NCAPPS Monthly Webinar Q&A for June 2020

The following Q&A addresses several audience questions that we were unable to speak to due to the time constraints of the PAE Attention Framework webinar, originally broadcast on June 15, 2020.

Thank you to all our speakers (Erin McGaffigan, Bob Weir, Anne Fracht, and Keith Jones) for their time, and their willingness to share additional knowledge and resources. The recording, presentation slides, transcript, and other resources for this webinar can be found on our website: https://ncapps.acl.gov/webinars.html

Question 1: "A lot of individuals don't know how to speak up because they've never been encouraged to do it. I almost consider this a skill that needs to be cultivated. What are some strategies that could be used to get others to take initiative and speak up because a lot of time they won't when they are given the opportunity because they just don't know how. AND Do you hold self-advocacy training that complements stakeholder engagement? If so, can you provide details on a follow-up call?"

> <u>**Erin**</u> - Participating in advisory councils and other forms of stakeholder engagement absolutely is a skill that all of us need to learn. Engagement requires that we be able to listen to others as well as feel confident enough to provide our viewpoint and ask questions. There are a few ways we can support individuals to assume this very important role. For one, there are numerous self-advocacy and community advocacy organizations that have formal trainings to support people to be prepared to be a part of advisory groups and councils.
>
> National Mental Health Consumers' Self-Help Clearinghouse - Freedom Self-Advocacy Curriculum: https://www.mhselfhelp.org/training-old
>
> National Rehabilitation Information Center - Advocacy, Self-Advocacy, & Self-Determination for Individuals with Disabilities: https://naric.com/?q=en/publications/volume-12-issue-1-advocacy-self-advocacy-self-determination-individuals-disabilities
>
> Partners in Policymaking: https://partnersonlinecourses.com/
>
> Self-Advocacy Resource and Technical Assistance Center: https://selfadvocacyinfo.org and https://selfadvocacyinfo.org/wp-content/uploads/2018/07/Self-Advocacy-Start-up-Toolkit-more-power-more-control-over-our-lives-2018.pdf
>
> National Core Indicators Data Highlight: What can states learn about people's involvement in self-advocacy activities? National Core Indicators (2018). https://www.nationalcoreindicators.org/upload/aidd/Data_Highlight_--_Self-Advocacy_Final1.pdf

Also, you can ask individuals who are experienced with engagement to act as formal or informal mentors to new participants. Another way to support individuals to be prepared, as they learn their new role, is to offer informal conversations with staff or other participants in between meetings. We have also found it helpful to dedicate thirty minutes prior to a scheduled meeting to support new participants to prepare for meetings, including to review meting materials and to ask questions. This does not take the place of engaging during the meeting, but sometimes is all someone needs to feel confident and prepared to participate. All of these activities can occur virtually with the right tools and supports.

Question2: "Should 'System' also [be] part of the PAE framework (promote systems thinking and breakdown the silos)?"

Erin - Maybe! But, promoting systems thinking will require that we put all three of the PAE Attention elements into action.

For instance, the PEOPLE *who are facilitating engagement* will be most effective with supporting systems change if they have training or experience in systems development and improvement. Also, the *people representing the silos that require change*, as people who have a stake in the change, must somehow be involved as partners in the process. *Individuals with lived experience* will be ready to move from discussing their own services to how to improve broader programs if they have opportunities to learn about these systems through thoughtfully design orientation and training and ongoing mentoring from system advocates.

The APPROACH also matters and needs to focus on systems change to actually change systems. For instance, the the stakeholder group's charter needs to emphasize the group's role in systems change and strategies that will be used to understand and inform the system. The facilitation questions used through the engagement process also needs to assist the group to move from examining individual experiences to discussing what these experiences mean for policy change and program improvements.

And, finally, the ENVIRONMENT also needs to be an environment primed for system change to actually experience systems change. If the push for eliminating silos isn't coming from advocates for change within the system, it absolutely needs to come from pressure from constituents. Sometimes a budget crisis or another type of crisis, like that of a pandemic, also provides a climate that demands change.

Question 3: "Culture change is the most difficult challenges to improve stakeholder engagement. Are funding agencies looking at the economics of how stakeholders are engagement (for example) in a Supported Employment Agencies in a state (or county) to place an emphasis on best practices of stakeholder engagement ("walk the talk")? The PAE Attention Framework can become an intangible "currency" that co-exists with budget allocation ($$$ by Congress) to achieve realistic outcomes & ensure equity and safeguard human rights."

Erin – Culture is in fact an ENVIRONMENTAL factor influencing stakeholder engagement outcomes. If you are attempting to make changes through stakeholder engagement within a culture that does not see stakeholders as experts, you can spend a lot of work developing innovative ideas and producing recommendations that sit on a shelf. This is where other Environmental factors, such as engagement mandates from funders or a very loud advocacy movement can make a difference. When an environment is not conducive to engagement, sharing concrete examples of how engagement as help similar agencies tackle difficult decisions can be helpful. While some people involve stakeholders because they think it is the right thing to do, some others will only do it because it is clear what they will gain from the process (e.g., political gains, less lawsuits, and positive public relations). Ask yourself what those who may be against engagement need and how engagement can actually help them get then. Then, find a talented independent group that can help you formulate your message.

Question 4: "Who is at the forefront (in USA) who have adopted the PAE framework? [I] Need to learn by example."

Erin - The PAE Attention Framework was first used in 2014 when Collective Insight was established. Collective Insight uses this model to improve stakeholder engagement activities among all of our clients, including peer driven community-based organizations, private health plans, and academic institutes. This Framework also has informed the assessment of existing engagement challenges and opportunities in multiple states looking to expand person-centered planning and systems through NCAPPS, including Utah, Ohio, and Montana. The PAE Attention Framework also informed the development of an Asset Mapping Toolkit, which will be available through NCAPPS in July of 2020, and supports the development of engagement strategies that build on, not replace existing People and Approach assets. PAE Attention also has informed the development of multiple case studies on meaningful engagement, including the ***One Care Implementation Council*** case study and the ***Children's Mercy Kansas City*** case study. We expect the PAE Attention Framework to gain significant attention as more people learn about this Framework over the next five years.

Question 5: "Was the CPIG empowered to make formal recommendations to government entities? Anywhere in your state law? If not, how does the CPIG operate with the state"

Erin - The CPIG was empowered to make formal recommendations to Massachusetts' Medicaid Office, Health and Human Services, and Elder Affairs on the design of self-directed service models in the Commonwealth. The CPIG was successful with doing so by demanding a seat at the table, developing representative strategies that included state partners at the table, and using grant funds to pay for the facilitation of an engagement process that was inclusive and led to feasible state recommendations. Success was possible thanks to the trust that was established overtime among state partners, provider associations, people with lived experience, and advocates. Time, patience, and good listening were all important to the trust building process. This project

led to an increased understanding of how to develop self direction models that include flexible budgeting, but also led to lessons learned on meaningful stakeholder engagement that transcending future grants and the design of new models of care.

Question 6: "How should we 'read the room' in a Zoom meeting?"

Erin - Successful virtual meeting facilitation takes a few steps. 1. if there are more than about 5 people, the facilitator should plan to call on people for brief introductions. That way, people have the experience of speaking. And then let people know they will be called on to share their ideas 2. Request that people keep their cameras on. For people who are used to visually "reading the room" in-person, it is helpful to be able to see people's faces. It's harder on Zoom to tell if people are engaged, but by seeing people, you can often get a sense if people are mostly following along, or are mostly checked out! If people are not really following along, it's time to do something to engage people like we describe in #3.. 3. Directly ask people what they think using polls, or just the simple: "raise your hand" feature in chat. Finally, if you are going to ask people to use the zoom or other on-line meeting platform to 'vote' or 'put their hand up', make sure to build in time to practice that at the beginning of the meeting, before you are asking people to answer your question.

Question 7: "For those being asked to provide their expertise for short-term, and more important, long-term engagement … what about compensation for their lived experiences being shared? This is our personal time, our personal lives being shared, and our expertise — and should be valued as such."

Erin- Yes! Stipends or payment are absolutely an "approach" factor. It is an approach that demonstrates value. We are all experts and all our time is valued. Stakeholder engagement should include budgets for incentives, and incentives often include compensation for time for those who are otherwise not already compensated for their time. Sometimes gift cards or stipends are provided for meeting participation (e.g., $35-50 for attending a two hour meeting). Sometimes, people are worried that providing these stipends will create problems with stakeholders' accessing public benefits. It always is important to provide information on how such compensation is considered income, and how to find out if such income will negatively influence benefits. It is never appropriate to make a paternalist decision that compensation should not be provided because of this risk.

If there are limited or no resources to compensate people with lived experience for their time and expertise, the use of a public/private partnership w/a "funder" other than the state may be possible. For example, a private foundation that has grants for inclusion may be one option. Also, other non-financial incentives, such as access to new training and mentoring may be helpful. Thinking "outside the box" on how to recognize people as experts and show their worth is always a great idea.

Question 8: "What do people think about setting up optional "pre-meetings" to help people think through and get ready for a discussion? What are the pros and cons? Re: pre-meetings. Lou Brown's "pre means never" really speaks to people who won't generalize to the real situation. I like teaching during the process so that those who don't struggle get educated about those who do. The issue that always challenges me with this approach, though, is how to balance what the individual needs with the group's tolerance for moving more slowly."

> **Erin** - Preparation meetings, when done as an accommodation, can help individuals build confidence in their opinions and ideas. A well-trained facilitator or staff person can use these preparation meetings as an opportunity to support an individual's growth and readiness. These meetings also provide insight on ways in which to support the individual during the meeting to make his or her points (e.g., advocating for a pause in a discussion for a point to be made). These preparation meetings should not replace the actual stakeholder meeting and the focus of the preparation should always be driven by the needs and interests of the individual being supported (as opposed to driven by a staff person or facilitator who may have his or her own agenda). Ideally, people with lived experience would assume this role (providing support prior to the meeting) as a paid mentor, which demonstrates how people with lived experience can and should influence systems change.

Question 9: "In the I/DD , Self-Advocacy world doing a pre meeting with committee or advisory group members is a must especially when it comes to Policy Decisions that may be made, and grant projects on things like Healthcare and I/DD for example."

> **Erin** - Sometimes, we have found it helpful in our work to create a space for people with lived experience and advocates to come together in a small group in a pre-meeting to have time to digest the materials, understand each other's questions and concerns, and prepare talking points and recommendations before a larger stakeholder engagement meeting. This helps some of the participants who may be less experienced in policy to learn and ask questions in a less intimidating environment. It also provides a more natural approach for mentoring. It is important to recognize that some stakeholders representing the systems targeted for change may feel threatened by this approach, which may weaken trust. Strong communication about why this approach is happening and the benefits to everyone, even policymakers (e.g., keeps people on the agenda), is helpful.
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> As long as the intention of the pre meetings are to make the decision-making meeting more accessible (not less) and agree on strategies most effective for the Individual stakeholders involved, a pre meeting can be useful and help the decision-making meeting more successful.

Question 10: "What is a reasonable goal in trying to resolve conflict if the parties involved refuse to address the issues involved causing the conflict?"

> **Erin** - This is a great question that is at the heart of the PAE Attention Framework. It sounds like you are working within an ENVIRONMENT that is not primed for meaningful

engagement. There may be leaders who have sent the message to their staff that stakeholder engagement is not a priority. Or, it may a culture that values professional expertise over lived expertise (so, they are having engagement meetings, they are just not with you). Sometimes, cultures are more closed in communication and are skeptical about engagement simply because that has always been the way.

I would ask what can you and others do to change this environment? Will a dose of loud advocacy crack a door? If so, connect with some of the state and national advocacy groups that know the tricks of the trade to get people to pay attention. Or, are there state or federal mandates for engagement that are not actively being applied? Shed some light on that. As for the PEOPLE factor, there are often one or two policy leaders who do understand the benefits of engagement and having a frank conversation with them about opening the doors to engagement may provide some great ideas for practical next steps that can build trust. Working with the PEOPLE to change the ENVIRONMENT will be important. Then, you discuss the APPROACH, which includes thoughtful facilitation and decision-making strategies that address conflict constructively so that you continue to move forward, not backward.

<u>Bob</u> - To answer it more literally, I think a reasonable goal is to see if the facilitator can name the conflict which often has two valid positions. Like Safety vs Autonomy. Wanting people to be safe and people being free to make their own decisions, including risky decisions,, creates conflict, naturally. Usually the conflict is made worse by extreme viewpoints on ether side of a continuum.

Everyone should always be able to make their own decisions

We must always error on the side of keeping people safe

I think a reasonable goal is to get movement off the extreme positions.

Is it ok to keep a person with dementia from walking into traffic?

Is it ok let a person make a decision that only has a risk of minor harm to self when the person understands the risks?

Once we can move off the extreme positions we may be able to find common middle ground, but the conflicting values of safety vs independent decision-making do not ever go away.

On the other hand whose issue is it?   If the organization is proposing change or policy but can't get traction from stakeholders, maybe, from a stakeholder perspective there are more pressing issues. Those may need to be addressed first before, "what is important to the organization," can be addressed.

<u>Anne</u> - The issue/ outcome needs to be explained/discussed in plain language then it's the persons decision

Question 11: "What are some ways those doing engaging can build trust with communities they have historically undervalued or oppressed?"

> **Erin** - Engaging underrepresented, undervalued, and oppressed communities is important to meaningful systems change. It is important to search for local community leaders who are already well respected within the communities you are seeking. Have coffee or a soda together. Ask questions and listen. Read about the communities you are trying to reach. Then, ask how you can partner with these community leaders to engage the communities they serve. They should have ideas on how best to do this, working with the community assets that already exist. Don't forget resources. Everyone's time is valuable and every meeting you ask others to help you with is time taken away from another important project or need. Budget funds to invest in community partners who can help you plan out accessible engagement strategies, facilitate discussions, and put what you hear into action.

Question 12: [for Erin] "Can you give an example of the concept you are currently addressing? [slide 17, of the presentation which discusses engaging folks with cross system skills and lived experience]"

> **Erin** - The point being made here is that often people are looking for "real consumers" to engage. This is sometimes a flag that people are afraid to engage advocates or people with systems knowledge or experience because this may bring conflict. Such thinking may be a sign of tokenism. Are people who are dependent on your services always going to feel safe enough to question how you provide your services? Involving participants from your program, regardless of their systems experience, is crucial and should always be a primary focus of your engagement work. It just shouldn't stop there.
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> Ideally, you are finding ways to engage people with lived experience AND advocates with systems change experience. Even better, you engage people receiving services, and if they have little knowledge of the program and systems of support beyond their own services, you ensure they have access to the information, training, and advocates that provide new insights on how systems work. This means they not only have input on their services, but also get a meaningful seat at the table to guide systems change.

List of Resources Shared by Attendees

Family Voices framework on family engagement/children with special healthcare needs: https://familyvoices.org/wp-content/uploads/2018/06/Assessment-of-Family-Engagement-Key-Criteria_2.2018.pdf And toolkit https://familyvoices.org/familyengagementtoolkit/

4 domains of family engagement: representation, transparency, impact, and commitment– https://familyvoices.org/wp-content/uploads/2018/10/FamilyVoices_LPFCH_assessing_family_engagement_April2018.pdf

Get on Board and Make a Difference from the Green Mountain Self-Advocates: http://www.gmsavt.org/get-on-board-and-make-a-difference/ good tool to use for boards and commitees

A PowerPoint presentation on plain language by the Self-Advocacy Resource and Technical Assistance Center: https://selfadvocacyinfo.org/wp-content/uploads/2019/08/Plain-Language-Webinar-SARTAC-August-22-2019.pdf

Getting Your Message Across: Communicating with People Who Have Intellectual Disabilities – http://www.gmsavt.org/wp-content/uploads/2010/12/Getting-Your-Message-Across-Communicating-With-People-With-Intellectual-Disabilities.pdf

Supporting Virtual Meeting Accessibility: https://ncapps.acl.gov/docs/SupportingMeetingAccessibility_NCAPPS_200519.pdf

Utah Community Engagement Resources Search tool: https://dspd.utah.gov/find-a-community-resource/