



## Full Participation in Independent Living: Are We Making Progress?

Published by the Research and Training Center on Independent Living (RTC/IL), The University of Kansas, Room 4089 Dole Center, 1000 Sunnyside Avenue, Lawrence, KS 66045-7555, voice: (785) 864-4095, TTY: (785) 864-0706, Fax: (785) 864-5063, email: [RTCIL@ku.edu](mailto:RTCIL@ku.edu)

**November 20, 2002 RIIL Webcast**  
**Presenters: Glen White, Ph.D., and Dot Nary, M.A.**

**LAUREL:** Good afternoon. This is Laurel Richards with ILRU in Houston, and we want to welcome you to a Webcast today on *Full Participation in Independent Living: Are We Making Progress?* We've got exceptional presenters today with Glen White and Dot Nary from the Research and Training Center on Independent Living at Kansas University. We want to extend our appreciation to the National Institute for Disability and Rehabilitation Research for funding this initiative whereby information that is obtained by researchers can be communicated to those of us who are not researchers, but have an interest in the outcomes or have a stake in the findings. This is a project that's jointly operated by those of us at ILRU and our colleagues at the Research and Training Center on Independent Living at Kansas, and we use this as a means of communicating to you all and to all of us who are in independent living and related areas. Today our subject is on full participation, and back in the '80s for about 15 years during the 80's and early 90's, we at ILRU conducted a series of surveys using the delphi method of independent living center directors and we asked what was the most pressing management need and typically we would come up with a final list after a couple of rounds and in the middle of the list there was reaching under served populations. It's always been a concern of people running centers. And today we will have a chance to hear a bit about the approach that the research and training center is using to address this kind of issue. Our presenters are Glen White, who as you know is the director of the Research and Training Center at University of Kansas. Glen, I didn't realize that you had been a founding board member of the center in Rochester, Minnesota.

**GLEN:** Right.

**LAUREL:** When was that?

**GLEN:** We wrote the grant with Dr. David Gray back in 1980.

**LAUREL:** Was that one of the early Title VII funded programs, right?

**GLEN:** Right.

**LAUREL:** One of the first ten?

**GLEN:** I think we were in the first wave but it was a fairly early group.

**LAUREL:** That's a fairly rural area?

**GLEN:** It's pretty rural around the Rochester.

**LAUREL:** You are on the disability forum and I wonder if you'd just take a second and tell us what that is.

**GLEN:** Well, the American Public Health Association is a large organization, probably about 25,000 people, and they have many different sections and divisions dealing with everything with health promotion to immunization, you can name it just about and they have interested groups in those areas, and one of the fairly recent groups in that area of the American public health is in the area of disability. We call it the disability forum, and we think about public health a lot of times, laurel, think more prevention and when you think about disability, I kind of think about their attitude is oops, missed that one. Oops, we missed that one and what we're trying to do is raise the level of awareness that there are 54 million American oops out there, and we have health needs as well. So, we're really trying to raise the bar in awareness about the importance of health promotion for people of all abilities.

**LAUREL:** And so we can kind of keep our eye on — it's called the APHA, isn't it?

**GLEN:** And our group is called the Disability Forum. We're excited about it. We've got some really neat things happening.

**LAUREL:** So we can keep our eye on you for stuff coming out.

**GLEN:** You bet. We're going to be movers and shakers.

**LAUREL:** They finally got a descent chair.

**GLEN:** I suppose.

**LAUREL:** Dot, now you've got a background in independent living center operations.

**DOT:** Yes, I worked at a couple of centers? Upstate New York.

**LAUREL:** I think one of them was in Binghamton. And she knows how to do advocacy the old fashioned way of —

**DOT:** She's been doing it a long time and she's over good at it.

**LAUREL:** How does a person with a strong independent living center services background get involved in research?

**DOT:** Well, I had a lot of interest in health with people with disabilities because I think that is going to be key to people taking advantage to the civil rights against ADA, opportunities to be employed and Glen was doing some work in the area of health promotion of people with disabilities so it was kind of a natural transition. You know I also want to mention that Glen several years ago was the one that pushed the ILs for the American Public Health conference. It

had been difficult to attend, and he really pushed the issue and they probably improved about 100 percent.

**GLEN:** I think filing that federal complaint against them with the Department of Justice kind of helped, don't you think so?

**DOT:** I think it did help tremendously and I think we're paving the way for other young professionals with disabilities to participate.

**LAUREL:** Glen, you filed a complaint?

**GLEN:** Right. We complained many times about being able to fully participate. I don't mind paying my dues which are substantial, but I want to fully participate in the conference like others, and each year they say, yeah, we'll get to it and Chicago was kind of the final straw and

**DOT:** He didn't only file a complaint, he called the Chicago Tribune and they did a front page article during the conference.

**LAUREL:** Glen.

**GLEN:** We didn't want to take any hostages on that one.

**LAUREL:** Here you are 30 years as a researcher in the field, and boy, they haven't got the advocacy out of you yet?

**GLEN:** No, that's for sure.

**LAUREL:** That's just great. You've done everything but go to prison?

**GLEN:** Yeah, I haven't went to prison yet.

**DOT:** We don't have any plans for that, do we?

**LAUREL:** Going to not chain ourself to that bus. So the research and training center has been — the one on full participation and independent living has been in existence since 2000?

**GLEN:** It was funded; we started business here for this research and training center in January 2001.

**DOT:** 2001.

**LAUREL:** So we've got a full year of experience and you've got quite a bit. So I'd like to turn it over to the two of you to give us some information about the r. and t. centers and the projects that have been accomplished to date. For those of you who are participating in this audiocast, as you'll see on the page for this webcast, there are a series of handout materials, excellent, especially the one that provides an overview of the projects to date. Also you'll notice that as we're talking, what we're saying is being captioned. This is realtime captioning, and right

beneath that is a link that says if you have a question, click here. And both Dot and Glen are expecting and hoping for a number of questions. So if at any time you have a question or wish to make a comment, click there. It brings up your e-mail software automatically and it's preaddressed so it will come right to us and we'll — when Glen and Dot get ready, they'll call for questions and we'll present there. And I believe Mark Richards is doing the questioning today and monitoring that part of it. So, guys, I'll turn it over to you all and listen with great interest.

**GLEN:** All right. I'll go ahead and get started. Glen White here. I want to thank Laurel and Mark and the good folks from ILRU for helping set up this webcast in conjunction with the Research Information on Independent Living Project at K.U. here. And this gives us a great pleasure to tell you a little bit about what we're doing. We feel very important to share with our constituent what kind of things we're doing and really invite and welcome questions, concerns, whatever. We want to make sure that whatever we do is above board and that's one of the reasons we're just trying to give a report. Dot and I have done a series of these discussions. We've invited people in from working groups. We've shared little bit of information at the APRIL conference and the NCIL conferences. We want to create this flow of information back and forth. For those of that you are a little bit new to our center, let me tell about you our Research and Training Center on Full Participation in Independent Living. It's one of about 40 Research and Training Centers funded by NIDRR, that's National Institute for Disability and Rehabilitation Research out of Washington, D.C. And our Research and Training Centers address everything from neuromuscular disease to alcohol and drugs, many of them surround issues about rehabilitation. Some of them about independent living, some of you know some of our colleagues at the University of Montana. There is a new Research and Training Center Right now for personal services. So many of these centers are concerned to issue that is are near and dear to our hearts such as consumers and advocates in the independent living field. At our center, we believe that independent living philosophy is important. We have about 50 percent of our management staff have disabilities and we recruit for staff and students with disabilities as well. So we believe it's really important to have people with disabilities in senior management and staff positions. So that's a real personal goal I have as instructor of this center. We're very involved with our constituents in the field. We have subcontracts with NCIL and with the National Council on Independent Living and with the Association of Programs for Rural Independent Living. And on our national advisory board we're well represented with professional scientists and also consumers and advocates with disabilities. So we feel that's really important. Let me just speak a moment to our mission. What is the mission of our center? One of the things we really want to see happen is that people, whether whatever disability they have, maybe it's a more traditional disability like I have, a spinal injury or a more emerging disability such as chronic fatigue syndrome, multiple chemical syndrome or who do we get individuals from these other type disability groups more involved and fully participate nothing society. And Dot and I are going to talk a little bit later on about some of the projects that we're doing in this area to learn more about what are the issues and concerns and from there we can start to develop projects that can do more work in this area to integrate and involve persons from emerging disability populations. So we really feel that's important, and we believe it's important to focus on the environment. We see a lot of barriers in the environment that prevent people from fully participating and also in the person sometimes, their personal competencies that we can develop that can better help us to integrate into society. So we see it really as not just the person or the environment, but really a

person/environment interaction. Some of our values that we believe in, society is enhanced by the leadership of people with disabilities because of their firsthand experience and expertise with disability issues. So we believe that the wisdom of the individual. For us we don't come with the attitude that we're here from the University, we're here to help you. It's really more, we want to come and learn from you, what are some of the issues that are facing you or concerning you that we can help. We believe that consumers as collaborators enrich all areas, and, Laurel, one of the areas that we really believe very strongly in and we preach this and we try to practice it as much as we can is PAR, or participatory action research. And that's really involving consumers, not just merely at the beginning of the five years, having them come in and say this is what we're going to do and at the end say this is what we did. We really want consumers to inform us and to help guide us throughout that five-year project. So we believe today in one sense it's an opportunity to do that, to get feedback from you all. And I want to thank each of that you are listening in today and we really appreciate the time you are spending recognizing that this is important time you could be doing other things as well. We believe that consumers' decision-making should extend beyond personal decisions to involvement and decision-making for design, operation and evaluation of services and in our case research for consumers from diverse cultures, and we also believe that there should be more opportunity for consumers and advocates to really help shape the priorities that NIDRR issues. For us as researchers we're often bound to respond to priorities and Dot will talk a little bit about the priorities in a moment that NIDRR issues, but we want to make sure they don't come just from the feds, but consumers themselves have burning issue that they are really interested in. Our mission for the Research and Training Center is really implemented through multiple research and training activities, hence the name Research and Training Center. We don't just develop a bunch of training activities and not test them. So we believe it's important to the training we're doing to make sure it really works. Otherwise you're kind of disseminating things that may not work and we know there is a lot of that out there. So we really believe that we want to make sure that whatever we do is positive and one of the things I ask as a researcher to each one of my investigators is not only making sure that you have good methodology, that whatever you do, you develop good research, but the question is more importantly in some sense, how not only rigorous, is the research, but how relevant. How will it improve the lives of people with disabilities. I wish I could tell you that every project we do or that NIDRR funds brings about some relevant product or activity for people with disabilities. But I can tell you that my commitment to this research is to make sure that as many of the research projects we have as possible do result in some kind of relevant product that will help improve the lives of people with disabilities, whether we're talking about some kind of a training product, such as increasing advocacy skills, or maybe some type of paper that can be used to influence policy, practices or procedures at the national, state and federal levels. So with that, I think what we're going to do is just give a brief overview and summary of some of our projects and I'll turn it over to Dot Nary and she's going to talk about one of our foundational projects, and that's R1: Independent Living and New Paradigm in Disability for Building Knowledge, Consensus and Action.

**DOT:** Okay, before I do that I'm just going to go over the priorities a bit. When we submit a grant to NIDRR, the National Institute for Disability and Rehabilitation Research, which funds this center, we have to respond to a number of priorities that NIDRR has posted I believe in response to consumer input. They are usually very diverse topics and we have to weave them into applying them to the priorities in the work we do. The priorities for this center, and there

are five of them, but they're very wordy so I won't read them, was to be sure that I had living encompasses diverse communities, people from cultural and ethnic diverse backgrounds, people with different types of disabilities who may not use independent living centers before, and as well as different aspects of the community that people should be able to participate in. So, again, when you do a center like this, you get a lot of very diverse topics to try to weaver together and build something. So when we go through the projects, you'll see how we incorporated issues in the priorities such as building an accessible community, cost effective advocacy, health communication networks, all sorts of things to try to increase the ability of people with did your abilities to live independently in the community. Now I'll go onto project 1. There is some information up on the website for ILRU for RIIL, and I've posted some of the preliminary results of the survey we did that is really the centerpiece of our first research project. The goal was to collect data using a canvas approach, trying to get as much responses as we could from people with the diverse disabilities from all over the U.S. We sat down with leaders in independent living. I think we had 14 people come in who have been involved in independent living as well as from emerging disability groups. We sat down together, and hammered out a series of survey questions using the consumer concerns report method. This is a method of surveying where people respond based on the importance of certain items as well as their satisfaction level. As a result of this meeting, we came out with 48 items in various topics: health care, media, community inclusion, employment, VR services, a number of items, and then we sent this survey out over the web. We had a web accessible survey. We sent paper copies to those who might not have access to the web or couldn't use the computer, as well as some e-mail copies to people with visual impairments. We got back over 1300 responses, and I guess if I were to summarize the core of what we have learned so far, and we only have preliminary data we have more analysis to do, I would paraphrase it and say the most important thing to people is employment, employment, and employment. Because when I look at the top ten problems out of 48 problems or issues that people identified, almost every group chose an employment issue as the top first and second issue. So we have data on the top problems that people identified from the entire group responses and we broke it down for several specific disability groups, those with asthma, hose with blindness and visual impairment, those with chronic fatigue syndrome, learning disabilities, multiple chemical sensitive advertise, polio and these were the groups who responded in the highest numbers to the survey, but with only one exception, the top priority for all of these groups was a question that read: employment, it's an employment topic. You can earn enough in salary and benefits in your employment to meet your living needs. So very clearly, people are identifying employment and access to resources as a primary issue.

The second most frequent response was you are given the same opportunities as nondisabled job applicants. So again, whether it's someone with asthma, a learning disability, multiple chemical sensitivities or psychiatric survivor, the key issue seems to be employment. Other issue that is came up very frequently were issues using the VR system, in particular the service you receive or have received from the state vocational rehab agency help you get the job or training you wanted. And again, I'm listing the problems. These issues were rated very high in importance and very low in satisfaction. So these are the issues people are most concerned about and perceive as problems. Other topics that came up were assistive technology, there were three issue in assistive technology. One was that the policies and practices related to purchase, repair and replacement of assistive technology devices are reasonable and allow for timely access to equipment. Additionally, questions about health care affordability and access, and the media.

One question that came up in the top ten was the media identifies you in a fair and accurate manner. So from this data, and we still have more to do, we're learning that for people with a variety of diverse types of disabilities, employment is a huge issue. We have more to do to analyze the data for different ethnics and cultural groups, which should also be interesting, but I thought that focus on employment was an important thing to mention. Glen, do you want to go to study 2?

**GLEN:** Do you want to talk about the strengths?

**DOT:** I can give you a little bit of information here. We found that for most — for many of the groups, strengths were listed in terms of voting. For most people, voting and accessibility seems to be something they're happy about that enough changes have been made. Consumer control — there are couple of items on that came out pretty high on strengths. You make your own decisions about your live and you pursue your own goals with or without help and parenting that people feel respected as parents. So not that there aren't any issues around that, but fewer than some of the other issues as employment. The media one comes up fairly frequently, and community inclusion. Again, you and your family are accepted as members of the community. That came up in the top ten strengths several times. Seems like we've dealt with some of the basic issues, but access to resources through employment seems to be a really big issue, and we know that, but it's for very diverse groups of people with disabilities.

**GLEN:** Maybe, Dot, talk not so much technically but how we tried to broadcast and disseminate this survey to folks.

**DOT:** Well, again, we had folks come in from both APRIL, NCIL and other emerging disability groups to come in to help us put the survey together and it's part of the plan for that type of survey work. Then we disseminated — ILRU was kind enough to send it out for us on their e-mail list which is very comprehensive. We got calls from individual centers wanting to distribute paper copies. We got calls from other types of disability organizations for people with multiple chemical or electrical sensitive it's, many of them called and asked that a paper copy be sent to them because a lot of these folks can't sit in front of a computer screen or be near a printer because of the chemicals involved. So I would say we sent out maybe 100 or more individual surveys to people who called to get them. We also went onto various disability list serves. We sent them to support groups all over the country. I believe we have responses from just about every one of the 50 states with a wide range of disabilities. So I think it was pretty comprehensive. I think we did good at reaching out to groups. We had some issues. We didn't realize that the original version on the web was not accessible to screen readers the way it should have been, so we developed an e-mail copy that folks said worked really well and we did get a good response from people with blindness and visual impairments.

**GLEN:** And we had it also translated into Spanish as well.

**DOT:** We did, yeah.

**GLEN:** All right, thank you. I want to go ahead then and give folks a heads up. I'm going to talk a little bit about the second project, and this is kind of a companion. On the first project we

did more of looking at a large broadcast survey that Dot briefly described and the results of this again will be posted more completely on our website. And Laurel, for our audience, that's [www.rtcfpil.org](http://www.rtcfpil.org) and you can post that up later.

**LAUREL:** We will. We'll put it on the discussion forum as well.

**GLEN:** We'll allow for people to give us continuous comments on that as well.

**LAUREL:** Good.

**GLEN:** Laurel, we're going to talk a little bit more about the second project here, which was conducted by Bonnie O'Day is a very strong advocate, recently involved with the National Council on Disability. I want to give a brief synopsis of her project and then we'll stop for a little and allow for questions and answered.

**LAUREL:** Okay.

**GLEN:** The purpose of Bonnie's project was to solicit views of key disability leaders to try to better establish advocacy issue that is are most relevant for this emerging area we're in. We tried to target people who are members of minority groups as well as those not involved with the agenda setting process within the disability community. And she conducted 16 30-minute interviews and they were audio taped and transcribed and coded to try to find out the key issues or concerns that people had, and I'm going to give you just a brief summary of that. Some of her findings, and you'll probably see a little bit of a resonance with some of her findings with some of the findings that dot just reported. We want to look for those things. We call it convergent validity if you see some things coming together that it means we're going in the right direction. Some of the findings are in health care the critical — and she has some "from people that she kind of pulled out like health care. The critical features that some people can get it and some people can't and many of us in the disability community know how important it is, especially in terms of the managed care and just tightening of health care all in general. Employment was another big ill in her findings and one of the "was in spite of everything I did, everything the rest of us did, we couldn't get people to take the leap of faith to go off to work and start to pursue the American dream. Here we are in 2002 and we have lots of people with disabilities not pursuing the American dream. The point was that many of them were wanting to do so but were not able to do so. Technology was another area. This is another quote from one of her informants, the kinds of technology that they are developing in the workplace and the school site and how people learn and transportation, all of these things could have the effect of broadening opportunities for people with disabilities or the exact opposite of hemming them in further. Long-term care was another issue that several of her people had brought up that she interviewed. One of them, this is a person with cerebral palsy that responded, and this person said a lot of people with cp feel that they can do it themselves, perhaps this opinion about being independent has been carried to an extreme. Very often, people with cp are reluctant to use personal assistants in the work place in a competitive environment in order to succeed, there are times and places where personal assistants are required. And I think that's something that we are all facing, especially as we age. I don't know the rest of you in the audience, but I know I'm getting older and thinking about maybe what am I going to need five years from now, ten years from now and

I don't know if any of you are asking the same questions, but those are certainly important issues and we think about long-term care. Is it going to be there for us? And is it going to be there in the way we need it, whether, good lord forbid, we go to a nursing home, or if we are blessed enough to live out in the community and have our own personal assistants. One other point that was brought up by some of their key informants was the issue of civil rights enforcement and I know this will bring a bell for many of us. Part it was a concern of universal design, which is a good thing, but some people think if we have these new wheelchairs that many of you may be familiar with this, the "I bought wheelchair that goes upstairs," people think why do we need ramps or why do we need elevators if we have these chairs? Another concern was erosion of ADA protection. There was a concern that we need stronger federal enforcement and implementation at the local level. So those are kind of issues that I think are real important. Just overall discussion points that Bonnie had for her research. There was agreement about the most important issues only in the broadest sense so there was a lot of kind of variety in maybe how people saw each of these broad points, but they had some kind of agreement on it. Within each issue informants emphasized aspects of the issue and I don't have the information here that gives you real specificity on that, but Bonnie is going to complete a full report on this and you'll have access on our website. There was more rising around a research agenda. There was significant agreement about advocacy strategies to advance the agenda, and one of the other ones which I thought was kind of interesting, key informants felt that research could be a significant component in advancing the advocacy agenda. And I know that. I hadn't been in the independent living movement long before I became a researcher that sometimes there is a distress or sometimes researchers or research may not always be a good thing, and I'm learning more — obviously I'm somewhat biased but I feel research can be helpful and one of our goals is how can we use research and how can you as advocates use research to leverage advocacy efforts. Whether we're talking about finding data to support a position that you have or data to refute your opponent's position. Both of those are very important, and one of the things we're trying to do and we would really love, sincerely love to hear from you all, about what kinds of things you need in the field. We're really sensing that people don't want long monographs that is go on and on. They want fact sheets or rehab briefs, things that can give them information that they can take and use to either write reports or use to convince the legislators. So those kind of things we really need feedback on because we want to turn a lot of the materials we have into training products that are helpful for you. Laurel and Mark, I think I'm going to stop there for few moments and just allow for our colleagues in the audience to provide some questions.

**LAUREL:** Okay.

**MARK:** Laurel, should go?

**LAUREL:** Please.

**MARK:** I've got greetings for all three of you from a man named Mitchell. Having been involved in public health for many years as a volunteer in different capacities, my congratulations to you for your fight and advocacy work. Keep up the fight. I look forward to joining you all in this in the future and he has two questions: he wants to know your views or the views of the participants on funding availability at the time?

**DOT:** Could you repeat that last part, Mark?

**MARK:** My main interest here is to say hello to every one here and find out the views of you two on funding availability in the future.

**DOT:** Funding for — did he say what?

**MARK:** No, he did not. I assume — no, he didn't. I assume he means some of these projects?

**GLEN:** I can speak a little bit, if I can, mark. A couple of thoughts: NIDRR — only a few players that I call them really that I think are funding anything that deals with the environment, we know that N. I. H. who probably gets one of the largest budgets does a lot of their work on cure, and for us really living the independent living dream, you know, cure is good, but not everybody is going to get the cure. We're not going to get the cure in our lifetime. So the point is what do we do for those that are left in trying to live our lives. So we need something else. And we need research focused on the environment. How can we make the environment more accommodating or policies or laws or whatever? There is some good news I think in NIDRR. I think the director of NIDRR comes from the independent living movement. I think he is compelled to do nor in that area of independent living. Lex Frieden, myself, David Gray and folks from St. Louis had talked to Steve recently about the RTC on PAS, personal assistant services, and it was originally funded at \$600,000 dollars or 650, something like that, and we were able to persuade them to get it up to 900,000 dollars. So there's a \$300,000 dollar jump a year. So we see some positive things moving there in the independent living at NIDRR. I think the Center for Disease Control is starting to do things in this area as we'll specially in health promotions for people with disabilities. Another area that people might want to consider seriously is the Paralyzed Veterans of America has a small training program and a research program and that's worth a look. Dot, do you have other thoughts?

**DOT:** No, I think you covered it. That's good.

**MARK:** I don't know if this is a question or just a statement from Mitchell, but he said I would like to talk and or chat with a representative from NIDRR and learn more about technology transfer for people with disabilities, specifically I would like to learn what types of scientific endeavors are underway and/or planned currently.

**GLEN:** Okay.

**DOT:** I think there is an RTC on Technology Transfer. I think at the University of Buffalo.

**LAUREL:** There are at least three of the NIDRR-funded — is it access?

**DOT:** RERC.

**LAUREL:** The thing on Technology for Independence. There is a group in Boston. I think Patricia Yeager and the California Foundation has one and, Glen, who is the third? I lost it.

**DOT:** Maybe if we could think of some of these we can post it later. One good thing would be to go to the NIDRR website and scroll through the centers.

**GLEN:** Dot, maybe the John Westbrook Center for Dissemination as well.

**DOT:** Right.

**LAUREL:** And NIDRR.

**GLEN:** Laurel, we could maybe post that.

**LAUREL:** Yeah. What about NIDRR's long-range plan? Might that be a source of the long term interest in technology or the direction?

**GLEN:** Yeah, that's true. The NIDRR long-range plan is one area one could look at. I think we have to face the fact that we're in this era of the economic melt down of our country here and I know that we have to make sure that we do keep funding high in research and services to be frank with you. We know that within our own state of Kansas there is also a real cut back on services so we have to advocate as well as far as research.

**LAUREL:** Good.

**MARK:** I have a couple more questions. One is something that you've already mentioned and I'd like to bring that up now. Substance abuse prevention and treatment programs continue to be some of the least accessible environments in the U.S. for persons with disabilities. Considering your comments about persons can disabilities becoming more active in society, and concerns about substance abuse among persons with disabilities, should CILs consider substance abuse programs as one of the services available to consumers?

**DOT:** I think that's a good point. I don't think CILs consider it a service, but I'm sure it comes under information referral and I think the caller is correct, the accessibility issues are huge, and I don't — I think there is work toward them, but I think there is still many, many barriers. There is a Research and Training Center on Substance Abuse Services and Treatment, and that is in Ohio, and that also — the address — I'm sure they have a website that could be gained at the NIDRR

**GLEN:** Dennis Moore is the director of that center.

**DOT:** But I think self-medication to address all the barriers that we are constantly reaffirming, despite some progress I think that is a big issue.

**GLEN:** Dot, maybe — one thing I'd like to just — if you're not familiar, is every ten years the United States puts out some objectives called Healthy People Objectives and they put them out in 2000 and in 2010 we have some now. The last set of Healthy People Objectives did not have anything in there regarding health for people with disabilities, very little.

**DOT:** That was the 2000 version.

**GLEN:** This most recent one we had input into it and there is a whole chapter dealing with issues regarding secondary conditions and health promotion and everything else for people with disabilities.

**DOT:** We could put the website up and I'll be honest, I'm not sure there are any on substance abuse and prevention.

**GLEN:** I believe there is one in there on increasing ADA access to these facilities. And so that's one of the Healthy People Objectives. I know we've discussed this and talked about it because trying to find treatment, especially for people who it's not accessible and there has been a lot of horror stories, many of you have probably heard of them where people have been denied treatment because they can't get access or some silly rule or procedure that the organization has where they've been denied services.

**DOT:** I think it's also an issue in terms of cultural appropriateness for those types of services.

**LAUREL:** Good point.

**GLEN:** These are great questions, everybody.

**MARK:** I have a couple more, but it's something we haven't discussed yet and I'd like to hold them.

**LAUREL:** Mark, I've got one. I've got a couple of questions on the handout, especially for the first project, R1, and, Dot, I was recording the categories of people from — or categories of disabilities from which you received the most survey returns, and I was surprised on the employment issue of employment being a problem. So many of these disability groups have invisible disabilities.

**DOT:** Right.

**LAUREL:** I just was surprised that they, too, found barriers to employment even with an invisible disability.

**DOT:** Which ones are you thinking of in particular?

**LAUREL:** Asthma or even multiple chemical sensitivity.

**DOT:** I think there are a lot of issues about toxins in the working place. Some people with multiple chemical sensitivities, they can't be near somebody who has perfume on. And I also wonder if there aren't issues around health insurance and employers not wanting to employ someone who may make their insurance rates go up. I mean those are things that would be almost impossible to prove, but let's face it, health care costs are going up.

**LAUREL:** It is striking though that — I mean, we hear of people with visible disabilities having perhaps some discrimination or lack very enthusiasm in hiring, but I don't know if there is misery loves company, but the fact that folks with psychiatric disabilities or learning disabilities that aren't necessarily obvious in the interview process are encountering problems.

**DOT:** I think it's also interesting that out of the 1300 plus survey respondents, 55 percent have three or more disabilities or chronic conditions.

**LAUREL:** Yeah.

**DOT:** So it might not be just the one disability, it might be the interaction on issue that is people have to deal with on a daily basis.

**LAUREL:** And on the other observation you made about employment, out of Bonnie's study, an individual commenting on the fact that the individual with a disability sometimes found it a great — somewhat threatening to leave the safety to become employed. And I guess that's an issue of self-esteem and empower.

**DOT:** I think it is also giving up benefits. That's scary. We know that system is often difficult to navigate in and out of.

**LAUREL:** Extremely difficult. One last one before we move on. You had down here on question no. 48 regarding the services you receive or have received from a center, help you to live more independently. I didn't quite understand how it was ranked?

**DOT:** Sure. For the whole group of respondents, which means people with all different types of disabilities that on the scale of issues, 1 to 48, we determined the top ten problems.

**LAUREL:** Yeah.

**DOT:** And it was the difference between the ratio of importance and satisfaction. So if there was a big difference, we figured that was a problem because they're saying it's important but I'm not satisfied. The bottom ten we figured were more like strengths because they were saying it's high in importance, but I'm very satisfied. The one question 48, which addressed independent living services, that fell someone in the middle but closer to the strengths.

**GLEN:** It was like No. 13.

**DOT:** It was the 15th lowest, so it didn't get into the top. It was five above that. So just to say it didn't fall in either very high or very low, but there certainly wasn't total satisfaction, but it seems like some people are accessing the services and really appreciating it.

**LAUREL:** Good.

**GLEN:** I think a comparison VR fell much lower.

**DOT:** Yeah, that came in as a top problem for a lot of groups.

**LAUREL:** Really. We don't want to draw too big attention to that, but everybody can raise their hands as to whether it's perceived

**DOT:** Let me read you the two questions that came in the top 10, the service you received or have received from the state vocational rehab agency helped you get the job or training you wanted, and that was rated fairly low in satisfaction. Another one was you have the services and support you need to obtain and succeed in employment.

**LAUREL:** And that's also low in satisfaction?

**DOT:** Yes. High in importance and low in satisfaction. So a lot of employment related questions were rated highly as problems.

**LAUREL:** This is important documentation of what we assumed was a fact. Good.

**MARK:** If I can interject, I've got one more question. In your latest R.1 and R. 2 findings, do you see any difference from earlier study priorities? For example, adequate funds still seems to be a high priority to live independently, although improvements have been made in areas such as transportation or accessibility.

**DOT:** I would say our results are similar to the results of other studies such as the Harris Polls that really, I think, emphasize that resource is still a huge issue for people with disabilities or access to resource. Is that what you're asking? Does that make sense?

**MARK:** Well, I assume it is, yes.

**LAUREL:** Glen, do the findings that you all have preliminarily, are they congruent with studies that you conducted sometime earlier in your 30 years?

**GLEN:** If you compare these to — I guess one thing we have to do or I don't want to just throw off the top of my head, yeah, they are. It would be nice. We've got a database of about 20,000 different responses to the concerns report method survey, and we've done these are a number — over 20 different states. It would be interesting to do a comparison analysis because we have a baseline of what things were and we can go back and look at those, what things have changed and my sense is that employment obviously is still a very, very high issue.

**LAUREL:** I think that would be real interesting, Glen. And it's almost a longitudinal kind of thing. It would be real nice.

**DOT:** Yeah.

**GLEN:** I think the beauty of these questions — to a certain degree they're going to change a little bit. If you don't ask the right questions you're not going to get the right answers. That's why we brought people in to help us identify what are the questions that need to be asked, other wise,

you just bring in a hired gun and say what are the questions we need to ask. We wanted to make sure whether they were consumer based.

**DOT:** One of the good points is there seemed to be very high expectations on the part of people with disabilities that they can and should be employed.

**LAUREL:** Now, that's encouraging.

**DOT:** People have not given up the dream that you can have a live. We have ADA, we have IDEA and other legislation. We should be able to work.

**LAUREL:** I like that sense of — that's excellent. That's a great mental attitude.

**GLEN:** One thing that has come out on that on the first survey, but on one of the strengths laurel, a couple of things I noticed, I think it really puts an exclamation point to what we've been trying to do with the philosophy of independent living and one of the things I think that people are able to articulate more and they feel more satisfied with is the issue of being able to take control of their own lives and make their own decisions. Those are some things I saw came up that didn't come up in earlier surveys. Some people may not be able to do everything they want to do, but they have more of a sense that they can make their own decisions or at least the sense of empower. That they can do that.

**LAUREL:** Isn't that marvelous.

**GLEN:** I think that really speaks to some of the things we're doing in the movement.

**LAUREL:** I think so.

**GLEN:** Mark, should we move on then to? We've got a little bit more business to do on these others.

**MARK:** That's great.

**GLEN:** Let me go over R3 and the purpose of this project, ladies and gentlemen, was really to try to find out what do we know about – we know some things about people with more traditional disabilities, what do we know about the emerging disability populations. I think indicate had coined this term, emerging disabilities populations. So a colleague, Mike Fox, not to be confused with the guy on TV, he set about doing three different projects to try to find out more about these people with emerging disabilities. And one of the things he did was a focus group on the number of people with varying types of disabilities and he looked also at a population based survey called MEPS. And again, these are individuals like with chronic fatigue syndrome, multiple chemical sensitivity syndrome and so forth. I'm just going to give some very brief summaries from that aped know this is going to be kind of superficial, but again, a lot of this is posted on our website. Can you find out more information on this, ladies and gentlemen? From the large population based survey that he analyzed, this MEPS, he found that people with emerging disabilities tended to have some different characteristics than those that we might

consider traditional disabilities and some of these points he found they had little less education, greater difficulties with activities of daily living, may be insured more frequently with Medicaid, indicating lower income, have less private insurance. They may see dock force for medical care more frequently and are much less likely to be working. From focus groups and consumer interviews, these are some of the points that he found, that some of the people with — maybe in certain populations tend to have more problems with medical acceptance. For example, some disabling conditions may not be very easily confirmable with a diagnosis. Doctors may think they're malingerers or making things up when they may have a valid problem or issue. They may have difficulty inaccurately diagnosing the problem. Some of these individuals reported they felt kind of invisible in society and I wonder if they don't feel invisible in the disability community. Certainly when we were talking with a lot of key leaders on the R1 disability survey that we were working on, just the philosophical discussion on disabilities, a lot of us believe in disability pride and disability culture, if you have someone on the other side of the table, they may not recognize themselves as disabled. So there are some things philosophically that we have to kind of discuss and learn from each other, i.e, those with permanent disabilities and those with chronic conditions. Some of these individuals in the focus groups have a fear of productive lives. Some reported pain as an underlying issue or problem, self-recognition needs to broader understanding, many of them felt that was kind of an issue. So this is just kind of some brief findings from the large demographic survey and then the focus groups. Now, Dr. Fox did one other thing. He looked at legal opinions and summaries from circuit court cases, test thing limits of the ADA and he was looking at each of the different circuit districts and trying to find out, who were filing the cases and what were the cases. My sense is another way to kind of test participation of the emerging community and here is some of his findings on these court cases. Injuries are dominant test case followed by cognitive and behavioral problems. They may not be the best measure because of the unique nature of each case. Among chronic disease test cases, there appears to be a geographic advantage to plaintiffs in the 6th and 10th districts. And these include the districts of Michigan, Ohio, et al, and Kansas, Colorado, et al. I wonder if the take home point is if you're going to file go to the 6<sup>th</sup> and 10th district. Emerging disabilities cannot be accurately defined and it is suggested that they are very difficult to accurately measure at the present time. If you sit in a room full of scientists, my colleagues here, a lot of them have a hard time defining what the heck a disability is and what is an impairment. So it's still kind of a challenge. I think each of us have a pretty good idea what we think it is. Another issue, service providers, both medical and social, appear reluctant to extend services to people with disabilities. They have difficulty categorizing because a lot of service people want to put somebody in a category, and we know that perhaps some individuals from more emerging disabilities may not have a special category or pigeonhole you can put them in. Finally, one of his findings was a societal understanding of poorly defined disabilities appears dependent upon expanded peer support, social action, clinical acceptance and legal protection. Now, one of the questions I think, Dot, remembering back — and I don't have the survey before he, but one of them was how supportive are you for advocacy actions, something like that.

**DOT:** I have that right here. How important is it that you work with — you work with others for the rights of people with all types of disabilities, chronic health conditions.

**GLEN:** Do you have the responses on that a letter all?

**DOT:** Yeah, I might. Let me check. Keep talking.

**GLEN:** Anyway, one of the things we found — we wanted to know how — the questions we asked in that r. 1 survey, we want to make sure it wasn't what do you think about other people, it was really asking what do you think or what do you do? We really wanted their own personal response and my sense is that the findings of that is that a lot of people felt it was important they're supportive of those kind of advocacy actions. So to me, no matter what I'm hoping no matter what disability group you may be from, you really want to be engaged in that process.

**DOT:** I'm looking at a few of the resulting and no. 4 came out as a strength, and it actually came up as the top strength for folks with psychiatric — people who are psychiatric survivors or have mental illness.

**LAUREL:** Meaning they feel it's important for themselves to support —

**DOT:** They feel it's not only important, but they feel it's one of the strengths versus one of the problems in their lives is that they work with others with disabilities.

**GLEN:** I mean I think that's cool. You would think in this day and age we'd all be on the same page, but I think it's saying more and more people with disabilities recognize that there is power in strength.

**DOT:** It also is in the — well, the top ten strengths for people with learning disabilities and folks with polio.

**GLEN:** Okay, that kind of finishes the report there for the R3. Maybe Dot if you want to talk about the R4 and 5.

**DOT:** We don't have data from these but to let you know what's on tap or might be covered in future webcasts. Project 4 and 5 was combined. The topic is to identify strategies to promote accessible cost effective advocacy and generic community services. And since this got started, the ticket to work was just coming into play and looked like it would be a major way for people to access employment. These two projects were combined and if goal is to look very carefully at workforce development centers and one stop centers to see how these are working for people with disabilities. So they've done a series of focus groups, both with users of these centers and with staff, to see how integrating employment services for people with disabilities with those of the general population will work and will it work for people with disabilities? Will there be enough knowledge about the accessibility issues and accommodations that it will work well. So that's one — do you want to add anything to that, Glen?

**GLEN:** No, not really.

**DOT:** Again, these have not produced findings yet, but there certainly will be some soon. Did you want to review R6?

**GLEN:** Yeah. Maybe what we'll do — maybe take the next couple and then we'll stop for questions or how do you want to do that? Should we go through the remaining?

**DOT:** I think they'll be pretty quick because we're going to describe them.

**GLEN:** Let's do that. R6 is one done by a colleague, did have David Gray out of Washington University. David is quadriplegic gentleman and helped to actually start the independent living center for Minnesota with me in the early 80's. He was a former director of NIDRR. And he's done a lot to help us. But did goal of the project is to really study how the participation in life activities is influenced by the environment factors and one of the things he's really looking at is we think about people who use personal assistant services, how does that help increase their access to participation in the environment? Many of us are going to agree that PAS is an important thing and want to know, how does it really help us to be more engaged in the environment. And he did interviews with I believe over 50 people — 50 to 60 people, and I'm going to share with you just some brief findings. He did an initial interview with 50 people and presently has 30 that completed second interviews. A majority of these were women and many were African American and this was working with Paraquad out of St. Louis. So the services through Paraquad are reimbursed through Medicaid. Some of the findings David found were that 66 percent of the participants indicated an annual household income of less than \$10,000. And 90 percent indicated having — receiving personal assistant services was very important, and the majority interviewed were females. I mentioned 69 percent and African American, 72 percent. Participants receiving service had a wide range of different disabilities with a large disability group receiving services of people with stroke, at 10.9 percent. And the age range was between 18 and 77 and the mean was about 55. 35 percent of the participants replied they had little or no choice in the personal assistant services they were currently receiving. Over 35 percent were dissatisfied with the service they were receiving. 53 percent required 30 or more hours a week in attendant services, and about 47 percent said that their family members were providing over 30 hours of unpaid services per week. So sometimes if you're getting service from family members, you're in an awkward position as many may recognize. Dot and I have had these conversations and if your mom is not providing good services it's kind of hard to fire her. Kind of hard to fire your mom. They went back and six months later and showed personal assistant services information after receiving services from pair a quad. So that first survey was before they served them and was a baseline. After they started receiving services from Paraquad, and some of them talked about employing relatives as their attendants. They still reported it being very important, 89 percent. I think that was up from — it was at 89 percent versus 90 percent. After receiving pas for six months, 82 percent reported having a lot of choices in services they were receiving. So that choice went up quite a bit. And the percentage participants reporting that they were either somewhat satisfied or very satisfied with their services was somewhat similar between the first and second visits. Prior to services, 64 percent and after receiving service it went up to 75 percent. So they are still tracking that to see the effects of those services. In discussions with colleagues, one of the things we really want to be careful with is we look at these services, how the outcomes in that really affect MICASA. We want to make sure the results of the report will have as positive an effect on policy as we can. But that's an area that we're still looking at and will be following for the next couple of years. Dot, I'm going to turn it over to you.

**DOT:** Okay, when I talked about project 4/5, the one on cost effective advocacy and generic community service, I forgot to mention that Daryl Mellard here at Kansas is the investigator on that one and I basically I think their preliminary data so is that they're not sure that people with significant disabilities are really going to be integrated into the service system which is more generic and not specifically focused on disability so there may be some issues around that. Project 7 in this center is a project on understanding health and wellness needs and investigating communication networks of people with disabilities from ethnic and racial minorities. We know in the general population that there is health disparities between majority and minority cultures. So in people with disabilities who come from minority backgrounds or people of color, those health disparities are more pronounced, and this project will look at ways that people access wellness and health promotion information and whether, for example, their primary care providers refer them for things like mammograms and other preventive services. So that should yield some good data and they're actually putting together a model health services guide for the community that could be replicated in other areas. And not much else other data on that one but good things coming. Glen, how about R8?

**GLEN:** This is done by a colleague up in University of Illinois at Chicago, Hispanic gentleman who name is Fabricio Balcazar and this is called taking it to the seats. Seeking to improve accessibility and participation in their communities. He's going to be working in conjunction with Access Living in Chicago, and they're working with — they will be working starting the first of the year with some African Americans and Latino adults with disabilities, and the idea is they wanted to do some training to teach these individuals to have contact with ADA compliance in minority communities. So they're going to be taught how to file formal complaints with federal or local authorities and they're going to go out and do assessments on businesses and African American and Hispanic business communities and give them feedback how to make their buildings more accessible and we'll also teach them how to file complaints if they're not making them accessible. And they're going to replicate that later other in Miami and Washington DC. The goal is to increase awareness and knowledge of ADA public accommodations among people from minority cultures and really help promote that. So we're real excited about that trying to reach out to another population that may be in centers are continually trying to seek and reach out to. So that's just — and we'll be hearing more about that in the future. Fabricio is really excited about that and we'll see some wonderful things as a result of that one. Dot, you want to take R0.

**DOT:** The last project is titled development and evaluation of a community disability planning method for American Indian Tribal Concerns Report. So this is to use the same methods that we used in the R1 study that we gave data from a short time ago in the Native American community, and basically it will be geared toward issues that that community of people, from a variety of reservations and communities feel is important to them. So it will be a similar survey, but probably with different items to reflect their interests and that project is being pursued by Dr. Tom Seekins up at the University of Montana who is a special lift in rural issues so that background would help also. I should also mention that the previous project I described on health and wellness from people with minority cultures, that's being conducted by Dr. Katherine Froehlich here at the University of Kansas. We cover a variety of areas and really look at those emerging disability issues including different cultures of people who often haven't accessed independent living services but could certainly benefit from them.

**GLEN:** One of the things that each of these projects have, ladies and gentlemen, is we really make a concentrated effort to get consumers with disabilities involved in advising us and sharing with us and helping us shape the goals of the project and the procedures and helping us to understand what the outcomes are, and also dissemination. So we feel that's really important and if any of you have interest or want to know more about things we're doing in the future, we really welcome your input and interest. So we're real excited about that. So, Mark, I guess — and Laurel, we're willing to take some other questions.

**MARK:** All right, I have one — I guess related to Dr. Balcazar and the question is how can ILC's best address the disability needs of minorities whose cultures sometimes make disability a closeted issue?

**DOT:** I'm going to let you take that one, Glen. (Laughter)

**GLEN:** That is a very difficult question, and I've had discussions with Lee Shultz in Milwaukee, and it's not an easy thing to do, you're absolutely right. There are some cultures that they don't want help from outsiders. They would rather handle it inside and we certainly have to respect those cultural variations, and I'm sure I would really love to hear Steve Brown weigh in on this discussion as well. I wish I had a magic bullet for that. I do know that one of the things that Lee Schultz has done is try to hire people, you know, from those cultures to help reach out to them. I know we can't just hire everybody from every single culture, but he's been doing with Vietnamese community in Milwaukee. So if others have ways to do that, we certainly want to make those available and we'd be happy to — as I know ILRU would — to make these available in fact sheets or just kind of what works. One of the things that we try to do sometime ago was look at the 704 reports and try to find out what were exemplary practices as far as people trying to do outreach and it was pretty difficult from what I observed but I think there are some real wonderful programs out there.

**DOT:** You know, this might be a good time to mention, we did a best practices competition for outreach to emerging populations in rural areas. This year we did it in conjunction with APRIL, the Association of Programs in Rural Independent Living, and we will have the four winners, profiles of their programs and presentations on the web shortly. And I'm thinking of both Michael Blatchford from Arizona who is Native American and John who has done a lot of outreach up in Wisconsin to Native Americans there. They both had programs that sounded really good and seemed like they'd be very helpful for others to learn from. Both emphasized that you need to engage people from those populations and certainly hire them to do outreach, but John also made a good point. He said, you know, we think that peer counseling happens maybe inside an office with two people sitting together. Well, we know that it happens in a lot of different settings. He said we do a camp out or do recreation trips and the peer counseling happens with people sitting around the fire together. We need to broaden our views of what services are and how we provide them in order to address some of those issues but we should have them up on the website in two weeks. And those might be helpful for folks and I'm sure the presenters would be happy to be contacted to talk about what they're doing.

**LAUREL:** Wonderful.

**GLEN:** The other two areas were in aids and multiple chemical sensitivities outreach.

**DOT:** We have a lot of learning to do, every one does. One of the respondents who evaluated the panel we did presenting these programs at APRIL, one of the comments was I didn't realize that having perfume on would be a barrier to some people coming to the center. So, you know, we all have a lot to learn.

**MARK:** Well, I've got a greeting here from Jane Smelling at the University of Iowa, he asked in your experience, do these people with emerging disabilities self-identify as persons with disabilities or as part of the disabled — or disability community?

**DOT:** I would say it depends on the individual. I think a lot of people do not feel that they would use that label themselves, but I'm wondering that the benefits of independent living and the liberation of identifying is something that is not something to be ashamed of might encourage more people to do so in the future. So I don't really have an answer but I think, yes, there are a lot of people for whom that type of self-labeling is very difficult.

**GLEN:** I wonder if one of the issues is we sit down and if we sit down a dozen of us, we could think about the leaders, those that went ahead of us Justin Darts, Ed Roberts, we can name several more, that went before us and really were able to stand up and hold the torch high, and I don't know, this is a question, are there people with chronic conditions that they can identify with that are leaders that can lead them forward. That would be interest to go research kind of those models of advocacy.

**MARK:** Here is another one along the same line: How do you determine an emerging disability from a chronic condition, i.e., lupus or fibromyalgia, which are often debilitating?

**DOT:** That's a good question. I think it's dependent on the view of the person who has the chronic condition. For example, I think there are people many in the multiple chemical sensitivity and electrical sensitivity community who recognize that independent living holds great promise for them in order to participate in society. So I don't know if they really care whether it's called a chronic or a disability, they just recognize that there are things that really benefit them.

**GLEN:** Right. I don't think there is a lit must test where you're in or out. And I think what we know about science, just that to recognize that there is a population out there that is not being served by anybody else. The question is what are CILs do and what could they do to help reach out to these individuals. I know that has a whole lot of implications, ladies and gentlemen, for resources. Many of you are bust go out at the seams trying to serve the people are you serving. How can we take the information when we have from this research and how can we take what we're learning from this and push it further and try to find the resources that we can to reach out. That's another dialogue I think we need to have somewhere down the road here.

**LAUREL:** Are you thinking that at some point where you look at emerging populations, a lot of times we characterize them by cultural distinctions or linguistic distinctions, things that set them a part and perhaps maybe push them toward the fringe in terms of being incorporated wholly, but are you thinking that maybe at some point folks who are aging, both those with disabilities and without, it's going to be such a huge group of people in just a few years and acquiring disabilities as they age, do you think that would have to be perceived as an emerging disability? Especially folks who are having age related disabling conditions.

**DOT:** I think independent living at some point will just become the norm. Well, I mean I think there are going to be so many people living with some type of limitation due to age, people surviving accidents, and I think the generation of baby boomers who have seen people with disabilities come into their own and participate, I don't think they're going to stay home or go into institutions the way previous generations have. I think they're going to say, hey, the community has got to accommodate us. That's my personal feeling. I don't know how accurate it is. I just think that independent living has so much to offer anyone that I think it will be much more prevalent.

**GLEN:** Aren't we seeing that in our centers, you have younger people coming in. A lot of us old dinosaurs that have fought the fight to get access or curb ramps or elevators or whatever it is and you've got people come nothing now whether they're younger or people aging in the disability that don't recognize the advocacy and the issues it took. Can but recognizing as we start thinking about these new emerging disability populations there is still a lot further to go.

**LAUREL:** That's a terrific point. It's sort of like transportation or access to hotels and ten years ago you really had to plan hard if you were going to travel and now it seems to be a bit more accepting.

**DOT:** Well, this is very simplistic, but when I'm at an airport and go to use the large stall because I use a wheelchair and there is someone in there with a huge piece of luggage and I have to wait, maybe we should lobby our legislators for larger stalls because we all like to use them.

**LAUREL:** Here. Here. Mark you have another?

**MARK:** I have a couple more. Can you expand on how you involve consumers with the PAR process?

**GLEN:** One thing we can do if people are interested, laurel, is we've written an article — a number of articles and we really try to preach this not only to ourselves, but to our brothers in the research community and we've written an articles one of them called consumers as collaborators and we'd be happy to send that out. We'd mail that to people who have interest in it to get a reprint on that and we give kind of examples of how we do that. We talk about the philosophy and we give you examples. I think it would be helpful for people to see the process.

**LAUREL:** That would be very welcome, Glen. We can either send it out or post it on the page that has your handouts now and we'll have you archived and we can post it on your website and just put links to it. There are various ways.

**GLEN:** I can post it. I'm a little nervous — sometimes the reprint things, they have way to do that, but if people have access to the things I'm happy to make it available to you in a pdf. file.

**LAUREL:** Thank you. That would be grand. I think, Glen, you know that — and Mark, along those lines, we're working with the folks at Iowa, I should remember this because James is probably on the line, but the Center for Law and Health Disability Studies. We are working with them on a project, a resource center for technology that's going to involve PAR and collaborations between researchers and consumers. I think Glen you're a consultant on that project.

**GLEN:** Uh-huh.

**LAUREL:** And we — what you all have done there at Kansas has been a model for others to observe and I think not just the publication you're talking about, but I think the primers that you're developing on research are going to be real, real valuable.

**GLEN:** It's interesting because sometimes it's a little lonely, especially as researchers because sometimes I've talked to dot about this, because we get criticized for things we do, but I feel you have to go out to your constituency and have them give you feedback and lightning is not going to strike unless you have a lightning rod up. We want to learn from the feedback and so we feel that's important.

**LAUREL:** You sure stick your neck out, Glen, but good for you.

**DOT:** And that article will also be available in alternate formats so if anyone has questions.

**LAUREL:** Thank you, Dot. Dot, I've got a question about the project on — I think you call it the one stop project.

**DOT:** Right.

**LAUREL:** You know, I think from what I've heard, I just was – found myself in the middle of a bunch of rehab counseling professionals and they were discussing the one stops, and they were I think it was in preparation to preparing an. RA's position paper on the rehab act and they expressed very deep concern about whether or not the one stops were — had the capacity to reach out to disabled populations and I think— I wanted to know if is this project scheduled to start or has it started? Is it scheduled to start a little bit later?

**DOT:** It's started, we just don't have data compiled, but the researchers have done focus groups, both with consumers or potential consumers after these centers and with staff. And I think they are really looking at the issue of how can people, particularly with significant disabilities who need many times of accommodations are the staff well versed enough to know what to offer people or to be able to provide it.

**LAUREL:** That's right.

**DOT:** I think this would be a good one to do another webcast on. I think it would be useful, and they have started it but not enough to be able to put a lot of data out. But I think those concerns will be articulated.

**LAUREL:** I'm not sure it's a volatile issue with regard to the tension between RSA doing voc rehab and the department of labor.

**DOT:** Well, I think it might be, but people are going to have to deal with this if the goal is employment for people, and the services are not preparing to deal with all the types of accommodations, then we've got to deal with it.

**LAUREL:** That's good.

**DOT:** Because if the job search and identification and training process can accommodate with people, how do we expect employers to?

**LAUREL:** You know, that's a really good point. And I know that along those same lines with: regard to employment and employers and attitudes toward people with disabilities, Susan Brewer and her colleagues at Cornell did that study. I think you probably know it where they interviewed a large number of human resource people at different companies around the country and they were — I think the hypothesis or the research was to what extent has the ADA affected negatively employers willingness to hire people with disabilities because of the impact on the health — and apparently it was minimal impact, that it was not problematic. A big surprise.

**DOT:** When was that?

**LAUREL:** A couple of years ago.

**DOT:** The health care crisis got worse and it's good if it was that recent.

**LAUREL:** Part of it is a reflection of employers' attitudes towards hiring.

**DOT:** Well, it's good to know.

**LAUREL:** Mark.

**MARK:** I have one interesting one that just came in.

**LAUREL:** Not that these others haven't been interesting.

**MARK:** This one is going to require some from you, too.

**LAUREL:** Oh, oh.

**MARK:** It's from Kathy at the University of Iowa. How much have your studies found those were repetitive motion or strain injuries, those are such prevalent injuries in our society, the number 1 occupational injury, it can be politically difficult to identify as someone with a work-related injury. Then how are you able to accommodate them in your webcast and studies? And then she says many thanks.

**DOT:** First of all, for R1, we did not list that as a specific condition or disability. We listed 29 different types of disabilities and then we had another. I do have a list of the others that people wrote in and I can produce that. We haven't had a chance to look at it. However, some of the surveys, the on line survey did not give an opportunity to list a specific disability. So good question. We probably might have some data, but not a lot. As far as the webcast, do you want to address that Laurel or Glen?

**LAUREL:** I think it's an excellent topic for a future one. It's incredible the number of — we used to call it the carpal tunnel type injuries and it's just serious and, my goodness, as we all sit before a computer more and more it's going to increase hugely, and I know the pain is distressful and it has tremendous impact I suspect on paid time off. It's serious.

**GLEN:** I think the question, too, is you know how broadly do we cast the net? We think about emerging disabilities and I know that — and many of you have probably seen this, but there was a report done from Conwell, many, many years ago looking at different definitions of disabilities by the feds and there was over 50 different definitions and some of them had different purposes or functions. As we start to think about these — this whole thing, do we want to get into really categorical definitions or the best way to approach this.

**LAUREL:** And does that serve us as a movement?

**GLEN:** Right. It really doesn't. Does it make it more inclusive or exclusive kind of thing.

**LAUREL:** That's an extremely pertinent now with reauthorization of the rehab act and the whole definition issue.

**GLEN:** That's right.

**LAUREL:** We have just a couple of minutes left. I wanted to give you all a chance to do a wrap if you'd like. Wrap up — not a rap like a song.

**DOT:** I will do a rap. I think we've covered a good range of topics.

**GLEN:** We'd be tickled to have — if any of you want to contact Dot or myself or the center, we'd love to correspond further with you and our e-mail information will be available to them; is that correct? Laurel?

**LAUREL:** Yes, that sure will.

**GLEN:** We're excited about that and we've got another three years on this project and one of the things, ladies and gentlemen, is we've purposely left some spaces open to do other research. A lot of times when you come into these projects, you've got five years filled up and no time to do other things. So one of the things we finished r. 1, we still have some other time now we can devote to other research and training activities. So we really want your ideas to help shape us and further identify things that we need to do with respect to full partition pacing in independent living. So we really welcome your ideas and we can't promise we'll do every single thing but we will give it a good read and contact you for more information. One thing I'd like to say, Laurel, if I could, and then Dot you can have a final —

**DOT:** I'm all set.

**GLEN:** This is just a little different topic and something to talk about in the future. We just received a CDC grant on disaster preparation and emergency response for people with disability impairments, looking at FEMA data what do we know about practices and policies that are out there in disaster counties declared by FEMA and what are they really doing to evacuate people with disabilities. We're trying to use this as another opportunity for a webcast.

**LAUREL:** We would love to have that. As you know, last year Lex Frieden and his — the tropical storm Allison devastated Houston, and Lex was up to — almost to the top of the wheelchair ramp in water in his home and it's t\*is of preparedness as well.

**GLEN:** That's right.

**LAUREL:** Just extraordinary, and it's just liable to hit anywhere. You guys out there with the tornados though can have it.

**GLEN:** Tornado alley here. That's something that will be coming down the pike.

**LAUREL:** Marvelous and timely especially now with 9/11 type issues as well. So we'd like to have you back for that and we'd like to hear more about the healthy people's 2010 when you have an opportunity. Dot are we okay?

**DOT:** Yes, I'm here.

**LAUREL:** I didn't know if you had any —

**DOT:** No, I've said everything I need to.

**LAUREL:** Let me just close with inviting people to dial in to the same website and you'll see at that starting probably there will be a means for you to connect to the discussion forum and we welcome, as Glen said, any comments, any questions, any way to further the discussion, any recommendations for additional research. We'll be following along on that for about at least four weeks or longer if need — if demand is there. I also want to thank again and recognize NIDRR support of these kinds of efforts whereby research information is communicated to those of us who can benefit from it but who aren't necessarily, you know, pencils in the pocket type

researchers. Although today we've had a demonstration that they are human beings, too. So thanks very much to Dot and to Glen. I also want to acknowledge our team here at ILRU who do the webcast and that includes Marj Gordon, Sharon Finney, Rachel Kosoy, Dawn Heinsohn and Mark Richards. Also to our technicians, Rob Dickehuth who makes this webcast happen through his — working with the input and output and the web and all the technological show biz magic and to Marie Bryant our captioner who is extraordinary especially given the fast talkers who were on the line today. So we invite you to join us again on our next webcast and to please join us and use the real database for researching other questions. Meanwhile, thank you for joining us and good afternoon.