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Involving People with Disabilities as Members of Advisory Groups

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Rural Practice Guideline

July 2006

Involving People with Disabilities as Members of Advisory Groups

Service providers, schools, parks departments, public health agencies and other organizations make decisions and policies that profoundly affect the health, employment, income and well-being of people with disabilities. This capacity carries the obligation to involve the people most affected by including individuals with disabilities in the decision-making process. This Practice Guideline offers suggestions on how to involve people with disabilities as active members and advisors of your group. Many of these suggestions may be helpful to all participants, including those without disabilities.

Educating Yourself and Your Group

Many people are unfamiliar with the complex social, economic, political, and cultural ramifications of disability in our society. Your group should educate itself about the basics of disability: 1. It is a normal part of life; 2. As many as 54 million Americans experience disability; 3. Citizens with disabilities share the same rights and responsibilities as other Americans; and 4. It is important that these people be represented in community and government decision-making.

With proper accommodations, many people with disability can effectively participate in advisory groups. An important step is becoming aware of how we talk about disability. How society views and treats people with disabilities affects how they feel and how they feel about themselves. If we use “people first” language for example, we acknowledge that a disability is one attribute of the complex package that makes up a human being. It’s not a person’s primary identity. People first language describes what a person has or does, not what a person is. For example, instead of saying “a wheelchair-bound woman,” say “a woman who uses a wheelchair”. Emphasize a person’s role in our society: “An employee with a disability” or “A student with a hearing impairment”. If you’re inviting people with disabilities to join an advisory board, your language should emphasize their primary roles as “members”, “participants”, and “advisors.” To learn more about people first language, visit the Disability is Natural web site at <http://www.disabilityisnatural.com>.

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Alternative formats available

People with disabilities may need specific accommodations in order to participate fully in meetings, discussions and decision-making. Local Centers for Independent Living (CILs) offer a wealth of information on including people with disabilities and may welcome the opportunity to provide awareness training. To find the nearest CIL, visit the National Council on Independent Living at <http://www.ncil.org> and select “Find Your Center for Independent Living or Statewide Independent Living Council”. For more information on accommodating specific intellectual and developmental disabilities, visit The Arc of the United States at <http://www.thearc.org>.

Recruiting Participants

Recruiting advisory board members can be difficult. Many directors of policy-making groups may not know anyone with a disability, much less anyone willing and able to participate actively in guiding an organization’s decisions. The key is knowing whom to ask for recommendations. Here are some suggestions:

1. Call the director of your local CIL. CILs educate people with disabilities on legislative and policy issues, and support and train them in individual and collective advocacy on local, state and national levels.
2. Visit the National Dissemination Center for Children with Disabilities web site at <http://www.nichcy.org> and select “State Organizations”. The Center maintains frequently-updated lists of disability resources for each state. Then, solicit recommendations from your state:
 - Vocational Rehabilitation (VR) Services Division: Staff can refer you to local VR counselors who may be able to recommend individuals with whom they’ve worked.
 - Developmental Disabilities Division: Staff can refer you to local disability service providers for recommendations. Service providers are likely to know individuals who are effective at expressing their ideas and

opinions and directing their own lives.

- Council on Developmental Disabilities: Councils are excellent resources for recommending individuals with disabilities for boards as Council membership is 60% consumer driven. Councils can also provide valuable information on the training needs and assistance necessary to support individuals with disabilities in their leadership roles.
- People First; Self-Advocates Becoming Empowered (SABE); and/or ADAPT organization. These organizations train and support people with disabilities in advocating for their individual and collective rights. Members of these organizations will already be interested and experienced in communicating their opinions, traveling, attending meetings and following meeting procedures.
- Parent Training and Information Center: These provide information, support, training and assistance to families of children and adults with disabilities. Staff can refer you to parents and/or adults with intellectual/developmental disabilities who have been trained in advocacy.

Providing Accommodations and Access to Meetings

You will need to consider providing accommodation in two broad areas: physical access for people with limited mobility or short stature, and information access for people with cognitive or sensory-related disabilities. Think carefully about each step involved in planning, attending and participating in a typical meeting. How do participants find out about the meeting? Do they prepare for the meeting in some way? For example, do they read background materials or think about specific issues? How do they travel to the meeting? Do they stay overnight and if so, where? When they arrive at the meeting place, where do they park and how do they enter the building, the meeting room, and the bathroom? In the meeting room, where do they sit? How do they park and how do they enter the

building, the meeting room, and the bathroom? In the meeting room, where do they sit? How do they get information (oral presentations, hand-outs, Power Point presentations, posters, etc.)? How do they express their opinions and/or vote on decisions? When do they take breaks, and for how long? Where are the bathrooms and what are they like (single-stall, multiple-stall, large or small, equipped with grab bars and roll-under sinks, etc.)? Are food and beverages served at breaks or lunch? If so, how are they served and what food and beverages are provided? How long will the meeting last?

With all this and more to consider, it's amazing that so many of us manage to attend so many meetings. Participants with disabilities may have individual needs related to each of these steps. However, you'll find that providing an accommodation for a person with a disability frequently makes life (and meetings) easier for everyone else, too. When was the last time someone complained that the format of a document was too easy to read, that information was too easy to understand, and a meeting room was too spacious?

Access is the first thing to consider when you're planning an event involving participants with disabilities. Physical access involves travel plans, hotel rooms, parking lots, sidewalks, ramps, meeting rooms, meals, and bathrooms. Information access involves presentations, discussions, and materials. This is where it's important to understand participants' specific disabilities and how they translate into accommodations that help level the playing field. For example, people with cognitive disabilities will need different accommodations than people with mobility limitations. Here are some guidelines to ensure that all of your participants can access the environment and get the information they need to be effective.

Physical Access

Ask people what they need. Travel can be challenging for participants with disabilities, especially in rural areas where distances may

be great, the weather unpredictable, and airline services non-existent, minimal, expensive, and/or requiring the ability to climb stairs . Some travelers may need the reasonable accommodation of a personal assistant, a service dog, or a driver, so be prepared to factor that into travel expenses and hotel accommodations. Some participants may need equipment or supplies (such as oxygen or motorized scooters) available for use during their visits. If people arrive by air, appropriate transportation between airport, hotel, and meeting location must be arranged.

Use a checklist to assess the physical accessibility of the meeting location. The Americans with Disabilities Act Checklist for Readily Achievable Barrier Removal is available from your regional Disability and Business Technical Assistance Center by calling 1-800-949-4ADA or you can download it free at <http://www.usdoj.gov/crt/ada/checkweb.htm>. This checklist leads you through the steps of evaluating the four priorities for removing physical barriers: 1) accessible approach and entrance, 2) access to amenities, 3) access to restrooms, and 4) any "other necessary measures".

"Other necessary measures" meet individual needs, such as a text telephone (TTY/TTD) for participants with hearing impairments, or a restriction on the use of perfume or other scented products to accommodate participants with asthma and chemical sensitivities. Some people with mobility impairments are sensitive to cold, so check to see if you can control the temperature of meeting rooms.

Snacks and meals can present inadvertent barriers. Participants on special diets or with disabilities associated with increased appetite (such as Prader Willi Syndrome) may be distracted if food is available in the meeting room. In this case, it's best to restrict eating to a separate area. Participants who use wheelchairs, crutches, or walkers may have a difficult time negotiating a buffet line and may need someone to serve and carry their food. Participants with visual impairments also may need someone to describe the menu choices, serve and carry their

food, and orient them to the location of each item on their plates. Finally, when planning the menu, consider food allergies and include options for vegetarians and people on special diets.

Information Access and Exchange

Agenda: The best input comes from prepared participants who have time to think, ask questions, and form opinions prior to the meeting. One week before the meeting, provide the agenda to participants with cognitive disabilities, and offer to discuss it, the meeting's expected outcomes, and any unfamiliar words and concepts. Schedule preparation time close enough to the date of the meeting so that participants remember their careful preparations by the time of the meeting. Participants who use augmentative communication devices might need preparation time to compose responses for later use. Preparation time is also a great opportunity for the meeting leader to note participants' comments to use as discussion prompts during the meeting ("Eric, you were saying something interesting the other day about taking the city bus to work. Would you share that with the group?").

Outcomes and Transitions: Clearly state your anticipated outcomes at the beginning of the meeting and review them at the end of the meeting. Make sure that all participants (and their assistants) agree upon and understand work assignments and the schedule for future meetings. Send copies of the minutes (for alternative formats, see "Print Materials", below) to participants within two weeks and follow-up with a call to clarify work assignments and answer any questions. Transition times are important. As you move to the meeting, from the meeting to a break or lunch and then back to the meeting, let participants know what to expect and what's expected of them. Tell them how much time they'll have for breaks; where coat racks, bathrooms and dining room are located;

and describe the food set-up. Tell them if meal seating is assigned and if they'll be expected to continue working through lunch or listen to a presentation.

Oral information: Participants with hearing impairments may need sign language interpretation, real-time reporting, or preferred seating in order to see the interpreter or the speakers' lips. Videotaped information should be open-captioned, which means that the entire audience sees the captions without the need for special equipment. Sign language interpreters will appreciate receiving an advance print copy of each presentation. Advance copies are also useful for "cognitive interpreters" or personal assistants who can break concepts down into shorter, more-meaningful segments for participants with cognitive disabilities.

Presenters should organize no more than three major points for each 15 minutes of presentation. Speak at a comfortable pace, slowly enough to be clear but not patronizing. Orally describe all graphics (Power Point slides, flow charts, photos or other visual aids) for participants with visual impairments. For example: "This table shows the types of transportation used by people in our town for different activities. It has four columns labeled 'Work', 'Shopping', 'Medical', and 'Social'. It has five rows labeled 'Bus/Van', 'Automobile', 'Walk/Wheel', 'Bicycle', and 'Other'. In row 4, 'Medical', the numbers indicate that most people use automobiles for transportation, but many also rely on buses and vans. These are higher numbers than for work, shopping or social activities."

Discussion: Allow time during the meeting for participants to ask questions and make comments. If participants use alternative forms of communication or augmentative communication devices, allow adequate time for them to formulate their responses. Draw passive participants into the discussion by asking questions that require more than "yes", "no", or one-word responses: "Susan, if the bus stopped in your neighborhood, where would you like to go on it?", rather than "Susan, do you wish the bus would stop close to your house?".

Print materials: All materials used at meetings or focus groups should be available in alternative formats for participants with visual disabilities. Save a copy of each document as a text file (without formatting) for easy conversion to large print and/or for copying and distributing on CD or disk for use with computer screen-reading software. Please note that only the most-current screen-reading software can read PDF (portable document format) files and that figures, tables and graphics still require narrative descriptions.

Identify and anticipate your audience's needs. Print information is accessible to most people, but is a significant barrier for people with visual or cognitive disabilities. Provide information in multiple modes and allow enough time to review print materials prior to the meeting. Write clearly and simply at a 4th to 6th grade reading level. Although materials should be visually appealing, use a plain font and minimize the use of bolding and italics. People with cognitive and specific learning disabilities may find pictures easier to understand than text. Using color is also effective, for example: "On the pink page, there's a map of local bus routes, and page 2 has a bus schedule inside the blue box." Participants with limited dexterity may find turning pages easier if meeting materials are hole-punched and provided in a binder. If there are a lot of materials, think about giving everyone a complimentary tote bag (with the group's name and logo) for carrying their meeting materials. Supports like this can foster a group identity and provide a means to transport handouts and supplies more easily.

Additional References and Resources

Disability Awareness:

Axis Center for Public Awareness of People with Disabilities: <http://ada.osu.edu/resources/accessiblemeetings.html>

Copenhaver, J. (2003). A primer on people first language. Logan, UT: Mountain Plains Regional Resource Center. <http://www.taese.org/cms/images/publications/peoplefirst-eng.pdf>

Disability Rights Section (2002). ADA business brief: Service animals. U.S. Department of Justice: Civil Rights Division. <http://www.usdoj.gov/crt/ada/svcanimb.htm>

Hogan, G. (2003). The inclusive corporation: A disability handbook for business professionals. Cincinnati: Ohio Univ. Press/Swallow Press. <http://www.ohioswallow.com/book/The+Inclusive+Corporation>

Independent Living Research Utilization (2002). Understanding & accommodating multiple chemical sensitivity. <http://www.ilru.org/html/publications/bookshelf/MCS.html>

Indiana Governor's Planning Council for People with Disabilities. The Power of Words. <http://www.usi.edu/extserv/outreach/EpihabThePowerofWords.asp>

Resource Center to Address Discrimination & Stigma, U.S. Center for Mental Health Services. <http://stopstigma.samhsa.gov>

Roth, H. (2006). Checklist for Enhancing the Participation and Input of People with Disabilities. Published by Independent Living Research and Utilization & the MEDSTAT Group. http://www.hcbs.org/files/96/4767/ILRU_ACCESS_CHECKLIST.pdf

Physical Access:

North Carolina Office on Disability and Health. Removing Barriers: Planning Meetings That Are Accessible To All Participants. <http://projects.fpg.unc.edu/~ncodh/pdfs/rbmeetingguide.pdf>

Educational Resources Information Center/ Clearinghouse on Disabilities & Gifted Ed. Planning accessible conferences and meetings: An ERIC/OSEP information brief for conference planners. Arlington, VA. <http://www.hoagiesgifted.org/eric/e735.html>

Information Access:

American Printing House for the Blind: <http://www.aph.org/>

Closed Captioning Web Aim, Org <http://www.captions.org/>

Disability Rights Section (2002). ADA Business Brief: Communicating with guests who are deaf or hard-of-hearing in hotels, motels and other places of transient lodging. U.S. Department of Justice: Civil Rights Division <http://www.usdoj.gov/crt/ada/hotelcombr.htm>

Literacy Information and Communication System (LINCS): Links to literacy research, statistics, multimedia curriculum, and national, regional, state and local networks. <http://lincs.ed.gov/lincs/>

Making materials useful for people with cognitive disabilities. (2003). The Research Exchange, 8:3. http://www.ncddr.org/products/researchexchange/v08n03/2_materials.html

National Center for the Study of Adult Learning and Literacy: Information, tools, materials, research reports, presentations and a comprehensive list of health literacy links. <http://www.hsph.harvard.edu/healthliteracy/>

Rehabilitation Research and Training Center on Blindness and Low Vision: <http://www.blind.msstate.edu/>

Sutton, J. (2002). Guide to Making Documents Accessible to People who are Blind or Visually Impaired. Washington, DC: American Council of the Blind. <http://acb.org/node/742>

For more information, contact:

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