

## **Paper 1**

**Title:** Adaptation and Implementation of Cognitive Behavioral Therapy for Adolescents and Young Adults with Intellectual and Developmental Disabilities: A Systematic Review

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### **Background/Purpose:**

Adolescents and young adults (AYA) with intellectual and developmental disabilities (IDD) often struggle with depression and anxiety, which adversely impacts their health and occupational outcomes across the life course. Despite disproportionate risk for mental health symptoms and its sequelae, AYA with IDD are less likely to receive appropriate, evidence-based mental health treatment in comparison to typically developing AYA. Interventions, such as cognitive behavioral therapy (CBT), can be effective when adapted to meet the needs of AYA with IDD. However, there is little understanding of the types of adaptations employed in CBT, nor guidance on implementation strategies for this population. The objectives of this systematic review are to describe: 1) types of CBT interventions tested for AYA (aged 11-25 years) with IDD; 2) efficacy of these CBT interventions on depression and anxiety outcomes; 3) adaptation strategies to make CBT accessible to AYA with IDD; and 4) implementation strategies and outcomes.

### **Description/Design:**

A literature search of EMBASE, PubMed, PsycINFO and CINAHL databases was conducted by five bachelors and masters level reviewers using relevant terms. Key terms used in the search process included: intellectual and developmental disabilities; cognitive behavioral therapy interventions; depression and anxiety symptoms and diagnoses; and adolescence and young adulthood. Studies were included if they: 1) pertained to AYA age 11-25 with IDD; 2) examined depression and/or anxiety diagnoses or symptoms; 3) tested a cognitive-behavioral intervention using a randomized control trial, quasi experimental, or pre-post study design; 4) utilized participant samples of greater than N=8; and 5) included implementation data. After citation tracking, 3,241 articles were identified for review. Data were extracted from the articles and coded by reviewers. The FRAME framework and the Proctor taxonomy were employed to code adaptation and implementation strategies, respectively. Reviewers and their supervisors met regularly to review coding decisions and resolve inconsistencies. A total of 24 articles met inclusion criteria and were included in the final synthesis. Risk of bias was assessed using the Cochrane risk-of-bias tool (RoB 2). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) and Cochrane Handbook for Systematic Reviews of Interventions guided the process and reporting for this systematic review.

### **Outcomes/Findings:**

The majority of studies focused on autistic AYA (n=18), followed by AYA with attention deficit hyperactivity disorder (n=4), intellectual disability (n=1) and stuttering (n=1). Sample size varied from 9-159 AYA, with a pooled sample of N=971. Adaptations included modularized intervention delivery, visual supports, language adaptation, specific skills training, parent involvement, and incorporation of AYA interests. Implementation factors were inconsistently reported, with acceptability, feasibility, and fidelity findings being the most common outcomes. Overall, CBT had positive impacts on AYA mental health; only 2 studies reporting null findings.

**Implications/Impact:**

Unmet mental health needs can negatively impact life course trajectories for AYA with IDD. Our findings suggest that CBT can be adapted and implemented in diverse ways to address the mental health symptoms of AYA with IDD. Although evidence suggests adapted CBT is effective for AYA with IDD, these findings largely pertain to autistic AYA. Additional studies on adaptations for varying types of IDD are needed to extend access to CBT to a broader population of AYA with disabilities. Finally, research on implementation outcomes among AYA with IDD is needed to enable replication of CBT interventions in diverse community contexts.

## **Paper 2:**

**Title:** Applying a Community-Engaged Research Approach to Adaptation of a Mental Health Intervention for Adolescents and Young Adults with Intellectual and Developmental Disabilities

**Authors:** Deana Herrman, *Leah Bernard*, Anja Herrman, Katie Arnold, Chengshi Shiu, Kristin Berg, Rebecca Feinstein, Kruti Acharya, *Katherine Buchholz*, *Tracy Gladstone*, *Benjamin Van Voorhees*, Iulia Mihaila

### **Background & Purpose/Aims:**

A major barrier to accessing mental health supports for adolescents and young adults (AYA) with intellectual and/or developmental disabilities (IDD) is the limited availability of accessible, community-informed interventions. Research practices that include AYA with IDD are necessary to adapt and develop interventions that specifically meet the needs of this population. The B.E.S.T. project adapted an online mental health intervention using a community-engaged research (CEnR) approach to involve AYA with IDD. The CEnR framework engages communities in decision-making and centers their experiences and perspectives throughout the research process. The purpose of this study is to describe how engagement of AYA with IDD through a CEnR approach impacted the adaptation of a mental health intervention.

### **Description/Design:**

We implemented a CEnR approach with AYA with IDD to elicit community insights and priorities in relation to mental health treatment and to maximize the acceptability and relevance of our online mental health intervention. Implementation of the CEnR approach occurred through the following five steps:

1. Outreach/Recruitment: Six B.E.S.T. Study Scholars (AYA with IDD consultants), a Youth Advisory Committee (YAC) composed of 8 AYA with IDD, and 3 AYA with IDD staff were recruited through outreach to disability rights organizations, disability community partners, parents and AYA self-advocates.
2. Consultation: Stakeholder advisory groups, staff positions, and summer scholar positions were created to allow multiple points of feedback from AYA with IDD.
3. Involvement: Principles of universal design were employed to facilitate maximum involvement of AYA with IDD, including an accessible online platform, flexible timelines, plain language and diverse mechanisms for participation and feedback.
4. Shared leadership: A decision-making process was created to ensure AYA with IDD were co-decision makers and co-creators of materials related to all aspects of the research, ranging from promotional materials to intervention topics and content. All AYA with IDD in this study were compensated.
5. Community driven: Real life experiences of AYA with IDD guided the adaptation process. Detailed process notes, attendance tracking and transcripts of meetings were recorded and analyzed to monitor and assess the community engagement process.

### **Outcomes/Findings:**

There was consistent engagement by AYA with IDD in the research process. B.E.S.T. Study Scholars, YAC members, and AYA with IDD staff regularly attended meetings to produce materials, adapt intervention components, and provide feedback. No AYA with IDD dropped out of the project. AYA with IDD used multiple modalities to share feedback centered on the accessibility, cultural responsiveness, and age-relevance of intervention content/imagery. Feedback and decision-making led to significant intervention

adaptations (e.g., visual/language accessibility, timing/duration of sessions, interactive web-based tools, and culturally relevant imagery/language and practice scenarios) and the co-creation of innovative products, including videos, comic strips, cartoons, and artwork.

**Implications & Impact:**

Employing CEnR principles can be a feasible method for creating accessible, community-informed mental health interventions for AYA with IDD. Employing universal design principles and providing structure and compensation for shared leadership may facilitate sustained engagement in the research process. In addition to adding valuable insight to the project, involvement on a research team is an opportunity for AYA with IDD to develop transferable leadership skills (e.g., decision-making and teamwork). Researchers should consider collaborating with AYA with IDD to align their research with community needs, improve the accessibility/efficacy of interventions, and promote opportunities for AYA with IDD to gain leadership experience.

### **Paper 3:**

**Title:** Usability of an Adapted Online Depression and Anxiety Prevention Program for Adolescents and Young Adults with Intellectual and Developmental Disabilities

**Authors:** Iulia Mihaila, Sarah DeAngelo, Deana Herrman, Kruti Acharya, Kathleen Diviak, Chengshi Shiu, Rebecca Feinstein, *Katherine Buchholz, Tracy Gladstone, Kristin Berg, Benjamin Van Voorhees*

#### **Background & Purpose/Aims:**

A growing body of research indicates that adolescents and young adults (AYA) with intellectual and developmental disabilities (IDD) experience high rates of depression and anxiety disorders compared to their typically developing peers. Untreated depression and anxiety in adolescence may have significant consequences for transition to adulthood and quality of life outcomes in this population. To address the need for mental health promotion among AYA with IDD, an online depression and anxiety prevention program, adapted from the Competent Adulthood Transition with Cognitive-behavioral & Interpersonal Training (CATCH-IT) Program, was created. The aim of the present study was to 1) describe the adapted online depression and anxiety prevention program for AYA with IDD and 2) examine AYA with IDD perspectives on the program's preliminary usefulness, ease of use, and ease of learning, as well as their satisfaction with the program.

#### **Description/Design:**

The 9-chapter online depression and anxiety prevention program (entitled B.E.S.T.) uses principles from cognitive behavioral therapy to teach skills for examining helpful and unhelpful thoughts and understanding connections between mood, thoughts, and behavior. The program also teaches AYA with IDD how to describe depression and anxiety and when and how to seek help. Notably, B.E.S.T. utilizes a disability identity lens to discuss depression and anxiety in the context of stigma and ableism. Video examples from AYA with IDD engage participants and reinforce skills and ideas taught throughout the program. Additionally, skill builders embedded within B.E.S.T. help AYA with IDD apply the skills they learn to the context of their own lives.

The online B.E.S.T. program is being implemented as part of a larger study over the next 2 years. In total, 390 AYA with IDD, aged 13-20 years old, will have access to the online B.E.S.T. program. Upon completion of the B.E.S.T. program, participants will complete the USE Questionnaire (Lund, 2001) to report on the usefulness, ease of use, ease of learning of the program, as well as their satisfaction with the program.

#### **Outcomes/Findings:**

The online B.E.S.T. program will be presented as a potential model for online depression and anxiety prevention programming for AYA with IDD. B.E.S.T. implementation and data collection will begin in January 2022. By May 2022, approximately 100 participants will have completed B.E.S.T. program. Descriptive statistics will be utilized to describe usability of and satisfaction with B.E.S.T. Paired samples t-tests and chi-square analyses will be utilized to examine any differences in usability and satisfaction by age, gender, type of IDD, and initial level of mental health symptomology.

#### **Implications & Impact:**

Findings will have implications for the usability of online mental health prevention programmings with AYA with IDD and will inform recommendations for the future development of similar programs for this

population. If effective, this type of online programming presents a cost-effective and uniquely accessible delivery mechanism for promoting positive mental health in this at-risk population.