

Leaders with Disabilities Addressing Health Researchers

Recommendations for Disseminating Findings

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Many findings of disability and rehabilitation researchers never reach people with disabilities. For example, research shows that people with disabilities are more likely to have weight management problems, more likely to smoke, and less likely to receive clinical preventive services. Yet, many people are not aware of these findings. Without widespread knowledge and use by end-users, these research findings will have little effect. An effective dissemination plan is based on knowing *what* findings to disseminate and *how* to disseminate them to identified audiences. To identify effective methods for dissemination, we explored these questions with eight disability leaders who have close ties to their communities. Two public health researchers, Gloria Krahn and Jana Peterson, facilitated the discussion. The ensuing dialogue identified several key themes that can aid disability researchers and disseminators. This brief summarizes the themes that emerged.

Background

The RRTC on Health and Wellness for Persons with Long Term Disabilities contacted eight local leaders to participate in a “Dissemination Think Tank.” Participants in this facilitated dialogue varied in age, type of disability, gender, and rural or urban place of residence. All had been identified as leaders by their peers. We asked several stimulus questions such as:

- How do you get information about your health?
- Where do you actively seek information about your health?
- What makes health information useful to you?

Themes from the Dialogue: Different Media for Different People

The major finding that emerged is that researchers need to learn to disseminate study results in a range of formats to various audiences to reach potential users of the information. Individual participants described the several methods they preferred for getting health information. The most common methods for *seeking out* information were searching the Internet, asking

questions of peers, and asking physicians and rehabilitation specialists. While some participants described physician specialists as their best source of information, others described difficulties with finding physicians who understand their specific disability and its impact on their ability to engage in activities. An example was physicians who might not understand that for a person with cerebral palsy, anticipating an injection might trigger spasms suddenly making getting a simple flu shot very complicated.

The majority of participants, varying across ages and income levels, repeatedly cited the Internet as the medium for getting health information. One participant described the Internet as a valuable resource for information before scheduling expensive doctor appointments. Participants described various sources for getting both disability-specific information and general health information, including blogs, online forums, the *Web MD* website, and websites of disability advocacy organizations. They agreed that there is a lot of information to sort through, that it is scattered in different places, and there is no single clearinghouse of health information.

No participant mentioned television as a primary source for obtaining personal health information. However, participants view TV as having an important role in reaching people with disabilities with important health messages. They named TV as the most effective outreach method to communicate health messages to large numbers of people with disabilities. TV was seen as particularly important for people who are largely unreachable through Internet and peer connections (e.g., because they live in nursing homes). “People with mobility disabilities spend a lot of time watching TV—they’re not out there going places—they sit in front of the tube.” TV was described as important for actively reaching out to people who might not be looking for information. While some Think Tank participants were active seekers of information, others were passive. One participant said, “I will reach out in some ways but for the most part, it probably is going to have to fall in my lap.” Pharmacists were another source that the group generally agreed was effective for disseminating information since most people with disabilities visit with pharmacists: “We all take medicines.” Other sources were email listservs, disability organization newsletters (e.g., United Cerebral Palsy), Centers for Independent Living listservs, and updates from disability-related research projects in which they had participated. Schools were described as underutilized sources for disseminating health information to youth with disabilities.

Finally, participants mentioned type of disability as a factor that determines how people receive their information. Participants who have disabilities that occur more commonly described their peers with shared disabilities as important information sources, while a participant with a rarely occurring disability pointed out that she doesn’t know other people locally who also have her condition. How important disability advocacy groups are to obtaining health information also

varied by type of disability. United Cerebral Palsy was named, for example, as an organization that is long-standing and well equipped to provide reliable information to people with cerebral palsy. Participants mentioned that not all people with disabilities have such a strong advocacy group to access.

Disability-Specific or General Health Information?

Participants talked about identifying with a disability to varying degrees. One participant recounted the story of a friend who recently had been diagnosed with vision impairment. When offered information about a local Center for Independent Living, the response was that he “wasn’t ready” to think of himself as disabled. On the other hand, the participants clearly recognized that they were in the elite of people with disabilities because of their connections to advocacy organizations, and that many people with disabilities living in nursing homes do not have the same access to health information. Therefore, not only do some people with disabilities not identify themselves as “disabled,” others are grouped with an elderly population and do not have their disability-related health needs adequately met. Younger participants recognized that elders might not want to identify with disabilities, and young adults with disabilities do not want to be identified with elders.

For general health information, generic methods were described as most effective— “We’re going to get it the same way anybody else gets general health information, so if it’s accessible to the general population, it is accessible to us.” However, participants were clear that, if you have a disability, you have to modify the generic health information for it to be useful to you and your specific condition. “We have to have a pretty sophisticated understanding of what works for us and what doesn’t work for us...and what we need.” At the same time, participants noted that targeting information for people with specific disabilities brings it to their attention or makes the information seem particularly relevant to them.

Participants varied widely in how interested in they were in seeking out general health promotion information. Several people were clearly concerned with their general health and wellness, understanding that maintaining their overall health would have only good effects on their disabilities. As one participant stated, “I’ve been in a chair for over 50 years. That’s a long time. I didn’t do things to help my disability; I just wanted to be a healthy person.” Another participant said that, for himself, he is all about “the overall just staying healthy.” Other participants felt that they were not really interested in seeking out health information, since their condition had already taken up so much of their time and energy that “information just has to fall on me.”

Several participants, especially individuals who use wheelchairs, expressed frustration at the *lack of information* available about specific health promotion resources. People in wheelchairs were frustrated that they were not weighed and could not find accessible gyms and pools. They

wondered why there was no central resource center for finding information about accessible local services. Resource information should include the cost of various services.

Timing and Packaging of the Information

For information specific to disability, one participant said, “you learn 99% of the information” about your disability in the months after onset or injury and you spend the rest of your life learning that last 1%. Other participants echoed this perspective by saying that after living with their disabilities for so long, each is an expert on his/her own disability and has learned to handle secondary conditions (e.g., pressure ulcers or urinary tract problems) as they arise. At the time of diagnosis or onset, the amount of information provided could be overwhelming. Alternatively, one participant received a diagnosis with no additional information or referral to resources. That left the family adjusting to the diagnosis without supports. Another time to seek information is when a condition changes or a person acquires a new condition, like arthritis. One participant described having aging-related health problems that were independent of the disability and she was seeking out health information about it before visiting a physician.

There were several clear recommendations for formatting information:

- Accessible— make information available in alternate formats like large print or computer disks. Participants were frustrated with websites and materials that were inaccessible to people who use screenreaders and other assistive software or devices.
- Simple and concise—write in plain language, and avoid being “too slick.” Participants were wary of glossy, overly produced publications because they saw those documents as coming from a source they were not interested in hearing from – namely, one that spends its resources to produce such documents rather than on advocating.
- Bundled—consider packaging information with other useful handouts, such as free recipe booklets or other health tips. Examples of these are often available at pharmacy counters.
- Feature the disability—clearly but honestly use disability information to draw attention to your information. Although participants will use generic information, if a brochure or advertisement uses a photo of a person in a wheelchair or language that targets disability issues, they take notice. Such materials, however, need to be honest and accurate to the disability experience.

Power of a Peer

A consistent theme of the Think Tank participants was their reliance on peers to get health information. They have a high degree of confidence that the information received from peers is

trustworthy and valuable. Their sources could be friends who have a similar disability, or an online forum for people with a particular condition, or even a blogger with whom they have no personal connection but with whom they share disability experience. One person has a group of friends with a similar condition; whenever an issue comes up, he checks with his friends about a solution. Participants also looked to their peers to see how they had fared with new treatments before trying it themselves. One participant indicated that the most valuable information comes from a “friend or somebody you have a relationship with, less from a forum or blog, but even that stuff is more valuable than hearing it from a doctor whom I’ve never met before.” It is clear that peer connections, even those found in online forums, are a powerful channel of health information. As one person put it, “You cannot minimize the power of a peer.”

Trusted Sources

Trust was an issue that was raised in several ways. Peers were described as the most trusted sources of information. Other sources included pharmacists for health information, and staff at nutritional centers like GNC for help in choosing products to improve general health. Information from universities and research centers was generally trusted. One participant described attending to the suffix for websites, putting more faith in “.gov” and “.edu” sites, being somewhat cautious about “.org” sites, and not trusting “.com” sites. Another participant mentioned looking in the back of an article to check the references cited in the information.

Participants varied in the trust they placed in health care providers. Individual levels of trust ranged from the physician serving as the only real trusted source of health information (“I rely a lot on my doctors... That’s really where I get most of my information, is from medical providers”) to distrust of physicians (“I just don’t trust that all medical doctors are knowledgeable”). Participants reported that physicians were much more knowledgeable about disability than they had been in the past, but it seemed that the health information most often received from physicians’ offices was in the form of pamphlets. One response to this is to feel that if the physician doesn’t have time to explain it, then the information must not be that important. One participant recounted coming home from a doctor’s office with a stack of pamphlets and was too overwhelmed to read them. Participants also stated that needing to review their voluminous medical history with every new doctor resulted in feeling that they were in the position to give health information to the physician instead of the other way around.

Conclusions

This Think Tank was a valuable method of discovering how to disseminate research findings to people with disabilities. It takes different media methods to reach different people. There are specific ways in which people with disabilities prefer to see information formatted. Most importantly, you cannot underestimate the power of a peer to influence the dissemination of

health information. Beyond considering these issues when planning dissemination activities, we recommend that researchers take the time to talk with potential end-users of information when they are preparing to disseminate their findings, using participants most closely connected with the research. By meeting with the target audience, researchers can identify not only what specific information is needed, but how best to disseminate that information.

About the Participants:

Aimee Adelman

Aimee is a college student who is working toward a degree in marketing and business communications. Previously she attended Johnson and Wales University in Colorado. She has recently moved back to Portland, Oregon due to some medical complications. She currently attends Portland State University. Aimee also has extensive experience with healthcare and medical systems, having worked for OHSU for several summers in different capacities. She was diagnosed at age one with a rare, inherited metabolic disorder that significantly impacts her health and requires frequent follow up and an ongoing treatment regimen. She received a kidney transplant from her father shortly after high school graduation and is well versed in issues related to transition to adult care and chronic disease management.

Brian Burr

Brian graduated from Milwaukie High School in 1991 and Clackamas Community College with an Associate degree in 1995. He volunteers time to Oregon City School District as a “Lunch Buddy” and Teacher’s Aide. His areas of interest are health and wellness, quality of life, diet and exercise. Maintaining a healthy body and truly being involved in things bigger than ourselves is of great interest to him. Brian enjoys spending time with family, especially his nieces and nephews. He also enjoys camping, target shooting, eating, exercising, music, movies, and dating. He has quadriplegia resulting from a cervical 5/6 spinal cord injury.

Jan Campbell

As a two-year-old child, Jan developed a virus that attacked her spine and left her paralyzed from the waist down. She recently retired from the City of Portland after 34 years of working in the area of civil and human rights for persons with disabilities. She has chaired numerous committees, boards, and commissions focusing on issues pertaining to persons with disabilities. Currently, Jan is the President of Disability Rights Oregon (formerly the Oregon Advocacy Center) Board of Directors, Chair of TriMet’s Committee on Accessible Transportation and Chair of Portland Citizens Disability Advisory Committee. Jan is a member of the Oregon Disabilities Commission and Women with Disabilities Health Equity Coalition. In her free time, she enjoys fishing, hiking, and travelling.

Jeanne McClellan

Jeanne earned a BS at Wayne State University in Detroit and an MA in psychology from Antioch University in Los Angeles. She is also a licensed therapist (MFT) in California. Jeanne is currently

employed as Associate Director of Programs at Independent Living Resources (ILR). She has vision impairment and is committed to inclusion for all people with disabilities.

Jerry Pattee

Jerry is the Chair of the Oregon Institute on Disability and Development's Community Partners Council as well as a member of the Oregon Office on Disability and Health Advisory Council. He also serves on the Board of Directors of United Cerebral Palsy of Oregon and Southwest Washington. Jerry also serves on Self Advocates As Leaders Editorial Board for The People First Connection. He retired after 30 years of working with Qwest. He was born with Cerebral Palsy and received services from the Crippled Children's Division, the predecessor of what is now the Child Development and Rehabilitation Center.

Rob Pollock

Mr. Pollock is the Marketing Manager and Program Support at Incight where he brings years of experience and leadership to the organization. Rob has been a young life team leader for seven years working with high school aged youth developing programs and overseeing implementation and volunteer involvement in area schools. Rob is pursuing a master's degree in Art Therapy so that he can continue his work at Incight by assisting youth with disabilities through their rehabilitation process.

Barbara Ross

Barbara completed a bachelor's degree in management of human resources from George Fox University and with the help of her state's vocational rehabilitation department, became a registered counselor and certified peer counselor. She has spent the last few years working with victims of romance scams through the Victim Resource Center. She is a committed advocate for people with disabilities and volunteers with Disability Resources of Southwest Washington. She enjoys gardening (especially growing roses), reading, traveling, spending time with her family and her fiancé.

Amy Sharer

Like many students with disabilities, Amy struggled to get the help she needed in the K-12 system. After she graduated, she did not want anyone else to struggle as she did and began working with OHSU to get information about an array of transition options out to as many students with disabilities in high school as possible. These programs aim to enable students with disabilities to go to college. Thanks to a part-time course load and a service dog trained in balance and mobility assistance, Amy has been able to study for a business transfer degree at Clackamas Community College for the last two years. In her free time, she likes to spend time with her dog and her family.

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