

“It’s really complicated”: Engaging key stakeholders to inform a novel parent-led sexual health education program for autistic youth

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Background: There is a paucity of research on sexual health education for autistic individuals, despite a clear need for such work. Youth with autism spectrum disorder (ASD) often experience challenges navigating puberty, sexuality, and relationship changes that take place during adolescence. This can result in less perceived and actual knowledge of sexual health topics (Hannah & Stagg, 2016) and an increased risk of problematic sexual behaviors in adulthood (Stokes et al., 2007). Parents may be a useful source of sexual health information for their children with ASD. However, few evidence-based programs exist to support parents in navigating this role. Thus, there is a need for the development of such programs, particularly those incorporating the lived experiences of key stakeholders.

Objectives: The present qualitative investigation aimed to determine the sexual health education needs of autistic youth and to inform a novel, parent-led sexual health education program using data gathered through focus groups with parents and self-advocates.

Methods: Autistic self-advocates ($N=4$; ages 28-57) and parents ($N=4$) of 11- to 18-year-old autistic youth were recruited through local advocacy groups to participate in two rounds of focus groups (total 4 groups). Licensed clinical psychologists facilitated all four groups via teleconferencing with co-facilitation from an autistic self-advocate for the self-advocate groups. Groups were audio recorded and transcribed verbatim. The first round of focus groups (120-minutes each) was held prior to the start of a pilot cohort of a novel, parent-led sexual health education program. Stakeholders were asked to share their subjective experiences with sexual health education and provide feedback on an overview of proposed program content. Preliminary findings were used to tailor program implementation. The second round of focus groups (90-minutes each) was held after completion of the eight-week program. Programmatic changes based on stakeholder feedback were discussed and member checking confirmed themes derived from initial focus groups. The research team conducted rapid qualitative analysis on all four group transcripts. Focus group summaries were consolidated into structured matrixes by participant type to identify common barriers, facilitators, and implementation recommendations.

Results: Synthesized data across both rounds of self-advocate and caregiver focus groups revealed four overarching themes regarding the sexual health education needs of youth with ASD: “Empower parents

as educators,” “Individualize supports and education,” “Prioritize safety,” and “Consider cultural and intersecting identities.” See Table 1 for subthemes and illustrative quotes.

Conclusions: General sexual health education is insufficient for youth with ASD, and resources specific to this population are needed. Parents are a primary mechanism for providing this education and would likely benefit from participating in a program that considers the unique needs of autistic youth, the importance of safety, and the influence of other aspects of identity. Future research on the implementation of such a program is needed.