



Intercultural Challenges of the Deaf HIV/AIDS Epidemic

Guest post by Leila Monaghan

I grew up in New York and worked in the theatre industry in the 1980s. The profound impact of the AIDS epidemic was clear. Death was everywhere. When I returned to school to study Deaf culture I learned of the impact of AIDS on the Deaf community. One of my fellow students at the Gallaudet 1988 summer program was Gene Bourquin, part of the early Gay Men's Health Crisis buddy network providing support for people with AIDS across New York City. From him I learned how the city's flourishing gay Deaf community had been massively impacted. He shared the story of an isolated Deaf man in the Bronx he had worked with, his first buddy and one of the earliest to die.

By 2003, I had my PhD and had finished an edited collection, *Many Ways to be Deaf*. While editing this volume of ethnographic studies of international Deaf communities, I realized that Gene's experiences with the scourge of HIV/AIDS were not unique. Deaf communities from the US to Africa to Asia were struggling to disseminate information, protect people, and care for the sick. This led to a book co-edited with my colleague Constanze Schmaling, a scholar of Hausa Sign Language, *HIV/AIDS and Deaf Communities*, and ongoing intercultural dialogue, sometimes successful, sometimes failed, on the topic of HIV/AIDS and Deaf communities.

I have learned so much from my Deaf colleagues, including my co-authors Deborah Karp and Mark Byrd, and activists including Michel Turgeon and Don Pilling of the remarkable Coalition Sida des Sourds du Québec, and John Meletse of South Africa. My colleagues have shared with me stories of friends dying unsure of why they were so ill, the problems so many Deaf people have interacting with systems built on languages they don't understand, and the lack of attention to and funding of Deaf issues. My main roles have been publicist, organizer, and intermediary, trying to get officials and attendees of the biennial international AIDS conference to understand how the disease has an unusually deadly impact on Deaf communities.

I presented a poster about Deaf HIV rates in the United States at AIDS 2006 in Toronto, presenting data on how US Deaf people were twice as likely to be HIV+ as their hearing counterparts. There I met Michel and Donald Pilling from CSSQ and Deborah Karp from the Maryland Deaf AIDS Project. We organized an informal press conference. While there is often distance between Deaf

groups and Disability Rights groups, everyone came together to discuss the issues around the lack of recognition of the Deaf and Disabled communities within the larger fight against AIDS.

For AIDS 2008 in Mexico City, I organized a Deaf and Disability Pride Zone in the community village and various other events including panels and a press conference. I also lobbied for interpreters. Many people unacquainted with Deaf culture do not understand the practices and needs of professional interpreters. Although two interpreters fluent in Spanish, Mexican Sign Language (LSM), and American Sign Language (ASL) were hired for the conference, they were hired at the last minute and then subjected to grueling conditions.

For AIDS 2010 in Vienna, Jill Hanass-Hancock took over organizing the Disability Zone and I continued to organize Deaf outreach and lobby for interpreters. Because the official languages of the conference were English and Russian (part of an outreach to Eastern Bloc countries because of Russian bans on discussing AIDS), British Sign Language and Russian Sign Language interpreters were hired—languages that no one at the conference was actually using. It took a week of lobbying to get Austrian Sign Language interpreting for the one official Deaf outreach event.

AIDS 2012 in Washington DC presented different challenges and an opportunity was missed to do a Deaf oriented mini-conference at Gallaudet University despite months of lobbying. I was not able to attend AIDS 2014 in Australia or AIDS 2016 in South Africa. I know of no Deaf presence in Melbourne but was delighted to see that Nkosinathi Freddy Ndlovu lead a Deaf outreach in Durban.

Language creates the world as we know it. Successful dialogue shifts the world into new places. While the dialogue has not always been successful, I have learned much from my Deaf colleagues and some of this information is now part of the larger discourse at the international AIDS meetings. Deaf discourse is visual and depends upon understanding not only understanding distinct sign languages, in this case ranging from American Sign Language to British Sign Language, from Russian Sign Language to South African Sign Language, but also the logistics of space and movement involved with communicating in any sign language. Learning the requirements of communication is the first step to communicating ideas and needs.

There is still so much work to be done on the issue of HIV/AIDS in Deaf communities. My colleagues and I continue to try to bring awareness to the issue. Next stop is the AIDS 2018 conference in Amsterdam!

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