

Disability Policy Consortium

Call To Action: Urgent Need to Improve Access to Reproductive Health Education and Services for Women With Disabilities

“The day I found out I was pregnant I was shocked because I was under the influence all my life that medically I couldn’t have kids [because of my disability]. Doctors and my family didn’t explain that they didn’t want me to have kids because they didn’t know what it was going to be like 40 years down the road. Being a mother is the most awesome experience of my life. ”-Nicky Boyte, Austin, TX

“When's the last time you had a Pap smear? Did YOURS involve up to four extra staff picking your body up to transfer you onto the non-accessible exam table, undressed except for that little paper gown, and then stand there holding your legs open in the stirrups? It's incredible the dignity given up just to avoid dying of preventable disease.”- Olivia Richard, Boston, MA

Persistent Myths Versus Facts about the reproductive health needs of women with disabilities

Myth: people with disabilities have no sexual desires or needs:¹

Facts

- Results from a 2013 survey by the Massachusetts Department of Elementary and Secondary Education found that high school students with disabilities were more likely to have had four or more sexual partners and were also almost twice as likely to have been pregnant than their peers.²
- There is a lack of research on the needs of women with disabilities in terms of pre/postnatal care.³
- People with disabilities in general are less likely to receive sexual health education.^{4 5}

Myth: Women with disabilities don't need routine reproductive health screening.⁶

Facts

- Research shows that many pregnant women with physical disabilities in Massachusetts are not weighed since doctors do not always have the needed equipment to do so.⁷
- Between 2008 and 2011 86% of women in Massachusetts without disabilities had a Pap smear, compared with only 77% of women with a disability.⁸
- Nationally, the amount of women with any disability receiving a Pap smear decreased from approximately 74% in 1999 to approximately 59% in 2013.⁹
- In 2010, 81% of women with disabilities in Massachusetts versus 84% of women with no disabilities reported having a mammogram in the past two years.¹⁰
- Mammography rates for women with disabilities in the US between 1998-2010 rose from 70-74%, in contrast to an increase of around 73%-78% for those with no disabilities.¹¹
- Women with disabilities are more likely to die from breast cancer due to late diagnosis and treatment.¹²

The disparities in routine screening of women with disabilities can be attributed to a lack of gynecologist offices and medical equipment that are accessible to people with disabilities.¹³

Ask your doctor for more information about what your reproductive rights are. If you don't get the answers you want, contact the DPC at 617-542-3822.

Are you a woman with a disability? Know your rights!

The information below explains the rights you have in terms of reproductive health.⁵

- Section 504 of the 1973 Rehabilitation Act prohibits discrimination against people with disabilities by government agencies and federal funded organizations like adoption agencies and health providers.
- Title II of the Americans with Disabilities Act (ADA) prohibits discrimination based on disability in terms of people with disabilities' access to state or public programs. (For example: access to emergency services, and state offices and programs, such Public Health Department programs. It also requires public buildings constructed after 3/15/12 to be fully accessible.
- Title III of the ADA requires states to take measures to ensure that services and goods provided to the public are not denied to people with disabilities solely because they have a disability.
- The UN's Convention on the Rights of Persons with Disabilities (CRPD) protects the rights of people with disabilities. For example, it prohibits the denial of reproductive healthcare services to people with disabilities. Although the US has signed on to the CRPD in 2009, Congress has not yet ratified it.¹⁴

Find Out More!

Resources with sexual/reproductive health information for women with disabilities, include:

- **The Empowered FeFes:** a group of young women with disabilities based in Chicago created a guide about reproductive health for women with disabilities. It can be found here: <https://www.accessliving.org/index.php?tray=content&tid=top845&cid=180>.
- **The Massachusetts Department of Public Health and Department of Developmental Services'** guide with suggested resources for school districts could use to educate students with disabilities about sexual health. It can be found here: <http://www.mass.gov/eohhs/docs/dph/com-health/prevention/hrhs-sexuality-and-disability-resource-guide.pdf>.
- **Hesperian Health Guides Health Handbook for Women with Disabilities:** Chapters of the publication can be downloaded here: <http://hesperian.org/books-and-resources/>.
- **Womenshealth.gov:** has resources on reproductive health for women with specific disabilities: <http://www.womenshealth.gov/illnesses-disabilities/your-health/sexuality-reproductive-health.html>

What can advocates do to help women with disabilities get reproductive healthcare services they need?

To assist women with disabilities in getting more access to the reproductive health services they need, the Disability Policy Consortium (DPC) recommends that advocates:

- Conduct further research to develop best practices for reproductive care for women with disabilities.
- Work with staff at obstetricians' office to ensure their offices and medical equipment is accessible.
- Contact senators to urge them to ratify the Convention on the Rights of Persons with Disabilities.¹⁵
- Urge physicians to ensure the unique needs of women with disabilities, especially those with physical disabilities are addressed so that optimal health can be maintained in pregnancy.
- Provide more opportunities for women with disabilities to talk about reproductive health.
- Urge school districts to ensure they provide tailored sexual education to students with disabilities.
- Increase women with disabilities' knowledge of the importance of pap tests and other screenings.¹⁶

The DPC is a statewide cross-disability civil rights organization. Visit us online: www.dpcma.org.



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¹ Advocates for Youth (2008). Sexual health education for young people with disabilities: Research and resources for educators. <http://www.advocatesforyouth.org/publications/publications-a-z/2559>. Accessed 8/3/16.

² Health Survey Program, Office of Data Management and Outcomes Assessment Massachusetts Department of Public Health (2015). DATA BRIEF: Massachusetts adolescent health sexual health, experiences, and behaviors. <http://www.mass.gov/eohhs/docs/dph/behavioral-risk/mass-adole-health-sexual-health.pdf>. Accessed 8/3/16.

³ Iezzoni L.I, Yu J, Wint AJ, Smeltzer SC, & Ecker JL. Health risk factors and mental health among US Women with and without chronic physical disabilities by whether women are currently pregnant. *Maternal and Child Health Journal*. 2015;19(6): 1364-1375

⁴ Advocates for Youth (2008). Sexual health education for young people with disabilities: Research and resources for educators. <http://www.advocatesforyouth.org/publications/publications-a-z/2559>. Accessed 8/3/16.

⁵ National Council on Disability (2012). Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children. Accessed <https://www.ncd.gov/publications/2012/Sep272012.8/3/16>.

⁶ Todd A., Stuifbergen A. Breast cancer screening barriers and disability. *Rehabilitation Nursing*. 2012; 37(2): 74-79.

⁷ MASSLIVE (2016). Bill seeks to address health care disparities among people with disabilities in Bay State. http://www.masslive.com/politics/index.ssf/2016/03/bill_would_create_office_to_ad.html. Accessed 8/12/16.

⁸ Massachusetts Department of Public Health (2012) A profile of health among persons with disabilities in Massachusetts, 2008-2011. <http://www.mass.gov/eohhs/docs/dph/health-equity/a-profile-of-health-among-persons-with-disabilities-massachusetts-2008-2011.pdf>. Accessed 8/15/16.

⁹ Centers for Disease Control and Prevention (2015). Health United States 2015: With special feature on racial and ethnic health disparities. <http://www.cdc.gov/nchs/data/hus/hus15.pdf#071>. Accessed 8/29/16.

¹⁰ UMass Medical School and Massachusetts Department of Public Health (2013). Health needs assessment of people with disabilities Massachusetts: 2013. <http://www.mass.gov/eohhs/docs/dph/health-equity/needs-assessment-report-for-health-and-disability.pdf>. Accessed 8/29/16.

¹¹ Iezzoni L.I, Kurtz SG, & Rao SR. Trends in mammography over time for women with and without chronic disability. *Journal of Women's Health*. 2015;24(7): 593-601.

¹² McCarthy EP, Ngo LH, Roetzheim RG, Chirikos TN, Li D, Drews RE, & Iezzoni LI. Disparities in breast cancer treatment and survival for women with disabilities. *Annals of Internal Medicine*. 2006; 145(9): 637-645.

¹³ Lagu T, Hannon NS, Rothberg MB, et al. Access to subspecialty care for patients with mobility impairment: a survey. *Annals of Internal Medicine*. 2013; 158(6): 441-446.

¹⁴ United Nations (2016). Convention on the Rights of Persons with Disabilities. https://treaties.un.org/pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang_en. 8/24/16.

¹⁵ US International Council on Disability (2016). The Convention on the Rights of Persons with Disabilities. <http://usicd.org/index.cfm/crpd>. Accessed 8/23/16.

¹⁶ Swaine JG, Parish SL, Luken K, Son E, & Dickens P. Test of an intervention to improve knowledge of women with intellectual disabilities about cervical and breast cancer screening. *Journal of Intellectual Disability Research*. 2014;58(7): 651-663.

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