IFLA WLIC 2017 WROCŁAW

**Submitted on:** 23.06.2017

# Intersectional and intermodal: Making sexual health information accessible to LGBTQ+ Deaf people

**Martin Morris**
Schulich Library of Physical Sciences, Life Sciences and Engineering, McGill University, Montreal, Canada
martin.morris@mcgill.ca

**Darren Saunders**
Groupe de recherche sur la LSQ et le bilinguisme sourd, Département de linguistique, Université du Québec à Montréal, Montreal, Canada
saunders.darren@uqam.ca

**Alex Iantaffi**
Independent Scholar, Adjunct Faculty at University of Wisconsin-Stout and the University of Minnesota, United States
alex@alexiantaffi.com



## Abstract

***Introduction***
*The Deaf community is culturally and linguistically distinct, with its own history and traditions. Within this framework, Deafness is viewed as a cultural difference and not a disability, and sign languages are a cornerstone of Deaf culture. Deaf people experience discrimination within hearing dominant culture, which often views Deaf culture, including sign languages, as inferior. This type of systemic discrimination is referred to as audism.*

***LGBTQ+ Deaf Sexual health information***
*Barriers to providing sexual health information to Deaf people are linguistic and systemic. Deaf people in general have a lower rate of literacy and have greater trust for visual information originating within the Deaf community. Most sexual health information originates in spoken language which is harder to disseminate to Deaf people who prefer sign languages — a language modality with a distinct structure and culture. The result is a lack of accessible information and higher prevalence of STIs.*

*Deaf LGBTQ+ people are at the intersection between at least two cultures, each with its own cultural norms. In sexual health information these cultural norms may conflict — the greater levels of taboo which already around LGBTQ+ sexual practices are exacerbated with the need to represent these visually, for example. Further issues can arise when the information is supplied via an interpreter whose personal values may interfere.*

***Conclusion***
*In this presentation we will discuss the main cultural and intersectional challenges in designing sexual health information for LGBTQ+ Deaf people, and provide recommendations. We will support our suggestions with recent data from the US D-P@RK study with Deaf MSM, and with examples of good practice from the Coalition SIDA des sourds du Québec. The* authors believe that this information will usefully inform the work of health information providers working with Deaf LGBTQ+ people.

**Introduction**

The Deaf community is culturally and linguistically distinct, with its own history and traditions, and with sign languages being a cornerstone [1]. As most Deaf children (90-95%) are born within hearing families [2], this culture is largely transmitted horizontally, where they discover their Deaf identities and culture from other Deaf people outside their families, as opposed to vertically, where culture and identities are transmitted within families. With the cultural and linguistic heritage that exists in the Deaf community, members of this community identify as a cultural and linguistic minority as opposed to being disabled [3]. Deaf people experience discrimination within hearing dominant culture, which often views Deaf culture as inferior and limited when compared to the mainstream society. This type of systemic discrimination is referred to as audism [4]. Furthermore, this form of discrimination denies full and clear access to information to members of the Deaf community, as citizens in their own right. This includes sexual health information.

**LGBTQ+ Deaf Sexual health information**

Systemic barriers to providing sexual health information to Deaf people are language [5], communication [6] and audism [7]; the last of these three will be discussed here. Owing to poor access to education and systematic failings in the early years education of deaf children, depriving most of a natural language such as sign language, Deaf people have a lower rate of literacy. Since Deaf people form their own communities where they share identity, language and culture, these factors result in a greater trust in Deaf-originated visual information [8]. Most sexual health information, however, originates in spoken language, serving the hearing majority who use a different language modality (spoken with its written system); this makes it harder to disseminate crucial sexual health information to Deaf people who prefer sign languages — a distinct language modality. This form of audism, through discrepancies in the diffusion of sexual health information, results in a lack of accessible information which in turn leads to a higher prevalence of STIs and HIV among Deaf people [9].

While it is difficult to estimate exactly how many Deaf people are HIV positive or at higher risk of infection, data from Maryland (USA) indicate that the prevalence of HIV in deaf and hard-of-hearing individuals is 2 to 5 times higher than for hearing people [10]. The small numbers of studies available in various countries show that the level of HIV/AIDS knowledge is low among Deaf people, including adolescents [5]. This seems to be due to the lack of sexual health education in residential or specialist schools, as well as a lack of access to information in mainstream settings. Deaf people also experience a high prevalence of co-factors for HIV and STIs risk including stigma, polysubstance use, and a history of male childhood sexual abuse. Despite the greater risk, sexual health services available to Deaf people, including prevention, education and testing services, are very limited and, in some geographical areas, non-existent.

***Case Study: Coalition Sida des Sourds du Québec***

*Coalition Sida des Sourds du Québec (CSSQ)* is a provincial organisation which produces preventive sexual health information for LGBTQ+ and heterosexual Deaf people. It was founded in 1992 by a Deaf leader, is run by Deaf people, and provides services for Deaf people in Quebec with a full understanding of their needs, be it linguistic or cultural. It is currently receiving funding from both the federal and provincial governments, in recognition of the specific needs of the Deaf community in Quebec.

We provide here some examples of discussions of sexual practices provided on the CSSQ web site of CSSQ (www.cssq.org), in both Quebec Sign Language (LSQ) and American Sign Language (ASL); these are in the form of video capsules and illustrations. Signs relating to sexual health and practices are often graphic owing to the visual nature of sign languages; a discussion of which is beyond the scope of this paper. An example is shown in Figure 1:

**Figure 1: Screenshot of an ASL video capsule on the risks associated with anal penetration (http://www.cssq.org/english/intercourse-penile-anal.html)**

In addition to video capsules, CSSQ also produce a variety of literature which are geared for the Deaf community, in both English and French), which are also visual to ensure clarity of information. One such booklet, titled *"Safe Sex for the Deaf and Hard of Hearing Community"*, produced by CSSQ for free distribution, uses a system which resembles traffic lights but with four colours to indicate various degrees of risk associated for each sexual practice:

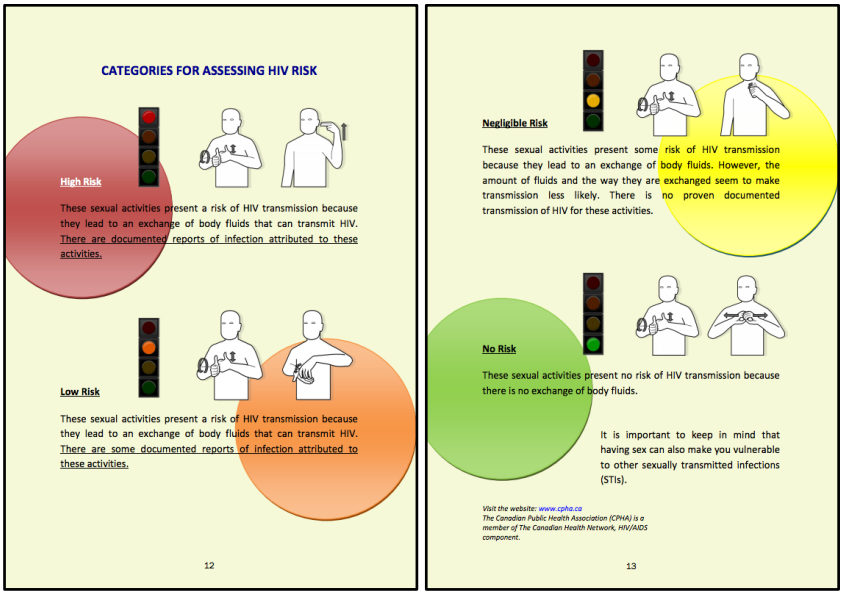


**Figure 2a: CSSQ (2013) "Safe sex for the Deaf and Hard of Hearing community", pp. 12-13**

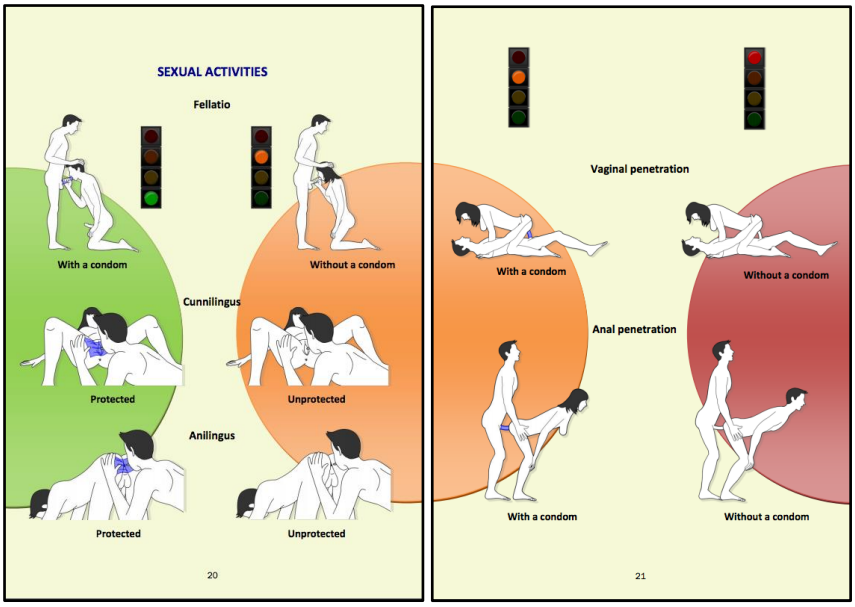


**Figure 2b: CSSQ (2013) "Safe Sex for the Deaf and Hard of Hearing Community", pp. 20-21)**

These graphics could be sometimes deemed too explicit by certain parties but CSSQ consider them necessary to ensure that their message is clearly conveyed to their Deaf readership. The illustrations are often presented with simple clear sentences in English and French:

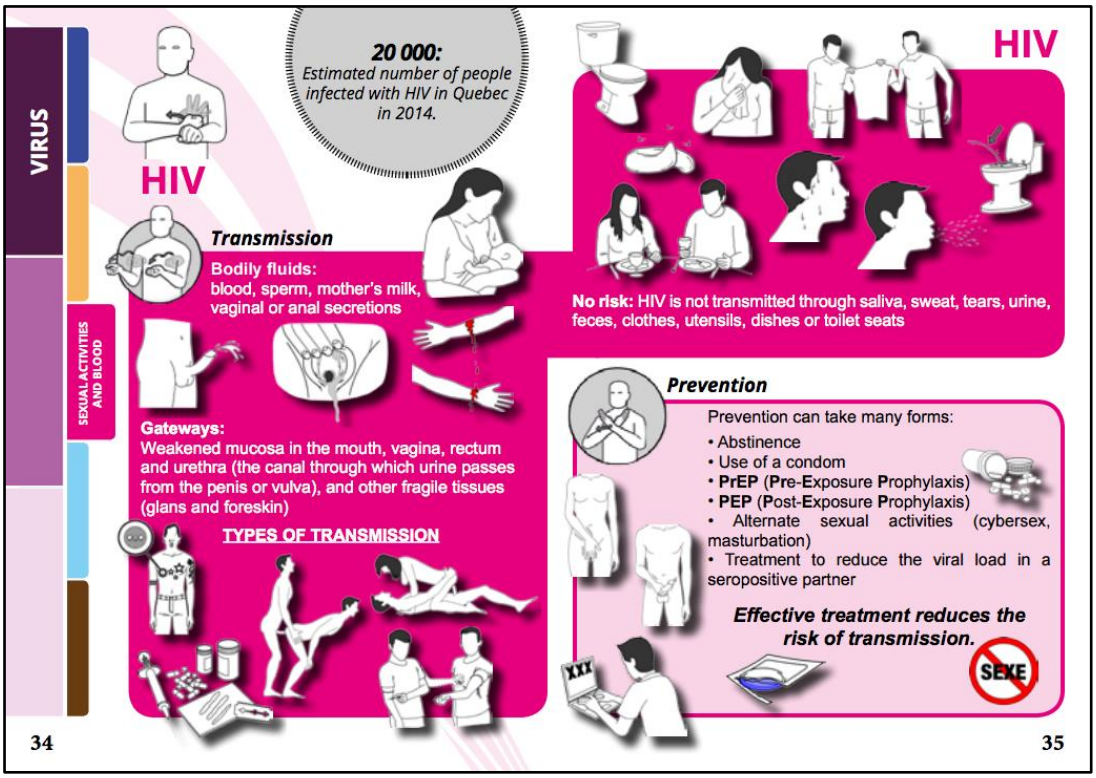


**Figure 3: CSSQ (2015), "Guide: Sexually transmitted and blood-borne infections", pp. 34-35**

This kind of literature are distributed in the Deaf community and to various organisations across the province to ensure Deaf people in all regions can have access to this accessible information to remove linguistic and cultural barriers encountered between the Deaf community and the society in general as well as Deaf LGBTQ+ communities within the Deaf community. However certain organisations who receive these literatures can feel uncomfortable about the LGBTQ+ contents which

raises a growing concern where some people or organizations might consider their values overrides the basic need of the Deaf community to have this accessible information. Should this happen, this can result in poor knowledge of safer sexual practices which can have unfortunate, if not fatal, consequences.

***DP@RK Study***

A taboo around the provision of visual, accessible preventative sexual health information is not the only barrier to the effective communication of this information to the Deaf community. As part of a study of Deaf Men who have Sex with Men (DMSM) in the US [11], Iantaffi and their team conducted qualitative interviews with 28 participants, including key informants such as HIV testing specialists working with this population. Participants were obtained through a video recruitment campaign promoted on a range of social media over a period of ten months. The length of the recruitment campaign included building presence and trust with Deaf individuals and communities both online and offline. Given the stigma associated with both HIV and men having sex with men in the Deaf community, building presence and trust was an essential component of this formative, national study. Overall, the research team conducted in-depth, online qualitative interviews in ASL with 20 DMSM (including trans masculine DMSM), and 8 Key Informants. Semi-structured interviews were conducted using a secure, tailored version of Adobe Acrobat Connect Pro 8, with simultaneous visual and text capacity. The participants were aged between 20 and 59 years old and 31% were people of colour, while the remaining 69% identified as white.

Eight major barriers to HIV prevention, testing and care were identified by participants:

- Communication with health care providers
- Challenges with trusting confidentiality of interpreting services
- Acceptability of HIV counsellors dependent on their identities and attitudes (trust issues)
- Lack of providers' cultural competence
- Limited access to spoken information, which is easily available to hearing MSM
- Mental health issues
- Fear and isolation
- Infantilisation and desexualisation of Deaf people

Power differences and systemic audism were major threads woven through all the barriers mentioned. Six major opportunities were identified by participants to improve HIV testing and services to this population:

- Increased availability of Deaf HIV counsellors or culturally competent and ASL fluent hearing HIV counsellors
- Availability of trained, qualified interpreters specializing in HIV and sexual health (both hearing and Deaf interpreters)
- Synchronous HIV education and testing events led by Deaf people (educate first, then test)
- Improved location of HIV testing to reduce impact of stigma: taking account of visibility and accessibility of the location, and showing awareness of the differences between Deaf vs hearing environments
- Information, education and visibility of HIV resources online, in ASL, to increase knowledge and build trust
- Home testing availability and access.

These results were consistent with the limited published evidence available for this population and experiences of the study's Community Advisory Board who reviewed the themes identified in the process of validating the coding schema.

**Intersectional considerations and implications for health info professionals**

Deaf LGBTQ+ people are at the intersection between at least two cultures [12], each with its own cultural identity and set of norms and communication needs, and each thus requiring distinct cultural competencies. We can see that in sexual health information these communication needs may be affected by taboos — for example, the greater levels of taboo surrounding LGBTQ+ sexual practices are exacerbated with the need for visual representation in communicating with Deaf people. Further issues can arise when the information is mediated via an interpreter or family member, who can potentially be impacted by audism along with other systemic issues such as homophobia or transphobia.

Recent research co-conducted by one of the authors (Morris) [13] strongly suggests that three underlying factors influence

how information professionals, including health information professionals and librarians, relate to LGBTQ+ patrons and to their specific information requests. These are (1) perception of their duty of care and of the vulnerability of the patron, (2) public visibility of the work being conducted, and (3) personal biases and prejudices. While most respondents advised that they were completely comfortable with all aspects of LGBTQ+ library work, a significant minority (roughly a third) were less comfortable with LGBTQ+ library work that is more publicly visible, such as the acquisition and display of sexually explicit material. They were also less comfortable providing sexual health information on such as safer sex and PrEP. We believe that these factors are likely to have a greater impact in a context where the sexual health information is necessarily highly visual.

**Conclusion**

Recent work to advance LGBTQ+ health sciences librarianship [14] has highlighted two paths to fostering a greater familiarity of and comfort with LGBTQ+ library and information work, which we believe are particularly pertinent in the context of Deaf LGBTQ+ sexual health information. These are relevant training and mentoring, and the wider adoption of critically reflective practice among information professionals. In this context we recommend both of these, and both with the input of the Deaf LGBTQ+ community. It is the hope of the authors of this conference presentation that, in highlighting the specific and intersectional context of Deaf LGBTQ+ health information, we might inform the development of future training and add context to the critical reflection we recommend to health information professionals.

**Bibliography**


1. Ringo A. Understanding Deafness: Not everyone wants to be 'fixed' [Internet]. Washington DC: The Atlantic; 2013 [cited 2017 Feb 10]. Available from: https://www.theatlantic.com/health/archive/2013/08/understanding-deafness-not-everyone-wants-to-be-fixed/278527/.
2. Padden C, Humphries T. Deaf in America: Voices from a culture. Cambridge, Mass: Harvard University Press; 1988.
3. Ladd P. Understanding Deaf culture: in search of Deafhood. Clevedon, England; Buffalo: Multilingual Matters; 2003. 502 p.
4. Bauman H-DL. Audism: Exploring the metaphysics of oppression. J Deaf Stud Deaf Educ. 2004;9(2):239-46.
5. Sadler GR, Huang JT, Padden CA, Elion L, Galey TA, Gunsauls DC, et al. Bringing health care information to the Deaf community. J Cancer Educ. 2001;16(2):105-8.
6. Bat-Chava Y, Martin D, Kosciw JG. Barriers to HIV/AIDS knowledge and prevention among deaf and hard of hearing people. AIDS Care. 2005;17(5):623-34.
7. Ferndale D, Watson B, Munro L. An exploration of how health care professionals understand experiences of deafness. Crit Pub Health. 2016:1-13.
8. Getch YQ, Young M, Denny G. Sexuality education for students who are deaf: Current practices and concerns. Sex Disabil. 1998;16(4):269-81.
9. Heiman E, Haynes S, McKee M. Sexual health behaviors of Deaf American Sign Language (ASL) users. Disabil Health J. 2015;8(4):579-85.
10. InterGroup Services, Inc. (IGS) for Associated Black Charities. 2003. An Assessment of the Needs of Deaf and Hard-of-Hearing Persons with HIV in the Baltimore Area. Baltimore, MD: IGS; 2003. Available from: http://www.baltimorepc.org/v2/files/pdf/DeafReport.pdf
11. Iantaffi A, Benoit, C, Rosser SBR, Rose S. D-P@RK Study: Overcoming health disparities to HIV testing for Deaf MSM through the internet. University of Minnesota; 2016. (Unpublished report).
12. Schaad A. An Interview with three deaf lesbians: Intersectionality and saliency of identity variables [dissertation]: Wright State University; 2016.
13. Morris M., Siegel J. Academic librarians and their LGBTQ+ patrons. Poster session presented at ACRL New England; 2017 May 12; Burlington, United States. Available from: http://digitool.library.mcgill.ca/R/-?func=dbin-jump-full&object_id=146486.
14. Hawkins BW, Morris M, Nguyen T, Siegel J, Vardell E. Advancing the conversation: Next steps in LGBTQ health sciences librarianship. J Med Libr Assoc. Forthcoming.

**Biographical Information**

**Martin Morris (likely presenter)**
Martin is a health sciences librarian at McGill University, Montreal, Canada. He has previously worked as a hospital librarian in Montreal, and as a public librarian in the UK. His research interests include the provision of library and information services to LGBTQ+ people, knowledge synthesis methodologies, and the spread of innovations in library and information settings.

**Darren Saunders**
Darren is a doctoral student in linguistics at Université du Québec à Montréal, where he is working on the gestural aspects and perspective changes in Quebec Sign Language (LSQ). He is also a past president of *Coalition SIDA des Sourds du Québec*, an organisation providing sexual health information to Deaf people by Deaf people in Quebec, which he continues to support.

**Alex Iantaffi**
Alex is a family therapist, independent scholar, writer and the Editor in Chief for the Journal of Sexual and Relationship Therapy. He is an adjunct at the University of Wisconsin - Stout and at the University of Minnesota. His research over the past two decades has focused on disability, gender, sexuality, Deafness, relationships, HIV and sexual health. He has undertaken a two years NIH-funded study of Deaf Men who have Sex with Men and HIV testing and prevention.