

ILRU NetWork

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Defining rural: easier said than done

You can define “rural,” right?

Sure, it means remote. Or does it mean small? Maybe it’s remote and small. But what’s remote? For that matter, what’s small? Are all small communities rural? Are all rural communities small? And what difference does it make to the independent living community anyway?

The truth is, having one definition of “rural” may not be as important to independent living centers and statewide independent living councils as it is to know there is no universally recognized definition. Understanding that “rural” means different things to different folks is an important element of any dialogue about carrying the independent living message to places beyond established service areas. It’s good to remember that—as we share information and offer solutions to “rural” issues—we may be talking about vastly different circumstances.

For the same reasons it’s hard to define “rural,” it’s difficult to come up with statistics that accurately define the size and location of the nation’s rural population—much less the portion of that population designated as disabled. The problem is compounded by multiple definitions of disability. Yet having statistics is important to the national IL community for things like demonstrating need and advocating for funding.

The Research and Training Center on Rural Rehabilitation Services, part of the University Affiliated Rural Institute on Disabilities at the University of Montana, looks at the demographics of rural disability from a lot of different angles. For the most part, RTC researchers set aside the U.S. Census Bureau definitions of urban and rural that rely on a simple number of residents to distinguish between the two (anything over 2,500 is urban—anything below is rural). This definition, the researchers believe,

“oversimplifies” rural because it does not address proximity to—or distance from—cities or population hubs and access to their services.

Instead, many of the RTC studies focus on the populations living outside of metropolitan areas. Generally speaking, the Census Bureau defines a metropolitan

area as any county containing a city with 50,000 or more people, or an urban area with a total population between 50,000 and 100,000. Through studies of census data and their own research findings, the RTC has developed a picture of rural

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The many faces of rural IL

...by Richard Petty, IL Net Director

Jerry Kainulaunen is a one-man satellite office for Southeast Alaska Independent Living (SAIL). Located in Sitka, Jerry serves an area he estimates to be about 20 thousand square miles, in the whole of which are approximately 14 miles of roadway. Most of the time, on his rounds to the small and isolated communities in his territory, Jerry travels by ferry. He usually has to sleep in his van when his trips require overnight stay. Lodging that will accommodate his wheelchair is hard to come by. And then there’s the challenge of sharing the independent living philosophy with people who—as evidenced by the remote environment they choose to live in—are pretty darn independent already. It can be a challenge—this thing called rural independent living.

With this issue of IL NetWork we salute Jerry and all the folks who accept that challenge and carry the independent living message over the back roads and into the small towns of rural America. Yes, they may get the pretty views and laid back lifestyles; but they often pay a price for the privilege. You already know the problems—we’ve all talked about them for years: limited transportation, affordable housing shortages and scarce local social services, to name a few. The purpose of this newsletter is not to rehash the problems.

Instead, we want to tell you about a few independent living folks who are applying some pretty innovative ideas to some of those problems. We want introduce you—in some cases reintroduce you—to people and organizations that are hard at work to assure that people with disabilities in rural areas have equitable access to independent living programs and services. And we’ve included some pointers to resources that could have just the information or support you need to boost your own efforts to reach out to the rural communities in your area.

Finally, this newsletter is a prelude, of sorts, to a presentation we at IL Net are looking forward to this fall. In October, we’ll join participants of the APRIL conference and present our plans to update the popular series of books focusing on various rural IL Issues that we published several years ago. Check out page 5 of this newsletter for more about APRIL and the conference. Don’t worry if you can’t be there. We’ll have more information on the series in an upcoming *ILRU NetWork*.

Disability in rural america

- One-fifth of the U.S. population (about 53.3 million people) lives in the nation's 2,308 nonmetropolitan counties—spread out over 75 percent of U.S. land area.
- Approximately 12.5 million of these rural Americans have disabilities, and six million have severe disabilities.
- People with disabilities make up 23 percent of the nonmetropolitan population, compared to 18 percent in metropolitan areas.
- Approximately 11 percent of the nonmetropolitan population reports a severe disability, slightly higher than the 9 percent reported for metropolitan areas.

SOURCE: *Demography of Disability and Rehabilitation in Rural America*, RTC: Rural, Rural Institute on Disability, University of Montana

“He was able to go more places—the mall, therapy, his apartment complex—but he was going by himself because his family and friends were back home,” Seekins says. “He told me he moved back to where he belonged, with people who cared about him and helped him get where he needed to go in a less accessible environment.”

If nothing else, Seekins says, this and countless similar stories remind us there are thousands of people with disabilities who, for a variety of reasons, choose to live in communities that are beyond the reach of independent living programs and services. The RTC estimates as many as 40 percent of the country has no access to IL services.

“One of the major objectives,” Seekins says, “is to create policies that bring about equity in the allocation of resources. Equity doesn't mean ‘the same’—in many instances people in rural areas don't want the same as their urban counterparts—but it does imply some sort of fairness.”

Seekins notes that a number of CILs and SILCs are taking up the challenge of reaching out beyond their immediate service areas to close the gap. There's no prescribed method for doing so, and the solution that works in one area may not work in another.

From the other side, Seekins points to community advocacy efforts that sprung up around the issue of rural hospital closures. “People are reaching across communities to organize,” he observes. “It's only recently that any rural sectors have started to organize from an advocacy perspective.”

All of which Seekins sees as signs that, someday, the gaps in services may disappear. That day's a long way off in his estimation. To get there sooner, he says, it's important to look at the resources that already exist in rural communities and try to understand how they can be reorganized, redefined or enhanced.

For more information about the demographics of disability in rural America, contact Dr. Tom Seekins at (406) 243-2654 or send e-mail to ruraldoc@selway.umt.edu. The Rural Institute on Disabilities' website address is ruralinstitute.umt.edu.

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America that some may find surprising. The nation's nonmetropolitan areas are home to a higher percentage of people with disabilities—including people with severe disabilities—than more densely populated areas.

“That's always surprising to folks,” says Dr. Tom Seekins, director of RTC: Rural. Logic might dictate that people with disabilities would move to the city where there's better access to a range of services and supports, he says. But that logic isn't supported by the facts.

“We did a full series of interviews of people with significant disabilities in rural areas,” Seekins says. “One of the questions we asked was ‘Why are you still here?’ Many people reported being told by doctors and service providers that the best thing they could do would be to move to urban areas.”

As an example, Seekins tells of a man with a significant spinal cord injury who followed the advice to move from his Montana hometown to a larger city that would offer more accessibility and better services. He moved to Spokane, Wash., and lasted about a year before returning home. The people at the rehab hospital were right, the man reported to Seekins. There were more services, more places were accessible and there was accessible transportation.

Did you know?

The Rural Institute on Disabilities reports that a higher proportion of people with disabilities live in nonmetropolitan areas (23%) than in urban areas (18%). The following are some circumstances that may contribute:

- Many rural occupations are among the most physically dangerous and produce high rates of injury.
- The proportion of older Americans in rural areas is higher than in urban areas, and rates of disability increase with age.
- Medical and other support services that may mitigate against disability are less available in rural areas.
- The environmental infrastructure is less well developed in rural areas and may contribute to reported limitation.
- Poverty is highly associated with disability, and poverty rates in rural areas are disproportionately high, equivalent to those found in our nation's central cities.

SOURCE: *Telecommunications and Rural Americans with Disabilities: An Overlooked Frontier* by Alexandra Enders and Tom Seekins, RTC: Rural, Rural Institute on Disabilities, University of Montana.

“Travelers checks” give rural consumers more transportation options

■ Some Georgia consumers don’t leave home without them

The idea is so simple—so uncomplicated. It can’t possibly work. Can it? Transportation for people with disabilities in rural areas is such a complex problem it’s bound to require an equally complex solution.

Maybe not. LIFE, Inc., a Georgia independent living center, has set out to prove the solution may be as simple as writing a check. Consumers in four rural counties served by the Savannah center are going anywhere they darn well please these days—and choosing when and with whom they go. For people who, as recently as a year ago, were virtual prisoners in their own communities for lack of transportation, a simple check has become their own personal declaration of independence.

Gone are the days of getting approval from special transit (if there is any). No more working up the nerve to ask a friend or family member (again) for the favor of a ride.

Want to go to the grocery store? Write a check. Looking forward to Sunday’s church service? Anxious to see the new movie in town? Write a check. It’s that simple.

Alice Ritchhart, LIFE’s lead independent living coordinator, explains that participating consumers are provided with a book of blank transportation checks that they may use for any purpose, with anybody they choose, at any time. For each trip, the consumer fills out a check with the name of the driver and the number of miles traveled. The check is turned in to LIFE, and the driver is reimbursed at the rate of 32 cents per mile.

LIFE pays for the transportation with grant funds from the University of Montana’s Rural Institute. One of the four participating counties is also providing limited matching funds. The idea was born out of frustration with a failed effort by the state human service agency to convince government agencies to contribute use of their vehicles to serve rural areas. Without that, if they had any transportation at all, consumers were left with the same old sketchy and rigid system built around

scheduled trips for medical appointments and travel to and from work.

“We wanted to steer clear of the concept of vouchers because that implies ‘welfare,’” Ritchhart says. “We came up with the idea of a checkbook and created something that works just like a checkbook, complete with a register and carbonless checks. They write the check, leave the carbon with the driver, send the original to us and keep track of things in the register.”

Each checkbook is good for 100 miles of travel and consumers can request another when they start to run low on miles. At the moment, there is no time limit. Consumers can use their miles in a week, a month—whatever. However, as the program grows, Ritchhart anticipates having to impose some limits to allow more consumers to participate.

Before the first checkbooks were issued, Ritchhart says, LIFE put considerable effort into establishing a pool of drivers. Being able to offer reimbursement, she says, was a real boost to the effort. The center set the reimbursement rate at the same level federal employees are allowed for mileage. And while nobody will get rich off it, Ritchhart says it’s enough to get people interested.

LIFE sent flyers to churches and senior citizen centers, among other places, to solicit drivers. In addition, a few taxi companies and private providers have joined in. With these options added to family and friends, consumers can create their own flexible transportation network that accommodates their own schedules—and even their spur of the moment whims, Ritchhart explains.

“The consumers tell us they really like having something to offer the drivers,” Ritchhart says. “It makes all the difference in terms of their dignity. One woman told me how happy she is to be able to shop for her daughter’s birthday present without having to ask the daughter to take her to the store to shop.”

That kind of story is circulating among consumers in the four counties and participation in the project has grown to 35 consumers. Ritchhart is already anticipating the day when demand will outpace the grant funds and is exploring future funding options. She plans to ask

the legislature to devote some of the federal transportation dollars the state gets to the program. She hopes to convince the counties that are not currently contributing matching funds to do so. And she’s working on presentations to local service organizations that might be willing to raise funds.

Beyond that, Ritchhart says the center is trying to locate more people and organizations with accessible vehicles to participate in the project. With the exception of one of the four participating counties, there are still very few options for people who require accessible transport—“and that is a problem,” she says. But it could also be an opportunity for some. Ritchhart reports that a consumer in one of the counties is currently developing a PASS (Plan for Achieving Self Support) in hopes of buying an accessible vehicle and becoming a transportation provider.

Consumer choice and control are important aspects of the project, Ritchhart says, and she envisions the day when the whole program will be turned over to consumers to run. As she works toward that goal, Ritchhart is also spending a lot of time with folks from other CILs who are interested in trying out the idea in their own communities. “I feel like the transportation queen, these days,” she laughs. “There’s a lot of interest in what we’re doing.”

There’s no reason Ritchhart can think of that the program couldn’t work anywhere. CILs might have to overcome “nay sayers” who, whatever their reasons, believe rural transportation problems can’t be solved. And, of course, they’ll have to figure out where the money comes from. Otherwise, the only other challenge might be convincing consumers—accustomed to stringent rules—that they can actually use the checks for any transportation purpose they want.

“We had one guy who just couldn’t believe we would allow him to use a check to go to happy hour,” Ritchhart says, amused. “He can.”

To learn more about LIFE’s “travelers check” project, contact Alice Ritchhart at (912) 920-2414 or send an e-mail to her at aliceritchhart@mindspring.com.

Click and come on in to CyberCIL

Arizona's newest independent living center doesn't have a front door—at least not in the traditional sense. The center is open 24 hours a day, seven days a week, all year long. And if you want to visit this CIL, you don't need to travel across town—you only need to take a quick trip through cyberspace to get there.

In June, after months of "construction," CyberCIL became a bona fide Arizona corporation and the first official virtual independent living center in the country—maybe even the world. For Bob Michaels, the virtual CIL is the culmination of five years of dreaming, planning and convincing others the vision has a future.

Michaels returned to Arizona in 1995 after working in a Pennsylvania CIL. He was struck by a big difference between small towns in the East and the Southwest—the physical distance between them. "Pennsylvania has its share of small towns," he says, "one right after the other. In Arizona, you'll have a town of 500, then 50 miles of nothing but highway, then a town of 700, then another 100 miles and so on."

As a result, "traditional models for serving remote areas don't work well in Arizona," Michaels says, "and there are vast areas of the state that are not served at all."

Michaels' first thought was to set up a website to provide independent living information and referral to people throughout the state. The more he explored that idea, the more he became convinced that all independent living services could be provided online. "As the concept evolved, I became convinced CyberCIL could reach anyone who is isolated, whether they live in a rural or urban setting," he says.

It was harder to convince others, though, especially prospective funding sources. The Arizona Statewide Independent Living Council put up some funding to help advance the idea, but Michaels needed more substantial financial and technical support if CyberCIL was going to meet its full potential.

He found just the help he needed at Northern Arizona University. For the Arizona Technical Assistance Program (AZTAP)—the state assistive technology project in the University Affiliated Program's Institute for Human Development—the idea was right down their alley. The folks at AZTAP were happy to contribute the computer server and the



services of a Webmaster—two things critical to launching CyberCIL and keeping the doors open all day, every day. With that hurdle cleared, Michaels, the Arizona SILC, the folks at AZTAP and a group of "interested others" were able to concentrate on some of the more practical matters of launching a CIL—cyber or otherwise.

Just like brick and mortar centers, CyberCIL will have a board of directors—people from all parts of the state who are knowledgeable about independent living and willing to check in on the online center's website at least four times a week. In keeping with the cyber spirit, the board members will receive their orientation online.

The search for board members is just beginning. Much of the website is still under construction. The collaborators still aren't sure exactly how some of the

core independent living services will be delivered electronically. And most of Arizona's consumers aren't even aware of CyberCIL—and some may not have ready access to a computer in order to access the electronic CIL. In fact, there's probably more work ahead of the collaborators than has already been accomplished.

But that doesn't discourage Michaels or diminish his enthusiasm for its prospect. "We are taking advantage of what we know will eventually be out there," he says. "It's getting to the point that there is some sort of computer access in every community and we are just now starting to reach out to consumers across the state," he adds regarding who will eventually use CyberCIL. As for what types of services consumers will find when they visit the virtual center, he's equally optimistic, pointing to the fact that visitors can already contact a peer counselor and I&R specialist on the site.

CyberCIL's relationship to other CILs and the Arizona SILC is another aspect of the cyber center's future that's uncertain at this early stage. The issue of funding is another. While he knows they are important issues, Michaels seems content to allow them to work out in the course of time. "The hardest part," he says, "is trying not to limit our thinking based on how big or hard the job is, or with the traditional models we're already so familiar with."

Michaels invites you to stop by CyberCIL at www.cybercil.com. Or, call or write him for more information at (480) 961-0553 or michaels@impulsedata.net.

INDEPENDENT LIVING IN BIG SKY COUNTRY

Sometimes we get so focused on the problems we deal with day-to-day that we forget to look at the upside. Thanks to Mike Mayer of Summit Independent Living Center in Montana, for accepting our invitation to write about the positive side of "being rural." —Ed.

It's true. Those of us involved with CILs in rural America do face some unique challenges as we strive to make independent living a reality for people with disabilities. On the flip side though, there are some distinct advantages as well.

Here in western Montana we live, work and play against a backdrop of unparalleled scenic beauty and natural resources. Each of our offices is within a stone's throw of spectacular mountain ranges, lakes and other natural wonders. We are truly fortunate to live in such close proximity to Mother Nature's finest offerings.

The same pioneer spirit that fueled the settlement of the West is alive and well in rural Montana today. You find a real "can do" attitude in people, a common sense approach to solving problems, and a willingness to work together. People tend to be down-to-earth, yet fiercely independent.

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APRIL: A VOICE FOR RURAL IL

Linda Gonzales tells of an independent living specialist in New Mexico who racked up so many miles making rounds to work with consumers in remote parts of the state that his travel reimbursement was bigger than his paycheck. When you're talking with folks about rural independent living, that kind of story comes up a lot.

The stories serve as simultaneous reminders of the good, the bad—and, yes, even the ugly—of trying to get IL services to people who don't live within the immediate reach of a center for independent living. They give insight into what those of us who work in more urban areas perhaps can't fully grasp—working in the “boonies” has its own problems and rewards.

Gonzales is national coordinator for the Association of Programs for Rural Independent Living (APRIL). She says the same things that make it hard for rural CILs to reach consumers make it hard for them to reach out to each other for advice and support in dealing with their unique circumstances. A lot of times, she says, “rural centers feel isolated and don't have resources to network like some of the bigger centers.” She says APRIL offers those centers “a low cost opportunity to have a resource to network.”

APRIL, the organization, dates back to April, the month, 1986. ILRU invited several rural CIL directors to a meeting in Houston. In the course of their time together, the directors came up with the idea of forming a national organization to focus on rural issues. By the end of that year, the charter group had completed the preliminary work and established APRIL as a non-profit corporation.

Fourteen years later, APRIL's membership has grown to more than 160 CILs, SILCs and interested organizations and individuals. Over the years, Gonzales says the APRIL board has stayed true to the original priorities—information sharing and networking opportunities for

members. Conferences, newsletters, topic papers, membership directories and a website provide plentiful opportunities for rural CILs to communicate.

Another benefit to members, Gonzales explains, is APRIL's close working relationships with leading research and training centers. Collaboration with organizations such as ILRU's IL Net, the University of Montana Rural Institute, the Uni-

she says, APRIL hopes “to bring more equity to rural areas.”

As an example, Gonzales points to APRIL's current emphasis on finding solutions to one of rural independent living's most chronic problems—transportation. She says APRIL has launched a “very proactive” campaign to explore and advocate for solutions that give centers and consumers more transportation options.

In this effort, APRIL is tackling the problem from several angles simultaneously. The organization is working to identify local programs to serve as models for other communities. At the same time, APRIL provides direct technical assistance to centers, Gonzales says, “teaching them how to get more involved in learning about the various state and federal laws and planning activities” that have a direct impact on local transportation issues. Finally, the association is positioning itself to be a major player when the federal Transportation Equity Act for the 21st Century (TEA 21) comes up for reauthorization in 2003.

APRIL is also expanding its efforts to provide training and technical assistance to rural CILs. In October, along with the Rural Institute on Disabilities (RID), APRIL will introduce the Rural Independent Living Leadership Mentoring (RILLM) Program, funded by a new grant from NIDRR. The RILLM will provide intensive, on-site training and technical assistance to ten rural CILs over a five-year period. The new program will also work with the Regional Rehabilitation Continuing Education Programs (RRCEPs) to provide regional and state training on rural IL, and will develop and facilitate a rural peer mentoring network.

(For more information about this or other APRIL programs call Linda Gonzales at 330-678-7648 or e-mail her at LGonz21800@aol.com or visit the APRIL website at www.umt.april.edu.)



6th Annual National Conference on Rural Independent Living
**CELEBRATING THE CREATIVE SPIRIT
IN RURAL AMERICA**
October 21-23, 2000
Salt Lake City, Utah
Sponsored by APRIL
Association of Programs for Rural Independent Living

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versity of Kansas Research and Training Center on Independent Living and the World Institute on Disability grants APRIL members access to the most current and innovative information available.

While some might view these as simple membership “perks,” it's apparent that Gonzales sees them as part of a bigger picture—the picture of rural independent living's future, as a matter of fact. By creating a strong and unified front representing rural IL's perspective,

AIRROW targets outreach to Native Americans

In Native American languages, there is no word that relates to the English word “disability.” In the Native American culture, where the good of the tribe takes precedence over the individual, the notion of self-advocacy is a foreign one. These are important concepts for anybody trying to reach out to the Indian community, says LaDonna Fowler, herself a Native American. But they are often misunderstood or overlooked completely, she adds.

Fowler is a cofounder of AIRROW, American Indian Rehabilitation Rights Organization of Warriors. She is also chairperson of the National Congress of American Indians’ Subcommittee on Disability. In a recent telephone interview, she and Robert Shuckahosee, another of the group’s cofounders, described AIRROW members as “hope warriors” determined to break down stereotypes and barriers that cause Native Americans to be excluded from programs and services they have every right to access.

AIRROW was created about a year and a half ago, Fowler says, out of frustration and anger that there was little to no Native American representation on national councils and organizations that represent people with disabilities. Individual efforts to change that, she says, simply weren’t working. “We needed to organize—to join together to bring more Native American leadership to the table.” Among other things, she continues, “we need to get more Native people involved on independent living center boards and statewide independent living councils.” Shuckahosee adds. “We want more than token representation. We want people who will really speak up.”

Today AIRROW has members in most every state that is home to an Indian reservation, with a core group numbering close to 50. Fowler and Shuckahosee, who have years of collective experience in independent living and related fields, see the organization’s role as twofold.

On one hand, they want to help tribes develop a better understanding of disability and all the things related to it that may impact tribal members. This is no small feat, they say, considering that Native Americans “aren’t anxious to deal with systems outside their own tribal governments, don’t recognize disability and don’t have to recognize ADA.” Fowler says, “One of the things we’re trying to figure out is how to train our own people.”

On the other hand, AIRROW wants to work with disability organizations, including CILs and SILCs, to help them develop a better understanding of Indian culture and how to be more effective in outreach to Native Americans. The first thing to understand about that, Fowler says, is that Native people are not likely to seek out a CIL for services. “You’ll have to go to them,” she says. Even then, don’t expect to make one quick visit and accomplish anything.

People in the Indian community may be slow to trust newcomers, Shuckahosee continues. “They’ll wait to see if or how often you come back, if you do what you say you’re going to do and what you leave there when you’re gone. Will they know how to find you later on? Will you respond if they call on you later? Will you be reliable?”

Rather than taking on a whole reservation at once, Fowler suggests starting small—getting to know one person who is already well established in the Indian community. “Go slow,” she says, “find that one person and ask him or her to help you work up a plan. Learn who you need to invite to the table to talk and take it from there.”

Where do you find such a person? Fowler suggests organizations that are already working with Native Americans as a good place to start. A community health representative who serves an Indian reservation or housing agency would be good choices, she says. In addition, she says, “some tribes or reservations have American Indian Vocational Rehabilitation programs, known in Indian Country as Section 121s—referring to the section of the Rehab Act that provides for these programs. This would be another resource.” Outside of that, Fowler recommends going to meetings and conferences that are sponsored by Native American organizations and becoming familiar with Indian news media outlets.

For CILs that are really serious about outreach to Native Americans, Shuckahosee says the surest bet is to have Native people on staff and/or on the board—people who are familiar with the community. Not only will that provide a direct link, it will speak well that the center staff reflects the diversity of its community.

To find out more about AIRROW, send an e-mail to robert_ndn@hotmail.com or call 406-883-3817.

Minority outreach with a personal touch

Liz Sherwin’s approach to reaching out to minority populations from her independent living center in southern Iowa is pretty straightforward: “Don’t just sit there! Get out of the office and into the community!”

Sherwin is director of the Illinois/Iowa Center for Independent Living (IICIL) that serves six counties evenly divided between Iowa and Illinois and separated by the Mississippi River. The center is located in a metropolitan area, but much of its service area is rural. And though the region’s minority population is small—only eight or nine percent—the CIL staff is making a big effort to reach out to every person in it.

Sherwin says the staff made a conscious decision to focus on minority outreach and backed it up with a budget to allow center staff to travel to rural areas—a lot. “We make it a point to participate in their events,” she says. “We go to places people are already going—are already comfortable—and work to be accepted in those settings. We look for organizations, churches, service agencies and anybody else that’s already working with people in the minority populations and we introduce ourselves to them. We go to their meetings. We go back to their meetings. We’re there. We’re in the community. Eventually, people come to realize we’re there to stay, and they begin to trust us.”

Trust, Sherwin says, is critical to successful outreach—especially in rural communities. “In a larger city, it might take a while for word to get around that you’re a screw up,” she says. “In small towns, you only have one or two chances. People have to know that you’re about what you say you’re about—and you have to follow through.”

It took a couple of years, Sherwin says, for the trust to take hold and for people in the minority populations to seek out independent living services. But, perseverance has paid off. Minorities now make up 16 percent of the center’s clientele—double the percentage of minorities living in the communities the center serves. “We’ve finally established credibility with minorities,” Sherwin reflects. “Where folks used to be skeptical about us, now they say ‘If you’re with the center, you must be OK.’”

Contact Liz Sherwin at (319) 324-1460 or execdirector@reveal.net.

Rural advocacy requires patience, persistence

The decision to sue the City of Hays in March 1997 wasn't an easy one for the folks at LINK. The staff of the independent living center, situated deep in the rural Kansas wheat fields, knew there would be more to worry about than points of law. In fact, their biggest worry was the impact such a big lawsuit would have on the CIL's relationship with such a small town.

The conflict—the need to be an advocate versus the need to get along—is familiar to many CILs in small, rural towns. “In your face advocacy” is markedly different in small communities than in large cities. There's a much greater chance that the face you're in belongs to someone you know—someone who watched you grow up, who knows your family. They may even be family.

“It's a lot more personal,” says Brian Atwell, LINK's director. That's the very same reason operating a CIL in a small town can be a good thing, he says. You're working in a comfortable environment and good things often come out of those personal relationships.

Nonetheless, when LINK's rapport with community leaders repeatedly failed to bring about changes in the town's compliance with ADA, Atwell knew the center had to take action. “It was our responsibility,” he says. “This being a small town was no excuse to drop the ball.”

In the lawsuit, LINK cited 25 local businesses that were not in compliance with ADA, including one owned by LINK advocacy director Lou Ann Kibbee's cousin. “A lot of people thought we were suing all the businesses, too,” Kibbee says. But even when it was clarified that they were just being used as examples, a number of business owners kept a frosty distance from the center.

“Some of the businesses trashed us, the city trashed us and so did the media,” Atwell recalls. “We even got hate mail.”

Atwell thinks it would have been a different scene if Hays were a larger city. “I don't think people would have heard so much about it—it wouldn't have been such big news,” he says. “And there may have been more pressure on the city to do the right thing.”

As it turns out, the court put the pressure on the city and ruled in LINK's favor. Now, many of the same businesses are coming to the CIL for help. In fact, the suit—or more likely, the victory—elevated LINK's visibility and standing in the community. The referral rate for center services increased. And, Atwell says, city officials became much more willing to involve the CIL in decisions that have an effect on people with disabilities.

While he's happy with the generally peaceful outcome, Atwell says he has learned from the experience and the center has changed some of its strategies, as a result. “We make it a practice to attend and watch city council meetings,” he says. “We see our role as the watch dog and have to make sure the city knows we're not going away.”

The trick, he says, is to maintain an assertive posture without sacrificing the positive and personal relationships the center relies on to carry out its day-to-day business. There again, the small town atmosphere may be a plus, he says. People in any community possess a variety of attitudes about disability issues. But in a small town—because you tend to know people better—it may be easier to know who feels what way about certain things. And because you often have more personal contact, it can be easier to hash things out one-on-one.

There are still occasions, though, that call for a strong show of support around an issue. Atwell says that can be hard to pull off in a small town like Hays. “We don't have much transportation in the outlying areas and it's hard to get consumers in to help,” he says. One strategy the CIL uses to overcome that is to join forces with other community organizations that have similar goals and values. Atwell says it's important to cultivate these relationships, even with organizations that don't deal directly with disability issues. “Other groups are usually willing to help us with our issues,” he says, “knowing we'll back them up when their time comes.”

For more information, contact Brian Atwell at (785) 625-6942 or send an e-mail to batwell@eaglecom.net.

Big Sky ... continued from page 4

In independent living this often translates into truly creative solutions to a variety of problems, including dealing with architectural barriers. For example, I've seen a construction hoist used to power a home made porch lift. Simple, safe, and much less expensive than a commercial lift. In a small community it's also not unusual to see ramps built at little to no expense through donated materials and volunteer labor — a modern version of the traditional barn raising. Groups hold fund-raisers to help families meet unexpected medical expenses. People volunteer their time and skills to build a senior citizens center or town hall that benefits the entire community.

This spirit of cooperation carries over into the social service system. Typically, local agencies and organizations in rural areas form a tight network and work together for the benefit of their mutual consumers. CIL staff are accepted members of this network. Because of this collaboration, there is less tendency for consumers to “fall through the cracks.”

This networking also happens on a broader, community level as groups come together to develop needed resources. Summit has enjoyed tremendous success over the past two years spearheading a campaign to expand transportation resources in Ravalli County through a cooperative venture involving consumers, the Council on Aging and a half dozen local agencies. Through group effort and lots of grassroots organizing, we have been able to secure county funding for transportation, win a Department of Transportation 5311 grant and acquire Public Service Commission authority to operate a public transit program housed at the Council on Aging. People with disabilities, seniors and folks on a limited income now have much greater access for rides in this very rural area.

Is the system perfect? No. More funds, more vehicles and more drivers are needed. But it's a great start and a good example of the cooperation, community spirit and “can do” attitude typical of rural independent living.

To contact Mayer, call (406) 728-1630, or e-mail mmayer@summitilc.com.

NetNotes

If you were planning to sign up for one of the courses announced in the *Learning Online 2000* brochure released earlier this year, we're sorry. You're too late! We had an amazing response to the courses and they are "full up." Stay tuned for announcements for *Learning Online 2001* in the near future. The courses are sponsored by IL Net, the ILRU/NCIL National Training and Technical Assistance Project and ILRU Research & Training Center on Independent Living.



In our December 1999 issue on planning, we featured the **Innovation Network, Inc.**, an organization devoted to "helping agencies succeed." InnoNet's website contains a number of tools CILs and SILCs might find useful in developing strategic plans, program budgets and the like. Allison Fine, InnoNet's executive director, wrote recently to share some new features on the website. "Now users can create their own budgets and fundraising plans, and download all of their plans in a common grant application," she writes. "Hope you'll check it out and pass it on!" InnoNet's web address is www.innonet.org.



Looking for more info and resources on rural issues? Our research for this newsletter turned up some useful websites you may want to bookmark. We've included a few here, but check out *ILRU NetWork Online* for more—www.ilru.org.

- **Facts about the Rural Population of the United States** - <http://www.nalusda.gov/ric/richs/stats.htm#demographics>
sponsored by the National Agriculture Library of the U.S. Dept. of Agriculture
- **Internet Resources for Rural America** - <http://www.rurdev.usda.gov/nrdp/resources.html>
sponsored by the National Rural Development Partnership
- **Resource Links for "organizations serving small metropolitan and rural America"** - www.nado.org/links/index.html
sponsored by the National Association of Development Organizations



When talking about her center's efforts to reach out to minorities in the surrounding rural areas (see p. 6), Liz Sherwin told us about a helpful manual produced by the Statewide Independent Living Council of Illinois. The *CIL Outreach Manual* is available online at www.fgi.net/~silc/. The Illinois SILC is also happy to mail print copies of the manual. To get one, call 217-744-7777 or send an e-mail to silc@fgi.net.

ilru NetWork

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