



# Supporting Parents as Sexuality Educators for Individuals with Intellectual Disability: The Development of the Home B.A.S.E Curriculum

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Published online: 18 July 2019

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## Abstract

All individuals with intellectual and developmental disabilities (I/DD) have the right to develop and express sexuality in an emotionally satisfying and socially appropriate manner. Questions have arisen as to whether sexuality education for this population should be the responsibility of the school or the family. Parents of children with I/DD report they want to be the primary sexuality educators for their children, but often overlook the responsibility because they do not know what to talk about, when to talk about it, or how to modify content so their child will understand. Available resources for parents of individuals with I/DD tend to provide opportunities for independent learning; Few in-person trainings where these parents can learn how and what to talk about regarding sexuality with their children exist. This article describes how the Home Based Adolescent Sexuality Education for Intellectual Disabilities (Home B.A.S.E.) curriculum was created to educate parents on their role as the primary sexuality educators for their adolescents with ID. The vision of the Home B.A.S.E. educational workshop is to increase parents' comfort and confidence in discussing sexuality and healthy relationship topics with their adolescents with ID. This curriculum has unique features considered in its development including: (1) The belief that sexuality is a human right for individuals with ID; (2) The perspective of individuals with disabilities speaking about their sexual rights and relationships; (3) Activities based on adult, social, and transformational learning theories; and (4) A small interactive group format that meets over multiple sessions.

**Keywords** Sexuality education · Intellectual disability · Parents · Adolescents · Curriculum · United States

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## Introduction

All individuals with intellectual and developmental disabilities (I/DD) have the right to develop and express sexuality in an emotionally satisfying and socially appropriate manner [1]. The Arc of the United States and the American Association on Intellectual and Developmental Disabilities [2], advocacy organizations for individuals with I/DD and their families, adopted a joint position statement on sexuality in 2008 that states, “Every person has the right to exercise choices regarding sexual expression and social relationships. The presence of an intellectual or developmental disability, regardless of severity, does not, in itself, justify loss of rights related to sexuality” (p. 1). Questions have arisen as to whether sexuality education for adolescents with I/DD should be the responsibility of the school or the family. However, one large study in the United States found most students enrolled in special education services in public schools have not received sexuality education classes [3]. Furthermore, many teachers do not view educating students with disabilities about sexuality as part of their professional responsibility or that the students would necessarily benefit from the sexuality education if provided [3, 4]. Because of these findings, there are opportunities for parents to play a vital role in educating their children with intellectual disabilities (ID) on sexuality topics, especially since it is believed parents should be providing the earliest and most thorough information about sexuality [5]. This article describes how the Home Based Adolescent Sexuality Education for Intellectual Disabilities (Home B.A.S.E.) curriculum was created to educate parents on their role as the primary sexuality educators for their adolescents with ID.

## Background

Parents of children with disabilities have expressed awareness that their children are not getting the sexuality education they need in school [6]. Couwenhoven [7] notes that parents often choose not to have their children in inclusive sexual education classes because they feel that their children will not understand the information or feel it is more than they need to know about the subject. Often when students with I/DD receive formal sexuality education in the school setting, it is in an inclusive health education class, where the pace of instruction and emphasis on a lecture-style format are not effective tools to meet their needs. In their review of the relevant literature, Rowe and Wright [8] noted, that from an ecological systems framework, it is essential to include the family network in providing sexuality education, as adolescents with ID place more emphasis on this system and relying on school-based sexuality education alone would be insufficient.

Research with parents of children without disabilities has identified the benefits of parents being the primary sexuality educators for their children. Children without disabilities prefer their parents as sources of information regarding sexuality education [9–11]. When parents serve as the primary sexuality educators for their children, they help to facilitate healthy sexual development, which is a central aspect of personality development, self-esteem, and social skills [9]. Adolescents who have repeated communication about sex, sexuality, and development with their parents are more likely to talk with their parents in the future about sexual issues [12, 13]. According to Jaccard, Dodge, and Dittus [14], parent-based approaches to adolescent sexuality education have many advantages. Parents can individualize what they teach based on their family life. They can control the timing and content as well as present topics based on their values, culture, and beliefs. Also, they can take into consideration the individual personalities and learning styles of their children. Parents can teach topics, not based on age norms, but what is appropriate for their children

at any given time, using a variety of learning strategies to help their child understand the various topics [5, 14].

Parents of children with I/DD tend to be uncertain about the appropriate management of their children's sexual development [15]. The problem most frequently mentioned by parents is an inability to answer questions [16]. Parents are also uncertain of what children know or should know [5, 15–19]. They often equate learning with intentions to perform sexual activities. Professionals have found parents have confused, anxious, and ambivalent attitudes toward the sexuality of their children and they claim both limited knowledge of sexuality and feelings of inadequacy in providing information [15–20]. Parents' involvement in sexuality education can also help address their concerns about the risk of sexual abuse, as they become more informed about ways to support their child's social interactions and development. [5, 20].

Research has shown parents of children with disabilities want to be involved in the sexuality education of their adolescent children, but often do not know where to turn for information and resources [6]. Recent studies from Turkey and the U.S. revealed that when parents received guidance on specific topics (i.e., hygiene, sexual behavior control, protection from sexual abuse, and communication skills) regarding sexual health of their adolescents with ID or Autism Spectrum Disorder (ASD), their comfort level and confidence did increase [18, 21]. Another study from Canada regarding parental concerns and sexuality education determined that parents benefit not only from acquiring the knowledge, but also from having a safe space to share their fears and dreams [10]. This study also suggests that parents need to be able to listen to their child before they can become good sexuality educators [10].

While there are currently numerous formal education programs available to address dating and relationship skills for people with I/DD, curricula geared toward educating parents/caregivers on this topic for their children are noticeably lacking. The resources and informal trainings available for parents are primarily designed to engage them in independent learning [22–25]. Terri Couwenhoven wrote a book, *Teaching Children with Down Syndrome about their Bodies, Boundaries and Sexuality* [7]. This book is not an actual curriculum but a resource guide for parents of children with I/DD in general and not just Down syndrome (DS). Couwenhoven also offers parent workshops across the United States based on the material written in her book. The common theme missing from these resources is an evidence-based training component where parents can learn in-person how and what to talk about regarding sexuality with their teens and have opportunities to practice and learn from other parents. The implementation of such a program could provide the knowledge parents need to begin to feel comfortable with this subject matter and empower them to educate themselves, their children, and their community.

Recently, several studies have piloted a workshop series to educate parents of adolescents with ASD on how to address the topic of sexuality with their children. Nichols and Blakeley-Smith [18] conducted focus groups to assess parent needs, followed by an eight-week sexuality education curriculum influenced by their findings. Parents' comfort with the topic of sexuality increased significantly over the course of the workshop series. In addition, the parents reported they most enjoyed hearing from other parents' experiences and participating in group problem solving with one another [18]. Corona et al. [6] conducted a six-session program held simultaneously for parents and adolescents with ASD to provide education on sexuality and relationships. Results indicate that the parents reported significantly less total concern and discussed significantly more topics with their adolescents following the program [6]. Promising research such as this merits expansion beyond the population of parents of adolescents with ASD to the broader population of adolescents with ID.

## Curriculum Development

The Home B.A.S.E. curriculum was developed by an occupational therapist and a clinical social worker to provide sexuality training for parents of adolescents (ages 12–19) with ID. The Home B.A.S.E. curriculum is a standardized, scripted, program manual.

The vision of the Home B.A.S.E. educational workshop is to increase parents' comfort and confidence in discussing sexuality and healthy relationship topics with their adolescents with ID. Overall, the curriculum and subsequent workshop were designed to help parents improve their relationship with their children and encourage development of a positive sexual identity. Two important value-based beliefs shared by the co-creators were integrated throughout the curriculum content: (1) The position that sexuality is a human right and (2) The importance of including the essential voice of self-advocates to the discussion of their sexuality. These value-based beliefs are cornerstone principles included in all aspects of the curriculum.

In designing a curriculum to educate and evaluate the role of parents as primary sexuality educators for their children with ID, the authors turned to three learning theories to guide the development and structure of the curriculum: adult learning theory, social learning theory and transformational learning theory. Malcolm Knowles, considered the father of adult learning, identified that adults learn differently than children and therefore should be educated differently [26, 27]. The timing of the learning experience needs to apply to the adult's current developmental stage and they need to be able to apply the new knowledge to a current life event [26, 27]. To do this, social learning and transformational learning theories were considered. The social learning theory, proposed by Albert Bandura, explains that learning occurs from observing other people in a social setting and thereby acquire knowledge, social rules, beliefs, and attitudes [28]. The transformational learning theory is similar to social learning in that transformative learning is influenced by the cultural context, however, it does imply a change in behavior therefore separating itself from social learning [29–33].

In addition, the authors reviewed literature on current sexuality education curricula for adolescents, both with and without disabilities and referred to knowledge gained from previous work in the field of sexuality and disability. Key learning included:

1. An understanding that parents want to be involved in the sexuality education of their children with ID [9, 12].
2. A small group format facilitated a secure environment that supported participation and learning [10, 18].
3. Using multiple sessions and a variety of learning activities increased participants' confidence to apply the new knowledge [12, 18, 34].
4. Increased communication between parents and their adolescent children with ID about sexuality improves the parent–child relationship [9, 12, 13, 34].

## Curriculum Format and Description

Home B.A.S.E. was developed to be used as an educational workshop, comprised of three sessions over the course of 1 month. The sessions are held for two consecutive weeks, followed by 1 week off, before the final session in order to allow parents time to work on their take home assignments. Each session is 3 h in length. The educational workshop is

facilitated by the authors of the Home B.A.S.E. curriculum with future plans to offer train-the-trainer sessions in order to disseminate the curriculum. Further program evaluation studies are currently being conducted to test the effectiveness of the Home B.A.S.E curriculum in improving parent self-efficacy as well as increase parent behaviors in discussing a variety of sexuality topics.

In order to satisfy the vision of the training and the curriculum, seven learning objectives were established. These objectives include: (1) Identify common sexuality myths of individuals with ID and parental fears that often impact formal education, and compare sexual rights of people with disabilities; (2) Understand what the evidence says about the topic of sexuality, dating, and relationships, and children with ID; (3) Analyze their role as a barrier or support to help their children learn about the topic of healthy sexuality, dating, and relationships; (4) Effectively action-plan how to implement their new knowledge and begin communicating and educating their children on the topic of sexuality, dating, and relationships; (5) Modify their current ideas on teaching about sexuality, dating, and relationships and utilize evidence and consumer-based strategies to communicate this topic with their children with ID; (6) Access resources to support and increase their learning on topics related to sexuality and healthy relationships for people with ID; and (7) Compare available resources to support and increase their learning on topics related to sexuality and healthy relationships for people with ID.

Each session of the workshop addresses many of the seven learning objectives and utilizes an assortment of activities, taking into consideration adult, social, and transformational learning theories. Key unique factors of the learning activities include watching a video of self-advocates sharing their thoughts on sexuality as a human right and having a couple with ID in a dating relationship and their parents share their experiences with the participants, allowing time to engage in back-and-forth dialogue. In addition, the small group discussion format where parents meet in person to learn and share their experiences over several sessions makes this an intimate and secure educational opportunity. Parents are instructed about different learning styles and complete an activity to determine how their child learns best. Case study and role play opportunities are provided to enhance parent learning. Parents have take-home activities at the end of sessions one and two. They also get to work through an action plan, so they have a process to use in the future when situations arise that need to be addressed. Although not a specific focus of content, resources to seek support for or address sexual violence against people with I/DD were provided to all participants. See Tables 1, 2 and 3 for detailed session descriptions.

## Evaluation

The authors are currently conducting a pilot study to test the effectiveness of the Home B.A.S.E. curriculum for parents of adolescents (ages 12–19) with DS. This specific sample has been selected based on the research and professional interest of one of the authors. Parents are being recruited through various DS parent organizations in metropolitan Chicago. In order to increase participation and representation in the sample, the educational workshop will be offered in four cohorts and in two separate locations over the course of 9 months. Quantitative and qualitative data will be collected before, throughout, and after the educational workshop.

**Table 1** Session one description

Objectives	Learning activities
Parents will:	
Identify common sexuality myths of individuals with ID and parental fears that often impact formal education and compare sexual rights of people with disabilities	True/false survey regarding parents' individual perspectives on myths/facts on sexuality and ID
Understand what the evidence says about the topic of sexuality, dating, and relationships, and children with ID	Define sexuality
Analyze their role as a barrier or support to help their children learn about the topic of healthy sexuality, dating, and relationships	Identify current issues/concerns
Effectively action-plan how to implement their new knowledge and begin communicating and education their children on the topic of sexuality, dating, and relationships	Introduce content on myths, barriers, and sexual rights
	Introduce playful versus reactive approaches and group activity on case studies
	Introduce learning styles and complete group activity on learning strategies
	Take home activity: begin action plan

**Table 2** Session two description

Objectives	Learning activities
Parents will:	
Understand what the evidence says about the topic of sexuality, dating, and relationships, and children with ID	Reflect on homework assignment from first session
Analyze their role as a barrier or support to help their children learn about the topic of healthy sexuality, dating, and relationships	Show a sexual rights video. Reflect on video
Modify their current ideas on teaching about sexuality, dating, and relationships and utilize evidence and consumer-based strategies to communicate this topic with their children with ID	Discuss benefits of sexuality education
Access resources to support and increase their learning on topics related to sexuality and healthy relationships for people with ID	Group activity on sexuality topics
Compare available resources to support and increase their learning on topics related to sexuality and healthy relationships for people with ID	Provide strategies framework
Effectively action-plan how to implement their new knowledge and begin communicating and education their children on the topic of sexuality, dating, and relationships	Role play activity
	Provide resources for parents to use
	Introduce problem solving process. Group activity to apply the problem solving process to a case study
	Take home activity: add to action plan

**Table 3** Session three description

Objectives	Learning activities
Parents will:	
Access resources to support and increase their learning on topics related to sexuality and healthy relationships for people with ID	Listen to a panel of self-advocates in a relationship and their parents. Parents will have the opportunity to ask questions
Modify their current ideas on teaching about sexuality, dating, and relationships and utilize evidence and consumer-based strategies to communicate this topic with their children with ID	Reflect on the panel session
Effectively action-plan how to implement their new knowledge and begin communicating and education their children on the topic of sexuality, dating, and relationships	Complete action plan and share with the group
	Complete course evaluation

## Conclusion and Future Directions

Individuals with ID have the right to receive sexuality education. The idea has been documented that parents play a significant role in providing sexuality education but are often hesitant because they do not know what to talk about, how to talk about it, or how to modify it so their child understands. Parents have reported that the educational system does not adequately address sexuality education for their children with ID. To fulfill this critical need, the authors developed the Home B.A.S.E. Curriculum to support parents of adolescents with ID become primary sexuality educators. This adds to the current literature in the United States as there are few evidence-based sexual education curricula for parents of adolescents with ID, especially with the format and structure of Home B.A.S.E.

This curriculum has unique features considered in its development including: (1) The belief that sexuality is a human right for individuals with ID; (2) The perspective of individuals with disabilities speaking about their sexual rights and relationships; (3) Activities based on adult, social, and transformational learning theories; and (4) A small interactive group format that meets over multiple sessions. Future research will include assessing the effectiveness of the Home B.A.S.E. curriculum.

## Compliance with Ethical Standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Ethical Approval** This article does not contain any studies with human participants or animals performed by any of the authors.

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