Family Perspectives:
Listening and Learning From Two Moms

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EXECUTIVE SUMMARY

The experiences of two families with sexuality education and their children with autism spectrum disorder are explored through a group interview with two moms. Both moms share fears, challenges, and successes as their families navigate providing sexuality education. Participant responses to prompts offer guidance and support for families who face similar circumstances. Family perspectives also offer insight to professionals providing sexuality education to families of children with autism spectrum disorder.

INTRODUCTION

This study fills a need to explore experiences of families and parents in providing sexuality education to their children with autism spectrum disorders (ASD) in order to identify common themes that may provide insight into ways to overcome barriers to children with ASD receiving sexuality education. Limited research exists exploring sexuality education access and interventions from a family perspective. This study explores the experiences of families, parents and their children as they navigate sexuality education concepts and work with ASD professionals. The study offers family members an opportunity to discuss their fears associated with providing sexuality education and any changes in those fears following interventions. Families offer their perspectives on roles of ASD and school professionals. Finally, the study explores how the support of professionals effected the sexuality education provided to their children.

Many adolescents gain sexuality and relationship knowledge through informal social interactions with peers. However, many young people with autism spectrum disorder (ASD) rely on parents and caregivers to help them understand concepts of their maturing bodies, sexuality and relationships (Corona, Fox, Christodulu, & Worlock, 2016; Whitby & Travers, 2019). Since parents play an integral role in educating their children with ASD about sexuality education topics, it is important for them to know what to teach and how to teach it. Multiple studies tell us that most parents feel that sexuality education is important for their children with ASD, however, most do not provide it for them (Ballan, 2012; Barnard-Bark et al., 2014; Howard-Barr, Rienzo, Pigg & James, 2005; Holmes & Himle, 2014; Nichols & Blakeley-Smith, 2009).

The literature consistently notes barriers in the provision of sexuality education for children with ASD. Barriers shared by parents include parental fears, misunderstandings of what or how to teach sexuality education topics, and lack of appropriate educational resources to help guide family interventions (Ballan, 2012; Nichols & Blakely-Smith, 2016; Mackin, Loew, Gonzalez, Tykol, & Christensen, 2016). The previous studies utilized focus groups and/or a combination of focus groups with telephone interviews for data collection to elicit parental/family perspectives on barriers to sexuality education delivery, important content, and preferred intervention strategies.

METHODOLOGY

The purpose of the study is to explore family experiences in regards to sexuality education and their children with ASD. The study will explore perceptions and shared experiences by engaging with parents in an interview process to investigate the following research questions:

1. What are parent/family experiences in providing sexuality education to their children?
2. What strategies do parents/families find effective in addressing sexuality education for children with ASD?
3. What resources do parents/families find effective in addressing sexuality education for children with ASD?

The perspectives of the parents/families interviewed, based on their personal experiences with their children, may offer guidance and support for families who face barriers, including fear of providing sexuality education. Their insight into

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