



Leaders with Disabilities Address Health Researchers

A fact sheet for disability and health researchers

We asked disability leaders who have close ties to the disability community to recommend ways researchers can identify both *what* information to disseminate and *how* to disseminate it to people with disabilities. You can find the full report at www.healthwellness.org.

General health information

What information are people looking for?

Participants varied widely in how interested in they were in seeking out general health promotion information.

- Some panelists reported being concerned with their general health and wellness, understanding that maintaining their overall health would have only good effects on their disabilities.
- Other panelists weren't really interested in seeking out health information since their condition already take up so much of their time and energy.

How do they get their information?

Panelists noted that they receive general health information in the same ways that everyone else does, though they have to modify all general health information for it to be useful for them. Internet sources such as WebMD and other general health websites were widely used. Pharmacists were also noted as sources of information.

Disability-specific health information

What information are people looking for?

People generally sought out disability-specific health information during two periods:

- Directly after onset or injury when they were adjusting to their new status
- When a condition changed or a person acquired a new condition (e.g., arthritis)

How do they get their information?

Participants who have commonly occurring disabilities described their peers with shared disabilities as important information sources. Some disability advocacy groups, like United Cerebral Palsy, are long standing resources and well equipped to provide reliable information to people.

Other sources of disability-specific health information are Centers for Independent Living listservs, disability organization newsletters, and online forums (especially for those with rarely occurring conditions).

How you say it counts

Make it accessible and provide alternate formats.

Make it simple with plain language and minimal production.

Make paper copies useful by bundling them with other information (e.g., free recipe booklets).

Make it clear who your audience is by using images of disability.

“You can’t minimize the power of a peer.”

Our panel reported a high degree of confidence that health information received from peers was trustworthy and valuable. One participant polled his friends about their experience with an intervention before trying it himself. Another participant stated that even strangers with disabilities can be more convincing than a doctor.

Peers might be:

- Friends with a similar disability
- People with a particular condition “met” through an online forum
- People they’ve never met but who share the disability experience

Images of people with disabilities or disability symbols on printed materials are an indicator that the information is intended for this particular audience. One panelist said when he sees a picture of a person using a wheelchair on a brochure, “I know they are talking to me.” It is important, however, to use authentic images because staged pictures are immediately obvious to this group.

Participants

Aimee Adelman- Aimee is a college student working toward a degree in marketing and business communications at Portland State University.

Brian Burr- Brian is the past Chair of the Oregon Institute on Disability and Development’s Community Partners and volunteers with the Oregon City School District as a teacher’s aide.

Jan Campbell- Jan is the President of Disability Rights Oregon, Chair of Trimet’s Committee on Accessible Transportation and Chair of Portland’s Disability Advocacy Committee.

Jeanne McClellan- Jeanne is the Associate Director of Programs at Independent Living Resources.

Jerry Pattee- Jerry is the Chair of the Oregon Institute on Disability and Development’s Community Partners Council and serves on Board of Directors for United Cerebral Palsy of Oregon and SW Washington.

Rob Pollack- Rob is the Marketing Manager at Incight and is pursuing a Masters Degree in Art Therapy.

Barbara Ross- Barbara is a certified peer counselor and volunteers with Disability Resources of SW Washington and the Victim Resource Center.

Amy Sharer- Amy is studying business at Clackamas Community College with the help of her service dog, Tux.

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