

# Saying the Right Things and Saying Things Right

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)

RIIL WEBCAST NO. 3

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Presenters: Jim Budde and Cindy Higgins

**Laurel:** Good afternoon. This is Laurel Richards with the Research Information for Independent Living project welcoming you to another webcast, and, at this time, the title is *Saying the Right Things and Saying Things Right*. In this case, it refers to effective and efficient research translation. We're going to focus today on the whole issue of researchers writing for nonresearchers. It is in part a response to the sometimes spoken criticism of people working in independent living and other fields that researchers pretty much write for researchers and those of us who have a stake, sometimes a very large stake in research outcomes, do not have opportunities to be exposed to findings that are being done by research projects. Today we have two individuals and perhaps three who have great expertise in the area of research translation, sometimes called dissemination and utilization of research, and that is Cindy Higgins and Jim Budde, who are also with the Research Information for Independent Living project. Prior to turning it over to them, I just want to recognize that this project is possible through NIDRR, National Institute for Disability and Rehabilitation Research. It's part of its initiative to facilitate and to promote use of research by nonresearchers. So, Cindy, I'd like to turn it over to you now.

**Cindy:** Hi, I'm Cindy Higgins, and by trade I'm a journalist. I've worked the last 14 years at the University of Kansas, taking information that people in the field say they want and need, and working to communicate that information in formats and language to different audiences. Right now, to make relevant information accessible, we have gone beyond the usual journal articles and conference presentations practiced by researchers. For instance, we're using our website, which is called [www.getriil.org](http://www.getriil.org), and that's a database that's full of easy-to-reach and easy-to-understand research information. To date, we have about 950 research summaries about independent living. In today's session, we would like to quickly discuss why science information has a tough time getting to the people who can most benefit from it. We'd also like to talk about ways to continue making research more accessible and more relevant and the language that is used to communicate research findings.

**Jim:** Cindy, this is really kind of a problem when we first started this. As you recall, people like a lot of those folks that are out there on the phone just wanted research but had really bad vibes about the research, simply because they couldn't get it and they didn't understand. And, I think from one standpoint, NIDRR, National Institute for Disability and Rehabilitation Research, recognized that. Then the challenge became ours, and, Cindy, I would have to say you've done a great job in both using the research to help people understand it and developing the products that people online can use, too.

**Cindy:** That's always nice to have your boss say nice things about you, and that's Dr. Jim Budde, the director emeritus of the Research Training Center. You have been in the field so long, before we get really into it, why don't you tell us some things you've picked up on research information dissemination.

**Jim:** It was interesting when we started the center in 1980, our Research and Training Center on Independent Living in 1980, the idea then was “let's listen to what people want in the independent living field and what they need in the field and let's develop something that will help them in our user research to make it better and prove that it works.” Then let's take that product and deliver it to the people. And in those days, we used a catalog. Well, things have changed, and I'm very thankful that we have this RIIL project because now we can use a lot of other techniques. When we first started three years ago, Lex [Frieden] and Laurel and a bunch said we don't think the internet will come into play. New studies proved that wrong and the whole information technology field is absolutely exploding, and I think it's important for us in our mission, and I'm talking about both RIIL and the Research and Training Center, that we keep up with the technology and provide information in a way that it's easy to understand. You can use it for advocacy, to improve your services or just for general information to improve your quality of life.

**Cindy:** Okay, well, as I said, when we started the project, the RIIL project, I did a big literature review to find out what was working and what wasn't in getting information out there. One of the problems has to do with science and research itself and the people who practice it. Because scientists are trained to document their research studies, and they emphasize the procedures used, so other people can replicate their studies. Now, scientists find that interesting, but audiences always want to know “what's in it for me?” So often when scientists are writing these articles, a lot of the information is all about the procedures. Another thing we found out is that —and this is no surprise — but scientists often view peer-reviewed journals or conferences as the only appropriate venue for their work. They want to talk to their fellow scientists, and they forget about the consumers sometimes. Or maybe it's the end of a research project and they've run out of time and money. Some scientists also just don't want to look like publicity seekers. They think if they go out there and they're in the popular media, in a way they're discrediting the whole field of research.

**Jim:** So if a researcher doesn't communicate to people that need the information, you know, it's really kind of their own fault. But in some ways we've got to find some ways to help them.

**Cindy:** I'm a journalist to works with researchers, but researchers are trained as scientists. They are not journalists or graphic designers or film documentary makers. Yet when they do their research, they're expected to disseminate this information and use all those traits and qualities, and they're just not trained to do that. So, I think that's a problem. But we're talking about problems, so we need to get into solutions, too. I think that if consumers are having a problem like “we don't understand the researchers, the research or it's not how we like it,” or the scientists aren't giving it out, they just have to remind scientists and researchers that usually they're publicly funded and the public does have a right to know this information. Also the Rehabilitation Act of 1992 amendments does require NIDRR projects to ensure widespread

distribution in usable formats and wide dissemination. So that's going back to the source, which is science and research, but another obvious barrier is that you want to get the information that people want to know. It's not what the researcher thinks would be exciting to go out and investigate; and that's the reason why they introduced participatory action research, probably around the early 1990's. I was very excited by it because it's also relevant to dissemination, and here at the Research and Training Center we've done a lot of work with that and the consumers report method. And Jim, I think you're the expert in that.

**Jim:** Well, again, in 1980, we hired people with disabilities so they could help us understand some of the issues concerning research. and went to the community, to the independent living centers to find people who could become members of our teams to help us to better understand what it was that was needed, if it would work, and how best to get it to the people that needed it. So we developed something before PAR called “consumer-powered teams.” In other words, the consumer would be part of research team and help us with it in the same way, and they would be with equal importance as any of the staff members. It was just really kind of a total quality management team where we all tried to find out better ways to find out what the problem was, how to make something better, how to use the research to do that, and to get it in the hands of the people that needed it. Now, one formal example of it that we've used for research, and it's a soft kind of research, is called the consumer concerns report method. We used it in the RIIL project to go to the field and ask you people in the field what kind of research information you needed. what we did was ask the people or a group of who we thought people represented everyone what are the questions that we should ask in terms of what research information do you need. It has a rating system on what is important to you, and what are you're happy with, and when something comes up that is very important and you're unhappy with it, all those items that fell in that category told us that that was an area that you thought something was important but you didn't have it in your hands. And guess what, the number 1 priority was? Anybody know?

**Cindy:** I can guess.

**Jim:** Go ahead.

**Laurel:** It must be advocacy.

**Jim:** That's what it was, advocacy. So in capsule here, what we were talking about is, is that from the beginning, it is so important to have consumers involved, people who are affected by what it is you're going to do helping you to better refine the problem. One case was that we used CRM to identify information that was needed and the other case when Cindy did the literature reviews of research that was out there that could tell us better how to communicate to nonresearchers, we used the research again.

**Cindy:** Laurel, I want to check to see if we have any questions to this point.

**Rachel [Kosoy]:** We have gotten a couple of questions and some of them you have actually answered along the way, but one of them — maybe you can elaborate a little bit more because people are interested to know if there is something people with disabilities can do to encourage researchers to better share their information, and you know, they're also asking how they can get

on these research teams or can they give you input you can then translate to the researchers? There is somebody out there who wants to give input or be involved, is there a way to do that?

**Jim:** You know, NIDRR has a list of all of the projects — research projects and other projects that they have. And they have a website, and my best guidance would be to go to that website, find out an area that you're interested in or location that's near you, and volunteer to serve on a consumer-empowered team. If that doesn't get any results, call me and we'll just see if we can't use a little advocacy to help you along the way with it. The other issue I think is how do you get researchers to use the brochures and the literature review that we have. I think there are two issues here, one of them is advocacy, which is you can take the brochure that we have that Cindy developed, which is very simple, and you can take it to the researcher or send it to the researcher and say, you know, here is a way to translate this so managers, service providers, even politicians can better understand what you do. Would you please do that? And, you know, at this stage of advocacy, that's almost the same thing as providing technical assistance. It's soft advocacy. And of course if researchers don't do that, then as a good advocate would do, you'd go on down the line and use approaches that are more aggressive to get their attention.

**Cindy:** Jim, don't you think if you were a consumer, just heads up, because most research organizations have a relationship with a different local organization. I know here at the University of Kansas, the center is tied in with several organizations, say, such as the local independent living center.

**Jim:** That's true.

**Cindy:** You could look for billboards. You could ask your local organization if there is a research project going on. And sometimes in newsletters you'll see those, too.

**Dot:** I think that's a good point. Can I check on that?

**Cindy:** This is Dot Nary.

**Dot:** Independent living centers get a lot of information and the staff has to wade through it and figure out had a people want to hear. You might want to contact your local center and say “if you have information about responding to announcements in the Federal Register or commenting or participating as research participants those are the things I'd like to see in the newsletter.” So there might be a way to get your local centers to provide information and certainly that makes every effort stronger because when consumers participate, we know — that's important.

**Cindy:** For me, it's exciting when consumers participate because I'm always interested in the format, how you're going to get that information to the consumer? What do they like? Do they want paper? Do they want something like, say, the webcast, internet? How do they want the information? And often we find that people like tiered information. You might have a one-page fact sheet for a lot of people who just want to know what's going on. Other people might want more in depth, so we might take the same information and make it into a brochure and then for people who really want to know every single detail, we have the entire research report. So I think

it's really nice if consumers would keep telling researchers if they're dissatisfied. Let people know. I want to do my job right. So let us know.

**Laurel:** Cindy, this is Laurel. One thing we can offer is that if folks out there have specific research projects or ideas they'd like to know more about, we can see if we can arrange a webcast with those researchers. We may or may not be successful, but we would certainly very much welcome that opportunity.

**Jim:** The other issue is if you have a concern, please go to [www.getriil](http://www.getriil) and see if those other studies might provide information that would help you.

**Rachel:** We have a couple of other questions, and I'm going to ask them out of order that they came in. So for the audience, just be patient because I just got a question that's really relevant to this discussion. And this question comes from a researcher, and they want to know what are your suggestions for getting the clear and simple write ups that we do create out to our audiences? This group actually writes plenty of stuff, but it's emphasizing that it's really a challenge to get it to the people, and they say they don't necessarily know about my organization or find us on the web or read our newsletters, and it's difficult to get news into the mainstream press. And their final comment is it doesn't matter how great a product you create if no one ever reads or watches it.

**Cindy:** That's a big question. I would say if researchers maybe should concentrate on research, and they should be open to hiring a journalist to take their information. I think a big thing, too, is once the information is written up, test it on consumers, have different people read it and say "did you understand it? Did it come across?" Regarding the general media, I don't think researchers understand how the general media works. I was just at a science writer's conference in Boston and we were talking about how to get science, just hard science, social sciences into the mass media. And they just don't have that much room. I mean, readers would rather read about sports or lawn and garden shows. Science — that's a smaller news hole. And the reporters want to know about breakthrough studies, you know, they want to know something new. Reporters themselves don't understand that research is almost like a point on a continuum with sometimes added incremental parts to it. So the reporters don't understand how that's done. And what we've been worried about here is that do the consumers even understand how research is done? And so, Jim, there was a product that Glen White and Dot just finished up.

**Jim:** Well, I'll go onto that, but I want to go back and answer the other part of this question. I think this group, the way it sounded to me, the researcher or group of researchers knew how to write in simple language. I would challenge them to compare that to the guidelines that we have up on site and available to see if it meets the criteria, and you can go — if it does, you go right ahead and boast that it meets the guidelines and use that for selling. The other issue is how do I get it out? You know, that's a thing that we keep struggling with in this new age of technology, but if you go back to marketing, it's like saying "who is that consumer audience?" And in this case, what we're trying to present in a simple format will work as well for a person with a disability as a service provider, as an independent living director or even a person in Washington that's making policy. Because it comes in a one-page abstract and goes right to the bottom line of what was found versus requiring the person to wade through it. So if you have a population of

people with disabilities, service providers, service managers and politicians, then one of the things you have to do is to get access to them. One of the ways to do that is to use mailing lists. You can buy them. ILRU has an extensive mailing list that they use to get information out. We have a mailing list, and then the question is, once we have the product, how do you advertise it in such a way that people will believe it's beneficial so that they will try to access it or to get to it? Then, of course, if you have addresses, you can do mass mailing of your product, but that gets to be pretty expensive as well. So, what I'm saying is, if you wanted to disseminate a product, you have to have a sound marketing plan. I will go to the *No Way Guide* in a minute, Cindy, but in all fairness, I would ask that we not answer any more questions before we give you time to go into how do you write research, what did you find in your research and how do you write the research up. I think we need to get into the techniques of doing that before we get too far down the road.

**Rachel:** Okay, I will hold these other questions.

**Cindy:** After we did the literature review, then we produced the *How to Guide: Condensing and Translating Research for the General Public*. I don't know if there is anything new. It's a compilation of journalism's best practices and information from the National Center for the Dissemination of Disability Research, which is dynamite. So we did that booklet and then we also have the guidelines brochure, which starts out with "know your audience." We always say when you're communicating with anybody, they're busy, they don't want to have to wade through a bunch of words, so you use your everyday language. I think that Walter Cronkite always said when he did his six o'clock broadcast he imagined he was talking to his mother. I imagine I'm talking to my Aunt Nancy in Iowa, and she would just look at me strange if I was speaking "researchese," so I have to bring it back to a different level. What we find with our research studies is that you have to focus. What's your most important information? And then you have to condense that information, because journal articles are 20 pages, and so you have to be able to digest our information and condense it down to one page, condense it to a paragraph, even one sentence because you really have to know your information. So focus on the few elements, which usually means telling the people the box scores and not the play by play action. In science writing, too, you use your metaphors and analogies to get your audience to understand. We had a question before the broadcast and it was from Kris Copeland there in Michigan, she does a lot of advocacy work, and she had said basically what you're doing is just translating research information. And that's right, it is a form of translation into plain English, and she said "is it a technical exercise just getting the who, what, where, why into the document"? And, yes, it is. You're getting your basic journalism w's. But then she also said do you view it more subjectively? Do you translate it word for word, phrase or phrase or do you have to know the topic? And what she was referring to is context and a lot of times researchers are so narrowed into their particular study that when they're trying to explain it to a general audience, they don't put the context in. And you need to have it be able to make sense. Sometimes I view a research study as maybe a spice in a really dynamite recipe. It's not the whole recipe, but with everything else it makes it come alive. You have to put it into the bigger picture. Quotes, see, that's something you don't usually see in a scientific report, but if you get quotes— that's what always drives a journalism story. It's not just dry writing. They get quotes from the people involved, what other people think about it from the researcher itself and I think that's a big thing that's not really practiced now, but making an emotional connection with your audience. You have to almost tell a little bit about the researcher, himself or herself, so that's a big thing, too, making

the emotional connection. I could go on and on, but Jim, did you have something to say or is there a question?

**Jim:** Did I? I didn't.

**Cindy:** Those are just some basics of how you give that information a little bit of life. I still find in newsletters I'll get from organizations of all different natures that people are still using citations. You know, the little footnotes. There is no reason for that. You need to kick those out. If you're going to credit a source, just do so in the article text. And you always have to restrain yourselves from technical terms, that is going back to using everyday language.

**Rachel:** Can I jump in with a question that might be connected to that?

**Jim:** Sure.

**Rachel:** There is a question from a researcher about, you know, if they do actually get their information into the media, then what can be done to help change the attitude that research, which is published in the public media, must have less scientific rigor than peer-reviewed journals?

**Jim:** Hmmm.

**Rachel:** That is a good question.

**Jim:** You know, that is a very interesting question because the research — and this is closer to Cindy's area, but my experience with it has been is how popular it is versus how good it is. For example, if you — a researcher came up with something that would increase the length of your sex life or something, probably would make it right to the pages. If you came up with a new way to prevent ulcers, you wouldn't make it to the front page. I guess where you are with this is where we are about probably 15 years ago when we did the media watch, and what we were trying to do at that time was to get reporters to portray people with disabilities in a much improved light, and so when we tried to do that, we got into the style book and there was one term, "handicapped" and that applied to golfing. There was nothing that was in the style books that the reporter could even go to. So therefore in colleges or on the job, they weren't trained. So you would have something like the "idiot with the gun who's mentally retarded, shot somebody" or something like that. So we developed another set of guidelines that we have here, which are reporting guidelines that are different from the one that is Cindy has, and we've distributed millions of those, and keep updating them just so we can train the journalists, and then we did a media watch with people with disabilities who read the newspapers and watched the broadcasts, and if there was a news caster that was portraying a person with a disability in an unfavorable light, they came down on him. First, they provided the guidelines and then if he or she kept doing it, then he got on them. So my guess is that there is a similar approach here in that if researchers are not following up with something in terms of the rigor of the research or they're not reporting research that is important, but not glamorous, that requires some kind of an intervention or advocacy with reporters.

**Rachel:** Okay and that actually leads into another question, there are some questions about what all RIIL does, and what kinds of activities do you guys do and what sort of resources do you offer? So if you could describe a little the scope of the project.

**Jim:** Okay, let's see if I can take a shot at that. First of all, we have a division of labor between the Research and Training Center on Independent Living at the University of Kansas, and ILRU, that is a program of TIRR. The webcast today is being brought through TIRR. They have the transcripts of similar presentations provided, and they also have discussion groups on topics that we're concerned with that you can get on any time, and those are virtual time versus the realtime that we have. The arm that's at the University of Kansas has two functions: one of them is a research and development function, and the other is a database function. Underneath research and development we've done things like conduct the CCRM survey where we identified the research priorities for information that you wanted. We have the product called the *No Way Guide* that was developed by Dr. Glenn White and Dot Nary and that is how to understand what research is, how it can work for you, and how you can use the power of research. That guide is underneath — or that one is on its way out now if I remember right. And you can obtain that from us. In addition do that, Cindy has three products, and Cindy why don't you describe those and then I'll finish up with the database.

**Dot:** And I'd like to put something in, too, after Cindy.

**Cindy:** I think we have on the website is that *Effective and Efficient Research Translation for General Audiences*, it's about a 35-page document written with all the footnotes and all that. I've developed the more easier to understand and kind-of-walk-your-way-through-it workbook, which is *Condensing and Translating Research for the General Public*. What I spend most of my time on is the database and taking scholarly articles or anything to do with independent living and writing about a 350- or 500-word summary. These summaries are not about what you'll find in the article. It's just the actual information, and I rely a lot on numbers in case people want to use it for grants. I want to put dynamite quotes if you're using a brochure or speech, and I try to make all the information useful. So it doesn't tell you what you'll find, it just tells you some of the best stuff that's in there. Those are the research summaries, Jim.

**Jim:** Well, I want to go on to Dot, which is about a specific research project in a second, and something for which we really need your information. Just let me say a bit about the RIIL database again. For the most part I don't think any of them are over a page long, and all you need to do is to type in [www.getrill.org](http://www.getrill.org), and the site will come up and the very first thing you see is a search, and you click on and hit submit and you'll come up with a roster of studies and then you can click on the ones you want to read and then you can go back and read the others. And we're finding that there are a variety of people who are using this from people who have disabilities to people who are improving services, to managers and policy makers, and even researchers who want to use the reviews for their reviews of literature. So I encourage you to go into that site. Now, I'd like to turn it over to Dot because there is a piece of research that is being conducted that will and could well have an impact on many of you that concerns how we might fully participate in society. So, Dot, you take it from there.



**Dot:** I'll be quick. I just wanted to follow up on both what you and Cindy said. I think one of the biggest features and benefits of RIIL is for busy people in the field when they're writing a grant, when they need to back up testimony, they can turn to RIIL and get information that's readily available to back up their assertion. That's a real good benefit for the people in the field. When I was working in independent living, I didn't have time to read a 10-page research report. I could read one or two pages that distilled the information, and that's a real benefit. I want to talk a little bit about a project we're pursuing now. We are looking at independent living and is it serving the needs of everyone? We know that it has huge benefits for anyone with a disability or chronic health condition, but we want to make sure that it is serving everyone, so we're doing a survey to assess participation in independent living. We want to know how well people are participating in the communities, and we want to know about people with what we consider more traditional disabilities versus those that are more emerging such as chronic fatigue syndrome, asthma, and also people from different cultural contexts and different ethnic groups. So we want to know and be able to compare levels of participation. We have an online survey, and we have paper surveys in alternative formats. So we're trying to reach everyone whether they have access to the internet or not. Here is the address of the online survey, it's <http://rtcpl.org> — my e-mail address is much shorter. It's [dotn@ku.edu](mailto:dotn@ku.edu). We'll send you a copy of our latest edition of the guidelines. If you're an organization that can help us get the word out, we would appreciate that, just e-mail me and hopefully we can really, no, come up with some information that will be helpful to help people assess what advocacy agenda that's needed and what are the issues that people are experiencing as barriers to full participation. Thanks, Jim.

**Jim:** I suggest that's along e-mail or not –

**Dot:** Can we post it? Yes, I will send something in for the online survey. If you want other method I'll put my e-mail address up, too.

**Laurel:** What we can do, Jim, is when we archive this on the contact page, we're going to add the contact information for the RIIL project and for the RTC/IL, and, Dot, maybe we can get the title from you and have the url for that survey.

**Rachel:** I have another question, which is somewhat connected. So let me throw it out and let me know if you want to answer it now or if you want to hold off on it. Sometimes consumers may not have research on their radar screens. So how can we as researchers help consumers better understand the issue of research and its value for improving their lives?

**Cindy:** Jim, I think that's the *Primer*.

**Jim:** That is really the *No Way Guide*. What Glen and his colleagues did when they developed that was to take a piece of research and show all along the line how the research was developed and how it could make an impact on the lives of people with disabilities for whom the research was being conducted. As he was doing that, he was talking about different research methods that were used. One of the things that we found was that when people with disabilities would go in to be reviewers for grants, they would go in with some pretty good ideas about what was needed, but when they would talk about a research design or dissemination of research, they didn't have an understanding of that. So that was the reason for the *No Way Guide*.

**Rachel:** And all this is on your website.

**Rachel:** There is another question from researchers who want to know — this sort of goes back to some of your initial comments about how really the biggest change in dissemination has been because of the technology changes. Can you talk a little bit about the statistics of access to the internet for people with disabilities?

**Jim:** I believe that the statistics to the access, and if I recall, this was from John Westbrook's survey, but it was a staggering amount like 75 or 80 percent of people with disabilities had computer access. I may be wrong on that. Dot, do you recall that?

**Dot:** I think it was much higher than expected. It means some people are going to the library. I know here in town folks can drop in to the library at the independent living center and log on to get their e-mail. So even if they don't have it in their homes, a lot of people do have access somewhere.

**Jim:** And one of the nice things at independent living centers are doing is they are reconditioning computers or taking computers in for donation and giving them to people with disabilities and they find ways to pay for access to internet kind of services, which was really surprising to us because we thought that people with disabilities may be put in a position of having to decide whether they wanted internet access or they wanted to pay for the burden of cost of having the disability. Like extra drugs or high cost of drugs or repairs of accessible equipment or whatever.

**Rachel:** I just got a follow-up question from the person. She writes: I want my research to be perceived as credible. Do I publish in a scientific journal or the media? The answer to scientists is I publish in the journal. Help me understand how we get information to the public in a scientifically rigorous way.

**Cindy:** Can I take that one, Jim? I was looking for an opportunity to applaud Cindy Jones' work that she's got over there at the Accessible Society, another NIDRR-funded project. She takes research reports and writes them in a way that they're almost just ready right to go into a newspaper or magazine and they're up at her website. She also lists the contact information, people you can call to get extra quotes from. If you would want to access that, it's at [www.accessiblesociety.org](http://www.accessiblesociety.org)

**Dot:** And we can put that up on the contact info.

**Cindy:** Part of the dissemination is finding the people who are doing it right and just copying them. Cindy Jones is a really great example to copy.

**Jim:** Also, I think what was being said here is that you don't just have one audience. Now, for researchers in the past that might be in a university department or maybe part of a research and development company or a company that just does research producing the product and giving it to the person that's paying for it, or publishing in a professional journal was enough. And I

believe today that consumers are asking for more. They should be asking for more. As a result, researchers really have to think about multiple audiences. As Cindy was saying before, how do you prepare the particular product or announcement or information for that audience? And if researchers need a little help with that, then it comes back to all of us to be advocates and people who provide technical assistance to help them out.

**Cindy:** I think no matter who you're writing the information for, you should still go back to using everyday language: common everyday language that anybody can understand is a form of accessibility. Researchers – disability researchers – should always keep that in mind.

**Jim:** That is really the important part. For a number of years, the Department of Rehabilitation had a publication called *Rehab Brief*. It was about a four-sided publication if I remember right and it had one or two studies on there and it came in the mail, and you picked it up and here was a piece of research that you'd go through easily. The only people who were benefitting from the complex designs and — and I'm not saying that that was wrong — and the terminology that was complex that was being used were the researchers that were within the group. And we still have that. I mean, physicians have to have medical terms, but researchers like physicians have to communicate that in simple language.

**Cindy:** I just wanted to say that part of the RIIL project does involve these webcasts, and I thought that it might be good, Laurel if you told us how effective you thought this format was going.

**Laurel:** Well, I think it's fabulous. But what's been interesting is the ability — Number 1, the eagerness of a lot of the researchers to use this format. We've had no turn downs and folks have been very eager to communicate their research findings using this format. I think so many of us have been accustomed to teleconferencing, doing presentations on teleconferencing and this is so similar that it's a comfort. What we had hoped to achieve with this was to provide a low cost means for people to connect like this without having to have long distance calls. Also, we believe that the archive, where each audio and then the transcript are and the questions are then followed up by a discussion forum for about a month period is a way to provide this same information in virtual time. So I think it's going well. We'll have an evaluation that will tell us the real truth, but it feels comfortable to me.

**Cindy:** And how many have you done to date?

**Laurel:** Golly — 20? I don't know.

**Cindy:** I was just wondering, because some people were asking me, “is this something say if I'm an independent living center say in Montana that I could do myself?” Is it that hard or do you have to have a lot of specialized knowledge to set this up?

**Laurel:** I tell you, we have a colleague named Rob Dickehuth who works with Baylor, and he's like our technical man and there is this box that he has which has lines coming in. One is a telephone line that receives — from the telephone as we're speaking right now. The other is a line that comes from our captioner's machine that goes right into the same box. That's Marie

Bryant and for those of you who are watching along and reading along, she's inputting our voices and our words as we go along. So it appears to me — and then we have the server at Baylor and there is things associated with it such as archiving costs and so forth. We've done estimates of the outside costs. It's not terribly expensive, but the secret is the service provided by Rob and Marie. They're the make or breakers and if they can't do it, we don't do it because that's the key. It's got to be extremely good captioning, and it has to be this marvelous device that Rob is able to do.

**Jim:** Cindy, I'd like to go back to you for a second again. When you did the literature review, what were some of the paramount findings and the research about communicating information to nonresearchers?

**Cindy:** Oh, gosh. I think after I wrote it, you must always clearly show the relevance. So no matter who you're talking to, always show the relevance. You have to always realize that. I think somebody earlier had said something about their organization and getting information out. If you establish your organization, people know who you are, then they're going to come to you and ask for information. And so that's a big thing, being viewed as a valid source of information. It kind of ties in with archives and databases. Sometimes you don't want the information now, and you remember it and later on you go back to it. Another thing is understanding how you have to keep your preciseness of the scientific abstract, but always give it the allure and interest that people want. And so those were just some findings throughout.

**Jim:** How many studies were in that review that you cited? Do you have any idea?

**Cindy:** I'm glad I have it right here in my hand. It's really tiny print, there is 75 or 100 sources in this little tiny print. And obviously what I said, a lot of it isn't necessarily new, but it's all put together in one spot. And then I'd always encourage people to go check out the National Center on Disability Dissemination Research. Their stuff has just been so impressive and something that I like to always look at. Are there any questions? Because I think we're getting ready to close.

**Rachel:** You guys have answered a lot of the questions. I guess there is one that stands out. People want to know if RIIL has a connection to the media, and if there is any way that you guys act as a conduit for researchers?

**Jim:** No.

**Cindy:** I think that goes back to Cindy Jones' Accessible Society.

**Dot:** Yeah, I think you're right.

**Cindy:** I would encourage, if you go to the RIIL website, my e-mail address is on there, and, you know, feel free to continue asking me questions or advice or anything. That's why I'm there.

**Jim:** Actually, we're talking about two different projects here that have different goals. Jones' project on Accessible Society was designed specifically to get information to the media. Ours was more along the lines of what can you do to repackage research, to get people with

backgrounds other than researchers, to understand the research and what are the most effective means to get the information out or make it available on command to people when they want to access it. So one of them is directed more at the media. The other one is actually designed to be more dissemination and utilization.

**Cindy:** And I also want to say about the RIIL database, just to underline again, it is on independent living topics. And that is part of information today. It's the selectivity of it. And so we're not trying to do everything in disability, but it's all the things that do tie in with independent living of people with disabilities.

**Jim:** Housing, advocacy.

**Cindy:** We touch into a lot of areas in empowerment, too, but we're trying to keep it on IL.

**Laurel:** Of course, it is such a broad topic. You've got excellent resource materials on voc rehab, on health and wellness, on things associated with mental health issues. It really is a very, very broad database and first rate. Cindy, with regard to two things: One is, can you tell us how you obtained the documents that you abstract?

**Cindy:** That's a lot of foot work. I'm pretty much cleaned out the University of Kansas library. I've been to public libraries around. I've gone to other cities to the college libraries. A lot of this information is found in university libraries. That's why it's been inaccessible, – I think we started the project a year and a half ago, two years ago. I watch any information that comes in here so it's a lot of foot work, but it's been fascinating to me how many people are putting information on the web and it's full reports. And so I like to do that, pull down a whole full report, do a nice summary, and then also in my abstract let the reader know where they can access the full report.

**Laurel:** Now, that's real important. For these folks who are NIDRR projects, research and training centers, et cetera, if they have materials that they're not sure if you've had a chance to abstract yet or that you've captured, would it be useful for them to bring that to your attention?

**Cindy:** Laurel, you know I've got a big smile on my face when you said that. It makes my life so much easier when people send me information. If anybody sends information that has to do with independent living, they can be pretty much sure that I'm going to take that abstract and put it on our website, which is a form of dissemination for them, too.

**Laurel:** You're preparing a series of quarterly — not exactly annotated readings or remind me what that is, please.

**Cindy:** Once again, you know, research studies are just a point a continuum. What I thought might be nice for people is to digest some of that information. So I think in the recent magazine *SCI Life*, Laurel came up with the idea that maybe I just look, say, at managed care. So I used all of the abstracts on the RIIL website as my parameter, and then I wrote just a small literature review, what's going on with managed care and how that influences people with disabilities. So we've done that. I'm not pretending to know everything about a certain subject, but it's information that's on the RIIL website.

**Laurel:** So in terms of folks, if they send you materials and you use them in these fact sheets, we'll probably be sending out alerts, I guess, maybe through our e-mailing lists that this fact sheet is now available or something along those lines so that this whole issue of how do we get our product in front of the target audience may be addressed in one small way in that regard.

**Cindy:** Yeah, Dot and Jim have been working a lot in that area. Jim, you got going on that?

**Jim:** I'm sorry, somebody just put their head in the door here. What was the question again?

**Dot:** Cindy is asking about getting the fact sheets out and what are we doing about that. Is that your question, Cindy?

**Jim:** Yes, the web designer is currently developing a new category, and, of course, the fact sheets are pulled from the RIIL database. They include a number of studies that will talk about an issue and what are the topics of some of the issues, Cindy?

**Cindy:** Just your basic advocacy.

**Dot:** And they will be posted on our website.

**Cindy:** People with psychiatric disabilities and homelessness, and we're always trying to touch base with the emerging populations in independent living.

**Jim:** All of this stuff, whether it's in the RIIL database or whether it will be in some of the products that we have or these fact sheets, it's all printable. You can print it right out and use it and we encourage you to read it and send it to your friends or whoever ought to be reading it.

**Cindy:** So send us what you have. We'd love it.

**Laurel:** Now, with regard to Cindy, you mentioned that if folks cared to pursue a conversation along these lines, they can e-mail you. I wanted to remind folks that we're establishing for about a month or so following this webcast, a discussion forum, you know, kind of like a bulletin board or news group or whatever, where there can be an exchange of perspectives on this subject, and we'll have some posting. We may even start with the answers to these questions. If you'd like to check back on this webcast page, there will be a button you can click or an underline you can click that takes you to the discussion forums, and there you can participate if you care to. Jim, and Cindy, where are we now?

**Cindy:** I think we're just about finished here, aren't we time wise?

**Jim:** I don't have anything else unless there are any more questions.

**Rachel:** We have one more question which might be a little bit of a repeat, but let me go ahead and throw it in. What do you think of researcher advocacy materials that come out in two

versions? For instance, the original document and one that's written for self-advocates? Shouldn't these purposes be integrated from the start? And this came from an advocate.

**Jim:** I mean they hit it right on the head. First of all, just in case we get cut off, I want to thank everyone for some really great questions. As for the answer to that question, we resolved this problem long ago, as I told you, by getting consumers involved and developing a product, testing the product and disseminating. For example, we have some checklists that people can use to advertise, employ and train their personal assistants. There was a good bit of research that was done on that. The final product of that that was available to people with disabilities who wanted to manage their attendants, but the research from that then became another product that was published in a professional journal. So this is not a matter of one or the other. As far as we're concerned, the important issue here is a product that meets the need of a consumer or a service provider or a manager or a policy maker that's concerned with disability. Then research is a technical tool that we can use to prove that what we have developed works, or to say what we have done is the truth. That can be published about how we did that in professional journals. On the other hand, the product that was developed for the advocate, they can be sure that when they used it, that if they use it the way we say to use it, that it's going to be effective.

**Cindy:** And I think it's great that somebody cares enough to be an advocate.

**Jim:** I do, too. There was one great example. We were trying to help people with disabilities and people at independent living centers provide testimonies to city councils. So that involved some pilot research where we went down and looked at what were the major components of making a presentation so that the city council would listen. Then we asked members of the city council if indeed these – if a person used these techniques, would they listen? And so we found out what they would listen to. Then we developed a training package. To find out if the training package was effective, we used another form of research that told us that the training package would, if followed, would it teach the advocates the kinds of skills that the city council paid attention to. And then, of course, the product was made available for people in the field and that was some years ago. That product is still a popular product, but Tom Seekins also published the results of the research in the journal.

**Laurel:** Perfect example.

**Cindy:** Thanks to every one for listening in today.

**Laurel:** I want to thank Cindy, Jim, and Dot for leading us through this discussion. I think you all out there can tell that we're fairly ardent about the importance of really repackaging research findings into a mode that those of us who are not researchers, but care a lot about what research is being done that will help us live higher quality of lives. This is important to us. And too, we want to acknowledge NIDRR and its support for activities such as this in which we are funded to promote the use of research in independent living and to promote independent living. Finally, I want to thank the members of the ILRU team who include Rachael Kosoy, Sharon Finney, Marj Gordon, Mark Richards, Dawn Heinsohn and thank — I think I've said enough about our two outside helpers, Rob Dickehuth and Marie Bryant, but in fact they are the best there is. Meanwhile, we'll have another webcast coming up. I invite you to come back and check our

webcast page and see what's upcoming. Please do participate in the discussion forum that's going to be taking place. Thank you very much for listening and good afternoon to all of you.