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ABSTRACT

Nonmetropolitan areas have the highest percentage of people with disabilities, including severe disabilities. However, rural people with disabilities may represent a population that is underserved or difficult to reach. Barriers to information dissemination in rural areas include limited transportation and communications infrastructures, greater numbers of older and less educated individuals, economic hardship, and lack of other services. Consequently, rural residents' awareness of disability research and its potential positive impact on the lives of rural people with disabilities is limited. This publication describes strategies to increase rural access to disability research information. Brief articles are "Shepherd Center's Web-Based Learning Connections" (Roxanne Pickett Hauber); "Access to Disability Research Information by Rural Consumers: Key Findings from the NCDDR 2001 Survey"; "Outreach Strategies of the RTC on Rural Rehabilitation Services" (Tom Seekins); "Strategies for Building Communication and Participation: Experiences from the Lower Mississippi Delta States" (Ari Mwachofi); and "Home-Based Video-Counseling for Rural At-Risk Adolescents with Epilepsy and Their Parents" (Robert L. Glueckauf). Summing up the strategies in these articles, 12 recommendations are presented concerning appropriate targeting and tailoring of information, using multiple formats and media, spreading information through local organizations and social networks, being aware of cultural diversity and age-related issues, minimizing transportation needs, involving rural residents with disabilities in participatory research, and asking for feedback. Related resources on rural issues are listed. (SV)

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The Research Exchange

At a Glance

This newsletter is available in alternate formats upon request.

SOUTHWEST EDUCATIONAL DEVELOPMENT LABORATORY
Building Knowledge to Support Learning

A project funded by the NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH NIDRR

Reaching Rural Communities:

Increasing Access to Disability Research Information

If all NIDRR grantees used only the World Wide Web for distributing information, as much as 93 percent of people with disabilities living in rural areas would not be able to access the information, according to Dr. Tom Seekins, Director of the RTC on Rural Rehabilitation Services. In a recent NCDDR interview, Dr. Seekins pointed out the need for a variety of channels and formats to ensure that consumers with disabilities in rural areas are able to receive information. Seekins and several other NIDRR grantees whose projects focus on rural populations were invited by the NCDDR to share information about their research and their outreach and dissemination experiences targeting rural audiences.

The dissemination mission of the NIDRR community includes potential users of research outcomes from rural America. For some NIDRR grantees, people with disabilities living in rural areas may represent a population that is underserved and/or difficult to reach. Specific strategies to overcome existing barriers for people with disabilities who live in rural settings are addressed in this issue of *The Research Exchange*.

For some NIDRR grantees, people with disabilities living in rural areas may represent a population that is underserved and/or difficult to reach.

Disability in Rural Areas

Studies of the demography of disability in rural America show that non-metropolitan areas have the highest percentage of people with disabilities, including people with severe disabilities. Data indicate:

- approximately 12.5 million of rural Americans have disabilities, and six million have severe disabilities,
- people with disabilities make up 23 percent of the non-metropolitan population, compared to 18 percent in metropolitan areas, and
- approximately 11 percent of the non-metropolitan population reports a severe disability; slightly higher than the nine percent reported for metropolitan areas (Seekins, Innes, & Maxson, 1998).

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A Word from the Director

Dissemination and Utilization for Rural Populations

Unlike many of America's past decades, more and more Americans are living in urban/suburban environments. Farming and agricultural vocations are employing fewer and fewer Americans. Although conducive to narrowing gaps that may be caused by geographical dispersion, Information Age technologies do not appear to be fully utilized to integrate rural populations. Most of the recent attention on universal access, physical accessibility and service delivery has been focused on meeting the needs within urban/suburban-based target groups of persons with disabilities in America.

While meeting the needs of urban/suburban Americans is essential, another significant group of Americans with disabilities reside within rural environments and present many, perhaps unique, challenges for service providers and those facilitating the dissemination and utilization of needed research-based information resources. Clearly, appropriate disability-related research outcomes need to find their way to people with disabilities who can use them, even though they may live in geographically remote or rural areas.

However, an important question remains regarding the extent to which research-based information is applicable or targeted to people with disabilities living in rural environments. Researchers may not consider characteristics of residency when establishing a research sample. The extent to which rurally-based people with disabilities are participants in a research design may go unmentioned, unless the research study is solely oriented to this target population. While it is generally accepted that most research designs and sampling techniques should randomly assign subjects according to race, ethnicity, and gender for generalization to the widest population base possible, much less clarity exists in regard to the characteristic of where a research subject may live. The ability of rural residents with disabilities to utilize specific NIDRR research findings may rest upon the degree to which the researcher was sensitive to including this group within the research process.

Research teams should also be aware of the way in which rurally-residing people with disabilities are integrated into Participatory Action Research (PAR) and project advisory activities. If research designs and dissemination/utilization activities are going to best fit the needs of rural Americans, their involvement in such participatory and advisory functions would be invaluable.

This issue of *The Research Exchange* highlights some ways in which selected NIDRR grantees have addressed some of these issues. These highlights may provide insights for other grantees that may be useful in adopting or adapting them within your research project and related dissemination and utilization activities. Additional technical assistance is available from the NCDDR for NIDRR grantees in planning and implementing rural outreach efforts.

John D. Westbrook, Ph.D.
Director, NCDDR

Reaching Rural Communities

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Possible reasons for the disproportionately higher rate of disability in rural areas are delineated by Enders and Seekins (1999):

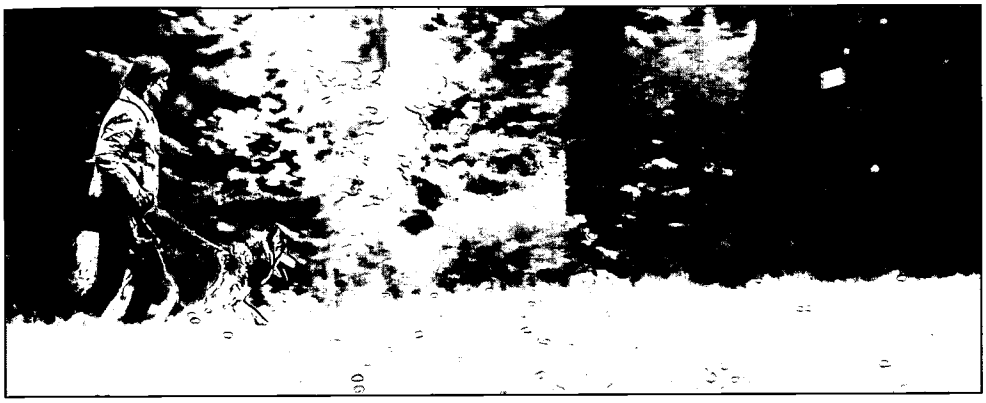
- Many rural occupations are among the most physically dangerous and produce high rates of injury that can lead to or result in disability.
- The proportion of older Americans in rural areas is higher than in urban areas, and rates of disability increase with age.
- Individuals who have attained higher levels of education tend to leave rural areas for employment in cities. This migration pattern leaves a higher proportion of less educated people working at dangerous occupations, potentially contributing to the higher injury rate.
- Medical and other support services that may help prevent disability are less available in rural areas.
- The infrastructure (such as public transportation and physical access to buildings) is less developed in rural areas and may contribute to reported limitation/disability.
- Poverty is often associated with disability, and poverty rates in rural areas are disproportionately high, equivalent to those found in U.S. central cities (p. 15).

Barriers in Rural Areas

What are the barriers to dissemination of information to rural people with disabilities? Some of the factors that contribute to higher prevalence of disabilities in rural areas also create barriers to disseminating information in those areas. The limited development of the infrastructure of transportation and communications systems impacts information sharing. Greater numbers of older and less educated individuals hold implications for the format and content level of information that is appropriate for dissemination. Rural isolation can create communication barriers when the sources of information are people perceived as "outsiders." Other factors complicating dissemination may include limited health care facilities, few rehabilitation services, and economic hardship. Overall, there is limited awareness of disability research and its potential positive impact generally on the lives of people with disabilities in rural areas.

NIDRR Grantee Experiences

The following articles present information from grantees describing their work within rural communities and strategies that may be useful for NIDRR grantees to use in reaching consumers with disabilities who reside in rural communities. Many of the strategies used and reported here by NIDRR grantees were helpful in overcoming some rural environment associated of the barriers. Other



strategies proved useful to gather information about the needs of rural people with disabilities. Some of the research using technology shows promise for ways to increase access to and ongoing communication with rural populations.

- **Roxanne Pickett Hauber, Ph. D., R.N.**, Manager and Nurse Researcher of the **Telerehabilitation to Support Assistive Technology** program at the Shepherd Center in Atlanta, talks about the use of telerehabilitation applications to provide follow-up support to recently-discharged patients, their families and their health providers. Implications and benefits of telerehabilitation applications for individuals from rural communities are discussed. Article on page 4.

- In an interview with **Tom Seekins, Ph.D.**, Director of the **Research and Training Center on Rural Rehabilitation Services (RTC:Rural)** at the University of Montana, NCDDR staff learned of the dissemination strategies used by the RTC:Rural in their efforts to reach rural communities. Among other dissemination formats, Dr. Seekins described the use of technology and the associated social and economic barriers that preclude many rural residents from the equitable use of technology. Article on page 6.

- **Ari Mwachofi, Ph.D.**, Principal Investigator, **Developing a Rehabilitation Service Delivery Model for Minority Farmers with Disabilities** at the University of Arkansas, talks about how personal contact, the development of trust, and collaboration with community leaders–all integral components to successful research and dissemination activities with rural audiences–facilitated their research project. Article on page 9.

- **Robert L. Glueckauf, Ph.D.**, Principal Investigator of **Home-Based Video-Counseling for Rural At-Risk Adolescents with Epilepsy and their Parents** at the University of Florida, shares some of their participant recruitment and information dissemination experiences from their project's research with teenagers who reside in rural communities across five Midwest and three Southeast states. Article on page 11.

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What is Rural?

The concept of rural can have a number of meanings, and there is no universally accepted definition of the term. Rural and non-metropolitan areas are generally defined by exclusion; that is, areas that are not classified as urban and metropolitan are rural and non-metropolitan, respectively. Several criteria are used to define urban and metropolitan areas.

The Census Bureau differentiates between rural and urban areas. The U.S. Office of Management and Budget (OMB) uses the terms metropolitan and non-metropolitan areas. The Department of Agriculture's Economic Research Service employs various codes such as rural-urban continuum codes, urban influence codes, county typology codes, and rural-urban commuting area codes (Rural Policy Research Institute, 1999). The more commonly used definitions are those of the Census Bureau and the OMB.

In 1990, the Census Bureau defined urban areas as places of 2,500 or more persons and comprising all territory, population, and housing units in urbanized areas (with some exceptions). Territories and places that are not urban are considered rural. The 2000 Census Bureau criteria uses "the territory designated as urban clusters, rather than the entity of places that have a specified population, to determine the total urban population outside of urbanized areas" (U.S. Census Bureau, 2000, p. 4).

The OMB uses a county-based definition where metropolitan areas are those counties with one or more major cities of at least 50,000 people or with a Census Bureau-defined urbanized area with a population of at least 100,000. In addition, those outlying counties that are economically and socially connected to the county-based metropolitan areas are considered a part of the metropolitan area. Non-metropolitan areas or counties are considered rural counties (RUPRI, 1999).

For more information:

Rural Policy Research Institute (RUPRI). (1999). *Rural policy context.* **http://www.rupri.org/policyres/context/index.html**

U. S. Census Bureau. (2000). *Census 2000 urban and rural Classification.* **http://www.census.gov/geo/www/ua/ua_2k.html**

Shepherd Center's Web-Based Learning Connections

***Roxanne Pickett Hauber, Ph. D., R.N.**, Manager and Nurse Researcher of the Telerehabilitation to Support Assistive Technology program at the Shepherd Center in Atlanta, talks about the use of telerehabilitation applications to provide follow-up support to recently-discharged patients, their families and their health providers. Implications and benefits of telerehabilitation applications for individuals from rural communities are discussed.*

NIDRR has provided leadership in redefining disability as "the product of an interaction between characteristics of the individual and characteristics of the natural, built, cultural and social environments" (Seelman, 2000). Within this new paradigm of disability one must consider:

- What is in an environment?
- Is it accessible and available to everyone?
- And if not, how can it be modified so that it will be universally user-friendly?

The new cyber-environment lends itself to being modified, even customized to the user so that resources and services are readily accessible. For that reason, cyber-environments have tremendous potential for changing the world for people with disabilities (Vesmarovich, Hauber and Jones, 2000). The use of these advances in telecommunications technology to inform and educate has resulted in the emerging field of interactive health communication (IHC) (Hauber, Vesmarovich and Testani-Dufour, in press).

In 1999, Shepherd Center in conjunction with Georgia Institute of Technology and corporate partners, Bell South, Cyber-care, and Siemens, Inc. were awarded a matching funds grant from the U. S. Department of Commerce National Telecommunications and Information Administration to develop a Next Generation Internet (NGI) network in the metro-Atlanta area linking patients' homes and rehabilitation service providers. Georgia, in general, is a rural state with a few major areas of urban concentration. Primary care clinicians cover the state reasonably well, but rehabilitation expertise for people with brain and spinal cord injury is limited to the major urban areas (Stachura, 2001). Therefore, mechanisms that can empower individuals with related disabilities and their families living in rural areas are crucial to optimize long-term outcomes.

Part of this project included the development of a server database that included disability-specific health and wellness information addressing patients' specialized care needs. This information is used to deliver, over the network, "just-in-time" interactive, multi-media instruction and support to patients and caregivers. The materials provide easy access to essential information about specific health care routines, community resources, and topics related to moving beyond disability such as travel, healthy life styles, recreation, and return to work and school. These instructional and resource materials can be accessed in the home, at work, at public libraries, in small clinics and anywhere people have access to the Internet.

"...cyber-environments have tremendous potential for changing the world for people with disabilities."

Prior to beginning this endeavor, a three-year retrospective survey of Shepherd patients was conducted to find out what percentage of our clients has access to computers and the Internet. Findings indicated that 73% of individuals surveyed had access to and used computers and 68% had access to the Internet (Hauber et al., in press). The survey also asked participants what types of health-related information they had found on the Internet that was useful, and what kinds of things they had not been able to find, but would like to have access to on the Internet. In addition, a consumer group made up of former Shepherd patients was initially brought together to discuss the kinds of information, resources, etc. they would find useful. Guidelines from the Science Panel on Interactive Communication and Health (1999) were used as the materials were developed.

All patients who receive rehabilitation services at Shepherd and their families are instructed on how to access and use the materials while they are in in-patient rehabilitation. To access this material go to Shepherd's website **http://www.shepherd.org/** ; Select *My Vital Connections*, choose *Patient Pages*, and then click on *Preview Page.*

Access to Disability Research Information by Rural Consumers:

Key Findings from the NCDDR 2001 Survey

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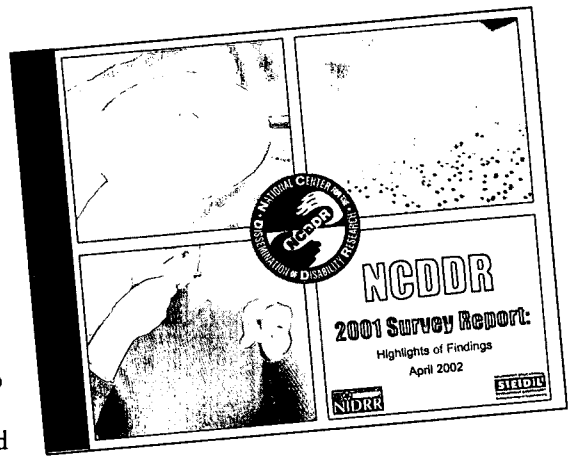
http://www.shepherd.org/shepherdhomepage.nsf/570df7070ad3783d852569c30075fbe2/bbc7c0e26a5568ab85256998007672a8

The NCDDR engages in an annual survey activity to help increase the knowledge base in the NIDRR community regarding the dissemination and utilization (D & U) of disability research findings. The survey focuses on obtaining information across major groups invested in disability research. A key component of the survey activity is to gain knowledge about what areas of disability-related research are important to consumers, how consumers prefer to receive disability research information, and how the use of computers and the Internet/Web are helping consumers' search for information. The knowledge gained helps to inform researchers from the NIDRR community about ways consumers with disabilities and their families obtain and use disability research information.

Survey participants included individuals with disabilities, representatives from organizations that focus on more direct consumer contact, and NIDRR-funded grantees). The consumer group consisted of people with disabilities and their families who participate in Independent Living Centers (ILCs) across the country. Following are some key findings from the *NCDDR 2001 Survey* concerning consumers with disabilities from rural areas and their information needs.



Demographics

- Thirty percent of the respondents reported they were from rural areas.
- The majority of rural respondents were female, aged 30-49 years, White, and had a physical/orthopedic disability.
- Thirty-one percent reported being employed full-time, while 23 percent reported they were unemployed and not seeking employment.
- Receiving information in English was preferred by the majority of rural consumers.

Disability Research Interests

- Rural consumers were most interested in research on independent living and community integration, followed by interest in research on legal/policy issues, research on assistive technology, and research on employment.
- Ninety-three percent of rural consumers agreed that disability research is useful, but fewer agreed (48%) they could easily find disability research.

Accessing Disability Research Information

- Rural consumers reported they contacted a community service provider/disability advocate most often (70%) when obtaining disability research information. Other approaches used to obtain information included calling a disability-related organization (64%); looking in brochures, fact sheets, or newsletters (56%); looking on the Internet (52%); and looking in research journals (25%).
- The majority of rural consumers (87%) preferred receiving disability research information via printed materials. Other preferred formats for receiving information included telephone/toll-free information line (78%); Internet/Web or e-mail (73%); pictures (62%); videotape (59%); and audiotape (54%).

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Hauber, R. P., Vesmarovich, S., & Testani-Dufour, L. (in press). The use of computers and the Internet as a source of health information for people with disabilities. *Rehabilitation Nursing.*

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Stachura, M. E. (2001). The Georgia state-wide telemedicine network: some lessons learned. *Journal of Telemedicine and Telecare.* 7(suppl.2) 62.

Vesmarovich, S. H., Hauber, R. P., & Jones, M. L. (2000). Using telecommunication technologies to change the world for people with disabilities related to catastrophic neurological impairment. *Cyberpsychology and Behavior.* 3(6) 925.

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Outreach Strategies of the RTC on Rural Rehabilitation Services

In an interview with Tom Seekins, Ph.D., Director of the Research and Training Center on Rural Rehabilitation Services (RTC:Rural) at the University of Montana, NCDDR staff learned of the dissemination strategies used by the RTC:Rural in their efforts to reach rural communities. Among other dissemination formats, Dr. Seekins described the use of technology and the associated social and economic barriers that preclude many rural residents from the equitable use of technology.

NCDDR: How does your project disseminate disability research information to consumers in rural/remote areas?

Seekins: As a national research center, we don't typically provide a lot of direct services. We are often in direct and intimate connection with consumers, people with disabilities, when we are working together on research projects designed to develop innovative practices. So, for example, one of our programs is a health promotion program called *Living Well With a Disability* that we've done around the country, working through rural centers for independent living. Well over 300 people with disabilities have participated in that and received services. So, in the sense that individuals with disabilities are participating in a research project that is designing or developing a new service model or new service program, we're in direct contact with consumers and providing them information and services.

Once the research is completed, our goal becomes broad dissemination of the findings and, when appropriate, broad adoption of the innovation. We use several strategies to accomplish that goal but the one that comes closest to reaching consumers involves our dissemination of the information that we gather, the findings, and the products that are developed from that research to what might be called intermediaries, that is service providers, support systems or networks. While the information that we develop from our research and other sources is available to individuals and we do provide information to some individuals, we believe our greatest impact comes from our research changing the way programs and service providers operate. Our perspective is that those networks are in place and their role is to reach the broad population. If they view our information and products as valuable, they will integrate them into their programs.

"...we believe our greatest impact comes from our research changing the way programs and service providers operate."

We disseminate information directly to the intermediaries in a couple of different ways. One is an electronic email distribution system that sends out, about once a month, research progress reports, rural practice guidelines and a series of brief fact sheets that summarize a finding or some important policy change or something that's going on that has implications for rural areas. A single paragraph abstract describing these information pieces goes out electronically with a Web site link for each, so that if the intermediaries read the electronic abstract and are interested in it, they can click on the specific Web site link and read more about the topic. We also have much more detailed information on these Web sites including further links to other resources.

It's important to say that we recognize that access to and use of the Internet in rural areas is much lower than in urban areas. So, in addition to the electronic system, we still maintain an actual mailing list used to send out the same information in hard copy as well. We don't feel that this is redundant. In fact, we look at it as using two different channels of communication for each of our messages.

In terms of a specific audience, what we have designed is a system that permits us to be very targeted in what we do disseminate and to whom we disseminate the information. We don't disseminate all the information we have to everybody on the mailing list. Depending on the content of the fact sheet or other information piece, we target our mailing to the constituent and intermediary groups that are really going to be interested in that particular topic.

One of the other important things that we have tried to do is use the media. A study on media and disability conducted by Cyndi Jones of the Disability and Rehabilitation Research Project to Disseminate Independent Living Research Information Through the Mass Media to Persons with Disabilities **http://www.accessiblesociety.org/** in San Diego found that most people with disabilities get most of their information about disability from mainstream media. And so, we took that to heart and tried to address the question, what media is most used in rural communities? There are two media

formats that we're trying to target. One is the use of small town and rural county newspapers. We have developed a mailing list of those around the country and we send them all of the information that we develop. We are also going to try to target the rural radio as well. For a lot of rural areas, radio is an important source of information. Unfortunately, we have not had the time or resources to evaluate the impact of this effort yet.

NCDDR: Who are some of these intermediaries that your project networks and collaborates with to help move disability research information to consumers in rural/remote areas?

Seekins: We have a list of about 36 different national service, advocacy, and support networks that do significant or substantial work in rural areas. So, for example, the Association of Programs for Rural Independent Living (APRIL) is a national association of Independent Living Centers that work in rural areas. The APRIL group is one network out of 36. There are 178 members of that group and probably about 120 of those are actually Centers for Independent Living. Our research shows that those programs serve over 25,000 individuals with disabilities living in rural areas annually. So, by targeting those 120 CILs, we hope to reach 25,000 people indirectly.

The 36 networks consist of major categories such as the Administration on Developmental Disabilities, American Indian Programs, the National Association of Protection and Advocacy Systems, and the National Rural Health Association, to name a few. These are further divided into different targeted groups.

Then we have the mailing addresses for all the regional and local vocational rehabilitation offices. It took us quite a while to develop this national listing of 1,235 vocational rehabilitation offices. We wanted to make sure that the contact persons receiving our information were vocational rehabilitation counselors who provide services directly to consumers. So, our information is reaching at least one contact person from 1,235 vocational rehabilitation programs that are working in rural areas. And so, that becomes an intermediary.

NCDDR: How successful are your dissemination strategies?

Seekins: One of the things we've tried to do in a couple of different cases is some systematic evaluation of satisfaction with the information that is provided. And we've run into a couple of problems with that. One is that when we have generic questions about satisfaction with materials that are distributed, they're not very meaningful questions because the information is too general. And so, the data we get back when we've asked generic questions have not been very useful. When we try to be more specific, the questions get so specific that we don't get very many responses. So, the combination of those two factors has led us to rely primarily on what we call spontaneous feedback.

What will happen, for example, is that we'll electronically send out a fact sheet on rural mental health issues and within the first week that it has been disseminated, we will have received a half a dozen responses electronically from some relatively well-known program directors and policy makers. Their feedback basically says thanks, this information is wonderful, send us some more, and how can we find out some more about this topic. That's one way we determine the utility of the information. We look at the number of comments we receive, the quality and content of the comments, and try to use that information to really shape what we disseminate in the future. It would be really nice to have more detailed evaluations of our dissemination activities, but the expense associated with evaluating it in terms of the funds we're able to allocate across all of our projects is more than we can afford at this point.

"...we can point to a broad range of impacts associated with the dissemination of our research."

What I can say, however, is that we can point to a broad range of impacts–changes programs have made in the way they go about their work–associated with the dissemination of our research. While that's the bottom line, we think we can do better and evaluation would help. It's just that we've chosen to invest our evaluation resources in the development of the research.

NCDDR: How does your project include consumers from rural/remote areas as participants in a research study?

Seekins: We believe we have a strong program of Participatory Action Research. Involvement varies pretty significantly depending on the topic or the issue we're trying to address. We tend to look at our constituents or the potential users of our research as not just people with disabilities, but also people who are those intermediaries, both from Centers for Independent Living, from rehabilitation programs, from Section 21 programs, or whoever they may happen to be. So, when we start off looking at a research project, we actually look at topics. We try to identify ahead of time research topics that are going to lead to programs that will have systems change effects. That is, changing the way that systems operate and are organized to be more conducive to promoting quality living for rural residents.

So, in the transportation program, for example, we worked very closely with staff and consumers of Centers for Independent Living and other kinds of community-based service programs, including developmental disability service programs to design and craft the program. When we went out to do the research, we worked with people representing those kinds of service networks. We worked with them to design and implement the model and facilitate the research and evaluation of the model. We collaborated on making modifications and designing something that would fit within the context of those service programs. Then, once we got it to a point where the research and evaluation showed that it was an effective model, we looked for ways of replicating it for wider use. In this case, APRIL secured a grant from the Rehabilitation Services Administration to demonstrate the utility of the program in ten states. The goal of this step is to demonstrate a program that can be sustained locally. In this way, the services eventually get to individuals with disabilities thus increasing their access to independent living, employment, and education

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Outreach Strategies of the RTC
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opportunities, areas to which they may not have had access earlier because of the lack of transportation.

NCDDR: What are some issues related to rural communities and access to telecommunications?

Seekins: A study Alexandra Enders did in collaboration with Dr. Stephen Kaye of the Disability Statistics Center at the University of California in San Francisco looked at the distribution of individuals with and without a disability who own a computer and use the Internet in metropolitan, suburban, central city and rural areas. The study found that people with disabilities who live in rural areas were less likely to own computers when compared to people with disabilities who live in metropolitan, suburban, and central city areas. This is a pretty consistent finding and similar to findings that disaggregate metropolitan areas into central city and suburban areas and then look at non-metropolitan or rural areas. Non-metropolitan areas and central cities have much more in common with each other than either has with suburban areas in the nation.

"...the percent of individuals who own a computer with no disability in central cities is about 47.4 percent. In rural areas it's 44.5 percent..."

For example, the percent of individuals who own a computer with no disability in central cities is about 47.4 percent. In rural areas it's 44.5 percent, so, you can see some similarity. In suburban areas, computer ownership is 58 percent. The percentage of individuals with a disability who own a computer in suburban areas is almost 30 percent compared to approximately 20 percent in central cities and rural areas.

Then, if you look at the percent of individuals who use the Internet in urban and rural areas and you look solely at people with disabilities, only 6.8 percent of the people in rural areas who report a disability use the Internet. So, it's somewhere around a third of those who have a computer are accessing the Internet. That means that about 93 percent of people with disabilities who live in rural areas do not use the Internet at this time. This has obvious implications for electronic dissemination practices.

Also, when you look at the demographics of income levels, poverty rates in rural areas are very, very similar to those in central cities, overall. A lot of people don't have that perception and understanding. They tend to look at rural areas as these bucolic areas of rolling farmlands and big families and happy times. There are a lot of myths that are invested in these kinds of concepts of rural living. But the reality is that rural areas are often very poor areas with disability prevalence rates that are higher than in urban areas.

Issues with access to telecommunications also include significant infrastructure problems that exist in rural areas. A couple of years ago, and you still see this from time to time, ads appeared in major metropolitan newspapers that said "sign up with blank Internet service, free access." If you read to the bottom of the advertisement, you'd see further information in small print "except in outlying areas that are difficult to access." Basically what those ads were saying is that if you live in a city, you can access the server free, but if you live in a rural area, you probably have to pay, not only a long distance call charge, but you may have to pay some other access fees. This presents an economic barrier to many rural residents.

In terms of the infrastructure, one of our staff, Alexandra Enders lives north of Missoula on a reservation, and she actually does a lot of work in telecommunications for our center. Although she owns a computer with access to the Internet, she has to drive in to the office to access the Internet. If she were to try to connect to the Internet from her home, it's a long distance telephone call to the server. And not only that, the quality of the cable infrastructure in her area and in a lot of rural areas is poor, still copper wire, which means that Internet access is extremely slow. The slow Internet access just means the cost will be even higher, since she's paying a long distance charge to access the Internet in the first place. So, despite the availability of the computer and Internet on her end, access to such telecommunications is a barrier due to the inadequate cable infrastructure.

There are a lot of national and state efforts to improve the infrastructure in rural areas for telecommunications. I think a sort of historic parallel to that might be like the rural electrification process during the early parts of the last century when there was a concerted federal effort to try to extend electricity services out into the rural areas of the country and later, on the heels of that, phone services. Cities and metropolitan areas all have the infrastructure much earlier than the rural areas and very similar kinds of processes are happening with the Internet and other types of telecommunications. But for the foreseeable future direct access to the Internet for information, services, and training for people with disabilities in rural areas is pretty limited.

We are presently conducting a study of Internet access and use for various service activities by rural centers for independent living. The surveys are literally out in the field and we're just starting to receive the data. In the past, we have been able to estimate that most centers for independent living serving rural areas do have computers and most do have access to the Internet.

However, there are a whole series of questions that have not been adequately answered. Questions like how many computers do they have? How many accounts do they have? How many staff has access to the Internet? How easy is it for them to get access to it? What's the capacity of their staff to locally use the potential capacity of electronic-based systems of computers and Internet, and even e-mail, for service delivery?

I think it's fair to say that the promises and declarations that are often made concerning how the use of the Internet or other telecommunications will be a boon for people with disabilities who live in rural areas,- are not yet true by any stretch of the imagination. Right now, it's a vision for the future. If those visions come true, there will be some substantial benefits. But right now it's just not the reality.

NCDDR: What general recommendations can you make to assist in guiding other NIDRR grantees in their efforts to disseminate information to rural audiences?

Seekins: We recommend working with systems or intermediary organizations. Given that we work in disability and rehabilitation under the Rehabilitation Act, we tend to view our "core constituency" as those systems in the Act. There are other systems that directly reach people with disabilities or that support those who do. If you have research that is valuable to them or their consumers, they provide a fantastic channel for dissemination. Better yet, if you have interest in research relevant to rural areas, use PAR approaches to work with those systems to design and conduct the research. That increases the likelihood that the results will address important issues, do so in appropriate ways, and produce significant outcomes. If your research meets those criteria, there's a good chance it will be adopted.

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For more details on studies mentioned in this interview see:

Rates of computer and Internet use: A comparison of urban and rural access by people with disabilities
http://ruralinstitute.umt.edu/rtcrural/TeICom/computer.htm

News coverage of disability issues
http://www.accessiblesociety.org/topics/coverage/

Strategies for Building Communication and Participation: Experiences from the Lower Mississippi Delta States

***Ari Mwachofi, Ph.D.**, Principal Investigator, Developing a Rehabilitation Service Delivery Model for Minority Farmers with Disabilities at the University of Arkansas, talks about how personal contact, the development of trust, and collaboration with community leaders–all integral components to successful research and dissemination activities with rural audiences–facilitated their research project.*

Background

The observations and suggestions presented here come from the experiences of a participatory action research (PAR) project, *Developing a Rehabilitation Service Delivery Model for Minority Farmers with Disabilities.* The purpose of the project is to build a dynamic and effective model of service delivery to minority farmers who have traditionally been underserved. The study involves farmers (rural residents) from the Lower Mississippi Delta (LMD) states–Arkansas, Louisiana, and Mississippi.

Dissemination strategies used to inform and recruit participants

The project began with a great deal of publicity informing farmers about the project's objectives so they would be prepared to meet with the project staff for interviews. Combinations of strategies were used to effectively disseminate the information. Strategies included use of the media, selection of key project staff, creating farmer-to-farmer referrals building farmer teams, contacting rural churches, collaborating with farmer organizations and agencies that work directly with farmers. The following are descriptions of strategies used to disseminate information about the project, recruit participants, and gather data for the research study.

Use of local media

Small locally-oriented newspapers were targeted to promote awareness about the project. These newspapers were more receptive and willing to publish articles than were the larger newspapers. Residents of small rural communities responded to these articles by requesting more information about the project. Articles were also published in rural newsletters such as *Farm Sense* and other farmers' cooperatives newsletters. These were especially effective because they targeted a particular audience of rural farmers. On occasion, the larger newspapers picked up the story about the project after it was published by the local newspapers. For instance, on 12/21/2001, *USA Today* published an article about the project after it had appeared in the local *Pine Bluff Commercial* newspaper. This provided the project with national publicity thus increasing awareness and willingness on the farmers' part to participate in the project.

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Strategies for Building Communication
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Collaboration with community leaders and local organizations

Staff contacted agencies that work directly with farmers such as the Cooperative Extension Service, Farm Service Agency, Natural Resource Conservation Service, and state vocational rehabilitation agencies in the three states. Letters were written to local community groups, farmers' cooperatives, churches, and farmer organizations such as the Black Farmers and Agriculturalists Associations, Southeast Arkansas Vegetable Growers Association, and other vegetable association cooperatives and farmers' cooperatives across the three states. These organizations were asked for assistance in disseminating information about the project and the research process to their members. Phone calls, meetings, and direct mailings were part of the information dissemination process. Other farmer-related organizations targeted included the Small Farm Projects at Southern University in Louisiana and at Alcorn State in Mississippi. This dissemination process proved to be effective because farmers soon began to call our project staff for more information.

Use of informal networks

In order to locate the most underserved farmers, the project went to rural churches, community groups, farmers' cooperatives, and other farmers' small organizations. Farmer-to-farmer referrals, where the farmers we talked to referred us to other farmers, were used and helped in building farmer teams to participate in the project. This was probably the most effective method because it also helped build the farmers' trust and willingness to communicate with us. Building of the farmer teams consisted of contacting active and influential farmers in the community, providing them with relevant project information, and emphasizing the benefits of the research for the participants. Once these key farmers understood the purpose of the project, they talked to other farmers about it. Community groups ranging from five to 20 farmers were formed. The project staff then set up informal meetings–we have learned that informal meetings work best when communicating with farmers–to further clarify project objectives and to recruit participants. Farmers with disabilities who were unable to join us at the community meetings were contacted in their homes where one-on-one interviews were conducted.

Use of researcher who is familiar with the culture of the target population

Perhaps the most useful strategy was the recruitment of key project staff. After a very slow start working with research assistants from academia, the project recognized the need to have a research assistant who understood the farming community. The project recruited and trained a female farmer who had been running a successful farm for the past 20 years and was preparing to retire from farming. She proved to be the greatest asset to the project. Her practical approach to the research study helped the farmers understand and be comfortable with the process of providing information via surveys and interviews. She brought to the project an understanding of farmers and how they operate and think. Not only did she know the best strategies to get farmers' attention, she knew many farmers and farming communities in Arkansas.

Development of trust through personal contact

The building of trust with the farmers was perhaps the most formidable challenge. Even after we found the farmers, we had to build their trust in us before they agreed to talk to us. In order to build that trust we resorted to unconventional interview methods. Farmers selected the meeting sites and we worked around their schedules. A very effective approach was to meet them in very informal situations. For example, after making contact with a key farmer who then contacted a group of farmers, a meeting would be set up in a local restaurant or at an outdoor evening cookout. This provided an informal and relaxed atmosphere. Farmers asked as many questions as necessary, and if willing, would fill out the questionnaires at the meetings. The assistance provided by the key individual farmers in organizing the farmer teams helped the project staff build the trust necessary for the success of the research project. Without them, the project would not have been able to get the farmers to respond to the survey questions.

"Even after we found the farmers, we had to build their trust before they agreed to talk to us."

Barriers to overcome

A difficult barrier for the project was locating the farmers to participate in the study. A comprehensive list of the farmers and their contact information was not available. Some of the agencies that serve farmers had lists of those farmers they serve and for legal reasons were not willing to share their lists. In any case, if we used their lists, we would be excluding the very farmers we wanted to talk to the most, that is, those who were not being served. In order to get a large enough sample of minority farmers, we used stratified random sampling. We focused on counties that had at least ten farmers who were minorities. From the 1997 Census of Agriculture statistics, the project located thirty-one such counties in Arkansas, 65 counties in Mississippi, and 42 parishes in Louisiana. The goal was to interview 200 farmers in each bringing for a total sample of 600 farmers.

Responding to the survey

Another challenge was the task of getting farmers' responses to the survey instrument. We found that a large number of farmers had genuine literacy difficulties and others just did not feel comfortable reading and/or writing. This problem was made more complicated by the length of the survey instrument and the personal nature of the questions. In an effort to overcome this problem, several methods were incorporated to obtain data. The most effective method consisted of going out to the field with student researchers who read the questions and recorded the farmers' responses on the surveys. Questions were also read to small groups of farmers and they, in turn, wrote their responses on the survey instrument.

Mistrust

The project found that farmers do not trust people from outside their communities. They become even more distrustful of any project that is even remotely connected to the government. The personal nature of most of the survey questions compounded this problem. The farmer teams used in the research process were essential in alleviating the farmers' mistrust of the project.

Racial issues

This is one challenge that we are still trying to resolve. Since we are from a historically Black university, we had difficulties getting white farmers to talk to us. On some occasions, we succeeded in meeting with them and obtaining survey responses from them. However, we are still trying to find ways to build an effective network with this

group of farmers. A possible idea that we may use in the future is emphasizing the similarities of the problems faced by the farmers, regardless of their racial status. The project intends to use these similarities as a way to promote the participation of white farmers.

Stage two of the project

In the second stage of the project, we are interested in learning about the farmers' perceptions and their recommendations on the best ways to serve them. Using lessons learned and the networks developed during the first stage, we changed our interview approach. In an effort to avoid the paperwork and mistrust issues experienced in the first stage, we decided to get the farmers' views through focus group discussions. Using the already established networks, we returned to the communities and located some influential and well-respected farmers. We trained 13 farmers (five in Louisiana and four each in the other two states) to facilitate focus group discussions with farmers in their communities. The purpose of these meetings was to gather the farmers' views about service delivery purely from their perspective without any outsiders' influence, thereby increasing opportunities for open and free discussions and decreasing mistrust.

The 13 farmer facilitators are in the process of conducting focus group meetings. So far (May, 2002), there have been 16 focus group discussions involving 216 farmers in the three states. The first stage survey results informed us that farmers generally have little knowledge about vocational rehabilitation services. As a result, we decided to combine outreach with stage two of the project. At the end of each focus group session, an agent from the state vocational rehabilitation agency provides information to the farmers about the agency's services. Thus, the focus group sessions serve several purposes: gathering feedback from the farmers, stimulating farmer participation in our research, and educating farmers with and without disabilities about vocational rehabilitation services in the state.

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Home-Based Video-Counseling for Rural At-Risk Adolescents with Epilepsy and Their Parents

***Robert L. Glueckauf, Ph.D.**, Principal Investigator of Home-Based Video-Counseling for Rural At-Risk Adolescents with Epilepsy and their Parents at the University of Florida, shares some of their participant recruitment and information dissemination experiences from their project's research with teenagers who reside in rural communities across five Midwest and three Southeast states.*

Project Background

Teenagers with epilepsy are likely to confront a variety of psychosocial and educational difficulties in coping with their medical conditions. Adolescents with seizure disorders are at a greater risk for developing psychological and school-related problems than are other teenagers with chronic disabilities as well as those without disabilities. Although advocacy organizations have called for the development of family counseling programs to address these difficulties, there continues to be a substantial gap between consumer needs and availability of epilepsy-related family services. The most damaging effect of this shortage of services can be found in rural areas, where local resources are limited and transportation to major medical centers poses severe obstacles to adequate specialty care. Counseling services for teenagers with epilepsy and their parents in rural America are at best inadequate and in most cases nonexistent (Glueckauf, Whitton, & Nickelson, 2002).

The primary purpose of this NIDRR-funded study is to assess the differential effects of *videoconferencing-based* versus *speakerphone-based* versus *face-to-face family counseling* on the psychosocial and educational functioning of at-risk rural teenagers with epilepsy. The intervention consists of six sessions of issue-specific family counseling provided in one of three service delivery modes: (a) home-based, video family counseling (VFC); (b) home-based, speakerphone family counseling (SFC); or (c) office-based family counseling (OFC). This multi-site investigation is still in progress and involves over 75 families of teenagers with seizure disorders who reside in rural communities across five Midwest and three Southeast states.

The first phase of the study involved participants from rural areas in five Midwest states: Indiana, Ohio, Kentucky, Illinois, and

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Michigan. A total of 39 rural Midwest families were recruited over a period of two years to participate in the project. Twenty-two teenagers with seizure disorders, 14 males and eight females, with a mean age of 15.4, and their parents (n = 36) completed Phase 1 of the project. The most cited reason for participant dropout was transportation problems (e.g., no vehicle and/or long distance travel would add wear and tear on their only vehicle).

Phase 2 of the study includes participants from rural areas across three states: Southeastern Alabama, Southern Georgia, and North and Central Florida. Phase 2, which includes an additional 36 families, is a replication of the Phase 1 study and will be completed by the end of the year.

Outreach strategies used to recruit participants

The following strategies were used to recruit participants for both phases of the study:

- Research project information was distributed via mass mailings of fliers and information packets to school counselors and nurses in middle and high schools in the rural areas. This strategy was the most successful format used to recruit participants for Phase 1 of the study. School counselors were responsive to the request for project participants and facilitated the distribution of the project information to the targeted adolescents. This strategy, however, did not prove as successful for Phase 2 of the study. One reason for the limited response to fliers and information packets may lie in the centralized control of research initiatives in Florida secondary schools, our primary recruitment target. Although we received approval for the project from the Florida Department of Education authorities, there were periodic inquiries from school administrative staff about the need for state authorization before information could be inated to prospective participants. Note that there were no such inquiries from Midwest rural schools in Phase 1 of the study.

"...Newspaper advertisements, television public service announcements and radio public service announcements were also considered successful formats."

- Print and other media were also used to recruit rural teens with epilepsy and their parents. Although a limited project budget precluded extensive use of these formats, newspaper advertisements, television public service announcements, and radio public service announcements were also considered successful formats for recruiting research participants for both Phase 1 and Phase 2 of the study.

- An additional participant recruitment effort included letters submitted to patients at neurology clinics. For Phase 1, letters were sent from Indiana University's Riley's Children Hospital to prospective rural teen-agers with seizure disorders and their families. This proved to be the least successful format used to recruit participants for Phase 1 of the study. Lack of personal contact to the patients may have been the reason for this recruitment effort's lack of success.

- However, letters sent to patients was the most successful format used to recruit participants for Phase 2 (Southeastern states of FL, GA, and AL) of the study. Letters were sent from the Division of Pediatric Neurology, College of Medicine at the University of Florida to adolescent patients who were enrolled at the Pediatric Neurology epilepsy clinic. Following the mailing of the letters, personal invitations to participate were made via telephone calls by research staff from this regional clinic.

Dissemination strategies used in informing rural population about project's work

The University of Florida Center for Research on Telehealth and Healthcare Communications, where the NIDRR project is currently housed, deploys a variety of strategies to inform rural consumers with disabilities about Center projects. Primary recruitment approaches include: (a) family forums at rural community centers, and (b) distribution of project brochures and fliers at local health departments, support groups, consumer organizations, and child service agencies. We also have created project CD-ROMs for distribution across several venues, including caregiver forums, schools, countywide jamborees, and rural conferences.

Dissemination of project research outcomes to participants from rural communities

Preliminary research results were published twice yearly in project newsletters. The newsletters were written in lay language to enhance readability and comprehension. Several families responded with notes of gratitude.

Barriers in dissemination and outreach strategies

A significant barrier to recruitment of research participants was the project's requirement that all families drive to the initial assessment session located at Dr. Glueckauf's university-based intervention suite. The principal investigator and project staff felt that due to the experimental nature of the study, it was ethically and therapeutically necessary to meet each family face-to-face before randomly assigning them to a home- or office-based counseling intervention. This would assure that the teens with epilepsy and family members had at least one direct personal contact with project counselors and research staff before counseling was initiated. A $60 honorarium and food coupons were provided to each family to defray the costs of travel. Unfortunately, despite our positive intentions, approximately 30% of families who expressed an interest in participating in the project did not attend the first assessment and subsequently, dropped out from the study. In future telehealth studies with rural populations, we plan to conduct the initial assessment session at the family's home to reduce pre-intervention attrition.

For more detailed information on this project, see the Special Focus Section on Telehealth and Chronic Disabling Conditions of Rehabilitation Psychology, Volume 47, Issue 1, February 2002.

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Glueckauf, R. L. (2002). Telehealth and chronic disabilities: New frontier for research and development. *Rehabilitation Psychology*, 47, 3-7.

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Implications:

Targeting Dissemination and Utilization to Rural Residents with Disabilities

Given the previous comments from NIDRR grantees, what does this tell us about dissemination and utilization to rural residents with disabilities? The following are implications that may be helpful in planning and implementing dissemination efforts that are targeting people with disabilities in rural environments:

1. Ensure that the information to be shared has been targeted appropriately to rural residents with disabilities.

Due to the differences in environmental infrastructure in rural environments, special considerations in your "message" would appear to be warranted in some cases. Establish that the message you are offering is targeted especially to "FIT" rurally-based people with disabilities.

2. Format or tailor your message appropriately to "fit" the known characteristics of rural residents.

Some evidence would tend to indicate that people with disabilities in rural environments might be less well educated than some of their more urban/suburban counterparts, therefore, tailor your message appropriately. Be aware of language usage and reading level in stating and communicating your message.

3. Do not assume that electronic formats will comprehensively reach rural residents with disabilities.

Data indicates that rural populations exhibit higher rates of poverty than in central cities. Do not assume that rural residents have access to computers, email, online Internet services, and World Wide Web resources.

4. Utilize multiple formats for communicating your message, especially those that currently actively network with rural populations.

Identify rural media outlets that target the area(s) you are trying to reach. Rural newspaper and radio media can be effectively used in rural outreach to people with disabilities.

5. Identify associations, organizations, or groups that are currently networking rural residents and use them as an informational outlet.

Data indicate that rural residents represent higher than expected rates of disability. Reaching into existing rural networks can be effectively in reaching target audiences within the rural population.

6. Use social networks as a way to spread targeted messages.

Churches, schools, and businesses can be centralized sources to reach many rural residents. Use these to target information that can be used specifically by rural residents with disabilities. Enlist their assistance in reaching others that may be in need of the information.

7. Avoid establishing "conditions" that must be met by rural residents to receive needed information.

Evidence indicates that rural residents exhibit high rates of poverty. Establishing costs with the receipt of information, no matter how reasonable, will establish a barrier between the intended recipient and the needed information.

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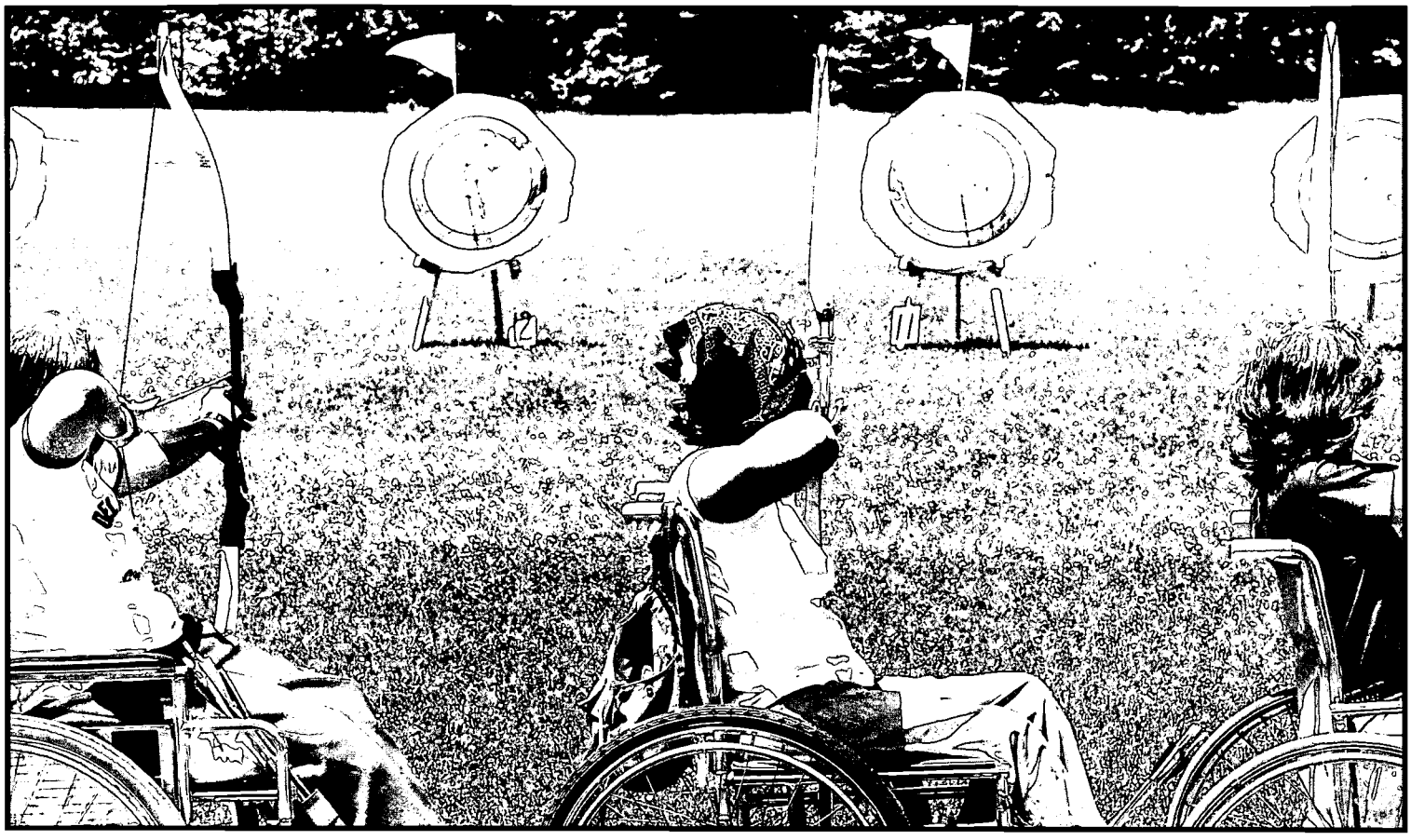

Implications
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8. Be aware that cultural diversity characteristics should influence your rural information dissemination efforts.

Trust can play a major role in how credible and reliable your "message" and its source are perceived to be. Be aware that cultural differences can play a part in these perceptions and maximize ways in which within-group dissemination can be organized and supported by your efforts.

9. Be sensitive to age-related issues of rural residents including those with disabilities.

Data indicates that rural residents tend to be older than their urban counterparts. Your dissemination efforts and selection of formats for communicating that information should recognize age-related needs in addition to disability-related needs.

10. Recognize that transportation issues exist with rural settings and minimize need for physical transportation.

Assuming that rural residents with disabilities and their families can congregate in situations requiring transportation may not be accurate. Due to the infrastructure of most rural environments such transportation requirements in a planned information dissemination activity would seem to inhibit participation.

11. Involve rural residents with disabilities in multiple aspects of your research activities – such as in Participatory Action Research (PAR) – in order to facilitate your dissemination.

The use of PAR and other participation enhancing activities will increase the "fit" of your research with the intended user audience. Involving rural residents with disabilities in this process will make utilization easier and appropriate dissemination channels clearer.

12. Ask for feedback from rural residents with disabilities not only about your information but also your dissemination strategies.

Recipients of information are easily able to tell you what they think of what you have to share with them for use. In addition, they are generally more than happy to tell you how easy or difficult it was to access or receive the information.

This information should be valuable to researchers as you tailor dissemination activities to meet the needs of specific user groups – such as rural residents with disabilities.

Conclusion

Many features and strategies are apparent to researchers that are interested in developing or improving your outreach efforts targeting rural residents with disabilities.

As with any dissemination effort, the degree your resulting efficiency and effectiveness rests upon the "fit" between the:

- characteristics of the intended user group,
- perceived need for the content of the information shared,
- context through which the content of your information must be accessed, and
- media through which you distribute the content.

Related Resources on Rural Issues

Administration on Developmental Disabilities

http://www.acf.dhhs.gov/programs/add/

Ensures that individuals with developmental disabilities and their families participate in the design of and have access to culturally competent services, supports, and other assistance and opportunities that promotes independence, productivity, and integration and inclusion into the community.

Association of Programs for Rural Independent Living (APRIL)

http://april.umt.edu/

APRIL is a national network of rural independent living centers, other programs, and individuals concerned with the unique aspects of rural independent living.

Directory of Rural Assistive Technology Resources

http://pasture.ecn.purdue.edu/ABE/Extension/BNG/plowshare22.html

A listing of resources, services, agencies, and programs that serve farm and rural families with disabilities.

Links to information about rural issues

http://www.ilru.org/news/NewsLetter/June2000/RuralLinks.htm

National Association of Development Organizations (NADO)

http://www.nado.org/links/index.html

Resource links for training, information, and representation for regional development organizations serving small metropolitan and rural America

National Association of Protection and Advocacy Systems (NAPAS)

http://www.napas.org/

NAPAS, the voluntary national membership association of protection & advocacy systems and client assistance programs,

National Rural Development Partnership (NRDP)

http://www.rurdev.usda.gov/nrdp/what.html

NDRP works to strengthen rural America through collaborative partnerships. The NRDP brings together partners from local, state, tribal, and federal governments, as well as from the for-profit and nonprofit private sector.

National Rural Health Association (NRHA)

http://www.NRHArural.org/

NRHA is a national membership organization, consisting of approximately 2000 members, whose mission is to improve the health and healthcare of rural Americans and to provide leadership on rural issues through advocacy, communications, education and research.

Rural Education

http://www.ael.org/eric/rural.htm

ERIC Clearinghouse on Rural Education and Small Schools (ERIC-CRESS)

Rural Health Care Links

http://www.commerce.usask.ca/ faculty/backman/ruralsit.htm

Listing of Canadian and International sites (including U.S.)

Rural Information Center Health Service (RICHS)

http://www.nal.usda.gov/ric/richs /index.html

RICHS is a joint project of the Office of Rural Health Policy (ORHP), Department of Health and Human Services, and the National Agricultural Library (NAL), United States Department of Agriculture. Operating as part of NAL's Rural Information Center (RIC), RICHS collects and disseminates information on rural health issues.

Rural Policy Research Institute (RUPRI)

http://www.rupri.org/

RUPRI provides objective analysis and facilitates public dialogue concerning the impacts of public policy on rural people and places.

U. S. Census Bureau:

- **Selected Historical Decennial Census, Urban and Rural Definitions and Data**
  http://www.census.gov/population/www/censusdata/ur-def.html
- **Revised standards for defining metropolitan areas in the 1990s**
  http://www.census.gov/population/www/estimates/mastand.html
- **Census 2000 Urban and Rural Classification**
  http://www.census.gov/geo/www/ua/ua_2k.html

Who's in the News

NCDDR staff members are on the lookout for popular and disability media pieces that present research funded by NIDRR.

In this issue, we share news items from the

- ***St. Petersburg Times***,
- ***Boston Globe***,
- ***HR Magazine***,
- ***Chicago Tribune***, and
- ***Atlanta Journal Constitution***.

Please let the NCDDR know when an item representing your NIDRR-funded project appears in the media. Call 1-800-266-1832, or send an email to **ncddr@sedl.org** and we will review it for Who's In The News. You may also use an online form: **http://www.ncddr.org/forms/submitnews.html**

St. Petersburg Times Online posted an article in the Tech Times section entitled *Tech Able* on March 11, 2002. The article discusses accessibility to mainstream technology by people with disabilities, the progress to accessibility that is being made as awareness of needs grows, and how the technology developed for people with disabilities is becoming mainstream as the population ages. The article features two NIDRR-funded projects.

- Katherine Belknap, Project Director of ABLEDATA, agrees that technologies have become more mainstream, "One of the best examples is voice recognition software. It originally began as a way to make computers accessible for people who didn't have use of their hands." She notes that voice recognition software is a "critical tool" for many who work with computers. The ABLEDATA project maintains a Web site that contains information on assistive technology and rehabilitation equipment and, in addition, provides information, links, and resources to meet the special technology product needs of consumers and professionals. For further information contact **Katherine Belknap**, Project Director, at belknap@macroint.com or at **301-608-8998**.

- Geoff Freed, Project Manager at the CPB/WGBH National Center for Accessible Media (NCAM) at the WGBH Educational Foundation in Boston comments on the issue of Web accessibility. Although he believes that "Web sites are designed more sensibly" than they used to be, he feels that Web accessibility "is not as widespread as it needs to be." NCAM is a research and development facility dedicated to creating access solutions for existing and emerging media technologies. For further information, contact Geoff Freed at geoff_freed@wgbh.org or at 617-300-4223.

The article originally appeared in the technology section of the March 11 print edition of the **St. Petersburg Times**. The article was written by **Dave Gussow**, Personal Technology Editor at the St. Petersburg Times, who contacted the NIDRR-funded projects for information. When asked why he selected these two projects for information on technology and people with disabilities, Mr. Gussow responded, "I was aware of the National Center for Accessible Media beforehand, though it was also mentioned by at least one other person interviewed for the story. I found ABLEDATA while doing research on the Web and called." An online version of the article is available at **http://www.sptimes.com/2002/03/11/Technology/Tech_able.shtml**

URLs for Web version only:

http://www.sptimes.com/
St. Petersburg Times Online

http://www.abledata.com/
ABLEDATA

http://ncam.wgbh.org/
National Center for Accessible Media (NCAM)

The **Boston Globe** published an article in their Sunday "BostonWorks" section on November 11, 2001 entitled *Technologically Enabled*. The focus of the article is on how assistive devices have made it possible for individuals with disabilities to enter the work force, maintain quality employment, and increase their career opportunities. A recent announcement made by Rush Limbaugh, talk show host who has lost his ability to hear, exemplifies "technology's ability to help those with disabilities enter–and remain–in the work force." Limbaugh vows that he will find ways to continue to communicate in spite of his hearing loss. William Kiernan, Ph.D., Director of the Institute for Community Inclusion (ICI) notes, "His announcement is symbolic because, essentially, he has said his hearing loss will not seriously compromise his ability to work, and he is correct." The ICI identifies and supports effective practices that facilitate participation in all aspects of the community, including employment, for individuals with disabilities. Featured in the article are excerpts of positive experiences with assistive technology told by individuals with disabilities whom the ICI assisted on the job.

Dr. Kiernan is Principal Investigator of the NIDRR-funded RRTC on State Systems and Employment. The RRTC is a project of the Institute for Community Inclusion/UCE at Children's Hospital and the University of Massachusetts Boston. He is also a Research Associate in Medicine at Children's Hospital and Adjunct Professor in the Graduate College of Education at UMass Boston. He can be reached at **william.kiernan@tch.harvard.edu**

The article was written by **Diane E. Lewis**, a staff writer with the ***Boston Globe***. The reporter, who worked closely with ICI staff to develop the piece, was initially contacted by ICI staff. Previously identified as a journalist "who covered workplace/labor issues for the city's largest paper," the ICI staff made it a point to periodically submit press releases and workshop announcements to Ms. Lewis. This ongoing contact by ICI staff developed into an opportunity to pitch a story on "the technology spin on employment," a topic that Ms. Lewis was interested in pursuing.

For further information contact **Danielle Dreilinger**, Communications Specialist, at **danielle.dreilinger@tch.harvard.edu** or at **(617) 355-2211**. An online version of the article is available for a fee in the ***Boston Globe's*** archives at **http://www.boston.com/globe/search/**

URLs for Web version only:

http://www.boston.com/globe/
The Boston Globe

http://www.childrenshospital.org/ici
Institute for Community Inclusion

http://www.childrenshospital.org/ici/rrtc/
RRTC on State Systems and Employment

http://www.childrenshospital.org/
Children's Hospital

http://www.umb.edu
University of Massachusetts Boston

HR Magazine, an official publication of the Society for Human Resource Management (SHRM), published an article entitled *Enabling Safe Evacuations* in January, 2002. Written following the September 11 tragedy, the article focuses on emergency preparedness and safe evacuation planning. According to the article, "The Americans with Disabilities Act (ADA) requires employers to modify their policies and procedures to include people with disabilities. These requirements apply also to evacuation plans." The authors note that those responsible for devising new plans and procedures for the safe evacuation from buildings "need to ensure that their plans include everyone." Ten steps are featured in the article that can assist employers in implementing safe emergency evacuation procedures for all their employees, including individuals with disabilities.

The article was co-authored by Susanne Bruyère, Ph.D., Director of the Program on Employment and Disability at Cornell University and by William G. Stothers, Deputy Director of The Center for an Accessible Society. Following the events of September 11, The Center for an Accessible Society contacted Elaine Ostroff, founder of Adaptive Environments Center, and with her help contacted all the NIDRR Centers working on Universal Design, and over 80 other experts that work on safety and universal design issues for people with disabilities. Mr. Stothers gathered the resources and information on safe evacuation plans and emergency preparedness to help employers and human resource personnel meet the needs of employees with disabilities during emergencies.

To disseminate the information to the intended audience, the authors pitched their story to ***HR Magazine***, whose readership includes over 165,000 members of the Society for Human Resource Management, the "world's largest association devoted to human resource management." Previous work and contact with SHRM by Dr. Bruyère facilitated the publication of the article. An online version of the article is available at
http://www.shrm.org/hrmagazine/archive/

For further information, contact **William G. Stothers** at **wstothers@accessiblesociety.org** or **(619) 232-2727**, and **Dr. Susanne Bruyère** at **smb23@cornell.edu** or **(607) 255-7727**.

URLs for Web version only:

http://www.shrm.org/hrmagazine/
HR Magazine

http://www.shrm.org
Society for Human Resource Management

http://www.accessiblesociety.org
The Center for an Accessible Society

http://www.ilr.cornell.edu/ped/
Program on Employment and Disability

http://www.adaptenv.org/
Adaptive Environments Center

The ***Chicago Tribune*** published an article entitled *Accommodate ADA and Get on with Business* on January 9, 2002. The article reflects on the decade-long debate about what constitutes a disability under the Americans with Disabilities Act (ADA) and how this ongoing debate costs society in terms of delayed justice and litigation fees. Noted in the article is the fact that "smart" businesses have moved on and "accepted the spirit of the ADA", and thus have experienced "improved employee morale, reduced turnover, and savings on retraining costs by implementing progressive ADA programs." In addition, these businesses have discovered that making "reasonable accommodations" is, in fact, a cost-effective venture. Despite these insights, however, some companies still refrain from hiring individuals with disabilities because they fear the high costs for accommodations and ADA-related litigation.

Quoted in the article is Peter Blanck, Ph.D., J.D., and Director of the Law, Health Policy & Disability Center at the University of Iowa College of Law. Dr. Blanck, a leading ADA advocate who has researched ADA's impact on work places, comments on why some businesses resist the law. "It's a general maxim that the federal government is seen as intrusive and disruptive to an employer's judgment," he says. "Some resist [embracing the ADA] even if it doesn't make a bit of difference to their cost."

Dr. Blanck is Principal Investigator of two NIDRR-funded research projects–the RRTC on Workforce Investment and Employment Policy for Persons with Disabilities and I. T. (information technology) Works. In addition he is a Professor of Law, of Psychology, and of Occupational Medicine at the University of Iowa.

The article was written by **David Greising**, a Business Columnist with the ***Chicago Tribune***. An online version of the article is available for a fee in the ***Chicago Tribune's*** archive at
http://pqasb.pqarchiver.com/chicagotribune/

For further information, contact **Dr. Peter Blanck** at **peter-blanck@uiowa.edu** or at **(319) 335-9043**.

URLs for Web version only:

http://www.chicagotribune.com/
The Chicago Tribune

http://www.its.uiowa.edu/law
Law, Health Policy & Disability Center

http://www.its.uiowa.edu/law/lhpdc/rrtc/index.html
RRTC on Workforce Investment and Employment Policy for Persons with Disabilities

http://www.uiowa.edu/
University of Iowa

The ***Atlanta Journal-Constitution's*** Sunday edition published an article in their Personal Technology section entitled *Enabling The Disabled: Science Helping Restore Brain, Body Connections* on February 10, 2002. The article focuses on the use of current and future assistive technology to help people with disabilities, and the variable costs involved in purchasing the technology – "everything from off-the-shelf systems...that turn lights on and off wirelessly to one-of-a-kind technological marvels..." Although purchasing "off-the-shelf" technology involves minimal expense, "technological marvels" that now include brain-computer interfaces that will be able to restore useful muscle movement to persons with paralyzing injuries can be quite

continued on page 18

Who's in the News, *continued from page 17*

expensive. The author notes that finding the technology can sometimes be much easier than finding the funds to pay for it. Featured in the article is Michael Jones, Ph.D., Principal Investigator of the NIDRR-funded project Telerehabilitation to Support Assistive Technology at the Shepherd Center in Atlanta, Georgia. He agrees that technology to help people with disabilities can be expensive, especially when it comes to "new" technology.

Dr. Jones is working on new technology that will monitor a person's movement in a wheelchair by the use of sensors and audible warnings. He states that for persons in wheelchairs, periodic movement is essential to avoid the development of pressure ulcers. Acknowledging that the expense of new technology can be quite a burden for persons with disabilities, he believes that returning a person to a productive life is important and that all of us should be concerned with the expense of assistive technology since its use is also something to be considered by aging persons. Jones states, "Whether we are talking about doorways or streets or buildings that are more accessible, it's an issue that all of us will confront sooner or later."

The article was written by **Bill Husted**, Personal Technology editor, of the ***Atlanta Journal-Constitution***. Mr. Husted contacted the Shepherd Center for information on his story idea. Over the past years, the Shepherd Center's media relations manager has actively marketed story ideas to Mr. Husted, and as a result, he is familiar with the Center's work in this area. An online version of the article is available for purchase in the ***Atlanta Journal-Constitution's*** Archives.

Two other NIDRR-funded projects are currently administered by the Shepherd Center. These include the *Georgia Regional Spinal Cord Injury Care System* and *Aging after Spinal Cord Injury: Three Decades of Longitudinal Research.*

For further information, contact **Kim Lathbury**, Shepherd Center Media Relations Manager, at **Kim_Lathbury@shepherd.org** or **(404) 350-7708.**

URLs for Web version only:

http://www.ajc.com/
Atlanta Journal-Constitution

http://www.shepherd.org/
Shepherd Center

NIDRR Grantee and Staff Recognition

The NCDDR continues to share the recognition given to NIDRR-funded researchers and their staff. All grantees are encouraged to send this information to the NCDDR for future issues. Email **ncddr@sedl.org**, call **1-800-266-1832**, or use the online form available on the NCDDR Web site: **http://www.ncddr.org/forms/submitrecog.html**

The American Association for Psychosocial Rehabilitation (AAPR) has awarded the *2001 Alice Fordyce Public Service Award* to **William A. Anthony, Ph.D.**, Executive Director and founder of the Center for Psychiatric Rehabilitation (CPR), Sargent College of Health and Rehabilitation Sciences at Boston University. This award recognizes his lifelong work in the field of psychiatric rehabilitation as a researcher, educator, and clinician. The award was presented to **Dr. Anthony** at the AAPR's 10th Annual United Nations Award Luncheon on March 13, 2002 in New York City. There are currently four NIDRR-funded projects housed at the CPR, including the **RRTC in Rehabilitation for Persons with Long-term Mental Illness.** For more information, contact **Dr. William Anthony** at **wanthony@bu.edu**

URLS for Web version only:

http://www.bu.edu/sargent/
Sargent College

http://web.bu.edu/cpr/
Center for Psychiatric Rehabilitation

http://www.bu.edu/cpr/research/rtc2004/
RRTC in Rehabilitation for Persons with Long-term Mental Illness

Tom Seekins, Ph.D., Director of the **Research and Training Center on Rural Rehabilitation (RTC: Rural)**, University of Montana, was awarded the first *Earl Walden Award for Outstanding Achievement in Rural Advocacy.* The award was presented to Dr. Seekins at the Association of Programs for Rural Independent Living (APRIL) Seventh Annual National Conference on Rural Independent Living in Portland, Oregon, November 3-5, 2001.

The award has been established by APRIL and Independent Living Research Utilization (ILRU) at The Institute for Rehabilitation and Research (TIRR) in Houston, Texas, in honor of the late Earl Walden, long time colleague and friend to APRIL and ILRU. Walden was instrumental in assisting APRIL in its early days of growth. APRIL, a nonprofit organization, is a national network of rural independent living centers that focus on rural independent living issues. For more information on the award and APRIL, contact Linda Gonzales, Executive Director, at 330-678-7648 or visit their website at **http://april.umt.edu/**
For further information, contact **Diana Spas**, RTC: Rural Information Specialist at **gargoyle@selway.umt.edu** or call her at **(406) 243-5760.**

URLS for Web version only:

http://ruralinstitute.umt.edu/rtcrural
RTC on Rural Rehabilitation

http://april.umt.edu/
The Association of Programs for Rural Independent Living (APRIL)

http://www.ilru.org/
Independent Living Research Utilization (ILRU)

http://www.tirr.org/
The Institute for Rehabilitation and Research (TIRR)

http://www.umt.edu/
The University of Montana

Two University of Pittsburgh researchers were recognized as *2002 Health Care Heroes* by the Pittsburgh Business Times at a March 7, 2002 awards ceremony in Pittsburgh. **Michael L. Boninger, M.D.**, Director of the Center for Assistive Technology (CAT), University of Pittsburgh/UPMC Health System, was awarded the *Health Care Innovation and Research Award*, one of six *Health Care Hero*

Award categories. The *Lifetime Achievement Award* winner was **Dr. Clifford Brubaker**, Dean of the School of Health and Rehabilitation Sciences at Pitt. The annual awards are given in recognition of "outstanding people and organizations that are making significant strides in the local health care field."

Dr. Boninger's research and work at the CAT have helped establish the Center as a "leader and innovator in the assistive technology industry" and as "the world's premier clinic providing technology for people with disabilities." He is currently the Research Director for the University of Pittsburgh's Department of Physical Medicine and Rehabilitation and the Medical Director for the Human Engineering Research Laboratories (HERL). **Dr. Boninger** is Principal Investigator for two NIDRR-funded projects, the **University of Pittsburgh Model Center on Spinal Cord Injury** and **Collaboration on Upper Limb Pain in Spinal Cord Injury**. Contact Dr. Boninger: **mlboning@pitt.edu**

Dr. Brubaker is described by his colleagues "as an educator, community leader, inventor and creator of disciplines." For over thirty years he has been involved in "refining a multidisciplinary educational and research model to address the full spectrum of rehabilitation. His educational model is now setting the standard for rehabilitation training programs throughout the world. " He is currently Co-Principal Investigator for the NIDRR-funded **RERC on Wheeled Mobility**, and PI for the **Research Training in Rehabilitation Science with Special Emphasis on Disability Studies** project. Contact Dr. Brubaker: **ceb1+@pitt.edu**

Read these online articles, with free registration for the online Pittsburgh Business Times:

http://www.bizjournals.com/pittsburgh/stories/2002/03/04/daily41.html
Six local health care professionals recognized

http://pittsburgh.bizjournals.com/pittsburgh/stories/2002/03/18/focus2.html
Innovation and Research Award: Michael Boninger

http://pittsburgh.bizjournals.com/pittsburgh/stories/2002/03/18/focus6.html
Lifetime Achievement Award: Clifford Brubaker

URLS for Web version only:

http://www.bizjournals.com/pittsburgh/
Pittsburgh Business Times

http://www.cat.pitt.edu/
Center for Assistive Technology

http://www.shrs.pitt.edu/
School of Health and Rehabilitation Sciences

http://www.herlpitt.org/
Human Engineering Research Laboratories (HERL)

http://www.upmc-sci.org/
University of Pittsburgh Model Center on Spinal Cord Injury

http://www.upmc.com/
UPMC Health System

Marian Minor, P.T., Ph.D., a researcher and principal investigator with the **Missouri Arthritis Rehabilitation Research and Training Center (MARRTC)**, was the recent recipient of the *Virginia P. Engalitcheff Award for Impact on Quality of Life*. The award was presented by the Arthritis Foundation during the foundation's National Meeting on November 17, 2001 in San Jose, California. The award recognizes "a specific achievement by an individual, organization, product or body of research that makes a dramatic impact on the quality of life for people with arthritis." **Dr. Minor's** extensive contributions both nationally and internationally in the form of research, publications, presentations, development of educational materials, and development of community-based exercise facilities have made a substantial impact on the lives of people with arthritis. **Dr. Minor**, a physical therapist, is an Associate Professor in the School of Health Professions at the University of Missouri-Columbia. See full story on the MARRTC Web site: **http://www.muhealth.org/~arthritis/spotlight/minor5.html**

Dr. Minor can be reached at **minorm@health.missouri.edu** or **(573) 882-1579.**

Karen Smarr, a senior research specialist with **MARRTC**, was named 2001 *Outstanding Graduate Student of the Year* by the Council of Counseling Psychology Training Programs (CCPTP) during an awards ceremony on August 24, 2001 at the national convention of the American Psychological Association in San Francisco. The CCPTP is a non-profit organization that represents about 75 doctoral programs in counseling psychology. Presented by the CCPTP, the annual award is given based on "evidence of quality scholarly contributions, professional contributions, distinctiveness of such contributions and the student's promise as a future scholar-professional." **Ms. Smarr** is the first University of Missouri-Columbia student to receive the award since its inauguration in 1997. An online story is available at **http://www.muhealth.org/~arthritis/spotlight/smarr2.html**
Smarr can be reached at **(573) 814-6000**, ext. 3679 or by email at **smarr.Karen@columbia-mo.va.gov**

For more information on MARRTC items contact **Dianna Borsi O'Brien**, MARRTC Senior Information Specialist, at **obriendi@missouri.edu** or **(573) 882-2914**.

URLS for Web version only:

http://www.muhealth.org/~arthritis/index.html
Missouri Arthritis Rehabilitation Research and Training Center (MARRTC)

http://www.arthritis.org
The Arthritis Foundation

http://www.apa.org/
The American Psychological Association

http://www.lehigh.edu/ccptp/
The Council of Counseling Psychology Training Programs

http://www.missouri.edu/
University of Missouri-Columbia

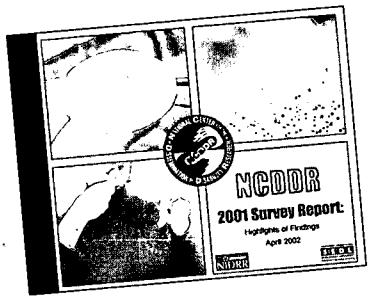
Access to Disability Research Information by Rural Consumers, *continued from page 7*

Computer Access and Internet Use

- Fifty-nine percent of rural consumers reported they had a computer at home.
- The Internet/Web was accessed most frequently at home (46%), followed by at work (34%), and at an Independent Living Center (31%).
- Of those rural consumers who did use the Internet/Web, 54 percent reported they used it to search for information/research. Forty-nine percent used it for email and 40 percent used it to communicate with a disability organization.
- Rural consumers reported slow Internet/Web connections (27%) and difficulty navigating Web pages due to unclear directions (27%) more often as barriers to using the Internet/Web than other barriers such as having limited access to a computer with Internet/Web (22%) or finding many inaccessible pages (15%).

NCDDR-Produced Resources Currently Available

To obtain a free copy of any of these NCDDR Produced resources call 1-800-266-1832. Online copies are available by following the Web link provided at the end of the descriptions.

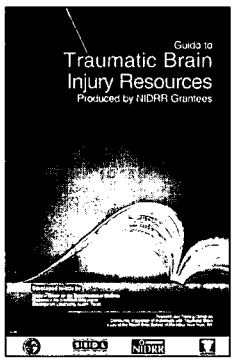


NCDDR 2001 Survey Report

Highlights of Findings

In this report, major findings are highlighted based on consumer, stakeholder, and NIDRR grantee feedback. Findings from the annual NCDDR investigations are reported to provide D & U insights and suggestions that the NCDDR and other NIDRR grantees can most effectively and efficiently employ in conducting D & U to consumers and targeted groups.

Available Online:
http://www.ncddr.org/du/products/survey2001/



Guide to Traumatic Brain Injury Resources

Produced by NIDRR Grantees

This guide was developed to assist researchers, professionals, and people with disabilities in locating research training materials related to traumatic brain injury and disabilities that were developed by programs funded by the NIDRR.

Available Online:
http://www.ncddr.org/du/products/tbiguide/index.html

Web Sites You Can Use

This brochure serves as an information reference highlighting the projects funded by the National Institute on Disability and Rehabilitation Research in the Knowledge Dissemination and Utilization area. Information about each project includes: website address, major services provided, and contact information.

Available Online:
http://www.ncddr.org/du/products/kdubrochuretxt.html

How To Contact The National Center for the Dissemination of Disability Research

Call Us
1-800-266-1832 or 512-476-6861 V/TT
8 A.M.–NOON and 1 P.M.–5 P.M. C.T.
Monday–Friday (except holidays) or
record a message 24 hr./day

Explore Our Web Site
http://www.ncddr.org/

E-mail Us
admin@ncddr.org

Write Us
National Center for the
Dissemination of Disability Research
Southwest Educational
Development Laboratory
211 East Seventh Street, Suite 400
Austin, Texas 78701-3281

Visit Us
Downtown Austin, Texas 4th floor,
Southwest Tower, Brazos at 7th St.
8 A.M.–NOON and 1 P.M.–5 P.M. C.T.
Monday–Friday (except holidays)

Fax Us
512-476-2286

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An electronic version of *The Research Exchange*, Vol. 7, No. 2 is available on the Internet at URL <http://www.ncddr.org/du/researchexchange/>

The Research Exchange is available in alternate formats upon request.

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National Library of Education (NLE)
Educational Resources Information Center (ERIC)

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