

Civil society sue government over absence of sign language interpretation in access to health care

15 August 2017, KAMPALA – Today the Initiative for Social and Economic Rights (ISER), an NGO committed to advancing social and economic rights in Uganda, together with the Uganda National Association of the Deaf (UNAD) converged on the Constitutional Court to call for an end to discrimination against people with hearing disabilities (hereinafter referred to as deaf) in Uganda’s health system.

Today’s petition urges the government to fully meet Constitutional obligations to the deaf by training health personnel in sign language and providing sign language interpreters to people with hearing disabilities at health facilities. Nearly 1.1 million Ugandans suffer from hearing disability, according to the 2014 National Housing and Population Census.

“Our interactions with persons with hearing disabilities across the country revealed a national health system consistently failing to fully protect the human rights of persons with hearing disabilities,” said ISER Executive Director Salima Namusobya. “When the absence of interpreters means an entire community can’t access health counseling or self-advocate in the same way other members of the public can, then what we are talking about is discrimination.”

Such discrimination, advocates for the deaf argue, keeps deaf individuals from being able to enjoy the equal benefit of life-saving public health education alongside the wider public.

“We are left out of health campaigns like *Obulamwamu*,” said Mr. Joseph Mbulamwana, UNAD’s executive director. A 2009 UNAD survey found 90% of deaf Ugandans had never heard about HIV, according to Mr. Mbulamwana and a UNAD policy brief. “During research UNAD conducted on deaf people’s access to HIV/AIDS information, a deaf person who was asked about the ABC (Abstinence, Be Faithful, Use a Condom) strategy to fight HIV/AIDS thought it referred to ABC toothpaste.”

Many deaf individuals reported to ISER that health workers often administer medication or laboratory procedures such as HIV testing to them without providing proper counseling before or after. Several reported that health workers often fail to clearly explain the purpose or results of testing.

Health workers have similarly voiced limitations in their ability to cater to deaf patients in the absence of sign language interpreters and health workers trained in sign language. These barriers complicate providers’ efforts to give patients HIV counseling or other information. “There are instances when I want to ask deaf patients questions in order to get more information about an illness, condition or sexual behavior, but there is no way of effectively communicating with them,” a medical doctor in Kamuli noted. “I want to know more about the problem I am trying to treat, but I fail because of the communication barrier.”

Deaf patients reported further concerns to ISER over the lack of privacy created by communication challenges. “There are times when I would prefer to communicate directly with the health worker

alone, but I have no option because I am deaf,” noted one deaf woman forced to include family members on consultations with health workers to aid in communication.

In some cases, family involvement goes even further. If a health worker is unable to directly obtain consent from deaf patients, family members may end up making medical decisions for them – with or without their knowledge. After her deaf daughter gave birth, one mother secretly asked health workers to administer contraceptives to her daughter. When her daughter cut her arm to remove the implant, the mother told health workers to bandage the wound “to trick her into thinking it had been removed,” she said. Only later would the two reach an understanding.

“Patient choice, right to refusal, informed consent– these are basic norms of medical ethics, formally safeguarded in Uganda by the Patients Charter of 2009,” ISER Right to Health Program Officer Nona Tamale said. “Without communication, the deaf don’t enjoy these protections.”

“The experience of being deaf and trying to navigate health facilities without being understood by health workers can be extremely isolating,” said Ambrose Murangira, former UNAD executive director and member of the deaf community. “When that misunderstanding involves insult or neglect on the part of health workers, as it often does, the experience is even more isolating and damaging.”

“The reality is that deaf patients are deprived of full autonomy over their bodies when health workers are unable to communicate even basic medical information to them,” ISER’s Right to Health Program Manager Allana Kembabazi said. “For women with hearing disabilities, the stakes are even higher, especially when they can’t receive the information needed to make their own choices on family planning or reproductive health.”

In recent years, Parliament’s most forceful action tackling discrimination against the deaf came with the 2006 passage of the Persons with Disabilities Act. Designed to broadly eliminate discrimination against people with disabilities, the Act includes the specific requirement that sign language be introduced in the curriculum of health workers and sign language interpreters be provided in hospitals.

“A decade later, ISER’s work monitoring the right to health for vulnerable groups reveals that much stronger action remains necessary to end discrimination against deaf patients,” said Ms. Kembabazi.

Today’s court filing comes after years of UNAD’s advocacy for both government and private institutions to expand sign language training for service providers and providing ad hoc training for some providers.

If the Constitutional Court grants today’s petition, the government will be given one year to furnish a comprehensive framework detailing plans to provide interpreters throughout the health system and to incorporate sign language instruction into curriculum for health workers.

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