**Effective Rural Outreach:**

**Using the Concerns Report Method as a Tool for Change**

**August 15, 2013**

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>> TIM FUCHS: Good afternoon. I'm Tim Fuchs with the National Council On Independent Living and I want to welcome you all to CIL‑NET's newest webinar, effective rural outreach using the concern report method as a tool for change. Today's presentation is brought to you by the CIL‑NET, a program of the IL NET training and technical assistance project for CILs and SILCs. It's operated through a partnership among ILRU, NCIL and APRIL with support by RSA at the Department of Education and we are recording today's call so we can archive it on ILRU's web site and we will be breaking several times during the presentation to take your questions. For those of you on the webinar you can ask questions in the chat pod under the list of participants on the right side of the screen in the bottom right‑hand corner. And for those of you on the telephone when we go to the Q&A breaks you can press star pound to indicate you have a question and it will put you in the queue. We'll remind you of those instructions each time we go to a question break. In you are on the webinar today, of course, the PowerPoint will display automatically. But if you're listening on the phone or you don't have the PowerPoint in front of you for any reason, you want to get that from the confirmation e‑mail that was sent to you. It was attached to that. And if you don't have that PowerPoint and you don't have the confirmation e‑mail handy you can e‑mail me at Tim@NCIL.org. Got my e‑mail open right here and I'll get it to you. You really are going to want the PowerPoint to follow along. It's going to make the presentation a lot easier to stay with. The other important thing I want to remind you of is the evaluation form. It's really important for us to know what you all thought of the presentation, if it worked for you, so please do take a moment after the presentation is over to fill out the evaluation form. It's very quick, very easy to complete. If you're participating in a group today, that's fantastic, we encourage that, but please do fill out the evaluation. We want to know what each individual thinks of our program so that we can improve them.

Okay. So I want to get started and I'll do that by introducing our presenters for today. Mike Mayer and Tom Seekins. Mike is the Executive Director of Summit independent living center in Missoula, Montana and has been since 1988. And Mike has extensive experience developing IL services through the branch office model. Tom Seekins is the director of research at the Rural Institute and has been there since 1988 as well. And he has served as director of University of Montana's training center on disabilities in rural communities since 1993. I have had a great time working with Mike and Tom to put this presentation together, and they've put a lot of careful thought into it and I know you're going to enjoy hearing from them. With that I'm going to turn it over to Tom to get us started today. Tom?

>> TOM SEEKINS: Thank you, Tim. Really appreciate this opportunity to work with you and ILRU folks and to be here with Mike and Tracy Bain is also with us, giving us a hand today.

My task at this stage is to review a little background on rural strategies for extending IL to unserved small towns and rural areas. I'm going to highlight some different methods, but in particular the Concerns Report Method for organizing those kinds of communities.

And Mike is going to provide some real‑world examples from the perspective of the CIL. I just want to point out the slide here has a picture of ‑‑ there we go ‑‑ I forgot to move that along. It has a picture of a rodeo and a cowboy riding a bucking Bronco holding on for his dear life. That's kind of the way I sometimes feel at the beginning of a presentation.

Next slide, please.

The picture in this one is a tree standing out in the middle of a big Hayfield in the brilliant sun of eastern Montana. I really believe that independent living philosophy and the IL model are among the most significant developments in health and human services of the last 50 years. It's changed the way we see ourselves. It's changed the way others see us. It's changed the focus from blaming individuals to fixing environments. It's created new laws that have transformed society and communities in which we live. It's been adopted by the World Health Organization as a model for health. It's emancipated thousands of people from institutions and it's brought people together. But not everyone in the country has access to the services and supports and developments that IL represents.

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Two pictures in this one. One is a small town in a mountain Valley and the other is a picture of a small town in eastern Montana. I picked these pictures because rural America is a diverse and changing place. Few people think about it, but there are over 32,000 towns with populations of 10,000 or less in the United States. Over half of the towns and communities we live in are under a thousand. Those 32,000 towns of less than 10,000 have a population that are as equivalent to the top 97 cities in our country. Some 57 million in the cities, some 54 million in those small rural areas. But residents of up to 40% of the counties that are home to some of those small towns, most of them rural, are often outside CIL service areas.

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The picture in this, I think, is by Sargent. It's the classic actually brother and sister on the Iowa farm with the pitchfork and the house in the back. It represents, I think, some interesting rural characteristics, and it's important to think about some of the characteristics of rural America as you begin to reach into its many small places.

So under potential strengths of rural communities, people have a commitment to place. They're often socially tightly linked. They have an independent spirit of self‑help and mutual aid. And socially, like each of us individually, the systems are very tightly linked. Unlike in cities where many of the systems are loose and unconnected and where you can make a change in one system without affecting another, in a rural community, if you make a change in just about anything, it affects almost everything else. So rural communities often get the anvil of ‑‑ handle of being conservative because they seem to be so slow to change. I see that as a strength as people think about change carefully and try to understand its many implications for the linkages within their community.

But there are some kind of problems that rural areas face in one form or another. One is low population density. Distance from resources and isolation. Generally speaking, while they're some of the most wealthy counties in the country are nonmetropolitan, many of the most poor pockets are rural. There are thinner economic margins. There's older infrastructure. Buildings and roadways and bridges. Fewer services. There's inequity of resource allocations borne often of an urban bias by policymakers.

Next slide, please.

This is a picture of a man in a wheelchair cruising down a sidewalk of a small town. The vision for rural America, as there was a new paradigm of disability, there is a new narrative of rural America that's beginning to emerge, shifting from one of dependence in agriculture to one that's full of vibrant small towns, rural communities, aided by Centers for Independent Living in which all residents participate and enjoy a sense of belonging. But how do we extend the IL model into those unserved and underserved areas?

Next slide, please.

This is a picture of a path in the woods diverging. When you see two paths, as Yogi Berra said, take 'em. And there are many paths to developing and extending services and supports in the unserved rural areas, and in general, the recommendation is take as many as you need, but be sure that they fit the local values.

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So there are several outreach approaches. I've listed several of them here. They include mentored satellites, branch offices, outreach offices, outstationing, circuit riders, local support groups and contacts, surrogate providers, virtual CILs, cooperatives, community education and awareness programs, and community development strategies. And if you're interested in any of those in particular, don't hesitate. I can get you more detail on those, but I just want to touch on them by saying there are many options.

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From one perspective, rural independent living is community development, a strategy using all of the approaches. Because as independent living shifted its attention from individuals' contribution or factors in disability to the environment's factors, the question is what is the environment? And environment really means communities in which we live, and advocacy to change environments means advocacy to change communities. There are many approaches and tools for community development.

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So the picture here is a beautiful wooden tool chest with hand carving tools for woodwork, and one of the missions ‑‑ just to put in a plug for our program, the research and training center on disability in rural communities, really has as its mission creating tools for building rural communities, tools that people use.

Next slide, please.

Some of the tools that we've developed and demonstrated in rural communities include rural economic development and business creation strategies, led by people with disabilities. Rural transportation programs around the voucher model of transportation. Advocacy strategies for promoting change and accessibility of environment. Self‑employment. And living well with a disability as a health promotion strategy.

I think, next slide.

I think we're at the question and answer period.

>> TIM FUCHS: We are, indeed. For those of you on the phone you can press star pound to indicate you have a question and we'll take those in the order we receive them in the queue and typically we would go to the web questions first, but I don't believe we received any yet. I just want to ‑‑ let me take a moment. I know one person was having trouble listening. While we wait for folks to get into the telephone queue, if you’re having trouble with the volume today, turn up not only your speaker volume, but the main volume on your computer as well. You can find that typically in your control panel or under your settings, and if you still find it frustrating, remember our telephone line is open and toll‑free to callers and audio is usually a little louder there. If you want to try to call into the telephone, that might be a better solution.

Well, a minute has gone by. Let me see. Patricia, do we have anyone waiting with a question on the phone?

>> OPERATOR: It looks like we do have a question. One moment.

>> CALLER: I have a question from slide number 9, advocacy, and to change the community. Is that with the community being willing to change or are we coming in and presenting something that's going to help promote change in the community?

>> TOM SEEKINS: That's an excellent question about strategy and goals. From a rural perspective, I think rural advocacy ‑‑ I'll mention this again in a minute ‑‑ is I think a different approach than the kind of typical advocacy associated with independent living in the larger cities. Historically, advocacy at an urban level has been what is technically referred to as social action advocacy. That typically involves groups of people or organizations who have identified a gap in services or a problem of one sort or another, social institution who isn't achieving its responsibilities. And organizing to try to force those people to do what they are supposed to do. So that's historically, I think, been the image of advocacy. To some extent I think that still takes place. It's gotten much more sophisticated broadly, but if you compare that social action advocacy to the kind of advocacy that works and is most well received in smaller communities, it tends to be much more collaborative, and that's part of the magic of the Concerns Report Method I'm going to describe in a minute. But I think it's fair to say that a lot of the work in rural communities where resources are so thin, there aren't as many people who are in positions of responsibility to provide services other than the people you already know, and it's working with those groups and smaller systems to improve their capacity that I think is the ‑‑ probably one of the most effective advocacy strategies for small towns and rural communities.

>> CALLER: Thank you very much.

>> TOM SEEKINS: Is that kind of what you were asking?

>> CALLER: Yes, sir, thank you very much.

>> TOM SEEKINS: All right.

>> TIM FUCHS: Thank you, Tom. I'm going to go back to the web because we have had a question roll in here. Jan from Morgantown is wondering if you could expand on the circuit rider from your list of approaches on slide 8.

>> TOM SEEKINS: Sure. Circuit rider typically is kind of a model where you've got a central office and have an area that you would serve that is sometimes at a distance, quite a distance, but dense enough in the number of communities that a person could be located at the main office and then drive out and ride a circuit. So that would be one model. So somebody who is living in the main office community, driving out in a circuit. And those can be done in a number of different ways. Some go out and come back to ‑‑ from a point to point. Some ‑‑ I know, for example, the North Central Independent Living Center along the Highline in Montana serves 17 counties that stretch 450 miles. At one point there was a circuit rider in the VR system. They would go out for a week at a time once a month. And make visits in the communities that they served. It's one mechanism. There are advantages to it, especially when there are smaller areas. It's very difficult in larger areas because of the time involved. And the downside of it is that you don't have a permanent presence in the communities you serve. But I'm happy to talk about greater details of any of these, too, later on, as we get into them.

>> TIM FUCHS: Great. Thanks, Tom. Let me go back to the phone and see if anybody's waiting in the queue. Patricia?

>> OPERATOR: And there are no additional questions at this time.

>> TIM FUCHS: Okay. Well, Tom, then quickly, I know we're going to explore these a little more, but we had another question on the web about the surrogate provider. Could you walk through that quickly?

>> TOM SEEKINS: Sure. One of the early IL rural models that had emerged involved working with libraries in small towns to be a center at which information was provided, and the librarians served as an information referral source for people in the local area, and there were materials in the library. So that there wasn't a center that was located in some of the communities that were being served this way. There was no circuit rider. But the CIL worked to orient the librarian who served as a surrogate center and provided some very basic local information, referral and assistance.

>> TIM FUCHS: Okay. Thanks. Cathy baker has ask, Tom, if you might recommend which of these approaches would be most effective for longer distance. She's in a very rural area covering 15 counties in northwest Georgia.

>> TOM SEEKINS: If you haven't started to serve the areas yet, or in a sense if you're in a position where you're considering it, I think the next part of the presentation will begin to address that question.

>> TIM FUCHS: Well said. Thanks. I think our final question for this Q&A break comes from Jeff. Jeff asks a difficult question for everyone at centers. And so I wonder in this context if you may have some advice from your perspective, Tom or Mike, Jeff asks how do you determine the balance of the need of advocacy as your primary focus when you also have the obligations to provide services? Anything in the rural context that you'd like to offer?

>> MIKE MAYER: This is Mike. For our center, the advocacy is from ‑‑ from the beginning has been so much an integral part of our approach to providing services as we went out into the more rural area that was just part of our development from the beginning as opposed to just starting with services and then working into that later.

>> TIM FUCHS: Okay. Thanks. Well, we're going to get back to the presentation now. If you did still have a question and you didn't have time to type it out, don't worry, we're going to break several more times during the presentation. So just hold that thought and we'll take another Q&A break in a few more slides. But I'll go to slide 13. Tom, and turn it back over to you.

>> TOM SEEKINS: Thank you. So the picture here to start with is a Charlie Russell painting called "Bronc to Breakfast." It shows a horse that's got a bee under its saddle at breakfast in a cattle camp and is taking the rider through the fire, and around the camp wagon, the chuckwagon, are a lot of guys just watching and laughing.

So one of the ways to begin to think about using community development strategies is to ponder a little bit about what is a community, and there are generally thought to be ‑‑ or often described three kinds of communities. There are many other perspectives on this, but three that can be helpful to think about, are communities of place, place who live together in a similar place but may or may not have similar interests. There are communities of interest. Many of us are parts of communities of interest, of different interests. Those often transcend place. And the third kind of community is community of relationship or family. Those three all occur within communities of place, which is where we typically do a lot of our work in terms of promoting independent live young.

So independent living emphasizes the environment, and "environment" means community. So community is people who participate in activities in our shared places.

Next slide, please.

So disability concerns in rural America, we have some of the same interests living in small towns as people in large towns, but the difference is the examples are different. So, for example, in a city, there's inconvenient schedules of transportation that are frustrating and troublesome, and in a rural area there's no transportation at all. It doesn't mean that there aren't similar issues to deal with.

Next slide, please.

This slide has several pictures of individuals in different situations, one protesting a civil rights, one group of people digging to work together, and a picture of a small area. In cities, advocacy means those with common interests working together to get others to do the right things. In small towns and rural areas, it means taking often responsibility to get things done for the community.

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Unlike larger cities, formal and informal systems in rural communities are tightly linked. A change in one is likely to affect others. Members of rural communities take their time to consider the many implications of any change. That means they're often seen as conservative, but conservative means protecting the good things that you have in many ways.

Next slide, please.

This is a picture of a small town in a mountain area. Community development involves building partnerships, and you build partnerships by identifying issues of importance around which you can organize together to create an agenda to contribute to a the commune. Agenda formation from a political science perspective is often seen as the single powerful ‑‑ single most powerful political act.

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What are some of the methods that might be used to expand the services of centers around unserved areas? Two principles... there are many paths to any goal and successful change has many parents.

Next slide.

Should I just keep going, Tim?

>> TIM FUCHS: You know, that's not a bad idea. We still have two more Q&A breaks after this one. We got through this quickly and there's nothing in the queue. So we'll break again, and I guess, what, about 10 slides or so.

>> TOM SEEKINS: Okay. Sounds great.

So the next slide, please.

One of the most widely used generic strategies for beginning community development is to conduct community assessments. There are lots of different ways of conducting community assessments. But one of the really productive strategies, one that's been used across different population settings, groups and countries, is called the Concerns Report Method. It actually has much of its genesis from independent living, surprisingly.

Concerns Report Method is an agenda‑building tool that involves by engaging people at the local level and involves local residents in assessing the environment, their community, and building an agenda, a joint agenda, for community improvement. It's been used by low‑income and wealthy neighborhood associations, mental health advocates, school systems and Centers for Independent Living around the world to organize and achieve their goals.

It is a tool that brings people together and begins to build community of interest in community of place. And it is a basic tool that can begin to set an agenda. Again, setting that agenda is a powerful act.

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This is a flowchart that shows how the Concerns Report Method works. I'm going to go through it kind of quickly. On the bottom panel are a series of boxes run young left to right. There's the context of the community, the process of assessment, agenda formation, assessment, planning & commitment, and implementation and monitoring & feedback. So in the center of the slide are ‑‑ or flowchart, on the left is the condition and context involves an unserved community. The Concerns Report Method is used as the assessment tool. The agenda formation occurs in issue identification in the Concerns Report Method. Assessment planning and commitment brings together the evidence‑based tools, local discussion groups and best practices to create local projects to address issues identified by the concerns report that people hold in common.

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So these are the components of the concerns report process. There's a local steering committee. It creates a concerns menu, from which community representatives select issues for a survey. The concerns items are organized into a unique survey format. And I believe I'll show you that in a second. Or talk about it. The concerns items are organized into that format of survey and is widely distributed to involve as many people as possible. This is not a statistical sample. Survey responses are analyze to do identify strength and problems in a community. The highest strengths and problems form an agenda. The community then comes together in a series of focus groups to discuss and create commitment around solutions to problems. The plans are derived from discussions among local citizens. It's widely circulated and presented to build awareness and support for those actions. Projects are implemented, and achievements are noted and momentum builds for more and more.

Next slide, please. A sample of the kind of items that come from a community concerns method survey are listed here. They include... the important places in your community are accessible, your community has enough accessible houses and apartments, you can get where you need to go both in and out of town, you have access to healthcare providers knowledgeable about disability, employers treat you fairly and so on. These are samples that come from menus of the past, but each community creates its own. It's not one‑size‑fits‑all, because rural communities vary tremendously. The steering committee selects somewhere between 25 and 30 items and then community leaders get to select, city/county officials get to select an additional several items, both to make sure that the survey is complete and to increase their interest in seeing the results.

Next slide, please.

This is a slide of the unique form of the survey questions. What I'll point out is that each question has two dimensions asked about it. One is how important is it to you that the important places in your community are accessible. The other is how satisfied are you that the important places in your community are accessible? The combination of these two items allow us to calculate scores that rank order each of the survey items as either a strength or a problem. So if you think about it, an item that has very high importance and high satisfaction is a strength, but strengths are often at risk. So it's important to consider how to protect community strengths and build upon them. If you have an issue that's very important and people are dissatisfied with it, then you've got a problem you need to solve.

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So the survey is distributed widely. You get results. You plan them. And you create a sample meeting agenda on this slide, which lists potential strengths and problems. This becomes the agenda for community discussions. There's a structured way of holding these discussions in which the description of the ‑‑ what it means to experience the problem, what are the aspects of the problem and what are preferred solutions, and as though discussions roll along in community settings, local residents begin to commit to implementing some of those solutions. So just as an example, in this community, a potential strength involved you ‑‑ the community has accessible houses and apartments. It's listed as 89% important, 82% satisfied. On the problem side, the important places in your community are accessible has a rating of 92% importance but 62% satisfied. The discrepancy is big.

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The structure of the conversations in discussing these agenda items is such that it's designed to provide information that directs immediately into a plan. So issues, solutions and responsibility. We want to develop and implement a plan or a program for routine monitoring the public accessibility of the communities in the county might be one of the goals that comes from a discussion group of the agenda we just described. The question then is who's responsible for that? Next column over in this slide are county, city, business, CIL or other. Check marks are indicated in the county, the city and the CIL. Those three groups then work together to create plan for implementing and addressing that problem, and you can go down the list, different committees forming around issues of interest that are shared and interest in places that people live in together.

So next slide, please.

So this is again a picture of people working together to raise a barn, kind of in a rural tradition, and a picture of a mountain town in springtime in the Rockies. I think the summary statement is to ‑‑ both our hope is to help you guys establish independent living in unserved rural areas by giving you tools that will facilitate working together to build sustainable communities for everyone. Thank you.

>> TIM FUCHS: All right. Thank you, Tom. Well, I'll remind the folks on the phone that for this Q&A session if you want to ask a question you can press star pound on your keypad and that will put you in the queue and we'll take those questions in the orders they're received. I'm going to start, though, with two questions that have already rolled in on the webinar. The first comes from Karen. Karen asks, the concerns report sounds like a valuable tool, but, Tom, she is wondering how she can even find consumers in a rural area. Do you have any tips?

>> TOM SEEKINS: That's an excellent question. It depends on the size of the communities you're working in and the degree of its organization. You know, a lot of different programs work within the context of rural communities that we often don't think of, so, for example, one of the ‑‑ one of the organized programs, if you're talking about very rural dispersed populations that you're working in, are the extension service often is in many of those areas and takes information out and works with individuals and kind of tucked away in different communities ‑‑ not even in communities, in open space, and with farmers and ranchers and folks like that.

We have in the past had a program in Montana, it's called the Range Exchange, that we worked through the extension service and the extension people literally had a case that they carried around in their car with them and had worked with them to recognize if individuals in a family they worked with had an individual with a disability, and if they did, could offer information about how to get hooked up to other service systems, and that became part of the agribility program. That's another system that reaches out to a group of people that are often living in some of the more dispersed rural community.

Churches are another good connecting point, and churches are from just a technical perspective, from my view, are a mixed bag. Many rural churches are very small churches and the variety of the theology in those churches range tremendously, and it's important to know which kind of church you're working with, not from a denominational perspective, but from a theological perspective, because about a third of the churches are very ‑‑ smaller churches tend to be very fundamental and do not have a perspective that good works are important, and other churches from the new enlightenment era do have a perspective that good works are important. It's most easy to work through those churches to help either identify individuals within their congregations that may benefit or that could help identify families that are outside of those congregations but could benefit from services.

There are a couple of other institutional kind of connections that have been reported at least in the literature, and that is utility workers are often out in communities and houses in isolated areas if they have electricity or telephone service, there's been some work with them to help identify people with ‑‑ in the literature it was elderly, but could be, I think, easily adapted for that purpose. And similar other strategies. Does that help?

>> TIM FUCHS: I think that's great. I'm going to take one more from the web and then we'll take some ‑‑ Karen says, yes, thank you. So thanks, Tom. I'll take one more from the web and then we'll switch to the phone. So Jeff asks ‑‑ Jeff states first that he's frustrated by funding trend that links population to funding rather than a per‑service cost, and with consumer contact costing so much more in rural areas, he's wondering if you have any tips for addressing the reality of those higher costs of reaching consumers in rural areas when communicating with funders.

>> TOM SEEKINS: I have a couple comments. It's an excellent question. The first one that it made me remember is just really the founding of the country and the creation of the House of Representatives to represent people and the founding of the Senate to represent broader communities, and that is one of the tensions, the enduring tensions, of the United States Senate really protects the area and the House represents the people.

The funding formula issues, the other thing that it made me recall was that in the '90s in particular during a lot of hospital closures people were arguing that it was less expensive to live in rural areas, so we didn't have to reimburse service providers at the same rate and there was actually a structural rate differential built into Medicare where for the same procedure hospitals were reimbursed 50, 60, 70% less. But if you looked at the data, while it is less expensive to live in rural areas, people in rural areas make less, and people in urban areas actually have much greater discretionary income than people in rural areas. So you have really pushed a button of mine. But one strategy that we've been working on for years and was the genesis to some extent for our work in the living well with a disability program is to find niches that are compatible with independent living philosophy but which have built‑in reimbursement mechanisms that CILs might take advantage of it, and one of those that is emerging, and certainly personal assistance services has been a model like that, I think, but one that's emerging that I would really encourage folks to watch for is within the Affordable Care Act, as medicine is really changing, and one of the changes that is going about right now is that the likelihood that hospitals are going to continue to be paid for services is declining. In fact, it's already changing. In the future they're going to be reimbursed for population, at least that's one of the models. And you get a flat fee. So they need to be more efficient and effective in making sure that when people leave the hospital and go home that they're going home to a situation in which they're going to heal and get back to doing what they want to do. But discharge planning has been one of the weakest components, especially to rural areas, from a systems perspective. We believe, and we've got a project that's going to be starting this fall, that independent living, the kinds of things that centers for independent living do, could find a useful reimbursement mechanism in this new age of the Affordable Care Act and trying to do exactly what you already do but in a context that may reimburse you for doing it. And that would ‑‑ rural areas ‑‑ and the reason I'm pointing it out is that rural areas have few resources out there, CILs are one of the resources, they're exactly the kind of resource that's needed for that problem, and there's a demand for it ‑‑ or will be.

>> TIM FUCHS: Great. Thanks, Tom. Let's go to the phones and then we'll come back and address these last couple questions from the webinar. Patricia?

>> OPERATOR: We do have a question on the phone lines. One moment, please.

>> CALLER: Hello.

>> TIM FUCHS: Go ahead.

>> CALLER: Okay. My name is Stan, and I'm calling from Bainbridge, Georgia.

>> TOM SEEKINS: How are you? It's been a while. Great to hear your voice.

>> CALLER: Yours also. I was very ‑‑ I was very thrilled when I heard you.

My question is ‑‑ it's more like a two‑parter. Number one, how do you keep the consumers involved once they receive whatever the service or whatever, which is one of the problems that we've seemed to have, and also how ‑‑ I would like some pointers on being able to keep that open communication thing going due to the fact that our CIL, we are very small and we only have two peer supporters and we cover 11 counties. And the funding issue, as far as being able to travel is kind of tight. So we may ‑‑ well, once we serve a consumer for whatever their goal is, how do you keep them involved? And how can we keep that communication going without the face‑to‑face meetings and stuff? Thank you.

>> TOM SEEKINS: You ask tough questions, always have. I think it's an excellent question. One of my perspectives, and I'm not sure ‑‑ I'm looking at Mike here, too ‑‑ not everybody wants to stay involved and that to some extent a CIL may be achieving its mission when people don't stay involved, but pragmatically there are important reasons to want to have people continue to be involved, and many do want to be involved because they find community of interest, and by organizing events and activities in which people have responsibilities, if they're interested in staying involved, it's more likely that they will. And having a need that someone else ‑‑ if you're helping them, and you have a need that they can help you, one of the more fulfilling things for many people is to help others, and I think not that you don't do this, but having a clear opportunity and a need that they understand may increase the likelihood that they'll help out. So those are my thoughts.

>> TIM FUCHS: All right. Thank you, Tom.

Okay. We have time for just one more quick question on the phone and, again, if we didn't get to you, thank you for your patience and we will break for more questions. Patricia?

>> OPERATOR: And there are no further questions on the phone line.

>> TIM FUCHS: Oh, good. Let me do this, then. We are about to switch over and Mike is going to walk you through his experience with a concerns report at Summit independent living center. Mike, when you talk about the surveys that I know are coming up in a few slides, if you could weave in the mechanics of getting those surveys into the hands of people in the community, that would be fantastic. That was one of the lingering questions we had. I'm going to go ahead to slide 29, and you can continue.

>> MIKE MAYER: Well, thank you, Tim. Again, my name is Mike Mayer. I'm the Executive Director of Summit independent living center. I work in our main office here in Missoula.

Could I have the next slide, please?

Just a bit of an overview of our center to set the context t we serve seven primarily rural counties in Western Montana. It's a little over 19,000 square miles with a total population of 304,000, which is roughly a third of the total of Montana. So we have a couple larger communities. One is Missoula, which is the only metropolitan community in our service area. We probably have about 80,000 population in our area, but in the other seven counties we have a mix of very rural areas with lots of ranches, very small towns of a few hundred people. Up in the north end of our service we have ‑‑ area we have Kalispell, which is a pretty good population base. It's situated right at the base of Glacier National Park so there is a lot of tourism there.

At any rate, our center was founded in 1981 in Missoula, and originally we were department of community Medical Center, which had a rehabilitation program, and still does to this day, but we actually were started as a program there, and in 1988 we separated and have been a standalone center since then.

Over those many years, our original service area was basically the City of Missoula, and over the years we expanded to four counties, the counties in which we currently have our main and branch offices, and then over time to the current seven‑county service area.

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As part of that development, we sought and were awarded some grant funding through the Robert Wood Johnson Foundation's "improving service systems for people with disability" program in 1991. We were one of 12 CILs nationally that participated in that, and it really was aimed at helping CILs develop strategies to ‑‑ particularly through collaborative efforts with other service providers, particularly any of the health system providers, to result in better independent living outcomes for people with disabilities. The grant came in two cycles. One was a one‑year planning grant that was followed by a three‑year implementation phase. It was during the planning grant that we utilized the concerns report to help us pursue a number of the grant objectives, one of which was to set up the branch offices. And prior to this grant, in those outlying three counties of Ravalli, Lake and Flathead, we had staff from our main office traveling out, and in many cases it was only about one trip a month to the communities that were farther away that would involve an overnight, and some of the closer communities we would make a couple of trips a month. But as we really looked at our commitment to the rural area, our board recognized that in order to provide really a meaningful level of service we had needed to contribute more resources there, and we felt that a real advantage to us would be to have an actual branch office in those communities where you have a physical presence, you have a staff member there who is a resident of those local communities. So as part of that, we worked with Tom. He had helped Summit actually a little bit before more my time, used the Concerns Report Method here in Missoula to set an agenda for addressing some initiatives just here in the city.

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We really have that found that it's a great tool to help us get ‑‑ excuse me ‑‑ get a handle on what are the needs that people in the community feel are important, and it really can help you with that information in hand put together some successful ways to meet those needs and expand independent living services.

So going into this, some of the goals that we wanted to come out of this process included: Putting together advocacy efforts that were not our ideas for Missoula, but what did the people in those communities feel were the important issues that needed to be addressed? And through that process it was important that that agenda was driven by them and not by us as an outside group from Missoula.

We wanted to develop some buy‑in and support for the branch offices that were brought online about a year after the Concerns Report Method was done. We wanted to promote some new and expanded independent living services that we had available ‑‑ that we planned to have available through the branch offices.

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Overall our focus with this was to look at ways to improve service systems and independent living options for people in the more rural areas of our service area. Of course, we wanted to make sure that that process was consumer driven and really based on the IL principles of choice and self‑determination and development of community resources.

We really wanted to expand the network of peer advocates, community partners and allies in these areas.

And part of our goals were to develop some financial resources to help support the expansion of these services.

I should say, too, that because we had been doing outreach, as I described earlier, for a number of years, we had an established network to some degree in each county. We also had peer advocates who were local people with disabilities who had gone through a training program and really helped us with our outreach to the communities and a lot of the community awareness and advocacy activities we had been doing on a more limited basis before the branch offices.

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The survey was conducted in 1991. It covered those four counties in western Montana, Missoula, Lake, Ravalli and Flathead. And we used two separate questionnaires, one to get feedback from consumers and a second one to get feedback from service providers.

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Consumer survey... we mailed out 1421 questionnaires. We received 258 that were usable for a return rate of about 18%. Some of the questions that we were really interested in were levels of employment, levels of health and independence, what were the relative strengths in their communities as far as resources that were there to meet needs or opportunities to improve things. We really measured what are the problems and barriers that people identified in their towns. We wanted to get a sense for their knowledge and current use of Summit services and gauge some interest in some of the additional services we hoped to offer as well as their interest in participating in advocacy efforts along with us to address the problem.

Next slide.

The provider survey, we received 84 surveys out of 250 that we mailed, which was a 34% return rate. We wanted to get a sense for what populations they served and the types of services that were available through their agencies to gauge their satisfaction with existing service systems, find the gaps that they recognized. Their interest in partnering with us to address systemic problems. As well as some interest in potentially buying services through our CIL.

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Once we had the survey information in hand, we had the luxury of hiring Tom to help us synthesize all of that into some summary reports. There was kind of a global survey summary that covered all four and then one that was specific to the results for each county. What we did, then, is followed up with a series of town hall meetings in targeted communities and essentially we shared the results and really engaged people in a conversation about what that meant to them and their community and their ideas for addressing the kinds of problems that had clearly been identified as well as some opportunities for advancing things.

We also ‑‑ and this was the next step in our process, really wanted to recruit people who wanted to work together with us to solve some problems.

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In each area we set up what we called a planning and action committee. They were consumer driven. As members, we included consumers, advocates, service providers. We tried to get someone from local city and/or county government, CIL staff and the peer advocates who were already onboard with us. And these committees basically hashed through the results and came up with an agenda specific to each area for systems change initiatives.

They met regularly. Most of them met monthly to put together strategies to further the kinds of things they felt were important. We did a lot of coalition building with other local ‑‑ with some of the agencies as well.

And just to give you an idea of some of the more nuts and bolts things that these committees helped us to do, one was just to identify the best location for our branch office. In some of the counties we have several kind of ‑‑ several small communities, and so just gauging the best place to locate that, both geographically and taking into consideration some of the cultural or other issues that make ‑‑ would make the best fit for our local office.

They really helped us steer and promote and support those offices the first few years of their operation. And in most cases, too, we actually had them ‑‑ a member of these planning and action committees sit in on the interview for the staff members that we hired.

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As Tom mentioned, a lot of the results are very particular to each area, and we found that each county really had a flavor of its own, and so this is just a sample of some of the issues that were tackled. One that was huge was just to improve the accessibility of public facilities. In pretty much all counties we heard loud and clear that access to restaurants, businesses, government offices, was a big problem. We heard a lot about the need to improve enforcement of accessible parking laws. Also ways to expand outdoor recreation opportunities for people with disabilities. One of the reasons people live in Western Montana is we're blessed with lots of opportunities for hiking, fishing, hunting, just getting out and enjoying the outdoors, and, of course, there are a lot of barriers for people with disabilities. So we saw some real opportunities to partner with local groups to advance some recreation opportunities.

Transportation was huge and one of the upcoming slides I kind of step through a procession we used to build a rural transportation program.

Promote rural ‑‑ excuse me ‑‑ affordable and accessible housing. We worked on hospital transition services. And a variety of others over the years.

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Outcomes... probably the biggest thing initially was the significant increase in the number of people we served. It's pretty self‑evident when you have a staff member in a local office 40 hours a week versus someone coming out a day or two a month, there's just so much more opportunity to provide service.

Our three branch offices are still in operation today. That has been painful at times. At one point we had to kind of reorganize our program and we ended up having to lay off some staff in our main office to maintain the commitment to the branch offices because our board again felt it was important if we're truly going to serve people in the rural areas of our service area that we needed to keep the offices open.

Given the timing of when the branch offices opened in 1992, the ADA was being implemented, and so we did a lot of education, training and technical assistance. We did scores of accessibility consultations to help businesses identify and remove barriers. We helped a number of communities step through the Title II self‑evaluations and transition plans that they needed to do. We did a lot of work with both the Forest Service and the state fish, wildlife and parks to improve access of state and federal outdoor recreation sites. An example of that is through the Kalispell office, as I mentioned, it's literally at the doorstep of Glacier National Park, and so the Park Service contracted with us to do an assessment and consultation on ways to make some of their facilities more accessible. One that was a few years in the making but definitely started through our local efforts was an amendment to the state building code statute in 1997 to strengthen enforcement of exterior access. Prior to that time the state building inspectors and local building inspectors didn't enforce anything outside the building door. So, really, that from grass roots level, working in the rural areas to improve access, it became clear that the only way to really address it was a statute change.

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I mentioned earlier that transportation was a high need, and in particularly Ravalli County. That was probably the highest priority that was identified by the local group, and so through that we worked with a variety of people to put together the first Transportation Advisory Committee, which is required for local communities to receive grant funding. There's funding available through federal monies to purchase vehicles as well as to support operations of transit programs, and so I think that was a key outcome because really out of that initial planning and action committee formed this first Transportation Advisory Committee.

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I've kind of outlined a few of the things, the step‑by‑step, that that group worked with to put together a rural transit program. One of the opportunities that was identified through the concerns report process was that the local council on aging had some accessible vehicles, but they didn't really have funding to do anything other than provide rides to their clientele. So we worked with them and some other partners to develop a five‑year transportation plan that was required for grant funding. We put together a grass roots effort and went to the county commissioners to secure funds through provide matching monies that were required. We assisted with writing the grant proposal that started the Bitterroot bus rural transit program, which is still running today. So it's not perfect by any means. It doesn't meet all of the needs, but prior to this process, there was no organized transportation assistance for anyone with a disability other than people who might qualify through the council on aging.

That group has continued over the years to improve funding as well as coordination of services in that county. 20 years later they are still continuing to meet as founding part of this original process.

Next page.

Tips and strategies... as Tom mentioned, there are many paths to solving problems, and there are lots of ways to tailor this report to your unique goals, needs and your service area. In our case where we were really looking at some specific goals with our grant, but very much invested in wanting to bring about local change that was not driven by us but done by people in local areas was the best ‑‑ it was a good thing that we ‑‑ I'm sorry ‑‑ I'm not feeling well here a second. I'm be all right.

One second. I'm sorry.

Starting over here.

Tailor the report to your unique situation. Build on any of the existing contacts that you have in the areas, especially if you have good relations with existing consumers, peer advocates or obviously a good ‑‑ are obviously a good resource. They understand the issues in their areas. Don't forget to include decision‑makers. That's why we included local city and county folks in our work. Tackle problems and issues you have a reasonable chance of accomplishing. That's one of Tom's ‑‑ forever he's ‑‑ part of the strategy he's helped us with is you can't tackle a problem that has no solution and expect to get anywhere. So try to tackle those that you have a reasonable chance of getting done.

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Be prepared to follow through. The process is very labor intensive, can take a long time for change to accomplish. As I'm sure a lot of you have seen in your own experience. Systems change takes a long time.

Each community is different. There are some unique challenges, some unique opportunities, and I think having the local buy‑in for that agenda is critical.

You have to celebrate small victories along the way. It's fun to stop and see the progress, and it's essential to kind of give you that energy to keep working on some of the longer term goals.

And I think it's important to continue to touch base. We still use kind of a slimmed down version of the concerns report every three years as part of our three‑year planning process to get some feedback about needs in each community.

Next slide. I think we're there.

>> TIM FUCHS: We sure are.

>> MIKE MAYER: I apologize. I have not felt well the last half of the presentation.

>> TIM FUCHS: Well, we couldn't day. So sorry you're dealing with that, but nice job, Mike. Let's do the same we did last time. I'll start with some webinar questions that have already come during your presentation, Mike, but I'll remind everyone on the phone you can press star pound on your keypad to indicate you have a question and we'll take those in the order received. First I'll start with the questions from Jan and Dorci. First of all, a common question between the two is if you would be willing to share the survey tools that were developed at your center, Mike?

>> MIKE MAYER: Sure. We could certainly have those as examples. As Tom mentioned, there's a whole menu of survey items that you can use, and he helped us work with the steering committee to craft something that met our unique needs, but by way of an example, yes, we could do that.

>> TIM FUCHS: Great. As a starting point we'll just ‑‑ what you all can put together we'll get into an e‑mail and send out to all of you that are participating together.

Then a little more involved, let's see, Dorci also wanted to know which services do you offer for purchase to providers?

>> MIKE MAYER: We often get reimbursed through voc. rehab for training peer advocates. Tom mentioned living well with a disability classes as well. Those we've had pretty good luck from Medicaid, the home and community‑based service teams, will provide funding for those. Voc. rehab will also pay for some of those classes. And it slowed down a lot. In the early years we generated a fair amount of revenue through doing accessibility consultation work. So there's some of that sporadically, probably two or three paid referrals a year for access work. On the consumer side, it's primarily for training and classes.

>> TIM FUCHS: Okay. Good. Thanks. So Jan again writes with a broad perplexing problem and I'm going to paraphrase. She said that she is struggling to do outreach in all 13 of her rural counties, but she finds that in finding new consumers there's no new money to provide those services. That would result in waiting lists. They really want to be effective in their outreach and reach these new consumers but their concern about their resources. And she asked if you all have any tips to get them out of that cycle, that catch 22?

>> MIKE MAYER: That's a tough one. I think we all struggle with adequate funding to do what we do. Tom, do you have any ‑‑ any silver bullets?

>> TOM SEEKINS: Let me give Mike a minute to think, and I'll offer just a comment that one of the strengths I've always felt of the independent living movement was peer‑to‑peer counseling and that that is not only incredibly effective but can be one of the less expensive kinds of organized efforts you can invest in. That may be one of the strategies, but it's frustrating. It's incredibly frustrating to know how much good could be done with just even a little more, and it always is just out of reach.

>> MIKE MAYER: So obviously the technology now offers some opportunity to do that but in order to do that people need to have access to it, and in our experience, a lot of folks don't have computers. You could certainly do some remote connections between folks, but in some cases you just need the resources to have that face‑to‑face contact with consumers, and it boils down to how far your existing resources stretch. I obviously understand the frustration and the barrier that you run into. We do, too, to some extent still, but not nearly as much as we did in the past.

>> TIM FUCHS: Thanks for the tips. Let's go to the phone. Patricia?

>> OPERATOR: And we do have a question on the phone line. One moment, please.

>> CALLER: This is Roger from pray independent living center in Kansas, and my question is, when you did the initial surveys, how did you determine who you were spending the surveys to in regard to the consumers and then the service providers?

>> MIKE MAYER: A lot of it was based on existing mailing lists that we had, because we had ‑‑ in some communities we had been, as ‑‑ as I described earlier doing the outreach for probably five to seven years. So we had a fairly good network of contacts to begin with. We also at that time were able to obtain the contact information for the folks who had been issued parking permits, accessible parking permits, and so that broadened the scope beyond what we already knew of internally. And then through networking with providers tried to get contact information, too. And that's one of the challenges, is it's a lot easier to communicate with people you're already connected with than it is to get feedback from people who aren't aware of you or haven't used your services yet.

>> TIM FUCHS: All right. Thanks, Mike. Any other questions on the phone?

>> OPERATOR: There are no further questions at this moment.

>> TIM FUCHS: Okay. So, Tom, I'm going to come back to you here. Cathy Baker wants to repose her question now that we've heard the presentation. She's still wondering about those outreach approaches and which ones you think might be most effective for long distances that so many rural centers are facing.

>> TOM SEEKINS: mike's comment about virtual CIL possibility seems like there's some potential in that. I know in Arizona there was one out of Arizona for a while, and it may still be operating to some extent. But my personal sense of rural communities around the country is that if you are part of the community, you're part of the community. If you're coming in from the outside, you may be appreciated, but you're not part of the community. And that in the long run, to see growth and development and the kind of influence that I believe the independent living philosophy really brings with it, you need to be part of the community. You need to be part of the community in the sense that they recognize you when you show up to the schools to talk about transition, to show up at the hospital, to talk about discharge planning, to show up at the nursing home, that you're not there just professionally but you're there because you're part of the community, and that brings a level of trust in small towns that is, I think, just really important to seeing long‑term change.

So if I had my druthers, I'd say that doing something to be there in place. Otherwise, I think it's the case that you're taking another kind of model and trying to figure out how to remain in touch. How do you get there often enough? How often is enough? How can we supplement this? Can people come in to visit us? And so on.

So that's my advice. But it's more expensive.

>> MIKE MAYER: Our experience here at Summit, obviously it was a huge improvement when we were able to set up branch offices, but it's certainly expensive to do that. You have to have the means, and I know that one of the other independent living centers in Montana, instead of having an actual office, they do have a staff person who basically works out of their home, but they are out in the service area so that you have the local presence that Tom was just talking about, plus you don't have the travel back and forth and all the spec sense and difficulty that goes with that long distance. So, I think there's some difference ways to have someone stationed out in the more rural areas, kind of depending on the resources that you have.

>> TIM FUCHS: Okay. Thanks, you all. That's great. So on the web, Matt Peterson from Maine, I believe, said that he missed the bit about the virtual CILs, and he was wondering if you all think that is ‑‑ he says: What are the distinguishing factors of a virtual CIL and do you all think this is a trend, continuing more cloud‑based services and moving away from brick‑and‑mortar type centers? What do you all think?

>> MIKE MAYER: This is Mike. I guess I think a virtual CIL could do a good job of providing information and trying to facilitate connecting people with people in a variety of agencies. I guess I'm skeptical about how affective that is when it comes to the real nuts and bolts of what we do because it really revolves around the relationships we develop with consumers and our work in the communities to address the barriers that are there. So I don't know. I guess ‑‑ I see the usefulness in getting information out, but as far as a way of delivering services, I am doubtful, I guess, about that. Tom?

>> TOM SEEKINS: I'm with Mike.

>> TIM FUCHS: Yeah, here at the national level, I'll chime in, I think the two virtual centers that I'm aware of that you mentioned, Tom, were created some time ago, and so if it's a trend, it's a forthcoming trend. It hasn't happened yet. Okay. That was the end of the questions on the webinar. Is anybody waiting in the phone queue, Patricia?

>> OPERATOR: No, there is no one on the phone queue as well.

>> TIM FUCHS: That's probably appropriate because we're at 4:29 here. So I had gone back to that approaches slide, but let me go back towards the end of the presentation on slide 46 you can see Mike and Tom have been generous enough to provide their contact information. I want to thank you all for doing that. I would also like to offer myself as a point of ‑‑ as a contact. If you all have any questions, whether it be in a few hours or a few weeks, please do feel free to contact me. I'm at Tim@NCIL.org. And feel free to pass along your questions, whether they're about today's presentation or the larger IL NET training program. If I can't answer them or if they're content specific I'll share them with Mike and Tom and get back to you. We'll also make sure we organize the resources that Mike offered to share about the survey tools and get those out to you in a follow‑up e‑mail.

On the next slide you'll see the evaluation. This is a live link. So if you're on the webinar you can click right on this. If you're using the printed PowerPoint today, you can get this live link in the confirmation e‑mail that was sent to you before the call with the connection instructions. Again, when you click on that you'll see it's a very brief survey but we take them very seriously. We really want to know what you thought. So please do fill it out. Again, if you are participated in a group, that's great, but we do ask that you to fill these out individuals so we know what each of you thinks. With that I want to thank all of you for signing up and participating. Don't forget, this will be fully archived on ILRU's web site, including the PowerPoint and captions within 48 hours. And, Mike and Tom, and Tracy behind the scenes, I want to thank each of the three of you for a fantastic presentation and for your time. This has been really helpful. So with that, thanks, everyone. Have a wonderful afternoon. Bye‑bye.