

Submission Id: 5332

Title

Recognizing Adults with intellectual and Developmental disabilities In Advocacy Through Engagement (RADIATE)

Priority 1 (Research Category)

Community based participatory research

Presenters

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Abstract

Context: Young adults with intellectual and developmental disability (IDD) are at risk for poor health outcomes related to health behavior and experience more health-related social needs (HRSN). Young adults with IDD are not often included engaged to determine their perspectives and self-identified needs. Objective: Develop local coalitions, capacity for participatory research and self-advocacy, and a research agenda to address health disparities among young adults with IDD using established community engagement approaches. Study Design and Analysis: NA. Setting: Colorado Springs and Mesa County, Colorado. Population: Young adults with IDD and people who care about them including family members, educators, and service and healthcare providers. Intervention: Engagement process involving group forming, capacity building in self-advocacy and research engagement, Photovoice, and sharing with the wider community through presentations and discussion. These presentations were followed by community input to create a final research agenda for future community-engaged research aimed at improving health outcomes for young adults with IDD. Outcome Measures: results on the Research Survey Engagement Tool (REST) and focus group discussions with community coalition participants. Results: The final research agenda found the following topics for future research to be most important to young adults with IDD and their communities: Colorado Springs: independence around finances and life decisions, improved access to healthcare and healthy foods, improved mental health, and opportunities for exercise; Grand Junction: increasing community support for young adults with IDD, improved opportunities for health promotion, recreation and social connections. The results of the REST showed that the majority of participants responded that their ideas were treated with openness and respect “always” and principles such as collaboration, consultation, and cooperation were rated as “excellent”. In focus group discussions, participants described impactful learning and engagement through the process and expressed interest and willingness to continue engagement and partnering in research activities. Conclusions: young adults with IDD have many ideas about how to improve their health outcomes and are interested in learning about research and self-advocacy. Research projects that involve young adults with IDD may be more impactful and relevant following meaningful engagement processes.