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Engaging People Who Receive Services

A Best Practice Guide
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This document was prepared by Mark Friedman, PhD and Ruthie-Marie Beckwith, PhD for the National Center on Advancing Person-Centered Practices and Systems

The purpose of this Guide is to assist State, Tribal, and Territory human service systems to fully and effectively including people who receive services in system planning and improvement efforts. It is relevant for all systems that support older adults and people with disabilities. This guide was originally developed as part of technical assistance activities through the National Center on Advancing Person-Centered Practices and Systems (NCAPPS).

Five Strategies to Successfully Engage People Who Receive Services

This Guide details five strategies and proven practices to directly involve people who receive services in system planning and improvement.

1 Authentic Membership

Provide equal status and recognition of the importance of the person's presence as any other member of the work group.

- Confirm leadership commitment
- Show hospitality
- Provide financial assistance
- Form partnerships to recruit participants

2 Full Participation

Provide people with the means to be present and engaged in carrying out their responsibilities.

- Appoint at least three participants to teams and work groups
- Offer interpretation and captioning services
- Hold orientation sessions
- Hold pre-meetings
- Facilitate meetings with proper techniques
- Take frequent breaks
- Provide training sessions
- Promote participation in committees or sub-committees
- Engage in team-building activities or exercises
- Encourage contact with work group leaders between meetings

3 Effective Communication Supports & Mentors

Provide people with tools and coaching and opportunities to prepare for and be effective at work group meetings.

- Offer multiple means of engagement

- Provide transportation support
- Give travel advances
- Provide agendas two weeks in advance of meetings
- Create easy read, plain language documents and alternative formats
- Ensure materials are culturally and linguistically accessible
- Offer mentors
- Provide accommodations for people with disabilities
- Plan meeting room arrangements

4 Meaningful Contributions

Allow people to provide input and assistance that is important to the policy-making body in ways that utilize their ideas and lived experience.

- Provide important assignments or roles to participants on behalf of the work group
- Solicit agenda items from all members
- Assist participants in identifying preferred areas of input or concerns

5 True Influence

True influence occurs when participants enhance or alter the substance, direction and outcomes of policymaking in ways that positively impact the lives of people who receive services.

- Provide leadership roles for participants in the work group
- Follow through with recommendations by participants
- Adopt the mantra "Nothing About Us Without Us"

Background

For decades, people with disabilities and others who rely on long-term services and supports have said, "Nothing About Us Without Us" when it comes to human service system planning and implementation. And over the last several years, the federal government and foundations have increased their demands for enhanced engagement with people who receive services in the projects they fund. As a result, more engagement efforts are occurring across the country, in all social service fields and with multiple constituencies.

Authentic, meaningful engagement with people who use services is essential for planning and implementing a person-centered system that promotes self-determination, quality of life, and community engagement. This means:

- ensuring communication is accessible and relatable;
- bringing diverse voices to the table that are representative of the community in terms of disability experience, age, race, ethnicity, gender identity and expression, and sexual orientation;
- supporting people participating in services and system change efforts;
- transforming policies to reflect person-centered values and culture; and
- establishing a consistent vision and universal understanding of a person-centered system.

Guidelines for Engaging People Who Receive Services

This Guide outlines barriers and benefits to engagement and details five strategies and proven practices to directly involve people who receive services in system planning and improvement.

Purpose

The purpose of this Guide is to assist human service systems to fully and effectively include people who receive services—also referred to here as participants—in the public policy decisions in systems change efforts. These evidence-based guidelines are built from a national research study and decades of direct work in the field of social services (Friedman, Beckwith & Conroy, 2016). They showcase:

- desired goals and outcomes of engaging people who receive services;
- current best practices in the United States and Canada; and

- tips to assist agency leadership, staff, and service providers in effectively engaging people who receive services in work groups, public policy, and decision-making processes.

These guidelines are based on the goal of people who receive services being fully included in decision-making bodies on an ongoing basis. This premise requires that people who receive services be at the table and in the room when decisions are being made. This is best enunciated by the disability rights movement's mantra, "Nothing About Us Without Us." The planning, design, implementation, and monitoring of systems change efforts are vested in fully including people who receive services in policy making through membership in work groups and teams that engage in systems change activities. Work groups are often a small group of people who represent a target group or organization and come together with a common goal or deliverable. While other forms of engagement are useful—listening tours, focus groups, surveys, public forums, and interviews—research clearly shows that connection and ongoing direct involvement are necessary to encourage full participation and allow everyone to learn from each other.
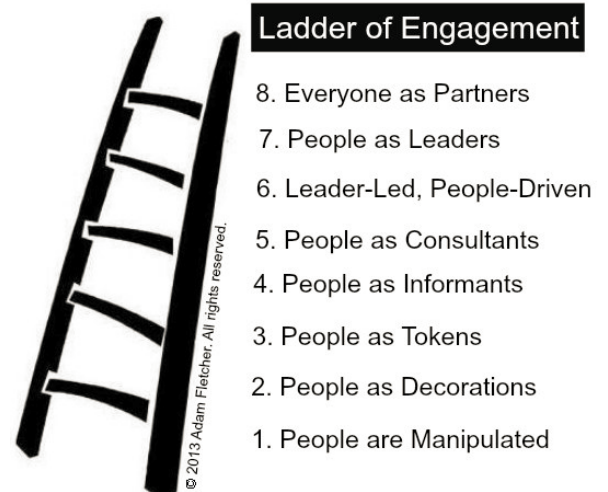
Barriers to Engagement

To be successful in these efforts, we must recognize the barriers faced by people who receive services and people who work in human service systems:

- **People who receive services** have often been treated as second-class citizens and face many barriers to full participation, including trusting government efforts.
- **People who work in human service systems** have conflicting priorities and face significant time and resource constraints to pursuing engagement efforts with people who receive services.

Given these known barriers, it is critical that efforts to fully engage people who receive services in public policy utilize proven and successful evidence-based practices.

Benefits of Engagement

There are varying levels of engagement as people move up the "Ladder of Engagement" from tokens to full partners in decision-making.

Ladder of Engagement

8. Everyone as Partners
7. People as Leaders
6. Leader-Led, People-Driven
5. People as Consultants
4. People as Informants
3. People as Tokens
2. People as Decorations
1. People are Manipulated

Expected Benefits of Full Participation by People Who Receive Services

A key question in fully including people who receive services in public policy is: What are the benefits of this effort? There has been a long history of the effort to fully include constituents in policy making going back to the Great Society programs of the 1960s. These efforts have resulted in stronger voices for women, racial and ethnic groups, older adults, young people, people with disabilities, and people with lower socioeconomic status. The expected benefits of full participation of people who receive services include the following:

1. Improve program designs and strategies.
2. Make more informed decisions.
3. Gain buy-in and support of people who receive services and their families/supporters.
4. Implement successful system changes.
5. Increase equity through more culturally responsive and relevant policies, programs, and services.
6. Enhance accountability and credibility.
7. Find common ground among people who receive services and human service agency officials.
8. Build the capacity to successfully engage people who receive services in projects.
9. Develop the leadership skills of people to effectively participate in systems change policy making and implementation activities.
10. Empower people who receive services in a safe and welcoming environment.
11. Model behavior for other advocates, families, professionals and providers on how to successfully engage people who receive services in person-centered thinking, planning, and practices.

System-Level Commitments

To ensure long-term success, human service agency leadership must take two essential actions:

1. Designate one person in each division/department/program as the person responsible for leading engagement efforts with people who receive services. Responsibilities include selecting and inviting participants, promoting attendance, and encouraging active participation.

2. Acknowledge and support the staff time and resources required for successful implementation. Engagement with people who receive services does not happen on its own or without someone having this effort as their focus.

Five Strategies to Successfully Engage People Who Receive Services

These guidelines detail five strategies and proven practices to directly involve people in work groups and teams engaged in system planning and improvement.

Authentic Membership → Full Participation → Effective Communication Supports and Mentors → Meaningful Contributions → True Influence

First Strategy: Authentic Membership

Authentic Membership provides equal status and recognition of the importance of the person's presence as any other member of the work group.

Practices that Promote Authentic Membership

1. **Confirm Leadership Commitment** – As Tia Nelis, founder of Self-Advocates Becoming Empowered, succinctly states, "Get the support of the leader or go home." Without the support of leaders, it is very difficult to make progress.

2. **Show Hospitality** – Many people who receive services have been devalued, excluded, and had their voices suppressed by society. Being made to feel welcome and building relationships with other group members are important comfponents to being able to speak up and contribute. Encourage and create opportunities to get to know fellow members. Other group members may need help in meeting and getting to know other participants and overcoming their own fears and uncertainties.

3. **Provide Financial Assistance** – Staff, providers, and professional advocates are often paid to participate in engagement efforts. Most other participants are not paid, and many live on limited incomes. Consider providing stipends for participation; it is critical to cover travel and meal expenses.

4. **Form Partnerships to Recruit Participants** – Will members be recruited as individuals or as members of a constituency group? Forming partnerships with constituency- or peer-run organizations and matching the interests of participants with the needs of a work group greatly

helps recruitment. Participation is also shown to be more effective when people are representing and accountable to a constituency group. Partnerships with leaders and trusted community members from traditionally under-represented groups will promote more equitable recruitment and representation.

Second Strategy: Full Participation

Full Participation provides people with the means to be present and engaged in carrying out their responsibilities.

Practices that Promote Full Participation

1. **Appoint at Least Three Participants** – Research conducted primarily by women's groups shows that it takes at least three members of a historically devalued group to be present to have an impact on policy. When there is one person, the participant can be fearful of speaking up and afraid they will not be listened to. Two people represent a potential "clique." It takes three people to show different and countervailing opinions, which become valued within the group.

2. **Offer Interpretation, Translation, and Captioning Services** – Demonstrating linguistic competence by offering interpretation, translation, and/or closed captioning services demonstrates a commitment to equity and inclusion.

3. **Hold Orientation Sessions** – An initial meeting helps all group members learn the purpose and expectations of the work group and helps everyone become a contributing member in a shorter timeframe.

4. **Hold Pre-Meetings** – Informal meetings prior to work group meetings provide a time to answer questions, review the agenda, and identify priority areas of focus. These meetings are helpful for both people who receive services and other group members who choose to attend.

5. **Facilitate Meetings with Proper Techniques** – Implementing good meeting techniques makes a big difference on the success of the meeting for everyone. Promote a welcoming and safe environment that encourages active participation. Welcome and solicit participants' voices and opinions. Discourage jargon and acronyms.

6. **Take Frequent Breaks** – Most participants are not used to sitting for long periods and discussing complex issues in closed meeting rooms. Breaks allow downtime and the ability to ask questions about the discussion topics without interrupting the meeting or feeling embarrassed.

7. **Provide Training Sessions** – Schedule meetings to help participants understand the issues and changes under consideration.

8. **Engage in Team-Building Activities or Exercises** – Create team-building opportunities, such as icebreakers to get to know each other, share meals together, and set up discussion opportunities.

9. **Encourage Contact between Meetings** – Create phone trees and establish ongoing check-ins via phone, text, or video conferencing.

Third Strategy: Effective Communication Supports and Mentors

Effective Communication Supports and Mentors provides people with tools, coaching and opportunities to prepare for and be effective at work group meetings.

Practices that Promote Effective Communication Supports and Mentors

1. **Offer Multiple Means of Engagement** – When possible, provide participants with options for engaging in a way that is convenient and accessible for them. This may include holding multiple sessions at different times of the day and offering opportunities to engage in-person or online via videoconference, phone, or social media.

2. **Provide Transportation Support** – Transportation is often the biggest barrier to participation. Many people who receive services do not own a car and are dependent on others to be able to attend meetings. People should not be responsible for their own transportation when they have little control over its provision. It is critical to provide support to help with meeting attendance.

3. **Give Travel Advances** – Most people who receive services have limited funds and do not have cash to pay upfront for gas or public transportation as they await travel reimbursements. Travel advances can solve this problem.

4. **Provide Agendas Two Weeks in Advance of Meetings** – Some people who receive services need help reading or comprehending meeting documents. Providing documents two weeks in advance of the meeting allows people the needed time to review the materials.

5. **Create Easy Read, Plain Language Documents and Alternative Formats** – Use basic fonts, large sizes, color coding, icons, and plain language to create agendas, meeting minutes, and other documents for your work group members with low literacy, vision issues, or other invisible disabilities. Know what your work group participants need and give them information in alternative formats (audio, braille, electronic versions, large print, or readable PDFs) as needed.

6. **Ensure Materials are Culturally and Linguistically Accessible** – Translate materials into commonly spoken languages for participants whose first language is not English. Make sure that content – including pictures, examples, and stories – reflect and are respectful of the cultures and values of participants.

7. **Offer Mentors** – Mentors can be helpful in assisting people who receive services with learning the meeting processes and understanding agendas and documents. Mentors can help people more quickly become effective members of the work group. Some organizations find it beneficial to offer mentors to all work group members in the beginning stages of formation. Mentors can be helpful on an ongoing basis both before and during meetings to offer advice and to facilitate and enhance the full engagement of all participants in meetings.

8. **Provide Accommodations for People with Disabilities** – Some people who receive services will need accommodations in order to fully participate. These may include accessible documents, American Sign Language interpreters, breaks, captioning, Communication Access Realtime Translation (CART), meals, note-taking, perfume-free events, personal care attendants, and physical space. It is necessary to identify and plan for accommodations prior to the meetings.

9. **Plan Meeting Room Arrangements** – Room arrangements play a major role in successful meetings and should not be overlooked. Consider meeting details such as round vs. square tables, where someone in a wheelchair or with a cane sits, the ability to hear each other, who speaks first, how often someone speaks, and who is listened to. Seating near leadership or speakers can often be helpful for people who receive services.

Fourth Strategy: Meaningful Contributions

Meaningful Contributions allow people to provide input and assistance that is important to the policy-making body in ways that utilize their ideas and lived experience.

Practices that Promote Meaningful Contributions

1. **Provide Important Assignments or Roles to People Who Receive Services** – Assign people who receive services to serve as co-leaders, committee chairs, reporters, timekeepers, greeters, distributors of documents, or Sergeant at Arms.

2. **Solicit Agenda Items from All Members** – Include participants' areas of interest in meeting agendas.

3. **Assist in Identifying Preferred Areas of Input or Concerns** – Find agenda items that relate to the participants' interests and where their engagement can make a meaningful contribution.

Fifth Strategy: True Influence

True Influence occurs when participants enhance or alter the substance, direction, and outcomes of the policy-making body in ways that positively impact the lives of people who receive services.

Practices that Promote True Influence

1. **Provide Leadership Roles for Work Group Participants** – Appoint people who receive services to serve as committee or sub-committee chairs, co-chairs, and officers.

2. **Follow Through with Recommendations by Participants** – After a meeting or engagement activity, provide participants with a summary of what was discussed and what actions will result. Highlight and document participants' ideas, comments, and discussion points. Demonstrate that you are using feedback to inform system changes by regularly reporting back the status of actions taken and reconvening to develop additional strategies if the outcomes fall short of expectations.

3. **Adopt the Mantra "Nothing About Us Without Us"** – Commit to practice and implement the mandate that people who receive services will be at the table whenever policies are discussed, or decisions are made.

Resources

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