

IL NET

an ILRU/NCIL National Training and Technical Assistance Project

Expanding the Power of the Independent Living Movement

INNOVATIVE INDEPENDENT LIVING PROGRAMS

A National Teleconference

Participant's Manual

January 24, 2001

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IL NET is funded through a special provisions cooperative agreement with the U.S. Department of Education, Rehabilitation Services Administration, Agreement No. H132B99002.

Innovative Independent Living Programs

A National Teleconference

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Learning Objectives

Participants will learn:

- more about ILRU/IL Net's Innovative CILs and SILCs Competition and how to participate
- how three previous winners of the competition envisioned and designed their programs
- what management and philosophical questions were addressed to create and maintain these programs
- what impact these model programs have had in their communities
- what funding resources may be available to support innovative programming
- how innovation can broaden IL core services to a more specialized level
- how innovative programs can expand the reach of services and advocacy

INNOVATIVE INDEPENDENT LIVING PROGRAMS

January 24, 2001

Agenda

- Welcome and Introductions – Darrell Lynn Jones
- ILRU's Innovative CILs and SILCs Competition – Carri George
- Access Design Services, Alpha One – Ketra Crosson and Denis Pratt
- Questions and Answers
- Interpreters Membership Insurance, Resource Center for Independent Living – Burt Danovitz and Kathleen Dyman
- Questions and Answers
- Peer Mentor Volunteers – Arizona Bridge to Independent Living – Donna Redford and Ann Pasco
- Questions and Answers
- Wrap-up – Darrell Lynn Jones

ABOUT THE TRAINERS

Ketra Crosson

is a graduate of the University of New Hampshire and is a licensed Occupational Therapist with over 19 years of experience in developing and providing independent living options for people with disabilities. She has worked for the last 10 years for Alpha One, a Center for Independent Living, as an Independent Living Specialist, and the last 4 years as Branch Manager for the Alpha One's Augusta branch office. As branch manager, Ketra leads the independent living team in providing access design consultation, independent living skills assessment and training, information and referral, peer support, assistive technology consultation, adapted driver evaluation and education, advocacy and consumer directed personal assistance services. The team also processes loans for the Adaptive Equipment Loan Program. In October of 1999, Alpha One was awarded a contract to administer Maine's Title VII Part B program. Ketra is the program manager for the Title VII Part B program and lead the transition of the program from another organization, developed statewide service delivery methods, staff training, and day-to-day coordination of services.

Burt Danovitz

is Executive Director of the Resource Center for Independent Living located in Utica, NY. RCIL is one of the larger independent living centers in the country serving in excess of 15,000 people per year through a combination of direct services and individual and systems advocacy. RCIL's current budget is \$5.6 million with 300 full and part time employees. Danovitz has been involved in the promotion of several key disability rights activities in NY including: voting access, transportation, and long term care. In addition Danovitz serves on a number of boards including: Workforce Investment, United Way, Central New York Arts Council and Mohawk Valley Physicians.

Kathleen E. Dyman

has over 20 years experience in the health care arena. She earned her B.S. in Health Care Administration from State University of New York College of Technology, Utica, New York. She started out as a Nursing Home Administrator, owned her own training company and for the last 6 years has been the Executive Vice President for 5 of the 62 county Medical Societies in New York State. They include Oneida, Herkimer, Madison, Chenango and Oswego in Central New York. She is also the EVP of the Central New York Academy of Medicine, which is the educational arm of the Medical Society, and Four County Management Corp., which is the holding company for the other 6 corporations. Kathleen is the chairperson for the Health Care Access Committee for the Oneida County Health Dept., and sits on numerous community boards, to include the United Way and United Cerebral Palsy. The mission of the Medical Society is to ensure quality patient care and to advocate for physicians, their patients and the community.

Carri George

Before joining the Independent Living Research Utilization staff in April 1998, Carri George worked 14 years at VOLAR Center for Independent Living in El Paso, Texas. During that time she served in various leadership positions in the center, including four years as executive director and four as program coordinator. Ms. George has served as Region VI Representative on the National Council on Independent Living Board and is known for her successes in public accommodation access advocacy. At ILRU, Ms. George has been responsible for coordinating publications for the IL NET and helped to launch the successful *Innovative CILs and SILCs competition*.

Ann Pasco

is the Volunteer Coordinator for Arizona Bridge to Independent Living. Her primary responsibilities are the recruitment, training and placement of peer mentor volunteers. Ann brings extensive experience to this position, having coordinated the activities of several volunteer programs over the past twenty years. Prior to moving to Arizona, Ann was the Director of Northern Illinois Radio Information Service, a broadcast service for persons who are unable to read printed materials due to blindness or other disabilities. She supervised 150 volunteer readers who broadcast news and information to listeners. In addition, she has also coordinated volunteer activities for a home delivered meal program and a food pantry in Rockford, Illinois. Ann served for two years on the Board of Directors of an Independent Living Center in Rockford, Illinois.

Denis R. Pratt, AIA (Architect)

Employed by Alpha One as an Accessibility Specialist since January, 1992, Denis has over 30 years of experience on a wide range of private and public building projects. In addition to his seasoned working knowledge of design and construction, Denis has a strong background in accessible design and code administration from previous employment experience with the Maine State Housing Authority and the State of Maine Office of Energy Resources. He also has over 25 years of experience working on private commercial, institutional and residential projects including historic preservation / adaptive re-use projects, most of which incorporated accessible design. Since his employ at Alpha One, Denis has been involved in hundreds of access design consultations, projects, and presentations and has become a recognized expert across New England on "design for universal access" and regulatory compliance. He has developed and presented seminars for Code Enforcement Officials, Design Professionals, Real Estate Brokers, Appraisers, Bankers, and other professional and consumer audiences on access design and compliance in Maine, New Hampshire and Massachusetts. Licensed in Maine and New Hampshire, Denis specializes solely in "barrier free" and "universal" design. His clients include state agencies, municipal governments, school districts, hospitals, non-profit & religious organizations, business owners, housing managers, large corporations, lawyers, individual home owners, contractors, and design professionals.

Donna Pace Redford

is the Advocacy Director at ABIL, the Center for Independent Living for Metro-Phoenix Arizona. Donna coordinates community advocacy efforts, manages self-determination education and outreach, and volunteer coordination. Over the last 10 years, she has fostered the growth and development of the Peer Mentor Volunteer Program. She is a frequent writer for ABIL's monthly newsletter, The Bridge, and facilitates workshops on disability oppression/liberation. While Donna has a Masters in Counseling from Arizona State University, she also has 23 years experience practicing and teaching peer counseling. Prior to her current position, she managed ABIL's Community Integration Unit, coordinated a mental health crisis clinic and worked with teenagers in mental health and correctional settings. Donna is a Board member of Arizona Citizens Action, and the public policy committees of the Arizona Statewide Independent Living Council and State Rehabilitation Counseling.

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ABOUT ILRU

The Independent Living Research Utilization (ILRU) Program was established in 1977 to serve as a national center for information, training, research, and technical assistance for independent living. In the mid-1980's, it began conducting management training programs for executive directors and middle managers of independent living centers in the U.S. Since 1985, it has operated the ILRU Research and Training Center on Independent Living at TIRR, conducting a comprehensive and coordinated set of research, training, and technical assistance projects focusing on leading issues facing the independent living field.

ILRU has developed an extensive set of resource materials on various aspects of independent living, including a comprehensive directory of programs providing independent living services in the U.S. and Canada.

ILRU is a program of TIRR, a nationally recognized, free-standing rehabilitation facility for persons with physical disabilities. TIRR is part of TIRR Systems, a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities. Since 1959, TIRR has provided patient care, education, and research to promote the integration of people with physical and cognitive disabilities into all aspects of community living.

ABOUT NCIL

Founded in 1982, the National Council on Independent Living is a membership organization representing independent living centers and individuals with disabilities. NCIL has been instrumental in efforts to standardize requirements for consumer control in management and delivery of services provided through federally-funded independent living centers.

Until 1992, NCIL's efforts to foster consumer control and direction in independent living services through changes in federal legislation and regulations were coordinated through an extensive network and involvement of volunteers from independent living centers and other organizations around the country. Since 1992, NCIL has had a national office in Arlington, Virginia, just minutes by subway or car from the major centers of government in Washington, D.C. While NCIL continues to rely on the commitment and dedication of volunteers from around the country, the establishment of a national office with staff and other resources has strengthened its capacity to serve as the voice for independent living in matters of critical importance in eliminating discrimination and unequal treatment based on disability.

Today, NCIL is a strong voice for independent living in our nation's capital. With your participation, NCIL can deliver the message of independent living to even more people who are charged with the important responsibility of making laws and creating programs designed to assure equal rights for all.

ABOUT THE IL NET

This training program is sponsored by the IL NET, a collaborative project of the Independent Living Research Utilization (ILRU) of Houston and the National Council on Independent Living (NCIL).

The IL NET is a national training and technical assistance project working to strengthen the independent living movement by supporting Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs).

IL NET activities include workshops, national teleconferences, technical assistance, on-line information, training materials, fact sheets, and other resource materials on operating, managing, and evaluating centers and SILCs.

The mission of the IL NET is to assist in building strong and effective CILs and SILCs which are led and staffed by people who practice the independent living philosophy.

The IL NET operates with these objectives:

- ' Assist CILs and SILCs in managing effective organizations by providing a continuum of information, training, and technical assistance.
- ' Assist CILs and SILCs to become strong community advocates/change agents by providing a continuum of information, training, and technical assistance.
- ' Assist CILs and SILCs to develop strong, consumer-responsive services by providing a continuum of information, training, and technical assistance.

Innovative CILs and SILCs 2001

Innovative CILs and SILCs 2001

Share the Secrets of Your Success

Does your CIL or SILC have a program that is innovative or unique?

Don't keep your success a secret. Join the previous Innovative CIL and SILC winners in sharing what you have learned so that other CILs and SILCs can find the keys to successful services and advocacy.

What makes your program unique?

Your Innovative CIL or SILC program may be a way to help consumers become more independent, or it may be a way to make your organization run better. It might be one of the core services, or it might be a program designed to meet a specific need in your community or state. Tell us about it.

Complete a concise two-page description of the program which you feel is innovative in design, approach or outcomes. In your summary, identify what need or problem the program addresses, why the program is unique, how it pertains to the independent living philosophy and how successful the program has been.

A team of colleagues familiar with the state-of-the-art in independent living will review all submissions.

What happens if our program is selected?

Programs identified as most innovative will be asked to expand their papers for inclusion in the Readings in Independent Living series that you have been receiving monthly from the IL NET.

A stipend of \$800 will be paid to each center or SILC upon publication of the paper.

Some submissions may be similar or complementary and may be combined into one paper for the Readings in Independent Living series. Center or SILC submissions combined with others into one paper will receive a stipend of \$400.

But I've never written anything for publication before.

Don't worry. You will work hand-in-hand with ILRU's editorial staff. They will guide you through the process and help you produce a high quality paper.

Winners of the Innovative CILs and SILCs competition will be chosen based on a) the uniqueness of the program, b) consistency with the independent living philosophy, c) the likelihood of other centers or SILCs being able to replicate it, and d) the willingness and ability of the applicant to participate in completing papers.

"We will receive a \$35,000 contract from the State of Wisconsin to support Leslie Meyers'

work with women with disabilities and abuse. I truly believe that the publicity received from the Innovative CILs and SILCs award, the presentation at the NCIL conference and the national teleconference training later all helped to build our capacity and Leslie's reputation. I doubt we would have been successful without the opportunities you gave us. Thank you, thank you, thank you."

–Lee Schultz, Executive Director IndependenceFirst, Milwaukee, WI

"Winning the Innovative CILs and SILCs competition has resulted in many benefits. One unexpected result was the increased pride and feeling of accomplishment by the staff and members of the program. A second result was the recognition by other centers in our state. Finally, while the jury is still out, we anticipate that the recognition will result in greater levels of local funding."

–Joseph Castellani, Executive Director Ad Lib, Inc., Pittsfield, MA

"Peer mentor programs targeting other populations have looked to ABIL for technical assistance and advice. This exposure has helped us not only with referrals but has given ABIL an even stronger role in the community as an advocacy organization."

–Darrel Christenson, Director of Community Integration, ABIL, Phoenix, AZ

Submit your paper in electronic format (e-mail or diskette) by **February 9, 2001** to cgeorge@ilru.org or to ILRU; 2323 S. Shepherd, Suite 1000; Houston, Texas 77019

Substantial support for development of this publication was provided by the Rehabilitation Services Administration, U.S. Department of Education. The content is the responsibility of ILRU and no official endorsement of the Department of Education should be inferred. ILRU is a program of TIRR. TIRR is part of TIRR Systems, a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities.

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ACCESS DESIGN SERVICES CIL's as Experts

by Ketra S. Crosson
Alpha one
South Portland, Maine

Getting Started

Alpha One is Maine's largest center for independent living and offers the state's broadest array of independent living services to customers across the state. With all of our services, Alpha One has a twofold objective. We strive to provide the best service one-to-one with our customers, whether they are individual consumers or businesses. At the same time, we strive to educate policy makers and those who carry out the laws with an understanding of disability and independent living. In the case of our Access Design Services, our ultimate goal is 100% accessibility in our state.

Alpha One's beginnings in 1979 and growth as a center for independent living closely mirror the path of legislation for accessibility and customer demand for access design, both locally and across the nation. In 1974, Maine had enacted one of the earliest laws in this country for access to public accommodations in its Maine Human Rights Act. However, architects and contractors were not very knowledgeable about how to interpret the law and build access features that were usable. Examples ranged from ramps that were too steep to use, a step at the top or bottom of a ramp, or bathroom dimensions too small to get a door closed. Consumers were filing charges of discrimination using the Maine Human Rights Act, but businesses were unsure as to how to go about implementing the changes mandated.

Through our information and referral contacts with consumers, we knew that they wanted to take a more active role in their family and community. This meant being able to get in and out of their home independently, modifications to bathrooms that optimized independence with personal care, and modifications or additions for ground level bedrooms. With these market needs, Alpha One established Access Design Services as a core product.

These services were begun by essentially "hanging out a shingle" and establishing a fee-for-service. To market Access Design, we focused on why we wanted to be seen as the expert resource. This included the fact that our employees had personal experience with disability; we had a broad understanding of needs for all people with disabilities; and that through our other services, we were becoming a clearing house for service and product information unique to disability. All independent living staff were expected to be part of the access design team and provide these services. We provided on-the-job training and opportunities for staff to attend workshops, conferences, and drafting classes.

Over the years this service has expanded as new state and federal legislation was enacted. Alpha One is viewed as the expert resource for access design in our state. This has allowed us to participate in the development of access legislation and to influence the fabric of the construction community. Consumer need and demand for independence at home has also greatly influenced the skill development of our access design staff. By actively seeking funding for home access we have improved the skills of this team. For example, in 1987 we created the Environmental Access Grants and Loans (EAGL) program in collaboration with the Maine State Housing Authority. This enabled more than sixty consumers to make needed access changes to their homes for entrances, bathrooms and kitchens. The funds covered access design consultation, skills training and self-advocacy for consumers in locating products and contractors, and the actual costs of the modifications. While this program was seen as highly successful by both consumers and policy makers, the funding was finite. However, the project helped our access design staff to further focus and define

our services, and developed a framework for skills instruction and self-advocacy materials that we continue to use today.

Access Design Services at the Brink of the Millennium

Following passage of the Americans with Disabilities Act, Alpha One decided to add its first licensed architect to the access design team. With the foundation of the ADA, we anticipated that demand for our Access Design Services would increase, especially in the building and construction industry. We sought an architect who could not only communicate in the same language as other design professionals but who also had an understanding and ability to educate the construction professionals about disability and independent living. In 1992 we recruited such an architect. This indeed was a beneficial decision, and we added another licensed architect to the team in 1997.

Today our access design team includes staff statewide in four regional locations. This group draws upon backgrounds of staff who have disabilities, occupational therapists, peer support providers and others with accessibility and design experience. The team expands its expertise through continuous inservice education, project collaboration, brainstorming and information sharing. For example, an architect and an occupational therapist will make a visit to the consumer's home. Together with the consumer, they problem solve the customized access needs to optimize his or her independence and function around the house.

Focus of Services

Services for Individuals - These services were developed initially to meet the needs of customers with disabilities. Today we have expanded our services to include the fast growing group of seniors who seek to remain independent and safe in their homes. These services include meeting with consumers at their home to identify their access and assistive technology needs. This may include a room-by-room review of existing barriers to identify solutions or to develop plans for new construction. We also assist in product research via resources such as ABLEDATA, the Internet, and our own resource collection of local and national products and vendors.

Choosing a contractor who understands access and is easy to work with can be a daunting process. We assist consumers in this effort by providing educational workshops to contractors on ADA and accessibility and guiding the consumer through the decision making process.

For customers who live in public or private sector housing we provide education around the Fair Housing Act and how to advocate for personal accessibility needs. We also address public and private sector housing barriers and availability issues by working with local planning boards, state and local housing authority staff, landlords and developers. Financing home access construction and assistive technology for many consumers is the biggest barrier to independence at home. In Maine, there are a variety of funding options available; however, each option has its own eligibility criteria, limitations and exceptions.

Alpha One staff assist consumers in determining whether they can access this funding for their particular situation and provide contact information and assistance through the process if requested.

Understanding that this "hodgepodge" of funding is difficult for consumers to access equitably, Alpha One successfully created a revolving financial loan program, the Adaptive Equipment Loan Program (AELP), in 1988. AELP, the first of its kind in the nation, provides consumer financing for a variety of assistive technology products, from hearing aids to adapted vehicles and home modifications. Borrowers must show that they are credit worthy and have enough discretionary income to make a payment on what they want to borrow. The loans are low interest with extended payment terms. The program makes loans to individuals who in many cases would not be eligible for loans from traditional lending institutions.

Commercial Customers - Our Access Design Services for businesses and the construction community continue to evolve to keep pace with state and federal access laws and innovations in technology. We actively promote our expertise in accessibility to this group and have developed our high demand information & referral service (I & R) to provide technical assistance and product information. In 1998, of 5300 calls for I & R, 2000 were access or ADA related. Typical questions from contractors or architects include interpretations of the ADA for a particular situation, design guidance, and how ADA interfaces with other design standards such as plumbing codes, state access laws, town ordinances, etc. From these calls, we establish long-term working relationships that develop into paid fee-for-service work. For example, an initial successful collaboration with a landscape architectural firm eight years ago has led to our inclusion in bids this firm has made over the years. We have provided consultation on projects ranging from multi-use recreational paths to contracts with a local city to redesign playgrounds and outdoor access at five schools. In another instance, a company that specializes in pre-fabricated buildings contracts with us to review plans for ADA compliance for their commercial customers, such as a home heating business or a real estate office.

We are unique in our state among services that specialize in ADA information in that we do on-site work with customers. Meeting with the contractor or business owner, we have a chance to educate and demonstrate that universal or barrier-free design benefits everyone. We provide comprehensive accessibility compliance surveys and reports, assist with barrier removal plans, and provide budget, product and vendor information. We charge \$60/hour for this service. An average consultation is about 10 hours including travel, site work, research, report writing and plan drawing. The work continues to increase both with new customers and with firms or companies that come to us for assistance with all their projects.

In Maine, all new construction must be approved by the state fire marshal's office to meet state and federal access laws. A unique service of our access design professionals is "plan review" prior to a business seeking state approval. Through this process, developers, contractors and architects gain a greater understanding about barrier free design. Once at the fire marshal's office, plans are quickly approved.

Businesses also find funding access a major barrier in implementing the ADA. We work with businesses to locate local funding sources and understand tax credits and tax rebates for accessibility. The previously mentioned Adaptive Equipment Loan Program is also

available in Maine to businesses to borrow up to \$100,000 for accessibility features such as ramps, elevators, accessible transportation vehicles, and automatic door openers, to name a few. Favorable rates and terms are available.

In addition to one-to-one contacts with the construction community, our Access Design Services also include public education on barrier free and universal design. The state has contracted with us to develop a training manual and multi-session workshop for code enforcement officers in all municipalities. Other groups that have received training include architects, town planning boards, chamber of commerce members, contractors, and other business community groups. We also receive funds from the regional ADA Technical Assistance Center to educate consumers on the ADA and how to advocate for changes to businesses in their community.

We have recently begun to focus our consumer education efforts on employment issues, reasonable accommodation and the use of assistive technology. For example a local restaurant made access modifications for customers, and this had the added advantage of creating an employment opportunity in the business office for a bookkeeper who has a disability. In another situation, Alpha One was hired by a university to address reasonable accommodation needs of an employee with progressive multiple sclerosis in order to keep her working productively on the job.

Nuts & Bolts for CIL's

For Alpha One, providing Access Design Services promotes 100% accessibility and also provides a funding stream that will continue to grow and expand. As a fee-for-service product it has successfully broadened our base of income, thus decreasing our reliance on fluctuating public funding. It also generates revenue to recruit and provide professional development to a highly skilled staff that can continue to promote a quality service.

In addition to fee-for-service on a cash basis, we continue to seek contracts and other funding to broaden this base. For example, in Maine, access design service for a consumer may be funded through Vocational Rehabilitation, Title VII, Worker's Compensation, or an insurance settlement. Home based long-term care services funded through Medicaid in Maine are now understanding how accessibility can affect personal care needs. We have been contracted by Medicaid to meet with consumers to strategize on home access and assistive technology needs that can make them less dependent on personal care services.

Difficult Decisions

One of the difficult struggles our company has had is how to meet the twofold objective of meeting customer needs and at the same time advocating for access. Initially, this produced an adversarial situation between the CIL and the commercial businesses that were our potential contractors. For example, we advocated on behalf of consumers for access at restaurants and other public buildings by filing more than 30 charges of discrimination through the Maine Human Rights Act. In many ways this tactic was successful in improving access in our communities in Maine. However, the business

community was disinclined to contact us for technical information or site work for fear that we would file a charge of discrimination against them. In 1992, our company made the decision to no longer file these charges and began to promote our services as a resource, educator, and consultant to businesses and law makers. Since that time, we have been able to make a greater impact on improving access in our state. Over time businesses have come to see us as a resource, willing to help, and tell us we make "access easy." On an individualized basis, we continue to assist consumers in their own advocacy by providing them with the tools and information about access laws to help them successfully work with a local business to improve access.

Maintaining our expertise in this area also continues to be a challenge. Access laws are broad, subject to interpretation, and continue to change and evolve. Advances in technology create more choices in products or options for access. If a CIL is to promote and be successful with Access Design Services, then they need to commit to staff who do this on a full time basis. This allows them to keep current with changes and trends as well as to educate and update the entire independent living staff.

Conclusion

CIL's across the country are in a strategic position to be the experts in their states on accessibility for individual consumers, businesses and the design/construction community. We have first hand experience with disability, knowledge of the range of functioning among people with disabilities, and the creative ability to develop common sense solutions. We can educate, remove myths and misunderstandings, and effectively promote consumer choices and options. The goal of complete community integration for people with disabilities is achievable through our continuous commitment and hard work.

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The IL NET is a collaboration of Independent Living Research Utilization (ILRU) Program and the National Council on Independent Living (NCIL), and organizations and individuals

involved in independent living nationwide. Now in its second three-year funding cycle, the IL NET is building on its strong foundation to address the spectrum of needs expressed by centers for independent living and statewide independent living councils.

The mission of the IL NET is to provide training and technical assistance on a variety of issues central to independent living today. Training activities are conducted conference-style, via long-distance communication, through widely disseminated print and audio materials, and through the promotion of a strong national network of centers and individuals in the independent living field.

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Peer Mentor Volunteers: Empowering People for Change

by

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The Problem

Arizona Bridge to Independent Living (ABIL) currently serves a metropolitan area of over 2 million people. With a total of 26 staff, the only way to provide independent living skills instruction, peer support, early intervention, leadership development and advocacy to such a large community is to have a solid volunteer base.

The Plan

ABIL began its Peer Mentor Program in 1990. A staff member with a spinal cord injury wanted to provide the peer support he lacked while undergoing rehabilitation in Phoenix, Arizona. Another staff member received a mentor at the Kessler Institute. We researched what other CILs were doing to provide peer support and found that most were providing peer support through their staff. The CIL in Montana had the only program similar to what we had envisioned. However, Montana paid their mentors.

ABIL believed that mentors should be volunteers for several reasons. We thought it would mean more to the mentee if their mentor were someone who really wanted to be with them. We also believed that mentors needed to be available to the mentee evenings and weekends. Finally, we wanted the relationship to be a natural extension of the community where friends help friends without expecting to be paid for it.

The Success

At first a staff member whose job was providing independent living skills instruction was also assigned to coordinate the volunteers. The first team had six people and the training was 48 hours long. Within three years it became clear that the mentoring program was effective. However, if we wanted it to grow, we needed a full-time volunteer coordinator. We use Part C funding to support the position. In addition to the volunteer coordinator, ABIL has added three other full-time staff who provide substantial volunteer coordination as well as systems change work through additional funding resources to outreach specific populations. Those funders believed our Peer Mentoring program was beneficial enough to support its expansion.

Today, ABIL has 50 active mentors who volunteered over 4,000 hours during 1998. Mentors promote community advocacy and work with consumers on achieving independent living goals. Some of the mentors, along with other volunteers, provided an additional 1,000 hours of technical and clerical support to ABIL programs.

What is a Peer Mentor?

Peer Mentors are individuals with disabilities who:

- are already living independently

- are integrated into their community
- have a desire to help others do the same

Peer Mentors are not, nor do they try to be, medical professionals. They offer guidance through the maze of services. They are people who:

- have "been there"
- can be called after business hours
- offer friendship and encouragement
- are eager to listen
- have hard earned wisdom
- are willing to confront bureaucracy (advocate for system change)

ABIL Mentoring Programs

Mentors work with anyone who is adapting to a disability or seeking to increase their independence. Peer Mentors also volunteer in a variety of other capacities (e.g., outreach presentations, providing information and referral, and community advocacy). Mentors:

- help newly injured individuals adapt to their disability
- assist in finding community resources
- teach people how to use the public transit system
- assist those who are new to the area
- provide friendship
- advocate with service providers

Over the years our mentor program has expanded to include several focus areas, each with a different funding source:

- Early Intervention (EI) to rehabilitation centers has been supported through a United Way grant for the past four years. We have outreached over 1,000 newly disabled individuals and family members. The EI coordinator was part-time until this year and has now expanded to nursing home outreach.
- This Is MY Life provides system advocacy to promote self-determination and mentoring for persons with developmental disabilities who are entrenched in the system. The first two years were supported through a Robert Wood Johnson grant to our Arizona Developmental Disabilities (DD) Division. This year the program has been expanded countywide and is supported by the AZ DD Division.
- The Community Living Options project works with higher functioning adults with DD who do not qualify for services from the DD Division. These individuals need more community support to lead productive, satisfying lives. This is supported half by the United Way and half by Social Services block grant (TitleXX) funds.
- People First of Arizona start-up project provides self-determination training, leadership development and informal peer mentoring for persons with DD.

- Young Adults Having Overcome Obstacles (YAHOO) is the most recent mentor opportunity being added to ABIL's mentoring programs. Young adults with disabilities entering high school begin to pull away from their parents, as do all youth. However, meeting peers is not as easy for youths with disabilities as it is for their counterparts. This program matches young adults with disabilities (and family members) with youth from the community.

Peer Mentor Recruitment

Ongoing outreach for new mentors is a must as most mentors only volunteer for a year or two, then move on to higher education, employment, or other forms of volunteerism. About 1/3 of our Peer Mentor Volunteers called ABIL looking for volunteer opportunities. Another 1/3 are recommended by ABIL staff and mentors as persons with disabilities whom they believe would be good role models. As mentors successfully achieve their own independent living goals, the next step is to share their experience with others. About 1/3 of our mentors are recruited through publicity in ABIL's monthly newsletter, The Bridge; local publications; and through community outreach presentations.

Mentor Training

The Peer Mentor Volunteer recruits are given a 50-page resource book with handouts on orientation class topics and important information and referral resources during an initial 12-hour orientation training that introduces volunteers to:

- ABIL programs
- Independent living philosophy (includes the Ed Roberts video)
- Adaptation to disability and the grieving process
- Disability oppression
- Community resources
- Crisis intervention and the "duty to report" policy
- Goal setting
- ABIL program guidelines and procedures

Mentors are then invited to monthly team meetings and follow-up training opportunities that include:

- Peer counseling (re-evaluation counseling model) techniques
- Self-advocacy
- Community advocacy (i.e., legislation process)
- Disability awareness panel discussions
- Civil rights (i.e., ADA and Fair Housing)
- Attitudinal barriers: disability oppression/liberation
- Other topics requested by mentors

Supervision

Some volunteers need little supervision. Others are just one step ahead of their mentees and need more supervision. Some mentors decide they do not like working one-on-one but really enjoy community advocacy. Mentors need to be treated individually, just as consumers do.

All staff who work directly with a consumer who is matched with a Peer Mentor Volunteer serve in some capacity as a volunteer coordinator. Some of those duties include recruitment of volunteers, assisting with the training, setting up the initial meeting between the mentor and mentee, and evaluating the mentee's progress. The volunteer coordinator is responsible for outreach, recruiting, training, coordination of matches, assignments to staff (for volunteers who are not mentors and assist with technical or clerical work), volunteer support, and documentation. Most recently, we created a Mentor Team Leader position as a method of better supporting each mentor. This position was created in response to a suggestion from a Peer Mentor. Currently, five Peer Mentor Volunteers serve as Team Leaders and liaisons between the volunteer coordinator and the mentors. Team Leaders can invoke a phone-tree to pass information on to the mentors, encourage their efforts, and remind mentors to call in their volunteer activities for program documentation.

ABIL tracks mentor volunteer activities for two purposes: 1) to document contact with mentors in the consumer service record and 2) to track hours volunteered by mentors which can be used as in-kind donations to ABIL for purposes of program funding matches. It has always been difficult to get the Peer Mentors to report their mentoring activities. We have created a form to help them track their volunteer time and the kind and topic of their mentee contacts (i.e., phone or face-to-face, employment or housing location). Some mentors send this form in monthly. Others call in on a designated phone line and leave a message about their activities. In the beginning, when the team was smaller, the volunteer coordinator would listen to these messages and enter the data into a data base that could be used for running reports on time volunteered and for running off documentation for the consumer files. As the team grew, this became too time consuming for the volunteer coordinator and a support staff person took over this responsibility.

During training, mentors are encouraged to call the staff person assigned if they need supervision assistance regarding the consumer and the volunteer coordinator regarding volunteer issues. All mentees are informed of and given a copy of ABIL's "duty to report" policy which advises them what to do if their mentee reports feeling suicidal, homicidal, or reports any incident of abuse.

Program Coordination

Program Application Form. We designed an application that asks for:

- basic information
- days of availability
- work history (if any)
- counseling experience

- experience with people with disabilities
- affiliations with community service agencies
- what they wish to gain from volunteering
- how they feel they can be effective as a mentor
- what is independence

Character Reference Form. It is important to check character references even if the person is well known through the CIL. We also interview the applicant via telephone or in person. We designed a character reference form which asks information about the applicant, such as:

- the length of time they have known each other
- if they have abused drugs and/or alcohol
- if they were involved in a felony or crime
- dependability
- patience
- concern for and respect of others
- punctuality
- cleanliness
- maturity
- trustworthiness
- performance ability

Mentor Guidelines. Finally, we use a list of guidelines the mentor must sign agreeing to:

- maintain confidentiality
- report any consumer suicidal or homicidal thoughts or suspicion of abuse
- be a facilitator (do not work harder than mentee to achieve goals)
- teach from personal knowledge
- maintain proper mentor/friendship relationship (do not date mentee)
- have regular contact with mentee
- attend meetings and training as appropriate
- report hours of service each month
- be responsible to arrange or provide their own transportation

On-Going Training and Mentor Team Meetings. Team meetings are held twice a month. One is during normal business hours for mentors who depend on public transportation. One is after normal business hours for mentors who work or have transportation and prefer evening meetings. The meeting serves as an avenue for ongoing training and/or information and as a forum for the mentors to know one another. Historically, meetings are not well attended unless the topics are truly useful.

Mentor Resource List. We keep a database, which includes all previous and current Peer Mentors, their areas of expertise, and those assigned to them for mentoring. Lists containing the areas of expertise and phone numbers of each mentor are mailed regularly to all active mentors. The mentors are encouraged to be part of a team and to call each other for questions about a specific area of expertise of other mentors, support, and assistance working on mentee issues. The mentors are provided home telephone numbers of the staff to call in case of a crisis situation after business hours.

Program Evaluation

The effectiveness of the program relies on evaluations of both the mentors and mentees. Mentees and mentors are evaluated separately. The surveys are conducted at one, three, and six months from the date of the initial meeting. Staff who referred the mentee are responsible for the mentee evaluations. The volunteer coordinator or her representative is responsible for conducting the mentor evaluations. The questions on the survey mirror each other so each person is asked about his or her perception of the match and the goals achieved. Previous program evaluations indicated that early evaluation was the best way to find out if the mentor match is working and assure match compatibility. Therefore, it is imperative that an evaluation process be proactively implemented early and periodically after the match is made.

Mentors and mentees will not necessarily call you when there is a problem; they will often just simply fade away.

Benefit to Mentors

The mentor experience is as beneficial for the mentors as for the mentees. Most mentors report that the experience is empowering and fulfilling. Peer Mentors report satisfaction from being able to "give back," while simultaneously benefitting by increasing their own advocacy skills, awareness of community resources, leadership skills, sense of community, knowledge of civil rights and self-esteem.

Examples of former ABIL mentors who benefitted from the experience are abundant. For example:

- One of our original mentors (eight years ago) completed an internship with ABIL, graduated with a degree in Social Work, and was recently hired to head up ABIL's program to reintegrate consumers from nursing homes into community living.
- One is the current coordinator for our People First start-up project.
- One is now the director of the independent living center on the Navajo reservation.
- One contracts with state VR to provide IL skills instruction.
- Six members of the Statewide Independent Living Council (SILC) are current or former ABIL mentors.
- About 20% of those who are mentored become mentors themselves.

We reimburse mileage or public transportation expenses related to their volunteerism (though few take advantage of this reimbursement).

Volunteer Recognition

Funding constraints limit the frequency and types of recognition we can provide (e.g., luncheon, T-shirts, gifts). However, this doesn't seem to discourage their participation. In fact, some volunteers are embarrassed when their achievements are singled out. We have sponsored an annual holiday party in December to which staff, mentors and mentees are invited. The past two years we have joined with the local Parent Training and Information Center, Raising Special Kids, for the holiday event so that parents and children can meet more adults with disabilities. In some years we have provided small calendars with the ABIL logo for mentors as holiday gifts. We have featured on occasion mentor/mentee stories in our monthly newsletter, and periodically recognize all our volunteers, listing their names. Our county Volunteer Center mentor task force supports group recognition and warns against individual recognition.

Difficulties

Roles. It has taken several years for our board and staff to really understand and support the Peer Mentor Volunteer program and to recognize the importance of a designated funded volunteer coordinator position as a human resource specialist. It has taken a few years to get the staff to understand their role as a volunteer coordinator and to learn the appropriate referral process, work cooperatively with the mentors, and actively recruit new mentors.

Funding. It became clear that in order for our volunteer program to be successful we needed staff dedicated to this role. Our executive director, having had a peer mentor during her rehabilitation, has been an advocate for this program since she came to ABIL. We decided to dedicate Part C funding for the volunteer coordinator position so that it was stable funding and the position could maintain continuity. This has been a very beneficial decision.

Volunteer Hour Reporting. It has always been and continues to be a struggle to get all the Peer Mentor volunteer hours reported. While some mentors function independently and recognize the value of the volunteering they do, many other mentors either don't have the skills, the cognitive ability or the motivation to report their volunteer activities. To get hours turned in, they often require coaxing. In most cases we have chosen to do this rather than ask them to stop volunteering, because they have continued to benefit consumers even though they don't report volunteer hours. It appears that some of our mentors had not developed a work ethic, while others feel more like a friend and actually resent having to report on the relationship. We have explained the value to the program and ABIL repeatedly and continue to do so. In some cases, mentors and mentees decide to re-evaluate their relationship and drop out of the official mentoring program and remain lifelong friends. We want to keep the relationship as informal and natural as possible, knowing that those kind of relationships are what mentees often need.

Matches. Sometimes matches don't work and we encourage mentors and mentees to let us know if this is the case. We will simply find another mentor. We recognize we are doing our best to match people based on the mentees' requests for particular qualities, whatever

they consider most important. In matching we consider a variety of qualities: sex, age, disability, skill, experience, background.

Role of the Mentor/Inappropriate Behavior. In eight years of the program we have only had one incidence of inappropriate behavior. In that case, it was reported by the mentee. After staff investigation, we told the mentor that they would not be able to continue being a mentor due to a pattern of inappropriate behavior. We have actually had more difficulty with mentees acting inappropriately with their mentors. Some mentees have expected mentors to be available 24 hours a day, have become too dependent upon the mentors, or expected mentors to do or pay for things that were not part of their mentoring role. In most of these cases, the volunteer coordinator intervened to explain this was not appropriate, as well as to coach mentors on how to set boundaries. In some cases, the mentee was re-matched to a new mentor after the mentor was coached on this issue and agreed to try the relationship. In other cases, the mentee was told that this program would not fit their needs and we tried to make an appropriate referral.

On-Going Need for New Mentors. Because Peer Mentors move on to other activities, the programs expand, and requests continue to grow, we need to continually recruit new mentors. Sometimes we do not have the appropriate mentor for a mentee and we are unable to provide a match. We have found that mentees and mentors both will drop out of the program if they do not get matched fairly quickly. Keeping this balance can be challenging.

Meeting Attendance. Often it is only the new Peer Mentors that attend the monthly meetings. Evidently they are the ones needing the support. However, the new mentors benefit from interacting with the more experienced mentors and need this contact. We have noticed that as accessible public transportation and community accessibility has improved, fewer active mentors attend monthly meetings--they are too busy with their own lives now!

Transportation. Maricopa County has no regional public transit. Thus, traveling from city to city takes an inordinate amount of time and dedication. It is difficult for mentors and mentees to get together if they reside in different communities. Also, some communities have little or no public transit, and communities that do have public transit have none on Sundays or in the evenings.

Distractions for the Volunteer Coordinator. Because our volunteer coordinator is a resourceful and talented person, she has too often been pulled into other projects that take time away from volunteer coordination. Thus, recruiting, mentor evaluations, and eliciting volunteer hours have been compromised.

Conclusion

ABIL's Peer Mentor Volunteer Program has had far reaching benefits for ABIL as an organization and for our community. It has literally changed the way ABIL does business. It has redefined the role of staff in some cases to include volunteer coordination. It has empowered persons with disabilities to help each other increase their independence, improve their self-confidence and achieve their independent living goals.

ABIL has always created programs based on community need, and here we go again! We continue to be asked for mentors for young people with disabilities. As no one is currently addressing the mentoring needs of youth with disabilities in our community, we are in the process of creating a mentoring program to meet this need which will include collaboration with Valley Big Sisters and Brothers.

Peer Mentoring is at the heart of the independent living movement. Having paid staff persons in the role of providing "peer support" can unintentionally dis-empower persons with disabilities. No matter how hard we try, if we are getting paid to be there, then we are just one more service provider.

For more information on ABIL's Peer Mentor Volunteer program, contact:

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Interpreters Membership Insurance

By
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INTERPRETERS MEMBERSHIP INSURANCE

by
Linda Allen

Communicating with a doctor is a critical part of maintaining health and dealing with illness. The importance of good communication is demonstrated by the number of articles that regularly appear in both health related newsletters including-- the Harvard Women's Health Watch-- and more general publications, such as Consumer Reports, the Ladies Home Journal, McCall's and Redbook. The articles describe the errors that can often result when the doctor and patient do not understand each other and provide an array of suggestions to increase communication. For patients who are deaf, the communication problems are significantly compounded, sometimes compromising the quality of medical care.

In the pre-Americans with Disabilities Act period, effective communication between a doctor and a deaf patient was more likely to occur by chance than by design. Lacking any legal prerogative, deaf patients had little choice but to either have another individual, often a family member, accompany them or to write notes back and forth. The reliance on a third party sacrificed the deaf patient's right to confidentiality and placed the so-called "interpreter" in a position to decide what the patient should or could know. Note writing was a laborious and time-consuming activity that often reduced complicated diagnoses and treatment instructions to a brief summary. In some instances, a staff member with often limited knowledge in American Sign Language (ASL) would be called upon to finger spell the "important" areas of the conversation. None of these approaches ensured a clear and precise exchange of information. Both doctor and patient could only hope they were understood.

While the potential liability was very high, the risk did not serve to improve the situation as sometimes happens. Indeed, the issue was seemingly ignored, providing yet another indication of the low value placed on the needs of deaf patients and the lack of power they possessed.

At best, the situation for the deaf patient was frustrating and demeaning; worst case scenarios could be life threatening. Relegated to a back seat, so to speak, deaf patients were denied the power to control their own healthcare and treated in a paternalistic manner with little or no recourse available. Deaf patients could either choose to receive medical care on the physician's terms or not at all. Small wonder that many deaf individuals put off going to the doctor until they had to. And then they rarely complained for fear the doctor would not see them.

This was the situation when the ADA was passed in 1990. Communication barriers are covered under Title III.: "Public Accommodations are required to provide auxiliary aids and services when they are necessary to ensure effective communications with individuals with hearing impairments." Qualified interpreters are included in the listing of auxiliary aids. The Department of Justice regulations list health as an area that would require an interpreter for effective communication due to the length and complexity of the situation. Due to the

various methods by which deaf individuals communicate, the patient should be consulted to determine the most effective means of communication. When an interpreter is required, the public accommodation must secure the services of a qualified interpreter unless the result would be an undue burden.

While the ADA put the weight of the Federal government behind the needs of deaf individuals, implementation has been both difficult and confusing. Indeed, the proper and regular use of interpreters is one of the most contentious ADA issues and a continuing point of friction between physicians and patients. Unlike building a ramp, which only has to be done once, using an interpreter is an ongoing activity and expense. The cost of an interpreter is likely to be more than the reimbursement the doctor receives for the medical service provided and adds to the billing paperwork overload. As few physicians have ever worked with an interpreter, the situation is foreign and uncomfortable. The presence of an interpreter is viewed by some doctors as a fundamental interference in the doctor-patient relationship and therefore inappropriate. The obvious inconsistency of objecting to a professional while readily utilizing a family member to interpret is often lost on the physician.

The Resource Center for Independent Living (RCIL) has long been involved in advocating for the medical needs of the deaf. Those efforts were intensified with the passage of the ADA. In addition to increasing the accessibility and improving the quality of health care for deaf individuals, increased utilization of interpreters also presented a business opportunity, as it would increase RCIL's fee-for-service revenue.

There is a large deaf community in Oneida County and the surrounding counties that make up RCIL's catchment area. This is due, in part, to the location of the New York State School for the Deaf--a residential school serving children ages 2-21--in Rome, New York, just twenty miles away. Over the years, many of the school's students have remained in this area following graduation, or they return here after college. Other deaf individuals are drawn by this deaf community with the result that the use of interpreters is a major local issue. Due to these demographics, one of RCIL's first initiatives was providing and coordinating interpreting services for the local community.

RCIL has taken a multi-pronged approach to the problem, including individual and systemic advocacy activities, outreach to the deaf community and direct service provision through the Deaf Services and Interpreter Services department. RCIL provides interpreters 24 hours a day under contract with six local hospitals. We have developed a pool of local professionals who are skilled in interpreting in many settings, including medical environments. Regular skill building workshops utilizing our video and print resources are provided for area interpreters. Advocacy efforts have included educational workshops for physicians presented in cooperation with the Medical Societies of Oneida, Herkimer, Madison, Chenango and Oswego Counties and self-advocacy training for the deaf community.

RCIL has been involved in several difficult situations locally and has long sought a method to resolve the problem in a way that would address the concerns of both the medical and deaf communities. During a series of discussions with the Director of the Medical Societies of Oneida, Herkimer, Madison, Chenango and Oswego Counties, a membership concept was suggested. The idea was to develop a program similar to both the Automobile Club of America and a capitated rate generally negotiated with Health Maintenance Organizations (HMO). The Interpreter Membership Insurance program which resulted is offered through

the Medical Society and is only available to society members. As such, it also serves as a recruiting tool to increase their membership. For an annual fee of \$95, a physician enrolled in the plan can call RCIL and receive an interpreter for up to 12 office visits per year. Rates are for individual doctors. When at least five doctors in a single group practice join, the annual charge is \$90 each. Interpreters are available with a 48-hour notice. Members also receive a 25% discount on RCIL's Barrier Removal Consultation Service and a quarterly newsletter with ADA related information and updates. Rates were established based upon the number of hours of service provided in the prior three years and on anticipated utilization.

The program helps the doctors save money. The \$95 annual fee is a savings of \$805 over the per office visit charge if all 12 visits are utilized. It also eliminates fee negotiations, the uncertainty of unexpected expense and the need for multiple billing, another cost savings. Time may also be saved during office visits as the laborious writing of information and passing it back and forth, a common communication practice, is eliminated. Additional timesaving may result from removal of the wrangling over interpreters that frequently takes place.

The program was launched in July 1998 with an article in the Societies' newsletter, followed by a personal letter to all physicians in the five county area, both society members and non-members. A second letter was sent in January 1999. At the present time, 38 doctors have joined, most of whom have never previously utilized an interpreter. The success of the program has been gratifying to everyone.

The program provides substantial benefits to patients, physicians, and the deaf community as a whole, and for RCIL. Of primary importance is the increase in accessible healthcare available to the deaf community as the use of interpreters is integrated into the healthcare system. This eliminates the tension that often exists and makes the relationship between deaf patients and their physicians more comfortable for everyone. Physicians and patients receive quality service that ensures clear communication and compliance with the law. Patients gain a better understanding of their own medical condition, and doctors are assured that their instructions are understood. As a result, deaf individuals are more willing to seek healthcare, and the doctors are more willing to see deaf patients. As communication improves, the relationship between doctor and patient is enhanced, with each gaining greater respect for the other. Using an interpreter maintains the confidentiality of the doctor-patient relationship, which is compromised when a friend or family member interprets. This protects the privacy of the deaf patient and puts them in control of their personal medical information, a given with hearing patients. This outcome fulfills not only the letter but also the spirit of the ADA, which seeks to enable a person with a disability to have the same opportunity as a non-disabled person to obtain goods, services or privileges.

The Interpreter Membership Insurance program minimizes the liability risk which previously had not been seriously considered, as illustrated by RCIL's experience. Shortly after the passage of ADA, a physician called inquiring whether he had to provide an interpreter. When questioned, it turned out that he was discussing a potential surgical procedure. In addition to explaining the requirements of the then recently passed law, staff discussed the liability issue related to "informed consent," the need for both parties to fully understand the other, potential problems, risks and areas to be concerned about. The surgeon expressed little concern about the potential liability. However, under ADA this situation has been

changing and liability is increasingly recognized for the grave risk it can present to the medical community. Some of the thorniest ADA lawsuits involve the communication rights of deaf individuals. The publicity given to the filing of a lawsuit against the SUNY Health Sciences Center in nearby Syracuse on behalf of a deaf patient may have alerted local physicians to the risk of not using an interpreter and made them more amenable to our proposal.

The program has also provided greater exposure for RCIL. As more people learn about the Center, more consumers are reached and additional programs or service opportunities arise, creating more business. The expansion of the concept to other markets, such as lawyers, dentists, physical therapists, is under consideration. Other suggested markets include museums, theaters and facilities that provide lectures and similar public programs. Our long-term goal is to so integrate the use of interpreters into the community that their presence is routine.

The Interpreter Membership Program has proven to be a simple and effective method to address the concerns of both patients and physicians. As a benefit available only to the membership of the Medical Societies, the program receives the Societies' full support. Based upon our experience, we believe similar programs could be replicated nationally. This would increase access for deaf individuals and help to resolve a difficult ADA issue.

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Substantial support for development of this publication was provided by the Rehabilitation Services Administration, U.S. Department of Education. The content is the responsibility of ILRU and no official endorsement of the Department of Education should be inferred.

ILRU is a program of The Institute for Rehabilitation and Research (TIRR), a nationally recognized, free-standing medical rehabilitation facility for persons with physical and cognitive disabilities. TIRR is part of TIRR Systems, which is a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities.