

ILRU Network

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Planning for accountability, credibility—and survival

“Nonprofit service providers have a moral responsibility to make sure that every dollar spent is going toward solving problems. Not knowing whether this is the case is an inexcusable sin of omission.”

—Allison Fine, Foundation News & Commentary, March/April 1997

Allison Fine can't be accused of being wishy-washy when it comes to taking a stand on planning. Fine is the executive director of Innovation Network, Inc. (InnoNet), a nonprofit organization she founded in 1992. InnoNet works with public and nonprofit organizations to “better plan, execute and evaluate their structure, operations and services.”

Fine and a small staff of experts work one-on-one with an impressive array of

organizations to figure out better ways to collect, analyze and present information that substantiates their value to their constituents and communities. But InnoNet's assistance is available to anyone with a computer and Internet connection.

Reflecting the philosophy that good planning is more common sense than rocket science, InnoNet's website is chock-full of useful planning and

evaluation tools. An interactive workstation offers resources for start-up organizations that are developing new programs. A repair center offers tools for more seasoned nonprofits that want to do a better job of evaluating existing services. InnoNet staff will even review materials developed with the tools—all for free.

InnoNet's focus on “participatory evaluation” may be of particular interest to state independent living councils and centers for independent living that want to involve consumers and other stakeholders in developing plans and evaluating programs. Through its own research, InnoNet has learned evaluations developed with high stakeholder participation are more likely to be used than those developed with more traditional, analytical processes. The website features a smorgasbord of guidelines for activities that encourage participation including surveys, interviews, questionnaires and group discussions.

Beyond the moral obligation, Fine believes the very survival of the nation's nonprofit community will be determined by how well it establishes credibility and accountability through effective self-evaluation and needs assessment to build programs and services that deliver certifiable results. From her Washington, D.C., vantage point, Fine sees plenty of evidence that diminishing government funding and increasing competition for foundation dollars are forcing nonprofits to plan better—or perish.

See page 5 for some tips on conducting focus groups—a sampling of the information available at InnoNet's website: www.inetwork.org. —Ed.

PUTTING THE PUBLIC INTO THE PLAN

...by Richard Petty, Program Director

All of us can readily agree on the importance of consumer involvement in charting the course of independent living advocacy and services. This is a basic tenet of our IL philosophy. It's no surprise then, that federal law and the Rehabilitation Services Administration have clear expectations that centers for independent living and statewide independent living councils will involve consumers in meaningful ways as they plan their activities.

The concept is simple, but making it happen is often much more difficult than it might seem. At ILRU many of the technical assistance requests we receive have to do with how the independent living community conducts needs assessments and gets meaningful public input. Why? SILCs and CILs tell us there is too often too little return for all the time, energy and expense devoted to these activities.

What's the problem and what can SILCs and CILs do to get a better return on these important planning activities? We went to our resident experts for some answers.

In this issue Laurel Richards, ILRU training director, Pamela Dautel, research coordinator, and Bob Michaels, project associate, share their expertise and experience to shed some new light on the old problems associated with planning, needs assessment and public input. We also hear from colleagues in three states who are trying out some new approaches to involving constituents in planning activities.

Needs assessment and public participation are important—and not just because they are required to fulfill a statutory obligation. When they work, they can provide important insight to what consumers want, need and expect from our advocacy and services.

First aid for forums



Putting new life in the old public hearing

... by *Laurel Richards, ILRU Training Director*

As you can see, this issue of *ILRU NetWork* deals with approaches you can use to obtain information from your consumer constituency on what they see as their most pressing independent living and disability rights needs. As attractive as one or more of these approaches may sound to you, however, many of you will find yourselves back to using the old standby of public hearings.

Amidst the groans, we wish to make two points: one, some things we will have with us always; and, two, there are steps to be taken that can improve effectiveness of public hearings.

For dealing with point two, we turned to our colleague, Kaye Beneke, whom we met in the early 1980s when she was given responsibility for organizing public hearings for the state voc rehab agency of Texas. Like many of you who invest considerable time and energy in setting up hearings, she became frustrated after several sessions characterized by poor participation and low attendance. To learn why the hearings drew so poorly and produced so little useful information, she contacted a number of representatives of disability organizations around Texas.

The responses were what you would imagine—the public-hearing process is intimidating and unwelcoming; hearings are not held in communities across the state so that people can attend with little travel; notices of the hearings are not circulated effectively among people with disabilities (and even when they are, sometimes the way hearings are publicized can put people off); objectives for the hearings are not clear (alas, to consumers and advocates, it appears that public hearings are staged more for the purpose of satisfying some legal requirement than to get meaningful and useful information); and feedback to hearing participants on issues identified through the process is not provided, indications of how the information is being used is never made clear, etc.

Based on the feedback she received, Beneke significantly altered her approach to organizing public hearings, seeing increased participation of consumers who provided meaningful information. She identifies the following five points as key to more effective public hearings:

- ✓ Give folks something specific to talk about, something that relates to their everyday experiences with the organization, program or services. Public meeting notices are often too vague or too general—“join us to comment on the state plan” or “give us your input on independent living services statewide.” Many consumers do not feel they know enough about these broad and lofty areas to offer comments or suggestions. Rather than risk embarrassment, they may remain silent throughout the public hearing—if they come at all.
- ✓ If you’re not getting the turnout you want in the place you’ve always had these meetings, try a different place! Folks may not feel comfortable speaking freely about your organization if they are sitting in your conference room. Choose a neutral location. Find a place that is likely frequented by the people whom you want to participate. Shopping malls, popular restaurants, churches, independent living centers and similar locations offer opportunities to go where your consumers are.
- ✓ Choosing the right time of day to hold a public hearing can be a real challenge. The key is to be flexible and innovative and most of all recognize that no schedule will be convenient for everybody. Provide other options for people to contribute their comments if they can’t attend the hearing. Publicize addresses, websites or phone numbers people can use to write or call in their comments.
- ✓ Ditch the traditional inquisition-style room setup for something less intimidating and more conversation-friendly. Do away with the head table full of imposing authority figures. Ask your organization’s officials and other “head table types” to spread out and sit among the participants. Replace the stand-up microphone with a hand-held mike and allow people to speak from their seats. Assign someone who is skilled in facilitating group discussions and “bringing people out” as facilitator.
- ✓ Follow up your public hearing with some sort of accounting of what you learned at the public hearing and, most importantly, what you’re doing with what you learned. Write it up in a newsletter story, send it in a letter to folks who attended the hearing or post it to your website. However you do it, find a way to communicate that you value the time and energy participants devoted to the hearing and that their efforts were not a waste of time.

... and the survey says

...by *Bob Michaels, ILRU Project Associate*

From 1995-98, ILRU surveyed SILCs to find out about their methods of collecting information for needs assessments and their satisfaction with those methods. SILCs responding to the surveys repeatedly expressed dissatisfaction with public forums as an effective way to get input into their planning efforts. They reported more satisfaction with other methods such as focus groups, summits and surveys—but did not make widespread use of those methods. The number of public forums held took a dramatic dip in the second and third years. But in the fourth year, more SILCs staged public forums than in any of the previous years—and they reported being a little more satisfied with the results.

SILC Congress '99 participants took an interest in the report from the last year of the survey, especially the upturn in satisfaction. The sudden increase in the number of forums may have been the result of timing—state plans were due that year. But, why were they more effective?

The SILC Congress surfaced two possible explanations: 1) the forums weren't held in conjunction with the designated state agencies; and 2) they attracted more people who had no affiliation with current service providers.

Assessment made easy

You may already collect the information you need!

...by Bob Michaels, ILRU Project Associate

Conducting a big-time survey to find out what your community needs by way of independent living services is probably going to cost big-time bucks. Right?

Not necessarily! In fact, you may not need to look any further than your own office to find a lot of useful information that won't cost you a cent. Have you taken a look at your information and referral log lately? What does it tell you about your community's needs? Can you categorize the types of needs the inquiries reflect? Are there two or three topics that generate the most calls? How do these topics relate to what you already know about people with disabilities in your state or community?

Simply by answering these questions, you've established a good foundation for a needs assessment built on information you're collecting (hopefully) already. If you keep records about complaints your SILC or CIL receives, you can use them in the same way.

You can supplement this "home grown" information with statistics and demographic detail that is readily available to anyone with a telephone, fax machine or computer. Dozens of organizations and government agencies conduct surveys as a part of their function or because they need the data to get funding. Don't be concerned that the agencies will be reluctant to share the information with you. Government agencies realize that, as a taxpayer, you have a right to the data. Private organizations want to share their findings, especially if it may result in new programs or services for their constituents.

The U.S. Census Bureau is a good starting place. You can find basic demographic data for the national, state and local levels. It's broken down by age, sex, ethnicity and a multitude of other categories. There is also an analysis of disability, although you won't find specific disability types identified. To make the most effective use of census data, pull down data that matches the way you keep information in your own record-keeping system as closely as possible.

For information specific to your community, try organizations like the Better Business Bureau, Chamber of Commerce and/or local realtors'

association. They collect data for their members and often have news about local trends and changes which may impact your organization.

Locating reliable statistics about disabilities—particularly specific disabilities—can be a challenge. You may be able to find local or state resources through organizations such as the state council on developmental disabilities, the vocational rehabilitation agency or other state agencies that serve people with disabilities. State and/or local chapters of disability advocacy organizations might also be able to help.

If you're interested in how your stats compare with national figures, the *Chartbook on Disability in the United States* is a good resource. Produced by the National Institute on Disability and Rehabilitation Research (NIDRR), the book is available in print or on-line (see website address below).

As we collect data from these and other resources, it's important to remember that consumer control is one of the basic tenets of the independent living movement. We must take care to assure that the plans we develop using this data reflect the desires of people with disabilities—not other well-meaning (and sometimes self-serving) advocates. We know that many of the organizations that purport to represent the views of people with disabilities are often parents, professionals and/or service providers with their own needs.

The demographic data we gather to compare to our centers' statistics may come from a wide variety of organizations and government agencies. But if we are serious about finding out what people with disabilities in our community actually need, we had better go to organizations run BY rather than FOR people with disabilities.



Got Links?

Addresses for the websites Bob Michaels recommends in his article on this page are included below. We've thrown in a few other sites which offer useful information about a variety of aspects of planning we hope will be useful to SILCs and CILs. Find direct links to these sites on the NetWork Online page of ILRU's website: <http://www.ilru.org> —Ed.

U.S. Census Bureau

<http://www.census.gov/hhes/www/disable.html>

National Institute on Disability and Rehabilitation Research (NIDRR)

<http://www.infouse.com/disabilitydata/chartbook.choices.html>

Civil Practices Network

<http://www.cpn.org>

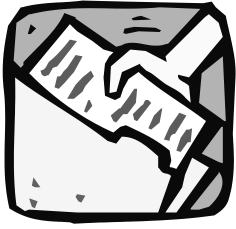
Management Assistance Program for Nonprofits Free Library

<http://www.mapnp.org/library/index.html>

Nonprofit Genie

<http://www.genie.org>

SILC lets statistics speak for themselves



According to the statistics, 97.5 percent of the residents of Idaho think it is “important” or “very important” for the state government to

provide support for people with disabilities. Three out of every four Idahoans believe their state legislature should transfer funds from institutions to community supports. Two-thirds prefer in-home support services for persons needing long-term care.

The most remarkable thing about these statistics is that they are, in fact, statistics. Reliable data about public perceptions of people with disabilities can be hard to come by. But not in Idaho.

These stats are the result of two surveys initiated by the Idaho State Independent Living Council in 1995. The SILC’s previous efforts to get public input for planning purposes surfaced the same three priorities—housing, transportation and personal assistance services—time and again. Without minimizing the importance of those issues, Kelly Buckland, executive director, says the SILC wanted a different kind of information—something that might be useful in advancing those priorities and other issues important to people with disabilities.

The fact that the Idaho SILC conducted a telephone survey might not come as a surprise, but who they surveyed just might. They contracted with Washington State University (WSU) to poll ordinary, not necessarily knowledgeable about disability issues, citizens to find out what they know and how they feel about people with disabilities. Using a survey developed in collaboration with the university, they queried folks—more than enough for a statistically reliable sampling—on 22 issues ranging from personal perceptions and attitudes to preferences for spending public dollars.

Who cares what ordinary citizens of Idaho think about people with disabilities? The Idaho Legislature cares—because a lot of those citizens vote. So the SILC made sure the legislature was filled in on the survey results. Buckland says it was an extremely useful educational tool for the SILC’s use in promoting any number of programs and services to support people with disabilities.

The public opinion survey is only part of the foundation for the SILC’s current state plan for independent living. Teaming up with Boise State University, the SILC conducted a second survey—this one targeting people with disabilities—in an attempt to determine the level of unmet need in the state.

Beyond that, the council took advantage of the opportunity presented by its own statewide leadership conference to ask participants in that gathering what they would like to see in the plan. Then, for good measure, the SILC paid small stipends to consumers throughout the state who volunteered to review and critique the draft plan. “We truly want the SILC to represent what consumers want,” says Buckland, “so we try to incorporate a

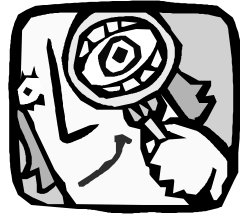
number of different approaches to finding out what that is.”

While the SILC is generally pleased with its efforts to generate input, there is one area that needs improvement—consumer response and participation. Relatively few Idaho consumers choose to offer feedback. “We don’t know why some people don’t participate,” Buckland says. “It could be that some consumers feel so unempowered they feel like it’s not going to do any good anyway.”

“Or maybe,” he says, “they’re really just into their own lives. This stuff is really important to us, but they’re busy trying to manage their day-to-day lives.”

(Check out the Idaho SILC’s website for more information about its public surveys: <http://www2.state.id.us/silc/index.htm> —Ed.)

CIL “focuses” efforts for input



As a “fairly young” CIL guided by board members who, themselves, are relatively new to the independent living movement, Independent Resource, Inc., pays close attention to how other centers serve their communities. It’s a good way to pick up general information about what works and what doesn’t. But executive director Larry Henderson says that approach is lacking in one major area—it doesn’t provide any information about what Delaware consumers want and expect from their center.

Henderson says past efforts to get input from consumers have been limited to customer satisfaction surveys completed by individual consumers after they’ve received a service from the center. The information collected from these surveys is useful for fine-tuning programs and services. But, he says, it still doesn’t get at the bigger picture that he and the board need to see in order to map out long-term plans and goals.

In November, Independent Resources launched a new effort that Henderson and the board hope will provide that broader view. Consumers in each of Delaware’s three counties have been invited to participate in what might best be described as a cross between a focus group and a public forum.

Unlike a true focus group, participation in the activity was open to anybody who wanted to come. The center mailed announcements to every consumer on its statewide mailing list.

But unlike most public forums where the topics are potentially unlimited, participants were asked to focus on five questions developed by the center staff and board. Consumers were asked to describe what they like about the center, what’s working and why it’s working. And they were asked what’s not working and what other things the center should be doing. Finally, participants were asked what one thing they would like to see the center change within the next three years.

The effort to collect feedback wasn’t limited to independent living consumers. In separate activities, the center’s staff and board were given the chance to answer the questions, too. The entire collection of responses, Henderson hopes, “will give us a rounded perspective of where the board is coming from, where the staff is coming from and if that in any way relates to what our consumers want.”

At this writing, Henderson and the board are consolidating all the comments gleaned from the three forums in order to evaluate the input they received and determine how it will translate to a five-year plan.

Turning the tables on telephone surveys in Texas



You know those calls you get from people who want to sell something or ask you a bunch of survey questions when you've just pulled up to the dinner

table or are about to find out "whodunit" on your favorite TV show? Members of the Texas State Independent Living Council had those very same calls in mind as they considered using a telephone survey to gather information for a statewide independent living needs assessment.

Telephone surveys offer the opportunity to communicate with a larger number and more diverse group of people than generally found at traditional public forums. But concerned about the potential of annoying more people than might participate in the survey, the Texas SILC was hesitant to go that route. Instead, with the help of a consultant, they launched a telephone survey with a twist.

Consumers who wanted to participate in the survey placed the call themselves. An "800" number and operator equipped with the 18 survey questions allowed callers to participate in the survey when it was most convenient for them—24 hours a day, seven days a week. The survey period ran for two months earlier this year.

"We really thought this was a cool approach," says Jonas Schwartz, SILC vice-chair. "We had never seen or heard of anything like it. Our main concern was if the folks we were trying to reach would actually feel comfortable."

To get a feel for that, they launched a pilot project and encouraged Texas CILs to have consumers check it out. As a result of the pilot, SILC members learned it was useful for consumers to know the questions they would be asked before they placed the call. When the survey went statewide, the questions were included in the publicity.

Schwartz says the SILC and consultant publicized the survey to "everybody we could think of," yet the participation was disappointingly low. The council had hoped for as many as 2,000 calls. They got 344.

Schwartz speculates that the number of survey questions might have been an issue for some potential participants. "You probably need no more than ten

questions," he says. But he doubts that was by any means the sole factor in low caller response. "A lot of people just don't participate in surveys," Schwartz says.

As the telephone survey was underway, the SILC also staged three public forums in hopes of collecting even more input. Two of the three were poorly attended—leaving members of the Texas SILC scratching their heads over how to increase participation in future efforts.

With the consultant's final report hot off the press, the Texas SILC is just now setting to the task of analyzing the data collected through the surveys and forums—as well as the value of trying the call-in survey approach again. "We need to do something periodically just to know what's going on around the state," Schwartz says. "We just need to find a vehicle that more people will participate in so we can get more of a cross section of information."

LET THE DISCUSSION BEGIN!

InnoNet offers practical tips for focus groups

Are you planning to facilitate a group discussion or focus groups? Ask yourself the following questions to be sure that you are on the right track.

If you answer "YES" to these questions, you are in good shape. If you answer with a resounding "NO" to any question, you need to change your plans.

PREPARATIONS

- ★ Have you invited enough people so that you can reasonably expect 6-10 participants show up for each focus group discussion?
- ★ Have you arranged for transportation, child-care, or other services which might be needed by the attendees?
- ★ Are you conducting the focus group at a time that is convenient for the potential participants (e.g. weekends or evenings for working people, or during program hours for program participants)?
- ★ Are you being careful not to invite any person (or group of people) who will be seen as having more authority than the rest of the participants?
- ★ Is the focus group moderator (or note-taker) someone who the participants will see as neutral and will respect?
- ★ Are you holding more than one focus group?
- ★ Have you scheduled at least two hours for your focus group?

FOCUS GROUP QUESTIONS & CONTENT

- ★ Does your introduction state the purpose of the focus group and assure people that all of the information gathered will be kept confidential?
- ★ Have you prepared a list of open-ended questions that you will ask the group?

- ★ Have you included introductions for everyone and one warm-up question that everyone can participate in answering on your list of questions?
- ★ Are you starting off with a general question and then moving to more specific questions?
- ★ Does your list of questions include "Prompts" or "Probes" to help move the conversation along if things get slow or go off-track, or if the conversation is not as in-depth as you wish? Be sure that your prompts aren't leading people to certain answers (i.e. don't fish for the answer you want to hear.) Here is an example of a question and its possible prompts: "Which of the Center's services have you used?" Prompt: "Has anyone used the career center or the computer room?" Or "Here is a list of the Center's services. Are there any on here that you have used, that we haven't heard about yet?"
- ★ Do you have a note-taker who will record the main points and key comments of the focus group? The moderator should not be the note-taker. Never record or videotape a focus group without informing the participants that you are doing so.
- ★ Do you plan to thank the participants at the end of the session? In some cases you may even want to pay or otherwise reward participants for joining you. If you plan to reward your participants, you may want to tell them of the reward beforehand so that they will be more enticed to join.

This article is excerpted from the "Group Discussion Repair Station" on the InnoNet website. The full text and a lot more practical information is available on the InnoNet website: www.innetwork.org.

SOURCES & RESOURCES

For more information about the stories in this newsletter, go straight to the sources. Thanks to the following for sharing their valuable time, knowledge and experience in our effort to advance the independence of all people with disabilities.

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