English

The contribution of the Distance Communication Offices in the precision of the right of access to health in children and adolescents

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Abstract

Project for the incorporation of telehealth resources at the National Center for Medical Images in Costa Rica. This article aims to situate the context of the implementation of Teleradiology at the National Center for Medical Images in Costa Rica. The processes related to the satisfaction and demand of users from remote areas, outside the metropolitan area, will be reported, as well as the elements for the conformation of the Teleradiology service, depending on the demand and need, to achieve this improvement.
Keywords: *Child Health; Telehealth; Right to Health*

Resumen

El aporte de la Red de Oficinas de Comunicación a Distancia (OCD) Telesalud en la concreción del derecho de acceso a la salud en Niños, Niñas y Adolescentes

Proyecto de incorporación de recursos de telesalud en el Centro Nacional de Imágenes Médicas. El artículo tiene como objectivo situar o contexto de la implementación de Teleradiología no Centro Nacional de Imágenes Médicas na Costa Rica. Se informarán los procesos relacionados a la satisfacción y demanda de usuarios de zonas alejadas, fuera del área metropolitana así como se identificarán los elementos para la conformación del servicio en Teleradiología, en función de la demanda y necesidad, con la finalidad de alcanzar dicha mejora.
Palabras clave: *Salud Infantil; Telesalud; Derecho a la Salud*
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Resumo

A contribuição da Rede de Oficinas de Comunicação a Distância (TOC) Telessaúde na efetivação do direito de acesso à saúde em Crianças e Adolescentes.

Projeto de incorporação de recursos de telessaúde no Centro Nacional de Imagens Médicas da Costa Rica. Este artigo tem como objetivo situar o contexto da implementação de teleradiologia no Centro Nacional de Imagens Médicas da Costa Rica. Apresenta os processos relacionados a satisfação e demanda de usuários de zonas remotas, fora da área metropolitana, assim como os elementos para a configuração do serviço de teleradiologia em função da demanda, necessidade com fins de alcançar melhorias.

Palavras-chave: *Saúde da Criança; Telessaúde; Direito à Saúde..*

Introduction

Health is an inalienable right of every human being[1]. The health care of Children and Adolescents (*NNyA acronym in Spanish*) is a responsibility of the State, and must always especially contemplate the rights of patients, since childhood is a stage of vulnerability, and what happens in it will determine the quality of life of each person even in adulthood.

The required care from a child influences (and includes) his entire family group. Some of the objectives pursued by the OCD Telehealth Network are preventing children and their families from having to travel long distances to access health care, reducing or eliminating costs, avoiding separation from the family group, bringing quality care in pediatric health closer, reflecting the search to effectively protect that right.

In the development of this task, contrapositions of rights, confidentiality issues, ethical dilemmas sometimes arise, but it is about always seeking to attend to the Best Interest of the Child[2].

Argentina is a federal country, which has 24 jurisdictions (23 provinces and the Autonomous City of Buenos Aires) and an area of 2,780,000 square kilometers. According to statistics from the last census, 13,711,568 of its almost 40 million inhabitants are children and adolescents, who access health services through three subsystems: public (45.30% of children and adolescents have exclusive public coverage), social security (42.75%[3]), and prepaid medicine (11.95%[4])[5].

Pediatric Hospital "Prof. Dr. Juan P. Garrahan" is a highly complex public hospital of national and regional reference. This institution is a S.A.M.I.C. (*Servicio de Atención Médica Integral para la Comunidad - Comprehensive Medical Care Service for the Community*), financed with contributions, and managed from the Ministry of Health and Social Development of the Nation *Ministerio de Salud y Desarrollo Social de la Nación*) (80%) and the Ministry of Health of the Autonomous City of Buenos Aires (*Ministerio de Salud de la Ciudad Autónoma de Buenos Aires*) (20%) and the payment of benefits by Social Works or Prepaid when patients have them.

The hospital was created in 1987 under a patient-centered care model, with an organization for progressive care and a matrix structure. It is a national pediatric reference following a logic of integrated health networks and assists children and adolescents from Argentina and other countries.

In this context, the network of Distance Communication Offices (OCD acronym in Spanish) Telehealth seeks to contribute to a better quality of health care as close as possible to the place of residence. Thus, a knowledge exchange network has been built with very particular features, with contributions from a number and variety of professionals who day by day involve their knowledge and expand it to improve the care of pediatric patients.

We will show the development of the pediatric network to analyze its scope. It started with the creation in 1997 of the Office of Distance Communication (OCD) of the Garrahan Hospital as a management device, its initial administrative medical model and its expansion to an interdisciplinary team, its transformation into a national network, the evolution of the processes, the relationship between institutions, technological advances and the subsequent intervention of the ministries, until formally connecting the 24 national jurisdictions in 2018.

This is how the network of OCD Telehealth is a consequence of years of development with different references, which evolved until the scope it has today, with projections to continue growing and improving in the future.

In the values held and the practices developed by this network, we can identify aspects that contribute to the right to health of children and adolescents (NNyA acronym in Spanish)[6]. This work will deal with the analysis of the contribution of the Network of OCD Telehealth in the concretion of the right of access to quality health in NNyA in dialogue with international and Argentine legislation on the subject.

Method

The development of this work is based on the analysis of bibliographic material (material on NNyA Rights, Telehealth, Quality in Public Health care), historical archives of the network of OCD-Telehealth, statistical data of the Garrahan Hospital OCD, projects with international organizations, of experiences registered in chronicles of meetings and participant observations in the Hospital Garrahan and other institutions of the network.

Results

Right to health

"Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity"[7].

In addition to this definition of the preamble of the Constitution of the World Health Organization (WHO), we also take other fundamental principles[8]:

√ The enjoyment of the maximum level of health that can be achieved is one of the fundamental rights of every human being without distinction of race, religion, political ideology, or economic or social condition.

√ The extension to all peoples of the benefits of medical, psychological, and related knowledge is essential to achieve the highest degree of health.

√ Governments have the responsibility to guarantee the health of their people, which can only be fulfilled through the adoption of adequate health and social measures.

The right to health is recognized in all Human Rights declarations, since the Constitution of the World Health Organization (WHO) in 1946; in the Universal Declaration of Human Rights in 1948; in the International Covenant on Economic, Social and Cultural Rights of 1966; in General Comment 14/2000 of the UN Committee on Economic, Social and Cultural Rights; in the International Convention on the Elimination of all Forms of Racial Discrimination, of 1965; in the Convention on the Elimination of all Forms of Discrimination against Women, of 1979; in the Convention on the Rights of Persons with Disabilities, of 2006; and in article 24 of the Convention on the Rights of the Child, of 1989. The right to health is also recognized in article 10 of the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social, and Cultural of 1988[9].

In the right to health in the Argentine National Constitution, article 14 bis establish that "the State will grant the benefits of social security that will be integral and inalienable. In particular, the law will establish: "compulsory social security", and article 41 states that "All inhabitants enjoy the right to a healthy, balanced environment, suitable for human development and productive activities to satisfy present needs without compromising those of future generations; and they must preserve it"[10].

This is the duty of the State to guarantee access to health not only to its citizens but to every person who is in Argentine territory. Even with difficulties, it is sustained and made effective.

Regarding the concept of quality in health, taking some definitions from the Code of Ethics of the Argentine Medical Association (*AMA- Asociación Médica Argentina)*, three aspects can be distinguished: the person, the system, and the health team.

If we talk about the person, the patient, the Code of Ethics of the Argentine Medical Association in its Chapter 8, Art. 117 states:

> *Despite the difficulties in finding a universally accepted definition, the concept of Quality of Health Care is linked to the satisfaction of the needs and demands of the individual patient, their family environment, and society as a whole[11]. (…).*

Therefore, it is in line with the WHO precept that defines health not only as of the absence of disease but also considers the person integrally, as part of a family and a society.

For the system, the AMA takes up the definition of the WHO in its Art. 118:

> *The World Health Organization defines the following factors as requirements to achieve Quality in Health: a high level of professional excellence, efficient use of resources, a minimum risk for the patient, a high degree of patient satisfaction, and the assessment of the final impact on Health12.*

This high level of professional excellence must be placed at the service of the patient, and efficient use of resources would indicate not transferring patients who do not require it, resolving as many situations as possible, bringing the resources of the health system closer to him and not the other way around.

Regarding the health team, AMA emphasizes training, expressed in Art. 38:

> *To obtain an adequate level of training that allows them to offer the best quality of medical care in all their actions, the members of the Health Team must maintain continuous training that allows them to be up-to-date with the scientific/technological changes that occur in all areas of their work13.*

The constant updating of the health team necessarily benefits the patient, who receives the most appropriate care for his pathology, origin, family situation, etc.

Rights of children and adolescents

The concept of childhood has evolved. For centuries, the child was invisible, childhood was the time to become an adult. Only in the 20th century, children and adolescents are considered as such, and subjects of law. From this century, relevant advances are produced.

The greatest conceptual change is generated by the International Convention on the Rights of the Child since it achieves the passage from the perspective of needs to the perspective of rights[14].

The importance of this paradigm change can be summarized in four central points:

√ Needs become rights when they are established as an obligation for those who must provide them.

√ The incorporation of human rights instruments into the internal law of the countries implies obligations for the States.

√ This gives the possibility of requesting and demanding compliance, so this nature of enforceability is an essential condition.

√ In the case of children and adolescents, the obligation corresponds to the adults (family, institutions, State, school, etc.).

NNyA Rights - International Legislation

Since its publication in 1989, the international standard par excellence is the Convention on the Rights of the Child (*Convención sobre los Derechos del Niño* - CDN). In it, the rights of children and adolescents are recognized and made explicit and the commitments and actions that the States that adhere to it must take are listed.

In the right to health, the CDN in its article 24 not only recognizes the child's right "to enjoy the highest possible level of health and services for the treatment of illnesses and health rehabilitation", but also commits States parties to ensure that this right is fulfilled, and apply (among others) measures to[15]:

a. Reduce infant and child mortality;

b. Ensure the provision of necessary medical assistance and health care to all children, with emphasis on the development of primary health care;

c. Combat disease and malnutrition within the framework of primary health care through, inter alia, the application of available technology and the provision of adequate nutritious food and safe drinking water, taking into account the hazards and risks of contamination of the environment.

NNyA Rights - Local Legislation

Argentina has adhered to the Convention on the Rights of the Child (*Convención de Derechos del Niño* - CDN) since 1990 through Law 23849[16], and confers constitutional status along with other international treaties in the reform of the Magna Carta of 1994, in article 75 inc. 22CN[17].

There is also national legislation in this regard such as the Law for the Comprehensive Protection of the Rights of Children and Adolescents[18], which determines the obligation to comply with the CDN, sets the guidelines to be followed in terms of public policies, the role of the family, defining the Superior Interest[19], government responsibility, among others.

Regarding the right to health, article 14 states:

> *"Every health institution must give priority to girls, boys, adolescents, and pregnant women.*
> *Children and adolescents have the right to comprehensive health care, to receive the necessary medical assistance and to have equal access to services and actions for prevention, promotion, information, protection, early diagnosis, timely treatment and recovery from health".*

The Civil and Commercial Code of the Nation, in its Article 25, establishes how a person is considered according to their age: a minor has not reached the age of eighteen, and an adolescent is a person under the legal age who has turned thirteen[20].

Telehealth

Making a general reference to the concept of telehealth, we can observe that, in 2005 at the 58th World Health Assembly, the WHO prepared a document that deals with the Implementation of a Telemedicine Service, making a historical review, providing definitions of its components, uses, services, application areas, etc., and it establishes that it adopts a definition of Telemedicine that includes the entire health team and broadens the perspective of its uses:

> *"The provision of health care services, where distance is a critical factor by all health professionals who use information and communication technologies for the exchange of valid information for the diagnosis, treatment and prevention of disease and injury, research and evaluation, and for the continuing education of health professionals, all in the interest of advancing the health of individuals and their communities"21.*

Within this framework, four main axes can be distinguished:

1. Telecare: Remote patient care, second medical opinion consultations, or other health team professionals (kinesiologists, nurses, etc.)

2. Tele-education: Courses, athenaeums, talks. Distance training.

3. Telemanagement: Remote activities that facilitate the definition of shared codes and the establishment of work agreements between health teams from different institutions. These purely operational meetings are related to the implementation of collaboration projects, the transfer of processes and care models, among others.

4. Tele-investigation: remote activities related to the development of multicentric investigations. They enable to generate or increase the frequency of meetings between researchers, strengthening research by providing a greater number of instances of exchange between participants.

Network of OCD Telehealth

The construction of the network of OCD Telehealth takes more than 22 years of work, since the creation of the OCD Garrahan. It was the first Telecare device in the public system, promoter of a network of institutions and people, which, due to its relevance, is the basis for the development of national telehealth public policies, first with the Cyber

health Plan (2014) and then the Plan National Telehealth[22]. It currently carries out telecare activities, distance continuous training, and Telemanagement, in an interdisciplinary way[23].

The Garrahan is a highly complex hospital that cares for children and adolescents up to 18 years old. It was created in 1987 under a patient-centered care model, with a progressive care organization and a matrix structure. It is a national pediatric reference following a logic of integrated networks of health services. It is located in the Autonomous City of Buenos Aires and around 40% of its patients live in the interior of the country[24].

In this context, in 1997 Garrahan had sufficient organizational maturity to develop this conception of patient-centered care outside the walls and generate inter-institutional strategies such as the Distance Communication Office aimed at the health teams of the different care centers in the country to carry out remote consultations with Garrahan professionals, avoiding unnecessary transfers to the City of Buenos Aires.

One of the aspects that left a particular imprint on the OCD device was the initial medical-administrative binomial, with a spirit that considered not only care proposals as the sole objective of the OCD but also valued all procedures in favor of the patient and his family in pursuit of the right to health.

Initially, point-to-point agreements were established, that is, collaboration agreements were signed between hospitals directly. Thus, a network was created with hospitals in the different provinces with the following initial objectives.

Table 1: *Initials Objectives*

To answer inquiries about diagnosis or treatment of patients.
To carry out the joint follow-up of the patient in their place of origin with local professionals and those of the Hospital.
To facilitate and complement the exchange on diagnosis, evolution, and follow-up of patients discharged from the Hospital.
To plan shifts by Day Hospital in cases where referral is required for interdisciplinary diagnosis or resolution.

Source: (Carniglia, 1999[25]).

Sequentially and based on the results obtained in the initial stage, the objectives were expanded:

Table 2: *Objectives. Second Stage.*

To receive remote studies.
To provide information on Diagnosis and Treatment standards.
To search and send bibliography.
At a later stage, to participate in epidemiological studies and clinical trials.

Source: (Carniglia, 1999[26])

As the work progressed, we concluded that the point-to-point agreements did not generate an adequate mode of relationship between health institutions, because provincial levels of progressive care were unknown.

Thus, in 2002, a project was launched based on the reformulation of the "point to point" strategy, financed by the Pan American Health Organization (PAHO), which was developed in the province of Jujuy and was the basis of the Subprogram of Distance Communication. It was called "*Telemedicine Project in Support of the Establishment of Hospital Services Networks*" and a network of OCDs was created that respected the provincial reference levels, trying to give local resolution to optimize the resources of the provinces and minimize Intra and Inter provincial transfers[27] that were framed in collaboration agreements between Hospital Garrahan and different provincial ministries.

In this way, and with the creation of OCDs in hospitals in different provinces, an inter-institutional and interpersonal solidarity network was built, which works with telehealth tools and has been defined as a network of networks because it facilitates relationships and concretion of other forms of collaboration between health teams.

Currently, the network has more than 300 OCDs throughout the country and is organized from hospitals and people (professionals, technicians, and administrative staff) referred by jurisdictions according to the level of complexity, who share values such as innovation, honesty, perseverance, passion, commitment, equity, inclusion, respect, diversity, solidarity, teamwork, and empathy.

About synchronous Tele-education activities -in real-time- (athenaeums, courses, talks, conferences, symposiums, seminars, etc.) other non-care institutions are also integrated such as universities, or even hospitals without OCD that have video conferencing equipment or applications for computers or mobile devices that allow them to participate remotely.

At the end of 2011, Hospital Garrahan signed an agreement with the Ministry of Science, Technology and Produc-

tive Innovation for the execution of the Project "Development and innovation of an inter-hospital communication model for remote patient care and monitoring".

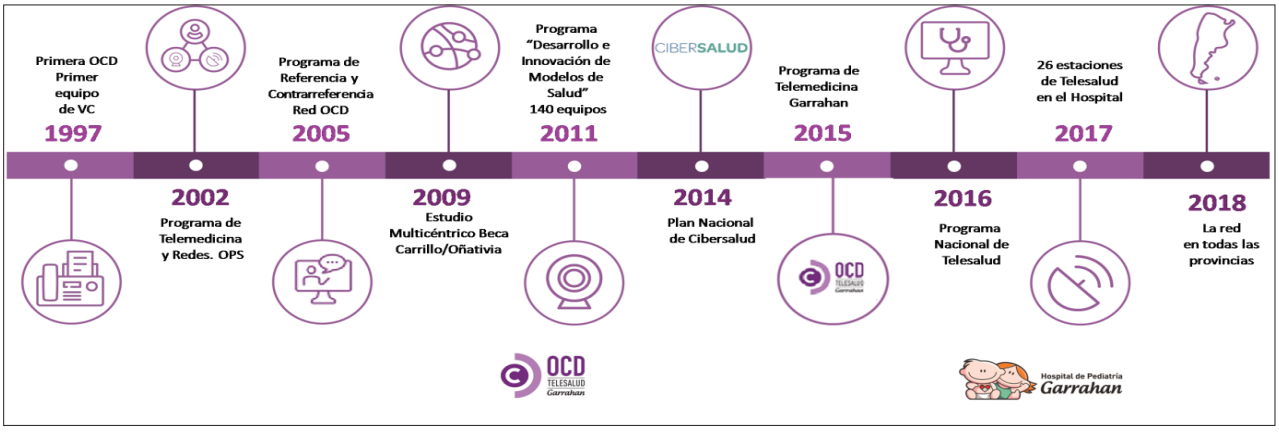
This project strengthened the videoconference communication system between health teams throughout the country. There were 140 pieces of equipment and 500 licenses to carry out high-definition videoconferences to hospitals and Ministries of Health in the provinces.

In 2014, the Telemedicine Program was created to generate new synchronous practices of remote care and the migration from paper to digital support.

In 2016, the task of designing the National Pediatric Telehealth Program was undertaken together with the Ministries of Modernization and Health of the Nation, with the participation of more than 80 professionals.

Finally, in 2018, the 24 jurisdictions of the country were formally connected, when the Agreement was signed with the province of Córdoba in June. In this context, the increase in simultaneous massive synchronous exchanges, the growth of the production of each venue, and the need to have a backup system for the operation of the videoconference, generated the need to investigate new technological responses related to other platforms of videoconferencing (SaaS Software as a service).

Figure 1: Timeline of Distance Communication in pediatrics in Argentina



Source: (OCD Telehealth Garrahan, 2018[28])

Figure 2: Statistical data of the Garrahan Hospital Distance Communication Office in 2018 (summary).

As mentioned above, the work of the network is understood as a network of networks. This is how inside the Garrahan Hospital, they work with the same logic. In this way, all the services and areas of the hospital are part of the OCD (and also of the OCD network), based on the queries they answer, the virtual consultations they carry out, the counter-referrals, the meetings they share, the training they provide and in which they participate and all the joint projects they develop.

This form of networking and remote work meant that, in 2016, the Garrahan Hospital formally recognized remote care as a new care modality, in addition to the traditional, outpatient, and inpatient care, by including it in its clinical history record.

Discussion

Although all legislation recognizes health as a right and the assumptions that must be fulfilled are reflected in laws and treaties, and quality care objectives are established, access to health in our country is hindered by multiple factors (sometimes concurrent each other): great distances, geographical barriers, and adverse climates, the concentration of professionals and health centers in the capitals, lack of economic resources.

These factors not only hinder the arrival of patients to health facilities but also limit the access of professionals to training (courses, updates).

In such a large country, and where a third of the population is treated in the public health system[29], this tool contributes to access to rights, shortening gaps, providing quality health without extra costs for the patient and his family, and making better use of system resources, connecting public health facilities across the nation.

Garrahan Hospital laid the foundation stone and the network grew in size and complexity, achieving a network of people and institutions in which queries are often resolved locally or regionally, by consulting closer institutions, without the need to raise the query to that center or to transfer the children to the provincial capitals or even to the City of Buenos Aires.

Since the beginning, Garrahan Hospital collaborates with the planning and assembly of the provincial networks. It trains the people who are going to work as references in OCD, transferring the collaboration model that today is broader than that first doctor and administrative duo, and suggests a set of interknowledges[30] to seek success in care.

This is how the network of OCDs works interinstitutional and interdisciplinarily to facilitate access to health through quality care, continuous training of its members, and collaborative management between effectors with telehealth tools.

In this sense and relation to the contribution of the right to health in children and adolescents, the following aspects can be highlighted as strengths of the Network of OCD Telehealth:

- It facilitates access to health: through this remote care system, patients have access to specialist care that they otherwise would not reach, equalizing the opportunities to arrive at the appropriate diagnosis or treatment for their situation.

- It shortens distances: in the case of NNyA, the need to move generates great costs for families, such as economic costs, being uprooted, having to separate from the family, missing days of school or work, etc. By bringing quality care closer to home institutions, stress is significantly reduced for patients and their families.

- It favors continuity of care and coordination between levels: by scaling consultations by levels of complexity, the information is available to the different effectors that intervene in the care of that patient, and in this way, continuity of care can be provided avoiding loss of data or repeating studies that can expose the patient and waste valuable time. Thus, the family is no longer the only transmitter of information between the health teams that assist the patient in different institutions.

- It enables rapid responses to unforeseen situations.
It allows dialogue between health teams: being connected by the language of networks and working with this dynamic, it is easier for professionals to relate to each other because they are all considered to be part of the same health team. The members of the OCD are also facilitators and translators of the idiosyncrasies of each institution for the members of the network of other organizations. The technological factor also contributes to the advantages of all the communication tools available and their adaptation to local resources.

- It reduces hospital stay: when transfers are necessary, by carrying out prior consultations instead of direct transfer (outpatient or inpatient), patients attend with the studies already carried out, with clear information on why their care is required in that institution and with an assigned date and time.

- It updates knowledge of the health team: its members can stay updated without having to travel, share educational activities with their colleagues, and access permanent training remotely. This generates motivation and raises the quality of care.

- It promotes flexible collaborative proposals: adaptation of these to local realities for the strengthening of the actors involved in favor of providing the best health care, taking into account the economic, social, and cultural resources of each region.

On the other hand, the following opportunities for improvement are detailed below:

- Connectivity: Although there is a long way to go, there are a large number of places that do not have connectivity, so accessing an e-mail or a web platform is impossible.

- Unified registry: Each province keeps its statistics, but there is no national registry that reflects all the steps taken. For example, the results presented in the work refer to the 2018 production of the Garrahan Hospital.
Digital literacy: it is common to find people (from administrators to postgraduate university students) who are

not familiar with the use of Information and Communication Technologies (ICTs).

- Legal and institutional regulatory framework: it is necessary to enact laws that regulate the activity of Telehealth so that the practice is regulated and protected for both patients, professionals, and institutions. Also, it is necessary that all provinces adhere to the national plan, approved from Resolution 21/2019 Ministry of Health and Social Development of the Nation, and that Telehealth services are contemplated in the organizational charts of provincial ministries and effectors, with identified referents, giving continuity to the procedures and people in their roles within the network.

Conclusion

Considering that health is much more than the absence of disease[31] and that the quality of care is linked to a multiplicity of factors, not only having a health center or professional nearby but also having access to timely and adequate care, we can say that the network of Distance Communication Offices Telehealth makes a significant contribution to access to the right to quality health for children and adolescents.

In this sense, it stimulates inter-institutional collaborative work, favors care at origin, strengthens local health structures, reduces unnecessary transfers, promotes joint monitoring in a context that includes cultural diversity, shortens distances, bringing the gaze of qualified professionals closer together who provide their expert opinion to patients who do not have these services in their places of origin, and they do so through the public network, respecting the precepts of laws and treaties that indicate that this quality care is the responsibility of the State.

This communication network allows the information on each patient (affiliation data, personal and family history, professionals who treated them, complementary studies, practices carried out and interconsultations requested) to be available to authorized patients on the remote consultation platform, both for the local team and for the rest of the health establishments that attend to it, avoiding data loss, duplication of studies (which implies multiplying expenses for the health system, and stress for the patient), and giving a continuity in the care of the person over time.

Telecare, both synchronous and asynchronous, is a gateway to the right to health for children and adolescents throughout the country, complying with the provisions of Law 26,061 on the comprehensive protection of children and adolescents, article 14, access to Health must be guaranteed by State Organizations.

It also contributes to compliance with article 24 of the CDN, which indicates the right that children have "to enjoy the highest possible level of health and services for the treatment of diseases and rehabilitation of health"32 because resources are used locally and others are sought remotely to provide the best possible level of patient care.

As a way of closing this work, we considered it pertinent to return to the own words of members of the team of Distance Communication Offices from all over the country that synthesize what has been developed so far:

The network of Distance Communication Offices is a plural, supportive, creative network that is committed to children's health so that Children and Adolescents can access health care no matter where they live.

We are a great work team that shares the same values: honesty, fairness, commitment, perseverance, passion, inclusion, respect, diversity, empathy, always emphasizing human bonds and capabilities.

We generate healthcare, educational, research, support networks, we are a network of peers.
We are people taking care of people. We do telemedicine, and telemedicine is health beyond distances33.

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