Consumer Involvement Toolkit

A Resource for State Agencies

Produced by the
Systems Transformation Grant

a Collaboration of the University of Massachusetts Medical School/Office of Long-term Support Studies, the Executive Office of Elder Affairs and the Executive Office of Health and Human Services/ Office of Disability Policies and Programs

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COMMUNITYFIRST

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Foreword

The vision of the Executive Office of Health and Human Services (EOHHS) is that the Commonwealth's long-term support system addresses the needs and preferences of the consumers served, that is, people with disabilities and elders. It would not be possible for the Commonwealth to achieve this goal without ensuring that consumer representatives participate in a meaningful way in the development and implementation of EOHHS' policies and projects. Consumer representatives offer the unique and invaluable perspective about what is important in an effective long-term support delivery system from personal and direct experience, and from what they've learned of the strengths and weaknesses of the system from their peers.

We have full confidence in state agency leadership to bring this vision to fruition. In fact, we have already seen successful consumer involvement in many state agency projects. These agencies' program and policy planning approaches clearly reflect the belief of the agency leadership that active consumer involvement adds value, and that real and effective service system improvement can only happen with consumer input. We hope and are confident that this level of commitment will spread and grow throughout all state government agencies.

We are happy to have contributed to the creation of this toolkit. This toolkit can provide guidance in making consumer involvement an integral part of the way state agencies develop, deliver and evaluate the effectiveness of long-term support services. We hope that you find it useful.

Jonathan Delman
on behalf of consumer representatives
who contributed to this Consumer
Involvement Toolkit

Introduction

About this Toolkit

The Consumer Involvement Toolkit is a product of the Systems Transformation Grant. The intent of consumer involvement is to encourage, value and use consumers' views and experiences in planning and operating activities. Our goal is to provide guidance for state agencies to effectively engage consumers in policymaking, program design and evaluation activities. The guidance in this toolkit will help agencies ensure that meaningful dialogue is fostered, meetings are accessible and the state has mechanisms for effectively evaluating consumers' experience in these activities. Provider organizations may also find some of the tools in this document useful.

In 2005, Massachusetts was awarded a five-year Systems Transformation Grant funded by the Centers for Medicare and Medicaid Services (CMS). The grant has supported consumer involvement in all aspects of long-term services and supports, policymaking, and systems change activities.

The following state agencies have been involved in grant activities:

- Executive Office of Health and Human Services (EOHHS)/Office of Disability Policies and Programs
- Executive Office of Elder Affairs
- Department of Mental Health
- Department of Developmental Services
- Department of Public Health
- Massachusetts Rehabilitation Commission
- Massachusetts Commission for the Blind
- Massachusetts Commission for the Deaf and Hard of Hearing
- Medicaid (MassHealth) Office of Long-Term Care

The Office of Long-Term Support Studies at the University of Massachusetts Medical School has provided the staff support for the coordination and evaluation of grant activities. People with disabilities, elders, family members and providers who support them have been involved in all phases of the work of this grant. throughout all state government agencies.

Through its Olmstead Plan, Massachusetts has established a vision for its human service delivery

A Vision for the Future: Community First

> **"Empower and support people with disabilities and elders to live with dignity and independence in the community by expanding, strengthening, and integrating systems of community-based long-term supports that are person-centered, high in quality and provide optimal choice."**
>
> **MA Community First Olmstead Plan Vision Statement**

system that emphasizes full integration of people with disabilities and elders into their communities. Key in attaining this vision is the ability of state agencies to be committed to being attuned to the expressed preferences, aspirations, and concerns of those they serve.

Agencies vary in how successfully they engage the people they serve. Many agency staff expressed the desire to involve a diversity of consumers more routinely in developing, delivering and evaluating long-term supports. Most EOHHS agencies that deliver long-term supports are also obliged by law (Chapter 171 of the Massachusetts laws of 2002) to engage consumers and family members in meaningful dialogue regarding policymaking. All have infrastructures in place to do so.

Commitment to consumer involvement begins at the top and leadership support provides the guidance, flexibility, and resources necessary to involve consumers. Commitment to active consumer involvement makes programs and services more effective in meeting the actual needs of the persons served. The quality of programs and services are strengthened when the experience of the people who are directly affected by them is considered in their design and evaluation. Furthermore, agencies that publicly promote consumer involvement in program and policy development create a culture that fosters positive relationships between agency staff and consumers.

This toolkit and the action steps, checklists and stories within it were created to help staff more effectively include consumers in projects, including operational activities and evaluation of services and supports.

What Is Meaningful Consumer Involvement?

It is not enough to simply invite a consumer to join a meeting if the context for the discussion has not been well-explained and accommodations are not available for comfortable and active participation.

Meaningful consumer involvement is an ongoing process where "interested and affected individuals are consulted and included in the decision making of an agency, planning group, or collaborative entity".

To be effective, consumer involvement includes:

- A thoughtful process in which consumers are invited to participate in an environment that is sensitive to the diverse levels of understanding of the agency's policy language and/or the context for certain conversations. Consumers are experts at how they experience the services but may not know the policy language used at your agency.
- An activity where everyone involved has adequate information and necessary support to understand the materials, context and discussion in order to make a meaningful contribution. Supports may include additional assistance beyond the usual formal meeting framework.
- A process through which consumers are told at the outset what input is being requested from consumers, the proposed process for gathering that input that is open for discussion, and what supports will be provided to the individuals involved in the project.
- A plan for insuring that the status of recommendations and plans made by workgroups that include consumers are clearly relayed back to those who participated on a regular basis.

"One measure of an effective public involvement program is whether you can identify specific ways in which the final decision is responsive to public comment. If nothing has changed as a result of the program, it has probably met the letter of the law but not the spirit of public involvement."

James Creighton, *The Public Involvement Manual* Cambridge: Abt Books, 1981.

Why Is Consumer Involvement Important?

Consumers bring experience and expertise that can enrich all aspects of policymaking and systems change activities. Consumer involvement promotes personal responsibility, quality and cost-conscious decision-making. Best practices in consumer involvement, particularly in health care, repeatedly show that involving consumers in meaningful ways improves services — making programs more responsive to "real" needs and often shifting (not increasing) funds. Consumer involvement has frequently been shown to lead to better service delivery and improved outcomes.

How Your Agency Can Benefit from Using This Toolkit

- Suggestions for how to engage and include consumers in projects
- Tips for finding and inviting consumers to participate
- Resources for providing reasonable accommodations
- Ready-to-use tools and checklists
- Examples from state agency colleagues

How to Use This Toolkit

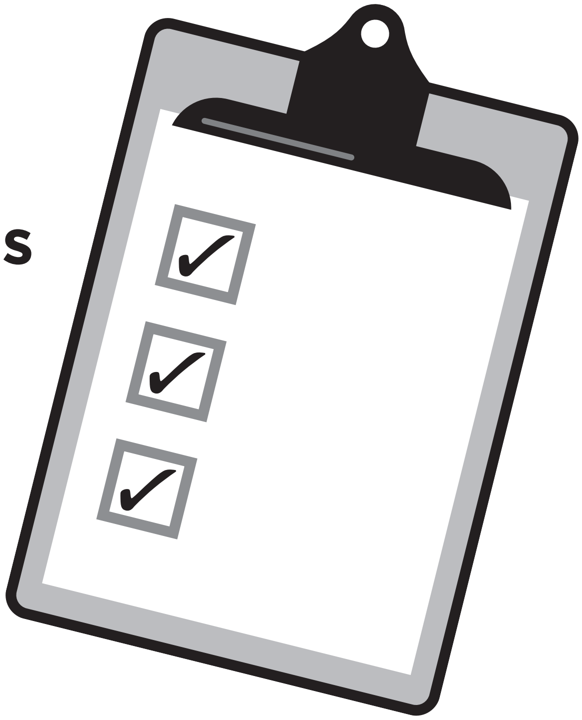
The toolkit was created to assist all state agency personnel and their contracted community agencies, regardless of their experience with consumer involvement. It can assist with determining how and when to involve consumers in any project, from new to ongoing projects.

The toolkit is divided into four sections related to four key steps in initiating, supporting and improving consumer involvement. They are:

- **STEP 1:** Determine Consumer Roles and Expectations
- **STEP 2:** Outreach and Recruitment for Consumer Participation
- **STEP 3:** Support the Process of Consumer Involvement
- **STEP 4:** Evaluate Consumer Involvement Experiences

Step 1:

Determine Consumer Roles and Expectations



Often projects go off track or fail because we were not clear about our mutual expectations. Expectations can range from the length of time a consumer may believe he or she is committing to a project to the actual level of involvement and level of decision-making authority he or she actually holds during the process. It is critically important that both agency staff and consumers share openly and honestly about what each person's expectations are regarding the consumer involvement process in general, and the specific projects and activities to be undertaken in particular.

Not all projects will require the same type of consumer involvement; therefore, it is important to consider what you would like the scope of consumer involvement to be and the timing of participation at the outset of the planning process. It is important to be clear about what is needed and what is being offered. One of the most important things in creating successful partnerships is to communicate expectations upfront.

It is helpful to tell consumers why you're including them. Specify how much of their time will be needed and how input will be used. When you are clear about what you are asking, it's easier for consumers to decide whether or not they want to be involved. It also gives consumers the opportunity to suggest other approaches to what you are proposing.

LEVELS OF CONSUMER INVOLVEMENT

Level	Description
6	Consumers have control, with guidance from organization
5	Consumers agree to make certain decisions about the project, or are delegated to make such decisions
4	Consumers plan/work jointly with staff to make decisions
3	Consumers advise staff
2	Consumers are consulted intermittently
1	Consumers receive information
0	None

Create a Work Plan

Typically, the first step to any project is creating a work plan. It is important in this early stage of work plan development to consider each of the activities of the project and to determine how and when it will be most effective to involve consumers. In planning, you may find it helpful to ask and answer the following questions, and then integrate these decisions into your project work plan:

1. What is the consumer role in this activity/project?

Consumers can perform many roles in any project. Some roles are established for advisory purposes, while others are partners in policymaking or evaluation of services. It is vital that roles and responsibilities are clearly articulated.

The table above was developed by Consumer Quality Initiatives, Inc. It displays six levels of consumer involvement in planning, policy development and quality improvement. Decide in advance what level of involvement you are seeking from consumers.

2. When should consumer involvement begin?

A project, whether it is short-term or ongoing, has many aspects including initial design, implementation steps, evaluation and continued improvement.

Will consumers be involved in one, some or all of these project components? One of the first things every manager should do is consider the steps pertaining to how and when to engage consumers in the project.

A common tension in the planning process is over when to involve consumers. Consumer involvement may be best begun at the early planning stage because in many cases it is counter-productive to move too far along in planning without getting input from consumers. This is particularly the case if getting the consumer's perspective early on will make the quality of the project, programs and services more effective in meeting the needs of the persons served.

Conversely, there may be projects that include activities that may be only relevant to the internal operations of the agency, or in which consumer input would not be considered or in which certain aspects must logically occur before involving consumers would be appropriate. In these cases, consumer participation at the wrong time would be a poor use of everyone's time and could potentially create misunderstandings about expectations and roles.

3. **What obstacles could limit consumer involvement in this activity/project?**

   Consider any policies, practices or historical issues that may deter agency staff or consumers from working together. It will be helpful at the outset to try to identify and plan for ways to overcome these issues.

4. **How will you involve consumers in this activity/project?**

   In order to involve consumers, you will need to think ahead about what level of commitment you are expecting and what support you should and can provide.

5. **Are there other staff members in your agency or a sister agency that have had successful experiences with consumer involvement who can help you answer these questions and apply the answers to your work? Have you spoken with consumer-run agencies for technical assistance and support?**

   A list of consumer-run agencies in Massachusetts is available in Appendix A of this toolkit.

6. **What steps do you need to take to provide compensation for participating consumers?**

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Be Prepared – Common Questions Consumers Ask Before They Commit

- ✓ What are you asking the consumer to do?
- ✓ What are you offering in exchange for the consumer's participation? (e.g., stipend, gift certificate)
- ✓ How much of a time commitment are you asking for? (e.g., 1 hour a month for 3 months)
- ✓ What are the consumer's options for participating? (e.g., attend meetings, respond to emails, review draft materials)
- ✓ What is the extent of this group's decision-making power?
- ✓ What do you expect to accomplish as a result of this activity?
- ✓ How long do you expect the process will last and will there be a product at the end?
- ✓ When and how will you communicate to consumers involved regarding what happens with the work and the result of recommendations made?
- ✓ Who will be the contact person if the consumer has questions or concerns?

Identify Necessary Resources

Resources are needed to meaningfully involve consumers. Here are some of the resources you may want to think about in order to determine your resource needs for successful consumer involvement.

1. Staff

✓ In addition to the staff support needed for the actual work of the project, you should plan for staff support to prepare meeting materials, to contact consumers before and/or after meetings, and to handle various accommodation needs.

2. Time

✓ Plan the time of meetings to be convenient for the individuals you want to include. Early mornings may be difficult for people with physical disabilities. Evening meetings may be better for individuals who are employed but difficult for older adults who have trouble with night-driving or for those caring for children.

✓ Provide materials well in advance of meetings so that individuals have a chance to read them and/or have them interpreted if they need assistance. A minimum of one week in advance should be expected, although two weeks is generally considered best.

3. Accommodations

✓ A meeting room should be selected that is physically accessible and has enough space to accommodate the size of the group, including free space to allow movement for those using scooters or wheelchairs.

✓ Ability to provide materials in alternate formats for persons with visual impairments including CD, large print and Braille.

✓ Access to Communication Access Realtime Translator (CART) and American Sign Language (ASL) interpreters as needed.

✓ Sound systems may be needed if the group is large, to accommodate the needs of persons who are hard-of-hearing.

4. Stipends

✓ For consumers who are participating independent of their jobs, payment of a stipend puts them on equal footing with other participants and sends a strong message that their time is valued. If possible, this is strongly encouraged. It is important to determine whether your organization enables you to provide stipends and what the process is so you can explain it to your consumer participants and help them utilize the stipend process if so.

5. Transportation

✓ Transportation to and from meetings is costly and often logistically challenging for many consumers with disabilities of all ages. Providing reimbursement is one important support. It is even more helpful if the agency can make arrangements with transportation providers that enable consumers to arrange transportation without having to pay the up-front costs. Transportation vouchers and other methods can be used for this purpose. Assistance in coordinating transportation is an additional support that some consumers may request.

Determine the Consumer Role – LESSON LEARNED

A good lesson about what not to do when involving consumers was learned from the first Real Choice grant awarded to Massachusetts in 2001. The application for the grant and the first year and a half of grant activity involved almost no consumer input. When the state was finally ready to bring consumers to the table, they faced what has come to be known as the "Real Choice Revolt". Consumers voiced their frustration at the first public forum sponsored by the grant. They threatened to boycott further efforts unless they were involved in a meaningful way in the grant activities.

This rough start eventually led to a good outcome. A Consumer Planning and Implementation Group was established, with eighteen consumers representing various disabilities and ages. Five members were chosen by the group to meet monthly with five representatives of the state on a Collaborative Team that oversaw the grant activities. Consumers and the state agency representatives had an equal voice in decisions and both groups learned that they had a lot in common and that they could "accomplish a great deal more by working together."

— N. Lomerson, E. McGaffigan, D. O'Connor, and K. Wamback. *When CPIGS Fly: Meaningful Consumer Involvement in Systems Change*, Center for Health Policy and Research, University of Massachusetts Medical School, February 2007.

Step 2:

Outreach and Recruitment for Consumer Participation

Develop Guidelines for Selecting Diverse Populations

Develop guidelines for selecting key populations to be involved in consumer involvement. It's important to think about non-traditional approaches to outreach and recruitment. When you are working to bring more consumers to the table, your relationships with persons and organizations in the community are key in assisting you to identify and reach out to consumers for participation.

In addition to including individuals you currently serve, initiatives in which you desire to involve consumers should seek to engage:

- All ethnic, racial, socioeconomic, and cultural groups. This includes the deaf and hard of hearing community and the gay/lesbian/bisexual/transgender (GLBT) community—not just individuals who have a specific racial or ethnic background.
- Persons who are not served because they may not be aware of currently funded programs, they are not eligible for services or they won't need services until some future date due to the progression of their disability.
- Persons living in nursing homes, state facilities or other institutional settings who are not typically asked to participate.

- Persons who are homebound or who, due to the significance of their disability, homelessness or other factors are under or un-served.
- Family members/loved ones/caregivers of the above.

How to Create Opportunities to Network and Explore

Many other agencies and states seek to engage consumers. Look for opportunities to network and explore the techniques that others are using.

The following are some ideas you can try for outreach and recruitment of consumers:

- Go online and use social media like Facebook and Twitter and existing organizational and advocacy web sites and listservs
- Identify contacts from previous consumer-focused initiatives
- Work with trusted community leaders to reach consumers
- Connect with individuals through faith-based organizations, civic organizations and festivals
- Solicit interest through media including radio and cable TV if available

Resource tip:

"States can use web sites and listservs to share information with the broader consumer and advocacy communities and provide a conduit for feedback. To facilitate communication as it developed its new managed care program for the ABD population, Ohio created a web page that was updated regularly to provide current information for the public."

John Barth, MSW,
The Consumer Voice in Medicaid Managed Care: State Strategies, Center for Health Care Strategies, March 2007

This policy brief provides other examples of how states have involved consumers in program development and policy-making. It is available for download at **www.chcs.org.**

Ten Questions to Answer for Successful Recruitment and Outreach Efforts

1. Do you have an outreach or recruitment strategy already in place?
2. Do you use consumers as resources to reach their peers?
3. Are you making sure your outreach materials are accessible and in appropriate formats?
4. Do you know what questions to ask consumers when you ask them to participate? Is their role clearly identified?
5. Are you aware of existing groups of individuals who come together? (e.g. support groups, resident councils, consumer councils)
6. Is anyone on your staff already connected to these groups?
7. Are you aware of gaps in your contact lists? Who is missing?
8. Are you covering the appropriate geographic area with your outreach?
9. Do you have a plan for follow up with consumers once you've asked them to participate?
10. Do you have staff identified to manage the contact lists and conduct the outreach?

Step 3:

Support the Process of Consumer Involvement

How to Ensure Reasonable Accommodations for Meetings

As you increase consumer involvement in your agency, you may have to rethink issues of access and accommodations. It is important to plan prior to convening meetings for how to ensure reasonable accommodations are made, materials are accessible and that everything is in place to foster active and meaningful consumer involvement.

The following checklist can help to determine what is needed before convening your meetings:

- Identify meeting locations that are accessible
- Consider the use of teleconferencing and internet forums and identify mechanisms to do so
- Prepare materials in accessible formats
- Meet or talk with consumers in advance of meetings to determine background information and other information they may want or need in order to participate knowledgeably

- Determine whether you want separate meetings or conversations to occur periodically or be available as needed to support ongoing understanding of topics discussed
- Determine who will be responsible for following up with consumers to ensure they understand the meetings/processes, and to bring them up to date when meetings are missed
- Determine whether you want the meetings to be co-led by a consumer or consumers and if so, determine how you will select these individuals
- Consider asking consumers whether there are others they would like you to invite who would help support their participation.

When planning for your meetings, it is important to consider the potential accommodation needs of the consumers who you have invited to attend. Ideally, you should always do a site visit to the selected location prior to the meeting to evaluate your accommodations. The following checklist provides considerations for selecting meeting sites.

Meeting Access

- Be sure your meeting site is in an accessible location. Can the consumers who may drive to your meeting park their vehicles and get to the meeting location without having to travel long distances? This may be difficult for those who use wheelchairs, scooters or crutches, or for others in bad weather.
- Be sure the meeting is in a location where it can be reached by accessible public or Paratransit means. Is it near an MBTA Station or in an area where consumers who use The RIDE can get to?
- Be sure the meeting environment is accessible. Can a consumer get into the building and into the room where your meeting is being held? Is there an accessible bathroom if needed? Based upon the length of your meeting, are you planning on feeding consumers? If so, have you provided straws or other items/assistance to those consumers who may need accommodations for eating?
- Be sure the room where your meeting is going to take place is large enough for individuals who have mobility impairments, assistive animals or need the assistance of American Sign Language Interpreters (ASL) or Communication Access Realtime Translator (CART).

Preparing Materials to Ensure Consumer Participation

The materials that you intend to use at your meeting must be made into the accessible format(s) that an individual requests. When preparing for your meeting, always remember to ask individuals about their needs in advance.

1. ***For Individuals who are blind or visually impaired -*** Materials must be put in the format which the individual prefers. Options may include Braille, large print, on audio tape, or in an electronic version.
    - **Braille printing** can be done by a Braille printer or documents can be sent to either: the Braille and Talking Book Library at the Perkins School for the Blind, *www.perkins.org/community-programs/*; or The National Braille Press, *www.nbp.org/ic/nbp/company/index.html* in order to have them transcribed.
    - **Large print** should be in Times New Roman 18 point **BOLD** font.
    - **Audio tape:** Written materials can be put onto audio tape by Reading for the Blind and Dyslexic. *www.rfbd.org/Contact-Us/40/*.
    - **Electronic versions:** JAWS, Window Eyes, Systems Access and NVDA are types of software that provide voice access to electronic files by computer. Files with the extension. pdf have to be configured in an Adobe Acrobat Reader format.
    - **Text version:** In order to make pictures and diagrams in electronic files accessible in Word, caption all of your pictures and write descriptions of diagrams in text.
2. ***For Individuals with cognitive impairments-*** Individuals with cognitive impairments, intellectual disabilities or developmental disabilities may need to have materials mailed to them well in advance so that they can review them at their own pace or get the needed assistance to fully comprehend the content. You might also want to design a sheet for them where the main ideas in the meeting are broken down into a list of simple bullet-pointed ideas, rather than having them go through excessive pages of documentation.
3. ***For individuals who are deaf or hard of hearing-*** For individuals who attend your meetings and are deaf or hard of hearing you will need to provide access through an American Sign Language (ASL) Interpreter or a Communication Access Realtime Translator (CART). You should ask the individual what their communication preference is in advance.

- **American Sign Language (ASL)** is a complex language with its own grammatical structure that is used by many Deaf people in America. A certified American Sign Language Interpreter should be provided to someone who requests this service. It is important not to assume that because someone knows sign language that he or she has the skills necessary to serve as an interpreter.

  Before the meeting, it is important to consider the location of the American Sign Language Interpreter and the individual(s) using his or her services. If the meeting is theater style, reserve an area near the speaker and the screen (if applicable) for the interpreter(s) to stand. Also reserve seating near the front of the room within view of the interpreter(s) for those individuals using the service. Make sure there is a clear walkway for all speakers so they do not block the interpreter(s). Always ask the deaf attendee if the set up is appropriate and conducive to participation.

- **Communication Access Realtime Translation (CART)** is a system that is used to convert speech to text and is displayed on a large screen or laptop screen. A trained operator uses a specialized keyboard to transcribe spoken speech into written text. You will need to tell the CART reporter if you will have a screen for them or if he or she will need to bring their own. Also, if only one person is using the CART service, the CART reporter may just use a laptop screen. In this case, ensure that you have adequate space around the table for the CART reporter and laptop.

- **Requesting ASL and CART:** Both ASL and CART can be obtained by calling the Massachusetts Commission for the Deaf and Hard of Hearing at: 617-740-1600 and placing a request or by filling out one of these forms: *www.mass.gov/Eeohhs2/docs/mcdhh/interpreter_request_form.rtf* or *www.mass.gov/Eeohhs2/docs/mcdhh/cart_fax_request.rtf.* For both of these requests it is imperative that you give yourself enough lead time in order to get the accommodation that you are requesting. It can often take at least a month to secure these so the more time you can allot to this, the better off you will be in the long run.

4. ***Individuals who are deaf-blind*** are distinct from individuals who are either deaf or blind. For these individuals, communication is through tactile signing. Different types of tactile signing include:

   - **Hand-over-hand** (also known as 'hands-on signing'): In this method, the receiver's hands are placed lightly upon the back of the hands of the signer so that he or she may read the signs through touch and movement.

- **Tracking:** In this method, the receiver holds the wrists of the signer to keep signs within field of vision and to gain information from the signer's movements. This is sometimes used when the receiver has a limited field of vision.

- **Tactile Finger spelling:** In this method, every word is spelled out using a manual alphabet. Different manual alphabets may be used, such as the one-handed ASL alphabet, where the receiver places his or her hand over the back of the hand of the signer, or the two-handed manual alphabet, also known as the deaf-blind alphabet, in which letters are produced onto palm of the receiver's hand.

- **Co-active signing:** In this method, the signer moves and manipulates the hands and arms of the person who is deaf-blind to form sign shapes, or finger spelt words.

- **On-body signing:** In this method, the body of the person who is deaf-blind is used to complete the sign formation with another person. E.g.: using the chin, palm and chest. This method is often used with people who have an intellectual disability.

- **Tracing** or 'print-on-palm': In this method, the signer traces letters or shapes onto the palm or body of the person who is deaf-blind. Capital letters produced in consistent ways are referred to as the 'block alphabet' or the 'Spartan alphabet'.

- **Braille signing:** In this method, the signer uses six spots on the palm to represent the six dots of a Braille cell. Alternatively, the signer may type onto a table as if using a Braille typewriter and the person who is deaf-blind will place his or her hands on top of the table. This method can have multiple individuals who are deaf-blind working with an signer at the same time; however, the individual who is deaf-blind and sitting opposite the signer will be reading the Braille cells backwards.

5. ***Modifications*** to think about when preparing for your meetings involving persons who are deaf-blind:

   Lighting is vital to individuals who are deaf-blind. Mostly bright and even light is best to have in your environment and it is important to avoid glare. However, some individuals prefer dim light, so it's best to ask. It is important to have your interpreter(s) consider appearance and attire when working with deaf-blind clients:

   Interpreters should wear clothes that provide contrast for their hands. They should consider the following when selecting clothing:

   - Dark colors (black, navy blue, brown, dark green, etc.) for persons with light skin

- Light colors (off-white, tan, peach, etc.) for persons with dark skin
- Solid colored clothing (avoid stripes, polka dots, etc.)
- High necklines (no scoop necks or low v-necks)

Contrasting colors between skin tone and background walls can also help.

It is better to avoid jewelry which can be distracting, either tactually (e.g. rings and bracelets) or visually (e.g. sparkling drop earrings). Fingernails should be short and smooth. A neutral color of nail polish may be worn, but bright reds and dark colors can be too strong. Because interpreters are working in close proximity to individuals who are deaf-blind when using tactile sign, they should be aware of strong smells such as perfumes, scented deodorants or cigarette smoke.

Tactile signing can also be exhausting for both the interpreter and the person who is deaf-blind. Breaks are even more important than with regular interpreting, and should be taken more often. Correct seating can also reduce the risk of strain of injury; both communication partners should be comfortable and at an equal height. Specially designed cushioned tables for tactile signing can be used.

Provide Support and Assistance

- Some individuals may need assistance comprehending agency or project materials. Individuals may have someone working with them already as a peer or advocate. If not, offer the assistance of a staff person or a peer support mentor.

- Make every effort to accommodate consumers' needs, particularly in relation to health difficulties. When a consumer returns after taking time off, agency staff and contacts should take the time to bring him or her "up to speed".

- Be open to and encouraging of peer support relationships. As an example, a Consumer Council at a state agency was very successful in providing input and sustaining the members' participation because the Consumer Affairs staff made peer support an integral part of the meeting.

- Getting to your meeting may be costly and time consuming for some of your consumers who may have to travel long distances or who may live on a fixed income. Consider providing reimbursement to consumers for the cost of tolls and parking.

- Consider providing stipends for specified amounts, based on the amount of time a consumer has participated in your meeting.

The Key to Success Is Communication

One of the biggest assumptions we make when we discuss issues together is about a common understanding of language. In the field of human and social services, our language is filled with acronyms, references, clichés, hidden meanings, and assumptions. In order for both agency staff and consumers to engage in meaningful dialogue, we must be very clear about the language we all use, and terms must be clearly defined. Language includes the level of conversation and sophistication of sentence structure as well as tone and body language.

It is important for everyone participating in the consumer involvement process to have very clear and open communication. To communicate effectively it is important to use plain language in both speech and written materials. Adopting plain language as an operating principle can save everyone time, ensure that everyone at the table understands the most important points under discussion and enable you to prioritize and focus on crafting messages that people need to know. The successful use of plain language will:

- Always put the most important information first.
- Identify the complex concepts and break them down into understandable ideas.
- Use simple language and define technical terms.
- Use the active voice.

It is important that you create materials that are consumer/user-friendly. One way to do this is to ask consumers to assist in development of the materials. Ask consumers to review materials in advance or engage a consultant experienced in preparing materials that are in plain language.

Resource tip:

Visit *www.plainlanguage.gov* and check out the Quick Tips to Help You Write More Clearly.

Visit *www.health.gov/communication/literacy/quickguide/factsbasic.htm* to read a Fact Sheet on Health Literacy Basics. The Fact Sheet provides an overview of health literacy, including plain language, and offers additional resources.

Communicating Clearly to Ensure Satisfying and Effective Consumer Involvement

- ✓ Have a glossary of terms and acronyms that you can share with consumers when you begin a project.
- ✓ Be sure ground rules for conversation are stated up front and are clear and respectful.
- ✓ Talk with agency staff in advance to help ensure they will conduct themselves with sensitivity to consumers and that they are more sensitized to the language they use when referencing abilities and disabilities. Do they know what terms may be offensive or politically insensitive? (This keeps changing, so are you sure you are up-to-date regarding preferred terms or terms to avoid?)
- ✓ Talk with staff in advance about how to support communication and language with individuals who might exhibit specific disabilities (e.g., communicating with a person who is deaf or hard-of-hearing and who uses an interpreter, communicating with a person with a speech impediment, acquired or traumatic brain injury, or developmental disability).
- ✓ Be sure all accommodations, including assistance you have planned to provide to consumers during the meetings, are in place (e.g., staff person to turn pages).

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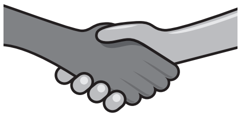
Tips Specific to Engaging People with Intellectual Disabilities in Policymaking

1. Make sure to engage two or more consumers with intellectual or developmental disabilities in each specific project.
2. Have the support person review materials and the agenda with a consumer prior to the meeting. Make sure that the support person is helpful and not overpowering.
3. Always send materials for meetings to the consumer via direct mail unless the consumer specifically states that it is ok for him or her to get materials via email.
4. Consumers with intellectual or developmental disabilities may be very uncomfortable using the computer, the internet or chat rooms.
5. Ask the consumer what services he or she likes and doesn't like and what could be improved.
6. Consumers with intellectual or developmental disabilities are capable of advocating for themselves. Family members, friends, loved ones should always be involved in decision-making if this is what the consumer wants.
7. Consumers with intellectual or developmental disabilities may be at a different level of learning and understanding.
8. Do not always go for the first answer from a consumer with an intellectual or developmental disability unless you are sure that the consumer understood everything.
9. Make sure that any materials for meetings are written in language that a consumer with an intellectual or developmental disability is able to understand.
10. Consumers with intellectual or developmental disabilities need to know that they are being listened to and that what they say is making a difference.



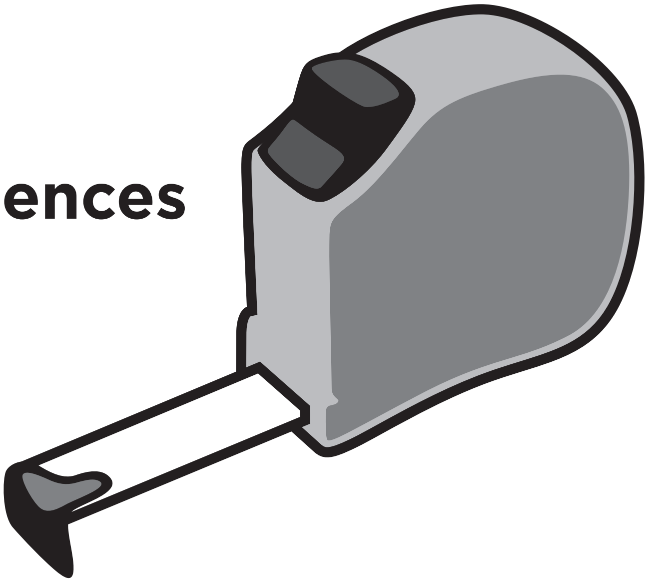
Support the Process of Consumer Involvement – LESSON LEARNED

During a recent training event, a Communication Access Realtime Translation (CART) specialist chose to place her equipment and screen in the corner of the room. The panel of speakers was located in the middle of the room. Although seating for deaf and hard of hearing attendees was placed in front of the presenters, the attendees had to turn sideways and look towards the corner of the room in order to access the information. This made it difficult for deaf and hard of hearing attendees to interact with the presenters and understand the context of the discussion because they could not watch the presenter's body language to determine tone or follow along with the PowerPoint presentation. The attendees were frustrated with the experience. This type of scenario can also make a deaf or hard of hearing attendee feel disengaged and powerless. Also, it could result in feelings of embarrassment if a question or comment becomes "outdated" because the attendee is not able to follow the flow of the presentation or topic.

The host of the event learned several things from this event. Whenever possible, ask your deaf and hard of hearing guests where they prefer the CART specialist or ASL interpreter to place their equipment or stand. If the guests have not arrived or it is not possible to ask the guests, place the screen or ASL interpreter in close proximity to the presenter or panel. It is important not to place the ASL interpreter in front of the CART screen. Whenever possible, the ASL interpreter and CART screen should be placed on opposite sides of the presenter(s). The deaf and hard of hearing guests should be able to see the CART screen and/or ASL interpreter and the panelists without changing direction or looking across the room. Also, it is important to reserve seats close to the presenters and CART specialist and/or ASL interpreters for deaf and hard of hearing guests. If a video will be shown during the event, the host should check if the closed captioning is functioning on the television and recording. If the captioning does not work, the ASL interpreter and CART specialist should be told in advance. Also, when showing a video, lights should not be dimmed to a level that the ASL interpreter can not be easily seen.

Step 4:

Evaluate Consumer Involvement Experiences



Evaluation is a key component of continuous quality improvement for any program; it is also an important activity to monitor and continuously improve the process of involving consumers in policy and program development.

Feedback on the effectiveness of and consumer perspectives about their involvement can guide future policymaking and enable policymakers to continually improve their approaches to engaging consumers in policy and program development.

When Should an Evaluation Be Conducted?

In an ideal world, evaluation activities should begin at the start of any project, including projects involving consumers. Activities can involve determining the goals of the consumer involvement and developing a logic model that relates the specific activities engaging consumers to expected outcomes that can be measured or documented in specific ways.

One advantage of beginning these evaluation activities early is that it helps to ensure that the necessary information is incorporated into program forms or other mechanisms for documentation of the impact. Another advantage is that by collecting information early about the consumer perspectives about their involvement, agencies can then use what they learn to make changes and adaptations that improve the process.

If evaluation activities are not designed at the start, all is not lost. It is possible to introduce evaluation activities at any stage in the process. For example, you can ask people to reflect on their past experiences as well as their current experiences with consumer involvement.

What Are You Hoping to Learn from the Evaluation?

In planning an evaluation, it is important to consider what you are hoping to learn from the evaluation. Examples could include:

- How do consumers feel about their degree of involvement in the process?
- How diverse is the representation of consumers in the process?
- How does the involvement of consumers impact the outcomes of the project?
- What improvements can be made related to consumer involvement?
- What lessons about consumer involvement can be learned for future projects?

What Approaches Can Be Used to Evaluate Consumer Involvement?

Any traditional evaluation methods can be used to evaluate consumer involvement including surveys, focus groups, interviews, and reviews of documents (e.g. meeting minutes).

Surveys:

Web-based surveys have become an increasingly popular and relatively inexpensive method of reaching a broad number of individuals. Electronic survey tools such as Survey Monkey have made the development of such surveys and the compilation of data relatively easy.

However, it is important to recognize that not all consumers have web access and thus you should offer alternative means of participating in the survey. Surveys can be administered in person, by phone, and by “snail” mail, depending on resource availability.

Surveys are most effective when there are concrete questions for which you are trying to get information. Putting adequate time into developing a good survey tool and testing it ahead of time with some consumers will help to assure that your target population understands the questions you are asking and that you can interpret the results when you get the surveys back.

Interviews:

Interviews are another useful approach to consider, particularly if there are areas that you want to be able to probe more deeply or on which you want to ask follow-up questions. As with surveys, it is important to develop a good interview guide, and if possible, test it ahead of time to be sure that the questions are clear and meaningful to those you intend to interview.

Interviews can be completed in person or by telephone. You will need to consider training for interviewers, possible payment for people being interviewed and how you want to record data (e.g. taking notes or transcribing recordings).

Focus groups:

Bringing together a small group of consumers to talk about their experiences is another good way to learn about consumers' experiences. When these discussions follow a structured format, they are called focus groups, but even a less formal discussion group can provide you with good information. Focus groups provide an opportunity not only for each individual to share his or her perspective but also to hear what others are saying. This can often trigger memories or experiences that one individual might not have thought to share. Like with interviews, focus groups also provide an opportunity for probing or following up on specific issues. Similarly, focus group considerations mirror interview considerations noted above.

Can/Should Consumers Be Involved in the Evaluation Activities?

Yes, definitely! Involving consumers in the design, implementation and analysis of evaluation activities is a good way to demonstrate transparency, to ensure that the evaluation is truly focused on the issues of concern to consumers and to recognize consumers as true partners in all aspects of the program design, implementation and evaluation. For example, in the evaluation of the Massachusetts Real Choice grant, consumers participated on an advisory committee that developed the questions for the evaluation. Consumers were also among the individuals interviewed for the evaluation. In addition, consumers who were interviewed were asked to review the summaries of their comments to be sure that their perspectives were captured accurately.

Another way that the Real Choice Grant engaged consumers was to hire a consumer-led research group, Consumer Quality Initiatives (CQI), to conduct interviews with the participants in the Real Choice Pilot Project. In this component of the evaluation, persons with disabilities from CQI helped to develop the interview guide, conducted the interviews, analyzed the findings and wrote up the results.

CQI is one of only a few such consumer-led research groups in the country, but opportunities for consumers to be involved in research are growing.

Participant Questionnaire

Developed by the Consumer Planning and Implementation Group for The Real Choice and Independence Plus Consumer Experience Project

Instructions:

1. **Please take the time to answer the following questions to the fullest extent possible. Under each question, you will notice prompting questions. These questions are to assist you to think about your answer when writing. Please try to touch upon each area. Please also feel free to provide additional information as you see fit.**

2. **If you need any accommodations or assistance filling out the questionnaire, please contact ______________.**

3. **Once you have completed the questionnaire, please use the self addressed stamped envelope to return to___________.**

4. **Please explain your experiences with consumer involvement in _________ . When answering this question, please think about any or all of the following:**

   Ⓐ How did this consumer involvement process differ from other initiatives you've been a part of in the past?
   Ⓑ What worked?
   Ⓒ What did not work?
   Ⓓ What have you learned?

   What would you change about the procedures?

5. **Please explain your experiences with the ___________________ as a cross-disability initiative. When answering this question, please think about any or all of the following:**

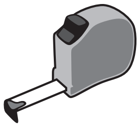
   Ⓐ Have you been involved in any other cross-disability initiatives?
   Ⓑ If so, how did this compare?
   Ⓒ What are the reasons to create cross-disability policy? What are the reasons not to?
   Ⓓ How did this project help in introducing diverse groups of stakeholders of various disabilities and backgrounds?
   Ⓔ How could we have done it better?

6. **Please share your experiences, thinking about any or all of the following:**

   Ⓐ What led to the creation of the ____________?
   Ⓑ Was the _____ appointment process effective?
   Ⓒ Who did the _______ represent? Who did it not represent?
   Ⓓ What kinds of support helped the __________ do its work?
   Ⓔ Should we have done things differently? If so, how?
   Ⓕ How did your experiences on the __________ change over time?

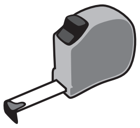
7. **What were your experiences related to accessibility? Please share your experiences, thinking about any or all of the following:**

   Ⓐ How was this model different from your other grant experiences?
   Ⓑ What were some challenges at start up?
   Ⓒ What were some barriers to progress?
   Ⓓ What are some lessons learned that could be applied to future grants?



Are You Maximizing Consumer Involvement? Take the Tool Kit Test!

- ✓ Do you ask consumers what their accessibility and accommodation needs are when you invite them to participate?
- ✓ Do you organize, coordinate, prepare appropriate materials and make arrangements to ensure participation from a diverse group of consumers?
- ✓ Do you physically visit a meeting location prior to using it in order to ensure it is accessible?
- ✓ Do you know who to contact in order to translate materials into alternate formats?
- ✓ Do you have a budget in place to pay for materials to be translated into alternate formats?
- ✓ Do you ask consumers if they have any specific needs that might require specialized support or flexibility? (e.g. work schedule, PCA support, frequent breaks due to fatigue)
- ✓ Do you communicate with consumers in between meetings to see if they require any follow up, additional review of materials or help understanding the information discussed or to be discussed at a future meeting?
- ✓ Do you have a staff person identified as the consumer liaison who will communicate with the consumers regarding meeting times and locations?
- ✓ Do you work to create a welcoming and inviting environment at each and every meeting?



Acknowledgements

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Appendix A: Consumer Organizations

1. AARP Massachusetts State Office

Deborah Banda
AARP Massachusetts State Director
One Beacon Street, Suite 2301
Boston, MA 02108
Toll free: 866-448-3621
ma@aarp.org

AARP's mission is to enhance the quality of life for all as we age, leading positive social change and delivering value to members through information, advocacy and service.

2. Advocates for Autism of Massachusetts

Amy Weinstock
217 South Street
Waltham, MA 02453
781-891-6270
www.afamaction.org

Advocates for Autism of Massachusetts will strive to assure the human and civil rights of individuals of all ages across the entire Autism Spectrum and promote the availability of essential supports so that they may live fully and enjoy the same opportunities as other citizens of the Commonwealth.

3. Advocates, Inc.

William J. Taylor, President & CEO
One Clarks Hill, Suite 305
Framingham, MA 01701
508-628-6446
www.advocatesinc.org

Advocates, Inc. helps people achieve their hopes and dreams within the fabric of their communities. They partner with people with disabilities, elders, and those with other challenges to overcome personal obstacles and societal barriers so that they can obtain and keep homes, engage in work and other meaningful activities, and sustain satisfying relationships.

4. Alzheimer's Association

James Wessler, President & CEO
311 Arsenal Street
Watertown, MA 02472
617-868-6718
www.alz.org/manh/

The Alzheimer's Association's mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

5. The Arc of Massachusetts

Leo Sarkissian, Executive Director
217 South Street
Waltham, MA 02453
781-891-6270
www.arcmass.org

In conjunction with local chapters and The Arc of the United States, The Arc of Massachusetts has a mission to enhance the lives of individuals with intellectual and developmental disabilities and their families.

6. Brain Injury Association of Massachusetts

Arlene Korab, Executive Director
30 Lyman Street, Suite 10
Westborough, MA 01581
508-475-0032
www.biama.org

A not-for-profit organization that provides support services to brain injury survivors and their families, offers programs to prevent brain injuries, educates the public on the risks and impact of brain injury and advocates for legislation and improved medical services.

7. Citizens Housing and Planning Association

Aaron Gornstein, Executive Director
18 Tremont Street, Suite 401
Boston, MA 02135
617-742-0820
www.chapa.org

CHAPA's mission is to encourage the production and preservation of housing that is affordable to low-income families and individuals.

8. Coalition for the Legal Rights of People with Disabilities

Polyxane S. Cobb, Chair
1770 Massachusetts Avenue, Suite 156
Cambridge, MA 02140
Polyxane@aol.com
www.psychiatry.com/clrd/index.html

The Coalition for the Legal Rights of People with Disabilities (CLRD) is a broad coalition of legal and other advocates, including people with disabilities, united to promote empowerment, liberation, and integration of all people with disabilities in the Commonwealth of Massachusetts.

9. Disability Law Center

Rick Glassman, Acting Director
11 Beacon Street, Suite 925
Boston, MA 02135
617-723-8455
www.dlc-ma.org

The Disability Law Center provides legal advocacy on disability issues that promote the fundamental rights of all people with disabilities to participate fully and equally in the social and economic life of Massachusetts.

10. Disability Policy Consortium

Bill Allan, Executive Director
59 Temple Place, Suite 669
Boston, MA 02111
617-542-3522
www.dpcma.org

The Disability Policy Consortium promotes inclusion, independence, and empowerment by guiding statewide development of policies that ensure that programs and services enable people to participate in the political, economic, and social mainstream of the Commonwealth of Massachusetts.

11. Easter Seals

Kirk Joslin, President
484 Main Street, Suite 600
Worcester, MA 01608
508-757-2756
www.eastersealsma.org

Easter Seals' mission is to provide exceptional services to ensure that all people with disabilities or special needs and their families have equal opportunities to live, learn, work and play in their communities.

12. MAB Community Services

Barbara Salisbury, CEO
200 Ivy Street
Brookline, MA 02446
617-732-0238
www.mabcommunity.org

MAB Community Services' mission is to work with individuals with disabilities to eliminate barriers and create opportunities.

13. Massachusetts Advocates for Children

Jerry Mogul, Executive Director
25 Kingston Street, 2nd Floor
Boston, MA 02111
617-357-8431, Helpline: 617-357-8431, ext. 224
www.massadvocates.org

MAC is an independent and effective voice for children who face significant barriers to equal educational and life opportunities.

14. Mass Advocates Standing Strong

Ed Bielicki, State Chair
500 Harrison Avenue
Boston, MA 02118
617-624-7791
Toll free (MA only): 866-426-2253
www.massadvocatesstandingstrong.org

Mass Advocates Standing Strong's mission is to empower self-advocates through education so we can make choices that improve and enrich our lives.

15. Massachusetts Association of Older Americans

Chet Jakubiak, Executive Director
19 Temple Place, 4th Floor
Boston, MA 02111
advocacy@MAOAmass.org
www.MAOAmass.org

MAOA enriches the lives of all people through education, advocacy, and action on the issues that keep elders economically secure and engaged in life.

16. Massachusetts Down Syndrome Congress

Maureen Gallagher, Executive Director
PO Box 866
Melrose, MA 02176
Toll free: 800-664-MDSC
www.mdsc.org

The organization ensures individuals with Down syndrome in Massachusetts are valued, included, and given the opportunities to pursue fulfilling lives by providing information, networking opportunities, and advocacy for people with Down syndrome and their families, educators, health care professionals, and the community-at-large.

17. Massachusetts Families Organizing For Change

Diane Huggon, Statewide Coordinator
PO Box 61
Raynham, MA 02768
508-824-6946
Toll free: 800-406-3632
Fax: 508-824-6946
www.mfofc.org

Massachusetts Families Organizing For Change is a statewide, grassroots coalition that believes that supports for individuals with disabilities and their families can be more flexible and better designed to respond to their actual needs.

18. M-POWER

98 Magazine Street
Roxbury, MA 02119
617-442-4111
Toll free: 877-769-7693
Fax: 617-442-4005
www.m-power.org

A member run organization of mental health consumers and current and former psychiatric patients, M-POWER advocates for political and social change within the mental health system, the community, city and statewide.

19. NAMI of Massachusetts

400 West Cummings Park, Suite 6650
Woburn, MA 01801
781-938-4048
Information and Referral Line: 800-370-9085
Fax: 781-938-4069
helpline@namimass.org

NAMI is a grassroots organization of individuals with brain disorders and their family members whose mission is to eradicate brain disorders and improve the quality of life of persons of all ages who are affected by them.

20. Parent/Professional Advocacy League (PAL)

Lisa Lambert, Executive Director
45 Bromfield Street, 10th Floor
Boston, MA 02108
617-542-7860
Fax: 617-542-7832
Toll free: 866-815-8122
info@ppal.net

Parent/Professional Advocacy League (PAL) is an organization that promotes a strong voice for families of children and adolescents with mental health needs. PAL advocates for supports, treatment and policies that enable families to live in their communities in an environment of stability and respect.

Independent Living Centers (ILCs) are private, nonprofit, consumer-controlled, community-based organizations providing services and advocacy by and for persons with all types of disabilities. Their goal is twofold: to create opportunities to promote independence; and to assist individuals with disabilities to achieve their maximum level of independent functioning within their families and/or communities.

ILCs across the Commonwealth:

1. Ad-Lib, Inc.

215 North Street
Pittsfield, MA 01201
413-442-7047
TTY: 413-442-7158
Fax: 413-443-4338
adlib@vgernet.net

2. Boston Center for Independent Living

60 Temple Place, 5th Floor
Boston, MA 02111
617-338-6665
TTY: 617-338-6662
Fax: 617-338-6661
BostonCIL@hotmail.com
www.BostonCIL.org

3. Cape Organization for the Rights of the Disabled (C.O.R.D.)

106 Bassett Lane
Hyannis, MA 02601
Voice/TTY: 508-775-8300
Toll free: 800-541-0282
Fax: 508-775-7022
Coreen@cilcapecod.org
www.cilcapecod.org

4. Center for Living and Working

484 Main Street, Suite 345
Worcester, MA 01608
508-798-0350
Fax: 508-797-4015
centerlw@centerlw.org

5. Independence Associates

141 Main Street, 1st Floor
Brockton, MA 02301
Voice/TTY: 508-583-2166
Toll free: 800-649-5568
Fax: 508-583-2165
indassoc@iacil.org
www.iacil.org

6. Independent Living Center of the North Shore and Cape Ann

27 Congress Street, Suite 107
Salem, MA 01970
Voice/TTY: 978-741-0077
Fax: 978-741-1133
information@ilcnsca.org
www.ilcnsca.org

7. **Metro West Independent Living Center**
280 Irving Street, Suite 401
Framingham, MA 01702
508-875-7853
Fax: 508-875-8359
www.mwcil.org

8. **Multicultural Independent Living Center**
110 Claybourne Street
Dorchester, MA 02124
617-288-9431
TDD: 617-288-2707
Fax: 617-265-2597
www.milcb.org

9. **Northeast Independent Living Program**
20 Ballard Road
Lawrence, MA 01843
Voice/TTY: 978-687-4288
Fax: 978-689-4488
info@nilp.org
www.nilp.org

10. **Southeast Center for Independent Living**
Merrill Building
66 Troy Street
Fall River, MA 02720
Voice/TTY: 508-679-9210
Fax: 508-677-2377
scil@secil.org
www.secil.org

11. **Stavros Center for Independent Living, Inc.**
210 Old Farm Road
Amherst, MA 01002
Voice/TTY 413-256-0473
Fax: 413-256-0190
staff@stavros.org
www.stavros.org

ILCs for the deaf and hard of hearing across the Commonwealth:

1. **AdLib Center for Independent Living**
215 North St.
Pittsfield, MA 01201
Voice/TTY: 413-442-7047
Fax: 413-443-4338
Toll-Free Voice: 800 232-7047
adlib@adlibcil.org
www.adlibcil.org

2. **Cape Organization for the Rights of the Disabled (C.O.R.D.)**
106 Bassett Lane
Hyannis, MA 02601
TTY/Voice: 508 775-8300
Fax: 508 775-7022
Toll-free Voice/TTY: 800 541-0282
cordinfo@cilcapecod.org
www.cilcapecod.org

3. **Center for Living & Working**
Deaf and Hard of Hearing IL Services
484 Main Street, Suite 345
Worcester, MA 01608
Voice/TTY: 508 755-1003
Fax: 508 755-1072
jphilip@centerlw.org
www.centerlw.org

4. **D.E.A.F., Inc.**
105 William Street, Room #25
New Bedford, MA 02740
Voice/TTY: 508 990-1382
Fax: 508 996-2170
VP: 508 990-1382
dhils@deafinconline.org
www.deafinconline.org

5. **Greater Boston D.E.A.F., Inc.**
215 Brighton Ave.
Allston, MA 02134
Voice/TTY: 617-254-4041
Fax: 617-254-7091
dhils@deafinconline.org
www.deafinconline.org

6. **Northeast Independent Living Program**
20 Ballard Road
Lawrence, MA 01843-1018
Voice/TTY: 978 687-4288
Fax: 978 689-4488
IP: 192.168.1.45
info@nilp.org
www.nilp.org

7. **North Shore, Salem D.E.A.F., Inc.**
35 Congress Street, Suite 204
Salem, MA 01970
TTY: 978 740-0394
Voice: 978 740-0329
Fax: 978 740-0389
VP: 978.740.0394
dhils@deafinconline.org
www.deafinconline.org

8. **Stavros Center for Independent Living, Inc.**
262 Cottage Street
Springfield, MA 01104-4002
Voice/TTY: 413 781-5555
Fax: 413 733-5473
VP: 413 781-5553
pbatch@stavros.org
www.stavros.org/deafservices.html

9. **Southeast Region D.E.A.F., Inc.**
66 Main Street
Taunton, MA 02780
Voice/TTY: 508 802-9605
Fax: 508 802-9606
VP: 508 802-9607
dhils@deafinconline.org
www.deafinconline.org

Appendix B: Massachusetts Disability Councils and Commissions

1. Architectural Access Board

Thomas Hopkins
One Ashburton Place, Room 1310
Boston, MA 02108
617-727-0660
www.mass.gov/aab

The Architectural Access Board (AAB) is a regulatory agency within the Massachusetts Office of Public Safety. Its legislative mandate states that it shall develop and enforce regulations designed to make public buildings accessible to, functional for and safe for use by persons with disabilities.

2. Braille Literacy Council

Kim Charlson, Contact, Director
Braille and Talking Book Library
Perkins School for the Blind
617-972-9249

This nine-member council is an advisory council to the State Board of Elementary and Secondary Education.

3. Committee for Public Counsel Services—Mental Health Litigation Unit

Stan Goldman, Director
21 McGrath Highway
Somerville, MA 02143
617-863-5170
Fax: 617-863-5185
www.publiccounsel.net/Practice_Areas/Mental_Health/civil_mental_health_index.html

The primary mandate of the Mental Health Litigation Unit is to provide trial and appellate representation to indigent persons against whom are filed petitions seeking commitment to public or private psychiatric facilities or seeking surrogate decision-making authority (e.g., guardianship or authorization to administer or terminate "extraordinary" treatment modalities).

4. Disabled Persons Protection Commission

Nancy A. Alterio, Executive Director
300 Granite Street, Suite 404
Braintree, MA 02184
617-727-6465
Toll free voice/TTY: 888-822-0350
Fax: 617-727-6469
www.mass.gov/dppc

DPPC's mission is to protect adults with disabilities from the abusive acts or omissions of their caregivers through investigation, oversight, public awareness and prevention.

5. Family Caregiver Support Groups

Toll free: 800-AGE-INFO
www.mass.gov/caregiver

The Massachusetts Family Caregiver Support Program empowers elders and caregivers by providing information, education, support and services that enhance quality of life.

6. Governor's Advisory Commission on Employment of People with Disabilities

Department of Employment and Training
Policy Office
19 Stanford Street, 3rd Floor
Boston, MA 02114
617-626-5190

The Commission shall promote employment to maximize the independence, productivity, and integration of all citizens in the commonwealth with disabilities.

7. Governor's Commission on Intellectual Disability

James Brett, Executive Office of Health and Human Services
One Ashburton Place, 11th Floor, Room 1109
Boston, MA 02108
617-573-1737
www.mass.gov/gcid

Examines the quality and comprehensiveness of the Commonwealth's program of services designed to address the wide variety of needs of people with mental retardation and to discuss and resolve systemic disputes raised by individuals with mental retardation, their families, or their guardians, for which no other forum exists, or which have not been adequately resolved by existing avenues of redress.

8. Massachusetts Developmental Disabilities Council

Dan Shannon, Executive Director
1150 Hancock Street, 3rd Floor, Suite 300
Quincy, MA 02169
617-770-7676
www.mass.gov/mddc

The mission of the Massachusetts Developmental Disabilities Council (MDDC) is to provide opportunities for people with developmental disabilities and their families to enhance independence, productivity, and inclusion.

9. Massachusetts Interagency Council on Homelessness and Housing

Liz Curtis, ICHH Executive Director
100 Cambridge Street, Suite 300
Boston, MA 02214
617-573-1106
www.mass.gov/governor/ichhh

The Commission's plan calls for a new statewide "housing-first" approach that will end homelessness in the Commonwealth by 2013.

10. Massachusetts Statewide Independent Living Council

Steven Higgins, Coordinator
280 Irving Street
Framingham, MA 01702
508-620-7452
www.masilc.org

MASILC was established to participate in planning with and advise the Massachusetts Rehabilitation Commission and Massachusetts Commission for the Blind concerning the provision of independent living services for persons with disabilities in compliance with the requirements of the Rehabilitation Act.

11. PCA Quality Home Care Workforce Council

Jack Boesen, Director
600 Washington Street, Room 5189
Boston, MA 02111
617-210-5715
www.mass.gov/pca/

The mission of the Council is to insure the quality of long-term, in-home, personal care by recruiting, training and stabilizing the work force of personal care attendants.

12. Special Education Advisory Council

Robin Foley, Chair
75 Pleasant Street
Malden, MA 02148
781-338-3000
www.doe.mass.edu/boe/sac/councils/sped.html

The Special Education Advisory Council is a group of parents and professionals who to provide policy guidance with respect to special education and related services for children with disabilities within the Commonwealth.

13. Statewide Advisory Council - Department of Developmental Services

Lusa Lo
617-624-7755
citizenleadership@state.ma.us
www.mass.gov/?pageID=eohhs2terminal&L=5&L0=Home&L1=Consumer&L2=Volunteering+and+Giving&L3=Department+of+Developmental+Services+Volunteer+Opportunities&L4=Citizen+Advisory+Groups&sid=Eeohhs2&b=terminalcontent&f=dmr_g_cab_sac_about&csid=Eeohhs2

The Statewide Advisory Council advises the Commissioner on policy, program development, and priorities of need in the Commonwealth for services and supports in intellectual disability.

14. Statewide Advisory Council – Massachusetts Commission for the Deaf and Hard of Hearing

Michelle Lavoie, Assistant to Commissioner
Voice: 617-740-1611
TTY: 617-740-1711
michelle.lavoie@massmail.state.ma.us

The Statewide Advisory Council is made up of individuals whose knowledge or experience enables them to represent the concerns, needs and recommendations of deaf and hard of hearing persons, to the Commissioner of MCDHH.

Appendix C: Selected Massachusetts State Agencies

1. **Department of Children and Families**
   Angelo McClain, Commissioner
   24 Farnsworth Street
   Boston, MA 02210
   617-748-2000
   www.mass.gov/dcf

   The Department's vision is to ensure the safety of children in a manner that holds the best hope of nurturing a sustained, resilient network of relationships to support the child's growth and development into adulthood.

2. **Department of Developmental Services**
   Elin Howe, Commissioner
   500 Harrison Avenue
   Boston, MA 02118
   617-727-5608
   www.mass.gov/dds

   The Department is dedicated to creating, in partnership with others, innovative and genuine opportunities for individuals with intellectual disabilities to participate fully and meaningfully in, and contribute to, their communities as valued members.

3. **Department of Mental Health**
   Barbara Leadholm, Commissioner
   25 Staniford Street
   Boston, MA 02114
   617-626-8000
   TTY: 617-727-9842
   www.mass.gov/dmh

   The Department of Mental Health, as the State Mental Health Authority, assures and provides access to services and supports to meet the mental health needs of individuals of all ages, enabling them to live, work and participate in their communities. The Department establishes standards to ensure effective and culturally competent care to promote recovery. The Department sets policy, promotes self-determination, protects human rights and supports mental health training and research. This critical mission is accomplished by working in partnership with other state agencies, individuals, families, providers and communities.

4. **Department of Public Health**
   John Auerbach, Commissioner
   250 Washington Street, 6th Floor
   Boston, MA 02108
   617-624-6000
   www.mass.gov/dph

   The mission of the Massachusetts Department of Public Health is to promote the health and well-being of the people in Massachusetts.

5. **Department of Transitional Assistance**
   Julia E. Kehoe, Commissioner
   600 Washington Street
   Boston, MA 02111
   617-348-8500
   www.mass.gov/dta

   DTA strives to provide individuals and families, including those with disabilities, with food assistance, job assistance, and cash assistance.

6. **Department of Veterans' Services**
   Thomas G. Kelley, Secretary
   600 Washington Street, Suite 1100
   Boston, MA 02111
   617-210-5480
   Fax: 617-210-5755
   www.mass.gov/veterans

   This office provides information on state and federal benefits for veterans, including details about where and how to apply.

7. Department of Youth Services

Jane Tewksbury, Commissioner
27 Wormwood Street, Suite 400
Boston. MA 02210
617-727-7575
www.mass.gov/dys

The Department of Youth Services is the juvenile justice agency of the Commonwealth of Massachusetts. Their mission is to protect the public and prevent crime by promoting positive change in the lives of youth committed to our custody, and by partnering with communities, families, government and provider agencies toward this end. They accomplish this mission through interventions that build knowledge, develop skills and change the behavior of the youth in their care.

8. Division of Health Care Finance & Policy

David Morales, Commissioner
2 Boylston Street
Boston, MA 02116
617-988-3100
www.mass.gov/dhcfp

The Division produces reliable and objective analysis of the Massachusetts health care delivery system.

9. Executive Office of Elder Affairs

Ann Hartstein, Secretary
One Ashburton Place, 5th Floor
Boston, MA 02108
617-727-7750
TTY: 800-872-0166
Toll free: 800-243-4636
Fax: 617-727-9368
www.mass.gov/elders

The Executive Office of Elder Affairs promotes the independence and well-being of elders and people needing medical and social supportive services by providing advocacy, leadership, and management expertise to maintain a continuum of services responsive to the needs of our constituents, their families, and caregivers.

10. Executive Office of Health and Human Services

Dr. JudyAnn Bigby, Secretary
One Ashburton Place, 11th Floor
Boston, MA 02108
617-573-1600
www.mass.gov/eohhs

EOHHS is a cabinet-level agency in charge of health and human service programs and policy development.

11. Massachusetts Commission for the Blind

Janet LaBreck, Commissioner
48 Boylston Street
Boston, MA 02116-4718
617-727-5550
Toll free (MA only): 800-392-6450
Toll free TDD (MA only): 800-392-6556
Fax: 617-626-7685
www.mass.gov/mcb

The Massachusetts Commission for the Blind (MCB) provides the highest quality rehabilitation and social services to blind individuals, leading to independence and full community participation. MCB accomplishes this critical mission by working in partnership with legally blind consumers, families, community agencies, health care providers, and employers.

12. Massachusetts Commission for the Deaf and Hard of Hearing

Heidi Reed, Commissioner
150 Mount Vernon Street, 5th Floor
Dorchester, MA 02125
617-740-1600
TTY: 617-740-1700
Fax: 617-740-1880
Toll free: 800-882-1155
Toll free TTY: 800-530-7570
Videophone: Dial 617-265-8447 or use the following IP address:
70.22.152.162
www.mass.gov/mcdhh

MCDHH enables deaf and hard of hearing individuals to have access to information, services, education, and opportunities which will be equal to those of able-bodied people who hear and which will enable each deaf and hard of hearing individual to live productively and independently while assuming fullest responsibilities as a citizen.

13. Massachusetts Office on Disability

Myra Berloff, Executive Director
One Ashburton Place, Room 1305
Boston, MA 02108
617-727-7440
www.mass.gov/mod

The purpose of the Office is to bring about full and equal participation of people with disabilities in all aspects of life. It works to assure the advancement of legal rights and for the promotion of maximum opportunities, supportive services, accommodations and accessibility in a manner which fosters dignity and self determination.

14. Massachusetts Office for Refugees and Immigrants

Richard Chacon, Executive Director
18 Tremont Street, Suite 1020
Boston, MA 02108
617-727-7888
www.mass.gov/ori

This Office promotes the full participation of refugees and immigrants as self-sufficient individuals and families in the economic, social, and civic life of Massachusetts.

15. Massachusetts Rehabilitation Commission

Charlie Carr, Commissioner
27 Wormwood Street
Boston, MA 02210-1616
617-204-3600
Toll free voice/TDD: 800-245-6543
Fax: 617-727-1354
www.mass.gov/mrc

The Massachusetts Rehabilitation Commission (MRC) promotes equality, empowerment and productive independence of individuals with disabilities. These goals are achieved through enhancing and encouraging personal choice and the right to fail in the pursuit of independence and employment in the community.

16. Office of Medicaid

Terry Dougherty, Director
One Ashburton Place, 11th Floor
Boston, MA 02108
617-573-1770
www.mass.gov/masshealth

Medicaid's mission is to help the financially needy obtain high-quality health care that is affordable, promotes independence, and provides customer satisfaction.

17. The Soldiers' Home Chelsea

Michael Resca, Commandant
91 Crest Avenue
Chelsea, MA 02150
617-884-5660
www.mass.gov/che

The mission of the Soldiers' Home in Chelsea is to provide, with honor and dignity, the highest quality personal health care services to Massachusetts Veterans.

18. The Soldiers' Home Holyoke

Michael J. Pasterczyk, Superintendant
110 Cherry Street
Holyoke, MA 01040
413-532-9475
www.mass.gov/hly

The mission of the Soldiers' Home in Holyoke is to provide, with honor and dignity, the highest quality of personal health care services to Massachusetts Veterans.

Appendix D: Organizations that Provide Assistance with Reasonable Accommodations

1. **Cambridge Community Learning Center**
Mina Reddy, Director
19 Brookline Street
Cambridge, MA 02139
617-349-6363
Fax: 617-349-6330
dhsp@cambridgema.gov

The Community Learning Center provides free services to Cambridge residents. This organization has an exterior screen magnifier, keyboard alternative & trackball, and 15 workstations. They will provide auxiliary aids, services and materials in alternative formats. Reasonable accommodations will be provided to qualified individuals with disabilities.

2. **Massachusetts Bay Transportation Authority: THE RIDE**
MBTA Office for Transportation Access
10 Park Plaza, Room 5750
Boston, MA 02116
617-222-5123
TTY: 617-222-5415
Toll free (MA only): 800-533-6282

THE RIDE, the T's Paratransit program, provides door-to-door transportation to eligible people who cannot use general public transportation all or some of the time, because of a physical, cognitive or mental disability.

3. **Massachusetts Commission for the Deaf and Hard of Hearing**
Heidi Reed, Commissioner
150 Mount Vernon Street, 5th Floor
Dorchester, MA 02125
617-740-1600
TTY: 617-740-1700
Fax: 617-740-1880
Toll free: 800-882-1155
Toll free TTY: 800-530-7570
Videophone: 617-265-8447 or use the following IP address:
70.22.152.162
Heidi.Reed@massmail.state.ma.us
www.mass.gov/mcdhh

MCDHH enables deaf and hard of hearing individuals to have access to information, services, education, and opportunities which will be equal to those of able-bodied people who hear and which will enable each deaf and hard of hearing individual to live productively and independently while assuming fullest responsibilities as a citizen.

4. **National Braille Press**
88 St. Stephen Street
Boston, MA 02115
617-266-6160
Toll free: 888-965-8965
Fax: 617-437-0456
www.nbp.org

The guiding purposes of National Braille Press are to promote the literacy of blind children through Braille, and to provide access to information that empowers blind people to actively engage in work, family, and community affairs.

5. Perkins Braille and Talking Book Library at the Perkins School for the Blind

175 North Beacon Street
Watertown, Massachusetts 02472
617-942-3434

The Perkins Braille and Talking Book Library provides free services to Massachusetts residents of any age who are unable to read traditional print materials due to a visual or physical disability.

6. RFB&D-Reading for the Blind and Dyslexic

Ted Washburn, Production Director
New England Region
2067 Massachusetts Avenue, 3rd Floor
Cambridge, MA 02140
617-577-1111
Direct line: 617-500-2714
twashburn@rfbd.org
www.rfbd.org/Locations/New-England-Region-Home/70/

RFB&D's mission is to create opportunities for individual success by providing and promoting the effective use of accessible educational materials.

7. Media Access Group at WGBH

One Guest Street
Boston, MA 02135
Voice and TTY: 617-300-3600
Fax: 617-300-1020
access@wgbh.org
www.wgbh.org

The Media Access Group at WGBH provides captioning and descriptive services.

8. The Described and Captured Media Program

National Association of the Deaf
1447 East Main Street
Spartanburg, SC 29307
864-585-1778
TTY: 864-585-2617
Fax: 864-585-2611
info@dcmp.org
www.dcmp.org

The Described and Captured Media Program provides captioning and descriptive services. A downloadable "Captioning Key" has guidelines for creating captioning and audio descriptions.

Appendix E: Selected References

1. Advocates Inc. (Producer) (n.d.) *The Advocates Way* [Film]. (Available from Advocates Inc., 1 Clark's Hill, Suite 305, Framingham, MA 01702

Available online at: www.theadvocatesway.org/4.html

2. Anderson, S., Duerscheidt, D., & McLean, D. (2004, February 18). *Mike's plan* (Web cast handout). Houston, TX: Independent Living Research Utilization.

This is a plan that can be written out by a person with a disability, which explains who is in their support network, who is in their family, what their specific needs are, how an assistant such as a PCA can help them with their needs and what to do in case of an emergency.

Available online at: www.hcbs.org/files/26/1250/Mikes_Example_plan-MH.doc

3. Bailey, D. B. (1984, September). A triaxial model of the interdisciplinary team and group process. *Exceptional Children,* 55(1), 17-25.

This is a three-dimensional model for conceptualizing problems in the functioning of interdisciplinary team's for handicapped students: (1) as a developing and changing entity, (2) as a set of subsystems, and (3) as a function unit. Each dimension is described and examples of team dysfunctions within each dimension are provided.

4. Beinecke, R. H., & Delman, J. (2008). *Commentary: client involvement in public administration research and evaluation.* The Innovation Journal: The Public Sector Innovation Journal, 13(1), Article 7.

Available online at: www.innovation.cc/peer-reviewed/beinicke_7_commenta-_client_public_admin.pdf

5. Bergman, A., Ludlum, C., O'Connor, D., Starr, J., & Terrill, C. F. (2002, March). *Stakeholder involvement in home and community-based services: Roles in state planning, program development, and quality improvement* (HCBS Issue Paper: 04). Chestnut Hill, MA: Home and Community-Based Services Resource Network.

The goal of this paper is to provide states (both the legislative and executive branches) with background about how to involve stakeholders in planning, program development, and quality improvement related to home and community-based services and supports.

Available online at: www.hcbs.org/files/7/342/Bergman.pdf

6. *Consumer involvement: Lessons learned.* (2007). Retrieved from http://www.hcbs.org/moreInfo.php/doc/1812

Two materials, a fact sheet and presentation, highlight the lessons learned during the 2001 MA Real Choice Grant regarding consumer involvement.

Available online at: www.hcbs.org/moreInfo.php/doc/1812

7. Deegan, P. E. (1993). Recovering our sense of value after being labeled mentally ill. *Psychosocial Nursing and Mental Health Services 31*(4), 7-11.

8. Delman, J., & Lincoln, A. (2009). Service users as paid research workers: Principles for active involvement and good practice guidance. In J. Wallcraft, B. Schrank, & M. Amering, (Eds.), *Handbook of service user involvement in mental health research* (pp. 139-151). Indianapolis, IN: John Wiley & Sons.

9. Description of Independence Plus grant initiatives: Massachusetts. (2007, December). In J. O'Keeffe, C. O'Keeffe, J. M. Wiener, & K. Siebenaler (Eds.), *Real Choice Systems Change Grant program: Increasing options for self-directed services: Initiatives of the FY 2003 Independence Plus Grantees* (pp. A-33–A-36). Baltimore, MD: Centers for Medicare & Medicaid Services.

Project Purpose: Review the history and effectiveness of the consumer involvement strategy used within the Real Choice and Independence Plus grants from the consumer, grant staff and state partner perspectives. Identify lessons learned and create recommendations to strengthen consumer involvement in future grant activities. Inform future consumer involvement methods in Massachusetts and in other states.

Developed by the University of Massachusetts Medical School. Commonwealth Medicine. Center for Health Policy and Research.

Available online at: www3.cms.gov/RealChoice/Downloads/IPpaper.pdf

10. Edwards, B. C., Garcia, S. P., Lashbrook, A. E., & Flowers, L. (2007, October). *Let the sunshine in: Assuring policy involvement in state Medicaid policy making.* Washington, DC: AARP Public Policy Institute.

This report explores whether and how states ensure public input during various phases of both the Section 1115 Waiver process and the SPA process including policy development, federal review and policy implementation from the perspectives of state officials and consumer advocates. In addition, they make recommendations about how states and federal government can improve or enhance existing opportunities for public involvement in the Section 1115 Waiver and the SPA process.

Available online at: assets.aarp.org/rgcenter/health/2007_17_medicaid.pdf

11. *Give people a chance to speak up on changes to Medicaid.* (2007). Washington, DC: AARP Public Policy Institute.

This paper is a summary of the AARP Research Paper *Let the Sunshine In: Ensuring Public Involvement in State Public Policy Making.* The report concludes that the best way to involve the public is to make all proceedings transparent; create opportunities that are predictable and meaningful and make available accurate, objective and timely information.

Available online at: assets.aarp.org/rgcenter/health/inb148_medicaid.pdf

12. Home and Community-Based Services Resource Network. (2003). *Making accessibility real: A guide for planning meetings, conferences, and gatherings.* Retrieved from http://www.hcbs.org/moreInfo.php/doc/52

This working document provides strategies for making meetings and conferences truly accessible. It includes guidelines for ensuring that appropriate accommodations are identified and provided with respect to meeting spaces and materials, communication, room and board, and transportation. The document also provides suggestions for responding to specific functional issues, as well as sample documents and a list of additional resources.

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

13. Horvath, D. R. (2004). *Finding common ground: Creating inclusive communities in West Virginia.* Morgantown, WV: West Virginia University, Center for Excellence in Disabilities.

In December 2003 a select group of individuals with disabilities, advocates, state agency representatives, and service providers met in Institute, West Virginia, to discuss the subject of community inclusion for individuals with disabilities and long-term care needs. This gathering of stakeholders included two days of information sharing, brainstorming, and planning. This report attempts to capture the essence of Finding Common Ground: Creating Inclusive Communities in words and pictures for the benefit of participants and other interested parties.

14. Lomerson, N., McGaffigan, E., O'Connor, D., & Wamback, K. (2007, February). *When CPIGs fly: Meaningful consumer involvement in systems change*. Shrewsbury, MA: University of Massachusetts Medical School, Center for Health Policy and Research.

Transcript of the 19:26 minute video in which consumers, grant staff and state employees explain the beginning of consumer involvement process in the Real Choice Systems Change grant.

Available online at: www.umassmed.edu/uploadedFiles/CPIGS.pdf

15. Long Term Care Authority of Tulsa. (n.d.) *Educational handouts: Oklahoma partnership 2002-2006.* Retrieved from http://www.hcbs.org/files/129/6432/EdMaterials1.pdf

The fundamental structure to both of Oklahoma's Real Choice System Change grants is an infrastructure that supports a service delivery system that is accountable to Oklahoma long-term care stakeholders. Grant monies will be used to create and support an Oklahoma Partnerships consisting of consumers and advocates. This handout offers an introduction to the system and terms used in the grant partnership.

Available online at: www.hcbs.org/files/129/6432/EdMaterials1.pdf

16. McGaffigan, E. (2008, March). Discussion paper: *Redefining quality: Participant-directed services.* New Brunswick, NJ: Rutgers Center for State Health Policy.

This paper explores the various participant-direction models, existing quality management strategies, and the potential for change that allows participant-directed quality management systems to remain true to the core values they were founded upon.

Available online at: www.hcbs.org/moreInfo.php/doc/2199

17. More can be done: *Involvement of older consumers in the design, implementation and oversight of home and community based services.* (2008, February). Washington, DC: National Association of State Units on Aging.

This paper explores the role of older participants in planning, developing and overseeing home and community based service (HCBS) programs. It seeks to help State Units on Aging and others in the aging network identify concrete steps they can take to support the role of these older individuals as public policy advocates. The report addresses the extent of older HCBS participants' current involvement, the barriers to success, and the strategies being used to attain participation.

Available online at: www.hcbs.org/files/133/6623/NASUA_Rpt.pdf

18. *My personal compass.* (2006). Tallahassee, FL: The Delmarva Foundation, Florida Statewide Quality Assurance Program.

A tool which a consumer in Florida can use to evaluate how well services are being provided to him/her. The information also includes an agency and phone number where consumers can register complaints if they feel that they are being abused.

Available online at: www.dfmc-florida.org/Public2/trainingCenter/documents/PersonalCompass.pdf

19. O'Keeffe, J., Tornatore, D., & Siebenaler, K. (2002, September). *Systems change grants for community living evaluation: Partnership development activities: Comparative analysis of FY 2001 systems change grantees.* Baltimore, MD: Centers for Medicare & Medicaid Services.

The purpose of this report is to provide an overview of the various individuals and entities that the 52 Grantees partnered with in the development of their Grant applications, the ways these partners were involved and plans for partner involvement in Grant implementation activities.

Available online at: www.hcbs.org/files/35/1723/SystemChangePartnershipEval_rti.pdf

20. *The Oklahoma partnership tools for team building* (Slide Presentation). (2002, October). Tulsa, OK: Long Term Care Authority of Oklahoma.

Using initiatives from the Centers for Medicare and Medicaid (CMS), the Oklahoma Health Care Authority (OKHCA) chose to begin transforming Oklahoma's current long-term care system by increasing the capacity of the current home and community based services system to support additional individuals whom choose to live in the community.

21. Pell, E. (2006, November 24). *A case study of the Massachusetts Department of Mental Retardation's development & implementation of Quality Councils.* Cambridge, MA: Human Services Research Institute.

This case study provides an overview of MA DMR Quality Councils which are composed of state agency staff, consumers, family members and providers. Many subjects are covered including implementation, membership, funding, and information sharing between regional and statewide councils, accomplishments and next steps.

Available online at: www.hcbs.org/moreInfo.php/doc/2175

22. *A roadmap to quality services in Florida: The developmental services home and community based services waiver.* (n.d.) Tallahassee, FL: The Delmarva Foundation, Florida Statewide Quality Assurance Program.

The Developmental Services HCBS Waiver provides Medicaid funding for a wide array of services and supports that assist people with developmental disabilities to live, work and engage in meaningful activities in their homes and communities.

Available online at: www.dfmc-florida.org/public/docs/consumer_road_map_rt1_020403.pdf

23. Roth, H. (2006, July). *Checklist for enhancing the participation and input of people with disabilities.* Houston, TX: Independent Living Research Utilization in Collaboration with The MEDSTAT Group, Inc.

The items on this checklist are designed to assist in identifying and eliminating barriers for people with mobility, sensory, cognitive and various other types of disabilities. Accommodation needs may be individual; nonetheless, one significant shared characteristic is that the environment is often replete with barriers that interfere with the civil rights of people with disabilities and their full participation in life.

Available online at: www.hcbs.org/moreInfo.php/doc/1665

24. Sander, A., & Cheek, M. (2004, April 26). *Facilitating a productive advisory committee: "Engaging advisory committees to provide effective and meaningful input and direction"* (ADRC-TAE Issue Brief). Falls Church, VA: The Lewin Group.

ADRC grantees are required to designate an Advisory Board or Committee. This policy brief explains how to develop and engage an effective committee, necessary considerations including facilitation, accessibility and providing reimbursement, and additional resources about Advisory Boards.

Available online at: www.hcbs.org/moreInfo.php/doc/937

25. *Tips for effective techniques for consumer input at task force meetings.* (2004, August 18). Retrieved from http://www.hcbs.org/files/50/2494/Tips_for_Consumer_Input_at_Task_Force_Meetings.pdf.

Tip sheet to be shared with consumer task force or advisory board members regarding how they can be effective at the meeting and in the between times.

Available online at:
www.hcbs.org/files/50/2494/Tips_for_Consumer_Input_at_Task_Force_Meetings.pdf

26. Weaver, P. (2002). *Involving consumers on boards* (Issue Brief Vol. 3, No. 8). Washington, DC: Center for Medicare Education.

Many organizations try to recruit consumers for their boards, but few know how to utilize those consumer board members in an effective way. In this brief, how you can best recruit and keep consumers on your organization's board is explored.

Appendix F:
Work Plan Template

Priority:

Action Steps *What will be done?*	**Responsibilities** *Who will do it?*	**Timeline** *By when? (Day/Month)*	**Resources** *A. Resources Available* *B. Resources needed (financial, human, political & other*	**Outcomes** *How will you know you are making progress?*	**Communications Plan** *Who is involved? What methods? How often?*
Step 1:			**A.** **B.**		
Step 2:			**A.** **B.**		
Step 3:			**A.** **B.**		
Step 4:			**A.** **B.**		
Step 5:			**A.** **B.**		

Evidence Of Success *(How will you know that you are making progress? What are your benchmarks?)*

Evaluation Process *(How will you determine that your goal has been reached? What are your measures?)*

Appendix G: Focus Group Planning Guide

Overview

ABC Agency will partner with organizations serving consumers (such as XYZ), to conduct a focus group with the target audience. Based on the results of this discussion, we will write up recommendations to share with the ABC Agency and the participating group of consumers.

The session will last 1 to 1.5 hours. A recorder will take notes during each session. Participants will be provided a $75 incentive fee (optional).

Protocol

The focus group moderator will follow a standard protocol that includes:

- Welcome and opening remarks
- Explanation of the purpose of the discussion group
- Explanation to ensure understanding of informed consent
- Discussion
- Closing

Welcome and Opening Remarks (10 minutes)

1) We are here to focus on opinions -- there are no right or wrong answers.
2) We will not use anyone's names, but we may use quotes of what people say.
3) The discussion will last approximately one hour.
4) We will be taking notes throughout the session.
5) The moderator will ask participants to sign an informed consent statement. For example: "Please read and sign the informed consent statement. Information provided during focus group discussion will be kept confidential and only be used by ABC Agency to enhance their consumer involvement activities."

Introductions (10 minutes)

Start by going around the room and doing introductions. Ask participants to share the following:

a. Their first name;
b. Where they're from;
c. And one thing they may have heard or know about consumer involvement.

The moderator will start, for example: "My name is________ and I'm from _________.

The one thing I know about consumer involvement is that it is an important piece to include when creating a program".

Discussion (60 minutes)

The moderator will begin asking questions to the group.

1. What do you think is the main idea of consumer involvement? [Assess participants' level of understanding.]
2. When you think of the ABC Agency, what is the first thing you think? See? Feel? What jumps out at you? [Probe to determine if what jumps out is helpful or if it distracts from feeling welcome.]
3. How do you currently communicate with the ABC Agency? Email, phone, meetings, etc? And, which method of communication would you prefer? Why?
4. Have you ever given feedback on an ABC policy? If so, what happened? In your opinion, what would you see as a productive way to give feedback?
5. Have you ever participated in a planning, strategy or decision-making meeting at the ABC Agency? If so, tell me about your experience. If not, why not?
6. Do you think the ABC Agency is accommodating to the needs of people with disabilities? Are they accessible? How or how not?
7. Is there anything about the ABC Agency and the way they communicate with consumers that you don't like? [Probe for specifics.]
8. Can you think one thing that you think the ABC Agency does well in terms of involving consumers? [Probe for specifics]
9. Do you have any more comments, opinions, or suggestions?

Closing

The moderator will conclude the session by thanking participants for sharing their opinions and suggestions. As they leave, each participant will be given the incentive.

Appendix H:
10 Key Lessons for Consumer Involvement

From N. Lomerson, E. McGaffigan, D. O'Connor, and K. Wamback. When CPIGS Fly: Meaningful Consumer Involvement in Systems Change, *Center for Health Policy and Research, University of Massachusetts Medical School, February 2007.*

1. Involve people with disabilities as early as possible to ensure meaningful involvement.
2. Develop an atmosphere of trust and collaboration. In this climate, both consumers and state partners will learn much from one another.
3. Offer reasonable accommodations to ensure meaningful consumer involvement. Assure that accommodations are met, but empower consumers to assist in the process…
4. Provide support for facilitation and documentation of progress.
5. Enable consumers and state partners to participate as equal partners in policy decisions. More effective policy will arise from such a dialogue.
6. Struggle for consensus rather than simply assert the power of the state or the power of the majority vote. The process of coming to consensus helps both sides to listen to one another and truly hear their concerns.
7. Connect policy and research agendas with the real-life experiences of people with disabilities.
8. Maximize resources by creating cross-disability policy rather than policy through disability silos.
9. Work intensively to sustain successful initiatives.
10. Believe that systems can change…!

Consumer Involvement Toolkit

A Resource for State Agencies

COMMUNITYFIRST