Effectively Including People with Disabilities in Policy and Advisory Groups

By
June Isaacson Kailes
Associate Director
Center for Disability and Health Policy
Western University of Health Sciences
Pomona, California

Edition 2, 12.12.12

Harris
Family
cdhp
Center for Disability
and Health Policy

Western University
OF HEALTH SCIENCES
Harris Family Center
for Disability and
Health Policy

Required citation:

Kailes, J.I. Effectively Including People with Disabilities in Policy and Advisory Groups, Edition 2, 2012, published and distributed by the Harris Family Center for Disability and Health Policy, http://www.hfcdhp.org.

Copyright © 2012

You can download a pdf file of this publication at http://www.hfcdhp.org. Click on Online Resources.

This guidance provides how-to information for effectively including people with disabilities in policy and advisory boards, councils or work groups. It contains material on developing and sustaining an advisory group, why include people with disabilities as well as how to identity those who are qualified people with disabilities. The "Planning Checklist" covers defining purpose, structure, size, lines of communication, membership, recruiting, budgeting, staffing, minutes, accountability, meeting access and accommodations. A planning "Recruiting Matrix" and an "Agenda and Minutes" template are also included.

The word "group" is used in this document to refer to a broad array of options: board of directors, committee, panel task force, work group or advisory council.

Why Include People with Disabilities?

The expertise of health care professionals, emergency managers and planners, and many other corporate, profit and not-for-profit organizations can be augmented by utilizing external qualified advisors with disabilities. Qualified advisors are those who understand and can think through issues from disability, access, functional needs and universal design perspectives. These advisors can help an organization take advantage of the wealth, depth and breadth of information available from diverse disability communities, and effectively plan to include these groups, as well as prevent making sometimes-costly mistakes.

A process that includes qualified individuals with disabilities in, not token ways, but major significant and powerful ways, can result in exceptional improvements in an organization's understanding and responsiveness to diverse communities of people with access and functional needs.

Unfortunately, the history of including people with disabilities has been, in large part, one of paternalism. Entire professions of "experts" have emerged who have taken control over basic life decisions away from people. However, experience demonstrates that people with disabilities and others with access and functional

needs can devise creative approaches to remove barriers that have stumped the experts. For example, today's popular lightweight "sports" wheelchairs were designed by innovative wheelchair users, not by the established wheelchair industry (Kaplan 1992). People with disabilities can be excellent problem solvers and can offer recommendations that serve the mutual interests of an organization and its customers.

Benefits of involving people with disabilities include:

◆ Listening and learning about the issues facing individuals with disabilities;

◆ Understanding the value of accessibility for a very large segment of the population, beyond the communities who self-identify as having a disability;

◆ Allowing for free and frank discussion between an organization and knowledgeable people;

◆ Utilizing expertise to develop accessible, inclusive and appropriate programs;

◆ Providing respectful and targeted critiquing and problem solving to help an organization be more successful;

◆ Allowing for identification and resolution of issues in a cooperative rather than a confrontational environment;

◆ Creating a forum for thoughtful people to discuss needs, concerns and obstacles to achieving mutual goals;

◆ Allowing for the growth of disability advocates in understanding how an organization operates and continues to evolve; knowledgeable and qualified people with disabilities and activity limitations can be one of an organization's best and most articulate allies;

◆ Strengthening an organization's ability to be inclusive of people with disabilities and others with access and functional needs and to better plan, set priorities regarding existing and emerging policies, and determine how to effectively deliver services;

◆ Evaluating all levels and methods of communications between an organization and people with disabilities;

◆ Providing insightful input on strategies, tactics, policies, practices and processes to help test, improve and strengthen programs and products;

◆ Applying best thinking to effectively include people with disabilities; and

◆ Enhancing an organization's credibility and accountability with the disability and senior communities.

Who Are Qualified People with Disabilities?

It is important to be specific regarding who is qualified to serve. For example, consider these qualifications:

◆ Identify as a person with a disability,

◆ Have a user's perspective,

◆ Have personal experience with disability and disability advocacy,

◆ Can speak broadly on disability issues as opposed to only addressing personal needs,

◆ Are knowledgeable about cross-disability access issues (hearing, vision, mobility, speech and cognitive limitations),

◆ Are knowledgeable about a variety of physical, communication and program access issues,

◆ Are connected to and actively involved with segments of national, state or local constituencies of disability communities, including such disability communities and organizations that are of, by and with (as opposed to just for and about) the blind, deaf, hard of hearing, learning disability, intellectual disability, developmental disability, independent living, chemical sensitivities, etc.

◆ Have in place and use communication arteries to facilitate two-way communication with the segments of the disability communities they represent.

In addition, other types of experience may be needed. For example, qualified advisors, trainers, contractors and consultants with disabilities need to have:

◆ Specific technical expertise; and

◆ Advocacy experience, management experience and training skills.

How to Recruit Qualified People with Disabilities

Avoid Haphazard Random Recruitment

> Planning for and not with people with disabilities reflects an old paradigm "a lot about us without us."

When including perspectives from the disability communities in planning, organizations sometimes seek and get less than adequate representation. This is because selecting representatives can be a haphazard and random process where planners don't take time to think through the type of representation they need. It is common for people responsible for recruiting representatives to automatically think of and choose a co-worker, colleague, neighbor, friend, relative or acquaintance that happens to have a disability or activity limitation. Sometimes recruiters call the first disability organization they can think of. These individuals may or may not be qualified representatives.

Pay for Participant's Time and Expenses and Clearly State Expectations

It is sometimes incorrectly assumed that people representing not-for-profit organizations are able to volunteer their time. Reimbursement

> It is important to include people with disabilities as contributors and collaborators, not just as people viewed as patients or victims to be rescued. It is time to revise methods and embrace the approach "nothing about us without us!"

of expenses and providing an honorarium demonstrates that you value these individuals' expertise and time, and expect full and valuable contributions. Offering a wage-replacement honorarium is especially important for people who have to use their personal time (versus job time) to participate.

Commitment Involves Attention to Details

Lack of attention to accommodations and travel details; orientation of members; and minutes, follow-up and report-backs on pending issues can show a lack of true commitment on the part of the sponsoring organization. If the effort is undertaken only because it is required, it will show! Use the "Planning Checklist," "Recruiting Matrix" and the "Agenda and Minutes Template" to assist you in attending to these important details. Take time to think through specifically how your organization can benefit from the efforts involved in successfully sponsoring a group. Value and use members'' time wisely and present real issues you are struggling with and trying to solve.

> "One thing you can't recycle is wasted time."
> – Anonymous

Planning Checklist

Use the checklist starting on the next page as a tool to evaluate your organization's readiness to sponsor or sustain a board, panel task force, work group or advisory council. Use the listed items to identify areas needing attention and to set priorities. This checklist can also be used over time to track areas of improvement.

√ Check Not Applicable if the question does not apply.

√ Check Unsure if you do not know and need to find out.

Item	Complete	Needs work	Unsure	Not Applicable	Follow-up and Comments
1. Purpose					
1.1. Define					
2. Structure					
2.1. Develop bylaws or operational guidelines (processes, procedures, protocols and policies)					
2.1.1. For example: individuals who are not members or who are alternate members may participate in subcommittee meetings, subcommittee may meet in between full committee meetings or at full committee meetings. Subcommittee chairs will submit subcommittee meeting schedules and agendas for approval. A quorum of two-thirds of membership is required to make recommendations in behalf of the full committee, the sponsoring organization can at any time if the meetings are not productive, the sponsoring organization may discontinue meetings at any time if the meetings are not productive.					
2.2. Authority					
2.2.1. Advisory					
2.2.2. Decision making					
2.3. Officers, Chair (elected or appointed)					
2.4. Decision-making method(s) (majority voting, two-thirds vote)					
2.5. Size					
2.5.1. Number of members					
2.5.2. Term length					

Item	Complete	Needs work	Unsure	Not Applicable	Follow-up and Comments
2.5.3. How are members chosen (see Recruitment)					
2.6. Lines of communication					
2.6.1. Where and how the group fits into organization's structure					
2.6.2. What are the feedback loops (i.e. local to regional to state to governing body; board of directors to Executive Director to staff, etc.)?					
2.6.3. Flow of information and input to and from:					
2.6.3.1. Organization to group					
2.6.3.2. Group to organization					
2.7 Membership					
2.7.1. Identify desired diversity of stakeholders, ethnicities, socio-economic backgrounds, ages, disability (see Recruiting Matrix)					
2.7.2. Develop a job / responsibility description					
2.7.2.1. Qualifications (see Who Are Qualified People with Disabilities?)					
2.7.2.2. Responsibilities					
2.7.2.2.1 Project time commitment (i.e. including preparation, subcommittee work and travel time. For example the time commitment is approximately 9 days per year.) (include information from: # 2.8-2.9, 7 of this checklist)					
2.7.2.2.2. Members are encouraged to attend all meetings. If an alternate member attends a meeting(s), the member should brief the alternate member on the group's discussions, as well as share background information and documents.					

Item	Complete	Needs work	Unsure	Not Applicable	Follow-up and Comments
2.7.3. Who appoints					
2.8 Meetings					
2.8.1. Schedule					
2.8.2. Frequency					
2.8.3. Length					
2.8.4. Methods for completing work:					
2.8.4.1. Large group (committee of the whole)					
2.8.4.2. Committees (recommended for a deeper exploration of details)					
2.8.4.3. Individual assignments					
2.9 Attendance					
2.9.1. Requirements; for example: If a member or their alternate member is not present at two consecutive committee meetings, they may be removed from the committee.					
2.9.2. Can people attend using technology (phone, Skype, online meeting software) especially for those "off the travel grid," unable, or who have difficulty travelling)					
3. Budget					
3.1. Staff					
3.2. Travel [transportation, lodging, food]					
3.3. Accommodations (see 6.3 under Accommodations)					
3.4. Honorariums					
3.5. Food (snacks, beverages, meals)					

Item	Complete	Needs work	Unsure	Not Applicable	Follow-up and Comments
4. Staff					
4.1. Qualifications					
4.1.1. Eager to take on this responsibility					
4.1.2. Good facilitation skills					
4.1.3. Other					
4.2. Responsibilities					
4.2.1. Constructs agenda					
4.2.2. Oversees organizing staff reports based on objectives and action items and accountability reports (see Accountability)					
4.2.3. Guides discussion					
4.2.3.1. Keeps meetings on track and follows agenda					
4.2.3.2. Can diplomatically intervene or even interrupt to keep things on track, if needed					
4.2.3.3. Even-handed and fair					
4.2.3.4. Encourages participation					
4.2.3.5. Notes decisions and commitments that are made					
4.2.4. Minutes oversees keeping, completing, and distributing (see Agenda and Minutes sample)					
4.2.5. Documents Maintenance					
4.2.5.1. Consider use of a shared and organized space for providing documents online (Web site access is built in by following 508 regulations). This also helps reduce time spent covering old ground, finding source documents, making for "Greener meetings." (see Resources 4)					

Item	Complete	Needs work	Unsure	Not Applicable	Follow-up and Comments
4.2.5.1.1. For example: minutes, readings, presentations, membership roster and bios, presenter bios, reimbursement policies and forms, processes, procedures, protocols, policies and training etc.)					
4.2.6. Accountability					
4.2.6.1. How is success measured (outcomes, metrics, what happens to the input, what has changed, if nothing, why?					
5. Recruiting Members					
5.1 Create an application for:					
5.1.1. Interested individuals to nominate themselves or organizations to nominate representatives					
5.1.1.1. Ask applicants:					
5.1.1.1.1. to name their back-up / alternate representative (if they are unable to attend)					
5.1.1.1.2. Describe qualifications					
5.1.1.1.3. How they will communicate with the constituencies they represent					
5.1.1.1.4. State reasons why they would like to participate					
5.1.1.1.5. List relevant background, experience, or specific knowledge, expertise					
5.2. Send recruiting announcement, job description and application to disability focused organizations.					
5.2.4. Methods					

Item	Complete	Needs work	Unsure	Not Applicable	Follow-up and Comments
5.2.4.1. Social Media					
5.2.4.2. Newsletters					
5.2.4.3. Word-of-mouth					
5.3. If you need help determining where to send recruiting information, ask one or more established disability organizations for assistance in locating organizations in your community (see Resources 5-7).					
5.4. Solicit applications from interested people continually.					
5.4.1. Maintain a list of interested future members and consider including interested future members in subcommittees that may meet between the large group meetings.					
6. Meeting Access					
6.1. Physical access – hold meetings at facilities that individuals can get to, enter, and use (accessible: paths from public transportation drop off points and parking (curb cuts, ramps) rest rooms, hotels and meeting facilities etc.). Use a checklist to determine facility accessibility such as (see Resource # 1and 2)					
6.2 Accommodation - provide upon request:					
6.2.1. Information (minutes, readings, presentations are provided in alternative formats (braille, large print, disks, audio)					
6.2.1.1. People who hand out written materials at meetings need to provide a sufficient number of copies for members, including accessible formats for committee members and alternate members who request such formats.					

Item	Complete	Needs work	Unsure	Not Applicable	Follow-up and Comments
6.2.2. Sign language interpreters					
6.2.3. Assistive listening device					
6.2.4. Computer aided real-time transcription					
6.2.5. Language translator					
6.2.6. Transportation assistance					
6.2.7. Specific diet foods					
6.2.8. Chemical sensitivity notices					
6.3. Provide assistance with travel logistics					
6.3.4. Hotel					
6.3.5. Meals					
6.3.6. Airplane, bus, train – reservations					
6.3.7. Ground transportation					
7. Orientation					
7.1. Provide members with a thorough overview of the group's mission, purpose, history, background, challenges, successes, etc. (Cover information from section 1, 2, 4.2.3- 4.2.6, and 6 of this checklist).					
7.2. It is helpful to include new as well as seasoned members in the orientation as this process can be a refresher and reinforcer of important and newer information.					
7.3. Consider pairing new members with seasoned members to help new members assimilate, catch on, catch up and have a specific individual they can check in with regarding questions or concerns.					

Recruiting Matrix

Member / Candidate									Comments
Disability:									
Cognitive (learning, remembering, understanding, etc.)									
Developmental disability Intellectual disability									
Hearing									
Mental Health / Behavioral Health									
Mobility									
Vision									
Organizations:									
of, by and with									
for and about									
socio-economic background									
Age:									
18-25									
26-50									
51-65									
65+									
Race:									
White or Caucasian									
Black or African American									
Native American, Alaska Native, or American Indian									
Asian American									
Pacific Islander (Hawaiian, Samoan, etc.)									
Hispanic, Latino, or Spanish origin									
Gender:									
Male									
Female									
Expertise:									
Other:									

Agenda and Minutes Template

Meeting:			Date: / / Time: AM PM
In Attendance:			
Next Meeting: / / Time: AM PM			
Location:			
Call In #:	Passcode:		

Agenda & Follow Up Items Pending

Date		Who Is Responsible	Topic	Comments / Follow Up
Discussed	Due			

Miscellaneous Items:

Summary

Planning for and not with people with disabilities reflects an old paradigm "a lot about us without us." It is important to include people with disabilities as contributors and collaborators, not just as people viewed as patients or victims to be rescued. It is time to revise methods and embrace the approach "nothing about us without us!" Being diligent regarding seeking qualified representatives will yield positive payoffs.

Resources

Checklist, Survey Tools and How-to Information

1. **Accessible Meeting Facility Checklist** - see p. 50 in Communication with Vulnerable Populations: A Transportation and Emergency Management Toolkit, 2011, http://onlinepubs.trb.org/onlinepubs/tcrp/tcrp_rpt_150.pdf, File Format: PDF/Adobe Acrobat, last accessed 08.31.12

   Transportation Research Board's Transit Cooperative Research Program (TCRP) Report 150: describes how to create a communication process to reach vulnerable populations regarding their transportation options in emergencies.

   The toolkit provides a guiding framework and tools for constructing a scalable, adaptable communication process built on a network of agencies from public, private and nonprofit sectors.

2. **ADA Checklist for Readily Achievable Barrier Removal, 1995** http://www.adachecklist.org/checklist.html, last accessed 08.30.12

3. **Planning Accessible Events** http://www.jik.com/PlanAcsEvents.html Contains links to accessible meeting planning guides and speakers guidelines for creating and giving accessible presentations, last accessed 08.31.12

4. **Web Site Access**

    Section 508 of the Rehabilitation Act requires access to electronic and information technology procured by Federal agencies.

    Web Accessibility Initiative (WAI) Web provides strategies, guidelines, resources to make the Web accessible to people with disabilities.

Recruiting

5. Directory of Centers for Independent Living, State Associations of Independent Living, and Statewide Independent Living Councils. http://www.ilru.org/html/publications/directory, last accessed 09.01.12

6. National Association of Councils on Developmental Disability http://www.nacdd.org, last accessed 09.01.12

7. Directory of Consumer-Driven Services (CDS), a project of the National Mental Health Consumers' Self-Help Clearinghouse http://www.cdsdirectory.org, last accessed 09.01.12

Reference

Easter Seals Project ACTION, 2012, Effective Transportation Advisory Committees: Creating a Group that Reflects all Community Voices, 2012, http://www.projectaction.org, projectaction@easterseals.com, last accessed 09.1.12

Kaplan, D., De Witt, J., Steyaert, M. (1992). Laying the Foundation: A Report of the First Year of The Blue Ribbon Panel on National Telecommunications Policy. World Institute on Disability, Oakland, CA.

Effectively Including People with Disabilities in Policy and Advisory Groups

By
June Isaacson Kailes
Associate Director
Center for Disability and Health Policy
Western University of Health Sciences
Pomona, California

Edition 2, 12.12.12

You can download a pdf file of this publication at http://www.hfcdhp.org. Click on Online Resources.

Harris Family
cdhp
Center for Disability
and Health Policy

Western University
OF HEALTH SCIENCES
Harris Family Center
for Disability and
Health Policy