

Module 3 – Supporting People with Disabilities and Families as Essential Stakeholders in Systems Change



Notes:

This module explores how Virginians with disabilities and family members are essential stakeholders to inform and direct change that improves the lives of people with disabilities. Components of supporting people with disabilities and families as essential partners in systems change that are covered in this module include benefits, supporting active membership, and keeping members engaged.

1.2 Partnership for People with Disabilities

Partnership for People with Disabilities

The Partnership for People with Disabilities is a university center for excellence in developmental disabilities at Virginia Commonwealth University. VCU is an equal opportunity/affirmative action institution providing access to education and employment without regard to age, race, color, national origin, gender, religion, sexual orientation, veteran's status, political affiliation or disability. If alternative formats of this document are needed, please contact the Partnership for People with Disabilities at (804) 828-3876 or (800) 828-1120 (TTY Relay) or www.partnership.vcu.edu.

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Notes:

This module is part of a series of training developed by Project Living Well staff

who work at the Partnership for People with Disabilities at Virginia Commonwealth University. The Partnership serves as Virginia's University Center for Excellence in Developmental Disabilities. Project Living Well is a grant from the U.S. Department of Health & Human Services' Administration on Community Living. More information about this project and the Partnership can be found by calling (804) 828-3876 or visiting www.partnership.vcu.edu

1.3 “Nothing About Us Without Us”



Notes:

A common disability rights movement saying, “Nothing About Us Without US”, refers to how decisions about policies, services, and supports should be made with representation of the people that are directly impacted. People with disabilities and their families are essential decision-makers within the developmental disability system in Virginia, working alongside state and local agencies, providers and organizations.

A system best plans for the people it serves by intentionally involving them in the planning process and by valuing their lived experience in making decisions about supports and services that will directly affect them. In Virginia, people that may come together to address issues about people with disabilities commonly represent:

Payers like the Department of Medical Assistance Services

Legal entities like the disability Law Center of Virginia

Policy and legislative agencies like the Department of Behavioral Health and Disability Services or members of the General Assembly


Researchers from the University Center for Excellence in Developmental


Disabilities which in Virginia is the Partnership for People with Disabilities at Virginia Commonwealth University
Advocacy organizations like The Arc
Monitoring agencies like the Virginia Board for People with Disabilities
Provider representatives like Community Service Boards, and public and private service providers
And people with disabilities and family members

1.4 Stakeholder Group

Stakeholder Group

- A group of people that are assembled around a topic of interest or concern
- Members of the group bring their perspective of the topic
- A mutual purpose is established





Notes:

A stakeholder is a “person with an interest in or concern about something”. Groups of stakeholders, like those listed on the previous slide, commonly come together for a mutual purpose to address a common interest or concern. Stakeholders may bring personal and/or professional perspectives to an issue. Often, the purpose of coming together is to create a plan of action to resolve or fix a problem or issue.

1.5 Values & Benefits of Diverse Stakeholder Perspectives

Values & Benefits of Diverse Stakeholder Perspectives	
Values	Benefits
<ul style="list-style-type: none">❑ People with disabilities and family members are equally valued in the group❑ Personal experience is just as important as professional experience❑ Collaborative decision-making❑ Trusting Relationships❑ Empowerment of all voices	<ul style="list-style-type: none">❑ Decisions are made and supported by people with lived experience❑ Designing services and programs with people who use them can improve business practice❑ Opens access to a wider community

Notes:

There are several values and benefits of including people with disabilities and family members among the diverse stakeholder perspectives on decision-making groups. Here are a few examples of values that your group may want to talk about:

People with disabilities and family members are equally valued in the group:

(Are people with disabilities and families at the table, not because you created extra seats but because some of you gave up your seats?)

Personal experience is just as important as professional experience: (Are their voices welcomed and sought? If so, how?)

Collaborative decision-making: (Are decisions made collaboratively among all members of the group?)

Trusting Relationships: (Is there a sense of trust among all members? If so, how is trust built and maintained?)

Empowerment of all voices: (Do members feel empowered to speak up and share their perspective? Do the members with disabilities and family have a sense of ownership and satisfaction with the decisions being made?)

Having diverse stakeholder perspectives in the group, including people with disabilities and family members, is a major benefit as it aligns decisions with the lived experience of those it will most greatly affect. This ensures that decisions are wanted and needed by those for whom it is intended rather than creating policies, programs or plans that don't match their needs. When the group's values, membership and purpose align, each stakeholder feels encouraged to participate more fully and encourages others to join the group.

1.6 Tokenism



Notes:

While there are several values and benefits to including diverse perspectives it is important to ensure that the group avoids tokenism.

What is tokenism? Merriam Webster defines it as doing something only to prevent criticism and give the appearance that people are being treated fairly. An example of tokenism is having one person with a disability brought onto a group to represent ALL people with disabilities.

(The image on this slide is from the website beyondtokenism.com. It is of a group of people gathered around a rectangular table. Three men and one woman are seated along the far end length of the table, three people of color are seated with one white person along the nearest length of the table, and one person is seated on either end. The person on the right end of the table is in a wheelchair with their arms spread out as if they are asking a question to the lady nearest them while others are engaged in conversations or attending to the paperwork in front of them.)

How do groups formed around disability issues avoid tokenism? First, people with disabilities and family members should be included in the group. Be sure to invite an equal number of people with disabilities and family members to the number of professionals in the group.

1.7 Empowering Leadership



Notes:

This is Mathew Townsend talking about what being a disability leader means to him. As he states: “my leadership is about aspiration, commitment and dedication.”

When an issue is important to someone they are more likely to be passionate and invested in participating in the group. When their voices and opinions are equally valued as everyone else’s at the table, they trust and agree the decision made was respectful. Leveraging the strengths of those with lived experience to share their perspectives with the group upholds important values of accountability...trust...and...empowerment.

Video (Slide Layer)

text after video (Slide Layer)

Empowering Leadership

When an issue is important to someone they are more likely to be passionate and invested in participating in the group. When their voices and opinions are equally valued as everyone else's at the table, they trust and agree the decision made was respectful.



1.8 Making space for engaged and active members

Making Space for Engaged and Active Members

Making space for group members to be fully engaged and active in guiding system change includes ensuring everything the group does is accessible to all members.

Communication  Time 

Physical environment  Meeting Structure 



Notes:

Making space for group members to be fully engaged and active in guiding system change includes ensuring everything the group does is accessible to all members. What does that mean? It means making sure all forms of communication, time, physical space where meetings take place, and meeting structure are accessible.

Communication accessibility includes the way information is both shared and received. Plain, common language and concrete examples support information being shared in understandable ways.

Acronyms, jargon, and academic terminology are not universally understood. Therefore, they should be avoided. Even if the group that comes together may

know what these words mean, it is easy to continue using these terms and forget that when new members join, they are not familiar with them.

Use concrete examples and illustrate with diagrams or other visuals to explain ideas and data. Check in periodically for understanding and clarify as needed.

Group members may use a variety of communication modes such as sign language, braille, or assistive speech devices. Or they may rely on the support of language or voice interpreters.

Aside from the way someone communicates it is also important to consider how people process information. Respect that some members may need time to understand what is being said, form their ideas or thoughts, and share them. One suggestion is that the group be flexible about the amount of time to submit discussion feedback -- for example -- offering up to a day or a week after the meeting for members to share input.

Another comment about time... Most group members like to have time to review materials ahead of the meeting, including agendas and action items. Receiving this information a week ahead of the meeting allows everyone in the group to come to the meeting prepared and ready to work. Mentoring is a method of supporting new or established members. A group may consider offering ways for members to connect with each other, before or after the meeting, to review or clarify what will or has been discussed.

Another consideration is the physical accessibility of the meeting space. This includes things like Americans with Disabilities Act, or ADA, compliant spaces, easy to access entryways and exits, welcoming spaces, comfortable room around the table, freedom to move away if the topic or person is uncomfortable, and acceptance of those who fidget or doodle. Accessible attention should also be considered for virtual meetings. If the group is using video conferencing, ensure that all members have been trained on how to log in and use the meeting features. Consider these questions: Does the meeting software work with screen readers for those with visual impairments? Does it offer captioning of conversation for those who are deaf or hard of hearing?

And finally, the meeting should be structured to meet group members' availability. It is common for meetings to be held during the day when agency and provider representatives are at the office. That may not work for people with disabilities or family members who cannot take time off of work or who cannot find child care, personal care, and/or transportation so they can attend the meeting. Groups may need to negotiate that some meetings occur during the weekday, and other meetings happen at night or on a Saturday morning. This gives everyone an equal chance to participate.

Communication (Slide Layer)

Making Space for Engaged and Active Members

Communication 

- a. Plain language
- b. Modes of communication
- c. Response time
- d. Processing and submitting feedback



Time (Slide Layer)

Making Space for Engaged and Active Members


Time 

- a. Review time
- b. Time to mentor





Physical environment (Slide Layer)


Making Space for Engaged and Active Members

Physical environment 

- a. ADA compliant
- b. Welcoming

 Does the meeting software work with screen readers for those with visual impairments?

 Does it offer captioning of conversation for those who are deaf or hard of hearing?



Meeting (Slide Layer)

Making Space for Engaged and Active Members

Meeting Structure

- a. Flexibility and convenience of schedule
- b. Formats (in person, phone call, online)



1.9 Navigating Difficult Conversations

Navigating Difficult Conversations

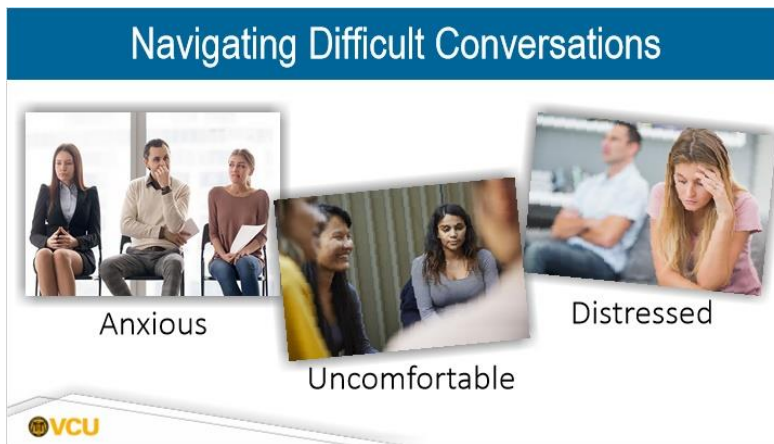


Notes:

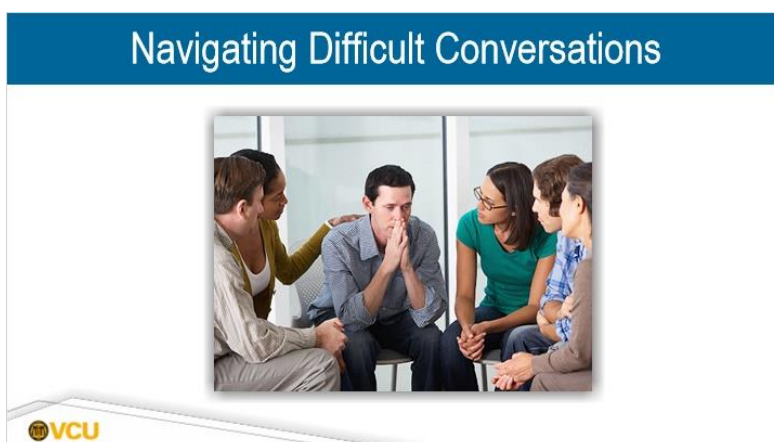
Sometimes, data can be shared in groups or in a conversation about an issue that has the potential for making people uncomfortable...may cause people to disclose personal information...or may result in people becoming very emotional. These conversations can be difficult to navigate. It is important to recognize when you or other group members start getting anxious, uncomfortable or distressed. Some things to look for are members becoming defensive or silent, raised voices, fidgeting, eye rolling, or members who suddenly leave the meeting. We are all human so we are bound to get emotional at times. It is best not to ignore emotions, but also not let your own emotions take over and completely stall a meeting. All members of the group have a role in identifying when conversations begin to affect group members or the group, and navigating difficult conversations. This role becomes more apparent as members evolve

from being individual stakeholders to group partners. While addressing issues in your group be mindful of whether every members' insight is welcomed, and if members are supporting the group by applying the suggestions listed on the slide. In addition, be mindful of when members need a moment to compose themselves. If the conversation gets heated, suggest a break so everyone can calm down and questions can be asked to get to the root of what caused the frustration. When the agenda includes a meeting topic that people may feel strongly about, it may benefit the group to have an unbiased, non-voting facilitator to assist with the discussion process.

group members (Slide Layer)



Emotional image (Slide Layer)



Welcome insight (Slide Layer)

Navigating Difficult Conversations

1. Welcome insight by:
 - a. Sharing perspectives openly
 - b. Respecting varying perspectives
 - c. Being open to perspectives that differ from your own
 - d. Asking for clarification when you don't understand another's point of view
2. Support the group by:
 - a. Modeling collaboration
 - b. Inspiring a shared vision
 - c. Remaining focused on solutions



1.10 Tips

Putting It All Together To Ensure People With Disabilities & Family Members Serving On Groups Are Successful

1. Acknowledge skills, knowledge, experience and connections that people with disabilities and family members bring to the team.
2. Orient new members to the group, its members, and its purpose.
3. Commit to build relationships with all members by pairing a veteran group member with a newer member.
4. Check in regularly with people with disabilities and family members on the group during meetings to answer questions.
5. Attend to physical, emotional and environmental needs.
6. Summarize what was discussed, decided and next steps at the end of each meeting.
7. Have clearly stated and documented action steps: who will do what, by when.
8. Send out notes from the meeting in accessible formats.



Notes:

In this module, we have discussed many ways to ensure people with disabilities and family members serving on groups are successful. These tips can be applied to ALL members.

Acknowledge skills, knowledge, experience and connections that people with disabilities and family members bring to the team.

Orient new members to the group, its members, and its purpose.

Commit to build relationships with all members by pairing a veteran group member with a newer member.

Check in regularly with people with disabilities and family members on the group during meetings to answer questions.

Attend to physical, emotional and environmental needs.

Summarize what was discussed, decided and next steps at the end of each

meeting.

Have clearly stated and documented action steps: who will do what, by when.
Send out notes from the meeting in accessible formats.

Remember, establishing and maintaining relationships among members of the group is essential to creating a welcoming environment where members feel important, valued, and ready to work. This begins when people are asked to serve on the group and continues throughout their membership. Relationship building occurs both in and out of meetings and starts with valuing the lived experiences and perspectives of group members.

By listening to each member's verbal communication and watching for non-verbal cues, the group will learn what works best for people with disabilities who may have a variety of support needs.

Team group (Slide Layer)



1.11 Resources

Resources

- https://familyvoices.org/wp-content/uploads/2020/02/Engaging-Diverse-Families-in-Leadership-for-Systems-Change_FINAL.pdf
- <http://www.gmsavt.org/get-on-board-and-make-a-difference/>
- <https://www.leadinggroupsonline.org/>
- <http://www.hqontario.ca/portals/0/documents/qi/qip/patient-engagement-guide-1611-en.pdf>
- https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy1/Strat1_Implement_Hndbook_508_v2.pdf
- Beyondtokenism: <http://www.beyondtokenism.com/>
- Green Mountain Self-Advocates: <https://drive.google.com/file/d/1-VBwFDm8G2IV900ym97b7ryXJUKP9x3k/view?usp=sharing>

Notes:

The module developers graciously acknowledge the following source materials used for this presentation.