

EVOLUTION OF THE CONCEPT OF DISABILITY IN CHILE.

Evolución del concepto de discapacidad en Chile.

Lorena-Mirtala Orellana.¹

AFFILIATIONS:

¹Depto de Prevención y Salud Pública
Odontológica Facultad de Odontología,
Universidad de Concepción, Chile.

CORRESPONDING AUTHOR:

Lorena-Mirtala Orellana.

Facultad de Odontología, Universidad
de Concepción, Chile. Avda Roosevelt
1550, Concepción, Chile. **Phone:** (56- 41)
2204232. **E-mail:** lorenaorellana@udec.cl

The concept of disability is dynamic and has evolved over time. Different communities sometimes use their own terminology to refer to disability, influenced by their idiosyncrasies, historical context and the barriers that society generates towards people with disabilities.

In ancient cultures, disability was viewed through a magical-religious context, associating it with powers over humans that put people to the test or was considered a divine punishment, which resulted in rejection and isolation. At the beginning of the fifteenth century, the approach to disability became technical and secularized, seeking to rehabilitate people with disabilities from a purely medical perspective, which generated massive and chronic hospitalization. After the Second World War, disability had a medical and assistance approach, which generated highly dependent people and attitudinal barriers in society. And in the second half of the 20th century, disability was viewed from a human rights-based lens where prevention, rehabilitation and social inclusion were prioritized.¹

Thus, in Chile in 1947, the *Society for the Help of the Crippled Child* (Sociedad Pro Ayuda del Niño Lisiado - SPANL) was created, an institution that was initially responsible for rehabilitating children affected by childhood poliomyelitis. Later, in 1978, the entertainer Mario Kreutzberger (known as *Don Francisco*) was invited to get to know this society, and he created a Telethon (TELETÓN) with the purpose of financing this institution.² Thanks to the efforts of Don Francisco and the successive Telethons, people with disabilities become visible in Chile for the first time.

In 1980 the World Health Organization (WHO) published the International Classification of Impairments, Disabilities and Handicaps (ICIDH), which establishes that disability represents a deviation from the norm that reflects the consequences of an impairment from the point of view of functionality and activity of the individual, therefore,

CITE AS:

Orellana LM.

Evolution of the concept of disability in
Chile.

J Oral Res.2022;11(4):1-12.

doi:10.17126/joralres.2022.035

there is a predominance of a negative perspective focused on deficiencies, considering disability as an individual fact and excluding social and contextual aspects.³

In 1994, The National Disability Fund (Fondo Nacional de Discapacidad - FONADIS) is created in Chile thanks to the enactment of Law 19,284, which establishes the rules for the full social integration of people with disabilities, which in its article 3 defines that a *Person with Disability (PwD)* is anyone who, as a result of one or more physical, mental or sensory deficiencies, congenital or acquired, foreseeably of a permanent nature and regardless of the cause that originated them, is hampered, in at least a third, their educational, labor or social integration capacity.⁴

Then, in 2004, the First National Study on Disability (ENDISC I) was published in Chile, which incorporates the concept of disability from the International Classification of Functioning, Disability and Health (ICF) promulgated by the WHO and the Pan American Health Organization (WHO-PAHO, 2001) that establishes that *disability is a generic term that includes impairments of body functions and/or structures, activity limitations, and participation restrictions, indicating the negative aspects of the interaction between an individual (with a "health condition") and their contextual factors (environmental and personal factors)*.⁵ Thus recognizing that people with disabilities are direct and active subjects of their rights, promoting their autonomy and social inclusion and recognizing the existence of environmental and personal factors.

In 2008, Chile ratified the International Convention on the Rights of Persons with Disabilities, which establishes that *disability is a concept that evolves and results from the interaction between people with disabilities and the barriers due to attitude and to the surrounding environment that prevent their full and effective participation in society, on equal terms with others*.⁶

Two years later, in 2010, the Chilean law 20,422 that establishes norms on equal opportunities and social inclusion of people with disabilities, which in its article 5 defines that *a person with a disability is*

one who, having one or more physical, mental, mental or intellectual, or sensory deficiencies, of a temporary or permanent nature, when interacting with various barriers present in the environment, sees their full and effective participation impeded or restricted in society, on equal terms with others.⁷

As such, greater emphasis is given to environmental contextual factors, which can be a barrier or a facilitator for the person with disabilities, therefore these influence the degree of disability of the person. In 2015, the Second National Study on Disability (ENDISC II) was published in Chile, which incorporates the term *Person in a Situation of Disability (PiSD)* establishing that *this is any person who, in relation to their physical, mental, intellectual, sensory or other health conditions, when interacting with various contextual, attitudinal and environmental barriers, present restrictions on their full and active participation in society*.⁸

Currently in our country two concepts are used to refer to disability: Person with Disability (PwD) and Person in a Situation of Disability (PiSD). In both concepts the word "person" recognizes the condition of the PwD or the PiSD as a subject with fundamental rights (civil, political, economic, social and cultural). On the other hand, the word "situation" refers to the temporality that a condition of disability has, which can be temporary or permanent, and to the influence that environmental contextual factors have mainly on the expression of disability, which can decrease the degree of disability of the person if these are more facilitators than barriers at a given moment.

Finally the word "disability" indicates the condition associated with that person, which can be physical, intellectual, psychic, sensory or multiple. Generally the concept of PwD is the one employed in most countries and the one that is present in the laws of Chile, therefore, it is a more international and legal term. The concept of PiSD has been used mainly by the Ministry of Health in Chile to present programs and guidelines that facilitate the care of these patients.

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