



RRTC-ILM

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3108 Main Street, Buffalo, NY 14214 (716) 836 - 0822 (Voice / TDD)

newsletter

One Year Later . . .

National CIL Database

Twelve months ago, the Western New York Independent Living Project Inc. (WNYILP) received good news. A proposal submitted to the National Institute on Disability and Rehabilitation Research (NIDRR) was approved. WNYILP became the first independent living center to receive NIDRR funding establishing the Rehabilitation Research and Training Center on Independent Living Management (RRTC-ILM).

With six sub-projects in the overall grant, startup seemed a monumental process. Looking back, the project partners, steering council members and RRTC staff pooled their expertise and resources to make progress in each area. All of these contributors came together for a two-day Steering Council meeting in March. Project partners and staff presented sub-project goals, plans and updates. Steering Council members provided input and feedback.

(P1) The first and most important accomplishment of the first year is the CIL Directory. Project 1 staff identified and contacted independent living centers across the U.S. and territories. Included in this list are federally and state funded centers and their satellites. With new centers starting up and centers frequently changing addresses and locations, updating the contact list is critical to this project and all project partners.

The Project 1 National CIL Database was one of the first sub-projects to get under way.
continued on page 5

How many times have you said to yourself, "I sure wish I could find the information resources (policy, practice, program, job description, financial information) to meet the challenges before me (a funding opportunity / new funding sources, the need to develop job descriptions, ever changing state and federal regulations)?"

If you are one of the hundreds of CIL Directors who is constantly looking to improve services, increase benefits, add new programs, or just get a handle on what has to be done to stay up with the demand for independent living services, we have the program that you will want to be a partner in.

The Rehabilitation Research and Training Center on Independent Living Management (RRTC-ILM) is housed at a CIL and is working on a national project to assist you and to provide you what you need. We need your help.

Our lead project at the RRTC-ILM is a national repository on independent living services, programs, practices, funding sources, and a variety of other information. This repository will assist even the oldest CILs. This project is a response to the needs of new CILs and centers that are going through transition (where the old way of doing business just is not working anymore).

First, we identified all of the CILs that exist in our country today. We telephoned every single one.
continued on page 6

CIL Management

What exactly is a CIL? How is a CIL program-matically constructed? What do I need to have in place? What practices, policies and management processes do CILs need?

These are just a few questions that people discover for themselves as they work, volunteer and interact with a CIL. Yes, there are standards, regulations and local information that tell us what a CIL should do. But, is there a management piece that clearly shows us what a CIL is? NO.

For years, CILs have operated under a common principle, functioned under standards and regulations and performed to meet funding source mandates. As an industry, independent living has not managerially defined itself. That is not a surprise. Most non-profits have not defined themselves. Yes, we have learned what to do and how to do it through years of sharing and teaching and with the assistance of national training programs and independent living consultants. But, what is available to guide us when we cannot afford the time or the cost of training and travel?

The RRTC-ILM is working aggressively on a project to provide CIL directors just that - a clear picture of what constitutes a CIL, what management practices should be considered, and most of all, how to find out what you need to know and where to obtain it.

Our current study of the independent living industry is yielding some exciting results. This first study of its kind is offering us a variety of information that will assist you in developing the programs, services and management of your CIL. Many of you participated in our national study on "What Are the Outcomes of a CIL?" To date, almost 200 participants have been involved in this study (executive directors, staff, board members, consumers of services, and funding providers.)

The study is comprised of independent living community members only.

What are they telling us? They are letting us know the management categories, the value of the programs, and the need of it. What makes this study so interesting is that, unlike many studies that have been done on other non-profits, this research has the added value of looking at a homogeneous group of community based organizations. All of the centers operate under common principles and accepted standards, yet are directed by their communities and are run independently of one another. This allows us to get a national look at how centers are run, what centers feel are important and where they do or do not concentrate their efforts. Human resources, organizational culture and community relations are a few of the management categories that are being revealed.

Once the management categories define themselves by your involvement in the research, we will conduct a two dimensional study of our industry (executive directors only). This survey will provide you a template of what centers need and what centers would like. The results will give each one of our Centers (directors, boards) an outline to verify, compare, or examine against other centers. We will have a model, not developed by university-based researchers in a vacuum, but developed by you and your colleagues, staff, board and consumers as to what a CIL is and what it needs to have to operate.

Please participate when we call on you for your contribution.



The Rehabilitation Research & Training Center on Independent Living Management is a member of The Family of Agencies of The Western New York Independent Living Project Inc.

Evaluation Bridges RRTC-ILM to Quality Through CIL Participation

When the Rehabilitation Research & Training Center on Independent Living Management (RRTC-ILM) went into operation on November 1, 2000, evaluation methods were implemented. RRTC-ILM's commitment to quality is a primary concern as we develop our research and training programs. It is our hope that these programs will help strengthen the national network of centers for independent living (CILs) in successfully carrying out our mission in tune with the independent living philosophy. We share in the commitment to improving the quality of life for people with disabilities in our communities. CIL staff, boards, and consumers have a stake in the RRTC-ILM's programs. You are our stakeholders for all of our evaluation efforts. Your input guides the programs and materials we create. As we achieve specific milestones, we will need your evaluative feedback to improve them before dissemination to the larger community of IL organizations.

RRTC-ILM projects are designed to achieve outcomes at four levels that will benefit CILs. First, the project will identify best practices and the corresponding CIL models that address several important CIL roles (Projects 2-5). Second, it built a comprehensive CIL Directory collaboratively with CILs (Project 1) and set up a National CIL Database of information that will benefit CILs and guide our research programs. Third, it provides training programs that are designed and implemented on the basis of need and our research findings. Fourth, the project produces and delivers training materials developed and tested in conjunction with the training programs.

Whether we are doing research or developing training programs and materials, our evaluation efforts address the achievement of quality. The purpose is to assess and assure both the *merit* and *worth* of our activities.

Merit involves questions of how effectively and efficiently our research and training programs are performing. It means using evaluation data for quality assurance, monitoring our processes as well as guiding their ongoing improvement. It also means measuring and tracking our outcomes. Thus, we collect ongoing data on our processes and outcomes.

Assuring the *worth* of our research and training programs requires that we track the project's impacts or value to our stakeholders. Identifying stakeholders' needs and expectations early on and striving to achieve them through our processes can best assure such value. By developing programs that specifically address stakeholders' needs, we hope to increase their potential for beneficial impact on CILs. Additionally, we will validate the project by following up and verifying its impact or value to stakeholders at the end.

We recognize that input and evaluative data from stakeholders at appropriate points in our process is indispensable if we are to produce outcomes of quality and utility to CILs. For example, the construction of the National CIL Database from ground level requires first-hand contact with new and emerging CILs and older CILs. This was effectively done with the participation of CILs in providing the information. We depend on their responses to our surveys and appreciate suggestions. Once the National CIL Database is posted on our website, we will need interested CILs to evaluate it for accessibility and functionality, as well as give us suggestions for improvement. Maintaining accuracy will require that CILs provide updated information.

When evaluating our training programs, whether they involve subject matter (for example, independent living philosophy), training methods (for example, training the trainer), or simulations (for example, organizational management), our participating stakeholders help us by providing two sets of data.

continued on page 4

Responses to our post-training survey (which is uniform across all training), tell us of the satisfaction level with the quality of training. Open-ended responses inform us of ways to improve our sessions in an ongoing manner. We hope to share a collectively perfected training system with all interested CILs by the end of the project. In addition, training materials that we develop will benefit from participant evaluations. Our follow-up questionnaires on the usefulness of the materials will help us revise them as needed.

Stakeholder participation has an additional special role in our research. Project 4A, for example, studies best management practices in non-profit agencies and then uses the findings to develop a suitable model culled from the experience and expertise accumulated to date in the world of IL organizations. Focus groups of CIL consumers, staff, executive directors and board members are now characterizing a successful CIL organization. This is our basis for observing and extracting the corresponding best practices from exemplary IL organizations that will be validated by surveys of national stakeholder samples. Models grounded in IL context will result from stakeholder participation.

Participating CILs will help us evaluate our project's success overall by helping us keep track of their performance on mutually agreed outcomes of common interest such as growing number of consumers, their growing satisfaction, advocacy outcomes achieved and so on. By tracking performance several years before and several years after the RRTC-ILM project, we can check the project's success and impact.

In summary, our evaluation process will address the following three issues: the extent to which we achieve our goals (the project's effectiveness), the way we manage our resources to assure quality and achieve goals (the project's efficiency), the extent of project's utility to and impact on its stakeholders (the project's relevance and validity).

We will address these issues by relying on continuous feedback and input from the CILs as we progress through the various stages of our project. We believe that this is the key to enhancing the mutual benefits that will ensue: our research and training programs will benefit from the stakeholders' knowledge and experience and be able to deliver quality outcomes; the CILs will benefit from outcomes that are more meaningful, finding them useful for maintaining or improving their current practices.

Distance-Learning Courses

San Francisco State University's goal is to improve the skills of middle managers and supervisors at centers for independent living. To this end, we will produce at least four short distance-learning courses. Each course will take six weeks and require two hours per week for students to work with the course material online. Some additional assignments, such as looking up resources on the Internet and applying what has been taught to one's home community, will be part of the coursework. We will provide opportunities for students to interact with instructors and with each other.

Planned courses include:

1. Background in the Core Services of I L
2. Supervision: How to Be a Good Supervisor
3. Operational Standards: Organization, Documentation and Reporting
4. The Big Picture: Issues and Trends in Independent Living

The development of cultural competence as it applies to CILs will be a part of all courses. Each course is given twice to provide an opportunity to obtain and analyze feedback and to improve it. We will work with the RRTC-ILM evaluation team to assure that we obtain useful and timely feedback.

The Independent Living Organizational Survey was developed and pre-tested in February. After Steering Council review, it was mailed to 610 CILs in April. Returns have been steady and the effort to obtain more responses continues. To date, nearly 200 CILs have replied and the survey data has been entered in the National CIL Database. This information will be available to participating center directors through the RRTC-ILM website.

(P2) The first *Non-Profit Centers Going Entrepreneurial* workshop for CIL directors was held in August. Seventeen applicants were selected to participate in this two-day presentation. Eight experts from New York State Small Business Development Centers presented critical aspects of starting a non-profit business in a center for independent living. A second workshop is being rescheduled. Openings are still available. Candidates completing the training will be selected for on-going support to start a small business at their CIL.

(P3) The University of Kansas Beach Center, well known for programs for families and disability, implements Project 3. Investigating the role of CILs in youth transition services, staff surveyed over 65 CILs that provide services to youth with disabilities. These CILs were identified from respondents to Project 1's Independent Living Organizational Survey. Survey results are being tabulated and reviewed. The investigators have successfully completed the first of three years on this study.

(P4) Project 4 has seen progress in three areas. In the first area, focus groups conducted at NCIL and via teleconference with CILs, have collected data from CIL stakeholders across the US. The elements and outcomes of a successful CIL have been collected and sorted for later use to identify management categories and management models. The ultimate outcome of this "Part A" of project 4 will be management models and training for CILs.

The second area of progress is in "Part B" of project 4 which is culture brokering training. This training was developed and designed to enhance the skills of IL specialists and peer counselors when working with foreign-born individuals with disabilities. Two culture brokering training programs were successfully completed with CIL directors in New Jersey and IL staff in New York. A training CD is in production incorporating written text and video excerpts from the training. Future culture brokering training sessions will be announced. The third area is the development of an executive management-training workshop called the *Independent Living Executive Management Simulation*. This 3-day program for CIL directors and managers has been updated and revised to focus on ILC management issues. It is the first of two simulation-training programs for CIL directors. The second, called *Start Up Simulation* for new CILs and directors will be developed in early 2002.

(P5) Identifying successful collaborations between CIL and state vocational rehabilitation programs is the goal of Project 5. Project partners have recruited an advisory team and have drafted a questionnaire. Surveys will be sent to CILs, state VR offices and SILCs to identify and model collaboration practices between CILs and state VR agencies. These models will be shared with CILs wishing to increase service to consumers through state VR contacts.

(P6) A curriculum for first level supervisors in CILs has been proposed under Project 6. This series of online courses is being designed to enhance skills of current and future managers. Planned for the spring of 2002, courses will be available through project partners at San Francisco State University.

In addition to these activities, the RRTC-ILM has provided technical assistance to the IL Division of the Rehabilitation Services Administration. And it has developed a

customized Independent Living Philosophy / History training program for the New York State Independent Living Council and its 48 CILs.

Many of these project activities continue throughout the 5-year grant. The RRTC-ILM is interested in hearing from centers regarding training needs and has undertaken investigative efforts to identify, assess and respond to those needs. Your input is important and valuable in achieving that goal. In order to be effective (do the right thing), knowing what training you - our customers - need is essential. The RRTC-ILM is excited about current and planned projects. If you want to participate in any of the projects listed, contact our office.

National CIL Database . . . continued from pg 1

We developed a database of those centers that met the following criteria:

- 50% or more of staff were people with disabilities
- 50% or more of the Board of Directors have disabilities
- provided the four core services of:
information and referral
independent living skills training
individual and systems advocacy
peer counseling
- community-based
- non-residential
- consumer controlled

The database of over 600 CILs is now available.

In April, we sent a CIL Organizational Survey to all centers in the database. The Survey provides us with a snapshot of your agency. This survey information is critical because it will provide the following information to CILs:

- How many centers in each state? region?
- What size are the centers?
- What type of job positions do they have?

- What funding sources do centers use?
- What programs and services are offered?
- What are the salary ranges of staff positions?

Nearly 200 centers have responded to the Survey. Add your information to the mix. Please send in your CIL Organizational Survey as soon as you can.

This is only the beginning of this exciting project. Our next step will be to get as much information from each center as you will share. We will ask you to share your policies on personnel, programs, safety, and service. We will ask for your bylaws, job descriptions, program descriptions and procedures. We expect that copies of your consumer rights and complaint processes, manuals and practices will be in demand. When this information is collected in an electronic format, we will put it online where all participating centers will be able to access it free of charge. Confidentiality of all source materials is assured.

Think about it! A National CIL Database where you can analyze what you want and how you want it. Information will be provided to you via the web. You can adjust it to the style and format that fits the way you need to have it. You will have a confidential partner that allows you to work independently. It will assist you in upgrading your services and programs and empowering your board and consumers. It will help you to assist your center in diversifying funding dependencies. You can see what other centers are doing, where they are doing it, and how they are doing it.

And what is your cost? Participation! ! ! Your participation is necessary for the success of this project. If you support the independent living movement, embrace the peer support concept, and believe that there is a CIL out there that can help you, this program is for you.

continued page 7

Please fill out the CIL Organizational Survey that has been sent to you and return it to us. The Survey can be re-mailed to you in print, Braille, tape, or diskette. We can e-mail it to you. If requested, we can interview you by telephone. Call Maureen Moffat, Research Coordinator, 716-836-0822 ext. 168.

You can send us your policies, practices, descriptions, bylaws, etc. via e-mail or diskette to share with your colleagues. Send them to: Maureen Moffat, (mmoffat@ilm.wnyilp.org).

Help us help the IL movement. Contribute the lessons that you have learned to prevent your colleagues from having to learn the hard way. Support our effort in keeping IL strong and up-to-date.

EXECIL

EXECIL, an executive management simulation, is the result of RRTC-ILM research on models to improve organizational effectiveness. Participants focus on ten elements that are critical to managing a successful CIL. EXECIL compresses one year's operating activities into a four-day period.

The goal of EXECIL is to have the simulation transfer to everyday life in the management of a CIL. A pilot simulation was tested in San Diego with twelve CIL directors selected from across the U.S.

The simulation process begins by assigning each participant to a team of four to six members who function collectively as the Executive Director of the Central Edwardsville Center for Independent Living. The role of the Executive Director includes responsibility for many of the essential decisions made regarding Center operations. As in real life, managing conflicting priorities is necessary.

The simulation is designed to challenge and enhance the decision-making ability of the team members acting in the role of the executive director. The small group environment provides an opportunity for discussion of controversial issues and permits utilization of the diverse talents, experiences, and viewpoints of each team member. Through these dynamics and the exploration of current practices and problems associated with a CIL, meaningful learning occurs. Computers contribute to problem solving by allowing the teams to have access to a library of CIL resources and to the web during the simulation. The simulation will be available as a training program in the near future.

Conference Announcement

The Center for International Rehabilitation Information and Exchange (**CIRRIE**) is pleased to announce an international conference called *Providing Services for Foreign-Born Persons with Disabilities* to be held May 6-8, 2002 in Washington, DC. Presenters will describe problems and best practices in providing rehabilitation and disability services in countries with high rates of immigration. Other sessions will focus on the cultures of the countries of origin: their views of disability and its causes and the influence of culture on the choice of service outcomes and methods. Sessions will also be organized on specific issues affecting different types of rehabilitation and disability services.

A "Call for Papers" will be issued soon. Information can be accessed at <http://cirrie.buffalo.edu/conference/CIRRIE2002.html>. For further information, or to be put on the conference mailing list, please contact Nancy Wilkins at nwilkins@buffalo.edu.

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Editor: Maureen Moffat
Design / Layout: John Moffat

For more information about the RRTC-ILM or to obtain this newsletter in alternate formats, contact: Maureen Moffat,
Research Coordinator
RRTC-ILM, 3108 Main St., Buffalo, NY 14214
Phone (716) 836-0822, ext. 168
Fax (716) 835-3967
E-mail: mmoffat@ilm.wnyilp.org



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Rehabilitation Research & Training Center on
Independent Living Management
3108 Main Street
Buffalo, New York 14214-1384