



Nothing about us without us.

Valeria Campos-Cannobbio.¹

Blind people feel infantilized, their abilities and skills are constantly questioned by our society. On the other hand, Deaf people are mostly illiterate, due to educational barriers, and communicate in Sign Language, so they are excluded from a mostly hearing society. This worsens in health care scenarios, where appointments and care time are limited, the vocabulary is complex and the disease puts all patients in a vulnerable position (*Campos & Cartes-Velásquez, 2019*).

Even though the Convention on the Rights of Persons with Disabilities (*CRPD*), which Chile ratified in 2008, specifies that States Parties require qualified health professionals to provide care of the same quality to persons with disabilities. (*United Nations, 2008*), in Chile, as in many countries, we are far away from meeting this goal.

Persons with Disabilities (*PwD*) must still face a paternalistic and medical model that does not recognize them as subjects of rights. In addition, health personnel are unaware of their reality, their needs, capabilities, and even how to address them. In sum, this results in a system that hinders access, generates low user satisfaction, frustration, mistrust and low usability of primary care centers. This becomes urgent if we consider what is indicated by the Shadow Report for The Review of The State of Chile before The Committee on The Rights of Persons with Disabilities, (*CIMUNIDIS, 2016*):

“Article 25. Health

...On the other hand the provision of health services in the public system represents a barrier for the deaf community and with visual impairment, and in particular for blind and deaf girls and women because among other things: the administrative staff and health personnel do not have the resources and modifications for deaf people, people with hearing loss, and blind people; the system does not contemplate the right to decide the form of communication with neutral and competent interpreters that can transmit the information about the reason for the consultation properly; the treating physician does not inform nor explains personally, as a direct patient, to the deaf person or with hearing loss or the blind person, the process of the visit, the diagnosis, the treatment or the need to avoid certain contraindications; it is required from the deaf or blind person to be accompanied by a relative, friend or another person that can interpret for them, this not only collides with the principle of independence, but also involves problems with privacy and confidentiality”

Moreover, PwD endorsed Chilean social outburst in October 2019, highlighting the urge of a constitutional recognition of PwD and the lack of universal access in health, among others.

We try to address this issue with the FONIS (*National Fund for Research and Development in Health*) project entitled “*Perceptions about health care of people with hearing and visual disabilities. Qualitative study of the experience of patients and primary care teams in the central south of Chile*”. The aim of this project is to reveal the perceptions about health care access of people with hearing and visual disabilities from the experience of patients and primary care teams in the central south of Chile, including the 8 provinces of the Ñuble, Biobío and Los Ríos regions.

On December 3rd, the International Day of PwD is commemorated, but there

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is little to celebrate. On the contrary, it becomes even more urgent to raise awareness about the barriers experienced by PwD regarding health care, so that they can be addressed in a successful way. This day seeks to commit countries to “*leave no one behind*”, as this is the only way to achieve inclusive, equitable and sustainable development. The CRPD, states “*nothing about us without us*”, which requires an active participation of PwD in decision-making, recognizing PwD as agents of change and with their own voice (Campos & Cartes-Velásquez, 2019).

The contribution that we can generate from the research, with a team composed of PwD and researchers, is to identify the existing barriers and propose feasible changes to be implemented by users and health teams. Also, to train health professionals who face and solve the barriers and prejudices that deny PwD their health rights.

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