

Public Policy and Sexuality Education for Youth with Disabilities: Impact on Sexual Behavior and Outcomes

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Abstract—This paper will examine the need for more aggressive public policies around bodily, reproductive and sexual health education for young people with disabilities in the United States.

This paper will consider the policies around sexuality education for students in the United States and the recommendation for national standards around sexuality education. We will investigate the intersection of these policies and recommendations for students with disabilities and the Individuals with Disabilities Education Act (IDEA); what this means for students with disabilities' access to comprehensive sexuality education and how it affects their behaviors and outcomes.

Keywords—Disability, sexuality, education, policy.

I. INTRODUCTION

JAMILA is a seventeen-year old who has been sexually active for two years. She was sexually assaulted, but did not report her abuse, nor has she received counseling. Jamila is a seventeen-year old girl with intellectual disabilities. Because of her child-like interests, her low IQ, and her diagnosis, the adults in her life do not consider her a sexual being. As a result, she has not received the same human growth and development information that her non-disabled peers have. She does not know the difference between public and private behaviors, nor does she understand the elements of a healthy and respectful relationship. The likelihood of an unplanned pregnancy or an STI for Jamila is higher than for her non-disabled peers. She will likely be a victim of sexual abuse again before the year is over.

Marvin is a twenty- five year old man who is on the registry of sex offenders. Marvin has pervasive personality disorder and is on the autism spectrum. He is a sex offender, not because he was seeking power and control, nor because he is abusive. Marvin is a sex offender because he never learned appropriate ways to express desire and sexual interest. Because of his disabilities, there was fear on the part of his family and service providers to give him any information about his own body and sexual feelings. Marvin will be on the sex offender registry for the rest of his life.

Jamila and Marvin are far from alone. People with disabilities of all kinds are often denied access to sexuality education, leaving them vulnerable to risky behaviors, abuse, unplanned pregnancy and disease. But this is not a hopeless cause. When people have this information presented to them in accessible, understandable, and clear methods, they gain the

tools they need to make choices that can impact their lives for the better.

It is no secret that rates of teen pregnancy and sexually transmitted infection are considered public health issues in the United States. Sexual and dating violence are yet another public health issue. While most agree that something must be done about reducing the rates of teen pregnancy and STIs, and eradicating violence, sexual assault and abuse, there is a great divide on how best to do so. A widely held concern on the part of both parents and teachers is that given access to information about sexuality, including birth control, contraception and other protection, youth will be more likely to engage in sexual behavior. There is an assumption that in these "tools", youth will see permission to act on sexual feelings and urges. In addition, sexuality is often steeped in issues involving morality, ideology and very strong beliefs about right and wrong, as is often the case in people with deeply held religious beliefs. This placement of sexuality on the moral compass, as well as the parental concern about sexual behaviors can lead to public policy of abstinence only programs in schools and community organizations. These programs often include no information on pregnancy, disease and protection. They also include opt-out options for parents who do not want their children to receive the information, and at worst, include no information at all.

Youth with disabilities, due to segregated programs in schools, different learning styles, and an assumption on the part of parents and teachers that sexuality and disability are somehow incongruous, are often even further denied sexuality education. Because of this inability to access information, youth with disabilities are more prone to become victims of abuse and sexual assault and may be unable to make informed decisions about their sexual health, which can then cause disproportionate rates of teen pregnancies and sexually transmitted infections.

II. THE IMPACT OF US SEXUALITY EDUCATION POLICIES ON YOUTH SEXUAL BEHAVIOR AND OUTCOMES

Only seventeen of the fifty states in the U.S. require that information on contraception be provided in their public schools' sexuality education programs. Alternately, thirty-seven of the fifty states require that abstinence be either stressed or covered as part of sexuality education [1]. It is clear that this approach is ineffective, given that the United States has the highest teen pregnancy rates of all the countries in the world [2].

The Sexuality Education and Information Council of the United States (SEICUS) [3]-[7] reported the top four states for

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teen pregnancy in 2011 were Mississippi, New Mexico, Arkansas and Texas. In addition, these four states are in the top twenty for Chlamydia and Gonorrhea infections and in the top ten for Syphilis. These states, according to the 2011 Gallup Poll [8], reported higher than average religiosity, often linked with more conservative sexuality education policy. Indeed, all four of these states have policies that mandate sexuality education shall be taught with abstinence-only or abstinence stressed curricula [3]-[7]. (Fig. 1)

Conversely, Connecticut, Maine, Oregon and Iowa—states ranking low in religiosity [8] and also have mandated sexuality education with requirements for medical accuracy, research-based and not abstinence-only [3]-[7]—are in the lower 10th percentile of teen pregnancies in the U.S. In

addition, they rank at the bottom 10-20% for Sexually Transmitted Infections. (Fig. 2)

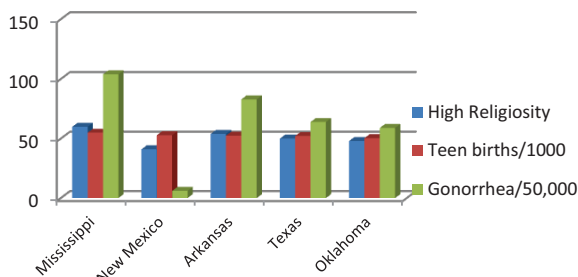


Fig. 1 Religiosity and abstinence-only education

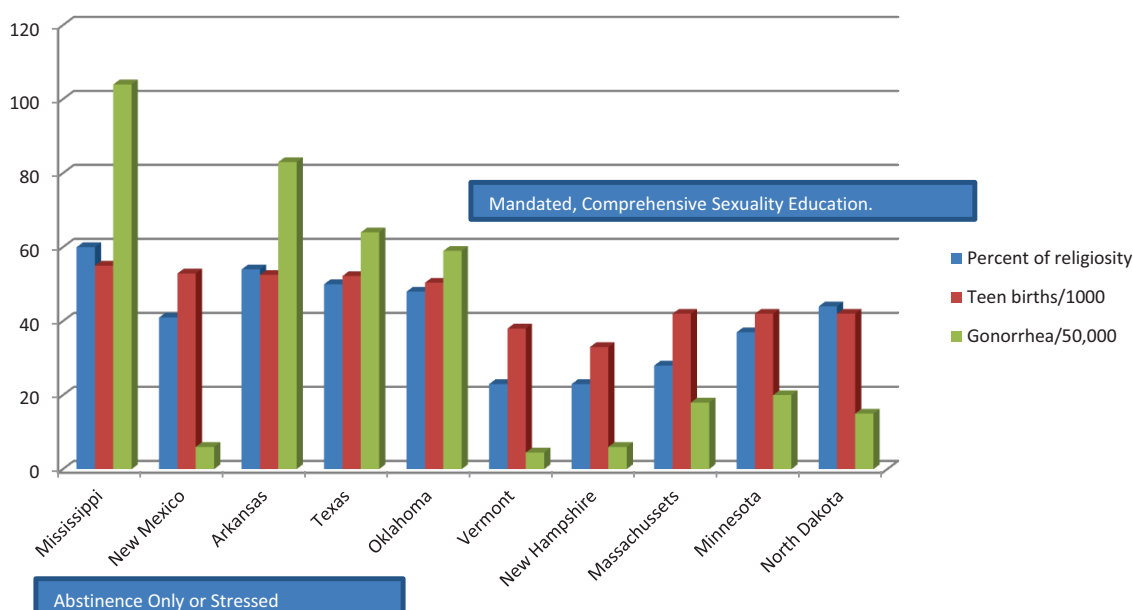


Fig. 2 Abstinence-only versus comprehensive sexuality education

These data suggest that abstinence-only programs are not leading teens to choose abstinence. Though abstinence only state grant program budgets total \$250 million from 2010-2014, a federally funded evaluation of these programs conducted by the Sexuality Education and Information Council of the United States [3]-[7] “handpicked to show positive results” failed. There is no evidence that youth receiving these types of instruction increase their rates of sexual abstinence. In short, abstinence programs are not effective. In fact, what the research does show is that young people receiving comprehensive, research-based sexuality instruction are reporting in studies that they have decided to delay their sexual activity or reduce the number of sexual partners.

On the national level, 46 % of females and 49% of males report being sexually active during high school. The states mentioned above (states with comprehensive mandated

sexuality education) report right around those rates and, quite often, just below them. The states with abstinence only policies have rates of sexual activity at a higher percentage. For example, Mississippi, the highest ranking state in the country in teen pregnancy, shows sexual activity rates of 53% for girls and 63% for boys [3].

Research shows that at least half of all teenagers are not waiting until marriage to have sex. We know that they are not practicing abstinence, even when abstinence makes up the bulk of their curricula. It seems that if youth have all the information they need about sexual health, including how to avoid STIs and HIV/AIDS and how to prevent a pregnancy with instruction on condom use, they are more likely than not to put off having sex or making risky decisions. Perhaps if young people have more access to accurate information, their decisions will be more informed, and therefore safer.

Looking at the sexuality education policy language in these top five and bottom five states in teen pregnancy is also telling. According to [3] sexuality education law in Mississippi “requires each school to adopt an abstinence-only or an abstinence-plus” policy. Indeed 75% of Mississippi’s sexuality education funding goes to abstinence related educational programs. Arkansas law “does not require schools to teach sexuality education or sexually transmitted disease education” and more than half of the state funding goes to Abstinence only programs [5]. Similarly, Texas policy [6] also requires abstinence based programs to be the norm, and when a local health council oversees sexuality education curriculum it must ensure “that local community values are reflected” in all instruction. And in cases where comprehensive sexuality is taught, the curriculum may not allow students direct practice with birth control methods. Many of the curricula adopted in these states are fear and shame-based, using language of blame to describe those who contract disease or become pregnant, yet Mississippi, Arkansas and Texas have higher than average rates of teen pregnancy and Sexually Transmitted Infections.

Both Vermont and New Hampshire, the states with the two lowest teen pregnancy and STD rates, have very specific language included in their policy relating to comprehensive, and, in most cases, medically accurate sexuality education. New Hampshire even includes language that, in the case of HIV/AIDS, instruction shall include that “HIV is not transmitted through casual contact and discussing the importance for having compassion for people with HIV/AIDS”. [3]-[7] This instruction strives to teach students empathy for others and does not blame victims of disease for the disease itself. Reference [7] states, “Minnesota state law requires every school to develop and implement a comprehensive, risk-reduction program”. The programs must be research-based and medically accurate. Included among those federally funded programs is Making Proud Choices, which teaches youth how to prevent pregnancy and STDs. While this and other research based programs do cover abstinence, they are also designed to help students become more comfortable with partner negotiation and condom use through direct instruction.

Facilitators of the Making Proud Choices curriculum have already seen a pattern of results in the curriculum that mirrors Minnesota’s federally funded one. Eighty-seven percent of the students who have taken the course reported that they will change their sexual behavior to include, delaying of sexual activity or less risky behavior as a result of the class. Eighty percent said that if they are approached in the next few months to engage in sexual activity without protection, they absolutely will not. Ninety-seven percent of the students reported that if involved in a sexual situation, they feel confident that they know how to use a condom correctly and will do so.

So if research shows that teaching youth comprehensive sexuality education can be linked to lower pregnancy and STI rates, thus enabling them to make safer and healthier decisions, why are we still so divided on the issue? Sexuality is a personal, private part of each human being’s life. Morality

and religion coupled with personal beliefs and ideals can filter through each aspect of sexuality. (Figs. 1 and 2) People’s personal beliefs about sexuality and how it should be conveyed to their own children, can be very daunting. This fear can result in the continuation of public policies of abstinence. But relying solely on abstinence instruction is not bringing about outcomes consistent with these values and beliefs that brought abstinence instruction on at the start.

III. ARE YOUTH WITH DISABILITIES RECEIVING COMPREHENSIVE SEXUALITY EDUCATION?

If youth in the general population suffer ill effects from lack of education, youth with disabilities certainly do. When states do have policy requiring comprehensive sexuality education, the language includes the following: that sexuality education must be medically accurate, age appropriate, culturally appropriate and unbiased, non-promoting of religion. Not one of the five states with the highest teen pregnancy rates requires medical accuracy. Conversely, four of the five states with the lowest teen pregnancy rates have policy that mandates medically accurate sexuality education [1].

While teaching sexuality education with medical accuracy can be linked to lower teen pregnancy and STI rates, while value-based abstinence curricula can be linked to higher teen pregnancy, the different learning styles and educational needs of students with disabilities is not represented here. Furthermore, while cultural and age appropriateness are certainly useful indicators to include in sexuality education, again the needs of students with disabilities is not taken into consideration.

The Individuals with Disabilities Education Act (IDEA) is a law ensuring educational services to children with disabilities. Part D, entitled *National Activities to Improve Education of Children with Disabilities*, [13] states that children with disabilities and their parents shall “receive training and information designed to assist the children in meeting developmental and functional goals, and in preparing to lead productive, independent adult lives.” Under IDEA, students receiving special education services are entitled to an Individualized Education Plan (IEP). A federally mandated element of the IEP is performance in social and emotional relationships. Sexuality plays a big role in productive, independent adult lives, yet in my thirteen years working with children and youth with disabilities, I have met only a handful who put sexuality education in their child’s or student’s IEP. The IDEA Improvement Act of 2004 added language stating that students with disabilities should “have the same education opportunities to the maximum extent possible as their non-disabled peers” [13]. This should include access to sexuality education—the same sexuality education their peers are receiving.

But, according to [9], TASH, an international organization working for people with disabilities and inclusion, opportunity and equity, found that less than half of students with emotional, developmental or cognitive disabilities are integrated in regular education at least 80% of the time [2]. When we look at all of our states represented in the upper and

lower percentiles of teen pregnancy rates, we see that all only 60% of their students with disabilities are spending 80% or more time in the general education courses and classrooms of their schools. What this shows us is that even with IDEA in place, even in the states that have policies mandating comprehensive, medically- accurate sexuality education, students with disabilities simply may not be in the classroom when this instruction is taking place. On top of this, students with disabilities affecting their attention, learning, cognition or development often need such accommodations as information presented in different formats, or information presented over longer periods of time, repeated as needed. Neither the policy regarding sexuality education, nor the policy regarding special education takes students with disabilities and sexual education into account.

The educational system and the policies therein are at the forefront of access to sexuality education. Access and inclusion in general for people with disabilities also seems to correlate with the accuracy with which they receive sexuality education and their pregnancy and STD rates. Each year United Cerebral Palsy releases a state-by state report card detailing the community living standards for people with developmental and intellectual disabilities [10]. The indicators include life satisfaction, employment and community policy and funding for programs. In 2013 four of the five states ranking highest in STDs and teen pregnancy also ranked in the bottom ten for inclusion for people with disabilities: Oklahoma, Mississippi, Arkansas and Texas. On the other hand, four of the five states ranking lowest in the same indicators were ranked in the top ten for inclusion: New Hampshire, Vermont, Connecticut and Massachusetts. Unsurprisingly, among all states, the poverty rate is highest in those states with low inclusion rankings and high teen pregnancy and STD rates while it is lower in those states with high inclusion and low teen pregnancy and STD rates. (Fig. 3)

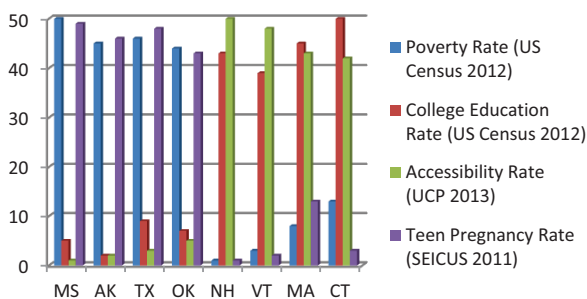


Fig. 3 Poverty, education, accessibility and pregnancy rates

Low funding and the resulting lack of educational resources, correlates with negative outcomes. This includes pregnancy and STD rates, likelihood of receiving a college degree, and inclusiveness for citizens with disabilities. The answer seems to be, across the board, education. Higher education is linked to lower poverty rates; increased sexuality education; and to lower teen pregnancy and STD rates. Reference [11] shows there is also a strong reciprocal

connection between disability and poverty. Access to information, whether it is comprehensive sexuality education or a university degree, leads to higher success, access and inclusion.

In January of 2012, [12] released National Sexuality Education Standards. These standards were based on the high teen pregnancy rates in the United States and the need for sexuality education to be taught based on standards that are clear and consistent throughout the country. The standards are divided into seven specific sexuality education topics and further divided by grade level. The topics cover such areas as disease prevention; influence of family, peers and media; ability to access health information; communication skills; decision-making skills; goal setting skills; self-management for better health; and advocacy. While the standards designate what information students should learn and comprehend and by the end of which grade level, there is no language specifically designed to accommodate or provide access to students with disabilities who might be segregated from their peers, or access information through alternative methods. Thus, even [12] with the interest of American youth in mind, has left behind youth with disabilities.

IV. YOUTH WITH DISABILITIES: PREGNANCY AND STIS; SEXUAL ASSAULT AND ABUSE

The lack of access to sexuality education in the United States extends even further for the community of students with disabilities. National policy around sexuality education is not reaching all students across the country and is certainly not reaching youth with disabilities; leaving them vulnerable to STIs, unplanned pregnancy, sexual assault and abuse.

Reference [14] assert, in their article in the *International Journal of Special Education*, that “the subject of sexuality and reproductive health is often avoided when teaching youth with disabilities, leaving them with an information void that decreases their chances of protecting themselves from unintended pregnancy.” Indeed, in it is believed that, more often than not, when the subject of sexuality is broached, that parents’ reactions range from hesitant and fearful to vehement opposition to their child having access to the information. In cases of youth with developmental and cognitive disabilities, they are often regarded as being childlike, that they are not considered to be sexual beings at all or on the other end of the spectrum—oversexed and therefore not wanting to give them the information.

Sexuality is far more than sexual intercourse and is part of the framework of a healthy individual across an entire lifetime. Sexual response is present in the womb and continues until death and is connected to a person’s relationships with self and others [15]. Looking at sexuality in this light, rather than simply focusing on sexual intercourse between consenting, and in many states, married adults, we allow a broader approach in education on the topic. The American Academy of Pediatrics recommends that talking about sexuality and sexual topics with children should occur as early as they begin asking questions and be an on- going conversation throughout the lifespan. Conversely, seeing a

person with a disability as child-like is no reason to withhold information about sexuality. And of course, youth with disabilities desire relationships, connection and a future with a partner and children as much as their non-disabled peers.

In addition, youth with disabilities are more likely to be victims of bullying and to participate in antisocial behaviors or behaviors against their better judgment [14]. Both of these factors can make it more likely for youth to engage in risky behaviors, sexual and otherwise as well as feel pressured to do things they may not feel comfortable with just to feel like they belong or avoid bullying and coercion.

While there is very little research intersecting disability with sexuality education, we do know that there is a link between poverty with disability, placing youth with disabilities more at risk for teen pregnancy and STIs. Based on this understanding, Indiana University's Secondary Transition Resource Center shared the recommendation that youth with disabilities receive access to the same information all teens receive regarding sexuality and shared general tips about effective teaching methods. Youth with disabilities require multi-method approaches including hands-on experience, individual assessment of learning style, small group instruction and visual aids [16]. In a 1996 study of youth with and without disabilities and sexual behavior, [17] it was found that sexual activity was no less frequent between youth with and without disabilities. Simply, having a disability does not make it less likely for a youth to engage in sexual behavior. This clearly shows that all youth need access to sexuality education. This study further showed that youth with disabilities were much more likely to be victims of violence and sexual assault.

With regard to sexual assault, in 2012, [18] released a report titled *The National Survey on Abuse of People with Disabilities*. This report, which was the first of its kind, found that a person with a disability is more likely to be abused than a person without disabilities. Seventy percent of the people in this study reported having been abused in their lifetime and nearly half of the victims did not report the abuse. For those who did report, nearly 54% said that nothing happened as a result [18]. This report also examined some reasons that people with disabilities are more vulnerable to abuse including dependency on others for care, social isolation leading to increased risk and "less education about appropriate and inappropriate sexuality". One recommendation, based on these findings, was more training on risk reduction for educators, within sexuality education in schools.

Smith and Harrell [19] from the VERA Institute of Justice, reported further on sexual abuse of children with disabilities. Their report suggested policy change regarding the largely ignored policy issue of sexual abuse of children with disabilities. It has been found by [20] that children with disabilities are three times more likely to be victims of sexual abuse with higher instances of abuse to people with disabilities such as intellectual or mental health. The same was found for abuse and violence, citing that 78.4% of people with mental health disabilities and nearly 70% of those with intellectual or cognitive disabilities are reporting abuse [18].

In the fall of 2012, VERA Institute of Justice held a National Roundtable Discussion on Sexual Abuse of Children with Disabilities to help inform the report on such abuse. In the discussion and literature review, the theme of education arose throughout the process. "Children with disabilities are systematically denied basic information about sexual health and relationships" and "family members may have personal anxieties about their children having sex and therefore will not raise such issues with them or the schools" [19]. The recommendations of the national roundtable and the report itself cover public policy and educational legislation, primary prevention and research on the topic, none of which are part of current policy.

In short, studies are finding that youth with disabilities are becoming sexually active and having sexual feelings at the same rates as their peers yet they are being abused at much higher rates and are at higher risk for pregnancy and sexually transmitted infection.

V. RECOMMENDATIONS

The correlation of poverty and persons with disabilities; the lack of access to education and community resources for people with disabilities; and attitudes and beliefs around sex and disability all leave youth with disabilities at increased risk. Their risk is increased for pregnancy, STIs and abuse. Youth in the general population who receive higher levels of education and instruction about sexuality, and how to protect themselves when they do choose to be sexually active have lower rates of pregnancy, STIs and abuse. This emphasizes the need for more aggressive policies for sexuality education to youth with disabilities.

In the case of the United States as a whole, policy around comprehensive, medically accurate sexuality education, *including* but not limited to abstinence could see reduced rates in unplanned pregnancy, sexually transmitted infections and HIV/AIDS across the country. When youth are given access to information and education and allowed to use those skills, coupled with education around the morals/ideals of their families and communities at large, they will be more willing to adopt less risky sexual behavior, including choosing abstinence and using protection when they do decide to become sexually active, thus protecting them against unplanned pregnancy and disease.

Where existing policy includes standards for instruction of sexuality education, adding language to the policies on accessibility and inclusion for students with disabilities can lead to greater access. This can be done while keeping in mind that those students in integrated settings might require alternative teaching methods and individualized instruction and that students in segregated settings still require the same instruction as the school population at large. Adding this language and understanding to public policy around both special education and sexuality education can help ensure access to information for all students, not just those without disabilities.

Youth and children are sexual beings as are their adult counterparts. Youth and children with disabilities are no

exception. Throughout our life span, all human beings have the need for connection with others through relationships, touch, affection and sexuality. Denying access to comprehensive education and furthermore, denying that sexual feelings and the need to connect exist in young people with disabilities leaves them vulnerable to abuse and assault and higher risk sexual behaviors.

With more rigorous public policy governing how and what we teach to youth in schools—all youth in schools—we can see a drop in teen pregnancy rates, STDs and sexual assaults. With more stringent public policy that includes language of accessibility and accommodation for students with disabilities, encompassing of learning styles and classroom inclusion, we could see a drop in these rates for youth with disabilities as well. Perhaps, then, people like Jamila and Marvin highlighted in the beginning of this paper would not be at such risk for being victims or perpetrators of sexual assault, they can have much higher expectations that their adult lives, in the spirit of IDEA, will be independent, productive and successful.

ACKNOWLEDGMENT

The author would like to thank Independence *First* for being truly consumer controlled and driven in its programs and services for people with disabilities. Specifically, the author would like to thank Lee Schulz, president and Deb Langham, Independent Living Services Director for their constant support, belief and encouragement.

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