



FIRST ISSUE

3108 Main Street, Buffalo, New York 14214-1384 • (716) 836-0822 (Voice/TDD)

## RRTC Funding Awarded to a Center of Independent Living

In the new millennium, Centers for Independent Living (CILs) across the US are collectively seeking to achieve economic self-reliance and excellence in management. To pool information regarding our diverse successes and challenges, and to support one another in a practical, programmatic, and technical manner is exactly the kind of opportunity the ILC of WNY's Rehabilitation Research Training Center on Independent Living Management (RRTC-ILM) project will present over the next 5 years.

Having been awarded a \$3,000,000 grant from the US Department of Education<sup>1</sup>, the RRTC-ILM project aims to make the forward progress of our nation's CILs a fundamentally achievable experience through training based on results of the five-year study. In the past, grants have typically funded traditional research institutions to investigate the dynamics and function of the Independence Movement. The award of such a grant to a CIL is uncommon.

Since Berkeley, California's first Center for Independent Living opened in the early 1970's, the Independence Model has provided groundwork structure and support for the now plentiful like-minded agencies across the country. Continuous development of the Independent Living Model has encouraged the fairly helpless "patients" of the 1970's to evolve into the self-advocating "consumers" of today. Over 400 Centers for Independent Living are currently operating in the US, which engender advocacy of consumerism, self-direction, self-help, peer service provision, civil rights, and quality of life for individuals with all disabilities.

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<sup>1</sup> Funding through the National Institute on Disability and Rehabilitation Research (NIDRR), and the Rehabilitation Services Administration (RSA).

## Introducing the RRTC-ILM Investigators...

**Douglas J. Usiak**, Executive Director of the Western New York Independent Living Project, Inc., and Project Director for the Rehabilitation Research & Training Center on Independent Living Management, has been active in leading disability advocacy for over 25 years in New York State.

He has served as technical consultant on independent living philosophy and management for disabled groups, across the US, and internationally, and has worked closely with the RERC on technology transfer.



**Douglas J. Usiak**

As the charter chairperson of the Coalition on Independent Living of New York State, and of the Statewide Independent Living Council (of New York State), Mr. Usiak has collected and united interests of the disabled with the greater community.

His views on self-determined rehabilitation, interests in assistive technology, community relations, education, evaluation, and public speaking, together with an ability to foster collaborative pro-

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Now that the terms of organization and function of Centers for Independent Living are well defined<sup>2</sup>, Centers have come to depend on Title VII funding<sup>3</sup> as a stable base from which to operate. The question of self-reliance turns now to the consideration of non-traditional funding sources, which involves issues such as philosophical compromise and natural consequences of expansion. The greatest needs at present are to discover and facilitate entrepreneurial methods for self-reliance, and to secure long-term funding from sources other than Title VII.

Most CIL managers from community advocacy backgrounds lack training or experience in managing a business, and have no school or course available to advise in the set up and operation of a multi-mission program. CIL's are also being pressed to construct better managerial plans because the "one boss CIL" has proved to render less than satisfactory results.

Among other things, a successful CIL is able to keep up with federal and state regulations, can work in cooperation with historically dissenting government agencies, reaches underserved populations (such as youth in transition and the disabled elderly), and provides a healthy employment environment for its staff who are, themselves, consumers of services for the disabled. The RRTC-ILM research project addresses these requirements, and its objectives also include methods to:

- Assist CILs in the areas of management, policies, and procedures.
- Improve funding and entrepreneurial opportunities.
- Upgrade programs and services by designing "best practices" protocol.
- Increase collaboration between CILs and other disability related programs.

In response to NIDRR<sup>4</sup> priorities, the Western New York Independent Living Project, Inc.'s RRTC-ILM project will conduct 7 individual evaluation, research, and training components.

Program I activities have recently begun, and focus on the creation of a confidential CIL database that makes economic and "best practices" information accessible to agency participants of the study.

Program I staff have identified 10 CILs for a pilot test and plan to have a final form sent out to every CIL in the US in early 2001. The Program I database will organize data that makes comparisons between CILs helpful in determining cost effectiveness and best practices. It is hoped that response to this call for continued cooperation will demonstrate the confidence of CILs in groups with disabilities to take a lead role in research activity.

On a local level, getting started on the RRTC-ILM here at the WNY Independent Living Project has been a somewhat tricky business as the physical limitations on space become more and more pressing. Individual Advocates are tripled in small offices until the next building addition is completed, and the RRTC-ILM research team has been fully enveloped into the activities of a very productive CIL. As a CIL, we are developing new programs, searching out new sources of funding, and looking for ways to ensure steady growth and quality of service in our existing functions. In short, we are experiencing many of the same challenges and successes of other CILs across the US. This is precisely why we feel best qualified to recognize and reflect the contemporary status of Centers of Independent Living.

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<sup>2</sup> Definition provided by the Rehabilitation Act of 1973, amended in 1992.

<sup>3</sup> Title VII of the Rehabilitation Act of 1973

<sup>4</sup> The National Institute on Disability and Rehabilitation Research.

We are exceptionally pleased with the opportunity to conduct research as persons with disabilities on the effectiveness of CILs. We hope to hear from each and every one of you. Thanks, in advance, for your necessary

contribution of information to the Program I Database. We are certain that use of it in the future will help you achieve the goals common to us all. ❖

## Investigators

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professional relationships has led this RRTC-ILM Project into the lap of a CIL. The accomplishment is especially important to Mr. Usiak because he believes useful research on Centers for Independent Living is most appropriately done in the realm of consumers, themselves. Mr. Usiak was able to enlist the cooperative efforts of six US universities, and looks forward to innovative results of this unique connection.

### Dr. Ronald B. House

is co-Principal Investigator and Director of Training on the RRTC-ILM Project. He earned his doctoral degree from Cornell University, and has thirty years' experience managing federally funded national and regional training projects at Cornell in independent living, community rehabilitation, and technical assistance.



Dr. Ronald B. House

Dr. House has been involved in the Independent Living Movement since 1980, when he worked with Lex Frieden, ILRU of Houston, Texas to develop a management training simulation for CILs. This past year, he and a management team under the direction of NCIL revised the simulation for training executive directors. Dr. House has developed several management simulations, in fact, and has published many articles on the management of human service organizations. He has

conducted international training courses, and serves on state and federal advisory boards on disability policy.

As Director of Training for the entire RRTC-ILM Project, Dr. House is responsible for the design, development, and test strategies to be used by CILs as translated from other successful community-based organizations. The results of the survey will be used to develop courses of study for CIL directors and supervisors.

**Dr. Machiko R. Tomita**, Principal Investigator of Program I; "CIL Database", is originally from Tokyo, Japan. She attended the University of Minnesota, at Minneapolis and earned an MA and Ph.D. in Social Research. Dr. Tomita currently teaches graduate level statistics, and research design and methodology as Clinical Associate Professor at University at Buffalo, NY.



Dr. Machiko R. Tomita

Dr. Tomita is Co-Principal Investigator and Director of Research for two federal grant projects on rehabilitation and self-care of the disabled. Most of her journal publications concentrate on assistive devices and functional status of the elderly.

The database being created by Dr. Tomita in this initial portion of the RRTC-ILM study will (Continued on page 4)

inform all consecutive projects, and will serve as the most accurate and comprehensive national repository of information on CILS in the US.

Dr Tomita's Program I Co-ordinator, **Ellen Stewart**, is a graduate of Binghamton University, and has been in service to a wide variety of disabled populations for over 10 years, most recently as a program coordinator at the WNY Independent Living Center. She is managing research assistance, correspondence, data acquisition and input in this initial project, and is editor of the RRTC-ILM Newsletter.



**Ellen Stewart and Mary Thorn,**  
Research Assistant

**James L. King** earned his M.B.A. in Finance and Marketing from Bowling Green State University, Ohio. As author, developer, and Director of the New York State Small Business Development Center (SBDC) since 1984, Mr. King has helped thousands of New York businesses to invest well over \$1.5 billion in the state's economy. The agency works in conjunction with the State University of New York and parallels its missions of instruction, research, and public service.

"This is an opportunity for the SBDC to apply its skill set to a new market area, and to encourage self-sustaining efforts that benefit the community," he said, explaining the role of his agency in Program 2; "Alternative Funding."

"The SBDC will evaluate successful CIL programs, provide suggestions, and document operations. The product of this effort will make effective replication possible for the national community of CILs."

Initial work on this portion of the RRTC-ILM study will include "best practice" identification.

The SBDC will then work intensively with targeted programs documenting business, organizational, and community environments. Building business models and developing a start-up package for use by CILs will be the final phase of SBDC efforts.

**Dr. Vathsala Stone** earned her doctoral degree at Florida State University in Educational Evaluation & Research Design. She is currently Research Director for the Rehabilitation Engineering Center on Technology Transfer, and teaches assistive technology evaluation at the University at Buffalo, NY. Her research and teaching expertise in designing and conducting evaluations of special needs populations will be put to use in estimating and guiding the success of the RRTC-ILM Project over its five-year span.



**Dr. Vathsala Stone**

Dr. Stone's first step is to make the plans of the project operational by setting up procedures for ongoing data collection, organization, and analysis. Her efforts will track project outcomes as they are shaping, and will provide adjustments and improvements in the project processes. By monitoring the RRTC-ILM project activities from beginning to end, Dr. Stone will ensure that our original goals are well met, and that the study has a truly beneficial impact on our stakeholders.

**Dr. Carl V. Granger** earned his M.D. degree at New York University, and is Chairman of and Professor in the Department of Rehabilitation Medicine at the University at Buffalo's School of Medicine and Biomedical Sciences. He is founder and director emeritus of the Uniform Data System for Medical Rehabilitation (UDSMR), and has received numerous national awards.

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Dr. Granger's interest and career work in rehabilitation tools for assessment and evaluation will follow a line of study on the RRTC-ILM project that brings to light a suitable method of assessment for use by CILs. Rehabilitation assessments used currently need to be reshaped to incorporate the philosophy of independent living. Dr. Granger's challenge is to create a functional assessment tool that is applicable by peer CIL staff members and that can be conducted with useful results by the heterogeneous community of Centers across the country.



Dr. Carl V. Granger

**Dr. William Charles Mann** received his doctoral degree in Higher Education from the University at Buffalo. He is presently professor and Chairman of the Department of Occupational Therapy College of Health Professions at the University of Florida, and directs the Ph.D. Program in Rehabilitation Science. Much of Dr. Mann's published work and research focuses on disability, assistive technology, and aging. He will contribute to the RRTC-ILM Program 3, "Transition", in cooperation with Dr. Michael Wehmeyer.



Dr. William Charles Mann

Dr. Mann will research CIL programs that make independent living possible for individuals who become disabled in old age, and will identify successful practices that can be applied to the population. Test programs will be developed for use by Centers that want to provide these services, including the creation of resource packets on housing, transporta-

tion, and assistive technology.

**Brenda Premo, M.B.A.**, earned her degree at Pepperdine University, and is the Founding Director of the Center for Disability Issues and the Health Professions at Western University of Health Sciences. Brenda was previously Director of the California State Department of Rehabilitation during the 1990's, was the two-time President of the California Foundation for Independent Living Centers, and has been active in disability advocacy, training, and management since 1980.

Program 5; "Vocational Rehabilitation Partnerships" objectives are to promote employment outcomes for individuals with disabilities. Work on this portion of the project begins with an inquiry into current collaborative relationships between CILs and Vocational Rehabilitation programs. Brenda's team is working with InfoUse, of California, and her team will conduct workshops within NCIL, NRA, and CSAVR.

**Dr. Michael Wehmeyer**, Principal Investigator for the "Youth in Transition" portion of the RRTC-ILM Project, earned his doctoral degree in Human Development from the University of Texas at Dallas. Currently, he is Director of Self-Determination Projects at University of Kansas' Beach Center on Families and Disability. His many publications focus on self-determination, student involvement, and transition of adolescents moving from secondary school into the community.

Staff in this program are reviewing current CIL programs and services which may exist for youth in transition, or which may be readily adapted to meet the needs of young people. Efforts to reach diverse ethnic, racial, and cultural groups will be facilitated by use of the Beach Center's connections with family organizations, like the Grassroots Coalition.

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Readers who are aware of exemplary efforts on the part of CILs to facilitate the transition from school to adulthood for young people with disabilities and to promote self-determination and self-advocacy are invited to contact Dr. Wehmeyer at [wehmeyer@ukans.edu](mailto:wehmeyer@ukans.edu).

### Dr. John Stone

earned his doctoral degree in Education from Florida State University, and serves as Principle Investigator for Program 4B, "Culture Brokering". Dr. Stone is Clinical Associate Professor in the Department of Occupational Therapy at the University at Buffalo, and Director of the NIDRR funded Center for International Rehabilitation Research Information and Exchange (CIRRIE).



Dr. John Stone

Having served a Peace Corps assignment in India, and a 17-year career in Brazil, Dr. Stone is especially well qualified to interpret "culture brokering" theory for use in CILs. Culture Brokering is defined as, "the act of bridging, linking, or mediating between groups or persons of differing cultural systems for the purpose of reducing conflict or producing change". Staff trainers of Program 4B, **Paula Sotnik** and **John Moffat**, will adapt for the context of CILs a workshop that CIRRIE has been successfully presenting to other rehabilitation service providers that assist foreign-born individuals with disabilities.

**John A. Moffat**, RRTC-ILM Project Coordinator, earned his MS.Ed at Buffalo State College, and has worked in independent living and in the service of persons with disabilities for more than seven years. Previously, he was a systems advocate and ADA Coordinator, and project coordinator for the consumer evaluation component of the Rehabilitation Engineering

Research Center for Technology Evaluation and Transfer here at the WNY Independent Living Project. John brings experience in training, organizational and program development, planning, coordination, and research.



John A. Moffat

John will monitor progress and report on the implementation of goals, as well as maintain the overall calendar of project events and activities. As facilitator of communication between the more than 30 various collaborative staff and steering council members, he will ensure that the RRTC-ILM project accomplishments are synchronized.

**Dr. Alice Nemon** earned her doctoral degree in Social Work, with a focus on Disability, from the University of California at Berkeley. She has been on the faculty of the San Francisco State University (SFSU) Rehabilitation Counseling Training Program since 1966 and serves as Program Coordinator. With the SFSU Disability Resource Center she developed a FIPSE proposal which is currently among the final group being considered for funding. A good deal of her research and training experience has been in the field of deafness, with several RSA funded grants and SFSU collaborations in teaching rehabilitation counseling skills to her credit.

Dr. Nemon is currently reviewing courses previously designed for a distance learning training program in Independent Living Services and Practices developed at SFSU with **Dr. Paul K. Longmore**. Together, they will modify the courses to fit the needs of the RRTC-ILM, Program 6. ❖

Like all NIDRR<sup>1</sup> Rehabilitation Research & Training Centers, the Western New York Independent Living Project, Inc.'s RRTC<sup>2</sup> must;

# The Rehabilitation Research & Training Center on Independent Living Management Program Descriptions

- Conduct coordinated, integrated, and advanced programs of research in rehabilitation;
- Provide training assistance to individuals who offer rehabilitation services;
- Serve as informational and technical assistance resources; and,
- Disseminate materials in alternate formats to ensure accessibility to individuals with disabilities.

The project has seven “programs”. Each program addresses NIDRR sub-priorities<sup>3</sup> as an individual plan for research, evaluation, and/or training. Our project will identify “best practices” in Independent Living Center management, service delivery, community change, and those of other human service agencies and businesses for the purpose of import and replication into CILs<sup>4</sup>. **Dr. Vathsala Stone** of the University at Buffalo will conduct evaluation of activities during the entire project to ensure that research is carried out in the best possible manner. Nearly every program will produce training materials and courses of study helpful to CIL management.

**Program I** involves the creation of a national CIL database. More than 300 Centers of Independent Living and their satellites will be profiled and recorded in terms of economic resources and “best practices”. Examples of factors to be recorded include; staff salary, operating budget, sources of private/public revenue, services and programs, organizational structure, and personnel policy. The database will serve as the primary source of data for each of the following RRTC-ILM programs. Modeled after a very successful, international database called, “The Uniform Data System”, created by **Dr. Carl V. Granger**, the CIL data-

base will evolve into a repository of information to be featured on DIMENET, and will be used by participating CILS as a source of reference. All known CILS in the US are currently being contacted for their most up-to-date statistics.

**Dr. Machiko Tomita** leads the **National CIL Management Database** program, with assistance from **Douglas J. Usiak**.

**Program II** is concerned with funding alternatives for CILs. Centers that have successfully secured non-traditional, fee-for-service, and entrepreneurial programs that broaden the financial base without compromising IL mission will be sought for study and model development. Following the Small Business Administration’s steps, the program will develop a standardized, “for-profit” evaluation of “best practices”. Next, cost analysis and competitive market potential will be determined for CILs. Finally, a model strategic plan and review process will be designed utilizing the broad-based skill set found uniquely in the **Small Business Development Center**. The question of consequence to Independent Living Centers involved in various funding options, especially those related to non-public financing, will also be considered and weighed. Links to small business development corporations as a result of this program will present new opportunities for the community.

**James L. King** is primary investigator for the program, **Generating Alternative Funding Through Business Development Practices**, with assistance from **Douglas J. Usiak**.

**Program III** investigates programming and services for disabled youth and elderly. Two separate, complimentary studies; one focusing

<sup>1</sup> The National Institute on Disability and Rehabilitation Research

<sup>2</sup> Rehabilitation Research & Training Center

<sup>3</sup> NIDRR Sub-Priorities for RRTCs

<sup>4</sup> Centers for Independent Living

on youth, and one on the elderly, will identify existing educational and transitional programs that prepare individuals for independent living, and will discover current “best practices”.

**Dr. Michael Wehmeyer** directs the **Role of CILs in Transition Services & Secondary Education: Serving Youth with Disabilities and their Families**, (3a). Currently, there is scant information about the role of CILs in transition services, although there is a tremendously rich literature on transition programs and services outside of the CIL network. In a model program funded by the Rehabilitation Services Program, the Beach Center on Families and Disability at the University of Kansas (conducting this CIL transition program) has successfully designed vocational rehabilitation services that encourage consumer choice. This program aims to bridge the divide between secondary education services and CILs by designing successful models for collaboration.

**Dr. William Charles Mann** directs the **Evaluation of an Approach to Increase CIL Service Use by Older Persons with Disabilities**, (3b). As a group, the disabled elderly have not commonly made use of CIL services. Identifying successful programming within CILs, creating models for replication, and educating the community about services available will be the major challenge for this program. The Rehabilitation Engineering Research Center (RERC) on Aging at the University at Buffalo’s open communication and interaction with several organizations, such as the AARP, the American Medical Association, and the American Speech-Language Hearing Association will facilitate the introduction of IL philosophy and CIL services.

The project will also develop and distribute a resource packet on housing, transportation, and assistive devices-topics of special concern for this population.

**Program IV** consists of two, separate studies. The first section, **Applying the Best Practices of Successful Management Models: Developing Core Competency Skills for CIL Personnel**, (4a), explores current structural and management models of CILs and other successful community-based organizations. One of the challenges of this program is to adapt outside innovative models so that they are congruent with the philosophy of the independent living movement. The program will also evaluate strategies for improved recruitment and retention of CIL staff from diverse backgrounds. **Dr. Ronald House** is principle investigator of this study, and will receive input from **Douglas J. Usiak**.

**Dr. John Stone** leads section 4b, **Developing and Disseminating a Training Program on Culture Brokering** in partnership with the NIDRR funded CIRRIE<sup>5</sup>. This portion of the program focuses on issues relevant for disabled individuals who are foreign-born and living in the US. The objective is to develop means for CILs to engage in *culture brokering*, which is defined as “the act of bridging, linking, or mediating between groups or persons of differing cultural systems for the purpose of reducing conflict or producing change” (Jezewski, 1995). Training developed in this program will provide disability specific information for direct CIL staff, and will enable them to provide culturally appropriate services for the newly immigrated consumer. **John Moffat** will assist Dr. Stone.

**Program V, Vocational Rehabilitation Partnerships** is led by **Brenda Premo, M.B.A.** Despite common interests and legislative origin, interaction between CILs and vocational rehabilitation agencies has often been conflicting. Unfortunately, the differing  
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<sup>1</sup> The National Institute on Disability and Rehabilitation Research

<sup>2</sup> Rehabilitation Research & Training Center

<sup>3</sup> NIDRR Sub-Priorities for RRTC’s

<sup>4</sup> Centers for Independent Living

<sup>5</sup> Center for International Rehabilitation Research Information and Exchange, at the University at Buffalo.

organizational goals and service philosophies of each have historically hindered collaborative work. The Center for Disability Issues and the Health Professions at Western University of Health Sciences will collaborate with InfoUse<sup>6</sup> using a systematic approach to identify cooperative VR and CIL policies that have led to positive employment outcomes for people with disabilities. Other related topics for study include; securing economic security for CILs as a result of VR partnerships, state law and regulations affecting the development of joint projects, and the employment outcome achievement for combined programs. **Stuart Hanson**, of InfoUse, will serve as co-investigator.

**Program VI**, led by **Dr. Ronald House, Dr. Alice Nemon, and Dr. Paul K. Longmore**, will coordinate training and technical assistance activities with the RSA<sup>7</sup>. The provision of high quality training for direct CIL staff has been prohibitively costly and time-consuming for many CILs. This program, working cooperatively with The Institute on Disability at San Francisco State University, will assess the specific needs of CIL staff, and will design distance and on-line training packages that are accessible to all, regardless of disability. Many current academic programs of disability study perpetuate a top-down professional approach based on the medical model.

The curriculum developed for this Internet training will incorporate the IL philosophy, and input will be solicited from CILs as courses are developed. The program will coordinate distance learning and certification opportunities for thousands of CIL employees in the US.

**Program VII, Developing a Program of Training and Dissemination for Stakeholders**, will present topics of the entire research study for training in a wide variety of accessible formats for CIL staff. Dissemination materials will include; the project CIL database, a website, semi-annual newsletters, results of best practices research, and self-contained training curricula related to Independent Living programs. One of the partners in this project is **DIMENET**, an informational network supporting the CIL mission of providing the vital linkage between the local disability community and full access of the Internet. DIMENET will provide technical computer and on-line support for the communication of study findings and training materials. This program will be led by **Dr. Ron House**, and **Kathleen Kleinmann** of DIMENET. ❖

<sup>6</sup> InfoUse conducted the VR-IL Employment Outcomes Partnership Project, 1996-1999.

<sup>7</sup> Rehabilitation Services Administration.



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Rehabilitation Research & Training Center on Independent Living



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For more information on RRTC-ILM  
or to obtain this newsletter in an  
alternate format,  
Contact: Ellen Stewart,  
Project I Coordinator,  
RRTC-ILM  
Western New York  
Independent Living Project, Inc.  
3108 Main Street  
Buffalo, New York 14214-1384  
Phone: (716) 836-0822, ext. 156  
Fax: (716) 835-3967  
E-Mail: [estewartrrtc@aol.com](mailto:estewartrrtc@aol.com)

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

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