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Meeting the Reproductive Needs of Female Adolescents With Neurodevelopmental Disabilities

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ABSTRACT

The complexity of caring for female adolescents with neurodisabilities often overshadows normal biological changes. These young women may require additional or individualized support as they adapt to normal puberty and sexual maturation. Many choices are available to assist in managing menstrual problems, hygiene issues, and contraception. Special considerations regarding contraceptive methods, sexual education, and improving service accessibility are explored for clinicians.

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Adolescence is a critical period of development during which choices made can have long-term implications for the health and well-being of the individual and for society as a whole. As adolescents begin to take on the more mature roles of adults, a key factor in the development of a healthy life perspective that will prepare them for healthy adulthood is the ability to interact with the people and places in their communities (Tylee, Haller, Graham, Churchill, & Sanci, 2007). Emerging from adolescence to young adulthood can be stressful. As adolescents move to greater independence, they may be presented with new threats in the form of alcohol, drugs, violence, and sexual maturation. This transition into the adult role is compounded in adolescents with disabilities.

Worldwide, it is estimated that 220 million adolescents have disabilities, and approximately 80% of youth with disabilities live in developed countries (United Nations [UN], 2014). In the United States, the National Center for Education Statistics (NCES; 2014) reported that in the 2011 to 2012 school year, 6.4 million or 13% of all students in the public school system age 3 to 21 received special education services, and of these students, 36% had specific learning disorders. No single term for *disability* exists; instead, definitions are contextual and can mean a physiologic condition that requires a medical intervention or an impairment or limitation that requires a social intervention, such as income support (Brault, 2012). *Intellectual disability* is a term used when a person's ability to learn at an expected level and capacity to function in daily life are limited (Centers for Disease Control and Prevention [CDC], 2014). Both of these definitions encompass neurodisabilities, which are most often described as delay and/or inability to sit, walk, crawl, speak clearly, form conversation, remember, follow social rules, and understand consequences of actions and solve problems (CDC, 2014).

In this article, we focus on optimal reproductive health interventions and education opportunities for office and clinic nurses, nurse practitioners, midwives, and other health care providers who care for female adolescents with disabilities defined as mild to moderate neurodevelopmental disabilities, movement limitations associated with neurodevelopmental disabilities, and/or seizure disorders.

Often female adolescents with disabilities are assumed to be asexual, and this conjecture can be an obstacle in providing education and support.

Puberty and Emerging Sexuality

The early, middle, and late stages of adolescence are critical periods of development characterized by the complex phenomenon of puberty and emerging sexuality. Typically for women in the United States, the onset of puberty begins between ages 8.5 and 13 years and continues to evolve for approximately 4.5 years beginning with early breast development (thelarche), growth of pubic and axillary hair (pubarche), followed by first menses (menarche) (Greydanus & Omar, 2008). Although few researchers have focused on age of menarche among adolescents who are developmentally disabled, it appears no significant differences occur in timing of puberty and emerging sexuality compared with adolescents of normal intellectual functioning (Burke, Kalpakjan, & Smith, 2010). However, for reasons not fully understood, some adolescent females with neurodevelopmental disabilities have an increased incidence of early pubertal changes or of precocious puberty (Murphy & Elias, 2006) that can present additional challenges during the maturation process. For this reason, providing age appropriate reproductive health education should be introduced when the adolescent is cognitively capable. Hopefully, early education will alleviate any fear or anxiety the adolescent might experience with the onset of puberty.

Movement from the nurtured role of a child into a more mature adult role is a stressful transition that is compounded by the shroud of secrecy and shame that surrounds human sexuality, particularly in the United States. Developing into a sexual being can be challenging to adolescents with disabilities and to their parents or caregivers. Sexual development is a complex and multidimensional process during which emotions are tightly woven within biologic and physical changes, gendered role expectations, and individual attitudes, beliefs, and values (Greydanus & Omar, 2008). Adolescents with disabilities may not know how to respond to these unfamiliar changes, and for some, this period may be a time of increased vulnerability when even inadvertent activity and experimentation may be met with catastrophic results such as rape or unintended pregnancy. Often, caregivers assume that female adolescents with disabilities are asexual, and this conjecture can be an obstacle for parents/caregivers and health care providers in providing education and support during this tumultuous developmental period.

Intellectual and Adaptive Disabilities

Intellectual disability, also referred to as *cognitive disability* or *mental retardation*, refers to limitations in mental capacity and adaptive behaviors seen at an early age that compromise intellectual functioning and the development of the social, conceptual, and practical skills needed for everyday functioning (Siddiqi, Dyke, Donohoue, & McBrien, 1999). Various disorders, such as Down syndrome, cerebral palsy, and autism are associated with intellectual disabilities and may range from mild intellectual disability (intelligence quotient between 50 and 75) to moderate-profound intellectual disabilities (intelligence quotient between 25 and 50) that require significant support and care from families or providers within institutions (American Association on Intellectual and Developmental Disabilities [AAIDD], 2014).

Of the estimated six million children in the United States age 6 to 21 years who are classified as intellectually disabled, approximately 80% fall into the mild disability category (AAIDD, 2014). As they mature, many of these individuals express interest in marriage and sexual intimacy. As they progress through the same stages of psychological development as their peers with normal intelligence quotients, adolescents with mild disabilities have the added burden of developing healthy self-identities as functional sexual beings within the contexts of their disabilities (Greydanus & Omar, 2008). Common misconceptions (sexual misconceptions that arise from the medical model that focuses on impairment and misconceptions stemming from the social model that emphasizes cultural and sexual norms) make the psychosocial adaptation to the adult role all the more difficult (Greydanus & Omar, 2008; Murphy & Elias, 2006). These misconceptions permeate the media and literature and promote biases that may hinder communication between health care providers and parents/caregivers (Parchomiuk, 2013; Rembis, 2010).

Movement Limitations and Immobility

Providing reproductive health care to adolescents with spinal cord injuries (SCIs) requires special