

Chapter 3: Involving Participants in Program Design, Implementation, and Evaluation

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Chapter 3

Involving Participants in Program Design, Implementation, and Evaluation¹

Research on states' efforts to change their long-term services systems—including those to initiate or expand self-direction programs—has found that their success depends to a significant extent on early and sustained stakeholder involvement and buy-in.² Program participants are the primary stakeholders and to ensure their buy-in, they need to be involved in program development, design, implementation, and evaluation.

This chapter describes several approaches for involving participants in two areas: program design, implementation, and evaluation; and peer support and mentoring. In this chapter—as throughout this Handbook—the term participant, when used generally, includes both current and potential participants and—when they are unable to provide input themselves—their formal and informal representatives.

A. Involving Participants

There are many phases during which it is important to involve and seek participants' input and feedback: the program design and pre-testing phase; program implementation; program evaluation; and continuous quality improvement. States should make it a priority from the outset to identify strategies for ensuring participant involvement in each phase and sustaining it for the long term. When a new program will serve a diverse population, states also need to ensure that participants from all target groups are represented. To ensure meaningful involvement, states need to be receptive to participants' input and use it to modify approaches and strategies.

Involving advocates should not be seen as an alternative to involving participants. An advisory group that achieves 51 percent “participant” representation by including a large number of representatives from advocacy groups will not effectively represent participants' views. Participants' experience provides a unique perspective. The opinions of advocates matter but their views may differ from those of participants.

Participants' involvement in design, implementation, and evaluation can contribute to a program's success in multiple ways. Their experience provides essential information about what does and does not work, what types of outreach and enrollment strategies will be most effective, and how best to meet the needs of all participants. For example, Rhode Island's participant advisory group provides input on marketing and other program operations and is currently helping the state to implement its marketing strategy. Members of the group have

been conducting outreach to community health and rehabilitation providers to educate them about the program—both individually and with project staff.

The remainder of this section discusses several methods for involving participants: formal advisory groups as well as focus groups, surveys, and telephone response lines.

Formal Advisory Groups

The most common method states use to involve participants (and other stakeholders) in program design and implementation is through membership in an advisory group or on a task force. States may expand the scope of work of an existing group or create a new group. For example, some states that received Systems Change grants used an existing Olmstead Task Force or Work Group to both develop the grant proposal and to oversee and work on grant activities. Others created a subcommittee of an existing group to serve as an advisory committee for the grant, and others formed a new advisory group when the grant was awarded.

Factors to consider when deciding whether to use an existing group or to create a new group include the scope of work and effectiveness of existing groups, the views of leaders from the disability advocacy community, the advocacy experience of participants and/or their respective advocacy community, and the strength of other stakeholder groups.

If a state's advocacy efforts are well developed and participants are experienced at providing input as part of a larger group, they should be able to effectively articulate their views even when other stakeholders have strong contrary views. However, states should be aware that inexperienced participants may need additional education and training to effectively participate so they are not “intimidated” or “drowned out” by more experienced and vocal stakeholders.

In some cases, participants may be more comfortable providing input as part of a stand-alone participant advisory group—at least initially. Rhode Island created a participant panel to oversee its Cash & Counseling grant; the panel meets monthly but also participates in diverse stakeholder meetings every quarter.

Several organizations provide training for individuals who are interested in developing their advocacy and leadership skills, and such training may assist participants to feel more confident about providing input when serving on Advisory Boards. For example, Partners in Policymaking, one of the best-known training programs, offers training to people with all types of disabilities. Some of their training resources are available free of charge at www.partnersinpolicymaking.com/online.html. Another organization, the Self Advocate Leadership Network, is specifically designed to train individuals with developmental disabilities to become self-advocates. For participants under age 28, the National Youth Leadership Network aims to develop a new generation of disability leaders and provides

opportunities for networking and leadership development (<http://nyln.org>). States can refer interested participants to these organizations.

Another consideration is whether to include participants from different disability groups in the same advisory group. If the program is serving several disability groups, a mixed participant advisory group is needed. However, if one disability group has a longer history of advocacy and there is a risk that others will be “drowned out,” it may be necessary to have separate groups initially. Over time, the groups can be merged.

Consumer Advisory Committees in virtually all of the states receiving Systems Change grants included a wide range of stakeholders, including providers and state staff, but by design and intent, participants, family members, and advocates constituted a majority of the members. Many Systems Change grantees reported that while including diverse stakeholders in the same group could be very challenging, it was essential because they all needed to understand differing needs and opposing views and to learn to compromise.³

To ensure that all relevant stakeholders are involved, advisory groups often have large memberships—30 or more individuals. A large group can make it very difficult to work on some program and policy issues that require focused work by individuals with specific knowledge and experience. To address this potential problem, states often establish subcommittees or smaller work groups to deal with specific tasks, such as developing outreach and educational materials. States need to ensure that participants are also included in these smaller groups.

Recruiting Participants

Recruiting participants to serve on an advisory group can seem daunting to state staff. One starting point is to identify and tap into existing networks such as Independent Living Centers, People First, and other advocacy groups. The overriding consideration when recruiting participants is their current use of services and their willingness and ability to fully participate.⁴

States with existing advisory groups can recruit from these groups but should also attempt to recruit new participants who have specific interests and/or new perspectives. Frequently, the same participants are recruited to serve on many different committees. But participants who are new to the process can often shed new light on problems, offer new ideas to solve those problems, and identify new problems.⁵

Many assume that elderly persons are too frail, impaired, or ill to serve on an advisory group or do not have the same interest as younger individuals in developing and improving programs. This view may be valid at times for individuals of all ages, not just elderly participants. However, lack of participation may also reflect significant barriers to participation. When it is difficult to recruit

participants with severe impairments and acute illnesses—as well as those in remote areas—to serve on an advisory group, states can secure their participation in other ways, such as through focus groups, as described below. See also a recent report prepared by the National Association of State Units on Aging at <http://www.cashandcounseling.org/resources/20080303-111313/>.

Another effective approach is to form a nominating committee of participants and advocates to recruit and select other participants to serve on an advisory group. The Massachusetts Real Choice grant project used this approach. (More information is available at <http://www.umassmed.edu/uploadedFiles/CPIGS.pdf>.)

Importantly, states should explore funding options to sustain advisory group activities in advance. States with grants may be able to use grant funds to support activities. If not, consulting with other state agencies with experience involving participants, such as vocational rehabilitation, can help to identify other potential funding sources.

New Mexico's waiver program—Mi Via (My Way)—has a large stakeholder advisory group called the Self-Directed Waiver Subcommittee, which includes participants and their families, service providers, advocacy organizations, and state officials.⁶

Each of the constituencies served by Mi Via is represented: elderly persons; medically fragile children; and individuals with physical disabilities, developmental disabilities, AIDS, and brain injuries. Unlike other constituencies, few elderly persons attend meetings, so their family members, providers, and sometimes advocacy organizations, such as AARP, represent their interests. Not all members attend each meeting but they are kept up to date through a listserv.

The Subcommittee has been meeting monthly since 2004 and the State uses an independent facilitator to help members reach consensus on issues. The State has also established a smaller group comprising one participant from each of Mi Via's constituencies to conduct more focused work on policies and materials, such as the Mi Via Participant Guidebook and the Mi Via participant satisfaction survey.

The Subcommittee has contributed to the design of Mi Via and to the development of program materials. For example, feedback from Subcommittee members led the state to change its budget methodology. Initially, participants' budgets were based on their previous year's service use but, because some geographic areas lack sufficient providers for certain services, some participants were unable to obtain all the services authorized and so their utilization was low. Members of the Subcommittee felt that this was unfair and the State revised its methodology to address their concerns.

Ensuring Participant Involvement in Advisory Groups

Many practical barriers can prevent participants from coming together to form an effective advisory group and sustaining the group over time, such as lack of transportation and accommodations to meet needs at meetings. Some of the solutions that states and other organizations have developed to address these barriers are presented below.

Accessibility

- Ensure that the meeting venue is entirely accessible—both inside (e.g. restrooms) and outside (reachable by public transportation and with accessible parking.)
- Determine prior to the first meeting what specific accommodations individuals need to participate effectively. If resource constraints limit the type of accommodations that can be made available, states need to choose participants to match those that are available. Accommodations that may be needed are accessible formats, such as Braille, audio tape, large print, and electronic files on disks; and meeting accommodations, such as Communication Access Real-time Translation (CART), microphones, and interpreters.
- It is not necessary to conduct all meetings in person. Telephone, video, and web-based conferencing can be used to involve participants who have difficulty traveling as well as to avoid some of the expenses of in-person meetings. However, these alternative approaches generally work better with smaller work groups or subcommittees than with larger groups.

Ensuring and Sustaining Regular Attendance and Participation

- Lack of transportation can prevent regular meeting attendance, particularly for participants with mobility impairments. Some states pay for participants' travel expenses when this is a more practical approach than directly arranging transportation for them. If resources are not available, states can work with participants to identify potential sources of transportation in their social networks or through community resources, such as paratransit services and Independent Living Centers.
- Use a skilled, independent facilitator. If resources will not permit hiring one, identify a community leader who is willing to assume this responsibility.
- Allow time for participants to coalesce as a group by learning about each other's interests and issues. This may include allowing the group to meet without staff present. Appointing a participant as a co-chair can also create a climate of collaboration and help build trust.

- Ensure that the views of the advisory group are recorded, synthesized, and used to inform program and policy development. It is also important that group members receive feedback about how their input has been used.

Focus Groups, Surveys, and Telephone Response Lines

Focus groups, surveys, and telephone response lines—as well as informal consultation—provide an opportunity for states to obtain input from a greater number of participants than those who can serve on advisory groups. These additional methods of involving participants can complement, but should not replace, the input provided by a formal advisory group.

Several states have used focus groups and surveys to obtain participants' input. For example, a major goal of Colorado's Systems Change Independence Plus grant was to establish a statewide backup and critical incident management system for all of the State's self-direction programs. In addition to analyzing the State's current system, grant staff conducted focus groups with participants and other stakeholders to obtain their views on whether a new system was needed. Responses indicated a consensus that the existing system was the most appropriate for self-direction programs and that a statewide backup system was not needed.

An advantage of focus groups is that they can be conducted on a relatively small budget if states partner with Centers for Independent Living, Area Agencies on Aging, the Arc, and other state advocacy networks to gain access to participants.⁷

As well as keeping costs down, involving participants in focus groups and surveys can elicit better responses than if professionals conduct them alone. *Ask Me!* is a Participant Quality of Life Survey administered by the Arc of Maryland for the Maryland Developmental Disabilities Administration (DDA). All community programs licensed by the state DDA participate and about 1,300 service users are surveyed each year by peer surveyors.

This approach is based on the belief that, as a result of their first hand understanding of disability and their receipt of services, people with developmental disabilities are able to elicit more meaningful responses from service users than traditional surveyors. Interviewers receive four to five hours of initial training as well as several training sessions throughout the year and are organized regionally to minimize transportation costs. The 35 interviewers work in pairs and receive assistance with setting up interviews, transportation, and answering questions. They are paid \$11 per interview. For more information, go to www.thearcmd.org/programs/ask_me.html.

Response lines are another method for obtaining participants' input, particularly during a pilot or initial program implementation when the “kinks” are being worked out. For example, Arkansas set up a participant complaint “hotline” for

its new self-direction program and program managers reported that the feedback received through the hotline was helpful in identifying and troubleshooting problems. When Arkansas' toll free self-direction information line receives many requests for information from the same geographic area, a state official goes out to meet with participants and providers in the area.

If participants have easy access to the Internet, states may be able to use listservs and other online forums to seek their views on specific issues. Oklahoma has made extensive use of information technology to involve participants in program design as part of their Systems Change grant work. In New Jersey, the Cash & Counseling grant's project director established a toll-free number and set aside a regular time each week during which participants could call in to exchange ideas and get questions answered by program staff.

All of these methods for ensuring accurate and timely feedback from participants and caregivers can also be key components of quality assurance and improvement activities. (See Chapter 8 for a discussion of quality management systems.)

B. Peer Support and Mentoring

In programs serving individuals with disabilities, peer support is generally defined as a structured relationship in which participants facing similar challenges interact to provide or exchange information and emotional support. Peer mentoring is a more formal type of peer support in which individuals with disabilities who have more knowledge and/or experience assist less-knowledgeable and less-experienced persons.

Peer support and mentoring can enhance participants' ability to direct their services. This section discusses several types of peer support and mentoring that states have used when designing and implementing self-direction programs.

Peer Support Groups

Support groups that bring together individuals with similar experiences provide a forum in which people can share the problems they are confronting and identify potential solutions to those problems. Independent Living Centers commonly offer peer support groups that bring together individuals with disabilities on a periodic basis to exchange experiences, brainstorm solutions to problems, learn about disability issues and advocacy opportunities, and provide a sense of community.

Similarly, local chapters of the Alzheimer's Association, the National Multiple Sclerosis Society, and other organizations concerned with chronic conditions host support groups for individuals with the condition or for their family caregivers. The local chapters of People First and other similarly organized self-advocacy networks serve as de-facto peer support groups and also offer an excellent opportunity to help educate individuals about self-direction.

Online support groups

Support groups are increasingly moving online (e.g., healthboards.com and caregiving.com). Online groups have several advantages over face-to-face groups. They can provide support to people who cannot leave their homes due to illness, disability, or caregiving responsibilities, and they allow individuals with rare needs to connect with people who share their needs and concerns, irrespective of where they live. Some people also prefer the anonymity of an online group as this may allow them to be more candid about their problems. Online groups can be less expensive to facilitate than face-to-face groups, although a moderator is often required to monitor conversations and ensure that the forum is not being misused.

At a minimum, states can inform participants about existing support groups in the community or online but they can also create opportunities for group support. Alternatively, the state can simply provide financial support and leave the organization to peers. For example, the Family Directed Support Network for Families of People with Disabilities in Utah consists of 35 local councils across the entire State that are run by volunteers with financial support and some technical assistance from the Governor's Council for People with Disabilities. Network members help each other identify available services and funds, decipher technical language, complete paperwork, locate employment and equipment, and support each other with advocacy efforts. More information is available at <http://www.cms.hhs.gov/PromisingPractices/Downloads/utfds.pdf>.

States can make use of existing networks to encourage peer support among participants who direct their own services, or set up a similar network solely for participants in self-direction programs.

National Participant Network

The 15 states that received Cash & Counseling grants are currently developing a National Participant Network to strengthen participant involvement in self-direction programs. The Network—comprising participants, caregivers, and advocates—shares ideas about how to improve self-direction programs, develops ways to advocate for self-direction at the state and national level, and partners with states to strengthen participant involvement in self-direction programs.

Peer Mentoring

Advisory groups and focus groups that include both participants new to the process and those with experience create opportunities for peer mentoring. However, peer mentoring opportunities and relationships can also be created intentionally and individuals can be trained to mentor their peers.

Independent Living Centers typically offer peer mentoring services. They recruit individuals who have learned to live independently and are willing to assist others to reach the same goal. States can both link participants to existing mentoring programs and establish peer mentoring opportunities for participants. For example, one of the more successful enrollment approaches in Arkansas' Independent Choices program came about when a woman in her late eighties who was homebound offered to speak on the phone with other elderly persons who were trying to decide whether they could really manage their own services. Her advice and mentoring gave many of her peers the confidence to enroll in the program.

As part of Virginia's Systems Change grant initiative, the Partnership for People with Disabilities at Virginia Commonwealth University established the Consumer-Directed Services Resource Network, a volunteer technical assistance network of participants, families, facilitators, and providers to assist people interested in trying out a self-direction option. This unique approach enables individuals who might have concerns about their ability to use the option to do so with additional support.⁸

In some programs, peers may be paid to provide specific services. However, to be reimbursed by Medicaid, the services must be listed as a waiver service and peers must meet specified provider qualifications. They may also be reimbursed through state general revenues or grant funds. In the mental health system, some peer support services, when provided by trained and certified peers, have recently been approved by CMS as a directly billable Medicaid service, and some Developmental Disabilities waiver programs offer peer services. Information and assistance services, which CMS requires to be provided in self-direction programs, may also be provided by peers who meet a state's qualifications.

Resources

Publications

Bergman, A., Ludlum, C., O'Connor, D., Starr, J., & Ficker Terrill, C. (2002). *Stakeholder Involvement in Home and Community-Based Services: Roles in State Planning, Program Development, and Quality Improvement.* Home and Community-Based Services Resource Network.

This brief paper offers tips to states for involving stakeholders in their decision-making process for planning, program development, and quality improvement. It also offers summaries of successful collaboration efforts in three states.

Available at: www.hcbs.org/moreInfo.php/doc/150

CMS State Medicaid Director letter regarding peer support services under the Medicaid program (2007).

This letter provides guidance to states interested in furnishing peer support services in mental health that can be billed under the Medicaid program. It covers supervision, care coordination, and training and credentialing.

Available at: <http://www.cms.hhs.gov/SMDL/downloads/SMD081707.pdf>

Holt, J., Jones, D., Petty, R., Crisp, S., Roth, H., & Galantowicz, S. (2007). *Facilitating Consumer Partnerships in State Policy and Program Design.* Houston, TX: Independent Living Research Utilization.

This 35-page publication provides a comprehensive discussion of methods states can use to develop and sustain consumer partnerships. It includes several checklists and practical information for ensuring consumers' involvement in state program and policy development.

Available at: <http://www.hcbs.org/moreInfo.php/doc/2071>

Lomerson, N., McGaffigan, E., O'Connor, D., & Wamback, K. (2007). *When CPIGs Fly: Meaningful Consumer Involvement in Systems Change.* Shrewsbury, MA: Center for Health Policy and Research, University of Massachusetts Medical School.

This brief publication describes Massachusetts' experience creating a participant advisory group as part of its Real Choice Systems Grant beginning in 2003. It includes 10 important lessons learned about meaningful participant involvement.

Available at: <http://www.umassmed.edu/uploadedFiles/CPIGS.pdf>

***Making Accessibility Real: A Guide for Planning Meetings, Conferences and Events* (2003).** Home and Community-Based Services Resource Network.

This guide is intended to help readers think broadly about the concept of accessibility in the context of planning meetings and conferences. It provides

strategies for identifying and meeting the accessibility needs of participants, including those with specific functional challenges, and provides references to accessibility standards.

Available at: www.hcbs.org/moreInfo.php/doc/52

Moseley, C. (2006). *The Guide: National Association of State Directors of Developmental Disabilities Handbook on Inclusive Meetings*. Alexandria, VA: National Association of State Directors of Developmental Disabilities.

This guide provides a framework for involving participants in state-sponsored activities where issues affecting their interests are being discussed.

Available at: <http://www.nasdds.org/pdf/TheGuide.pdf>

National Association of State Units on Aging (2008). *More Can Be Done: Involvement of Older Consumers in the Design, Implementation, and Oversight of Home and Community-based Services*. Prepared for the National Program Office for the Cash & Counseling Demonstration at Boston College.

This paper helps State Units on Aging and others in the aging network identify concrete steps they can take to support the role of older individuals as public policy advocates. It addresses the extent to which older HCBS participants are involved in public policy advocacy, the barriers to their successful involvement, and the strategies that are being used to attract, retain, and support older persons as participants in HCBS policy-setting activities. It is based on a survey of State Units on Aging with Cash & Counseling programs.

Available at: <http://www.cashandcounseling.org/resources/20080303-111313>

Sander, M., and Cheek, M. (2004). *Facilitating A Productive Advisory Committee*. Aging and Disability Resource Center Technical Assistance Exchange.

This publication provides practical tips on how to design and implement a successful advisory group.

Available at: <http://www.adrc-tae.org/tiki-page.php?pageName=Advisory+Committee+Brief>

Weaver, P. (2002). *Involving Consumers on Boards*. Washington, DC: Center For Medicare Education.

This publication includes practical tips for successfully involving participants on governing boards.

Available at: http://www.adrc-tae.org/tiki-download_file.php?fileId=26756

Web-Accessible Resources

Advocating Change Together

Web-address: <http://www.selfadvocacy.com/>

Advocating Change Together is a grassroots disability organization based in Minnesota run by and for people with developmental and other disabilities. The website has a useful online catalog of free educational materials to promote self-advocacy and disability rights.

Georgia Certified Peer Specialists Project

Web-address: <http://www.gacps.org/Home.html>

The project's website has extensive information about the role of peer specialists, relevant Medicaid regulation, a discussion of relevant ethics, and links to other resources.

Partners in Policymaking

Web-address: <http://www.partnersinpolicymaking.com/online.html>

This website has free online training courses for individuals and families who want to become active partners in the policymaking process.

Self-Advocate Leadership Network

Web-address: <http://www.hsri.org/leaders/>

This website has training tools for self-advocates and organizations interested in supporting program participants to become advocates. The website includes a training tool specifically related to self-direction, entitled Self Determination and You.

Citations, Additional Information, and Web Addresses

- 1 Vidhya Alakeson is the lead author of this chapter. Lee Bezanson and Janet O’Keeffe are co-authors.
- 2 O’Keeffe, J., O’Keeffe, C., Coleman, B., Greene, A.M., Brown, D., Anderson, W., & Osber, D. (2007). *Real Choice Systems Change Grant Program - FY 2001 Real Choice Grantees and Community-Integrated Personal Assistance Services and Supports Grantees: Final Report*. Baltimore, MD: Centers for Medicare & Medicaid Services. Available at: <http://www.hcbs.org/moreInfo.php/doc/1891>; and O’Keeffe, J., Anderson, W., O’Keeffe, C., Coleman, B., Greene, A.M., & Brown, D. (2008). *Real Choice Systems Change Grant Program - FY 2002 Real Choice Grantees and Community-Integrated Personal Assistance Services and Supports Grantees: Final Report*. Baltimore, MD: Centers for Medicare & Medicaid Services. Available at: <http://www.hcbs.org/moreInfo.php/doc/2172>
- 3 Ibid.
- 4 Holt, J., Jones, D. L., Petty, R. E., Crisp, S., Roth, H., and Galantowicz, S. (2007) *Facilitating Consumer Partnerships in State Policy and Program Design*. Houston, TX: ILRU Community Living Partnership. Available at: <http://www.hcbs.org/moreInfo.php/doc/2071>
- 5 Ibid.
- 6 The Subcommittee is part of a Policy Advisory Committee for the New Mexico Aging and Long-Term Services Department.
- 7 The Arc is the world’s largest community-based organization of and for people with intellectual and other developmental disabilities.
- 8 O’Keeffe, J., et.al. (2007). op. cit.