



## FACT SHEET | U of M LEND Program

# PROMOTION OF HEALTHY RELATIONSHIPS AND SEXUALITY FOR INDIVIDUALS WITH DISABILITIES

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### Background

Many individuals with disabilities face disparities in access to services, information, and education around sex and reproductive health. One reason behind this disparity is the prevailing belief that individuals with disabilities—especially those with intellectual or cognitive disabilities—are “childlike” or “asexual” and do not have sex or a sexuality and thus do not need reproductive health services, education, or information.<sup>3-6</sup> However, this notion is false as studies have found that individuals with disabilities are just as sexually active as their typical or able-bodied peers.<sup>4</sup> It also found that individuals with disabilities are also as frequently homosexual and bisexual as society as a whole, use alcohol and drugs, and are able to and do have children.<sup>4</sup> In addition, they are at increased risk for sexual and domestic abuse, unprotected sex, STIs, HIV, unintended pregnancy, and poor reproductive health outcomes.<sup>3-6,8</sup>

In US schools, individuals with developmental disabilities are often excluded from instruction about comprehensive sex education (including family planning,

contraception, healthy relationships, sexual abuse, and prevention of HIV and STIs), are denied access to reproductive healthcare and counseling, and have limited access to information about sexual health.<sup>5</sup> This stems from parental and administration concerns that if individuals with developmental disabilities are informed about their sexuality and sex, that they will be more likely to have sex and thus put themselves at risk for STIs, pregnancy, or abuse. However, paradoxically, rather than protecting these individuals from risky sexual behaviors, keeping them uninformed makes them more vulnerable to exploitation, abuse, unprotected sex, and poor reproductive health outcomes.<sup>5</sup>

### Facts

- Approximately 20% of Americans reported having a disability, with 12% of Americans reported having a severe disability.<sup>2</sup>
- Worldwide, over one billion people live with some form of disability, of which about 200 million have considerable difficulty functioning.<sup>1</sup>
- WHO estimates that 70-80% of all individuals with disabilities in the world live in developing countries.<sup>1</sup>

- In developing countries, 80% of individuals with disabilities live in rural areas, which further decreases their ability to access services, education, and support.<sup>4</sup>
- In a survey in the United States, women with cognitive disabilities were 49% less likely to report their health providers treated them with respect and 48% less likely to report their health providers spent sufficient time with them, compared to women without cognitive disabilities.<sup>3</sup>
- According to the UN, only 2% of individuals with disabilities are able to access basic services in their communities, including education, work, healthcare, and basic necessities.<sup>4</sup>
- In 2005, a nationally representative sample of US junior high and high school students found that, of sexually active students, those with intellectual disabilities were more likely to be exposed to or have STIs compared to their peers without intellectual disabilities with males at 8% and 3% respectively and females at 26% and 10% respectively.<sup>5</sup>
- In 2008, it was estimated that 2.5 million women with developmental disabilities (DD) in the US face significant barriers to reproductive care—in one study, women

with DD were 72% less likely than women without DD to have a Pap test within the past year—including inadequate informed consent practices, and the inability to take part in making decisions about their health.<sup>3</sup>

## Issues and barriers

- The perception that individuals with disabilities are asexual, “childlike,” and/or sexually inactive.<sup>3-7</sup>
- Discrimination, stigma, limited rights, and low social status for individuals with disabilities.<sup>3,4,6-9</sup>
- Providers find it difficult to communicate complex or painful medical options to patients with cognitive impairments.<sup>3,4,7-9</sup>
- Parents and providers lack appropriate resources to support the needs of individuals with disabilities.<sup>7-10</sup>
- Exclusion and marginalization of individuals with disabilities.<sup>4</sup>
- Family shame, overprotectiveness, and/or lack of knowledge about how to care for their family members with disabilities leading to dependence, disempowerment, and lack of autonomy.<sup>4,7,9</sup>
- Individuals with disabilities often experience decreased privacy and respect in regard to health visits, where their disabilities are the focus of the visit and the purpose of their visit is secondary, if it is even acknowledged.<sup>8</sup>
- Individuals with disabilities are often not supported—or vehemently discouraged—if they choose to have children.<sup>8</sup>
- Sterilization—often involuntary—is commonly used as a solution to deal with the reproductive health of individuals with intellectual disabilities.<sup>7</sup>
- No universal approach in caring for individuals with disabilities as the word “disability” encompasses a range of abilities and needs and there is no universally accepted specifications for who is included under the term disability and who is not.
- Lack of research focused on the sexual health and behavior of individuals with developmental disabilities.<sup>5,7,9</sup>
- The cycle of poverty and disability—which is that people are more likely to be disabled if they are impoverished and people who are disabled are more likely to be excluded from society and services

and thus become impoverished—makes it more difficult for individuals to receive care as both disability and poverty decrease access to care on their own and, together, exacerbate the problem.<sup>6</sup>

## Solutions

- Education and training of health professionals and service providers in the provision of reproductive and other health care for individuals with disabilities.<sup>3,4,7-10</sup>
- Inclusion of individuals with disabilities in education about sexuality and reproductive health so they are able to advocate for and care for themselves in regard to safe sex, healthy relationships, prevention of STIs, HIV, pregnancy, and sexual abuse. Increased understanding also can help people develop a sense of control over their health, relationships, and wellbeing.<sup>4,7,9,10</sup>
- Community education to encourage inclusion, and debunk myths and stigma around individuals with disabilities.<sup>4</sup>
- Education of family members, care providers, health providers, and others about appropriately educating, caring for, and empowering individuals with disabilities around the topics of sex, reproductive health, healthy relationships, and sexuality.<sup>3,4,7,9</sup>
- Creation of appropriate materials, tools, and supports to meet the individual needs of persons with disabilities.<sup>3,7,9</sup>

## Promising Steps

- In 2007, for the first time, the United Nations convened a convention on the rights of persons with disabilities.<sup>4,8</sup>
- In 2011, the Massachusetts Department of Public Health developed the Healthy Relationships, Sexuality and Disability Resource Guide to address sexuality education gaps for individuals with disabilities in the 2009-2016 Massachusetts Sexual Violence Prevention Plan.<sup>10</sup>
- In 2004, the US Department of Health and Human Services Office on Disability and Office on Women’s Health held a national summit that resulted in the recommendation to create and promote health provider trainings that specifically address the needs and care of women with developmental disabilities.<sup>3</sup>

- In 2006, researchers at the University of Kentucky created a “virtual patient” training module to educate medical professionals on how to effectively and appropriately provide reproductive health care for women with intellectual disabilities.<sup>3</sup>

## Resources

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