**Eugene Washington PCORI Engagement Award Lay Conference Summary Template**

# **Background**

**Title of Project:** Participation and Intellectual and Developmental Disabilities (#5964)

**Meeting:** Northwest Regional Meeting 2

**Meeting time:** 10 am to 3 pm

**Meeting location:** University of Washington, Seattle, WA
**Meeting date:** March 23, 2018

# **Meeting Summary**

# **Meeting Goals**

# 1) Talk about who should be involved in future research activities.

# 2) Define ‘community social participation’.

# 3) Understand more about what is important to the people we wish to work with.

# **Meeting Agenda**

**Morning—Large Group Discussion Focused On:**

* Things that people do that show that they have included everyone.
* Things that people do that show they have not included everyone.
* How this group should plan to include everyone in new activities.

**What we learned:**

* Including everyone is something that the entire community should be thinking about and doing.
* Everyone in a community, including the government, community groups, and others outside of ‘arts organizations’ should make an effort to create chances for all to participate.

**What we agreed on**: This is a big goal and will take time.

**What is needed to meet our goals**: Trust, making new relationships, learning from old and new chances to work together.

Attendee summary: “We are creating a transactional (and transformative) system for culturally relevant, accessible, resources and strategies, for including people in the fabric of society for everyday living and promoting health and wellness through participation.”

**Afternoon—Small Group Discussions (“Breakouts”) Focused On:**

1. Who should be involved in future research activities?
2. How should we stay in touch with each other, and with other interested people?
3. How do we measure what is important?

**What we learned in Group 1: Who should be involved in future research activities?**

* People want to participate in the community as children and adults.
* Our project should use a lifespan approach to think about research.
* Things we need to learn more about in Meeting #3 in Augusta, GA
	+ Does research need to focus on children separately from adults?
	+ Should future research include people all across their life?
* Things we need to do differently in Meeting #3 in Augusta, GA
	+ Include more self-advocates
	+ Make sure that information about the project goals is clearer to all people before and at the meeting.

**What we learned in Group 2: How should we stay in touch with each other, and with other interested people?**

* We need to think about cultural differences in what people want to do in the community.
* We need to think about changing the use of academic ‘terminology’
* The words ‘culturally welcoming’ are helpful to think about when making new programs
	+ This means that communication creates feelings of ‘belonging’, ‘safety’, ‘trust’
	+ Communication needs to be approved by the community-there are similarities and differences that we should think about across different communities.
	+ We should use more plain language, pictures, graphs, and follow accessibility guidelines.

**What we learned in Group 3: How do we measure what is important?**

* People shared ideas about important things to measure for individuals, family members and community programs.
* People agreed we should plan to measure changes over time. The changes people want to see would not tend to be seen immediately following an event.
* Technology could be used in different ways in the research.

**Common themes between Meetings 1 and 2**

* Meeting together face to face is good for sharing ideas
* Making sure the project team stays in touch is important.
* People connected to this project want to know what others are doing and about helpful resources.
* Things we should do:
	+ Make sure the summary of the meeting is shared with people who came to the meeting.
	+ Make sure we share ways people can find information on our website when it is done.
	+ Share information in an easy to use and accessible format.

Dissemination Plans

* We need to learn more at our Meeting #3 before we share what we learned outside of our small group.