

Forty high school students with disabilities were matched with adult mentors with disabilities to work together on each student's long-term goals. Two groups, consisting of twenty students and their mentors each, attended eight weekly sessions, lasting two hours per session. Students and mentors used a structured curriculum to work on goal attainment. After completing these sessions, both groups began meeting on a less formal basis as a support group for the students in July, 2003. This support group will continue for as long as the group desires to meet. A final social event was held on September 25, 2003 to celebrate their successful relationship with the Western New York Independent Living Project, Inc. (WNYILP).

The Beach Center on Disability at the University of Kansas evaluated all students at the beginning, middle and end of each module. They also measured students' goal attainment using a goal attainment scale. Three western New York school systems were involved: the Buffalo Public School System, the Ken-Ton School District and the Williamsville School District. All school systems evaluated this program as very successful in assisting their students as they transition from high school. Two of the three school districts have a continuing relationship with the WNYILP because of this program. This project was completed on September 30, 2003.

A final report will be submitted to the U.S. Department of Education which will include a manual for all independent living centers, vocational rehabilitation programs and school systems to use to replicate this program.

Howard Fetes  
Project Director, Deputy Director  
Western NY Independent Living Project, Inc.

## Training Announcement

The Independent Living Executive Management simulation training will be held in Spring, 2004. This training is for executive directors and senior managers of established CILs.

The Independent Living Start-up Management simulation training will be offered in January 2004. This training is for executive directors and board members of recently funded CILs.

For further information, contact Ron House,  
(716) 836-0822, ext. 165.

## For-Profit Business in a Nonprofit CIL

CIL directors, boards and staff are starting for-profit ventures within their centers. Turning a small business idea into a viable, for-profit business is a challenge for CILs to face. Recently, two forward-looking CILs have done it. A third CIL discovered that it is not for them, at least for now! In today's business environment, we are challenged to do things that allow us to meet our consumers' needs outside of the traditional model.

The New York State Small Business Development Center became a partner with the RRTC-ILM in November, 2000. Our work with CILs to develop for-profit ventures started with training courses held in August, 2001 and January, 2002 where CIL directors assessed the feasibility of creating a business within their CILs. The training provided information on decision making and planning to start a venture focusing on self-assessment for success, types of profit enterprises, legal issues, financial resources, feasibility studies and operational issues.

CIL directors were interested in finding new financial sources from non-traditional areas. Ideas about ways to achieve the CIL mission through non-traditional ventures were not in short supply. Each CIL manager focused on one small business concept to pursue with the assistance of SBDC business advisors and consultants.

Three CILs developed very different business plans. Projects included a building acquisition, a manufacturing and sales business and a service venture. Each project represented a business opportunity for each CIL in its community and required changes within the CIL's organization and management.

A project in Pennsylvania was an urban real estate deal to purchase the building that the CIL leased. It would establish the CIL as a tenant/owner and facility manager subletting extra space to other tenants. Initial data indicated that the building, in relatively good shape, would spin off sufficient revenues to eliminate the CIL's rental costs and encourage facility expansion. This would reduce the CIL's costs and lower their operating

costs. This project was viewed as a guaranteed success at the outset, with minimal risk and substantial fiscal return. But it had limited application to furthering the CIL's mission. Internal organizational obstacles blocked proceeding as anticipated.

In Virginia, a community-based project was developed to provide computer technical expertise and support in an area that did not have these services. While the market indicated customer needs and proposed business viability, the CIL lacked unique skills or advantages that provide comparable advantage to the CIL. Due to the generic business concept, this project had greater risk and lower expectations. The contribution to the CIL mission was at first limited. But, greater connection was recognized as the business concept matured and launched.

In Minnesota, the project was remotely located but viewed as ideally compatible with the CIL mission, focusing on prefabricated access ramp construction designed to meet ADA requirements. The project had limited potential competition, significant comparable advantages, and an excellent market potential with commercial viability. This project was identified as having the greatest long-term potential while directly contributing to the CIL mission.

These CILs are looking at new ways to do business in the current market. These changes will logically carry over to changes in other CIL operations, ideally making the CIL stronger. Time will reveal the full measure of the impact of these projects and their application for CILs. These diverse projects may trigger additional innovations by CILs and provide valuable lessons. Key outcomes have meant significant changes for two CILs and the SBDC business advisors with whom they worked. Underscored is the necessity for CIL business projects to be mission focused instead of straight business case evaluations.

Jim King, State Director  
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