Book Review

Title: The Facts of Life. And More: Sexuality and Intimacy for People with Intellectual Disabilities

Author: Leslie Walker-Hirsch


Cost: $29.95 USD  Available from http://www.brookespublishing.com or www.amazon.com

Reviewer: Rhonda S. Black

Leslie Walker-Hirsch is a pioneer in the field of sexuality for individuals with intellectual disabilities. She is the creator of the widely-used Circles® healthy sexuality curriculum for individuals with mild to moderate developmental disabilities (1993, Circles I: Intimacy and Relationships [revised]; 1986, Circles II: Stop Abuse; 1988, Circles III: Safer Ways; James Stanfield Publishing, http://www.stanfield.com) that utilizes a Circle of Friends approach to describe appropriate and inappropriate contact with different people at different levels of friendship/intimacy. Walker-Hirsch has been actively involved in providing sexuality training classes for young adults and adults with disabilities, parents, administrators and direct service providers for more than 25 years. With 15 contributors, Walker-Hirsch has presented a wide range of topics from various perspectives, creating one of the most comprehensive works on sexuality and individuals with intellectual disabilities to date.

The first chapter discusses sexuality education and intellectual disability across the lifespan. It describes sexuality as part of social development and outlines changes in appropriate socialization that occur when transitioning from childhood to adolescence to adulthood. Especially important is the discussion about behaviors such as tickling, appropriate for children, but not young adults – dispelling the myth that those with intellectual disabilities are eternal children. This chapter also highlights the need for sexuality education to decrease social isolation and dependence. Again, the focus is on appropriate social relationships, including intimate adult relationships. Accompanying each topic are case study-like scenarios that bring the issue to life. For example, one case tells of how a young man with Down syndrome touched the breasts of a girl because he was dared to by some popular boys at school. Another case describes how a 12 year-old girl with mild intellectual disability gave her mother a passionate French kiss one evening after her friend had told her that a peck on the cheek was not “real” kissing. The scenario also described how her mother explained different kinds of kisses for different people and purposes. Nine of these scenarios are presented in the first chapter alone.
The second chapter presents key components of a comprehensive sexuality education program based largely on Walker-Hirsh’s Circles® curriculum. In addition to basic anatomy and hygiene, this curriculum focuses on empowerment, social and relationships skills, and rights and opportunities. The third chapter covers stages of development and basic instructional techniques addressing attention, memory, incidental learning, and learning transfer. This chapter concludes with a section on positive behavioral supports.

The next four chapters are in my opinion, unique, and set this book apart from similar texts on the market today. These chapters discuss parent perspectives; skills needed by direct support workers; addressing cultural differences between staff/teachers and program participants; supporting gay, lesbian, and bisexual relationships; and includes a wonderful chapter titled “In Their Own Words: Couples Tell Their Stories.” The Parent Perspectives chapter, coauthored by Emily Kingsley, a nationally-known pioneer in parent advocacy, discusses awkward situations for parents, such as providing transportation for dates and arranging social encounters, and issues surrounding whether their adult offspring will become parents themselves. The Cultural Diversity chapter discusses how various aspects of culture affect sexuality of persons with disabilities. Courtship and marriage practices, expectations of acceptable behavior for men and women, communication styles, and expectations concerning adults roles are topics included in this chapter. I especially liked the section about avoiding cultural stereotypes. While understanding individuals and their families may have different values from one’s own, this chapter emphasizes the nonproductive and nonresponsive nature of making assumptions such as “the Chinese believe XYZ about sexuality.” The final chapter in this section is titled “Supporting Diversity in Sexual Relationships: On Being Gay, Lesbian, Bisexual, or Transgender with an Intellectual Disability.” This is the first text I have seen to explicitly and purposefully include information on this topic. Diversity in relationships is an especially sensitive topic for residential care providers and one that needs to be openly discussed. This chapter provides some valuable suggestions and resources for service providers to address sexual orientation and gender identity variations as “part of the human experience that deserve to be celebrated” (p. 169).

The next section contains two chapters related to risk management. This text fills a gap in the literature regarding this topic. Scholars such as Richard Sobsey (1991, Disability, sexuality, and abuse: An annotated bibliography; 1994, Violence and abuse in the lives of people with disabilities: The end of silent acceptance?) have warned us about the vulnerabilities of adults with disabilities with respect to sexual exploitation. In a more personal storytelling manner, Dave Hingsberger (1990, I to I: Self concept and people with developmental disabilities; 1995, Just say know!: Understanding and reducing the risk of sexual victimization) has taught about the social nature of sexuality and the risks of over-protection to people with intellectual disabilities. This text combines warnings with easy-to-read scenarios to inform the reader about the risks of both exploitation and over-protection. Topics, such as consent assessment and the components of a comprehensive sexual abuse prevention program, are extremely good resources for any service professional. Much of the information again comes from Walker-Hirsch’s Circles Curriculum® related to building a community of support and
teaching the differences between friends, acquaintances, and strangers. The final section focuses on treatment issues such as seeing an obstetrician/gynecologist for a pelvic exam, helping individuals recover from sexual abuse and sexuality, and mental health.

Overall, the text is well-written by noted authors in an accessible format complete with research findings, practical applications and case-study scenarios. The text covers a broad range of topics thus, filling gaps of previous books in this area. I would highly recommend this book for professionals working with young adults and adults with intellectual disabilities. On a more personal note, I have ordered a copy for myself as a must-have for my library.

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The book gives an excellent explanation of what sexuality education is and how it is so crucial to be teaching our children about it so that they live a high quality of life and equipped to be at a reduced risk for sexual abuse & exploitation. The anecdotal stories are well done and help see the reality of the topic. But when it comes to sex, sexuality and relationships, challenges remain. Many people—including parents and caregivers—still hold stereotypes about the sexuality of this population. "There is still the perception that people with intellectual disabilities are asexual, that they are eternal children, that they aren't interested in sex," says Shelley Watson, PhD, professor of psychology at Laurentian University in Ontario, Canada. People with I/DD may also be seen as incapable of sex or unable to be effective parents, adds Kara Ayers, PhD, of the University of Cincinnati Universit