

Preconception Health Recommendations for Young Adults with Disabilities:

A Final Report from an Action
Learning Collaborative



Oregon
Health
Authority

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Executive Summary



Preconception Health Recommendations for Young Adults with Disabilities: A Final Report from an Action Learning Collaborative

During the last century, quality medical care, healthier environments, and increased access to early and adequate prenatal care have improved infant health and pregnancy outcomes. However, in the last few decades reductions in adverse birth outcomes have slowed significantly and in some cases deteriorated. Today, with the increase in chronic disease in women of reproductive age, to continue to reduce the number of adverse health outcomes in infants, public health efforts must address maternal health before pregnancy occurs, or preconception health. Many national public health agencies and professional organizations have come together to promote preconception health and develop national recommendations.ⁱ However, current preconception health recommendations have not addressed the unique needs of young adults with disabilities.

While young adults with disabilities are just as likely to be sexually active and less likely to use

condoms, this group is often treated as if they were not sexual beings or would not become pregnant. Approximately one in five women in the United States has a disability (an estimated 16.8 to 28.6 million)ⁱⁱ and an increasing number of women with disabilities are becoming pregnant and report facing negative attitudes toward their pregnancies and difficulty receiving comprehensive prenatal care.ⁱⁱⁱ The purpose of this report is to share the recommendations the Action Learning Collaborative (ALC) team developed in hopes of initiating a discussion, draw attention to the further work needed in this area, contribute to knowledge about young adults with disabilities and preconception health, and hopefully initiate action within public health, medical providers, schools, families, and youth to better address the health of youth with disabilities of reproductive age.


This report was prepared as part of an Association of Maternal and Child Health Programs, Action Learning

Collaborative (ALC) project on Preconception Health. In Oregon, an interdisciplinary team of professionals reviewed the Center for Disease Control and Prevention's Mortality and Morbidity Weekly Review (MMWR) Preconception Health Recommendations^{iv} and other published literature and identified that no specific recommendations concerning preconception health exist for young adults with disabilities. While the universal MMWR recommendations are relevant to this population, young adults with disabilities have other specific issues that deserve additional focus. Because the scope of preconception health interventions is so broad and numerous, the team decided to focus on recommendations around reproductive health and safety.

In order to educate the team and develop meaningful preconception health recommendations for young adults with disabilities, the ALC team agreed on a specific methodology. The methodology used to inform and develop the recommendations was:

1. Perform a literature review to understand current knowledge of preconception health and youth with disabilities.
2. Conduct a data analysis to examine relationships and risk factors for youth with disabilities related to preconception health using existing data sets available to the ALC team.
3. Conduct a survey of youth with disabilities to authentically engage young adults with disabilities, incorporate their feedback and help develop the recommendations.
4. Draw upon the diversity of knowledge, expertise, and life experiences of the ALC team to inform the recommendations.





The following is a brief summary of the final recommendations from the Action Learning Collaborative team. They are organized using the socio-ecological model so that all sectors and individuals see what role they can play in addressing the recommendations.

Individual-level:

- Support preconception health care for young adults with disabilities (YAWD) by encouraging access, information, health equality and physical safety.

Relationship-level:

- Family members, caseworkers, and teachers should work to support and encourage environments that allow for access of reproductive and preconception health information and services.

Community-level:

- Community-based programs, social services providers and health systems play an important role in creating a community that is supportive, ensuring that young adults with disabilities are included in program and services design and implementation and recognized for their strengths and contributions to the community.

Societal-level:

- Preconception health policies, marketing and health messages, data collection and research should reflect the inclusion and support of young adults with disabilities.

To read the full narrative of the recommendations, see page 9 of this report. See the Endnotes for a list of citations on page 26.



Organizational expertise was provided by:

Oregon Public Health Division Center for Prevention and Health Promotion (including Adolescent Health and Women's Health)

Oregon Health & Science University's Center for Excellence on Women's Health

National Association of County and City Health Officials Disability and Health Workgroup

Women with Disabilities Health Equity Coalition

National Youth Leadership Network

GimpGirl.com

Portland Community College

Portland State University (PSU) Regional Research Institute on Human Services

Oregon Center for Children and Youth with Special Health Care Need(OCCYSHN)

Oregon Department of Education (ODE)



Acknowledgements

This report was prepared by members of the Oregon Action Learning Collaborative:

Michelle Berlin, Oregon Health & Science University
Jennifer Cole, GimpGirl Community
Emilee Coulter-Thompson, Oregon Public Health Division
Lesa Dixon-Gray, Oregon Public Health Division
Lisa Isabelle, Oregon Health & Science University
Marneet Lewis, Portland Community College
Julie McFarlane, Oregon Public Health Division
Marjorie McGee, Portland State University
Stacey Milburn, National Youth Leadership Network
Robert Nystrom, Oregon Public Health Division

Special thanks also to Oregon Public Health Division staff who helped make this project possible:

Kristen Becker
Mellony Bernal
Sarah Ramowski

Finally, the knowledge gained through this Action Learning Collaborative would not have been possible without the participation of the many youth and young adults who have a disability, and were willing to share their experiences. Special appreciation goes to them for their courage in speaking out about their life experiences.

Final Report: Action Learning Collaborative

Introduction


When infants are born, poor health carries significant financial, social, emotional and medical burdens on individuals, families, medical providers and society. During the last century, quality medical care, healthier environments, and increased access to early and adequate prenatal care have improved infant health and pregnancy outcomes. However, in the last few decades reductions in adverse birth outcomes have slowed significantly and in some cases deteriorated.¹ Today, with the increase in chronic disease in women of reproductive age, to continue to reduce the number of adverse health outcomes in infants, public health efforts must address maternal health before pregnancy occurs, or preconception health. Many national public health agencies and professional organizations have come together to promote preconception health and develop national recommendations. However, current preconception health recommendations have not attempted to tailor recommendations to young adults with disabilities.² While young adults with disabilities are just as likely to be sexually active and less likely to use condoms, this group is often treated as if they were not sexual beings or would not become pregnant. Approximately one in five women in the United States has a disability (an estimated 16.8 to 28.6 million)³ and an increasing number of women with disabilities are becoming pregnant and report facing negative attitudes toward their pregnancies and difficulty receiving comprehensive prenatal care.⁴ The purpose of this report is to discuss and present the Preconception Health Recommendations for Young Adults with Disabilities.

Framing the problem

It is important to recognize that in many ways young adults with disabilities are very similar to their peers who do not have a disability. Youth with disabilities are sexual beings who, like their peers, are very interested in pursuing romantic and sexual relationships, and may someday want to become parents. This is important to mention because in the course of developing the recommendations, the team received a lot of feedback

ALC Team Position Statement

- Age, gender and sexuality are best viewed and considered as an interactive continuum.
- Disability is a natural part of the human condition and will touch most of us at one time or another in our lives. ~ *ADA, March 1999*
- "We must understand that sexuality encompasses more than sexual behavior, that the many aspects of sexuality include not only the physical, but the mental and spiritual as well, and that sexuality is a core component of personality. Sexuality is a fundamental part of human life." ~ *Surgeon General, July 2001*
- Young adults with disabilities are sexual beings and have the right to comprehensive sexuality education.
- Since it is difficult to predict which women will give birth and when, we support promoting preconception health for all women and girls. This has value in itself as it promotes a healthier adult population regardless of reproductive decisions and outcomes.
- The ALC team supports the positive youth development framework and seeks to incorporate youth engagement.
- We need to challenge a culture that perpetuates violence through ableism, racism, sexism, heterosexism and classism. We want to create a world where all people feel safe and have access to celebrate their sexualities and bodies.



about assumptions from society, schools, providers and friends that this is not or should not be the case. Assumptions and judgments that youth with disabilities could not, or should not, be sexually active or become parents creates barriers to information and missed opportunities in medical care that will allow them to plan their pregnancies, have healthy, safe relationships and participate in preconception health behaviors. For example, while 19 percent of Oregon women who give birth have late initiation or no prenatal care⁵ youth with disabilities are at even higher risk of not receiving adequate preconception health support and services than their non-disabled peers.⁶

Young adults with disabilities

Young adults with disabilities (YAWD) may already face a variety of risk factors for having poor birth outcomes. Women in Oregon who have a disability are more likely to describe their health as fair or poor (38% vs. 6%), smoke (19% vs. 14%) and to be obese (36% vs. 19%); and less likely to receive information from health professionals about appropriate physical activity (81% vs. 88%),⁷ all of which are risk factors for poor birth outcomes.

Youth with disabilities may face unique challenges in early adulthood as they transition to independent lives away from their parents and caregivers. They may be more dependent on their parents because of their disabilities, yet more vulnerable as they strive to be independent of them. There is a higher percentage of youth with disabilities in foster care than in the general population. Approximately 40 percent of foster youth experience a disability. Young adults with disabilities in foster care often transition out of the system at age 18 and may be especially vulnerable during this time because many begin independent adult life with very little support. After leaving foster care, they experience higher risks of homelessness, unintended pregnancies and adverse health outcomes.⁸

In addition, many young people with disabilities lack basic education about sexual health.⁹ A survey of special education teachers found that while almost all teachers believed that sexuality education should be offered to all special education students in middle and high schools, the teachers reported a lack of professional preparation and that baseline sexuality courses were not being provided. Only 20 percent of teachers reported taking a sexuality course and more than 55 percent reported they did not teach any sexuality education to their students.¹⁰ In Oregon, professional development for health education teachers has been negatively affected by budget cuts to education. While 60 percent report wanting more professional development, in areas such as violence prevention and human sexuality, there has been a gradual decrease in the availability of such continuing education.¹¹ This has the potential to contribute to the already high rate of unintended pregnancies. While data on the rate of unintended pregnancy for young adults with disabilities were not available, more than 53 percent of births in Oregon to all women between the ages of 20–24 are unintended.¹²

Oregon sexuality education standards

Oregon has strong sexuality education laws and Oregon Health Education Content Standards (OHECS) (www.ode.state.or.us/search/page/?id=1745) that support comprehensive sexuality education (CSE). In addition, Oregon has comprehensive statewide plans that are outlined in the Oregon Youth Sexual Health Plan (OYSHP)¹³ to address teen pregnancy, and promote positive youth development. Oregon's plan was forward-looking to have acknowledged youth with disabilities within the primary objectives of reducing health inequities and promoting youth development. These recommendations are a first step to address the needs of youth with disabilities and their preconception health.

The OHECS and OYSHP support comprehensive sexuality education as a means to prevent unplanned pregnancies and sexually transmitted diseases (STDs), support healthy relationships and promote lifelong healthy sexuality. However, the unique challenges that youth with disabilities face, seemingly, have not been addressed to date in this sexuality education work, nor in national work on preconception health. This provides both challenges and opportunities for advocates, youth, providers, educators, parents and communities to plan an important role in the discussion.





Using knowledge and experience to inform the recommendations

.....
"Acknowledge that young people with disabilities need access to the same health information and services that other young people do, including sexual health."¹⁴
.....

The Socio-Ecological Model of Health (SeMH) was chosen as the model on which the preconception health recommendations for young adults with disabilities would be framed. Using SeMH as a framework, the Action Learning Collaborative (ALC) used the literature and data reviews, and the results of an online survey to develop and inform the recommendations. The following recommendations were categorized based on the SeMH to include recommendations at the individual level, interpersonal/relationship level, institutional, community, and societal (policy) levels.

Preconception health recommendations for young adults with disabilities

.....
"The problem is that most people, including mental health providers, see people with disabilities as a burden and they aren't really willing to help."
.....

Individual-level recommendations

Support preconception health care for young adults with disabilities (YAWD) by encouraging access, information, health equality and physical safety.

- Encourage young adults with disabilities to seek information, skills, tools, and promote access to appropriate services to ensure personal sexual health.
- Support YAWD in communicating and advocating for their needs for mental health, alcohol and other drug prevention and treatment, and tobacco cessation services as needed.
- Provide YAWD with accurate information about sexuality that focuses on healthy sexuality, mutuality and respect.
- Support YAWD in the development of individual reproductive life plans that include all preconception health issues focused on any special needs for YAWD, including a personal safety plan.
- Ensure YAWD have access to sexuality education, and anti-violence, harassment and bullying prevention education that meet Oregon's statutory requirements; and acknowledges, and is reflective of, disability status.

.....
“We are sometimes looked at as if we are half a person. As if your disabilities take away from the person. Also peers treat it as if it’s normal bullying. It’s way different for a person with a physical or mental handicap to defend themselves and it hurts deeper if you ask me. This is not something we can change. We can’t lose wait [sic] or be prettier. We can’t change what we have.”
.....

Relationship-level recommendations

Family members, caseworkers, and teachers should work to support and encourage environments that allow for access of reproductive and preconception health information and services.

- Caseworkers and teachers should understand that YAWD are active sexual beings and allow for easy access and referral for reproductive health services and family planning.
- Family members, caseworkers and teachers must advocate for youth with disabilities to have equal access to comprehensive sexuality and violence prevention education that includes an understanding of increased risks of violence for YAWD.
- YAWD should be encouraged to develop strong peer networks that establish healthy relationships and long-term friendships. Family members, caseworkers and teachers must advocate for safe physical and emotional environments in order to create those pro-social environments that allow for those relationships.
- Caseworkers and health professionals should ensure that YAWD receive needed interventions, focusing on high-priority risks, as a follow up to preconception health screenings.

.....
“Bullying is a huge issue for anyone different and it isn’t an issue that is confronted much from a disability angle.”
.....

Community-level recommendations

Community-based programs, social services providers and health systems play an important role in creating a community that is supportive, ensuring that young adults with disabilities are included in program and services design and implementation and recognized for their strengths and contributions to the community.

- Primary care medical homes, public health clinics, school-based health centers, and other health care providers that serve people with disabilities should ensure successful access to care and be models for inclusion in other services in their communities.
- Health care providers should be trained to provide the same reproductive health services to YAWD that they provide to other clients. They should be trained to conduct risk assessments utilizing the American Academy of Pediatrics Bright Future standards, and resources for providers in how to discuss sexual and reproductive life planning should be made available.
- Young adults with disabilities should receive additional health care interventions and support for issues as outlined in the MMWR recommendations for preconception health.
- Schools need to ensure access to the same comprehensive sexuality education that all students receive, and adopt and fully implement policies regarding violence, bullying and harassment, and be knowledgeable of the unique situations that affect YAWD.



- Promote community connectedness by ensuring youth with disabilities participate in community and after-school, extracurricular activities, including athletics.
- Youth-centered organizations and group homes for YAWD should encourage positive, non-coercive personal relationships, and ensure young adults with disabilities have access to information and services regarding sexual, reproductive, and preconception health.

.....
 “I think in general, society (including health care professionals and others responsible for sex education) doesn’t view people with disabilities as being capable of having romantic and/or sexual relationships.”

Societal recommendations

Preconception health policies, marketing and health messages, data collection and research should reflect the inclusion and support of young adults with disabilities.

- Researchers involved in survey design need to commit to including more disability questions on large population-based surveys.
- Disability should be considered as a demographic, rather than a medical condition. This would correspond with how many persons with disabilities view themselves, and allow for questions to be added to all standard population-based and school-based surveys regarding disability as a demographic description.
- Institutional Review Boards need to revisit criteria for considering “disability questions” as protected health information. While originally developed to protect people with disabilities, exclusion can serve as a barrier for

researchers to better identify the specific needs or impacts on this population.

- Institutions that develop policies and programs regarding preconception health and reproductive rights should ensure that YAWD are included and authentically engaged in the development of those national, statewide, and local policies and programs.
- Promote positive attitudes about disability in order to discourage victimization and sexual coercion.
- Engage media to depict role models and social norms that promote healthy sexual behaviors and ensure these role models and norms positively depict young adults with disabilities.
- Improve definitions of disability and sexual identity in data collection.



Development of the Preconception Health Recommendations

The development of the Preconception Health Recommendations for Youth with Disabilities was part of an Action Learning Collaborative (ALC) process. An ALC typically brings together a small group with diverse professional skills, expertise, perspectives and knowledge, as well as influence and passion to focus on a particular health or social issue. Their charge is to analyze a problem, propose solutions and develop an action plan to effectively address that issue. The ALC process combines formalized learning, professional expertise, and questioning the status quo to develop new strategies and solutions.

The Association of Maternal and Child Health Programs (AMCHP) occasionally sponsors ALC opportunities by supporting multi-disciplinary teams for an 18- to 24-month period during which the teams develop and implement action plans, share strategies and problem solve across communities around a particular issue. On this occasion, AMCHP's goal was to assist innovative teams from six states in incorporating the National Preconception Health Guidelines (MMWR 2006) into their current adolescent health programs, policies, practices, systems and culture and share lessons learned with the larger maternal and child health and education communities.

The Oregon team consisted of members from Oregon Public Health Division offices (Women's Health and Adolescent Health); Oregon Health & Science University, Office of Women's Health; Women with Disabilities Health Equity Coalition (WowDHEC); National Youth Leadership Network; GimpGirl Community; and youth with disabilities.

The team found it necessary to place parameters around the scope of the work to be conducted. Several issues arose regarding defining the target population and the level of work to be done. While it was important to include and consider adolescent health issues, as well as women's health, the final target for the recommendations were young adult males and females between the ages of 18 and 28. However, in focusing on this age group, it was also necessary to address adolescent health issues that lead up to other issues in young adulthood.

A decision also was made to focus narrowly on preconception health recommendations for young adults with disabilities (YAWD). Throughout the process, several issues continued to arise, primarily involving sexuality and personal safety. Because preconception health in general encompasses a wide range of issues, the decision was made to focus on the sexual health and need for violence prevention for young adults with disabilities.

Developing a theoretical construct

One of the first steps the team took was to educate each other on the different theoretical models commonly used when addressing this issue and develop a team position statement. Members with knowledge and expertise about disabilities initiated training and discussions on disability models in the context of disability justice and health equity, while staff from the Public Health Division provided a comprehensive overview of the Positive Youth Development paradigm and Preconception Health models. It was important for the interdisciplinary team to develop a consensus on approaching the issue. From this learning, a Team Position Statement was developed.

Methods

In order to educate the team and develop meaningful preconception health recommendations for young adults with disabilities, the ALC team agreed on a specific methodology. The methodology used to inform and develop the recommendations was:

1. Perform a literature review to understand current knowledge of preconception health and youth with disabilities.
2. Conduct a data analysis to examine relationships and risk factors for youth with disabilities related to preconception health using existing data sets available to the ALC team.



3. Conduct a survey of youth with disabilities to authentically engage young adults with disabilities, incorporate their feedback and help develop the recommendations.
4. Draw upon the diversity of knowledge, expertise, and life experiences of the ALC team to inform the recommendations.

The following is a discussion of each of the four components of the methodology.

Literature review

.....
 "I think a big problem is getting people to see us (people with disabilities) as sexual beings ... people who see me as someone with sexuality want to deny the fact that I am disabled, and people who see me as disabled want to deny that I can have a healthy, active sex life."

A review of the literature on preconception health for women and/or youth with disabilities informed the recommendations. A preliminary Ovid Medline search was conducted in March 2010, with key words including "risk factors," "sexual behavior," "smoking," "exposure to violence," "intimate partner violence," "pregnancy," and "unplanned pregnancy in adolescence." The search was restricted to adolescents and young adults aged 13 to 24, and limited to articles in English. Based on initial results, members of the team decided to focus more narrowly on sexual health and sexual abuse and violence. From the 14 articles reviewed by the ALC team, three themes emerged:

1. Young adults with disabilities are just as sexually active, and in some cases more sexually active than their non-disabled peers, and more likely to engage in high-risk activities. This puts them at increased proportional risk for sexually transmitted diseases and unplanned pregnancies.¹⁵

This dispels the myth that people with disabilities are not sexually active and may not become pregnant. Young women with disabilities are slightly more likely to have ever engaged in sexual activities. In Oregon, they are less likely to have used contraception.¹⁶ Little surveillance on the topic of pregnancy for women with disabilities has been conducted.¹⁷ In addition, evidence exists that young adults with disabilities are more likely to exhibit high-risk behaviors, including tobacco use, cannabis and other illegal drug use, and early sexual activity (before the age of 15).^{18, 19} This is particularly true for females.²⁰ Sexually transmitted infections also have been reported more often among young adults with disabilities (YAWD) than their non-disabled cohorts.²¹ These disproportionately higher rates of risk behaviors experienced by YAWD are seen in both Oregon and national data. This creates an imperative for addressing issues of sexuality and providing YAWD with more adequate and equitable preconception health care.

2. Violence in the form of bullying, sexual abuse and intimate partner abuse are large issues for both youth and young adults with disabilities. If safety is not addressed it may be difficult for youth with disabilities to adapt other healthy behaviors.

One of the most pronounced sexual health disparities for young adults with developmental disabilities is their heightened vulnerability to sexual assault and sexual abuse. According to a report by the Center for Policy and Partnerships Institute for Child Health Policy, youth with serious physical and/or developmental disabilities are four times more likely to be sexually abused or exploited than those without disabilities.²² One study found that 44 percent of all offenders against people with disabilities made initial contact with their victims through the network of medical, educational and residential services provided to people with disabilities.²³

While both men and women with disabilities experience more violence and peer victimization compared to their non-disabled peers, it is important to note that gender differences do exist

between young men and women with disabilities beyond the differences in depression and suicide attempts.²⁴ Young adult women with disabilities are far more concerned about safety and freedom from violence, abuse, bullying and harassment than are their male counterparts.

3. Stigmatization by caregivers, teachers, parents, medical providers and society impedes access to comprehensive sexual health education for youth and young adults with disabilities. It becomes important to advocate and promote the right to comprehensive reproductive, sexual, and preconception health education.

Historically people with disabilities have not been afforded the same sexual rights and freedoms as those in the general population, despite the same human need for love, affection, and fulfilling interpersonal relationships, as well as the desire to have children. Restrictions on sexual activity have been based on the false and often contradictory belief that persons with disabilities are asexual or sexually aggressive.²⁵

The tendency to downplay the sexuality of young adults with disabilities may increase the health risks of this population by limiting their access to health information, reproductive and preconception health care, and counseling. In public education settings, students with disabilities often are systematically excluded from instruction on topics such as contraception, family planning, pregnancy, and the prevention of sexually transmitted infections (STIs) and AIDS.²⁶ Current health promotion strategies do not provide young adults with disabilities with the resources to make informed decisions regarding their sexual health and safety.²⁷ Better instruction and systems to prevent sexual abuse, and promotion of family planning and STI prevention is necessary to the sexual and preconception health and social development of this population as they transition to adulthood.

Data sets and analysis

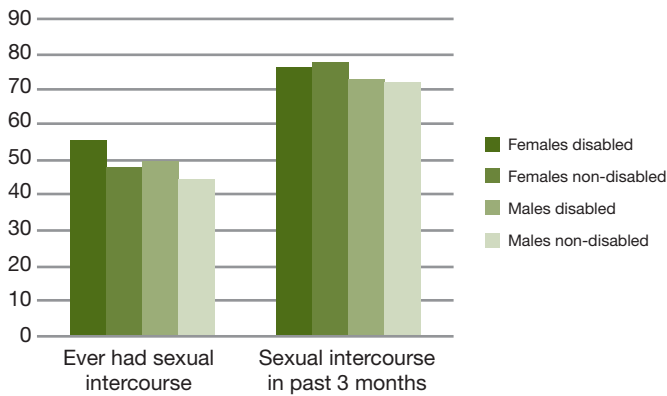
.....
"People with disabilities are always forgotten."
.....

While data were sought regarding disability and preconception health issues, not a great deal of data addressing young adults with disabilities were available for analysis. Most national and state health, wellness, sexuality, and lifestyle risk data do not ask specifically about disability. And while some data sets do ask a disability question, the ALC team felt that the questions were stigmatizing and did not address disability as a demographic.

Oregon Healthy Teens Survey (OHT) data (similar to the national Youth Risk Behavioral Surveillance System), had a previous module in 2008 that asked about disability, although that module is not done on a regular basis. The following tables show the relationship between disability status, contraceptive use and threatening or violent behaviors.

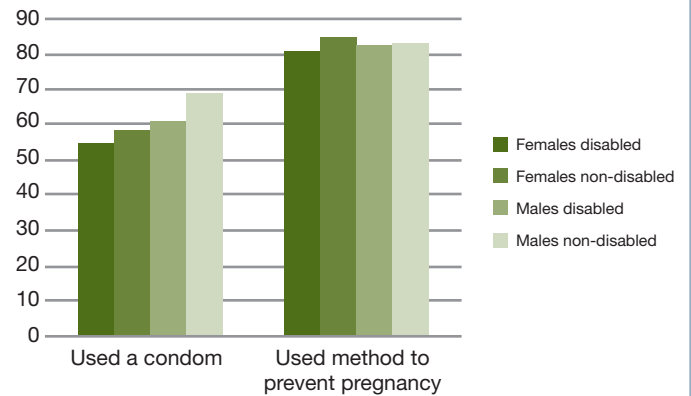
Woven within these themes is a key message: Youth with disabilities are not much different from youth without disabilities. However, the invisibility of youth with disabilities in matters related to sexuality education is concerning.

Sexual activity of 11th grade males and females by disability status



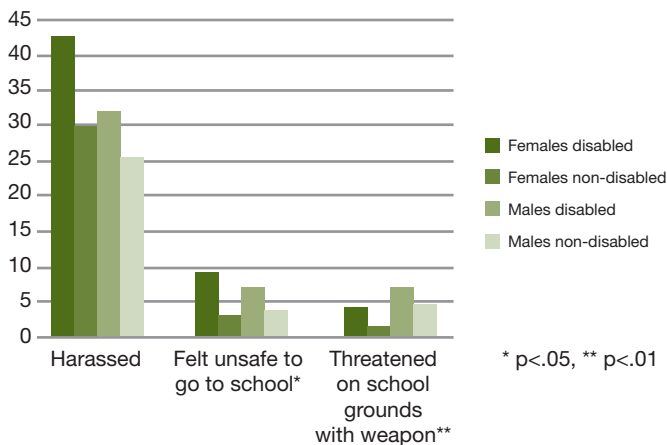
Source: 2008 Oregon Healthy Teen Survey, 11th grade (N=7091, weighted percentages; 23.7% disabled, 76.3% non-disabled)

Contraceptive use of 11th grade males and females by disability status

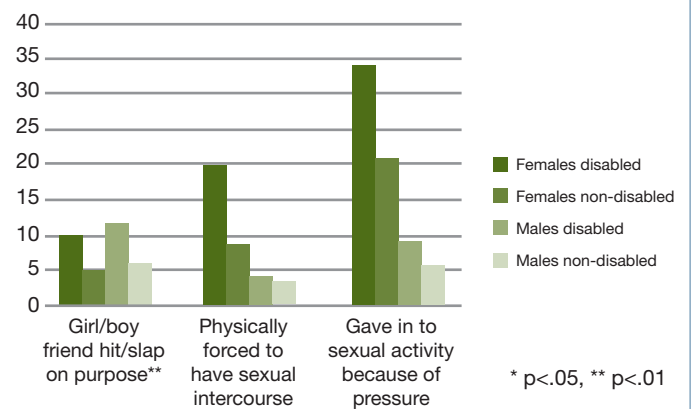


Source: 2008 Oregon Healthy Teen Survey, 11th grade (N=7091, weighted percentages; 23.7% disabled, 76.3% non-disabled)

Victimization among 11th grade males and females by disability



Sexual abuse among 11th grade males and females by disability



Source: 2008 Oregon Healthy Teen Survey, 11th grade (N=7091, weighted percentages; 23.7% disabled, 76.3% non-disabled)

Surveying youth with disabilities

.....
"Youth with disabilities need more visibility. I think that interacting with someone with a disability can be uncomfortable for able-bodied people, since they aren't sure exactly how to react. Making disability seem more normal would help others to see people with disabilities in a positive light."
.....

The ALC team was committed to involving youth with disabilities as much as possible in the process of developing the recommendations and making them relevant to that population. After draft recommendations were developed, the team developed an electronic Web-based confidential survey using SurveyMonkey. The survey was approved by the Oregon Health Authority Institutional Review Board. A nominal incentive for the first 100 respondents was provided. A copy of the survey is available online at <http://1.usa.gov/ALCYouthSurvey>.

Survey respondents were identified through various electronic media sources. The ALC team, and partners, posted the SurveyMonkey link on list serves, Facebook pages, in blogs, through several university websites, and via email on sites that were known to young adults with disabilities (such as www.gimpgirl.com). Respondents could go to the SurveyMonkey website, and, if they met the criteria, be allowed to complete the survey.

The survey asked respondents to self-identify as a youth with a disability, for demographic information, and how much they agreed or disagreed with each recommendation. The question about disability status was meant to provide as much latitude as possible, thus respondents could choose several statements regarding disability that included equipment or alternative formats used, others' perceptions of them as disabled, and invisible disabilities, such as cancer. Specifically, the disability question asked about disability at five levels:

1. I have a disability, such as difficulty remembering, seeing, hearing, or self-care (bathing), which doesn't require equipment of alternative formats.
2. I use equipment because of a disability (such as a cane, wheelchair, or an amplified telephone).
3. I sometimes/often need ADA accommodations to be able to perform day-to-day activities (such as movie captions, large text/Braille option, or an elevator).
4. People think I have a disability or impairment (such as fibromyalgia or cancer).
5. None of these apply to me.

The question regarding disability was used as criteria for inclusion into the survey. If the respondent could answer "Yes" to any of the disability questions (1 – 4), they were invited to continue taking the survey. In addition, if the initial respondent was over age 17, or under age 29, they were also included and could take the entire survey. If the respondent indicated that they did not have a disability, or were not 18–28 years old, they were thanked for their time and not permitted to continue.

Other demographic questions included race and ethnicity, gender, sexual orientation, and the state in which the respondent lived.

The actual survey questions were written from recommendation statements created by the ALC team. They focused on sexual health and sexual violence and harassment, and were based on the literature review and data analysis. Respondents were asked their opinions and if they agreed with the statements. The survey was designed with both open and close-ended questions.

Participants were asked five general questions. The questions dealt with how they felt about others addressing their sexual health, the amount of sex education students with disabilities received, and a list of issues that young adults with disabilities might encounter. Throughout the survey, opportunities were provided for individuals to comment on the questions; this was

done in great detail by many respondents. During analysis, comments were categorized into themes.

Respondents were asked questions about “sexual health care,” which was defined as “having good information and education about how to take care of yourself sexually.” Young adults were then asked about specific populations, and how well they saw those groups addressing sexual health care for young adults with disabilities. From there, the survey questioned respondents about specific sexual health care issues that they might have encountered. Respondents were asked to rank eight issues and to choose two as their “top” issues. They were also asked to identify how important they thought each issue was to young people with disabilities, and asked to identify which issue was the most trouble for people with disabilities. These included:

- How others see you or see other young adults with disabilities;
- Violence, abuse, bullying and/or harassment;
- Lack of friends or social supports;
- Getting good mental health services;
- Getting good health care services;
- Being included in sex education classes;
- Getting birth control, such as “The Pill” or condoms;
- Getting support from parents or family.

For more information on the survey design, see the survey at <http://1.usa.gov/ALCYouthSurvey>.

Survey results

A total of 329 people attempted to take the survey and 115 fit the survey criteria and completed useable surveys. The tables below reflect overall survey demographics.

Overall survey respondent information

Survey respondents	% (n)
Useable surveys	35.0% (115)
Disqualified because they were 29 or older	22.2% (73)
Completed the survey two or more times	14.3% (47)
Disqualified because they checked “None of these apply to me” for disability question	11.6% (38)
Did not complete survey beyond first few questions	9.4% (31)
Disqualified because they were 0-17 years old	7.6% (25)
Total number of people who began survey	329

Age of survey respondents (n=115)

Age	% (n)
18-20 years old	27.8% (32)
21-22 years old	29.6% (34)
23-24 years old	25.2% (29)
25-26 years old	11.3% (13)
27-28 years old	6.1% (7)

Gender

Gender	% (n)
Female	49.6% (57)
Male	48.7% (56)
Left blank	1.7% (2)

Sexual orientation

Sexual orientation	% (n)
Heterosexual/Straight	57.4% (66)
Bisexual	31.3% (36)
Gay man	6.1% (7)
Lesbian	2.6% (3)
Not sure/Undecided	0.9% (1)
Left blank	1.7% (2)

Latino ethnicity

	% (n)
No	77.0% (87)
Yes	23.0% (26)

Race

Race	% (n)
White	65.2% (75)
American Indian/Native American	16.5% (19)
Mixed race	12.2% (14)
African American	8.7% (10)
Asian/Pacific Islander	3.5% (4)
Arab American	1.7% (2)

Survey results were analyzed and stratified by gender. In some areas, results by gender were noticeably different and are summarized below by issues that were addressed in the survey.

HOW OTHERS VIEWED THEM

Both males and females felt that how they were viewed by others who were not disabled, and violence, abuse, bullying and harassment were the top two issues that young adults with disabilities had trouble with. Safety and freedom from violence and abuse was also ranked as the most important issue for young adults with disabilities.

VIOLENCE, ABUSE, BULLYING AND/OR HARASSMENT

Safety and freedom from violence, abuse, bullying, and/or harassment was clearly the issue that rose to the top for young adults with disabilities. Most of the respondents, 68 percent (n=71) felt that some sort of violence was the most important barrier to being healthy. When asked to choose two issues of primary importance to them, freedom from abuse and safety from violence was ranked the most important, most often. Thirty-five percent (n=41) indicated it was their top issue. Forty percent of women and 32 percent of men chose this issue as their primary priority.

ACCESSING HEALTH AND MENTAL HEALTH SERVICES

Young adults with disabilities were also concerned about getting good mental health services as well as health services, including access to birth control. Women were more critical about how well sexual health care was addressed for YAWD by a variety of professionals including policymakers, parents/grandparents/caregivers, school teachers, as well as their own personal health care provider. Second to safety from violence, both women and men were more likely to identify getting good health care services as a top issue. Women were slightly more likely to indicate that YAWDs have "lots of trouble" in accessing good health care services than men (17.3% to 12.7%, respectively); however, men were more likely to indicate that accessing good mental health services was "lots of trouble" (17.6% of women to 20.4% of men). Interestingly, 80 percent of women (n=41) versus 48



percent of men felt that getting good mental health services was very important.

BEING INCLUDED IN SEX EDUCATION CLASSES

When asked about how helpful information in sex education classes is for young adults with disabilities, far more females than males (45% to 9%) indicated that it was not helpful. In addition, 30 percent of young females with disabilities (n=16) stated that they have “lots of trouble” with being included in sex education classes. Twenty percent of young men indicated that they had trouble being included in sex education classes.

ACCESS TO BIRTH CONTROL AND PREVENTING STDs

Inclusion into sexuality education classes, and getting good health care services, were seen as problematic, getting access to birth control was not seen as difficult for most of the YAWD surveyed. Only 12 percent of those surveyed indicated that getting birth control was difficult. However, the importance of birth control was seen quite differently through the eyes of men and women. Sixty-seven percent of women (n=34) stated birth control was very important, versus only 36 percent of men (n=19).

SUPPORT FROM FRIENDS OR FAMILY

Survey participants were provided with a list of adult roles, including parents, grandparents and other caregivers, school teachers, personal health care providers, doctors and nurses, and policymakers. Overall, when asked which of those groups best addressed the sexual health of young adults with disabilities, parents were the preferred group. Policymakers were ranked the worst for both males and females. However, for both groups, more females stated that they did not address sexual health issues well.

On the other hand, both men and women agreed that the three top preconception health issues for persons with disabilities are: safety and freedom from violence, abuse, bullying, and harassment; receiving good health care services; and receiving good mental health services.

There are many limitations when using a convenience sample survey design with a small number of respondents. While the number of people who provided useable surveys was not enough for thorough analysis using correlations, the responses were enough to assist in confirming the draft recommendations that were developed from the literature reviews and data analysis. Small numbers did not provide the power to enable further analysis.

Qualitative data were especially helpful in forming preconception health recommendations although these results also cannot be generalized to the entire population of young adults with disabilities. However, the comments affirmed much of what was seen in the literature and in review of the available data.

ALC Survey

Themes from Qualitative Responses

Safety/freedom from violence, abuse, bullying, and/or harassment:

36% of respondents (41) chose this as one of their top issues

Themes: **Challenges to safety/freedom from violence, abuse, bullying, and/or harassment:**

- People with disabilities can be a target and/or taken advantage of (10)
- Lack of enforcement/ not taken seriously (5)
- The abuse/harassment is not always recognized by the person who is the target (2)

Themes: **What would make it easier for young adults with disabilities to have safety/freedom from violence, abuse, bullying, and/or harassment:**

- More education and/or information about abuse/violence/harassment (9)
- More support for people with disabilities (4)
- More enforcement (2)
- More people talking about abuse/violence (2)

Themes: **What others could do to improve safety from violence, abuse, bullying and/or harassment:**

- Believe people who have been abused (2)
- Speak up against violence/abuse/bullying/harassment (6)
- Take abuse/bullying/violence/harassment more seriously (4)
- Increase education about abuse/violence/bullying/harassment (4)

Good health care services: 30% of respondents (34) chose this as one of their top issues

Themes: **Challenges to getting good health care services:**

- Inaccessible equipment or facilities (7)
- Providers that do not listen to and/or empower their patient with a disability (7)
- Providers that do not have disability knowledge (5)
- Providers that do not accept their insurance (3)
- Financial challenges (3)
- Transportation challenges (3)

Themes: **What would make it easier for young adults with disabilities to get good health care services:**

- Increase provider knowledge of disabilities (10)
- Improve funding and access to medical care (both physical/equipment access and financial access) (8)
- Increase the amount of time available with a provider (2)

Themes: **What others could do to improve health care services:**

- Increase affordable care and/or improve access to care (3)
- Acknowledge the existence of people with disabilities (1)
- Improve provider knowledge of disabilities (3)
- Empower people with disabilities (2)
- More support for people with disabilities (2)

ALC Survey

Themes from Qualitative Responses (continued)

Getting good mental health services: 24% of respondents (28) chose this as one of their top issues

Themes: **Challenges to getting good mental health services:**

- The relationship between the mental health therapist and the patient with disabilities, including how they understand that client and their disability (6)
- Finding mental health providers that accept insurance/ insurance coverage of mental health services (2)

Themes: **What would make it easier for young adults with disabilities to get good mental health services:**

- Mental health providers that have more experience or knowledge in relating young adults with disabilities (6)

Themes: **What could others do to improve mental health services:**

- Increase funding for mental health services (2)
- Change attitudes/decrease stigma of mental health services (2)
- Increase knowledge of mental health providers on how to relate to young adults with disabilities (2)

Being included in sex education classes:

24% of respondents (27) chose this as one of their top issues

Themes: **Challenges to being included in sex education classes:**

- Not being included in sex education classes (4)
- Information is not specific to youth with disabilities (4)

Themes: **What would make it easier for young adults with disabilities to be included in sex education classes:**

- Information related to youth with disabilities (3)
- Information delivery in a way that is accessible to youth with disabilities (e.g. part of OT, in a small group, or as part of the IEP) (3)

Themes: **What others could do to improve inclusion in sex education classes:**

- Include youth with disabilities and information about disabilities in sexual education classes (4)
- Talk about sex, do not assume that youth with disabilities are not interested (2)

Getting birth control, such as “The Pill” or condoms: 17% of respondents (19) chose this as one of their top issues

Themes: **Challenges to getting birth control:**

- The assumption that youth/young adults with disabilities are not having sex (6)
- The assumption that youth/young adults with disabilities should not be having sex (3)

ALC Survey

Themes from Qualitative Responses (continued)

Themes: **What would make it easier for young adults with disabilities to get birth control:**

- Change provider attitudes about youth/young adults with disabilities and sex (5)
- Increase accessibility to birth control (3)

Themes: **What others could do to improve access to birth control:**

- Increase provider knowledge about youth/young adults with disabilities and sex (4)
- Help youth/young adults with disabilities access birth control (3)

Friends or social support: 17% of respondents (19) chose this as one of their top issues

Themes: **Challenges to friends or social support:**

- Difficulty that some people have in relating to people with disabilities (6)
- Inclusion in friendships (3)
- Unable to get out and meet people (3)

Themes: **What would make it easier for young adults with disabilities to have friend or social support:**

- Increased community awareness of young adults with disabilities (6)
- Better transportation options (3)
- Support groups or peer mentoring opportunities (2)

Themes: **What others could do to improve friends or social support:**

- Increase community awareness of young adults with disabilities (4)
- Provide more opportunities for shared activities for non-disable and disabled young adults (4)
- Increased support groups for young adults with disabilities (2)

Parent and other family member support:

17% of respondents (19) chose this as one of their top issues.

- There were no themes that emerged in these comments.

How others see you: 7% of respondents (8) chose this as one of their top issues.

Themes: **Challenges to how others see you:**

- Negative stereotypes that people have about disabilities (3)

Themes: **What would make it easier for young adults with disabilities for how people see you:**

- Increased awareness/visibility of young adults with disabilities (3)

Themes: **What others could do to improve how people see you:**

- Increased awareness of young adults with disabilities (2)

ALC Survey

Themes from Qualitative Responses (continued)

- Increased trainings, education, and/or community forums (2)

Other issue: 4% of respondents (5) chose another issue as their top issue

Themes: **Challenges to how others see you:**

- Lack of comprehensive, inclusive sexual education (3)
- Lack of awareness of young adults with disabilities and about their sexual activity (2)

Themes: **What would make it easier for young adults with disabilities for how people see you:**

- Increased provider knowledge of disabilities (2)

Themes: **What others could do to improve how people see you:**

- Listen to and include young adults with disabilities in policy making (2)



Conclusions – “Stop excluding us.”

Young adults with disabilities are a silent minority, not often considered in terms of sexual and preconception health.

Comments from those surveyed indicated that they have much to say on this topic and often are not asked for their opinions, nor are they offered information that meets their needs. While data indicate that they are as sexually active as their non-disabled counterparts, they experience higher instances of bullying, harassment, and intimate partner violence. Our investigations confirmed this, and recommendations need to be in place to address sexual activity and violence prevention, as well as more general preconception health issues.

From the perspective of those with a disability, they report that they are not included in decision making about their own sexuality, and feel overly protected by those around them. Their disability is often not seen as part of the natural human condition, and is not a consideration in the life process. The preconception health recommendations that currently exist, do not always apply easily to young adults with disabilities.

The intent of the work of the Action Learning Collaborative was to first learn from each other to develop a common understanding of preconception health, positive youth development, and issues faced by young adults with disabilities, and from there, develop recommendations to improve the preconception health of YAWD. While guidelines have been developed regarding preconception health for the general population,²⁸ the recommendations developed here cover an area and population that have historically been underserved and discounted. The recommendations in this report are a starting place for public health professionals, parents, providers, schools, communities, and young adults with disabilities to use in guiding them towards developing and maintaining a healthy life, whether or not they choose to have children.

Limitations in the ALC process

The link to the online survey was sent nationally through electronic media, including email and postings on list serves and Facebook. Only 115 people responded, and all self-identified as fitting the criteria (between ages 18–28, and having a disability). Their age and disability status were not verified. There was not an opportunity to randomly choose a sample. Thus, survey results should only be considered valid for the purposes of contributing to these recommendations.

The literature regarding sexuality and the sexual health of young adults with disabilities is scant. Further research is needed in this area. Data sources that specifically included youth or young adults with disabilities as a demographic are limited. While many surveys of youth exist, few ask about disability status.

Lessons learned from the ALC process

The medical model for disability is widely used by Institutional Review Boards (IRB), which do not usually see disability as merely a demographic group. This made surveying people with disabilities more difficult because standards set by the IRB for the survey were different, and in some cases unnecessary, from the perspective of some ALC team members. It was recommended that IRBs begin using a model of disability more aligned with a social justice model, rather than defining disability as a diagnosis.

For those people without disabilities, sexuality and freedom from violence are given expectations. However, these values typically have not been attributed to young adults with disabilities by those without disabilities. It cannot be stated enough that the key message in this Action Learning Collaborative process has been that youth with disabilities are not much different from youth without disabilities. However, the invisibility of youth with disabilities in matters related to sexuality and personal safety is concerning.

Afterword

The recommendations identified here should be seen as the beginning of a national effort to address the preconception needs of young adults with disabilities. Suggestions for further work regarding preconception health and disability include developing recommendations and suggestions for alcohol, tobacco and other drug use, obesity and physical activity, folic acid, diabetes, and special challenges that YAWD may face, such as physical barriers in receiving clinical care (as in a mammogram or Pap smear). The ALC team recommends that YAWD, stakeholders, public health entities, and the medical community continue this work, and contribute to the dialogue to improve upon these recommendations and test their viability.



Endnotes

- ⁱ Recommendations to Improve Preconception Health and Health Care — United States: A Report of the CDC/ATSDR Preconception Care Work Group and the Select Panel on Preconception Care. *MMWR: Recommendations and Reports*. April 21, 2006 / 55(RR06);1-23
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- ⁷ Oregon PRAMS, 2007
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- ¹³ Oregon Youth Sexual Health Plan,
<http://www.oregon.gov/DHS/children/teens/tpplyhsp-021109.pdf>
- ¹⁴ All quotes that appear in the headers of this paper are taken from direct comments made by young adults who took the ALC survey. The comments are in reference to questions regarding their sexual health and experiences as a young adult with a disability.
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www.pathwaysrtc.edu
- ¹⁶ Oregon Healthy Teens, 11th Grade, 2008.
- ¹⁷ http://www.nichd.nih.gov/about/meetings/2010/upload/Thierry_Pregnancy_in_Women.pdf
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