



RRTC-ILM

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newsletter

Center for Independent Living Technology Group - A Study of CILs Going Entrepreneurial

In August 2001, the Lynchburg Area Center for Independent Living (LACIL) participated in RRTC-ILM's dynamic "Non-Profit Centers Going Entrepreneurial" training workshop in Buffalo, New York. During the three days of this intense program, we learned about Project 2, Generating Alternative Funding Through Business Development Practices, met most of its principal players and gained valuable information about developing a for-profit venture as a subsidiary of our nonprofit corporation. When we first came across the information for this workshop, we enthusiastically submitted our application material since we had been examining the development of a for-profit venture for quite some time. Our goals included advocating for more socially responsible for-profit businesses by creating a model for one. Following the workshop, we completed our business plan and we were asked to participate in this project. Goals of this project include developing resources for CILs that want to start an earned income venture.

In March 2002, LACIL's Board of Directors passed a motion to begin the Center for Independent Living Technology Group (CIL Tech) and allocated seed funding of up to \$15,000.00 from our unrestricted funds. At the July, 2002 meeting, the Board also passed a resolution that would encourage collaboration with others being able to examine, follow/track, and receive reporting on the progress of this venture for the purpose of assisting other non-profits nationwide.

CIL Tech is an employee operated for-profit business with goals that include providing excellent customer services and products and profit sharing with LACIL. CIL Tech provides hardware, software, and technology solutions to businesses as a for-profit venture for LACIL. In the future, it may become more related to our mission by employing additional qualified persons with

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ILC-VR Collaboration on Employment: A Progress Report

During the past several months, we conducted surveys with three different types of organizations: independent living centers (ILCs), vocational rehabilitation agencies (VR) and state independent living councils (SILCs) to identify successful collaboration.

The response rates are encouraging, especially the response from ILCs. When ILCs filled out the Independent Living Organizational Survey, 136 ILCs reported that they provided employment services. Of these centers, 109 (80%) have responded to our survey. The response pool includes 38 of the 40 states identified with ILC employment services (95%). 78 VR agencies received our surveys. Of these, 54 agencies have responded (a response rate of 69%).

While we continue to follow-up in order to complete our data collection phase, we are reviewing our responses to date. At least ten candidate state examples have been identified in the surveys - states where collaboration appears to be working well from both VR and ILC viewpoints, or where a state has been "nominated" by their SILC because of a specific project or achievement.

While it appears in these preliminary results that many respondents expect collaboration to improve, barriers to collaboration are identified as well, including understaffing, limited tracking of employment outcomes by ILCs, and difference in philosophy. But new opportunities for collaboration appear to be emerging due to staff turnover, VR staff with ILC experience, staff deployment to other agencies, meetings between ILC and VR and cross-referrals.

Collaboration is a management skill. Our case study examples will be the basis for ILC training materials on collaboration.

Written by Sue Stoddard, PhD, FAICP, InfoUse

disabilities, serving as an internship site for persons with disabilities, and other outcomes related to our mission.

In less than one year, CIL Tech is a break-even venture whose business continues to grow. Its three full time employees and several contract employees strive to make CIL Tech prosper. It is similar to a "cost center" that continues to show promise in making a positive impact in our community, developing new financial avenues for LACIL and demonstrating more relation to our mission of assisting persons with disabilities in their quests for more equality, dignity and independence.

CIL Tech's business plan includes doing various forms of research (frequent and reliable market analysis), providing quality customer services and products for which the market has a demand (niche), anticipating and accommodating market changes (backup plans), structure that encourages employees to embrace productivity (good management, leadership, qualified and committed employees), collaboration (win/win business relationships), and accurate and trustworthy accounting (legal bookkeeping which would win if challenged).

We appreciate this opportunity to share some of the discoveries and milestones of our goal to make CIL Tech a vital part of our local economy. That goal requires analysis, positioning the corporation, the cooperation of many, and the provision of quality customer services and products to meet market demands.

ANALYSIS, POSITIONING AND BUSINESS PLANS: CIL TECH DEVELOPS AT LACIL

After the workshop in Buffalo, we created a one-page proposal summary and began spreading the word to our Board of Directors, staff and community that we were investigating and analyzing the development of business ventures as a means of "advocating by doing." Our research involved advocacy for more socially responsible businesses. More of them would most certainly generate greater opportunities for persons with disabilities and our mission includes helping create opportunities for persons with disabilities.

Over the course of several months, we researched the development of ventures that might be within our reach and the profits that would likely be generated by each venture. Profits were defined as new unrestricted revenues for LACIL and the potential for the venture to become more affirmative by year three. Initial business plans were developed for several different ventures from real estate to retail. Investment capital and capacity were the main influences for determining whether or not a particular venture was within our capabilities. For example, many nonprofits are not positioned to commit to a business loan from a lending source. In our case, we

began developing grant applications while also positioning capital from our unrestricted funds.

LACIL is a nonprofit organization with diverse funding including contracts/grants with the Virginia Department of Rehabilitation Services, grants from other sources, charitable giving, corporate support, and Medicaid fee-for-services. Our revenues from contracts and grants are restricted to the stipulations of those agreements while fee-for-services has enabled us to allocate small amounts of unrestricted funds as operational reserves. Our Board of Directors reached a consensus on how much of our operational reserves could be committed (even lost) as venture capital. Commitments to our day-to-day operations began to include more grant development activities for underwriting capital ventures. Those activities benefited LACIL in other ways such as a wider spectrum of collaborating organizations.

Eventually, we were approached by a small group of computer technicians who wanted to start their own technology company. Their vision included providing hardware, software, and credible technical services to businesses. LACIL could contribute venture capital and a methodology for bringing their vision to reality. With more investigation, we found this venture proved to be the most promising of all the ventures that we were examining at the time. When researching the market within LACIL's catchment area, we identified five other CIL Tech type companies with varying reputations and prices. A niche was identified for CIL Tech to provide trustworthy services and products. The goal of CIL Tech customer services includes helping ensure long-term relationships with customers (return business). In our study of markets, we also discovered how they differed. For example, within a one-hour drive from Lynchburg is Roanoke, Virginia, a larger metropolitan area, where the market may be described as flooded with CIL Tech type companies.

CIL Tech's business plan was formulated at several planning meetings which involved the Executive Director, Assistant to the Director, two computer technicians, LACIL's Board of Directors, our local Business Development Centre, the Small Business Development Center (SBDC) located at Buffalo State College, the Rehabilitation Research and Training Center on Independent Living Management (RRTC-ILM) and many of the principals of this project.

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DEVELOPING A BUSINESS PLAN: THE DESIGN OF CIL TECH

A written business plan offers a structured process for analysis, planning and evaluation and is a tool to help guide and educate others. There are many business plans that may be followed. The local SBDC is a vital community resource for business development <http://www.sba.gov/regions/states.html>.

LACIL's primary funding resources discourage commitment of staff time to activities other than those stipulated in our contract or grant agreement. Therefore, the design of our earned income venture included minimal involvement and time commitment from LACIL staff. Those that do occur must be related to our nonprofit's mission. For example, LACIL staff members are encouraged to provide information about CIL Tech in their day-to-day LACIL public education activities.

The structure of CIL Technology Group is an employee-operated design where CIL Tech employees benefit via a profit sharing formula when the company does well financially. This design may also help recruit qualified and talented employees who are interested in working for a company that has their best interests in mind. On an annual basis, profits are to be distributed according to a formula that includes the employee determining how the distribution is to be allocated. This design helps reduce the amount of supervision and other involvement needed by LACIL staff because CIL Tech employees are self-motivated to ensure creativity, innovation, efficiency and profit. This design thrives on good teamwork. There are many definitions of teamwork. CIL Tech's teamwork involves each employee anticipating and responding to the needs of others (customers and colleagues) with good customer services, marketing the company for success, helping all LACIL employees, consumers and volunteers to be set-up for success in the goals they choose. CIL Tech employees are challenged to find their own solutions to problems and to barriers preventing greater profits. This helps minimize LACIL staff involvement to that of a more general oversight and coaching role. As the parent corporation, LACIL provides CIL Tech with accounting and bookkeeping as a cost center in its annual budget.

In addition, the technicians must develop their own mechanisms for solving the technical problems of each customer. For example, CIL Tech provides a free one-hour consult that helps the technicians determine the products, time commitments and expertise that may be needed for helping each customer be successful. CIL Tech does not charge customers for the time needed to learn their particular computer system and may make referrals to several different businesses. CIL Tech main-

tains a registry of consultants to contract with if a particular situation is beyond our skills or time commitment capabilities.

Many retail outlets and national chains provide discounted hardware and software. CIL Tech cannot compete in that market. Hardware and software sold by CIL Tech is marked-up 30% (often less than that). Instead of trying to compete with other retailers of hardware and software, CIL Tech's primary thrust is services, keeping the customers' computer systems operating at peak productivity. CIL Tech technicians have skills (technical expertise) and strive to develop long-term relationships based on delivering outcomes that are in the customers' best interest.

CIL Tech provides a written fee-for-service scale that is currently below that of similar companies in our market, offers a Code of Ethics that other companies do not appear to offer, and provides reduced rates for nonprofit organizations.

THE FAST AND FURIOUS: DISCOVERIES AND MILESTONES

- Through the Lynchburg Chamber of Commerce and ACIL websites, a company in Houston located CIL Tech. We now have a contract for servicing IBM Point of Sale software in our area.
- Word of mouth marketing resulted in a job with a large trucking company that will net about \$15,000.
- Some long range planning is needed to address customer needs. For example, we are working with a retirement home to update systems and computers by October 2003.
- An area office machines company has referred several new customers. The company does copiers and other office equipment, and, if it relates to computers, refers those customers to us. We refer our customers who need office equipment to them.
- CIL Tech maintains a registry of technicians available for contract and consultant work. These technicians are also a pool of potential CIL Tech employees, should business grow and we need more full time staff.
- Expanding marketing efforts and addressing needs for legal counsel were hindered due to lack of funds. However, CIL Tech was recently awarded a grant for assisting with legal fees to help determine the structure of the business and to better define "employee owned." At this time, our options appear to be setting up a Limited Liability Corporation (LLC) or DBA (LACIL doing business as CIL Tech).
- Senior students in the Marketing Department, School of Business and Government at Liberty University in Lynchburg, Virginia recently considered CIL Tech as

a project for developing a comprehensive marketing plan.

- CIL Tech uses Microsoft Access for inventory and work-orders. CIL Tech bookkeeping is done with One Write Plus to keep its finances separate and distinct from LACIL's.
- In July 2002, a representative of the Small Business Development Center, Buffalo State College, Buffalo, New York provided a training session at our Board Training Retreat. This helped our Board of Directors to better visualize what we were trying to achieve and lent credibility to our efforts.
- Key LACIL employees and board members attended a conference titled "Mobilizing Resources for Independent Living" in New Orleans in August 2002. This three day comprehensive training provided very helpful information about funding CILs. Board members gained new insights and, upon returning, implemented changes in board membership that lead to new opportunities for LACIL and CIL Tech.

RESOURCES

The Rehabilitation Research and Training Center on Independent Living Management (RRTC-ILM), 3108 Main Street, Buffalo, New York, 14214, 716-836-0822 (V/TDD), <http://RRTCILM.org/>

Small Business Development Centers of the US Small Business Administration (SBA) are in localities across the country. SBA offers extensive information on most business management topics from how to start a business to exporting your products <http://www.sba.gov/>

Massarsky, C. W. & S. L. Beinhacker. (2002) Nonprofit Enterprise: Right for You? *The Nonprofit Quarterly*, 9 (3).

The Goldman Sachs Foundation Partnership on Nonprofit Ventures, Yale School of Management, has a comprehensive online Resource Center at www.ventures.yale.edu/

Massarsky, C.W. & S. L. Beinhacker. (2002) Enterprising Nonprofits: Revenue Generation in the Nonprofit Sector. www.ventures.yale.edu/

Entine, Jon. Shattered Image: Is the Body Shop Too Good to be True? *Business Ethics* (September 1994)

Can Corporations Be Good Citizens? *Sierra* (May 1999) http://www.findarticles.com/cf_dls/m1525/3_84/54492567/print.jhtml

Help For Socially Responsible Businesses. Inc.com. http://www.inc.com/articles/start_biz/22341.html/

Small Business Administration. The Business Plan - Road Map To Success: A Tutorial and Self-paced Activity. <http://www.sba.gov/starting/>

ILNET. Mobilizing Resources for Independent Living (seminar). Spearheaded by the Independent Living Research Utilization Program (ILRU) (www.ilru.org/) in partnership with the National Council on Independent Living (NCIL) (<http://www.ncil.org/>). IL NET provides a variety of resources to advance understanding of independent living.

Written by Walter Sabin, Executive Director, LACIL and Dana Jackson, with assistance from Charles Wood

Creation of an Independent Living Skills Evaluation Instrument

A newly launched project will create an assessment tool for independent living skills for deinstitutionalization and prevention from institutionalization. Machiko R. Tomita, PhD and Carl V. Granger, MD at the University at Buffalo and Douglas Usiak, Principal Investigator, RRTC-ILM direct this project. Vidya Sundar, doctoral candidate in the Department of Rehabilitation Science at the University at Buffalo will take this on as her dissertation topic. Maureen Moffat is the national coordinator.

The Olmstead decision requires states to ensure that individuals with disabilities be placed in the most integrated setting consistent with their needs. Currently, states are looking for effective methods to determine these needs. This project seeks to create a standardized evaluation form to evaluate multi-domain independent living skills in which the FIM™ Instrument (formally Functional Independence Measure) is included. With the successful creation of this instrument, CILs can evaluate needed services and the timing for deinstitutionalization as well as evaluate needed services for prevention from institutionalization. This project requires a minimum of 50 participants who either wish to move out of a nursing home or plan to move into a nursing home. Several CILs have been successful in deinstitutionalizing individuals and preventing consumers from becoming institutionalized. Among them, CILs from Alaska, New York, Florida, Vermont, California and Utah have shown interest in participating in this project. If you are also interested in taking part in this unique project, please contact Douglas Usiak, (716) 836-0822 or djusiak@wnyilp.org.

Written by Machiko R. Tomita, PhD



Developing Cultural Competency

Outreach to un-served and under-served populations is an important function of independent living centers. Being aware of and applying strategies to reduce and remove culture barriers that may hinder that outreach is an important function of the independent living center staff.

Cost effective, one-to-one training is now available for staff providing services to foreign-born consumers with disabilities.

RRTC-ILM, with its collaborating partner, the Center for International Rehabilitation Research Information and Exchange (CIRRIE), developed a computer-based tutorial for culture competency training. **Successful Outreach to Foreign-Born Consumers Through Culture Brokering** is a culture competency training program on CD-ROM for PCs. This tutorial is based on a CIRRIE publication called Culture Brokering: Providing Culturally Competent Rehabilitation Services to Foreign-Born Persons written by Mary Ann Jezewski, PhD and Paula Sotnik. The tutorial also contains video segments from live culture brokering workshops as well as links to worldview disability perspectives from eight countries. Your staff will learn:

- the meanings of and differences between race, ethnicity and culture,
- that terms like independence and self-determination may threaten persons from other cultures,
- that disability may be viewed differently and create barriers to providing service,
- a process to identify potential barriers and develop strategies to deal with them.

This CD-ROM tutorial was mailed to all executive directors of independent living centers. If you are interested in a copy or would like assistance in making the most of the one you received, contact: John Moffat, Project Coordinator, jmoffat@ilm.wnyilp.org, 716-836-0822, ext. 166.

Written by John Moffat, RRTC-ILM

Promoting Positive Transition Outcomes for Youth with Disabilities

In September 2002, the Rehabilitation Services Administration (RSA) requested that the RRTC-ILM develop a model mentoring program for replication throughout the 50 states. The operating principle of the model involves individuals with disabilities from the community acting as mentors to high schools students with like disabilities.

This project is entitled: Peer Mentoring To Promote More Positive Transition Outcomes for Youth with Disabilities. Implementation of this one-year project brings together a number of resources. The Beach Center on Disability at the University of Kansas in Lawrence, Kansas provides the model and training for peer mentors who will teach students self-regulated problem solving skills. This training program has been applied by Michael Wehmeyer, PhD at the Beach Center using teachers as mentors working with high school students. Self-regulated problem solving skills are typically not found in high school curricula. Students learn skills to enhance their critical thinking, set goals, solve problems and take necessary actions to achieve their educational, vocational or other life goals. In addition, these skills enhance their self-determination capacity and support greater independence.

Additional project supporters are the New York State Office of Vocational and Educational Services for Individuals with Disabilities (VESID), the Western New York Independent Living Project (WNYILP), the Commission for the Blind and Visually Handicapped (CBVH) and the Rehabilitation Services Administration (RSA).

Mentees are high school students from three of the largest school systems in western New York. Recruiting juniors and seniors with disabilities are: Jerry Halligan, Vocational Trainer at the Buffalo Public School System, Anna Ceiri, Director of Special Education at the Williamsville School District and Alan Erzkus, Director of Special Education from the Ken-Ton School District. Two groups of twenty students and their mentors will pilot test the model and method. Students will be evaluated before being introduced to their mentor. At the conclusion of seven weeks of mentoring sessions, they will be evaluated again to assess their success in achieving their goals and the benefit of having a mentor.

The Beach Center and RRTC-ILM staff members will evaluate the program and prepare a final report on the outcomes of the model. The report and replication information will be disseminated to independent living centers, state vocational rehabilitation programs and school systems.

Written by Howard Fetes,
Mentoring Project Coordinator

From the RRTC-ILM Director ...

We appreciate comments and feedback from those individuals who follow our progress and read our newsletter. Five years ago, I was not as aware of the forty RRTCs around the country and how they helped independent living centers and individual consumers. Throughout the twenty years that I have been a CIL director, I had not seen quantities of valuable material coming out of RRTCs. I may not have been aware of the source of these materials. Frankly, I was mystified as to how all this activity going on elsewhere could help my center and consumers in Buffalo. Recently, it seems, projects are generating results with training programs being offered and reports being disseminated.

When approached by the National Institute on Disability and Rehabilitation Research (NIDRR) and the Rehabilitation Services Administration (RSA) to compete for a Research and Training Center grant, I was more than intrigued. The grant was for the Rehabilitation Research and Training Center on Independent Living Management. I accepted the challenge of establishing an RRTC with three main tenets:

- the source of the research and training perspective would be the independent living consumer,
- the project itself would be directed by the centers for independent living (CILs),
- the outcomes and results would directly benefit CILs.

Now, two and a half years later, I believe that we are doing just that. Our Steering Council, composed of CIL directors and SILC representatives from all ten regions, provides direction and feedback on the activities and accomplishments of the project. Many Steering Council members are partners in several sub-projects. The RRTC-ILM tapped into major universities around the country to create research partnerships and conduct needed research. RRTC-ILM staff, housed at the Buffalo CIL, oversee and monitor overall progress and maintain a "Not For Me Without Me" philosophy. What does this mean to us at the RRTC-ILM? No project gets off the ground without CIL personnel being an integral part. We are not studying CILs or asking CILs what they think after the project is done. This means involving and integrating the CIL perspective from the planning stage to the implementation and final report. Steering Council and Curriculum Committee members are selected for their unique CIL perspectives and qualifications. These individuals insure that our projects are guided by people who are "there, been there, and will be there." This is our version of Participatory Action Research (PAR). This insures our ability to transfer the findings and materials of the RRTC and Rehabilitation Engineering and Research Centers (RERC) research networks to the CIL network in a format relevant to CIL personnel.

So what are we doing?

The **COMPENDIUM of Resources for Independent Living Management** is a repository of information on

independent living center organization and management. CIL directors suggested that we collect this information for their use. Over three hundred centers around the country have provided information for inclusion. We gathered information on: CIL organizational structure, programs and services, staffing and salaries, revenues and financial sources. In addition, your colleagues provided over 550 management documents. We continuously seek more policies, procedures, job descriptions, mission statements, program descriptions, etc. Your documents are kept confidential with any indication of the source of the material removed for confidentiality before posting on the web for others to use. The **COMPENDIUM** contains salary ranges for dozens of positions and funding streams from all levels of government as well as private sources. If you do not already have access, this information is available to you when you fill out our survey. Sharing is the name of the game. The **COMPENDIUM** is available on our website at www.RRTCILM.org/.

Our **CIL Directory** of over 650 centers is updated daily. Available online at www.RRTCILM.org/, you can find a CIL by searching under the CIL's name, the director's name, the city or the state.

The alternate funding through business development project directed by James King, Director of the New York State Small Business Development Center, is developing material on how to create businesses that will be a source of non-governmental funding to support work that is outside state and federal guidelines. Three exciting small business projects are nearing completion at three independent living centers:

- a CIL in Pennsylvania is purchasing their own building and becoming a commercial property landlord,
- a Virginia CIL has developed a computer technical service business for community businesses, and
- a CIL in Minnesota has started a building contractor business for home modification.

Stay tuned! Reports of their continued success will be coming to you soon.

Dr. Michael Wehmeyer at the Beach Center, University of Kansas, directs the youth with disabilities transitioning to work and/or school project. This project is in the last year of its three-year cycle. Breaking the stereotype of "can't do anything without lots of money," Mike goes to CILs that have youth transition programs as part of their service structure. Inexpensive (or free) ways to replicate these programs will be made available through manuals and training programs so that CILs can provide these desperately needed services to young people with disabilities.

While the youth transition program winds down, Dr. William Mann, Director, RERC on Successful Aging through Assistive Technology at the University of Florida is beginning a three year project focusing on independent living and

aging. The mission is to identify services that CILs are providing and to develop training materials for all CILs to promote services for people who are aging into disabilities. We will certainly hear more as this evolves.

Independent living management model research, directed by Dr. Ronald House and me, takes place at the RRTC-ILM's home in the Western New York Independent Living Project, Buffalo. The goal is to transfer community-based organizational management practices to CILs. We discovered early on that there are no documented models of CIL management to use for comparison to community-based management practices. Realizing that this information was critical to our overall project mission, we learned (sometimes, the hard way) what was needed and proceeded to identify and develop a model for independent living management. From my twenty years experience as a director, and in my heart, I knew what a CIL was and how it should be managed. Yet, we were not about to declare ourselves experts in all aspects of CIL management. So, we went out to get consumer input to develop a model. We contacted CIL directors, board members, staff and consumers. **YOU** told us what a CIL is. By asking the stakeholders what the outcomes of a successful CIL are, we can determine if CILs are working to meet the performance standards set forth ten years ago in the Rehab Act. We also asked the stakeholders what the elements of a CIL are and matched those elements to established management categories found in non-profit organizations. To date, we have identified and matched seven specific management categories of independent living centers. Soon, we will be coming to you to identify the practices. This information will give us an independent living management model to work from in identifying needed organizational training. In addition, it will provide to newly developing centers a structure and model of what they need in order to succeed.

Replicating successful collaborations between CILs and vocational rehab programs is a project directed by Brenda Premo, Western University for the Health Sciences (and Dayle McIntosh Center fame). Having surveyed CILs, SILCs and state VR programs, this project is moving toward replicating models and reporting practices of successful collaboration. Once these models have been reviewed, training and resource materials will be created for CILs to present to state VR programs to generate new collaborations and provide more services to consumers.

What is left for us to do? Get the stuff out, of course! Face-to-face training is very expensive with travel costs, time away from the office and related expenses. Often, these costs are beyond CIL budgets. RRTC-ILM is working on alternate and innovative ways to deliver training to you - our customer. Recently, we sent every CIL director an interactive training tutorial on CD-ROM called **Successful Outreach to Foreign-Born Consumers through Culture Brokering**. This tutorial provides you and your staff with basic knowledge, awareness and tools for working

with foreign-born people with disabilities. The Center for International Rehabilitation Research Information and Exchange (CIRRIE) directed by Dr. John Stone (www.cirrie.edu) contributed the source material for the tutorial. The positive reaction and feedback regarding this training format has encouraged us to developing similar tutorials on other topics. The RRTC-ILM staff is developing an IL Philosophy interactive training DVD. Dr. Edward Steinfeld, RERC on Universal Design (University at Buffalo), is developing a program on Visitability. June Kailes, disability rights consultant, is developing training on Community Organizing which features interviews from recognized leaders in the field of grassroots organizing. In addition, we are exploring various on-line training formats, webcasting and traditional face-to-face training programs.

These are just a few things to watch for. So, stay with us. Help us. And I am sure you will get what you want from the RRTC-ILM.

Written by Douglas Usiak, Director, RRTC-ILM,
Executive Director, WNY Independent Living Project, Inc.

TRAINING ANNOUNCEMENT

Executive Management Simulation Training May 4-9, 2003 Las Vegas, Nevada

The **Executive Management Simulation** is designed to provide the participant with the opportunity to exercise management decisions in a realistic (but simulated) center for independent living. As the executive, you will have the opportunity to increase your understanding of independent living philosophy, the mission of the center and experience hurdles, opposition, and concerns as you work with the board of directors, staff, parents, government officials and consumers. These matters are highlighted through critical incidents where you are able to see the consequences of your decisions. The activities of one operating year are compressed into four and one-half days of training.

The Las Vegas training event is co-sponsored by the State of California Department of Rehabilitation (Ben Harville, Chief) and the California Foundation for Independent Living Centers, Inc. (Patricia Yeager, Director). The RRTC-ILM appreciates their sponsorship and their continued support of independent living.

To attend this training, please contact Ron House at 716-836-0822 ext. 165 or rhouse@ilm.wnyilp.org

Written by Ron House, PhD, RRTC-ILM

Independent Living Centers Are Not Places to Live They Are Places to Dream

As manager of Independent Living Services for the New York State Education Department's Office of Vocational and Educational Services for Individuals with Disabilities (VESID) over the past ten years and as an employee deeply steeped in the philosophy of the field since the mid 1980's, I decided to open this article with a title that could easily be used as a banner or tee-shirt for the independent living movement. How many times have we fielded the proverbial caller asking if we have an opening at our facility? How many times have we heard the underwritten advertisement or radio commercial promoting assistive living at all levels including "independent living?" There is clearly an information gap about the role and function of independent living centers when it comes to housing.

Let's start at the very beginning. The Federal Title VII of the Rehabilitation Act specifies, among several compliance criteria, that an independent living center is nonresidential. Why? Is it because the federal government did not want us forming radical communes of disability activists? Is it because people who work together should not live together? Or is it simply because the residential model would look too much like traditional rehabilitation programs? There may be a small element of each of these in the answer, but as a whole, it does not come close to the rationale.

Have you ever seen a program-based living situation without regulations? And we all know what happens when the regulations are broken! We are asked to leave and move on to make room for someone who can follow the regulations. Housing presents the greatest opportunity to impose the most stringent system of rules upon us. We can only live in a certain place if we have a job. We can only live in the given congregate setting if we take our medication, contribute to chores and smile and say please. We can live in the new apartment if we do not care who we live with. What do you mean we cannot make up our own regulations? That's right. Usually we can't. Someone with incredible benign compassion for the well being of others has designed the rules and, by doing so, thus controls our lives. If the regulations are not obeyed, like I said earlier, we will be discharged, moved to a "more appropriate setting" or sent back to wherever we came from.

How can the entire experience of living under some set of rules other than our own chosen lifestyles and decisions be anything short of a form of control? It can't. So when people with disabilities established the premises for independent living and based them upon self-help, peer role modeling and consumer control, we meant in all aspects of our lives.

Certainly it is conceivable that among the continuum of choices anyone has, a person with a disability may choose to live under a prefabricated set of regulations in a group home or other segregated living situation. But should our movement own and operate such a place? No! Emphatically, no! It is contradictory to our philosophy. Independent living centers create an atmosphere where people with disabilities make decisions based on informed choices. We never promise that people make wise or risk free decisions. Thus, the consequences for the choice are also theirs alone. But any living situation has conditions, eligibility criteria and consequences if they are not followed that derive from policies and regulations of the residential setting. If we were to attach ourselves to residential programming, then we would need to enforce the conditions and ultimately own the power and authority over the control over where someone with a disability lives.

Another complex philosophical issue surrounding housing relates to what extent an independent living center should lend its name or resources to the development of segregated housing. It is well known that the lack of accessible and affordable housing presents one of the greatest obstacles to independence. We are keenly aware that there is a dramatic shortage of such housing options. So, should independent living centers stand in the way of making housing available to people with disabilities if the only choices appear to be segregated? Yes! Emphatically, yes! We should be diligent in preventing the development of additional segregated settings because to do anything otherwise is a demonstration of the acceptance of segregation of people with disabilities. Anytime a new dwelling is built solely for and specifically requiring disabled residents, we are creating another stain on the landscape of equality in a community. Have you ever seen bricks and mortar torn down because it symbolized segregation? Are you aware of any housing option that was segregated on the basis of disability eligibility suddenly open its doors to the non-disabled?

So where should our energies be directed if the only funding for housing options appears to be for segregated settings? We need to change the system that determines the eligibility criteria for funding. We need to advocate for new funding sources for additional options. We need to advocate for requiring integration of new accessible housing attached to other projects that are designed for affordability. We need to protest the groups that continue to build monoliths to segregation in communities because other choices do exist. Even if funding of integrated, scattered, and other appropriate models causes strain on resources to connect housing to services, then we need to advocate for more funding and fewer compromised solutions. If we continue to turn our backs on segregated

housing or lend support for it, then we are guilty of creating the next century of disability ghettos. We are accountable for perpetuating the stereotype that people with disabilities live "over there" and the rest of a community lives wherever they "choose."

It is well known that people who are forced to live clustered together because their community outcasts them will begin to see themselves as devalued and oppressed. They will be kept at arms length from the rest of the community. Look at American Indian reservations or low income housing projects. Devalued people will become subcultures and turn to socially unacceptable behaviors to cope with discrimination. We can see that in the chronic use and abuse of alcohol and other substances among American Indians, the disabled and cultures of poverty.

Independent living centers cannot be associated with promoting conditions that bring our disability culture

down. ILCs are vital catalysts of change and must bring hope and dignity to our culture. We count on ILCs to engage developers, management companies and residential realtors to incorporate accessibility into all housing projects, to consider people with disabilities as a viable part of the marketplace and to convince others to embrace the spirit of the Americans with Disabilities Act and 504. We are counting on continued adherence to a nonresidential policy that looks segregation in the eye and says "No" while raising consciousness to break down barriers that allow for greater integration of people with disabilities. We expect our ILCs to broker the necessary changes to grow integrated housing stock in the years ahead because we know that nobody else has the courage to uphold our philosophy.

Written by Bob Gumson, Manager, Independent Living Services for the New York State Education Department's Office of Vocational and Educational Services for Individuals with Disabilities (VESID)

Replicating Best Practices in Working with Youth in Transition

The Beach Center on Disability is examining the role of centers for independent living (CILs) in supporting transition services for youth with disabilities. Through a survey we conducted during the project's first year, we found that a number of CILs across the country were engaged in activities that enabled students with disabilities to participate in groups, often aligned with CIL peer mentoring programs, where they could learn how to take a more active role in their transition planning.

This survey finding led to our first effort to replicate and validate best practices in this area. High school students with disabilities traveled to a local CIL once a week to participate in a group that would engage them in activities designed to increase their participation in their own transition planning. Using materials that we received from CILs who responded to our survey along with additional resources from The Beach Center on Disability, activities were designed to provide students with instruction in skill areas such as decision-making, problem solving and self-advocacy. Our goal was to familiarize students with these concepts so that they would have an interest in being involved in their own transition planning process.

A number of steps needed to be completed before the group began. First, a relationship was established between The Beach Center and Independence, Inc., a center for independent living in Lawrence, KS. The project director met with the educational advocate from this center to determine interest in participating in this project. Second, a transition coordinator from the local high

school was invited to meet with project and CIL staff. She assisted in recruiting students that would benefit from being in the group.

It was important to distinguish this group activity from a more traditional "school class." We wanted to utilize the unique capacity of the CIL to empower students through self-advocacy and mentoring and provide an environment in which students would feel free to express their own ideas about their future. Though there was an agenda of material that we wished to cover, we wanted the students to feel that this group was theirs. Therefore, we left many of the decisions pertaining to group-related activities to the discretion of the students, including the name of the group, the rules of the group, and what type of refreshments they wanted.

The group met for seven one-hour sessions. During this time, ten students were engaged in activities to teach them how to dream about their future, how to develop goals that would take them toward that dream and how to respond if a problem arose. The students accomplished this by working individually and in small groups. By the end of the seven weeks, each student developed a transition goal and identified the steps they needed to take to accomplish it. Students generated goals that ranged from what type of employment they wanted after they finished high school to selecting a recreational activity in which they wanted to participate. As a final activity, the students planned what they wanted to do during their final group meeting. They planned

the logistics for the event. For example, if they wanted to go somewhere, they had to plan their own transportation. The group decided that they wanted to go to the local bowling alley for bowling, video games and pizza. They spent two sessions planning this outing. It was encouraging to witness the process they used to plan every detail. They used every skill that was covered during group sessions. Furthermore, they helped each other by offering transportation options to students who could not get to the bowling alley.

In conclusion, this project resulted in many positive outcomes. The CIL formed a relationship with the high school that will be useful to students who are transitioning out of high school. Students will be able to take advantage of a number of transition services. Second, this type of activity is easily replicated in other CILs because it requires very few additional resources to implement. Third, and most importantly, the students have a sense that they can make decisions about how they want their future to look and can act on those decisions.

Written by Stelios Gragoudas, Project Director

International Conference on Aging, Disability and Independence Advancing Technology and Services to Promote Quality of Life December 4-6, 2003 Arlington, VA, USA A Conference Integrating Research, Practice, Business and Consumer Perspectives

This conference is hosted by the University of Florida Rehabilitation Engineering Research Center on Technology for Successful Aging and the American Society on Aging, working together with professional and consumer organizational partners.

It is financially supported by the European Union, and within the United States, the National Institute on Disability and Rehabilitation Research, the National Science Foundation, the Veterans Health Administration, The Centers for Disease Control, private foundations and corporate sponsors.

The **International Conference on Aging, Disability and Independence** will bring together researchers, practitioners, business leaders and people involved in aging policy to focus on these issues. The conference will include sessions related to research and development, practice, products and services and policies. Commissioned papers will be published following the conference. Conference proceedings will be posted on the Rehabilitation Engineering Research Center on Technology for Successful Aging website (www.lerc.ufl.edu).

Conference Themes

- Public Policy, including payment & coverage
- Independence issues for elders with one or more impairments
- Caregivers & personal assistance
- Aging with Disability
- Diversity
- International Policy, Approaches & Issues
- Future Directions

To learn more, go to

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

According to the U.S. Census Bureau (2001), 14.2% of the elderly population had difficulty performing at least one activity of daily living (bathing, dressing, eating, mobility) and 21.6% had difficulty with instrumental activities of daily living (managing finances, cooking, housekeeping, shopping and using transportation). The U.S. Department of Health and Human Service, Administration on Aging (2001) reported that 35 million Americans were age 65 years and older which represented 12.4% of the U.S. population. Between 2010 and 2030, this number will increase dramatically with baby boomers reaching age 65. By 2030, the total U.S. elderly population will rise to 70 million (20%). The fastest growing segment of the older population is, and will continue to be, those persons over age 85. Therefore, as "boomers" age, they will become the most affluent and largest potential consumer base for centers of independent living (CILs) during the next twenty years.

The RRTC-ILM contracted with the University of Florida Rehabilitation Engineering Research Center on Technology for Successful Aging (RERC Tech-Aging) to address this as an area of research. Previously housed at the University at Buffalo, the RERC on Aging studied and documented the needs of older people to maintain independence.

Older persons have a substantial need for the type of services offered through CILs, including services related to: 1) transportation, 2) housing and 3) information about assistive devices. The RERC Tech-Aging identified these three areas as among the most important issues associated to independent living. As the number of older people increases, the group will include those individuals aging with disabilities as well as those who acquired disabilities later in life. Unfortunately, while they could benefit from CIL services, many older people with disabilities have not taken advantage of them. Identifying successful programs within CILs, creating models for replication and educating the community about services available will be the major challenges for this project.

The goal of this project is to implement and test a set of strategies aimed at increasing CIL utilization by older persons with disabilities and to increase their satisfaction with the services. There are four objectives within this goal:

1. Identify best practices currently used by CILs in meeting the needs of older persons with disabilities, including, but not limited to those practices associated with housing, transportation, and assistive devices.
2. Increase the understanding by CILs of the needs of this elder population and develop ways to implement the best practices identified in the project.
3. Increase the understanding of services offered by CILs by the major organizations representing older

persons.

4. Determine the impact of the strategies employed in this project on: (a) increasing the numbers of older persons receiving CIL services and (b) satisfaction by older persons with disabilities with the CIL services they receive.

Currently, we are working on the first phase of the project to identify services offered by CILs to older persons with disabilities (Objective 1). We are conducting a national survey of all CILs to determine the types of services they offer to older persons with disabilities, the number of older persons who used those services in the past year, and descriptive information about those programs and services for older persons with disabilities.

In December 2002, surveys were mailed to 176 CILs. 78 of these CILs were identified from their response to the RRTC-ILM's Independent Living Organizational Survey as having programs for seniors over age 65. The other 98 CILs reported having seniors use some of their programs. To date,* 54 surveys have been returned (31%). We need your survey responses.

Our next step is to review and evaluate survey responses. More surveys were sent to 200 CILs in March 2003. We will follow-up by telephone and e-mail with CILs identified through the survey as offering helpful, unique and outstanding (best practices) programs and services for older persons with disabilities. Once this is completed, a report of best practices will be prepared. In addition, a video of best practices will be developed based on visits to three CILs identified through the interviews.

**CILs who returned their survey by the requested date were eligible for a random drawing for a holiday gift of \$200.00. We are happy to announce that Northwestern Illinois Center for Independent Living of Rock Falls, Illinois was our winner.*

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