

Eugene Washington PCORI Engagement Award Lay Conference Summary

Background

Title of Project: Participation and Intellectual and Developmental Disabilities (#5964)
Meeting: Southeast Regional Meeting 3
Meeting time: 10 am to 3:30 pm
Meeting location: Morris Museum of Art, Augusta, GA
Meeting date: July 13, 2018

Meeting Summary

Philadelphia, PA January 2018	• See Meeting 1 report
Seattle, WA April 2018	• See Meeting 2 report
Augusta, GA July 2018	• 34 attendees representing: <ul style="list-style-type: none">• Individuals with intellectual and developmental disabilities (self-advocates)• Family members of individuals with ID/DD• Occupational therapists• Community organization representatives from faith, arts, afterschool programs, sports, and disability service/advocacy organizations• Researchers

What We Did Differently at This Meeting than Other Meetings

- 1) Gave attendees a 6-minute video introduction to the meeting, emailed 1 week prior to the meeting.
- 2) Gave attendees all questions we hoped to answer before the meeting so people could think of answers.
- 3) Asked questions more specific to each group to get at different stakeholder viewpoints in AM session.

Meeting goals

- 1) Talk about what “community participation” means to attendees.
- 2) Talk about how to know *when* things are changing and *how* can we tell?
- 3) Learn what participants want to do next in order to work together.

Meeting Agenda

Morning—Large Group Discussion

We asked these questions and the attendees gave us these answers.

1. A question for individuals and families: What does participation mean to you?

One person said: “I’ve had so little for so long that I don’t know what I want.”

- People said they want to choose how, when, and where they participate in activities.
- People said that organizations need to know that if they want to get people involved, that means they need to create opportunities for people to focus, interact, and engage.
- People were split about how they felt about special events, like “sensory-friendly events” that are held for the benefit of people with, and families of, people with ID/DD. Some

people said that these events make them feel safe because they're "among my people," while others felt that these events make them feel separate.

2. **A question for people from organizations: "When you heard what people said, what surprised you? What opportunities did you see? What reactions did you have?"**

One person said: "How do I know what I don't know?"

- Listening helped organizations understand what people need. It also helped them know what organizations need to do to help.
- It is important to know that small steps can get more people to participate.
- One challenge is that people have very different needs, so making programming that is meaningful or that meets everyone's needs is hard to do, and it means making hard decisions.
- Taking part and being included is important to people with ID/DD. It needs to be more than checking ADA boxes.

3. **A question for everyone: What can we do to increase participation?**

One person said: "Make inclusion and participation a part of the organizational culture [and] part of everyday practice."

- We can "connect the dots." We can help organizations, people, and systems all talk to each other.
- We can help organizations not feel alone. We can keep partnerships active and advancing.
- We can take what we learned today to our organizational leadership. We can discuss its importance and our role in making it happen.
- We can match organizations that need help with those who have experience. We can create support systems so people and organizations who need help can get it.

Afternoon—Small Group Discussion ("Breakouts")

In the afternoon, we divided people into groups. Each group had people with ID/DD, family members, and organizations. We asked every group to talk about the same questions:

How do we make sure we're including all the people who need to have a role?

- We should have face-to-face meetings whenever possible.
- We should create guides that explain the best ways to share information.
- When we want to involve others, we should make sure that we send out quality information. It's important to have the best materials possible, even if it's once in a while. Getting flooded with poor materials is not helpful. Quality over quantity.
- We should use every system we can to communicate: email, listservs, and social media.

How do we measure what's important?

- We can measure change in individuals by asking people for their stories.
- We can measure engagement through relationships and being with others.
- Organizations can measure growth and development.

What do organizations need so they can move forward?

- Organizations need to bring this information to their team and talk about it with them.
- Organizations need to keep talking and working with the people they've met here. They need to make sure that their connections and collaborations stay active. They may need to ask another organization to mentor them.
- Organizations need to "connect the dots." That means they need to find ways to continually trade information and ideas with everyone involved.

Pictures of Our Day

Photo Credits to Michael Iwama



Caption: Entrance and Registration at the Morris Museum of Art, Augusta, GA



Caption: Teal Benevides Talking about the Plan for the Afternoon



Caption: Breakout Session in Main Meeting Room of the Morris Museum of Art; Facilitator: Roxanna Bendixen



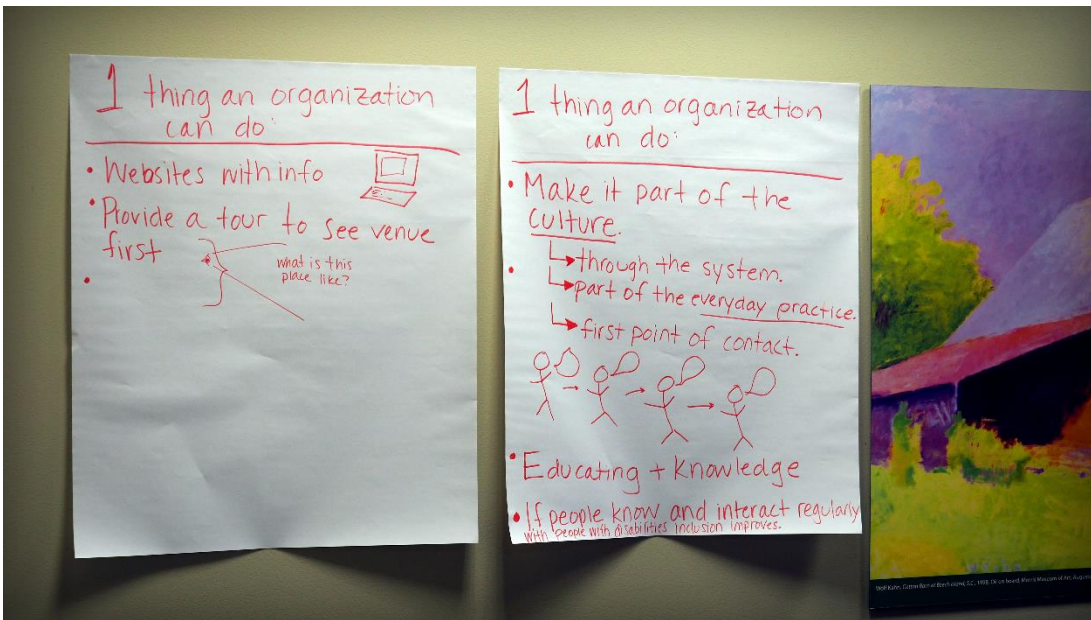
Caption: Breakout in the Conference Room of the Morris Museum of Art; Facilitator: Teal Benevides



Caption: Meeting Facilitator and Lead Engagement Coordinator, Robert Smythe



Caption: Attendees in Breakout Session Discussing Next Steps



Caption: Our meeting 'art' – listening and learning together in the Morris Museum of Art