The World Federation of the Deaf's submission
For 60th Session of the Human Rights Council on Indigenous Peoples' right to data, including data collection and disaggregation

A. Introduction

1. The World Federation of the Deaf (WFD) is honoured to submit its inputs to the draft study of the Expert Mechanism on the Rights of Indigenous Peoples on Indigenous Peoples' right to data, including data collection and disaggregation, to be submitted to the 60th session of the Human Rights Council.

2. The World Federation of the Deaf is an international non-profit and non-governmental organisation and has a membership composed of national deaf associations from 137 countries. The WFD has a consultative status with the United Nations and is a founding member of the International Disability Alliance (IDA). We promote the human rights of deaf people in accordance with the principles and objectives of the United Nations Charter, the Universal Declaration of Human Rights, the UN Convention on the Rights of Persons with Disabilities (CRPD), the 2030 Agenda for Sustainable Development, and other Human Rights Treaties. As the representative body, the WFD strives to ensure that deaf people across the world, especially in the Global South are equipped with the knowledge, tools, and strategies to advocate for, achieve, and defend their rights.

3. The present submission aims to highlight the specific barriers faced by deaf Indigenous people, especially deaf Indigenous women, in their participation in data collection and to provide recommendations to Member States to the UN on how to meaningfully include and engage deaf Indigenous people in data collection.

B. Barriers faced by deaf Indigenous Peoples due to their intersecting identities as deaf, Indigenous, and sign language users.

4. As a general comment, the WFD would like to emphasise that deaf Indigenous people face a unique situation compared to other Indigenous Peoples due to their disability, but also to their specific cultural and linguistic identities and the use of their own languages, their national and/or Indigenous sign languages. As highlighted in the WFD Position Paper "Complementary or diametrically opposed: Situating Deaf Communities within 'disability' vs 'cultural and linguistic minority' constructs," deaf people and their communities belong to both the disability movement and the minority cultural and linguistic movements. The adhesion of deaf people to their deaf communities is not based on their degree of hearing loss but rather on their shared experiences of living in a society that is inaccessible to them as well as the use of their common languages, their national or Indigenous sign languages. Deaf communities are interconnected to the disability movement by their right to access as citizens of a broader dominant language culture.

5. Not only do deaf Indigenous peoples belong to their Indigenous communities where they share cultural traditions and customs, among others, but also, they belong to the deaf community, either through the use of, respectively, their Indigenous sign languages or their national sign languages. National sign languages are minority languages used by Deaf communities within a given country, whereas written/spoken languages constitute the dominant language of the country[1]. Indigenous sign languages are the sign languages that were created naturally in Indigenous Deaf communities before having the influences of colonial sign languages[2], such as, for example, the Plains Indigenous Sign Language in Canada[3]. National sign languages and Indigenous sign languages must be recognised legally and on an equal step with spoken/written languages, and their use must be promoted by the States Parties as enshrined in Article 2.2 and Article 21(e) of the United Nations Convention on the Rights of Persons with Disabilities.

6. Deaf Indigenous People, especially deaf Indigenous women, face huge barriers in participating in society on an equal step with others since most information and communication is not provided in their sign languages. They experience additional intersectional discrimination when the country does not grant specific focus to the rights of deaf Indigenous Peoples and their Indigenous sign language rights in different areas, such as in education, in access to health, and in interactions with public authorities. This is exacerbated in the research conducted among Indigenous Peoples, as they are left behind due to the lack of accessibility and cultural understanding of the research teams on their specific needs. As a result of the exclusion of their participation in the data collection process, deaf Indigenous Peoples' specific issues are not addressed in the research results.

C. Citizen data and "Leave No One Behind"

7. Since many deaf people and communities, including deaf Indigenous Peoples, are excluded from data collection, we, the World Federation of the Deaf, decided to take action and to address this issue by undertaking citizen data collection in line with the Copenhagen Framework on Citizen Data, supported by the UN Statistical Commission (UNSC). This framework provides a scope that helps conceptualise and agree on the different ways citizens can play a role in data and supports formulating action points for the citizen data and statistical communities moving forward. In 2024, the WFD joined the Leave No One Behind partnership, aiming to promote the generation and use of community-driven data and to augment the voice and agency of marginalised groups who are at risk of being overlooked in the implementation of the Sustainable Development Goals.

8. Since 2021, the WFD has conducted three citizen data research projects, respectively in Nigeria (2022), Latin America and the Caribbean (2022-2023), and Bolivia (2024). For the latter, the WFD decided to focus on deaf Indigenous women as the previous research projects showed a real gap in the data collection on this intersectional and minority group. Each research project has been conducted by a team of deaf sign language persons who are experts, researchers, and representatives of the national/local deaf community in line with the frameworks addressed above.

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[1] Murray J. and Stiglich S., *Guidelines for Achieving Sign Language Rights. A WFD Advocacy Toolkit*, July 2023, available at: http://wfdeaf.org/guidelinesaslr/

[2] Adams. (2021, May 3). Indigenous Sign Languages - Rodney Adams. YouTube. Available at: https://www.youtube.com/watch?v=6NdrfgbOqgM

[3] Rice, K. (2020). Indigenous Sign Languages in Canada. In The Canadian Encyclopedia. Available at: https://www.thecanadianencyclopedia.ca/en/article/indigenous-sign-languages-in-canada

D. Good practice example: Pilot Study of Deaf Indigenous Bolivian Women's Health Experiences

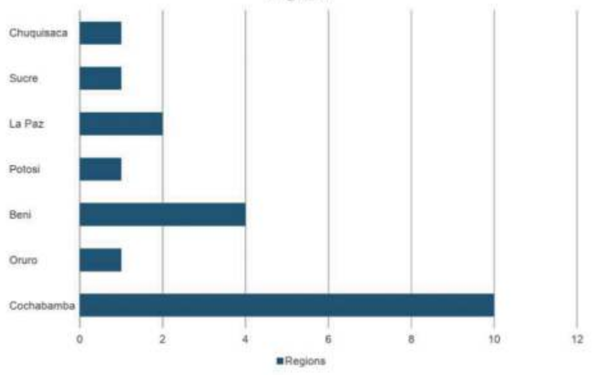
9. The World Federation of the Deaf conducted a pilot study on deaf Indigenous Bolivian women's health experiences in March 2024 in partnership with its Ordinary Member in Bolivia, the Bolivian Federation of the Deaf (FEBOS), with the financial support of the Christian Blind Mission Global Disability Inclusion (CBMG) and the University of Rochester.

10. The project team composed of the representatives from the organisations previously mentioned proposed to undertake a preliminary community assessment survey to identify gaps, facilitators, and barriers that deaf Indigenous women in Bolivia encounter when trying to access healthcare services in their lives. Twenty participants were interviewed for the pilot project. The deaf woman representative of the Bolivian Federation of the Deaf reached out to indigenous deaf women from outside of the cities through word-to-mouth among local deaf associations.

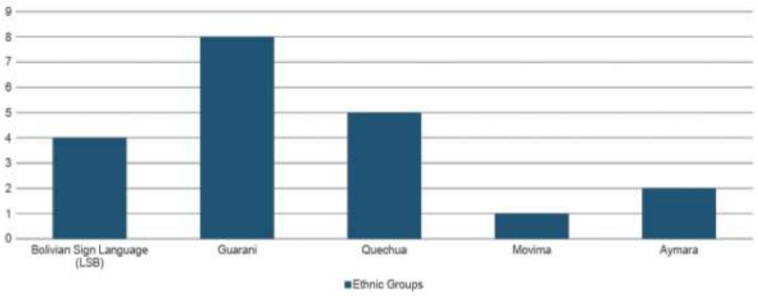
11. Twenty deaf Indigenous women were interviewed, with their ages ranging from 23 years old to 51 years old, and the average age being 32.2 years old. Regions represented in the population are as follows, as shown in Graph 1. Most were from near Cochabamba areas, with some from Beni, La Paz, Sucre, 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.

Appendix B

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



Graph 2 – Question 2: Ethnic Group



12. The survey consisted of 67 questions that explored demographic information, age of first exposure to sign language, family dynamics, education, access to COVID-19 vaccines, hospitalisation 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 issues 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 reactions to their personal experiences and, subsequently, community dynamics and other perceptions.

13. After the completion of the survey and interviews of their lived experiences with health access, training sessions were provided by two Deaf medical doctors using Bolivian Sign Language (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.

14. The research results demonstrated that the efforts undertaken by the Bolivian authorities are insufficient, as deaf Indigenous women do not feel supported in their access to healthcare that is not inclusive, accessible, affordable, and culturally appropriate for them. More information on the methodology, the procedure to undertake the survey research, and the research results can be found in the report of the Pilot Study[4].

15. Through this research, the WFD, FEBOS, CBMG and University of Rochester identified recommendations, and the WFD addressed them with the Bolivian government in June 2024 with the purpose of advocating for the rights of deaf Indigenous women to access to health, especially to healthcare services, and to be informed on their sexual and reproductive health rights. Thanks to the strong data collection and disaggregation in the Pilot Study, we, the WFD and our Ordinary Member in Bolivia, the Bolivian Federation of the Deaf, are able to shape policies addressing the health rights of deaf Indigenous women both at the national level, in Bolivia, and at the international level, through UN international fora and in the Global Disability movement events.

E. Recommendations towards the achievement of deaf Indigenous Peoples' right to data, including data collection and disaggregation

16. States Parties to the UN Convention on the Rights of Persons with Disabilities (CRPD Convention) must facilitate the use of sign languages in official interactions with deaf Indigenous persons under Article 21(b). It is of utmost importance that public-oriented information is given by the public authorities in the languages used by the deaf Indigenous persons, being either their national sign language or their Indigenous sign language. Furthermore, State parties must recognise the national and/or Indigenous sign languages used by deaf Indigenous persons in their country and promote their use, according to Article 21(e).

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[4]

17. Based on the great outcomes from the Pilot Study conducted in Bolivia, we, the World Federation of the Deaf, encourage the Expert Mechanism on the Rights of Indigenous Peoples to support the importance and significance of Citizen Data as a good practice of community-led data collection that can reach out to the most hard-to-reach people among the Indigenous communities and even the group of deaf Indigenous Peoples. The only way to get data from deaf Indigenous women was and is through their peers in a culturally and linguistically concordant environment and within a safe space where they can be assured their privacy is respected.

18. The World Federation of the Deaf strongly urges the national governments and especially the national statistics offices to collaborate and closely consult with the representatives of the deaf communities, including Indigenous Peoples, through the national organisations of the deaf to ensure the accessibility and cultural and linguistically appropriate data research collection on deaf Indigenous Peoples in line with Article 4.3 of the UN Convention on the Rights of Persons with Disabilities (CRPD). Through the disaggregated data collected in citizen data initiatives, national governments will be able to visualise the unique, multiple, and intersectional discrimination deaf Indigenous Peoples, and especially deaf Indigenous women, face in their lives.

If you have any questions or queries, do not hesitate to contact the WFD Executive Director, Ms. Pamela Molina, at pamela.molina@wfdeaf.org

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