

Guidelines for Adapting Health Promotion Programs for Youth with IDD and/or Autism

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Background

- Youth with Intellectual and Developmental Disabilities (IDD) and/or Autism face significant health disparities, including poor mental health and limited access to effective health programs.
- Barriers such as inaccessibility and lack of facilitator experience contribute to these challenges.
- During my MPH practicum last summer, I adapted a mental health promotion program for youth with disabilities. Through this process, I found a lack of clear resources and recommendations for health promotion programs for this population.
- This project develops practical guidelines to ensure welcoming and accessible health promotion programs for youth with IDD and/or Autism.

Purpose Statement

Provide guidelines for adapting health promotion programs to accommodate children with Intellectual and Developmental Disabilities (IDD) and/or Autism to increase access and health autonomy.

Methods

- A literature review identified existing recommendations and adaptation tools.
- To address research gaps, seven health professionals from multiple disciplines working with youth with IDD and/or Autism were interviewed on their experiences and field-specific recommendations.
- Interview questions focused on experiences with programs in this population, discipline specific recommendations, and challenges expected in a program setting.
- Using deductive thematic analysis, we created goals for each stage of program development in order to meet disability community needs.
- Based on these goals, we developed step-by-step adaptation guidelines along with tools & resources for usage.

Results

A literature review conducted through PubMed, Google Scholar, and the American Journal of Public Health identified numerous case studies, interventions, and disease prevention programs that described various adaptation processes. To improve the accessibility of these programs, the literature recommends applying universal design principles, offering flexible learning options (e.g., modality, seating), and equipping facilitators with the skills needed to effectively support different learners.

Health Professional Disciplines



“A person is not isolated to one healthcare condition, there are several things that impact how that person will interact with your program that are outside of that person.” P1 – Rehab Counselor

“How can you still work within the model and the things that you know and leverage your own strengths as a provider to meet the unique needs of this specific patient population.” P2 – Developmental Psychologist

“It doesn't have to be equal, just has to be equitable.” P3 – Occupational Therapist

“Create training around it for the people implementing the model so that you can make it make better sense to them within their context of their systems and their population.” P1 – Rehab Counselor

Conclusions

- A program truly serving youth with Autism/IDD should be adapted at all stages of program planning and implementation.
- Health professionals who interact with those with Autism/IDD have key experiences and perspectives essential to understanding the communities needs.
- An adaptation tool like this will streamline and ease the burden of program adaptation for youth with Autism and/or IDD.
- Accessibility improves the experiences of all learners, regardless of ability.

Implications

- Health promotion programs currently do not have readily available resources for adapting programs for youth with Autism and/or IDD.
- These guidelines contribute to a greater impact of normalizing differences in learning and reducing the stigma of needing accommodations.

References



Acknowledgement

This project was supported, in part, by the Health Resources and Services Administration (HRSA) under the Leadership Education in Neurodevelopmental Disabilities (LEND) Grant T73MC11044 and by the Administration on for Community Living under the University Center of Excellence in Developmental Disabilities (UCDEDD) Grant 90DDUC0014 of the U.S. Department of Health and Human Services (HHS). This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

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Health Promotion Program: An initiative aiming to improve health by changing behaviors and attitudes, empowering people to take charge of their own health.

1 Program Planning

- Goal: Ensure program facilitators are well-equipped to support youth with IDD/Autism.**
- Provide training on Autism, IDD, and neurodiversity addressing person first language, stigma, ableism, and the importance of strength-based approaches.
 - Train staff on using clear, simplified language and alternative communication.
 - Teach strategies for managing sensory and behavioral differences. Provide facilitators with community resources to share with families and participants.

2 Content Adaptation

- Goal: Create a flexible, accessible, and engaging program.**
- Conduct check ins with participants prior to program start to assess needs, establish rapport, and brainstorm accommodations.
 - Utilize universal design principles to make content accessible.
 - Incorporate structured routines, clear expectations, and various education formats.
 - Design sensory friendly sessions with movement breaks offered.

3 Program Implementation

- Goal: Deliver an engaging, embracing, and effective program.**
- Establish consistent staff and predictable routines to improve comfort of participants and family members.
 - Assess, acknowledge, and validate communication style and language preferences.
 - Use visuals, social stories, and interactive activities to enhance engagement.
 - Allow extra time and support for assessment tools.

4 Program Evaluation

- Goal: Measure effectiveness and refine the program for long-term success.**
- Use accessible evaluation tools (visual surveys, simple questions, caregiver support, etc.).
 - Use health outcomes validated for use with the IDD community.
 - Provide ongoing training for new staff and refreshers for existing facilitators.
 - Adapt materials and strategies based on emerging best practices and participant needs.

Tools & Resources for Implementing Guidelines

1 Program Planning

- The [National Education Association's Words Matter! Disability Etiquette Training](#) details how to be a disability ally through your words.
- The [Harvard Implicit Association Test](#) allows you to check your internal assumptions about people with and without disabilities.
- [NCHPAD's Health Promotion Programs: Access 101](#) video training teaches how to make your health promotion program accessible and welcoming to all.

2 Content Adaptation

- [WebAim's Contrast Checker](#) helps ensure materials are accessible and readable.
- The [CDC's Plain Language Resources](#) ensures content is easy to read and understand.
- Section 508.gov has [Universal Design Resources](#) that can be applied to any program to increase accessibility and usability.

3 Program Implementation

- Visual Schedules and Timers: Helps participants anticipate transitions and structure activities in a comfortable way.
- [Alternative Communication](#): Choice boards, chat functions, and universal signs allow non-speaking individuals to select activities and express preferences.
- [Social Stories & Role-Playing Guides](#): Helps prepare youth for new experiences and interactions.

4 Program Evaluation

- Utilize [Cognitive Interviewing](#) qualitative evaluation of measurement tools to understand literacy and usability of testing measures.
- Incorporate up to date reviews of outcome evaluation tools that have been validated for people with intellectual disability, such as [Kumar, et al \(2024\)](#).

Product Evaluation:

- Drafted product was sent to all participants for review and an opportunity for feedback.
- Product was also sent to 2 external reviewers, one cultural psychologist and one family member of someone with intellectual disability.