A Content Analysis of Youth Sexual Health Websites:

Exploring their Relevance and Accessibility for Youth with

Disabilities

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Abstract

Because web-based campaigns are an important part of health promotion campaigns for youth, this research examines sexual health websites aimed at youth and explores the messages on HIV/AIDS for their relevance and accessibility for youth with disabilities. The researchers' underlying understanding of disability is that it is socially constructed and that people with disabilities experience social exclusion. We used a directed content analysis method to analyze 21 websites that met our inclusion criteria based on our indicators of accessibility and relevance and for their key messages. We found that the messaging across all sites was highly consistent: sex-positive, gay-positive, and non-judgmental about youth sexual expression. However, none of the prevention information specifically considered mobility, verbal and cognitive disability, participation and information barriers faced by youth with disabilities, or their heightened sexual vulnerability. Only one site depicted disability in images and none depicted disability and sexuality. There is a clear need to better understand the sexual health information needs of youth with disabilities and to develop safe sex information that is relevant and accessible to them.

Key words: youth with disabilities, HIV/AIDS, health promotion/education

Introduction and Background

Sexual health is broadly defined by the World Health Organization as the

"state of physical, emotional, mental and social well-being related to sexuality,"

requiring that "the sexual rights of all persons be respected, protected and

fulfilled" (World Health Organization [WHO], 2002). These rights are identified in part as the "right of all persons, free of coercion, discrimination and violence, to: the highest attainable standard of sexual health, including access to sexual and reproductive health care services; seek, receive and impart information related to sexuality; and pursue a satisfying, safe and pleasurable sexual life."

Many youth experience a variety of barriers to realizing their full sexual health rights, particularly accessing physical sexual health services (Flicker et al., 2009). International sexual and reproductive health organizations have been redoubling their efforts to increase youth access to sexual health information and appropriate HIV/AIDS prevention strategies (UNAIDS, 1998; 2000; United Nations Educational, Scientific and Cultural Organization [UNESCO], 2001; United Nations International Children's Emergency Fund [UNICEF], 2002). Despite consensus that adolescents are both biologically and socially vulnerable, debate continues as to the best approach to optimize sexual health outcomes for this age group (Kirby et al., 2007).

The actual prevalence of HIV/AIDS among Canadian youth with disabilities is not known. In Canada, approximately 300,000 people between the ages of 15 and 24 live with disabilities (Health Canada, 2000), and more than half of all new HIV infections worldwide affect youth between the ages of 18 and 24 (Collins et al., 2001; Coren, 2003; Groce, 2003; Groce, 2004). We do know that HIV/AIDS follows patterns of inequity, disproportionately affecting society's

most marginalized populations in Canada and around the world (Farmer, 1999; Farmer, 2003; Farmer et al., 1996; Patton, 2002). As a group, people with disabilities tend to be socially, economically, and educationally disadvantaged (DiGiulio, 2003; Organisation for Economic Co-operation and Development [OECD], 2009; OECD, 2010). Research also suggests that many HIV/AIDS risk factors, such as poverty, lower education levels, lack of HIV information sources, and lack of access to health care are increased for people with disabilities (Andersen and Collins, 1992; Blanchett, 2000; Crenshaw, 2002; DiGiulio, 2003; Groce, 2003; Groce, 2004; Groce, 2005, Verma, 2003). The recognition of the impact of these social determinants of health has helped to frame some of this study's underlying assumptions about the social disadvantages that youth with disabilities face.

Furthermore, a social determinants of health approach complements the theoretical framework of this study, which is situated in critical disability studies. Research in critical disability studies aims to expose how current or past social arrangements create or perpetuate disability by marginalizing people who live with impairments. Disability is defined here—in keeping with the social model of disability—as a form of oppression. The social model understands impairment as a bodily difference or functional limitation; whereas disability is social exclusion, impoverishment, vulnerability, and/or restricted life chances that are produced socially by laws, policies, the built environment, prejudice, and other humanly

constructed factors (Barnes and Mercer, 2003; Oliver, 1990; Titchkosky, 2006; Titchkosky and Michalko, 2009). Thus, the current study attempts to look beyond traditional concerns of individual "risky" health behaviours to examine evidence of social exclusion and prejudice. For example, people with disabilities are sometimes incorrectly believed not to be sexually active, not to identify as gay, lesbian, bisexual, and/or transgendered, not to be victims of sexual or gendered violence, and to not engage in substance use (Goldman, 1994; Groce, 2004; Groce, 2005; Milligan and Neufeldt, 2001). These attitudes may mean health providers and services may not recognize youth with disabilities as a priority population.

Increasingly youth are seeking out sexual health information online (Keller et al., 2002; Sesselberg and Cantrill, 2005; Skinner et al., 2003). The internet offers free information that is available anonymously twenty-four hours a day. It is an ideal environment for accessing confidential or potentially stigmatizing information (Flicker et al., 2004). It is one of the first places that youth go to when they have a question about sex or want to know more (Flicker et al., 2009). As a result, mobile (Wei et al., 2011) and interactive computer-based sexual health promotion (Bailey et al., 2010) interventions are proliferating (Ybarra and Bull, 2007).

Despite the ease with which information can be segmented and tailored online, mainstream websites continue to exclude certain populations of young

people in their messaging. There has been a call for more HIV prevention

education targeted towards youth with disabilities (Gray and Klein, 2006), so

more research is needed to assess the accessibility and relevance of these online

campaigns/websites for youth with disabilities. Research to date has mostly

focused on sexual health education as part of school curricula (Newens and

McEwan, 1995; Lenhart, 2009).

This study analyzes internet-based sexual health educational materials

originating in Canada and directed at youth audiences. It takes a preliminary step

towards understanding how youth with disabilities experience sexual health

information available on the internet, and how health educators can make sexual

information more accessible and relevant to their needs and interests. To our

knowledge, there are currently no studies similar to this one.

Methods

We used a "directed content analysis" method for this study. Content

analysis is a flexible and practical method for analyzing text data with the aim of

"extending knowledge of the human experience of health and illness" (Hsieh and

Shannon, 2005, p. 1286), or in this case of health education efforts. As Hsieh and

Shannon (2005) explain, a directed content analysis facilitates analysis that

validates or extends a theoretical framework and uses existing research and

knowledge to determine an initial coding scheme. Based on the research team's

expertise in youth sexual health research and health promotion, we anticipated

three key messages about HIV/AIDS on websites aimed at youth: 1) Get tested; 2) Take specific actions to avoid infection; and 3) Take control of your situation. Table 1 supplies more details. We then developed several indicators of accessibility and relevance (Table 2), which were elaborated and refined as we proceeded through the analysis. Within a social model understanding of disability and based on the literature and the extensive collective experience of the researchers involved with this project, we hypothesized that youth with disabilities would be systematically left out of online sexual health program planning and outreach.

Sampling Strategy and Inclusion Criteria

Because the social model posits disability as socially constructed oppression, this approach focuses on the shared experience of disability, regardless of the type of disability. Thus, this study adopted this cross-disability perspective and did not segment our analysis by type of disability. The literature suggests that, while differences exist, youth with disabilities have significant commonalities with regard to their experiences of discrimination and sexual vulnerability. For example, youth with a range of sensory and cognitive impairments are less likely than nondisabled peers to have access to readable and understandable health information (Boyce et al., 2003; Byers et al., 2003; Gaskins, 1999; McCreary Centre Society, 1999).

We used a purposive sampling strategy to identify websites through 1) a Google search with the key words "sexual health", and "youth", and "Canada"; 2) websites suggested by research team members; 3) websites related to print materials gathered from events on youth sexuality and/or disability; and 4) a review of all links on all websites found. To be included, websites had to be in English and from a Canadian organization. The content had to be *about* and *for* youth, though the site may have other targeted audiences in addition to youth. The material had to address issues of HIV/AIDS, though they could include information on other sexually transmitted infections (STIs) and/or healthy sexuality among youth. Material could be disability-specific, cross-disability, or aimed at the general youth population. Only sites that offered health information specifically, as opposed to information about services or only links to information, were included. Chat rooms and commercial sites (e.g., those selling sex-related material) were not included. Only information available on the pages of the websites was analyzed; downloadable resources were not included because most were available only in PDF, which may not be readable by text-reading software.[1] Sites that were aimed at people with disabilities were searched for the word "sex." If this word did not appear in the search, the site was eliminated from the sample. The websites in this study were searched and reviewed by a single

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[1] Offering downloads in both PDF and word processing software is a standard practice for accessibility.

author during the period of March 24 to May 18, 2010. No human subjects were involved in this research, so an ethics review was not required.

Indicators

Relevance. We considered three aspects of relevance of the health promotion material under review: 1) Is disability depicted or directly addressed in a way that encourages youth to see themselves in these depictions and descriptions? 2) Does the material specifically and directly address sexual health issues for youth with disabilities? 3) If so, is the information in these materials actually applicable to youth with disabilities? For example, we examined the extent to which the material specifically aimed at youth with disabilities took into account the varying verbal, cognitive, physical and sensory abilities among this population and the barriers that hinder their full social participation, including information access.

Accessibility. We considered accessibility in terms of the reading level of the text, the format of downloadable material, text size and audio options, and stated compatibility with assistive technology. To determine the readability of each site, the Flesch-Kincaid reading level was determined by copying and pasting the first page of text under each of the first five tabs, icons, or transitions on the site and all information about STIs and/or HIV/AIDS on the site into a Microsoft Word document. The reading grade level was then determined through

Microsoft Word's spelling and grammar check function that provides the Flesch-Kincaid score.

To determine if the site was accessible to blind people and those with low vision, the site was reviewed for the presence of a button for increasing font size and for the availability of audio on the site, whether downloadable material was available in more than one format, and/or some explicit indication that the site was compatible with text-reading software. Sound connected with videos was not considered appropriate audio for this purpose, because the purpose of audio is to have all text read aloud as would be the case with text-reading software. To determine accessibility for deaf and hard-of-hearing communities, sites were reviewed for the use of American Sign Language and captioning of videos available on the site.

To determine accessibility for people with disabilities who rely on assistive technology, we reviewed each site for an icon or statement of accessibility (e.g., compliance with World Wide Web Consortium standards) or some other indication that the site was suitable for these technologies (Table 2).

Coding Framework

The key messages coded were as follows:
1. Young people are urged to get tested for HIV/AIDS and other STIs and offered resources for doing so;
2. The site promotes the prevention of HIV/AIDS and STIs and describes practices and resources needed to do so (e.g., condom use);
3. The site encourages young people to "respect themselves" or "take

control" of their sexual lives, or uses other similar messages of empowerment, particularly in the context of avoiding coercion. We used a broad definition of coercion ranging from unwanted sexual verbal or sexual contact to peer pressure to manipulation (e.g., trying to secure sex through money or gifts) to sexual assault.

Results and Analysis

Of the 79 websites reviewed, 18 met the inclusion criteria. In addition, the Health Canada and Public Health Agency of Canada pages on HIV/AIDS were included because a number of the included websites linked to them. The Canadian Federation for Sexual Health was also included because it had a disability and sexuality section, though not aimed at youth exclusively. Of the 21 websites in the sample, four discussed disability and sexuality. Three of these were youth-specific (Table 1). Overall, we found more disability-specific information than we had expected.

Accessibility and Relevance

Of the four websites with information on disability and sexuality, one depicted disability with three images showing wheelchair use. For information about HIV/AIDS and other STIs, the pages on disability linked back to the information aimed at the general population. As such, none of the prevention information on these websites specifically referred to mobility, verbal and cognitive abilities, disabling barriers, or the heightened sexual vulnerability of youth with disabilities.

Messaging

Generally, the messaging across websites was consistent: they were sex-positive, gay-positive, and non-judgmental about diverse sexual expression among youth. One of the most consistent messages across all of the sites was to encourage young people to ask questions, "get the facts," or "be informed" about sexuality, relationships, and STIs. More than half of the sites (13/21) provided interactive Question and Answer sections or blogs to allow youth to ask questions or read more online information anonymously. Most sites encouraged youth to seek health care from specialized clinics and provided contact information.

All websites urged young people to get tested, most noting that testing is the only way to be certain about having an STI. Nine of the 21 websites explained the nature and availability of anonymous testing. In those jurisdictions where HIV and other STIs are reportable, issues of confidentiality and disclosure, including disclosure to parents, were discussed. None of the government websites discussed anonymous testing, although they all stressed the importance of getting tested.

All websites in the sample advocated condom use explicitly and offered "how-to" information for condoms and other barrier methods. Fourteen of the 21 websites discussed the emotional and/or health risks of multiple partners in a matter-of-fact tone that stressed the importance of using new barrier methods for each partner and each encounter. Information on these websites frequently

encouraged youth to communicate with their partners, particularly about using condoms and other barrier methods.

More than half of the websites explicitly discussed the importance of consensual sex, usually in the context of encouraging youth to assess their readiness for sexual relationships: "Only you can know when you are ready" was a common theme. Websites that dealt with the issue of coercion (14/21) argued that any unwanted sexual contact is assault and provided referral information for youth who felt they had been coerced.

Disability-related information on healthy sexuality

The four sites in the sample that addressed sexuality and disability directly were Canadian Federation for Sexual Health (though not youth-specific); Spiderbytes; Teaching Sexual Health/Alberta Health Services; and Teen Talk Klinic. The information on sexuality and disability clustered around consistent themes: the nature of sexuality and its expression; sexual enjoyment and techniques for improving it; sexual and reproductive rights and responsibilities; safer sex; and sexual assault or coercion. The discussion aimed at people with disabilities about communication and sexual enjoyment did not include much about multiple partners and often appeared to assume an ongoing relationship between two people.

Three of the four sites with sections on disability aimed their material at people with disabilities themselves. One, Teen Talk Klinic, was less clear on its

target audience. Although some material seemed to be aimed at youth with disabilities themselves, most seem designed to combat ableist attitudes among non-disabled youth. For example, they use a Question and Answer format with questions such as "Do people with disabilities have sex?" This ambivalence about its target audience raises the question whether youth with disabilities using this site may feel as if they are being treated as "the other" when reading about themselves in this way.

However, the message that "people with disabilities are sexual" was strong throughout, implicitly or explicitly framed as a response to the "myth" that they are not. A related theme on these sites was that sexuality is individual and can be expressed many ways. All sites suggested general alternatives to sexual intercourse as fulfilling ways to express and enjoy sexuality. For example, the Spiderbytes site tells youth with disabilities: "There are many types of disability. People's bodies can also change over time. Everyone is different, as are their levels of ability. The key is knowing yourself." Another repeated message regarding sexual expression and enjoyment is that people need to be creative and flexible in their approach to sexuality (Teen Talk Klinic). A related message regarding sexual enjoyment was that communication is essential:

> A couple should talk about everything – from planning sexual activity, getting to know likes and dislikes, sharing sexual fantasies and other ways of turning each other on. It also means dealing honestly with anger, fear, frustration, shame and feelings about any loss of sensation associated with the disability (Spiderbytes).

The Teen Talk Klinic site goes so far as to suggest having a disability may be an advantage in relation to sexuality.

> In a way, having a disability can actually become a positive advantage when it comes to sex. It means that you need to learn how to communicate and be up-front about what works for you and what doesn't. Having to change and adapt the standard "script" means you have to be flexible and creative. And you have to focus on what actually feels best for you and your partner, instead of getting hung-up about what's "normal" or how you're "supposed" to have sex. And those are the real secrets of great sex for everybody (Teen Talk Klinic).

Two sites offered general how-to advice for enjoyable sex: Alberta Health Services and Sexualityandu. The Alberta Health Services site also offered advice for specific conditions (e.g., head and spinal injuries, arthritis, multiple sclerosis) on specific topics (e.g., male and female fertility, birth control, "altered sexual functioning", erectile dysfunction, and vaginal dryness), though not directed at youth with disabilities. The Spiderbytes site discussed the pros and cons of facilitated sex, that is, having personal attendants present to help with positioning and contraceptives.

The concept that people have sexual "rights" along with human and legal rights, figures more prominently in the disability-related material than in the information in the rest of the sample. Though other websites in the total sample did include many ideas related to a discussion of sexual rights, they did not discuss "rights" per se. One site that explicitly discussed sexual rights, Spiderbytes, offered the following: "There are several principles that the disabled

community, reproductive health organizations, and legal professionals all agree on. Knowing these rights can help you to safely discover your own sexuality." However, for specific advice on how to have safer sex, such as condom use, these sites linked directly to other parts of the site aimed at the general youth population.

The Canadian Federation for Sexual Health particularly emphasized rights, but primarily in their information on "Sexuality, Disability & GLBTQI". They point out that GLBTQI people with disabilities have a right to the "same kinds of services and supports that a heterosexual or non-disabled person would receive" including support in developing a social network, receiving appropriate sexual education, respect for their relationships, and access to comprehensive health care. This page urges readers to file a human rights complaint if necessary.

The issues of assault and coercion are also dealt with in the context of sexual rights. In the material on sexuality and disability, the primary safety advice is to "Inform yourself about how to be as safe as possible" and "Being informed about your sexual and reproductive rights can help to protect you from violence" (CFSH). Although there is an awareness of the increased risk of sexual violence that people with disabilities face, specific safety tips are derived from the information aimed at the general population. The Canadian Federation for Sexual Health site offers the following tips for avoiding coercion and violence.

- Learn more about healthy and unhealthy relationships so you can identify potentially abusive situations.
- Be confident and assertive when establishing your limits in a sexual situation.
- Be aware that excessive consumption of alcohol and/or drugs may put you in a potentially risky situation.
- Carry a whistle.
- Keep informed about violence against women in your community. If this information is not readily available, pressure the police to keep the community informed (CFSH).

Note that the only concrete suggestion in this list, "carry a whistle" may not be physically practical for people with certain kinds of disabilities.

Conclusion

As noted, we found more web-based information directed toward people with disabilities and youth with disabilities in particular than we had expected. Furthermore, the material studied offered clear, consistent sex-positive messages that supported sexual diversity, promoted prevention and testing, and encouraged self-awareness and personal choice. Those websites that addressed sexuality and disability challenged the stereotype of people with disabilities as asexual. They urged youth with disabilities to protect themselves from STIs, primarily through barrier methods, but also by considering regular testing and by developing self-confidence in sexual situations.

This study does, however, suggest that there is little Canadian-based information about sexuality and disability for youth. There are likely non-Canadian accessible and relevant English-language information for youth with

disabilities available. However, there are important clinical (e.g., finding a specialized clinic), legal (e.g., anonymous testing) and peer support components to STI prevention that make access to local information necessary.

Only one website we reviewed had images of disability, and all three of these images were wheelchair-related, reflecting only one part of the diverse disability community. Furthermore, the absence of a substantial discussion of multiple partners in the sexuality and disability material suggests an underlying assumption that youth with disabilities are less likely to have multiple partners and more likely to be in a relationship that allows for the extensive communication they recommend. Extant and recent research suggests that this assumption is dangerously false (Goldman, 1994; McClelland et al., 2012; Rioux, 1995).

A number of the websites seem to recognize the limitations of passive health information by offering workshops and training, which suggests that organizations recognize the need for more intensive support and education for youth in matters of sexuality. Presumably, this need is even more acute for youth with disabilities, who not only need information designed to be accessible and relevant to them, but who are also socially disadvantaged.

Finally, the messages about assertiveness and self-confidence may be somewhat abstract for some youth and are certainly acontextual. The difficulty of conducting health promotion campaigns that adequately address the social

determinants of health is widely discussed and is certainly not unique to those

working in sexual health and youth, with or without disabilities (Raphael, 2008).

A number of authors have argued that health education and promotion campaigns

reflect a neo-liberal illusion of individual responsibility for health risks that are

rooted in circumstances beyond any one individual's control (Adam, 2006;

Dodds, 2006). In the context of poverty, social exclusion, cultural norms, and

other social determinants of health, youths' lack of assertiveness and self-

confidence are not merely matters of their not having "the facts." Simply urging

youth with disabilities to develop their self-confidence could have little impact.

Overall, more research is needed to understand where youth with

disabilities access information about sexual health, how they interpret that

information, whether it affects their behaviour, and what kind of supports and

information are needed to do so. The material encourages sexual expression on

the one hand without specific tools for safety on the other—potentially a "perfect

storm" for increased risk of STIs among youth with disabilities.

This study has a number of limitations. We are not certain where youth

with disabilities look for information on sexuality. Finding this information from

websites depends on the skill of the user and the availability of the technology.

Furthermore, websites are not static: one of the websites reviewed has since been

completely changed.[2] This state of constant change in web-based health information makes the need for dialogue between health educators and youth with disability for future development of material even more apparent. We also need a rigorous analysis of the technical accessibility of these websites to youth with a range of disabilities.

Recommendations for health education providers

Improving the accessibility and relevance of sexual health information for youth with disabilities must be part of the broader discussion of equality and non-discrimination in health promotion to disadvantaged groups. Sexual health websites targeting youth should take disability into account, both in terms of information accessibility and usability.

A number of fairly straightforward strategies may help youth sexual health campaigns begin to reach out to youth with disabilities. One basic step is to include images of youth with various disabilities and images of sexuality and disability. In terms of information access, a first step is to provide large print and plain text options of both the website and downloadable information. More significant improvements in accessibility require redesigning websites to be fully compatible with accessibility guidelines, including the use of captioning as

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[2] Due to time and resource constraints, the revised website was not analyzed for this study.

necessary. This will, however, require a commitment from funders to ensure that organizations have the resources to make this a realistic option.

A more intensive analysis of the readability of website material is needed to ensure that it is understandable to a diversity of youth with disabilities. Although most of the websites we reviewed had low grade reading levels (Table 2), the Flesch-Kincaid scale is only one, rather basic measure, and perhaps not the best one for this audience (Friedman and Hoffman-Goetz, 2006).

There is a clear need to develop safe sex information that takes into account a wide range of physical, sensory, and intellectual access needs. Additionally, youth with disabilities need forums in which to explore and learn about how to safely navigate sexuality and sexual relationships in their social context. In doing so, the relative merits of cross-disability versus disability-specific approaches are worthy of investigation. Youth may benefit from – and indeed may be more likely to seek out – websites that address particular sexuality and sexual health issues in relation to physical, cognitive, visual, or hearing impairments. More research into the effectiveness of new and existing materials, as well as that of alternative education strategies such as one-on-one or small-group education for youth with disabilities, is also needed. The potential role of peer outreach also merits exploration.

This study indicates an urgent need to better understand and address the specialized sexual health promotion needs of youth with disabilities, and has

suggested several areas where research is needed. Agencies with a developed

program of education and outreach may be well-positioned to provide leadership

in the development of disability-related youth sexual health websites and other

materials. In addition to consultation with researchers and service providers,

engaging a diversity of youth with disabilities in the process of research and

development is important to help ensure that materials and strategies are

contextualized, relevant, and accessible.

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