



**WORLD FEDERATION
OF THE DEAF**



Pilot Study of Deaf Indigenous Bolivian Women's Health Experiences

March 9-13, 2024

I. Purpose

This is a pilot project focusing on community-based formative research to identify salient issues and factors relating to deaf indigenous women in Bolivia's retrospective and current health experiences. In collaboration with the Bolivian Federation of the Deaf (FEBOS), under the management and supervision of the World Federation of the Deaf (WFD) and with the financial support of the Christian Blind Mission Global Disability Inclusion (CBMG) and the University of Rochester, this research will help better understand future research directions related to lifespan health outcomes and disparities of the deaf women community in Bolivia. This research will also help in the assessment of Rapid Qualitative Inquiry approach as it relates to international deaf communities. The findings of this project may inform health and language policy, and raise community awareness of opportunities to reduce deaf health disparities.

The research team consists of Shazia Siddiqi, Doctor of Medicine at the University of Rochester as Principal Investigator (PI); Cuauhtémoc Contreras, Doctor of Medicine; Carla Caussin Poppe, President of FEBOS, and Alejandro López Florez, Logistics Assistant at WFD. WFD Executive Director, Pamela Molina, led the supervision of the project.

The interviews were conducted during March 9-13, 2024 in Cochabamba, Bolivia. Twenty indigenous deaf women from diverse areas in Bolivia were interviewed about their access to health, COVID-19, sexual and reproductive health knowledge, and Dengue Fever. The data collected attributed to socio-cultural, economic, geographical, health and access to health aspects, in accordance with the Convention on the Rights of Persons with Disabilities and the Bolivian Sign Language (LSB) Law.

II. Context

In Bolivia, deaf women face difficulties in accessing culturally and linguistically-appropriate information in LSB, especially on issues related to their reproductive health, sexual health, sexuality, reproductive rights, prevention of gender-based violence, and communication barriers. In general, research have shown that deaf people have higher rates of mental health issues [1], and higher illiteracy rates related to health knowledge such as cardiovascular health [2] and reproductive health issues [3]. There is high mistrust of medical professionals among deaf people [4]. Deaf



**WORLD FEDERATION
OF THE DEAF**

women have higher rates of reproductive healthcare barriers and adverse birth outcomes compared to their hearing peers [3]. Deaf women have increased risk of chronic medical and pregnancy complications such as pre-eclampsia, low birth weight, and preterm birth [3]. Majority of deaf children (90%) are born to hearing parents [5] and 98% of deaf children have no access to education in sign language [6]. Majority of parents do not sign with their deaf child. Deaf people have language delays when they do not have any full access to sign language from birth and this leads to deaf people having a high risk of language deprivation [7]. In consequence, deaf people have higher rates of illiteracy in reading and writing, lower health literacy, and experience higher rates of domestic violence compared to their hearing peers [8, 9] .

Bolivia signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD) [10] and the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (CIADDIS-OAS) [11], as well as the Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women, Belém do Pará'. [12] Bolivia also has Law 348 [13], the Comprehensive Law to Guarantee Women a Life Free of Violence. However, Bolivia has not yet recognized Sign Language as the official language of deaf people, unlike other countries in the region, which limits the full participation and inclusion of this population, especially deaf women and even more so those who belong to indigenous peoples.

Due to several factors listed above, this is an urgent situation in which the lack of health access and information among the deaf indigenous women of Bolivia needs to be thoroughly explored. Historically, deaf people have been excluded and often overlooked in several research and services pertaining to them. This study, sponsored by CBMG, under the direction of the WFD and FEBOS implementation, proposes a preliminary community assessment survey to identify gaps, facilitators, and barriers that deaf indigenous women of Bolivia encounter when trying to access to healthcare services in their lives and to provide recommendations for effective provision of services at the local and national levels. The overall aim of the community assessment survey is to better understand salient concepts and patterns of health access among deaf indigenous women in Bolivia, which can evolve for a theoretical model that can be tested and refined in subsequent participatory engaged research.

III. Subject Characteristics

Twenty participants were interviewed for this pilot project.

Inclusion criteria involved the following: must be 18 years old and over, self-identified as deaf person, self-identified as a woman, and a resident in Bolivia.

Exclusion criteria involved the following: if participant's age is under 18 years old, does not identify as deaf, does not identify as a woman, and not a Bolivian resident.

IV. Methods



**WORLD FEDERATION
OF THE DEAF**

Under the coordination and supervision of the World Federation of the Deaf (WFD), the national deaf community association, FEBOS, and its president, Carla Poppe, organized the groups and interviews. Ms. Poppe identified and recruited indigenous women from outside of the cities through word-of-mouth among local deaf associations. FEBOS organized discussion groups and interviews such as setting up venue, planning times, and staff check-in. Team members involved in this project, Carla Poppe, Maria Gutierrez Esprella (LSB interpreter), Pamela Molina (WFD Executive Director), Alejandro Lopez (WFD Logistics Assistant), and Cuauhtémoc Contreras (WFD consultant, MD) have undergone Human Subjects Protection (HSP) training based on the Spanish version of the Family Health International (FHI) Bioethics Training for Community Leaders, approved by the University of Rochester Research Subjects Review Board (UR-RSRB). Dr. Siddiqi, the PI, conducted the HSP training on March 10, 2024 to successful completion. Criteria used in implementing well-developed qualitative and quantitative study are that the project must be led by deaf researchers and trainers, research must be conducted in Sign Language, and there must be strong collaboration effort with local Bolivian deaf community.

As followed in the Rapid Qualitative Interview (RQI) Guide, participants were presented with request to video record and were asked if they were willing to be recorded. Waiver of documentation of written consent is requested since literacy is unclear and formal signing of documents in this population is typically restricted to formal legal and contractual transactions. Also, a signature would be the only written identifier in this study. An information sheet about the project and protections was provided to the participants (they got a copy of Spanish version and English version if desired). The information sheet contained the altered HIPAA language with permission to use interview participants' health experiences, which was included as part of the video-recorded interview and transcription. This identifier, video recording, was unavoidable due to the visual nature of Bolivian Sign Language. This project was approved by University of Rochester Research Subjects Review Board.

After potential participants were found (through word-of-mouth), they were asked if were interested in participating in this project through group or individual interviews. The information sheet was then distributed and signed in Spanish and English. Participants were told that the group is video recorded before the group started. Participants who did not want to be video recorded could decline to participate and leave the group.

Ms. Poppe, who knows both American Sign Language (ASL) and LSB, conducted the interviews with Dr. Siddiqi's guidance. When the participants replied in LSB, Ms. Poppe translated to ASL for Dr. Siddiqi. Some participants were offered to read the questions in Spanish (depending on their education level; generally speaking – most indigenous deaf women in Bolivia have no formal education). The information sheet and consent were recorded through sign on video using their own native sign language, LSB.

Once the information sheet was shared, participants were informed that they may choose to stop their participation in the study at any moment, and they may choose to answer or not any of the questions. Interviews averaged to take no more than 60 minutes. Participants were instructed not to disclose any discussion outside of the group or individual interview setting. No payment was



**WORLD FEDERATION
OF THE DEAF**

provided for participation. All interviews were voluntary. Identifying information were not collected on any study materials. Videos and transcripts were stored in secured encrypted computers, and data transmitted using security-compliant systems. All data were de-identified during the analysis process. Only RSRB-approved personnel have access to this information.

The semi-structured interview instrument acted as a guide for all interviews (see Appendix A for interview instrument) and focused on general thoughts and perceptions of deaf Bolivian women's retrospective and current health experiences. The survey consisted of 67 questions which explored demographic information, age of first exposure to sign language, family dynamics, education, access to COVID-19 vaccines, hospitalization for COVID-19, general health care access, communication access in health care settings, pregnancy, sexual and reproductive health, barriers to medical care, and needs for improving health care access. The interviews also covered pertinent public health issue of Dengue Fever as a public health warning was issued due to the rise of cases in March 2024 in Bolivia. Interviews included participants' own reflections of their personal experiences and subsequently, community dynamics and other perceptions. After the completion of survey and interviews of their lived experiences with health access, training sessions were provided by two Deaf medical doctors using LSB interpreters on deaf women's reproductive and sexual health, Covid-19, and Dengue Fever to assuage the participants' desire to fill in knowledge gaps in their native LSB.

V. Results (see Appendix B of survey graph results)

Twenty Deaf Bolivian women were interviewed with their ages ranging from 23 years old to 51 years old, and with the average age being 32.2 years old. Most interviews were conducted one-on-one due to participants' preferences expressing privacy concerns of not wanting their peers to know about their issues, deep culture shame of personal issues, and negative stigmatization. Some participated in group interviews between 2-3 participants.

Regions represented in the population are as follows as shown in Graph 1. Most were from near Cochabamba areas with some from Beni, La Paz, Sucre, Chuquisaca, Portosi, and Oruro. Provinces represented were Quillacollo, Cercado, Monteagudo, Riberalta, Trinidad, Guayaramerin, Llallagua, Murillo, Chuquisaca, Santa Ana, and El Alto. Ethnic groups represented by their native languages were Quechua, Aymara, Movima, Guarani, and Bolivian Sign Language (LSB) with the most coming from Guarani (Graph 2). All participants identified as female. Their occupations include housewife, volunteer, manicurist, seamstress, cleaner, student, and manager.

Ninety percent of the women were raised by hearing parents, mainly by hearing mothers and grandmothers (Graph 3). The average age that these women have their first exposure of sign language is at almost 10 years old, well past the neurocritical period of learning first language between age 0 and 5 years old (Graph 4). Some learned sign language as late as into their twenties with the latest being 25 years old. Graph 5 shows the level of education completed with the majority having completed only at the secondary level of education. Eleven of the women attended integrated schools (mainstreamed with hearing students) while eight attended deaf school and one did not attend school at all. Majority of the women used Bolivian Sign Language as their native language (16 participants) while two used indigenous sign language and two people used home



**WORLD FEDERATION
OF THE DEAF**

signs (Graph 6). Out of all twenty women, only three used hearing aids and none used cochlear implants.

All have been vaccinated for COVID-19 and eleven out of twenty did get COVID-19. Seventy percent of the participants got two doses of the COVID-19 vaccines. Six participants have been diagnosed with Dengue Fever in their lifetime with symptoms including headache, fever, vomiting, weakness, and stomach pains. Medical treatment was provided for all except one.

Four participants were confirmed to be currently pregnant and all said they received medical care during pregnancy (Graph 7). All participants have health insurance, noticeably called SUS – Universal Health System which is Bolivia's universal health insurance scheme provided by the government for vulnerable communities. In terms of health care access, the average time it takes for participant to reach the nearest health facility for them is 30 minutes, ranging from short 5 minutes walk to 3 hours distance. Twenty-five percent of the participants felt that their health care access changed after COVID-19. Eighty percent of the participants did not clearly understand the explanation given to them by health personnel (Graph 8). Ninety percent of the participants prefer using Bolivian Sign Language to communicate with health care professionals (Graph 9). Only one preferred lipreading and one preferred paper and pencil (Graph 9). Ninety-five percent had problems with communicating with healthcare professionals.

When asked about overall health, forty-five percent experienced current chronic illness that requires regular follow-up and prolonged treatment (Graph 10). Most of these illnesses involved headaches, heart problems, and reproductive issues. The average time they spent in the clinic was 55 minutes with time ranging from 10-minute visit to as long as 120 minutes visit. Fifty percent of the participants were not satisfied at all with their medical care while thirty-five percent of the participants were not very satisfied/poorly satisfied with their medical care (Graph 11).

Regarding the participants' sexual and reproductive health care, fifty percent have regular gynecological check-ups. Forty percent of the participants have children (8 participants) with the average number of children among participants to be two children (Graph 12). Out of the eight participants who have children, only one person had intended pregnancy, while the rest were all unintended pregnancies (Graph 13). Half of the participants said they did not receive any sex education (Graph 14). When delving further into the location of these participants, they were from more rural areas. The other half of the participants who did receive sex education lived closer to cities such as Cochabamba. Fifty-five percent did not have any knowledge about Sexually Transmitted Diseases (Graph 15). Eighty-five percent knew about their menstruation before getting their first period (Graph 16). Most found out about their menstrual cycles from mother and grandmother. Only seventy percent of participants use any form of family planning method (Graph 17). Of those who use family planning methods, condom, dermal implant, IUD, birth control pill, and timing natural method were mentioned as their main family planning methods.

Sixty-five percent of the participants feel that they do not get the same quality of public messages and information about health issues while the rest feel they get somewhat some quality messages and information about health issues (Graph 18). One hundred percent of participants say that their country does not include deaf people in the decision-making process regarding health care.



WORLD FEDERATION OF THE DEAF

Seventy-five percent of participants often and frequently feel frustrated or powerless about the lack of access to health care while fifteen percent feel frustrated or powerless sometimes about the lack of access to health care (Graph 19).

Three consistent themes emerged from preliminary analyses of focus groups and interviews with the deaf Bolivian women.

V.I - Theme 1:

Deaf Bolivian women have no communication when accessing health care or interacting with health care providers. These women said they had high level of frustration with hospitals. No interpreters were provided during their interactions in health care settings and they had no clear understanding of their health care needs. They cannot communicate freely with their health care providers. They often depend on hearing female family members such as their mother, grandmother, sister, or aunt during medical appointments to facilitate communication with health care providers, which violates their right to privacy. Because of these communication barriers, these women often feel frustrated or resigned to having poor access to health care and lower health care knowledge. They often have little to no insight about their health care history. Majority of them feel powerless in having control of their own health care access. When they go to the doctor's office, they are resigned to limited communication and have internalized the feelings of resignation and vulnerability. The involvement of family members in the medical settings is consistent with Bolivian culture of being family oriented and of collective nature, and at the same time is consistent with the stigma that deaf people and people with disabilities -specially women- cannot be autonomous and live independently.

Communication barriers also lead to medical and obstetric violence. They could also result in violation of the right to informed consent for medical treatment (denial of finding alternative ways of direct communication with deaf Indigenous women).

"I never go to doctor alone. I don't understand them. I always go with my aunt because I don't understand the doctor at all.

Participant #3, age 34

"Doctors wear masks. I can't understand them. There is no communication at all."

Participant #14, age 37

"The doctors and health care people don't have patience when communicating with me."

Participant #18, age 43

V.II - Theme 2:



**WORLD FEDERATION
OF THE DEAF**

When asked about how often they understand their hearing family members communicating with each other (not directly at them), such as at the dinner table or living room, the majority did not understand what was going on at all. Sometimes they talked with their hearing close siblings like sister or brother who use gestures with them. This phenomenon, known as Dinner Table Syndrome, explains the experience of deaf people being left out of conversations and can often make them feel isolated or ignored in family settings. These communication barriers can make them feel hurt, depressed, sad, anxious, stressed, or angry for not being able to be a part of the family dynamics. The communication neglect that they feel can make them feel marginalized and ostracized from their own loved ones. Because they do not have access to family members' dialogue, these deaf women may not have proper access to family health history such as knowing if someone close to them has cancer or heart disease. They may not be up to date on current events and family situations that may have a direct effect on their well-being such as they have to move at a short notice to another location or a family member is in the hospital. Using gestures and relying on lip-reading is not fully effective and can cause concentration fatigue. When deaf people are isolated from the situations, they often will leave the place and go where they feel safe such as their own room to scroll their phone (exposing themselves to cyberbullying or other internet risks) or go meet their deaf friends where they can communicate in their native sign language.

"I am so bored around my family. I don't understand what is going on. I tend to ignore them and then leave the place. I feel ignored so no point in being there with them."

Participant #2, age 29

"There is absolutely no communication at all in my family with me. I feel isolated."

Participant #8, age 51

"My family is all hearing. I don't understand them at all. I prefer using Bolivian Sign Language to communicate."

Participant #11, age 21

V.III - Theme 3:

When asked about their sexual and reproductive health experiences, many of them were scared to express their experiences because they are not sure if what they experienced were appropriate to discuss or not. In the beginning of interviews, when asked if the deaf Bolivian women have ever experienced any situation where they were raped or any kind of abuse, they denied any labeling of rape or domestic violence. However, when asked if they ever felt unsafe in any situation or someone harassed them inappropriately, then they started to share their emotions of fear, sadness, and anxiety with certain people. They explained how they felt uncomfortable and traumatized by their experiences. They expressed feeling scared and anxious about how other men would force themselves on them or bother them by trying to touch them. The deaf women had difficulties in labeling these experiences: they didn't realize it as rape or unwanted touch. They often felt powerless and hopeless in these situations and did not have any place to go to for assistance. If they expressed any information to their family members or friends, they were often brushed aside and did not have anyone believing their lived experiences. Moreover, deaf women experienced



WORLD FEDERATION OF THE DEAF

abuse mainly from hearing perpetrators, often from their family or their partners and have communication and information barriers in not being able to stand up for their own rights and safety. For many of them, this opportunity during the interview was the first time they ever shared their sexual abuse experiences. It was liberating for them to feel that they could express themselves in a safe space during the interviews. They did not have any deaf-friendly resources or domestic violence organizations that they could go to for assistance.

“Stepfather tried to force himself on me. I put shoelaces around my pants and waist. I tied shoelaces around my pants. At night, I felt him trying to use knife through the rope. I cried and screamed a lot. I would hold onto the bed post as tight as I could. I was so frustrated and scared...I felt him pull my feet off the bed and I kept kicking him as hard as I could...later that night, I tiptoed out of the home and ran away into the grass area...I did not feel safe at home because he would try to sneak into bathroom when I took shower or on toilet. I had to go far away into woods to do toilet.”

Participant #14, age 37

“One man kept chasing me. He said wanted to be friends with benefits. I did not understand that. I don't know what that mean. I asked my aunt what does that mean. She said it's ok. I did not understand her. So I went ahead with him. He forced me and kept chasing me. He kept saying he wants sex all the time with me...I felt ugly and bad. He kept going....That was my first time. No one explained anything to me. He told me to take a pill. I took the pill because he pushed it on me to take it.”

Participant #17, age 24

VI. Conclusion

Urgent attention is needed for the deaf women in Bolivia to improve their access to health services, medical care, and public health information. Not having any access to health care and obtaining poor quality of medical care often leads to negative health consequences in their long-term health well-being. The most common barriers are not having sign language interpreters during health care interactions, being ignored or neglected in family situations due to social stigma, and not having adequate domestic violence resources, all of which can lead to deep feelings of isolation, depression, and hopelessness. Improving communication through Bolivian Sign Language in healthcare settings involves making sure that there are sign language interpreters in their interactions with healthcare professionals, making sure that all health information is accessible through national sign languages, such as with the rise of Dengue Fever and COVID-19 cases during public health emergencies, and training healthcare providers in Bolivian Sign Language (LSB) and deaf culture. Health educational workshops such as through peer-to-peer community health programs in LSB on an ongoing basis would be vital to improve the overall health of the community.

Deaf indigenous women are often negatively stigmatized or socially marginalized from their hearing family members and friends, and as a result, feel internalized oppression and resignation that affects their mental and physical health. Since most are born to hearing families and their first exposure to sign language is roughly 10 years old, well past the neurocritical age of first language acquisition, these deaf Bolivian women face severe language deprivation and in turn, experience



**WORLD FEDERATION
OF THE DEAF**

several detrimental health effects. Special attention must be given to providing social support services in terms of early hearing detection intervention, early first language acquisition, and family support for those with deaf children.

Deaf women are at a greater risk for gender-based violence around the world. It is well known that one out of two deaf women experience domestic violence, which is at a much higher rate than hearing women which is one out of four hearing women [8, 10, 11]. Abuse in the deaf community often have additional factors than found in the hearing community. Many deaf women are not aware of deaf-centric power dynamics that can happen such as hearing abuser may use their hearing children against deaf mother as a form of wielding power and control over them or taking away the deaf women's phone as a form of financial abuse. Many deaf women are not aware that there are several different kinds of abuse that does not have to involve physical abuse such as emotional, verbal, spiritual, or financial type of abuse. They may not know that being isolated is a form of abuse since they have internalized the feeling of isolation from a young age. These deaf women may obtain false information from their abusers, believing that they do not have any place to go for assistance. There is no known domestic violence agency for deaf people in Bolivia. There is a critical need to make sure that there are deaf-centric domestic violence workshops and resources in LSB for Deaf women in Bolivia.

Recommendations to improve on these situations involve the following:

1. Propose to the health authorities of Bolivia in conjunction with the Federación Boliviana de Sordos, FEBOS, and the World Federation of the Deaf, WFD, to provide informational sessions to health staff on how to provide highest quality of medical care for deaf people.
2. Provide educational workshops in health knowledge for deaf women, and particularly, deaf indigenous women, about their own reproductive and sexual health, and to be able to take charge of their own health issues in LSB.
3. Implement training for health personnel on deaf culture and their use of Bolivian Sign Language or preferred method of communication.
4. Provide sign language courses for health personnel and health students at universities to break down stigma, address bias, and promote inclusivity of deaf patients.
5. Establish public policies adhering to laws and international treaties as well as improve and harmonize with them the national laws and public policies in the field of health and disability.
6. Investigate and model health concerns and needs of more deaf indigenous women in more areas of Bolivia.
7. Grow and strengthen collaborative research focus on global deaf health with deaf women.



**WORLD FEDERATION
OF THE DEAF**

8. Use peer-to-peer health education training using deaf peers fluent in LSB and go to different rural communities across Bolivia.
9. Since the women are less likely to visit hospitals and doctors on their own and depend on hearing family members, especially mothers, to interpret for them during healthcare visits, there is a great need for family-oriented support services from government entities to focus on providing services to support deaf family members.
10. Include staff professional and accredited sign language interpreters and deaf advisors in medical facilities, and ensure stable budget to make these positions happen at local, state, and national levels.
11. Implement deaf awareness and training in hospitals and promote universal design that applies to people with disabilities and benefits all.
12. Hire deaf experts in hospitals, healthcare facilities, and government health department.
13. Train and provide professional and accredited sign language interpreters in all departments and social services in Bolivia.
14. Support the Federación Boliviana de Sordos, FEBOS, in assisting deaf women across Bolivia with more programs and support services, especially in the fields of domestic violence, sexual and reproductive rights, and health care.
15. Focus on women empowerment, teaching them how to take control of own health, promote self-advocacy skills, and provide equitable opportunities for them.
16. Develop more research with intersectional focus across more deaf people in very rural areas since they are often only found through word of mouth. There is no set census to find deaf people so dependent on word-of-mouth is the main modality of communication.
17. Enable consistent communication through social media platforms, SMS texting, and video calls. Deaf people are visual and depend on visual modalities for communication.
18. In case of emergencies, emergency disaster planning must be accessible such as through SMS texting and video interpreters during crisis and after crisis. News media should have PIP screens with sign language interpreters embedded in the screens.
19. Develop and implement intervention programs that address culturally and linguistically-appropriate access for health care and language acquisition at local and state levels.



**WORLD FEDERATION
OF THE DEAF**

20. Develop anti-audist and decolonial programs in hospitals and schools on how to work with deaf people, with the direct participation of deaf experts, and address gender bias. When caring for women and their health, the whole family and society are able to thrive and be healthy. There must be a steadfast commitment to promoting deaf women's empowerment in health issues.

References

1. Fellingner, J., D. Holzinger, and R. Pollard, *Mental health of deaf people*. Lancet, 2012. **379**(9820): p. 1037-44.
2. McKee, M.M., et al., *Assessing Health Literacy in Deaf American Sign Language Users*. J Health Commun, 2015. **20 Suppl 2**(0 2): p. 92-100.
3. Panko, T.L., et al., *Experiences of pregnancy and perinatal healthcare access of women who are deaf: a qualitative study*. BJOG, 2023. **130**(5): p. 514-521.
4. Kuenburg, A., P. Fellingner, and J. Fellingner, *Health Care Access Among Deaf People*. J Deaf Stud Deaf Educ, 2016. **21**(1): p. 1-10.
5. Terry, J. and J. Rance, *Systems that support hearing families with deaf children: A scoping review*. PLoS One, 2023. **18**(11): p. e0288771.
6. Murray, J.J., W.C. Hall, and K. Snoddon, *Education and health of children with hearing loss: the necessity of signed languages*. Bull World Health Organ, 2019. **97**(10): p. 711-716.
7. Hall, W.C., *What You Don't Know Can Hurt You: The Risk of Language Deprivation by Impairing Sign Language Development in Deaf Children*. Maternal and child health journal, 2017. **21**(5): p. 961-965.
8. Anderson, M.L. and I.W. Leigh, *Intimate partner violence against deaf female college students*. Violence Against Women, 2011. **17**(7): p. 822-34.
9. Pollard, R.Q. and S. Barnett, *Health-related vocabulary knowledge among deaf adults*. Rehabil Psychol, 2009. **54**(2): p. 182-5.
10. United Nations: [Convention on the Rights of Persons with Disabilities](#), 2006.
11. Organization of American States, OAS: [Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities](#), 1999.
12. Organization of American States, OAS: [Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women, Belém do Pará](#), 1994.
13. República Plurinacional de Bolivia: [Ley 348](#), 9 de Marzo 2013.
14. Pollard, R.Q., Jr., E. Sutter, and C. Cerulli, *Intimate partner violence reported by two samples of deaf adults via a computerized American sign language survey*. J Interpers Violence, 2014. **29**(5): p. 948-65.
15. Crowe, T.V., *Intimate partner violence in the deaf community*. JADARA, 2021. **46**.

APPENDIX A: Deaf Women in Bolivia – Interview Guide



**WORLD FEDERATION
OF THE DEAF**

Background

1. What region are you from in Bolivia?
 - ☐ Cochabamba
 - ☐ Chuquisaca
 - ☐ Santa Cruz
 - ☐ La Paz
 - ☐ Oruro
 - ☐ Potosí
 - ☐ Beni
 - ☐ Pando
 - ☐ Tarija
 - ☐ Other: _____
2. Ethnic Group
 - ☐ Quechua
 - ☐ Aymara
 - ☐ Guarani
 - ☐ Chiquitano
 - ☐ Other: _____
3. Gender
 - ☐ Male
 - ☐ Female
 - ☐ Non-binary
 - ☐ Transsexual
 - ☐ I'd rather not say
4. How old are you? _____
5. Educational Level
 - ☐ Incomplete primary
 - ☐ Full Primary
 - ☐ Incomplete secondary school
 - ☐ Completed secondary school
 - ☐ Incomplete technical/vocational
 - ☐ Complete technical/vocational
 - ☐ Incomplete university
 - ☐ Completed university
 - ☐ No degree of studies
6. What kind of school did you go to?
 - ☐ School for the Deaf



**WORLD FEDERATION
OF THE DEAF**

- ☐ Integrated School
- ☐ None
- ☐ Other (explain): _____

7. Occupation: _____

8. Civil Status

- ☐ Single
- ☐ Married
- ☐ Divorced
- ☐ Separated
- ☐ Free Union
- ☐ Widowed

9. Mother tongue

- ☐ English
- ☐ Bolivian Sign Language (LSB)
- ☐ Indigenous Sign Language: () Aymara () Quechua () Other () Which sign language: _____
- ☐ Home Signs

10. Do you use hearing aids?

- ☐ Yes
- ☐ No
- If yes:
At what age did you start using them? _____

11. Do you have a cochlear implant? _____

12. At what age did you first learn sign language? _____

Access to vaccination during the Covid-19 pandemic

13. Have you ever been diagnosed with COVID-19?

- ☐ Yes
- ☐ No
- ☐ I don't know

14. Can you independently make your own decision to receive the COVID-19 vaccine, if you choose?

- ☐ Yes
- ☐ No
- If the answer is no, why not? (explain) : _____

15. Have you been vaccinated for COVID-19?

- ☐ Yes
- ☐ No



**WORLD FEDERATION
OF THE DEAF**

☐ I don't know

16. If your previous answer was yes, did you complete the two recommended doses?

☐ Yes

☐ No

☐ I don't know

Medical Care for Dengue

17. Have you been diagnosed with Dengue?

☐ Yes

☐ No

☐ I don't know

18. If your previous answer was yes, explain what were your symptoms?

19. Did you get medical consultation for Dengue?

☐ Yes

☐ No

☐ I don't know

20. If your previous answer was yes, explain what medical advice did you get:

Pregnancy

21. Are you pregnant?

☐ Yes

☐ No.

☐ I don't know

22. If your answer above is yes, are you receiving medical care during your pregnancy?

☐ Yes

☐ No

23. If you are pregnant, did you contact your doctor before receiving the different necessary vaccinations?

☐ Yes

☐ No

24. Can you access regular health services while pregnant?

☐ Yes

☐ No



**WORLD FEDERATION
OF THE DEAF**

Health Insurance

25. Do you have health insurance?

☐ Yes

☐ No

26. If your previous answer was yes, what type of health insurance do you have? _____

27. How long does it take you to get from your home to the nearest health center, such as a hospital, health center, clinic, or doctor's office?

28. Has your access of health services changed after Covid?

☐ Yes

☐ No

29. If your answer to previous question was yes, has your health changed because of this:

☐ Yes

☐ No

30. What is your preferred form of communication in the doctor's office?

☐ Lip Reading

☐ Bolivian Sign Language

☐ Paper and Pencil

☐ Other: _____

31. Were you able to understand clearly the health personnel explanation to you?

☐ Yes

☐ No

32. Please explain if you had any issues communicating with health professionals:

Overall Health

33. Do you suffer from any illness that requires periodic monitoring and prolonged treatment?

☐ Yes

☐ No

34. If your previous answer was yes, what type of disease do you have?



**WORLD FEDERATION
OF THE DEAF**

35. What kind of medications do you take?

36. Do you get them free of charge?

☐ Yes

☐ No

37. During medical care, how long does the consultation last? _____

38. Are you satisfied with your medical care?

☐ Very satisfied

☐ Satisfied

☐ Not very satisfied

☐ Not at all satisfied

Sexual and Reproductive Health

39. Do you regularly attend gynecological check-ups?

☐ Yes

☐ No

40. If the answer to previous question is no, why not? _____

41. Do you have children?

☐ Yes

☐ No

42. If your previous answer was yes, how many children do you have? _____

43. Was it planned?

☐ Yes

☐ No

44. Have you ever received Sex Education?

☐ Yes

☐ No

45. Do you have knowledge about Sexually Transmitted Diseases?

☐ Yes

☐ No

46. When you discovered your period, have you ever been told about your period before?

☐ Yes

☐ No



**WORLD FEDERATION
OF THE DEAF**

47. If your previous answer was yes, how did you learn about it? _____

48. Do you use any family planning methods?

☐ Yes

☐ No

49. If your previous answer was yes, what method of family planning do you use? _____

50. Do you receive information on family planning methods and prevention of sexually transmitted diseases?

☐ Yes

☐ No

Cultural and Sociolinguistic Identity of the Deaf

51. Who raised you most of the time during your first five years? Check all that apply:

☐ Deaf Mother

☐ Deaf Father

()

Hearing Mother

()

Hearing Father

()

Other: _____

52. Who do you communicate with the most in your home?

☐ Deaf Mother

☐ Deaf Father

☐ Hearing Mother

☐ Hearing Father

☐ Other: _____

53. How often did you understand what your family members were saying when they communicated with each other (not directly with you) such as at the dinner table or in the living room? Explain: _____

Recommendations for Improving Health Care for Deaf People

54. Do you think you receive the same quality and relevance as listeners in terms of public



**WORLD FEDERATION
OF THE DEAF**

messages and information about health issues?

- ☐ Yes
- ☐ No
- ☐ More or less

55. If your previous answer is yes, how do you receive health information? _____

56. Does health care in your country include deaf people in the decision-making process?

- ☐ Yes
- ☐ No
- ☐ I don't know

57. What is the main barrier to health care for you? Explain: _____

58. Do you feel frustrated or helpless about the lack of access to health care?

- ☐ Frequently
- ☐ Sometimes
- ☐ Rarely
- ☐ Never

59. Do you have any suggestions to improve access to health care for the government and health institutions? Explain: _____

60. Do you have any recommendations for health and medical personnel regarding the care of Deaf people? Explain: _____

In-Depth Health Questions:

1. Tell us about your health as you grew up. Do you have any health problems?
2. Tell us about your interaction with medical professionals, did you see a doctor for or because of your hearing loss or any other medical condition?
3. Please tell us about the health system - clinics, doctors, etc. How do you communicate? Do you use interpreters?
4. Please tell us about some challenges you have had in hospitals or clinics. Any emergency?
5. Tell us about the health challenges you see in your community. Which ones do you see in your friends?
6. Do you avoid going to the doctor because of communication? Do you understand the doctor when you are alone?
7. Do you have children? What was your pregnancy experience like? Tell us about your prenatal care.

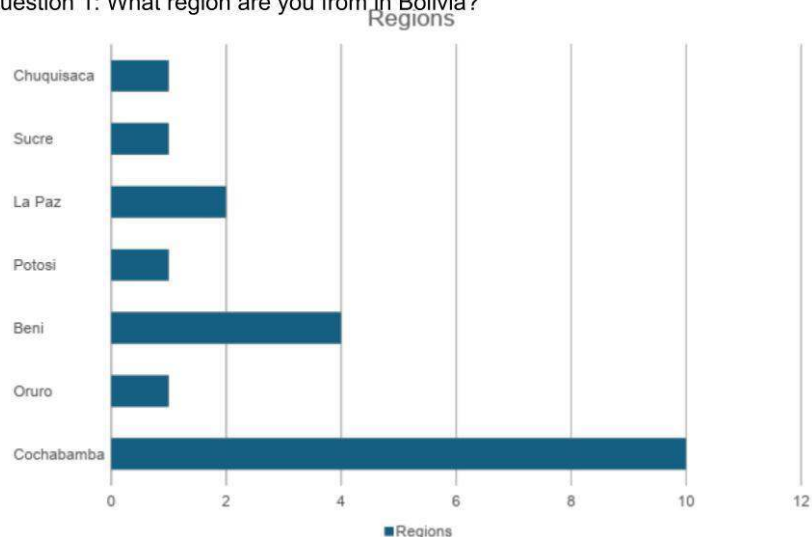
APPENDIX B: Graphs



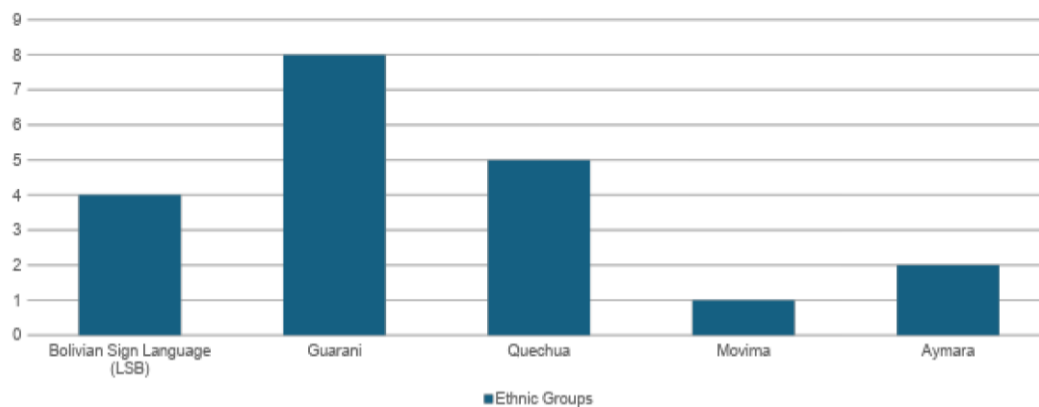
**WORLD FEDERATION
OF THE DEAF**

Appendix B

Graph 1 – Question 1: What region are you from in Bolivia?



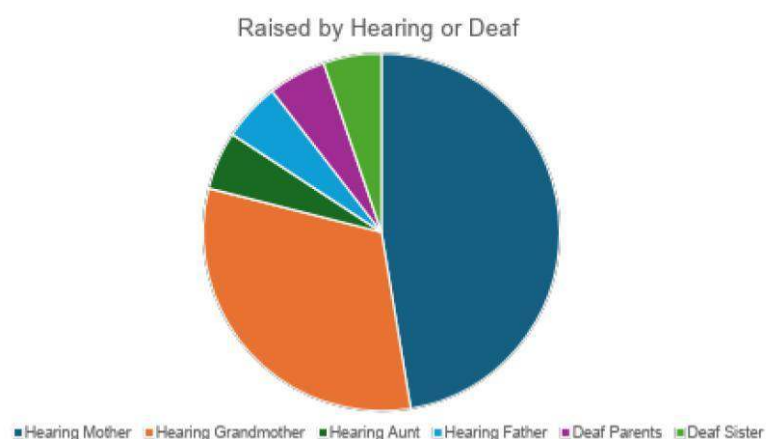
Graph 2 – Question 2: Ethnic Group



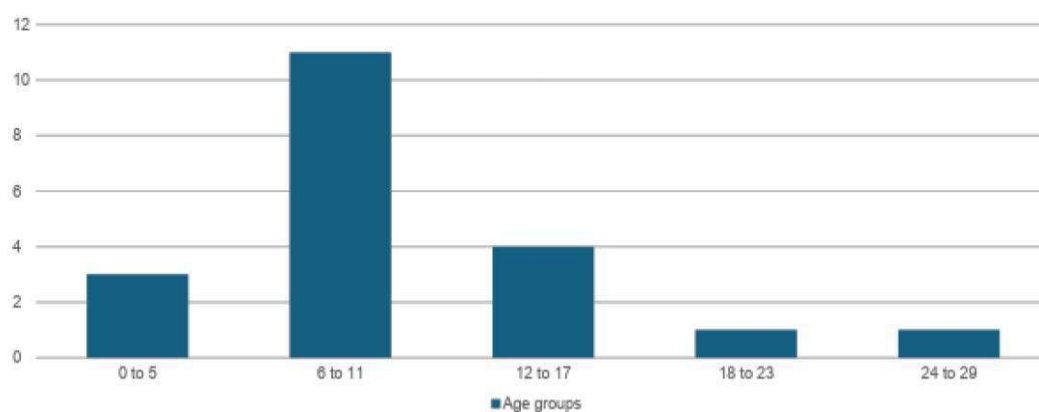


**WORLD FEDERATION
OF THE DEAF**

Graph 3 - Question 51: Who raised you most of the time during your first five years?



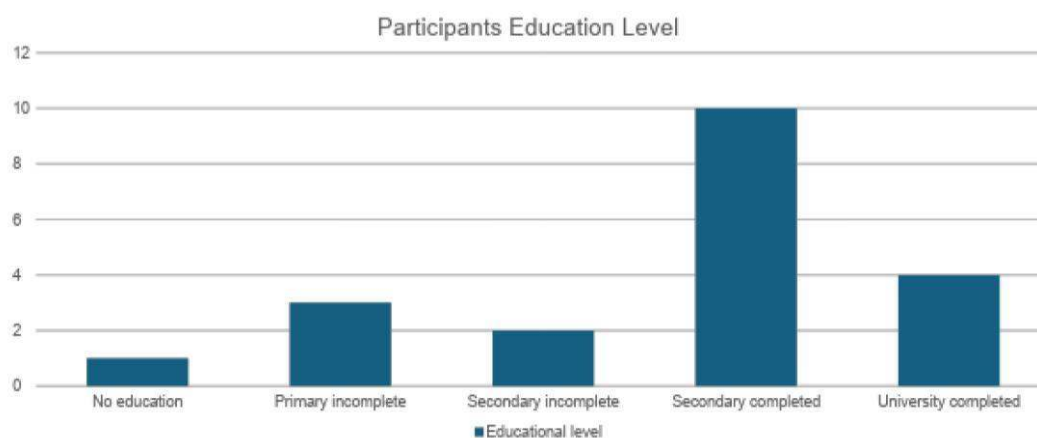
Graph 4 - Question 12: At what age did you first learn sign language?



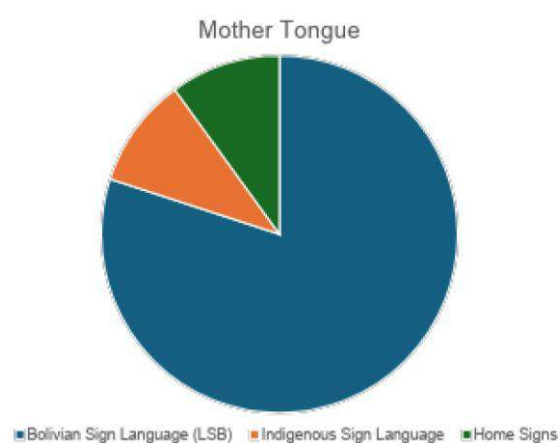


**WORLD FEDERATION
OF THE DEAF**

Graph 5 – Question 5: Educational Level



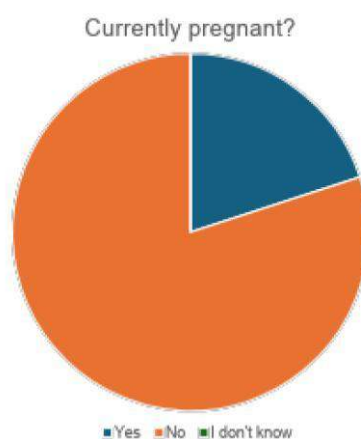
Graph 6 – Question 9: Mother tongue



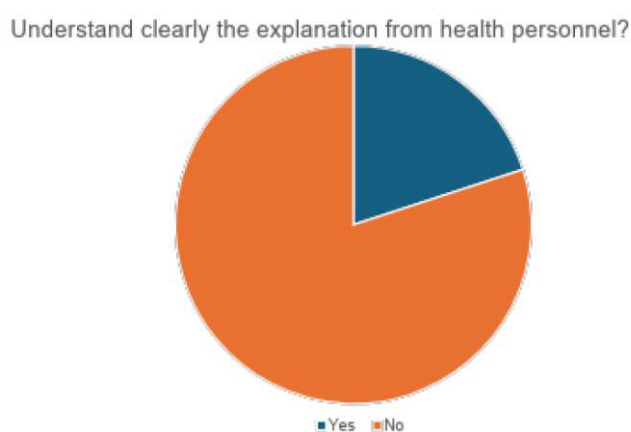


**WORLD FEDERATION
OF THE DEAF**

Graph 7 – Question 21: Are you pregnant?



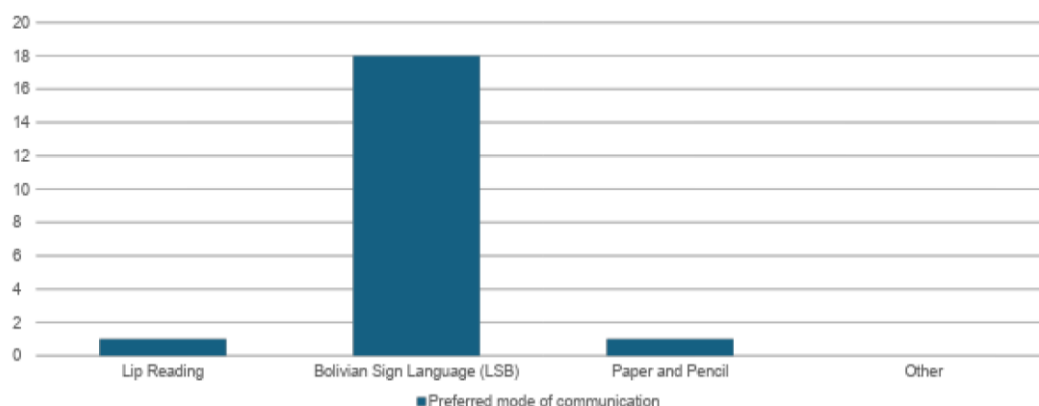
Graph 8 – Question 31: Were you able to clearly understand the explanation given to you by the health personnel?





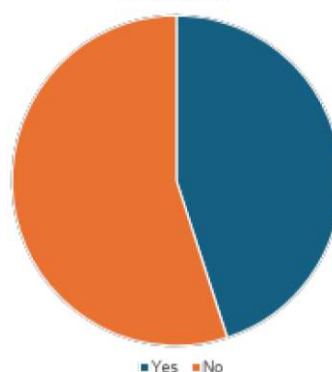
**WORLD FEDERATION
OF THE DEAF**

Graph 9 – Question 30: What is your preferred form of communication in the doctor's office?



Graph 10 – Question 33: Do you suffer from any illness that requires periodic monitoring and prolonged treatment?

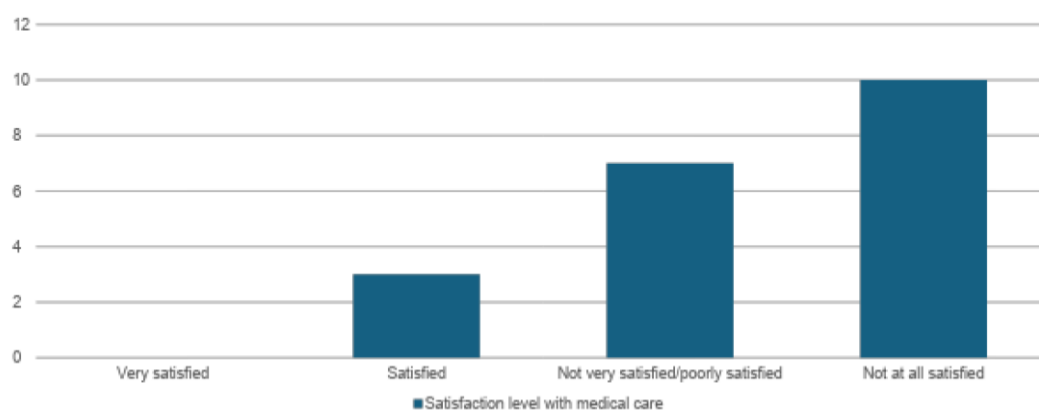
Do you suffer from any illness requiring regular follow-up and prolonged treatment?



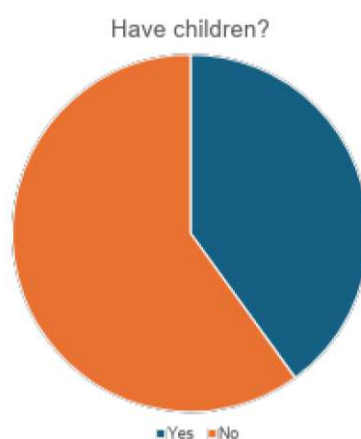


**WORLD FEDERATION
OF THE DEAF**

Graph 11 – Question 38: Are you satisfied with your medical care?



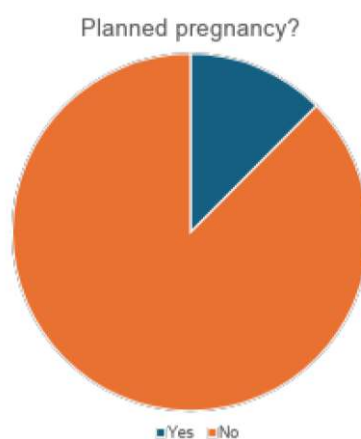
Graph 12 – Question 41: Do you have children?





**WORLD FEDERATION
OF THE DEAF**

Graph 13 – Question 43: Was it (pregnancy) planned?



Graph 14 – Question 44: Have you ever received Sex Education?

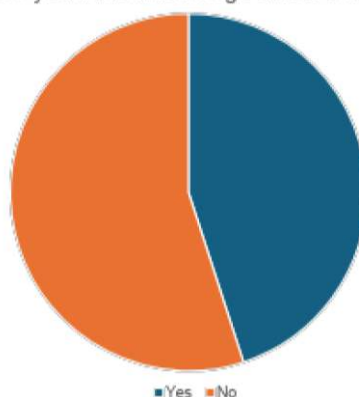




**WORLD FEDERATION
OF THE DEAF**

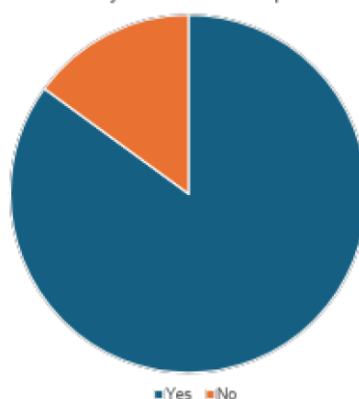
Graph 15 – Question 45: Do you have knowledge about Sexually Transmitted Diseases?

Do you have knowledge about STDs?



Graph 16 – Question 46: When you discovered your period, have you ever been told about your period before?

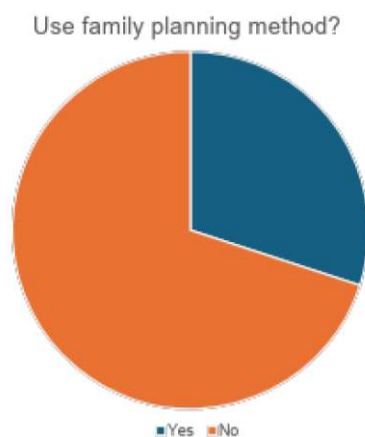
Were you told about your menstrual period beforehand?



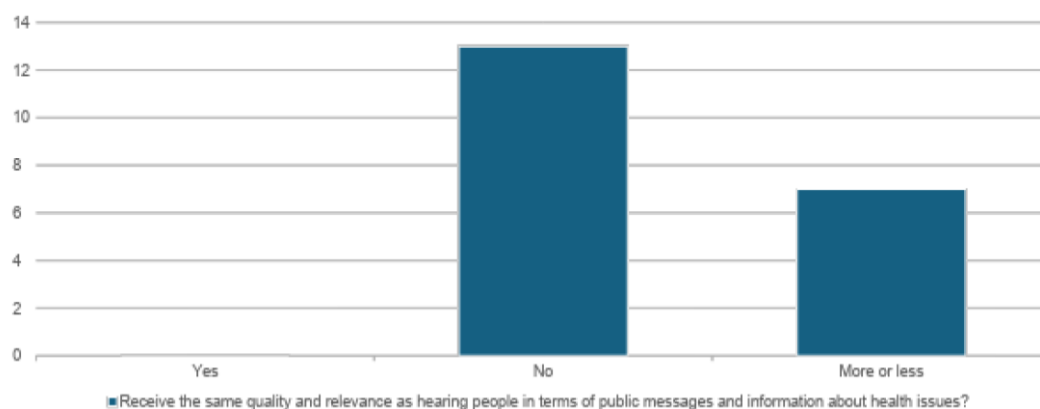


**WORLD FEDERATION
OF THE DEAF**

Graph 17 – Question 48: Do you use any family planning methods?



Graph 18 – Question 54: Do you think you receive the same quality and relevance as listeners in terms of public messages and information about health issues?





**WORLD FEDERATION
OF THE DEAF**

Graph 19 – Question 58: Do you feel frustrated or helpless about the lack of access to health care?

Feel frustrated or helpless about the lack of access to health care?

