Dare greatly: Involving youth with neurodevelopmental disabilities as co-researchers
AACPD 2017 Annual Meeting

- **Participatory action research (PAR)** is a research approach in which stakeholders are involved in all stages of research. This includes identification of research questions, research design, data collection, data analysis, and dissemination.
  - Other terms used to describe research that involves collaboration with stakeholders includes, emancipatory research, inclusive research, patient engagement, and community-based participatory research (Seekins & White, 2012; Walmsley, 2004).
  - There are a range of ways in which these types of research are defined, but all share the underlying value of stakeholder engagement.
- **Social validity** refers to the extent to which the goals, procedures, and outcomes are valued by and useful to the people most impacted by the research (Seekins & White, 2012; Wolf, 1978).
  - PAR is responsive to the disability community’s demand, “nothing about us without us.” PAR helps ensure the goals, procedures, and outcomes of the interventions or tools studied are important and acceptable to people with disabilities and their families.
- Evidence suggests PAR may be an effective approach for decreasing health disparities.
  - By engaging people with disabilities in the research process, PAR may more effectively identify the environment factors, social conditions, and lived experiences of people with disabilities that underlie health disparities.
- Youth with neurodevelopmental disabilities can engage in participatory action research when provided with appropriate supports.

**Notes:**

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| Refer to personal experiences or provide experiences | - Referring to actual experiences can support understanding of abstract concepts.  
- Opportunities to explore potential decisions and outcomes supports decision-making. | - To identify content for the measure, youth participated in an activity and simultaneously identified the skills needed to complete the activity.  
- To develop data collection activities, youth trialed focus group activities and then identified revisions or alternative ideas. |
| Break down complex tasks into multiple steps | - Scaffolds multi-step processes requiring reasoning and judgment.  
- Supports integration of information from multiple sources.  
- Can include adult researchers reducing data to more manageable amounts of information. | - Youth analyzed qualitative data about different rating scales using multiple steps:  
1. Sort qualitative responses into positive and negative comments about the words, images, and choices.  
2. Summarize the qualitative data on separate color-coded worksheets for words, images, and choices.  
3. Create posters to summarize the main ideas about the words, images, and choices.  
4. Compare the main ideas about each scale using a color-coded summary worksheet. |
| Incorporating Universal Design for Learning (UDL) standards into research activities and materials | - Use of multiple means of expression, such as talking, writing/typing, or drawing supports youth with diverse communication preferences.  
- Conveying concepts using visual images and manipulatives supports understanding for diverse learners. | - Youth created rating scales by mixing and matching notecards with different images and words representing ‘magnitude’ (e.g., a lot, a little) and ‘quality’ (e.g., hard, easy, good, bad) and placing these notecards on a notched line.  
- Field notes youth completed while performing everyday activities included images and could be completed on computer or paper, or by dictating responses. |
| Peer support | - Youth researchers work together to accomplish tasks with assistance from each other rather than relying on adult researchers.  
- Youth can learn from each other and experience increased self-efficacy by observing the accomplishments of peers.  
- Peer support facilitates an environment in which power is more equally distributed and youth feel more comfortable sharing perspectives that may be different from the adult researchers. | - Two youth created and presented posters depicting results of focus groups. These youth were able to support the rest of the youth in interpretation of the data.  
- Youth were paired based on complementary strengths. For example, to complete an interactive analysis, we paired one youth who was a good reader with another youth who was able to manipulate the slips of data into piles. |
General references/background


Reviews of PAR with individuals with disabilities


Examples of PAR with individuals with neurodevelopmental disabilities