HARD TO HEAR: ACCESS TO SEXUALITY RESOURCES IN DEAF COMMUNITIES

Deafness is a silent disability. Those who are deaf are excluded from dominant culture despite walking through it and cannot learn cultural cues or scientific information through overhearing, radio, or music.[1] Deafness can also separate children from their parents, who are rarely encouraged to learn sign language.[2] In addition to the physical attribute of deafness, there is a culture of Deafness with common characteristics, a particular way of life, and a common language which uses the capital letter D to differentiate itself from the physical condition of deafness.[3] Like other cultures and physical conditions, Deafness requires particular consideration when it comes to sexual education and health. Over five percent of the global population has disabling hearing loss.[4] Some of this hearing loss is a result of HIV/AIDS-related illnesses or the medication used to treat them.[5] The deaf and hard of hearing population experiences challenges accessing sexual information and health care. This paper explores such difficulties by examining the challenges of access, the impact that these challenges have on the Deaf community, and recommendations for change.

Problem

Issues with access to information and care begin as early as infancy, where most children would overhear simple information about sexuality, HIV/AIDS, and romantic relationships.[6] This trend continues into later life, with an inability to overhear and converse with peers at school or work, listen to the radio, or attend lectures designed for the hearing population.[7] Indeed, a study by Sarah Suter, Wendy McCracken, and Rachel Calam's found that 80 percent of deaf undergrads rely primarily on their friends for sexual information and 72 percent of deaf undergraduate women frequently asked their female friends for it.[8]

These problems continue through school. In "The Sexualized Body of the Child," Michel Desjardins explores the societal construction of mentally handicapped adults as innocent, child-like, and correspondingly asexual. The seraphic understanding of these adults impacts the choices they are given regarding their own sexuality.[9] Similarly, deafness is a type of physical condition that is stereotyped as asexual, which impacts the curriculum for Deaf schools. Many schools have overlooked basic education about the human body and sexuality required for understanding HIV and sexually transmitted infections.[10] School nurses are expected to tend to the needs of children while maintaining an image of the school that is acceptable to parents and the government, which can increase pressure to provide less sexual information.[11] Guest lecturers pose a new problem: since many popular lecturers are hearing and not fluent in

sign language, they require an interpreter. However, interpreters cannot capture the dynamism of a discussion well enough to portray the depth of information exchanged in a classroom with several students, and the bias or embarrassment of the interpreter may get in the way of the translation. As a result, schools have to decide which is more valuable: a guest speaker who may not be well understood, or a teacher fluent in sign language who is telling the story of another person which may have less impact.[12] This understanding of deaf people as seraphic also disregards their needs when creating sexuality pamphlets. The average reading level of deaf adults after completing school is between fourth and eighth grade, but pamphlets are designed at an eighth grade level. This, in addition to an absence of visual aids like pictures and drawings, can make these pamphlets particularly difficult for the deaf.[13]

Outside of school, deaf people are seven times more likely than their hearing counterparts to get most of their HIV/AIDS information from friends. This can lead to misinformation about sexual health.[14] While older Deaf people list newspapers and television as their primary sources of sexuality education, Deaf people in their twenties and thirties learned about sexuality through school programs.[15] This points to an increase in school-based sexuality education for Deaf people. There is still work to be done, however, and access to information is not the only hurdle with regards to sexuality.

Accessibility continues to be a struggle in health care, where problems begin before even getting to the doctor's office. Deaf patients usually do not seek medical care until they are very sick, and when they do seek help there are new challenges.[16] Even making an appointment can be a challenge, as it is impossible to call on the phone, and many doctors' offices do not have teletypewriters to allow written communication.[17] Not addressed in the papers explored is the advent of email communication and its prevalence in doctor's offices. While it is now theoretically possible to email a doctor, many offices still only accept phone calls, and finding an office that would accept appointments and inquiries via email is a new challenge. In addition, the reading level of the Deaf community is low, and email lends the possibility of very long emails that are difficult to read and understand.[18] Beyond teletypewriting and emailing, a deaf person could ask someone else to call for them. This, however, impedes their privacy, and particularly disincentivizes pursuing sexual health.[19]

Once in to see the doctor, a deaf person has limited options and multiple struggles with communication. As with making an appointment, they can elect to invite an interpreter or family member into their session, but this reduces privacy once more. Deaf patients are often reluctant to have their family members present for a meeting about sexual health, and complain of the small number of interpreters, which additionally reduces comfort.[20] Patients who have brought in family have found that their relatives are asked directly about the patient's sexual history, despite their potential lack of knowledge.[21] If a patient goes alone, they struggle with stigma of deafness and the doctor's ignorance on how to communicate with them. Many doctors do not know to ensure they are looking directly at their patient to facilitate lipreading.[22] Some, with an absence of sign language abilities, will attempt to communicate with gestures, or through nurses with a small amount of sign. One youth received a "thumbs up" from his doctor to let him know he did not have AIDS, and another former drug user was shown a nurse who knew only very basic sign language. He expressed frustration, and said he "wanted to be able to sign and discuss deeply," but was not able.[23] Patients have been treated disrespectfully when they admit they are deaf and will often feign hearing ability, increasing miscommunication.[24] These barriers between the Deaf community and the medical establishment mean patients are perpetually choosing between the potential for bad communication or an invasion of privacy from interpreters or family.[25]

A concern specific to HIV/AIDS is that of hearing loss that can be caused by the illness or the medication to treat it. A study by Yael Bat-Chava, Daniela Martin, and Joseph G. Kosciw found that two deaf people had lost their hearing due to AIDS-related illnesses, and had never been referred to an agency to help with hearing loss. One of these two only discovered their HIV status after losing hearing in one ear, causing both vertigo and tinnitus. There was no audiological care or follow up. They were instead referred to hospitals and eventually a hearing rehabilitation agency.[26]

Impact

The consequence of the obstacles with sexual understanding and medical health include issues with HIV/AIDS. The understanding of HIV transmission is limited, as many asked in the study by Bat-Chava, Martin, and Kosciw thought it could be transmitted by masturbation, could not be contracted by married people, and that sex with intravenous drug users did not pose a risk for transmission.[27] Deaf people's concerns about

confidentiality can keep them from getting an HIV test, and relatively few have been tested for HIV.[28] All this leads to an estimated five percent of deaf people living with HIV, as compared to 3% of the general population.[29] It is therefore logical that other sexuality, relationship, and sexual health issues are more widespread in the deaf community than they are among the hearing.

There is more than sexual health in jeopardy. Studies have shown that sexual offences are over-represented in deaf offenders seen for psychiatric evaluation. Susanne Iqbal, Mairead Dolan, and Brendan Monteiro performed a study to examine this in closer detail, examining the records of deaf sex offenders from 1969–2002 in the United Kingdom.[30] Before detailing this study, it is important to note that they define the offenders as people who have been convicted of *or* charged with sexual offences, and that these offences include anal intercourse.[31] The paper does not go into detail about which offences are which, nor does it differentiate between charged or convicted crimes. In their study of 140 male subjects, only one had received a sexual education.[32] 44 percent had a history of non-sex crimes, compared to 76.9 percent of hearing sexual offenders.[33] 89 percent of the crimes were only sexual in nature, much higher than the hearing group, and only 10.2 percent were non-contact offences such as exhibitionism.[34] The deaf population surveyed had a tendency to attribute their offending to their deafness.[35] Indeed, the highly sexual representation of the crimes and an overrepresentation of sexual offences in the Deaf community suggests a lack of education causes barriers to healthy sexual communication and function. Iqbal, Dolan, and Monteiro suggest that "lack of sex education and limited opportunities to develop intimate relationships may have contributed to an aberrant psychosexual development in [this] sample."[36]

Lack of knowledge has extended to sexual abuse of the deaf population. In 2012, a class-action lawsuit was filed against the Clerics of St-Viateur who worked at the Montréal Institute for the Deaf. 64 claimants filed against 28 religious staff and six lay workers who had worked at the institute from 1940–1982. Ex-students who have come forward relay stories of becoming "sex slaves," with one boy being repeatedly abused by at least six people in the school, and being sent to the infirmary to treat their anuses, which were injured from repeated "violent" sodomy, only to be abused more at the infirmary. One boy recalls thinking "that's how it worked. That... every night, you had to have sexual contact with the brothers."[37] The trials are scheduled to start some time in 2014.[38] While it is not unheard of for boarding schools to have histories of unwelcome contact with their students, the issue becomes muddier and more

difficult for the Deaf population. Firstly, the inability to overhear conversations about sexual appropriateness, radio shows about unwelcome sexuality, or other relevant topics means that there is less chance a Deaf student would become aware that they were being abused than a hearing one. Secondly, because many parents do not know sign language and deaf children struggle with oral language, it would be more difficult than for a hearing child to explain what was going on at school, or that something was going wrong at all. Thirdly, a dearth of alternative schools means revealing abuse may remove deaf students from their community. Even a teacher at the school Montréal Institute for the Deaf, who had been abused as a student, did not tell the police when his own student revealed abuse by the brothers. This combination of sexual misinformation, communication struggles, and desire to preserve community relates not only to issues in sexuality education, but also general accessibility for Deaf people.

Recommendations

Despite these examples, the situation of Deaf people is not all bad and is improving. The Bat-Chava, Martin, and Kosciw study showed that adolescents in 2005 had been taught about HIV/AIDS in school and perceived information as freely available.[39] Suter, McCracken, and Calam's study showed deaf students declared learning more about relationships at school than their hearing counterparts, and were more generally satisfied about how much they had learned at school about abusive and positive relationships, and feelings during puberty.[40] An excellent example of the positive impact of targeted sexuality education is Deaf people from the city of Rochester having a comparatively higher HIV/AIDS understanding than their New York state peers. This was attributed to the local college for deaf students which necessitated the surrounding community become more aware of the particular needs of deaf people.[41] These improvements are positive and hopeful, but there is still much work to be done in health care, education, and general society.

HIV/AIDS and other sexuality education for the Deaf is best offered in sign language, preferably in small groups to facilitate discussion, by culturally Deaf educators.[42] It is important that these courses include Deaf slang as part of the curriculum and demonstrate the different meanings of signs. For instance, one student referred to a close friend as a "lover," not knowing the difference.[43] The educational materials offered must use simpler language and be visually focused instead of literature centered.[44] In class, Deaf guest lecturers and role models should be brought in, so Deaf students can properly discuss and understand the

material addressed, and reduce the "it can't happen to me" attitude that can be common when using only hearing speakers.[45] When guest lecturers are not brought in, students stressed the desire for teachers being less embarrassed about the subject matter as their most important concern.[46] It is pertinent for school programs to discuss alternate families' structures such as step families and families of choice. Since the families of Deaf people do not always learn sign language, many Deaf students choose people from within the Deaf community as their family due to a limited ability to be close with their blood relatives.[47] Finally, it is crucial to recognize specific needs of different intersections within the Deaf populations such as sexual orientation, ethnicity, and education level. For instance, African American Deaf people have their own dialect of sign language and must have sexual education in that dialect to be effective.[48]

For medical accessibility, health care providers must know the different needs of the sign language using deaf population, the oral deaf population, and the hard of hearing, and be able to accommodate them.[49] For oral deaf and hard of hearing, this means ensuring face-to-face communication while speaking, and offering alternate means, like email, to make appointments or follow up on appointments. For deaf people who communicate through sign language, accessibility entails teletypewriters for appointment set up. Ideally, doctors who can communicate fluently in sign language would be encouraged, as well as receptionists and nurses. Short of this, it could be recommended to have an interpreter who deals primarily with medical issues and is bound under the same confidentiality rules as the doctor, to alleviate fears of privacy violation. Schools, hospitals, and organizations for the Deaf should offer lists of Deaf-friendly health services like HIV and STI testing sites, medical clinics, physicians, and sexuality hotlines that can be accessed with teletypewriters, such as the American Center for Disease Control's AIDS hotline, counselors, and service providers. Such lists already exist for gay and lesbian communities, and the Deaf lists can be modeled after them.[50]

HIV and STI testing must also be available for all people. HIV test sites should offer information on interpreter referral services, as well as employing an HIV counselor who can communicate fluently in sign language for areas with high Deaf populations. HIV testing clinics should have educational material available about HIV-related hearing loss referring patients to appropriate services.[51]

Something difficult to study, but still important, is the influence of parents. Adolescents surveyed by Suter, McCracken, and Calam stated they would appreciate being able to discuss sexuality with their parents. This could lead to less sexual misinformation and influence from peers.[52] However, the biggest barrier to discussing sex in this context is that often parents do not learn sign language, and can thus never communicate fully with their children.[53] This is a larger problem of acceptance of the Deaf culture, and relates to the social change that is required to accept Deaf people and encourage family contact through Deafness, rather than trying to cure it. Since Deaf students taught orally have less academic success than those taught through sign language, a good way to encourage familial bonds, education overall, and increased sexual understanding is to promote the learning of sign language for families of deaf children.

When asked, the Deaf people in the examined papers prioritized learning about relationship building, safe sex, the first time to have sex, and confidence building to say no to sexual intercourse.[54] All thought that sexual information should be taught in sign language, both in small group discussions and on video tapes. Closed captions often pose the same problems as textheavy reading materials, being difficult to understand.[55]

Conclusion

Deaf populations face considerable challenges in accessing sexual education, including some that require specialized solutions. One approach is to create visual resources like pamphlets which have clear images and are written at a lower reading level. This has the added benefit of making these resources more accessible to nonnative English speakers and other people with lower levels of literacy. Ideally Deaf students would have access to sexual education instructors fluent in ASL. A small group format would also be optimal, if not always practical. If this is not possible, video resources with ASL interpretation, as opposed to closed captions, are a good second choice. The ideal health care situation is one in which caregivers themselves are fluent in ASL, and where appointments can be made by teletypewriter. This includes STI and HIV testing clinics. Barring this, a good option is to have a confidential ASL interpreter available. Sexual health resources should include pamphlets about HIV/AIDS related hearing loss. Finally, there should be lists compiled of accessible sexual health care locations and sexual information resources for Deaf people, similar to the "Pink Pages" for gay communities.

To supplement this research, it would be pertinent to study the impact of the internet on the sexual education and perceptions of Deaf people. It would also be useful to compare rates of sexual health understanding and accessibility in different countries, including Canada, with both ASL and Quebecois Sign Language (LSQ). Of course, the benefits of improving the sexual education of Deaf people do not end with the improvement of sexual health for Deaf people. Because some have sex with hearing people, the benefits of improved education are unlikely to be confined to Deaf communities.

Endnotes

[1] Christine L. Gannon, "The Deaf Community and Sexuality Education," *Sexuality & Disability* 16, no. 4 (1998): 285.
[2] Yael Bat-Chava, Daniela Martin, and Joseph G. Kosciw, "Barriers to HIV/AIDS Knowledge and Prevention among Deaf and Hard of Hearing People," *Aids Care* 17, no. 5 (2005): 494.
[3] Gannon, "Sexuality Education," 284.
[4] "Deafness and hearing loss," *WHO Online*.
[5] Bat-Chava, Martin, and Kosciw, "Barriers," 623.
[6] Gannon, "Sexuality Education," 285.
[7] Bat-Chava, Martin, and Kosciw, "Barriers," 624.
[8] Sarah Suter, Wendy McCracken, and Rachel Calam, "The Views, Verdict and Recommendations For School And Home Sex And Relationships Education By Young Deaf And Hearing People," *Sex Education* 12, no. 2 (2012): 148–155.
[9] Michel Desjardins, "The Sexualized Body of the Child: Parents and the Politics of 'Voluntary' Sterilization of People Labeled Intellectually Disabled," in *Sex and Disability*, eds. Robert McRuer and Anna Mollow. (Durham, NC: Duke University Press, 2012), 70;
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[10] Bat-Chava, Martin, and Kosciw, "Barriers," 624.
[11] Suter, McCracken, and Calam, "Views," 149.
[12] Gannon, "Sexuality Education," 288.
[13] Bat-Chava, Martin, and Kosciw, "Barriers," 624.
[14] Ibid., 625.
[15] Ibid., 629.
[16] Ibid., 625.
[17] Gannon, "Sexuality Education," 285.
[18] Gannon, "Sexuality Education," 285.
[19] Ibid.
[20] Bat-Chava, Martin, and Kosciw, "Barriers," 632.
[21] Gannon, "Sexuality Education," 287.
[22] Bat-Chava, Martin, and Kosciw, "Barriers," 629.
[23] Ibid., 630.
[24] Ibid., 632.
[25] Bat-Chava, Martin, and Kosciw, "Barriers," 630.
[26] Ibid., 631.
[27] Ibid., 624.
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[30] Susanne Iqbal, Mairead Dolan, and Brendan Monteiro, "Characteristics Of Deaf Sexual Offenders Referred To A Specialist Mental Health Unit In The UK," *Journal Of Forensic Psychiatry & Psychology* 15, no. 3 (2004): 497.
[31] Ibid., 498.
[32] Ibid., 499.
[33] Ibid., 504.
[34] Ibid., 500.
[35] Ibid., 504.
[36] Ibid., 505.
[37] CBC News, "Montreal school for the deaf's ex-students allege horrific abuses," *CBC News Montreal*, November 26, 2012.
[38] Giuseppe Valiente, "Class-Action Accusing Montreal Clerics of Sexually Abusing Deaf and Mute Children Can Go Ahead, Judge Rules," *Sun News*, August 16, 2013.
[39] Bat-Chava, Martin, and Kosciw, "Barriers," 628.
[40] Suter, McCracken, and Calam, "Views," 153–154.
[41] Bat-Chava, Martin, and Kosciw, "Barriers," 628.
[42] Ibid., 632.
[43] Gannon, "Sexuality Education," 287.
[44] Ibid.
[45] Ibid., 291.
[46] Suter, McCracken, and Calam, "Views," 157.
[47] Gannon, "Sexuality Education," 290.
[48] Ibid., 289.
[49] Bat-Chava, Martin, and Kosciw, "Barriers," 632.
[50] Gannon, "Sexuality Education," 287.
[51] Bat-Chava, Martin, and Kosciw, "Barriers," 633.
[52] Suter, McCracken, and Calam, "Views," 148.
[53] Gannon, "Sexuality Education," 291.
[54] Suter, McCracken, and Calam, "Views," 156.
[55] Bat-Chava, Martin, and Kosciw, "Barriers," 629.

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