

Exploring Community Engaged Research with Adolescents and Young Adults with Intellectual and Developmental Disabilities: Priorities for the Transition to Adulthood

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Background

- Transition to adulthood is a critical period for addressing disparities in untreated depression and anxiety among adolescents and young adults (AYA) with intellectual and developmental disabilities (IDD).
- A major barrier for AYA with IDD is limited availability of accessible, community-informed mental health interventions.
- B.E.S.T. is a research study that seeks to integrate mental health supports into care coordination.
- B.E.S.T. adopted a community engaged research (CEnR) approach, which fosters stakeholder leadership, equitable participation, and centers community experiences.

Research Questions

The guiding research questions were as follows:

- How are AYA engaged in the project?
- How does AYA engagement inform the project?

Methods

- Time period: May 2022 – February 2023
- Content analysis of documents (Krippendorff, 2019; Saldaña, 2016)
- AYA engagement was captured in multiple ways including recordings and notes from the Youth Advisory Committee (YAC)
- Documented process through audit trail memos, notes, codebook, peer discussions and email

Data source	Number
Verbatim YAC meeting transcript	3
Verbatim YAC meeting chat transcripts	2
YAC meeting notes	2
Summary of Tier 1 feedback document	1
1-1 Assessment feedback transcripts	7
Assessment feedback notes	1

Results

Engagement of AYA with IDD highlighted unique priorities:

- Age relevance of materials
- Self-advocacy
- Accessibility
- Positive representations of disability

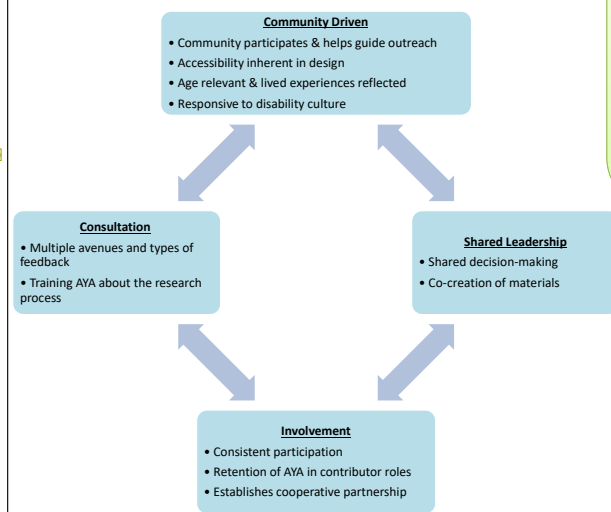
“Mental health needs a lot more awareness now...it was like, you're either crazy or normal. There should be a gray area.”



“Maybe have like different variations of an explanation set out like one that's has like more complex explanations versus one that has basic explanations and of course, you can be in between, but like maybe you can do it based on like reading labels like third grade reading level, etc.”

A crucial contribution was conceptualizing workshops for AYA and caregivers: “Some of the some of the youth ones I feel like could be opened up to parents...I think would have a similar workshop but from the lens of like your disabled children are allowed to be romantically...Here's how you support xyz and regarding the like safe sexual health practices.”

“Yeah like something around like... the accessibility of colleges... We know that this is an issue you're dealing with, or maybe dealing with here's how to not let it overwhelm your life and also like what about like asking for an [accommodation] in college like that all goes into like a general self-advocacy.”



Conclusion

- CEnR can be an effective pathway for addressing the priorities of AYA with IDD while adapting interventions.
- CEnR approach involved an iterative and nonlinear process between AYA and facilitators in which connections, understanding, and shared decision-making occurred to address community needs and desires.
- Engagement of AYA with IDD highlighted priorities that may have not been otherwise raised by the research team.
- The CEnR process may lead to more engaging, accessible, and effective interventions for AYA with IDD.
- Participating in the CEnR process can also foster leadership skills in AYA with IDD, including collaboration and communication skills.
- Researchers should consider partnering with AYA with IDD to promote AYA priorities, participation in research, leadership and equitable access.

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Slide 1

BKLO What does number mean? Number of transcripts or chats?

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