

ACCESSIBLE COMPREHENSIVE HEALTH CARE FOR DEAF WOMEN



LESSONS LEARNED AND CHALLENGES BASED ON AN
EXPERIENCE CONCERNING SORDAS SIN VIOLENCIA AT A
BUENOS AIRES CITY HOSPITAL



SORDAS
IN
VIOLENCIA



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SORDAS
IN
VIOLENCIA



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At the Dr. Teodoro Álvarez Hospital

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- María Varas, Pediatrician. Committee against Violence. Head of the Mother, Child, and Youth Department
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- Sabrina Grinschpun, Deaf Mediator
- Greiz Cusikanski, Interpreter

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INTRODUCTION



In 2018, Sordas sin Violencia (Deaf Women without Violence) started working together with the Hospital General de Agudos Dr. Teodoro Álvarez in Buenos Aires City on an initiative to facilitate access to comprehensive health care for deaf women participating in the programme.

The experience allowed many women to receive care for the first time in an accessible environment, respectful of their rights. These women and their children experienced a very different kind of health care from what they had ever had before.

One of the women participating in the programme explained this very clearly: “I had already been to see the doctor; both my children were born there. But I always went with my mother who communicated with the practitioner who would look at her, and I dared ask about my intimacy.”

This initiative started to set up an accessible system because Sordas sin Violencia and the health team of the Alvarez Hospital built synergies to provide visibility to and face the countless barriers that hinder deaf women from exercising their right to full health care. Also important was the external supervision by Dr. Alexis Karacostas, one of the creators of the Units for the Health Care of the Deaf (known by its French acronym UNISS) at the Salpêtrière Hospital in Paris.

Innovation and interest in overcoming the many obstacles leading to exclusion were present every day. We thus consider it an experience that is worthwhile sharing. When systematizing it, we unraveled incidents and spelled out lessons learned and challenges so that actions carried out to date could be a starting point for developing health policies to be replicated, scaled up and promoted, focusing on the intersection of gender, rights and disabilities.

“Being in a hospital does not always mean accessing health care. Deaf women go there and are treated as objects.

Can you imagine what it must be like to have a question on your health and not be able to solve it for ten years? This initiative created a space to ask and talk about what they had been told some time but did not quite understand”.

Lorena Cardoso, ILSA- E.

WOMEN BUILDING SORORITY

Sordas sin Violencia is the only organization in Argentina supporting deaf and hard of hearing women facing gender-based violence along the difficult path of empowerment and access to rights. It was created in 2016 based on a partnership between Fundasor¹ and Enlaces Territoriales para la Equidad² de Género (Territorial Links for Gender Equality), two civil society organizations in the City of Buenos Aires.

So far, they have comprehensively supported over 100 deaf women, victims of gender-based violence and held over 70 awareness-raising and information workshops attended by approximately 2,260 participants.

Furthermore, Sordas sin Violencia trains mediators and Argentine Sign Language Interpreters (hereinafter, ILSA) in gender, violence and human rights issues and carries out a series of activities to raise awareness on the barriers of society that isolate and deepen the vulnerability of Deaf women.

The Organization played a core role within the United Nations innovation initiative that analyzed and evaluated several 'access to justice' strategies for Deaf and hard of hearing women who are the victims of gender-based violence. The "Guidelines for access to justice of Deaf women, victims of gender-based violence", were prepared within this framework and are an unprecedented contribution to eliminating barriers in this crucial field of access to rights.

¹ FUNDASOR promotes accessible communication on equal grounds for all families with deaf members. For additional information see: <https://www.fundasor.org.ar/>

Enlaces Territoriales para la Equidad de Género² works on gender-based violence from a rights-based and intercultural perspective. More information at: <https://www.enlaces.org.ar/>

2

AN INITIATIVE TO TOPPLE WALLS



The United Nations Secretary-General's Campaign "Unite to end violence against women" affirms that women experiencing multiple forms of discrimination are more likely to face violence than other women, and that the consequences thereof can be more serious due to the difficulties they encounter in accessing services overall. Deaf and hard of hearing women are no exception to this harsh reality.

As women, they experience the consequences of gender inequality in everyday life and, as Deaf women, they find themselves in a society that is not ready to include them and adapt to the diversity of people, situations and cultures.

Barriers in the health system

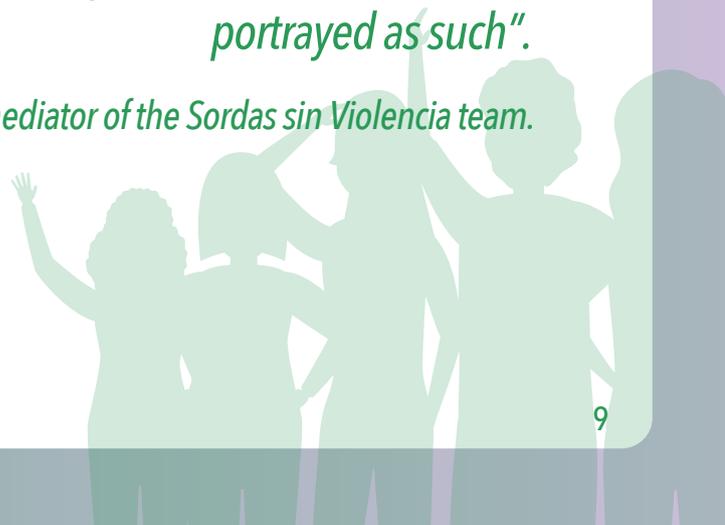
Within the health system, barriers begin at the time of asking for an appointment -in the City of Buenos Aires they can be requested on the phone or in person- and are then found in each of the health care circuits. In the doctor's office, dialogue becomes almost impossible and the same happens when having each of the required medical tests.

The stories of Deaf women are always a clear example of the above: they walk away from consultations with prescriptions and physicians' instructions to follow but not knowing why, with questions they were never able to ask and, in most cases, feeling that their privacy and rights have been violated.

For instance, informed consent, one of the rights of all people, is often delegated to family members or care givers who talk to health practitioners, thus accentuating situations of dependency and vulnerability. Frustration brought about by these experiences generates greater isolation and estrangement from the health system and, within contexts of gender-based violence, makes it easier for the cycle of violence to be perpetuated.

"This is the first time we have a space to talk about our body. Our health, our body had never before been portrayed as such".

Sabrina Grinschpun, Deaf mediator of the Sordas sin Violencia team.



Communication: a barrier or a challenge?

Information and communication are human rights, universal and indivisible from other rights. They are **the key to accessing health services** and an essential condition for Deaf women to be included in society, enjoy their autonomy and a life free from violence.

Although most Deaf women take on Argentine Sign Language (LSA)³ The cultural and linguistic identity of the Deaf was recognized by the International Convention on the Rights of Persons with Disabilities: Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.] as their main form of communication and identity, the population is most diverse. Different factors affect their communication practices, among them the family as well as the educational, social and cultural context in which each person's life unfolds.

There are Deaf people who only use sign language to communicate and others, for instance, who are oralized and can read lips. There are also bilingual people who can communicate in sign language and Spanish, with varying degrees of command of the oral and written language. There are also many Deaf women who have a very rudimentary command of sign language.

"I had never been to the doctor with an interpreter"..

Rosemary, Deaf woman having access for the first time to the health care system within this initiative.

³ The cultural and linguistic identity of the Deaf was recognized by the International Convention on the Rights of Persons with Disabilities: Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

It also must be said that sign language is a visual gesture language that changes according to the regions or countries. Argentine Sign Language (LSA), for instance, is quite different from the sign language used in Mexico or France. There are also different deafness and degrees of hearing that, in turn, bring into play other forms of communication.

Communication between Deaf persons and those who can hear is a great barrier but also a challenge as we learned along the way, which can be overcome with methodologies that work on it and raise awareness, and a good attitude to give rise to new communication strategies.

However, barriers with society not only concern communication: “It is not deafness that makes the Deaf suffer but also their fate in society. They suffer because they are not sufficiently welcome or heard”.⁴

– “I feel uncomfortable going to the doctor with my Mum. She interferes all the time”. –

– “Yes, my Mum does the same. I prefer to go on my own, like now, with an interpreter and the Sordas sin Violencia team”. –

Dialogue between two Deaf women -30 and 31 years old- participating in the initiative.

⁴ This quote is from Alexis Karacostas. For additional details, see Chapter 7 of this publication.

Never deny eye-contact

The experience of Sordas sin Violencia working with groups of Deaf women allows us to get a glimpse of the abandonment and isolation they experience as a result of a society that has never considered them and when it tried, did not know how to go about it.

Although all life stories are different, it is commonly heard that during their childhood their families excluded them from conversations, and that even as adults they made decisions for them; that they received a very unyielding education and were stigmatized for using sign language, or after having been diagnosed with a hearing disability, they were left without any kind of support within the health system.

On countless occasions of these women's lives, one can identify the footprints of stigmatization and denial of deafness looking at how they act and relate socially and emotionally.



"It is moving to see the transformation that takes place when Deaf women can access their rights. They are generally on their own because of the social and personal context and also due to family violence. From the time they were born they were not taken into consideration and here they are viewed as women with the right to health, to become informed, to get to know themselves, and care for themselves. And they can also partake in caring for the health of their sons and daughters".

Mariana Reuter, Deaf mediator and Coordinator of Sordas sin Violencia.

Communication barriers generate psychological, social and relational consequences that are even worse in the case of women or sexual dissidents, leaving them defenseless and vulnerable to gender-based violence. And, with regard to health, this is manifested not only in the lack of presence within the system but also in the lack of knowledge they usually have about their bodies, anatomy and also about their emotions and feelings.



3

A HOSPITAL WITH A LONG-STANDING HISTORY OF INCLUSION



The Hospital General de Agudos Dr. Teodoro Álvarez in the City of Buenos Aires has a long-standing history of health care **within an inter-cultural framework that respects human rights.**

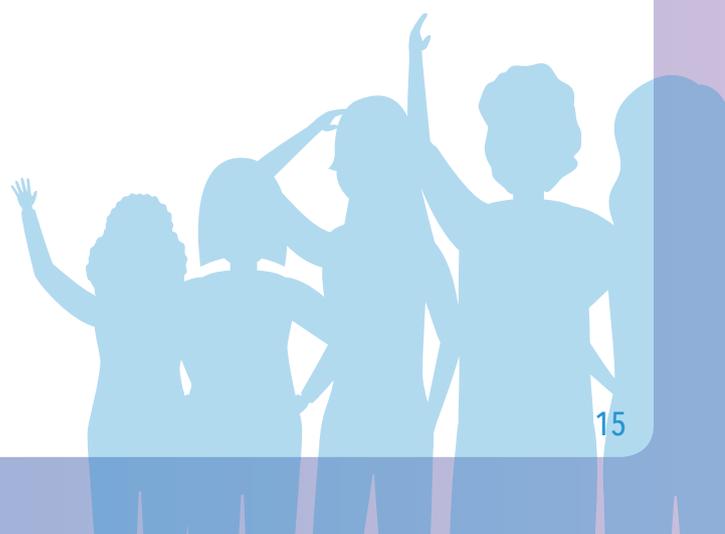
It is renowned for being one of the hospitals in the City of Buenos Aires that works under the premise of respected childbirth⁵. It is also known for its sexual and reproductive health services and assistance to victims of violence and sexual abuse. UNICEF granted it the award of "Baby-Friendly Hospital " for its activities related to promoting breastfeeding and preparing mothers therefor.

⁵ Law 25,929 on Humanized Childbirth is in force in the City of Buenos Aires but is currently enforced at four of the 23 hospitals and at two maternity hospitals in the city. <http://www.telam.com.ar/notas/201606/150204-aaa.php>

The hospital has a "Committee against violence" to study, prevent, detect and treat family, work, child and gender-based violence. This committee is made up of an interdisciplinary team and addresses violence from a comprehensive approach that includes medical, psychological and social perspectives.

The "Committee against violence" -through its president, María Varas, and Elisa Mottini, who is a member of the committee and of the Sordas sin Violencia team- accepted and promoted the project; they opened the doors so that, for the first time in the history of public hospitals in the City of Buenos Aires, the challenge of creating an accessible hospital for Deaf women, victims of gender-based violence, would be a dream come true. The Álvarez Hospital Directorate and the General Hospitals Directorate of the City of Buenos Aires supported the initiative by providing the necessary institutional backing for its implementation.

"This kind of intervention was possible mostly because we carried it out within the public health system, with its strengths and weaknesses. The initiative was proposed by Sordas sin Violencia and we accepted it at the hospital because we are practitioners who are aware of these problems. We met with them, studied approaches from elsewhere and decided to devote part of our time to enable Deaf women's access to health care. So that they could live without the violence of a system that excluded them, we created an ad hoc space", explained Analía Messina, Head of the Obstetrics Department, and also a member of the aforementioned committee.



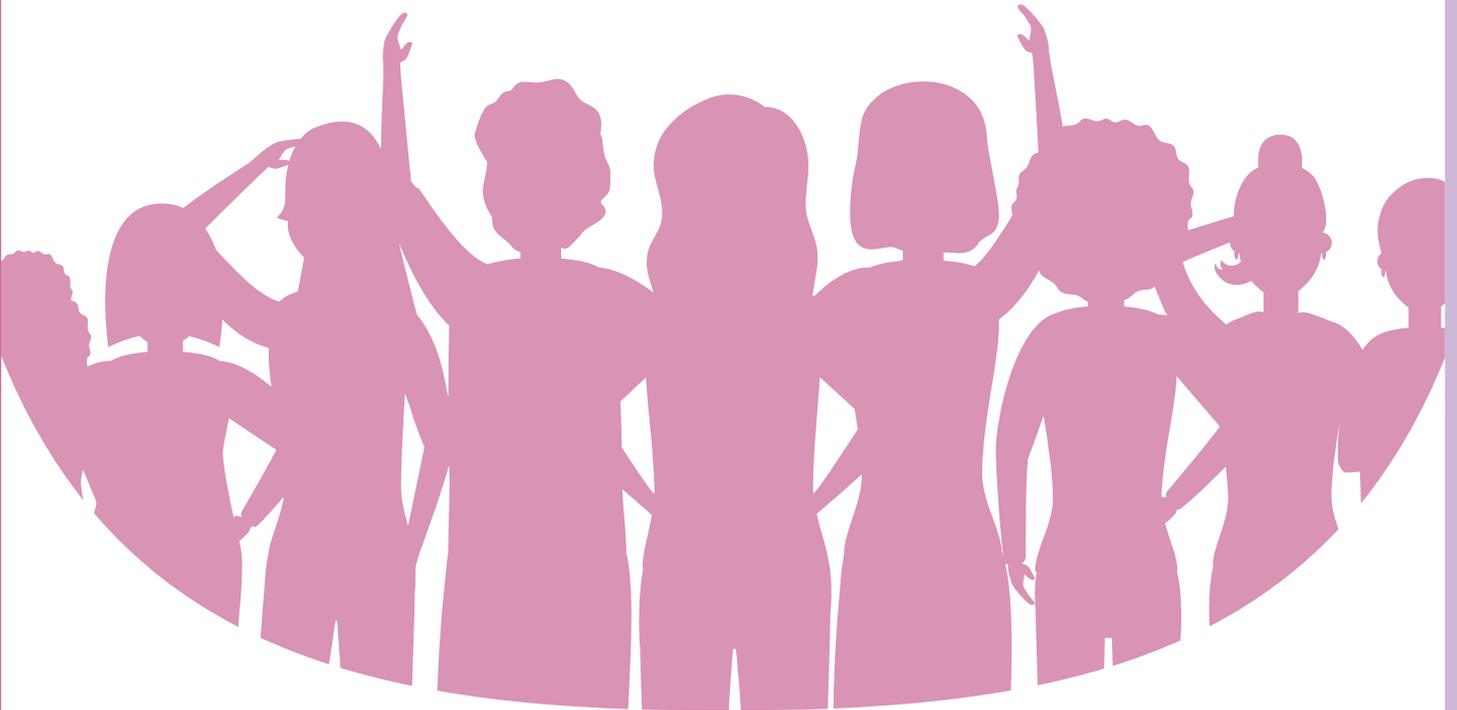
“The experience of caring for women of different nationalities and cultures helped us put together facilities for Deaf women so they could receive more appropriate care. Little by little we started providing a historical redress of violated rights for this population”

Analía Messina, Head of the Obstetrics Department, and member of the “Committee against violence”, Álvarez Hospital.



4

PRINCIPLES OF THE ACCESSIBLE AND COMPREHENSIVE CARE MODEL



The initiative is implemented from a gender, rights and disability perspective that puts into practice the principles that Sordas sin Violencia had already applied in other fields of work:

- **Empathy.** The willingness to understand feelings and concerns is always necessary but even more so when it comes to supporting women troubled by violence, isolation and invisibility.

- **Linguistic adaptation.** Every Deaf or hard of hearing woman is unique and has her own ways of communicating. To generate accessible services, hearing persons - in this case, the health teams - face the challenge of adapting to the communication skills of Deaf persons. Hence the importance of awareness-raising and training.
- **Respect for identities and cultures.** Recognizing the language and the sense of belonging that Deaf women feel towards their communities, favours exchanges and shared feelings.
- **Participation.** The slogan "Nothing about us without us" so widespread among women with disabilities also reaffirms the right of Deaf women to participate in decision-making and public policies. And it is a way of understanding each of the interventions: none of these are for Deaf women and all of them are with Deaf women.
- **Women's autonomy and empowerment.** It is a target and a process built on the bases of dialogue and of accessible facilities, adapted to ensure the well-being of women in all aspects.
- **Barrier visibility.** Universal services cannot be set up without identifying and providing visibility to the barriers that hinder access to rights. Hence the importance of raising awareness and ongoing training, especially aimed at hearing persons.
- **A framework for each case.** According to the particular situation of each woman, a way of connecting with her is established, and also of relating to the different existing care resources and facilities in such a way so as to achieve comprehensive and appropriate support for her specific needs.

THE RIGHT TO ACCESS

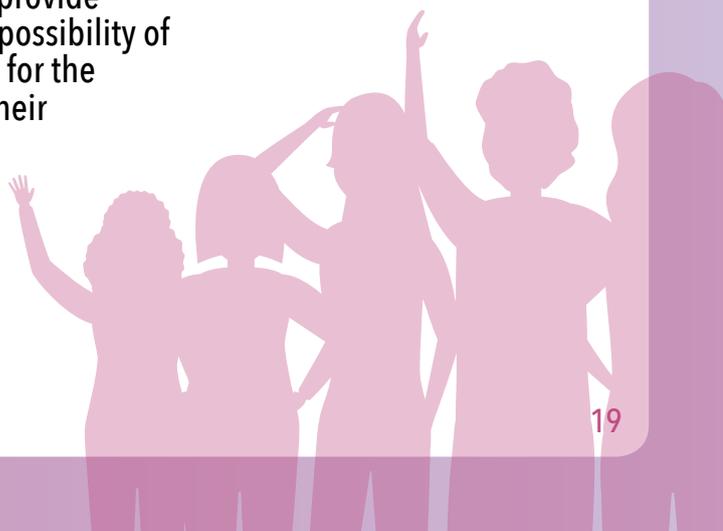
The Convention on the Rights of Persons with Disabilities proposes a social model based on universal accessibility, non-discrimination, participation, social inclusion and the elimination of barriers that limit or hinder the autonomy of persons with disabilities.

On the right to health, the Convention states:

“States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation”.

Convention on the Rights of Persons with Disabilities, Art. 25.

- **A present State.** The state is an interlocutor par excellence since it has the duty of protecting human rights, which it cannot delegate, adapting its services and generating the necessary conditions to enable adequate communication and care.
- **Teamwork.** The teams made up of Deaf and hearing women who come from different disciplines, provide unique wealth to each intervention, offer the possibility of learning from one another and become a tool for the personal and professional growth of each of their members.



5

FACILITY CHARACTERISTICS



A working group was set up by Sordas sin Violencia and the Álvarez Hospital health teams who wanted to participate in the experience, to enable coordination with the different areas and care services at the hospital. Particularly, the Sexual and Reproductive Health and Pediatrics departments that act as the key sectors to then access the rest of the hospital system. "Sexual health cuts across women's lives. We thought the health system owed these women something if they could not access this right because of being Deaf. To start reversing this situation, we created this facility especially designed for them", explained Estela Spasaro, one of the members of the Sexual and Reproductive Health team participating in the initiative.

After several meetings and training sessions on the culture of the Deaf and the specific approach thereto, a working methodology was agreed upon as follows:

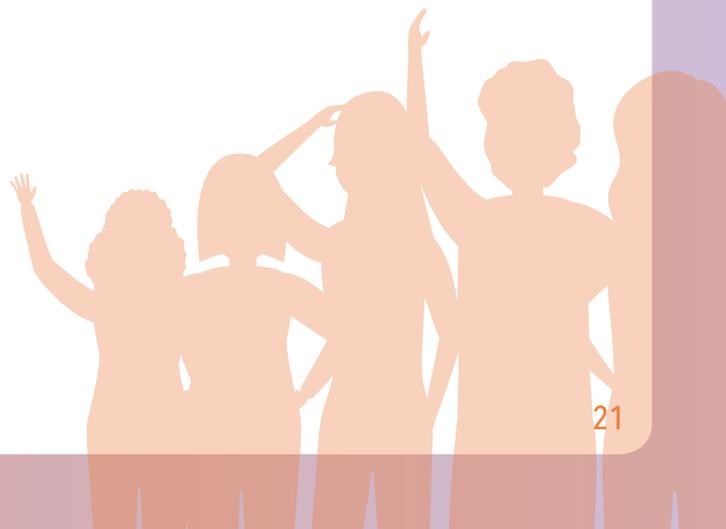
PERSONALIZED APPOINTMENTS

Accessing appointments within the health system entails crossing an important barrier since in the City of Buenos Aires hospitals there are no devices accessible to Deaf people (appointments are requested on the phone or in person). But in this case, in addition to overcoming the technological barriers to access appointments, there is an even greater challenge: bringing closer to the health system those women who have spent a lifetime neglected and excluded from it.

Aware of this reality, appointments agreed upon and available for the project are granted directly by the Initiative's coordinator through the means of communication mostly used by Deaf people: video calls and direct messaging services.

DURATION OF CONSULTATION

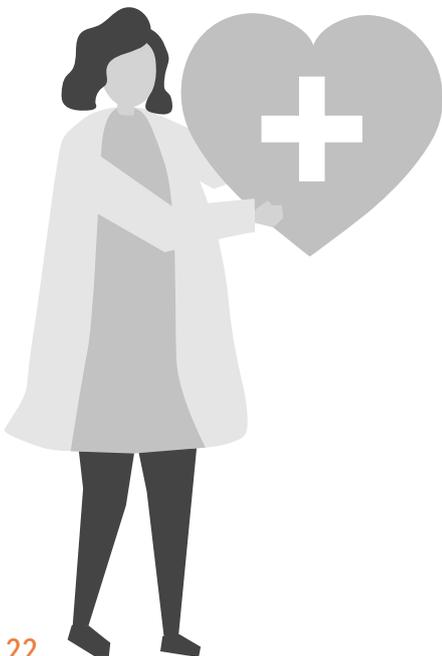
To ensure access to information and allow women to talk to the health teams to address their questions and issues of interest, the duration of each consultation is longer than what is usually allocated to an appointment, that is, double the time of normal appointments.



INTERDISCIPLINARY TEAMS

All consultations are carried out with previously sensitized practitioners to generate an environment of empathy and safety during medical care. But unlike the usual modality, Deaf women are accompanied in the doctor's office by the coordinator, a Deaf mediator and an Argentine sign language interpreter (known by the acronym ILSA-E), who facilitate communication.

This is a disruptive experience for health teams who are used to having fewer people in the office. According to one of the members of the health team: "It generated tension, although not necessarily a bad type of tension. Often times we ask questions that may be uncomfortable. We had to break the barrier to be able to talk about the patient's sexuality with more people in the office, while at the same time generating respect for her privacy". But according to the same interviewee: "It is a presence that is, however, better for everyone. For women receiving care and for the team, who we made sure understood what we wanted to convey to them."



"It helps build trust for these women and creates a protected place for them. Here they can speak. Although we are many in the doctor's office, it is the best we can do. Otherwise, if we were on our own, we would not be able to communicate".

Morina Caffoni, Alvarez Hospital OB-GYN.

COMMUNICATION BETWEEN THE HEALTH TEAM AND USERS

At all times, a Deaf mediator and an interpreter of Argentine Sign Language (ILSA-E) are present to ensure that dialogue is truly accessible to Deaf women.

In these exchanges, the gestures of the medical team are also important to facilitate communication, for instance, looking straight into the eyes, speaking slowly and without overlapping with the ILSA-E. In certain situations, drawings, diagrams, visual-tactile devices and videos are also used so they find it easier to understand complex concepts that are not easy to translate using sign language.

CONSULTATION UNDER A SPECIFIC MODALITY

The care space for women in the doctor's office has its own characteristics, not only because of what has already been mentioned. Most Deaf women, once they begin to trust the system, ask many questions -some accumulated over years-, making the space special, and leading the medical teams to use several strategies to explain, for instance, how an organ works, how to administer medication or what are the methods for contraception and prevention of sexually transmitted infections.



IN FIGURES

Throughout 10 months:

220 Deaf women and their children accessed comprehensive health care

126 healthcare services rendered to women.

13 healthcare services rendered to girls and boys.

23 health team training and awareness-raising fora.

SUPPORT AS FROM THE TIME OF ARRIVAL AT THE HOSPITAL

Since there is still no adequate signage at the Hospital to guide Deaf women on internal routes, the Sordas sin Violencia team waits for them at the scheduled time – generally half an hour before the appointment – at the Hospital’s entrance to accompany them throughout their visit. Often times the appointment is sent by direct messaging with a photo of the meeting point so that the women have it as a reference.

The waiting room also turns into a space to build trust.

My daughter had not been vaccinated. I asked her father to take her but years went by and he paid no attention to my request, now she has been vaccinated”.

Lis, a Deaf woman who accessed health care for the first time

COORDINATION WITH THE DIFFERENT DEPARTMENTS

The team ensures coordination so that women can, on the same day of the consultation, have routine tests. This entails a great coordination effort, and is, moreover, endorsed by the hospital that prioritizes health care within the project for carrying out tests such as a complete blood count, HIV tests, coloscopies, PAP smears, ultrasound scans, mammograms and urine cultures.

The creation of communication channels between the different areas of the hospital is core to achieving comprehensive accessibility and is one of the aspects that still needs to be worked on, mainly by raising awareness on the barriers in the health system.

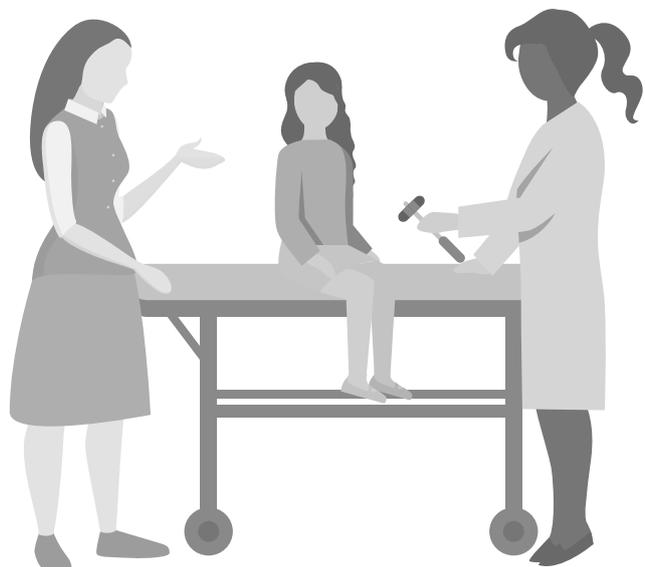
In this first stage, based on other inclusive interventions already implemented by the Hospital, coordination between departments was carried out based on contact persons: "Within our department we provide shelter to women who are facing special situations. We have different contact persons and over time, we have set up loops to facilitate health care", said Messina. In the future, the plan is to include the family medicine team and the senior residents from the different departments.



ACCESSIBLE CARE FOR GIRLS AND BOYS

The same model is also followed for the health care of the sons and daughters of Deaf women but taking into account the realities of boys and girls. In care models that are not accessible, if they are hearing persons, they end up by being the main recipients of the conversation that takes place in the doctor's office or acting as interpreters of the conversation between the professional teams and their mothers, despite what this entails for them - as boys or girls - and for building relationships within the family. María Varas, who closely follows up on this experience as president of the Committee against Violence and head of the Hospital's Maternal, Child and Youth Department explains the difference with the accessible model: "By having an interpreter and a mediator in the doctor's office who facilitate communication, this initiative allows boys and girls to be heard, to access health and be treated as what they are and not as adults."

Without ignoring all the above characteristics that are worth highlighting, for all the people involved in the initiative - in whatever role - the novelty of the care model is centered on the participation of the Sordas sin Violencia team from a three-pronged role as a coordinator, Deaf Mediator and Sign Interpreter (ILSA-E).



OUTREACH

After several meetings for outlining the plan, everything was ready to go. The team had agreed that the first day of consultation would be for the medical care of two Deaf women. With each of them, an appointment and a meeting point were scheduled. But that day neither of them showed up.

"At first, we were disappointed but what happened next was fantastic. We sought another strategy. We thought that we had to go out and meet them so we organized the system so as to visit them in a friendlier place; we believed Deaf women should meet with us first", recalled Gilda Diego, an OB-GYN, and member of the Sexual and Reproductive Health department.

The space they found to start building a closer bond was the Sordas Sin Violencia empowerment group. The Hospital's sexual and reproductive health team went there first to hold a workshop on contraception and prevention of sexually transmitted diseases. "We took pictures and drawings but above all we wanted that space to do away with the distrust they felt towards the health system."

The experience was then repeated with a Parenting Workshop conducted by the Pediatrics team. "It was a space in which they could take the floor and ask questions about caring for their children, about tantrums and about themselves, something they had never been able to do before," explained María Varas.

6

A THREE-PRONGED TEAM: A COORDINATOR, DEAF MEDIATOR AND INTERPRETER



Sordas sin Violencia supports access to health care of Deaf and hard of hearing women through an inter-disciplinary team that acts together, in an overarching manner.



Coordinator of the initiative

In this care model, the coordinator acts as the gateway for Deaf women to the health system. Elisa Mottini, who plays this role, explains that: “Coordination work is exciting, because it topples a barrier, and reduces institutional violence; it also calls for all pieces to fit together and when that happens it is gratifying because we are witnessing a reparation of rights”. **The task entails meticulous coordination among the parties, Deaf women, the teams and hospital, from organizing appointments, to centralizing the internal procedures necessary for accessibility.**

Furthermore, coordination entails a personalized follow-up of the women participating in the initiative. It also entails delivering tests and, if necessary, providing supplementary information, requesting the intervention of other professionals or managing consultations with other practitioners. The coordinator also organizes meetings and training and awareness-raising forums with the idea of having a greater number of sensitized professionals. **“Most of the work consists of setting up long-overdue meetings. On the one hand, to ensure that women overcome resistance and are encouraged to come to the hospital and, on the other, that there are more and more health teams willing to generate accessibility”**, concluded Mottini, who also keeps a record of each intervention in order to identify lessons learned and aspects to be improved.



Deaf Mediator

The Deaf mediator collaborates with the communication between Deaf women and health teams, with the participation of an Argentine Sign Language interpreter (ILSA-E).

Her intervention has a two-fold purpose that is interrelated:

- **Building a relationship of trust with Deaf women to facilitate their inclusion in the health system**
- **Making all efforts so women fully understand the topics addressed with the health team.**

Women who play this role within the team are a part of the Deaf culture and experience firsthand the barriers that hinder access to health. They also have the ability to understand the different communication possibilities of their Deaf interlocutors and, based on the above, establish appropriate ways to communicate. "Mediation goes beyond ensuring effective communication between the Deaf woman and the medical team, it also entails generating trust and empathy in an environment of respect and human values, qualities often times subdued or ignored by society", explained Mariana Reuter, one of the coordinators of Sordas sin Violencia who has specialized in this role."

Sharing a culture and being able to address different situations from a focused perspective gives rise to a type of support that is highly valued by Deaf women and by sign language interpreters, and is even of great help in situations in which it is necessary to clarify, reformulate or find new words to explain notions that are not easy to translate or are unknown.

Along the same lines, Sabrina Grinschpun, who trained as a Deaf mediator in the sessions organized by Sordas sin Violencia, added: "For me, the most important thing is to create a bond in which they can feel comfortable and tell me if they do not understand something, if they want to ask but do not know how to go about it or if they are afraid. My job is to accompany them, respecting each one's space and privacy."

ILSA - E (Argentine Sign Language Interpreter)

The interpreter is present in all conversations between the health teams and the Deaf women, conveying the meaning of what is being said in one language or another. The characteristic features of the interpreters working with Sordas sin Violencia are as follows: respect for accuracy of the original discourse, neutrality and professional secrecy. But, in turn, they have personal and professional backgrounds allowing them **to do their job with empathy and sensitivity.**

Lorena Cardoso, for instance, is a social worker and had one of her first professional experiences in the field of health. Regarding interpretation itself, she explained: "I usually say that everything can be translated and transmitted but you have to find a way to do so. Having knowledge of the area of intervention can be an added value.

Particularly emphasizing the need to "find a way" is what makes interpretation give rise to effective communication. Teamwork is another essential characteristic for rendering support through interpretation. **"When I am doing a fairly technical translation, mediators suggest how I should say certain things. Among all of us we find signs; complementariness among team members is important".**

Accessible surgery: testing the model

During one of the first consultations, something happened that, in principle, nobody wanted to face. A 32-year-old Deaf woman's gynecological results did not look good. The team quickly had to deal with organizing an accessible surgical procedure.

She had practically no relationship with the health system. The last time she had gone to a hospital was to give birth to her daughter, who was now eight years old. She had no check-ups when pregnant and arrived at the facility having started the labor process in the street, after experiencing an episode of violence with the man who was her partner at the time. The woman remembers the time of delivery: "I was alone, I saw the doctors arguing and did not understand anything, I could not voice an opinion."

The impending surgery put the team to work. The first challenge was to make the woman feel supported and begin to trust the health system. Several consultations were organized with the health team and Sordas sin Violencia, always with the support of the Deaf mediator and the sign language interpreter. The surgery was also a topic of conversation in the women's empowerment group in situations of gender-based violence since this is a space to share concerns and fears among peers. "If I had gone on my own, I would have been afraid, but with the whole team close to me, I was not," said the woman and one of her group colleagues, added: "She had had several conversations with physicians but thought she had another disease because sometimes acronyms are confusing. The topic was raised in the group and helped us all to have a better understanding."

The other challenge for the team was to create the conditions within the Hospital to ensure the treatment she was entitled to. "We worked intensely and raised awareness on a one-by-one basis so that the health facility would work in an adapted and coordinated manner," explained one of the practitioners. Perhaps the most important thing was that, from the time she entered the hospital, she had the support of the coordinator, the Deaf mediator and the sign language interpreter.

The interpreter was in the operating room throughout the surgical procedure. Morina Caffoni, the surgeon, recalled: "It was a good communication experience, it gave me peace of mind. Other times I had felt the patient left the consultation without understanding anything and I had not understood what she wanted to tell me either."

During hospitalization, she was accompanied by the team and by other Deaf women in the group. Elisa Mottini remembers when they met again after the patient had been discharged: "She had changed. She had a different attitude since for the first time she felt cared for, treated with dignity. She had another look on her face, walked straight, had a different relationship with her daughter. She used to express herself more from a position of anger and frustration but now she smiled and was more friendly and autonomous. Everything about her was different."

The intensity of the experience not only brought about changes in this woman but in all the participating practitioners: "It led us to further strengthen teamwork. We were on the alert, in contact, 24 hours a day", said Estela Spasaro.

7

UNISS, SPACES OF REFERENCE AND SUPERVISION

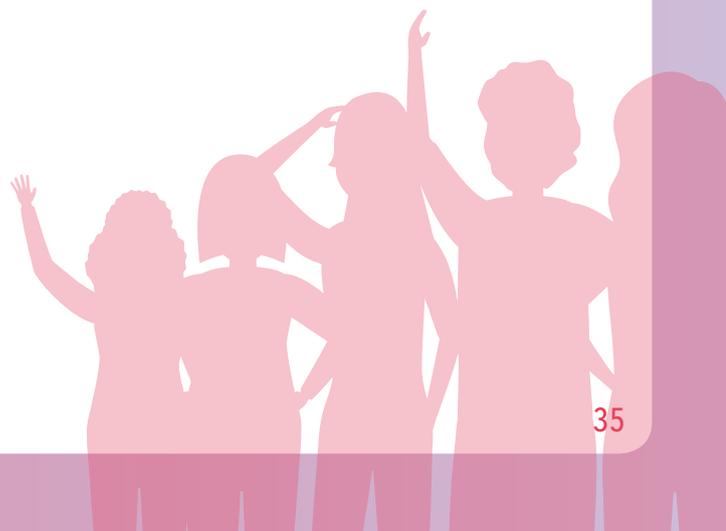


“The cornerstone of our work at the government-run Salpêtrière Hospital in Paris is sign language” explained Alexis Karacostas creator of the Units for the Healthcare of the Deaf (known by the French acronym UNISS) and an important reference person for developing the Initiative’s model, since he supported and supervised it from the very beginning. And more so, last year part of the Sordas sin Violencia team was able to travel to see on site how the UNISS worked.

Development of the French model began in 1996 to face the spread of HIV/AIDS, expanding access to health for disadvantaged populations. At present, **there are 19 units across the country, including the pilot mental health programme at the Sainte-Annen hospital in Paris, and all are governed by the same Action Protocol.**

At the UNISS, there are professionals from the Deaf community who are joining the teams in different disciplines, such as in intercultural mediation, nursing, social work and health education. To prevent situations of isolation and facilitate inclusion within the teams, there are at least two Deaf professionals in each unit.

“The possibility of attentive listening paves the way to a true consideration of the emotional, pedagogical, cultural, social and linguistic wounds and deficiencies experienced by Deaf persons while, at the same time, starting to affirm them in the social scenario by making public their cultural and policy claims”, held Karacostas, who underscored that the units over time have contributed to providing visibility to the health needs and demands of this population.



However, the specialist holds that vis-à-vis the psychological and social helplessness of Deaf persons, responses that go beyond the exclusively medical field are needed. Hence, the importance that he himself attaches to Sordas sin Violencia and to the community organizations that strive for inclusion and accessibility..

Sordas sin Violencia contacted the UNISS thanks to members of the Care Units for Deaf Persons created in the province of Santa Fe (Argentina). These units, also supervised by Karacostas, provide comprehensive health care for people from the Deaf community who live in the area, while Sordas sin Violencia promotes this initiative with a view to ensuring that violence is addressed in an overarching manner and health damages are repaired as much as possible.

SUGGESTIONS FOR A BETTER COMMUNICATION IN A HEALTH ENVIRONMENT

- 1.** Build trust.
- 2.** 1. Ask the Deaf person how he/she communicates and try to create conditions for communication in that manner.
- 3.** Maintaining eye contact is essential. It is not necessary to raise your voice, exaggerate your gestures, touch the person while speaking. It is important to be in front of the person and make sure you do not cover your mouth, or do anything else at the same time.
- 4.** Written information must be clear, with short sentences, to the point, including graphs.

8

LOOKING INTO THE FUTURE. SUGGESTIONS TO CONTINUE ELIMINATING ACCESS TO HEALTH BARRIERS



Experience gained so far is a first stage that is expected to expand, improve and reach higher levels of institutionalization. It has provided us with reflections, lessons learned and ideas to continue working at different levels since the challenge is to continue building a close link between Deaf women and health teams, and achieve accessibility policies that will remain in place over time and enable Deaf and hard of hearing persons to enjoy the right to health in equal conditions.

At the systematization meetings⁶, a decision was made to organize these ideas along two pillars: on the one hand, create comprehensive health care units for Deaf persons, based on the lessons learned from this experience. On the other hand, develop accessible, comprehensive public health policies, with actions supporting and strengthening these units.

- **Accessible, comprehensive health care units**

Accessible, comprehensive units could be institutionalized and implemented in other districts or territories. Beyond the characteristics that they adopt in each area, some features that we consider necessary to preserve are described below so that these units are true instruments for access to health for Deaf women.

- **Personalized welcome at the reception desk, respectful of rights**

After a long-standing individual and collective history of 'access to health' barriers, the way in which units receive Deaf people becomes a core issue. It is important that they be welcomed at the units, and that the latter have specialized staff to receive this population, respecting their forms of communication and their cultural identities. Empathy and the gender perspective should be the keys opening the door of the health system to Deaf people.

⁶ Systematization meetings and individual and group interviews were carried out to systematize the experience, with the participation of Deaf women, practitioners from all hospital departments who in one way or another participated in the proposal and members of the Sordas sin Violencia team.

The appointments should be managed comprehensively at the reception desk, in-person or through accessible technologies, such as video calls or direct messaging. Accessible information could also be provided at the front desk- through videos in sign language, brochures and other materials - within the communication and awareness-raising campaigns targeted to this population.

Internally, the reception desk could coordinate the intervention of the Unit's and hospital department teams that need to be involved in each case.

• **Composition of the health team**

Besides having an internal medicine or family medicine team, the unit should be made up of a Deaf mediator and a sign language interpreter, who can guide and facilitate rapprochement of the people to the health system.

The Deaf mediator and the interpreter can make an important contribution to accessibility by playing the same roles as in this experience.

• **Medical care modality**

The units would be in charge of providing medical care adapted to the situation of each Deaf person and of following up on their itinerary through the health system. To this end, besides having an interdisciplinary team, it will be necessary to generate broader consultation spaces, under a modality that gives rise to dialogue, questions and the possibility to ask again.



• An accessible institutional environment

The care units may set up the necessary coordination mechanisms for Deaf persons to be able to harness the health system facilities and have the support of the unit's Deaf mediators and sign language interpreters.

However, it will also be essential to carry out information and awareness-raising activities (grand rounds, lectures, etc.) contributing to training and, mainly, to the willingness of the teams from other areas to adopt accessible intervention practices.

Preparing protocols for Deaf persons to care for them in emergencies, and in those cases in which other hospital departments participate could also contribute to generating an accessible context with clearly established action guidelines. According to Deaf women's experiences, this is of utmost importance for obstetrics and those services calling for specialized care.

"Deaf persons are not the only ones to benefit from accessible health programmes. Experience shows us that barriers to accessibility affect everyone from a social and economic standpoint. For instance, they contribute to spreading epidemics and to deepening the consequences of gender-based violence".

Alexis Karacostas, founder of UNISS in Paris and advisor to this initiative.

• Signage

It would be important for the units to have signs and indications posted so they can be easily found. Moreover, accessible signage throughout the hospital would help Deaf persons to move around the different departments.

• Policy and economic feasibility

For the units to work properly, the authorities must commit themselves to developing such units and foresee human and hospital resources for their activities.

Accessible, comprehensive public health policies

• Accessible, comprehensive health care networks

A health care unit for Deaf women with the above suggested characteristics can seem too much when the health system lacks this kind of services but it is not enough if one considers the universe of Deaf persons that were historically denied this right and the many demands that could emerge once some of the barriers to accessibility are eliminated.

Thus, the importance of creating networks of health units providing access to other public health facilities, for instance, mental health institutions, early child care centers and ophthalmology hospitals.

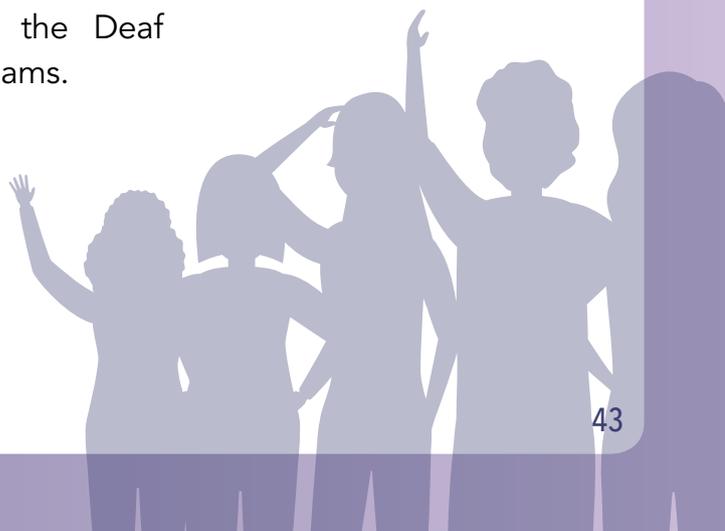
● **Bridges between institutions**

Just like synergy was achieved between Sordas sin Violencia and the Álvarez Hospital to counteract the isolation experienced by Deaf women, it is essential to create inter-institutional bridges in all areas, including Deaf Community organizations. Based on networks, coordination and partnership mechanisms, accessible, inclusive health spaces could be set up with a greater capacity to topple barriers.

● **Training and awareness-raising of health practitioners**

The training and awareness-raising meetings with the health teams showed the great interest aroused by this problem and also the invisibility of access to health barriers. However, in the exchanges held, situations were recalled in which the limitations of the health system to care for the Deaf population from a rights-based perspective clearly showed up.

Based on agreements with universities and the development of specialized training fora, in a few years there could be inter-disciplinary teams to communicate in sign language, with further tools to ensure accessibility. Additionally, agreements with accessible education institutions could train professionals from the Deaf community so they can then join the health teams.



• Communication and prevention campaigns

Deaf persons are usually excluded from Public Health communication and prevention campaigns targeted to the public at large. Seldom do they receive information on vaccination or STD, just to mention a couple of examples showing how serious this exclusion can be for society as a whole.

Within the context of an accessible health policy, communication campaigns can be carried out with organizations and leaders of the Deaf community, using sign language and communication devices, ensuring the greatest outreach.

Furthermore, an overarching communication strategy should be developed to allow Deaf persons become aware of accessible services, generate trust therein and start building a different bond with the health care system.



9

APPOINTMENT EXPERIENCES TRANSFORMED



At each meeting, Deaf women, the Alvarez Hospital health team and also that of Sordas sin Violencia hold valuable exchanges that raise questions and encourage the building and enhancement of accessible facilities.

Hereafter we share a few of the many statements we heard throughout this journey.

"It was very moving for me to go to the doctor and have an interpreter. Before, when I went with my sister, sometimes I would understand what was going on, others I wouldn't. It's important for communication to be direct, fluent".

Rosemary, one of the women who accessed accessible health care for the first time..

"I indeed understand what it is like to live in a society with barriers that lead to isolation and suffering, institutional violence has been naturalized".

Mariana Reuter, Deaf mediator and coordinator of Sordas sin Violencia.

"I went to the hospital and felt well cared for, before I could not communicate. Am happy. Communication must be for everyone".

Lis, a woman who accessed accessible health care for the first time.

"We have a history of lack of accessibility in all environments. It is important for society to become aware. We need all spaces in life to be accessible to us. This is a great first step, but we need more".

Sabrina Grinschpun, Deaf mediator of the Sordas sin Violencia team

"My dream is that physicians learn sign language. I would like to communicate directly with all. Sharing the language would entail equality".

Pamela, one of the women who accessed accessible health care for the first time.

"We achieved a change in paradigm: adapt to them and their culture, and not that they adapt to ours. We proposed that we, hearing persons be included, and not the other way around"

Elisa Mottini, coordinator of the initiative and member of Sordas sin Violencia and the Committee against Violence, at the Alvarez Hospital.





SORDAS
IN
VIOLENCIA

