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Commentary

The sexuality of young women with intellectual and developmental disabilities: A neglected focus in the American foster care system

Michelle S. Ballan, PhD [a], Molly Burke Freyer, MSW [b, *]

[a] Stony Brook School of Social Welfare, Stony Brook School of Medicine, USA
[b] New York University Silver School of Social Work, 1 Washington Square North, New York, NY 10003, USA

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ABSTRACT

Youths with intellectual and developmental disabilities (ID/DD) are overrepresented in the American foster care system and experience heightened rates of pregnancy compared to their nondisabled peers. Yet limited information is known about sexually active or pregnant young women with ID/DD in foster care. Consequently, important healthcare needs of this population are not adequately addressed. This article explores sexuality education and sexual healthcare for female adolescents in foster care with ID/DD and recommends practice guidelines to support and prepare their emergent sexual development.

Youths with intellectual and developmental disabilities (ID/DD) are overrepresented in the American foster care system.[1–3] Foster youth with ID/DD face the difficult task of navigating the transition into adulthood without the support of an involved biological parent or guardian. The absence or disruption of consistent support and guidance leaves this population at a particular disadvantage in addressing sexual identity development, a major aspect of young adulthood. This natural process is complicated when physical maturation occurs at a greater rate than the growth of emotional or cognitive skills, as is often the case among youth with ID/DD.

For this population, the turbulent physical and emotional changes that accompany adolescence can be especially confusing. Involvement with the foster care system and its associated hardships (e.g., disruption of routines, negative social labeling, lack of continuity across caregivers) can pose additional challenges for adolescents already struggling with disability-related prejudice.[4] However, very little is known about sexually active or pregnant youth with ID/DD in the foster care system and few services have been created expressly for them. Based on a review of the literature, this article provides both a preliminary overview of the sexuality-related healthcare and educational needs of this unique population and recommendations for professionals to support their emergent sexual development.

Background

Youth with ID/DD in the American foster care system

Research indicates that youth with disabilities are overrepresented and spend longer periods of time in foster care than nondisabled youth. The Adoption, and Foster Care Analysis and Reporting System (AFCARS) collects state-by-state information on youth who are under the responsibility of the child welfare system.[5] AFCARS data indicate 31.8% of youth in the foster care population have a disability[6]; of these, 3.2% have ID/DD.[5] Foster children with ID/DD spent, on average, 1631.6 days in care as compared to foster children without ID, who spent, on average 609.0 days in care.[6] However, AFCARS relies on a caseworker noting the presence of a child's disability in each state's respective case management data, and caseworkers may not have adequate training to identify a disability when present.[5] Absence of a universal definition of disability, failure to delineate specific disability types, and inadequate training of child welfare workers about identification of disabilities can result in undetected or unreported cases.[2,7] Regardless, the data indicate that for foster youth with disabilities, instability is a constant, impacting adolescent development.

Sexuality education and foster youth with ID/DD

Among the many developmental changes occurring on the path from adolescence to adulthood is an emerging sense of sexuality, facilitated by physical maturation and accompanying emotional

* Corresponding author.
E-mail addresses: Michelle.ballan@stonybrook.edu (M.S. Ballan), Mlb457@nyu.edu (M.B. Freyer).

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and social needs. Adolescents with ID/DD living in foster care are often isolated from traditional systems of support through which sexuality education and empowerment are generally transmitted (e.g., relationships with extended family). Foster parents may fill this gap, but in order to do so they must be prepared to address sexuality in an informed and comfortable manner. Unfortunately, foster parents are not always given sufficient guidance about how to meet the needs of foster children with ID/DD,[8] most notably in the area of sexuality. Since youth with ID/DD experience more placement disruptions than nondisabled youth while in foster care,[1] they may have several different social workers, and attend schools in various locations. Thus, it is crucial that sexuality education is provided within the settings that are a more stable aspect of these adolescents' lives, with parents, guardians, foster parents, and other caregivers who have daily contact with them. However, adults may ignore sexuality in youth with ID/DD because of their own discomfort discussing the issue or a misguided belief that these adolescents are eternally childlike, uninterested in sexuality and intimacy. Ultimately, the information is never communicated, leaving foster youth with ID/DD disadvantaged in terms of healthy sexual development.

Sexual and reproductive healthcare needs of foster youth with ID/DD

Research on youth living in foster care indicates higher rates of risky sexual behaviors, earlier age of onset of sexual activity, and higher rates of teenage pregnancy.[9] These risk factors are of particular concern for young women with ID/DD, who are less likely than their nondisabled peers to receive HIV/AIDS education, sexuality education in general, and preventive sexual health services.[10] Sexually active youth with ID/DD have a greater risk of contracting sexually transmitted infections (STIs) compared to those without disabilities,[11,12] and studies have found 40% of adolescent females with ID/DD had experienced a pregnancy, compared to 18% of adolescents of average mental ability.[11]

Given these statistics, consideration of the experiences of pregnancy among youth with ID/DD in foster care is prudent. Comprehensive physical and mental health care helps both to mitigate the risks associated with sexual activity and ensure the health of those adolescents with ID/DD who become pregnant. Research has shown that women with ID/DD experience significantly higher prevalence of adverse birth outcomes such as pre-eclampsia, low birth weight, and infant admission to the neonatal intensive care unit.[13] Mothers with ID/DD are also more likely to report mental health issues such as feeling depressed or anxious than mothers with other types of disabilities.[14] Prevention of STIs and pregnancy tend to be the sole focus of sexual health interventions for youth with ID/DD,[15] even though psychological and social well-being are equally important aspects of healthy sexual and reproductive development.[16]

Respect for bodily integrity

Preventive sexuality education and healthcare for young women with ID/DD should be addressed with sensitivity and deep respect for bodily integrity given the lack of choice and control associated with traditional approaches to sexuality for this population. Public responses to sexuality, pregnancy, and parenting among women with ID/DD have a dubious history, most notably in the form of involuntary sterilization and enforced contraception.[17] Although involuntary sterilization is no longer an accepted practice, many women with ID/DD find that others continue to make decisions regarding contraceptive use on their behalf.[18]

When young women with disabilities begin to mature sexually, parents often concern themselves with the onset of menstruation[19] or the possibility of sexual abuse,[20,21] and fail to promote healthy sexuality within the context of a consensual relationship. Some young women with ID/DD are prescribed birth control in order to treat physical or behavioral problems related to menstruation.[22] Others are prescribed birth control that does not require self-administration (e.g., Depo-Provera) at the first sign of sexual maturity,[23] with the justification that they will be protected from unintended pregnancy. This approach may prevent pregnancy, but it does not prevent the transmission of STIs nor does it help women to identify and report sexual abuse.

Effective contraception use requires an understanding about how barrier methods prevent pregnancy or infection and their impact on the body. For instance, anti-epileptic medication, which some young women with ID/DD take to prevent seizures, can interfere with the effectiveness of oral contraceptives. If medical professionals do not attend thoroughly to the complete medical histories and needs of young women with ID/DD when prescribing such medications, unintended pregnancy could occur as a consequence.[24] Also, knowledge about birth control may vary with age. Data from focus groups with adolescents and adults with ID/DD indicate those under the age of 18 had little knowledge of contraception.[25] While the capacity of young women with ID/DD to make decisions regarding contraceptive use will depend on the extent of their disability and attendant ability to understand what contraception entails,[22] youth should be included in the decision-making process.

Right to consensual sexual relations and choice of partner

Comprehensive sexuality education helps young women with ID/DD understand their right to consensual sexual relations. Females with ID/DD are at greater risk of abuse than those without disabilities,[26] a risk that is also heightened among teenage girls with ID/DD in foster care.[34] Women with ID/DD are subject to abuse within intimate relationships, with up to 60% experiencing interpersonal violence while in a romantic relationship.[27] Inadequate knowledge regarding sexual relationships and appropriate boundaries may result in an inability to distinguish between abusive and non-abusive relationships, heightening vulnerability to sexual abuse.[25] Furthermore, a lack of information on sexual matters deprives women with disabilities of the knowledge and vocabulary to identify and communicate when abuse has occurred.[28]

Since children with ID/DD are more likely to be removed from their home due to sexual abuse compared to nondisabled children in the foster care system,[4] it is prudent that sexuality education on consensual relationships is both a component of healthy maturation and identity development; and crucial in minimizing threats of sexual violence. The need for sexuality education as a protective factor is essential. For instance, young females with ID/DD are disproportionately targeted by sex traffickers, due to a lack of understanding of sexual or romantic relationships and sexually exploitative behaviors. This threat is of particular concern for girls with ID/DD in the foster care system, as running away from home or foster care is commonly connected to involvement in sex trafficking.[29]

Initiatives addressing the sexual health of foster youth

The development of pregnancy prevention programs for adolescents in foster care is in its nascent stages, as this population has only recently received attention as a special group at risk of teen pregnancy.[30] Initiatives addressing the sexual and reproductive health of this population are beginning to be explored throughout the U.S.[31] While there have been no empirical studies or reviews of