Eugene Washington PCORI Engagement Award Lay Conference Summary Template

Background

Participation and Intellectual and Developmental Disabilities (#5964)
East Coast Regional Meeting 1
10 am to 4 pm
Temple University
Philadelphia, PA
January 12, 2018

Meeting Summary

This is the first of three regional stakeholder meetings planned for Year 1 of the project. Thirty-one participants attended. The meeting participants broadly represented the following stakeholder groups: individuals with intellectual and developmental disabilities, family members, self-advocates, researchers, occupational therapists, and community organization representatives or administrators from cultural arts, public transportation, and public libraries. Participants also included all east coast regional advisory board members and project partners. Large and small breakout group discussions were used to engage the meeting participants in the following overarching meeting goals and objectives:

Engage stakeholders in research development activities to discuss and define 1) the target group/population; 2) community social participation; and 3) meaningful outcomes in the areas of health, well-being and quality of life linked to community social participation.

Questions to stimulate large group discussion focused on successes, barriers, "the ideal world," ways to make engagement possible, and steps toward meaningful change. Topics that emerged as themes and priorities from the large group were used to inform the focus of the small breakout groups. The three breakout groups held in the afternoon were titled: "Reaching the Under-Reached", "Power Dynamics", and "Economic Oppression."

Meeting 1 revealed that the stakeholders do not identify only with the goal of expanding community participation solely for individuals with intellectual and developmental disability. Rather inclusion and participation are seen more broadly as an issue within the disability community. "Reaching the Under-Reached", "Power Dynamics", and "Economic Oppression" were stakeholder-identified priorities that emerged and received attention in smaller groups. A more detailed analysis of the summaries from each of these small groups is currently underway. Future steps include more clearly defining 'community participation', identifying meaningful outcomes given the themes that emerged, and identifying the specific research questions that are prioritized by individuals with ID/DD, families, and community organizations who desire to expand their programming to reach this population.

Action steps in response to these topics and priorities include the refinement of meeting discussion questions for the remaining two regional meetings in Seattle, WA and Augusta, GA. The project team will aim to achieve a balance between the topics and priorities that emerged in meeting 1 with additional questions that more specifically target project outcomes identified in the work plan. As part of the first regional meeting follow up and evaluation we have also asked stakeholders who attended for specific advice for the future meetings. These topics have also been noted in relation to potential workgroups in Year 2

Diversity representation within the regional stakeholder communities was noted as a top priority, as well as outreach to a variety of sectors of the community (e.g., expanding beyond cultural arts). **Action steps** in response to this priority include active outreach to diverse communities as a follow-up to the East Coast meeting and as part of the planning process for the upcoming regional meetings in the West and South. This was identified as a potential focus for the proposed works groups in Year 2 of the project and possibly a workgroup that could be initiated earlier.

The in-person, face to face meeting format was valued by participants as well as the opportunity for stakeholders to make personal connections and network. Stakeholders want to see action following the meeting. Maintaining contact with the project team and meeting participants, the need for relationships, trust and transparency, and desire for efficient project-related communication updates were engagement priorities. **Action steps** in response to the stakeholder's stated engagement preferences and priorities include providing access to the meeting power point, executive summary and list of attendees; and development of portions of the project website as an information "hub"' so that resources and information can be shared with and beyond the current stakeholder groups. Methods for two-way communication, as well as the timing, content and mode (e.g., email updates) of project-related communication will be priorities for discussion among the project team, advisory board and stakeholders.

Dissemination Plans
Project dissemination will be a priority for Year 2. Specific dissemination plans will be developed following a systematic review and analysis of information from all three regional meetings; and using ongoing stakeholder engagement. A means to gather and disseminate the collective resources of the stakeholder group and a way to sustain and expand stakeholder engagement is also a dissemination priority.