



Disability and Health in Two Qualitative Studies: The Itineraries of Rehabilitation in Argentina and Chile

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Abstract. The objective of this article is to describe the therapeutic itineraries for the care and rehabilitation of people with disabilities in Argentina and Chile. Secondary data and some of the findings of two independent qualitative studies are presented. The results show that when pursuing healthcare, people with disabilities and their families face situations that are negative for their quality of life, social participation, and self-esteem. In this way, their position of disadvantage and social devaluation is reproduced.

Keywords: persons with disabilities; rehabilitation; medical care; health facilities; social inequality; health services accessibility; Argentina; Chile.

Acronyms and Abbreviations

CABA	Autonomous City of Buenos Aires (Ciudad Autónoma de Buenos Aires)
CASEN	National Socioeconomic Characterization Survey (Encuesta de Caracterización Socioeconómica Nacional)
CESFAM	Family Health Center (Centro de Salud Familiar)
COMPIN	Commission on Preventive Medicine and Disability (Comisión de Medicina Preventiva e Invalidez)
CONADIS	National Advisory Committee for the Integration of Persons with Disabilities (Comisión Nacional Asesora para la Integración de las Personas con Discapacidad)

CONICET	National Council for Scientific and Technical Research (Consejo Nacional de Investigaciones Científicas y Técnicas), Argentina
CONICYT	National Commission for Scientific and Technological Research (Comisión Nacional de Investigación Científica y Tecnológica), Chile
CRPD	Convention on the Rights of Persons with Disabilities
CUD	Single Disability Certificate (Certificado Único de Discapacidad)
CVA	Cerebrovascular accident
ENDI	National Disability Survey (Encuesta Nacional de Discapacidad)
FCS	Faculty of Social Sciences (Facultad de Ciencias Sociales)
FFYL	Faculty of Philosophy and Letters (Facultad de Filosofía y Letras)
FONASA	National Health Fund (Fondo Nacional de Salud)
FONDECYT	National Fund for Scientific and Technological Development (Fondo Nacional de Desarrollo Científico y Tecnológico), Chile
GBA	Greater Buenos Aires
GDP	Gross domestic product
IIEGE	Interdisciplinary Institute for Gender Studies (Instituto Interdisciplinario de Estudios de Género)
IIGG	Gino Germani Research Institute (Instituto de Investigaciones Gino Germani)
ISAPRE	Health insurance institutions (Institución de salud previsual)
PAMI	Integral Medical Care Program (Programa de Atención Médica Integral)
SENADIS	National Disability Service (Servicio Nacional de Discapacidad)
UBA	Universidad de Buenos Aires
UN	United Nations

Introduction

According to the World Report on Disability, unequal access to health services is one of the social barriers faced by persons with disabilities (Organización Mundial de la Salud, OMS, Banco Mundial, 2011). Health and healthcare are a universal and inherent human right (Pinheiro, 2010), although there is an unjust distribution of the risks and resources that guarantee these rights (Arcaya, Arcaya, & Subramanian, 2015; Kawachi, Subramanian, & AlmeidaFilho, 2002). Indeed, access to healthcare and the right to health – including access to rehabilitation, which especially affects persons with disabilities – are part of the debate for governments and economic interests in neoliberal contexts (Laurel, 2016). In addition to the provisions of each particular health system, this right is enshrined in the United Nations International Convention on the Rights of Persons with Disabilities (ONU, 2006) which requires its signatories, including Argentina and Chile, to guarantee these rights. Through this commitment by various states, civil society has signaled the right to health as an outstanding debt to persons with disabilities (Grech, 2015).

In addition to inequalities in access to healthcare, there is also a lower rate of participation of persons with disabilities in the labor market and in community life (OMS & BM, 2011). This situation is more acute in so-called “developing” countries, where it is estimated that close to 80% of persons with disabilities have their basic rights violated and live in extreme poverty (OMS & BM, 2011). In these spaces there is a bidirectional relationship between disability and poverty, which developed in the framework of neoliberal globalization: the pauperization of living conditions associated with this mode of production generates disabilities and, given the lack of “resources that allow for the maintenance of security and welfare networks”¹ (Barnes, 2010, p. 17), such conditions lead to even greater impoverishment (Joly, 2008). When such dynamics are superimposed on a lack of medical services and rehabilitation treatments, there are negative consequences for all areas of the lives of persons with disabilities, infringing on their dignity and constituting one of the principle elements in their impoverishment (Grech, 2015).

Currently, due to the influence of the **social model of disability**, there is an effort to move beyond approaches that reduce disability to a personal medical tragedy. The sociological approach maintains that it is necessary to act on the medium that impedes or hinders the possibilities for participa-

1 Translation by *Apuntes*.

tion of persons with disabilities, thus violating their human rights (Barnes & Mercer, 2010). Consequently, there is an emphasis on the importance of exploring the implications of disability in the specific social, political, and cultural contexts of the “majority world” (Barnes & Mercer, 2010). However, Latin Americans voices have rarely been heard on these issues (Grech, 2015). While in recent years qualitative research has been carried out in the region that critically reconstructs the ways of living with disability on the local level, thus far a body of systematic research has not emerged (Míguez, Ferrante, & Bustos García, 2017; Grech, 2015). For this reason, this article focuses on the itineraries followed by persons with disabilities in their search for health and rehabilitation in Argentina and Chile, with the objective of describing the difficulties they encounter and pointing out how these obstacles contribute to the reproduction of their disadvantageous situation and their social devaluation.

We focus on the **therapeutic itineraries** of persons with disabilities as a way of addressing the issues of healthcare and rehabilitation. We understand therapeutic itineraries as the searches for care that persons undertake as users of healthcare services, along with family members, when faced with a medical condition (Bellato, Santos de Araújo, Silva de Faria, Ribeiro Correa da Costa, & Tao Mayurama, 2009). In this sense, a human being is understood as a physical, psychological, social and political totality, and the search for care and health as a right that is inherent to human existence (Pinheiro, 2007, 2010). This search is mediated by the social links that function as support networks or inhibitors along this path, which include rehabilitation processes (Lacerda, 2010; Pinheiro, 2007; Martins, 2008). In line with this conceptualization and with the purpose of visibilizing the different searches for care that reflect the therapeutic itineraries of persons with disabilities in various social spaces, in this study we describe the bureaucratic and normative contexts, the main social networks for accessing healthcare, and the obstacles to achieving integral care.

To this end, we present secondary data and part of the results of two independent qualitative studies carried out in Greater Buenos Aires² and in Chile’s II Region.³ In so doing we seek to illustrate the meanings that

2 A study entitled *Discapacidad motriz, redes sociales y familiares: percepciones sobre la vida cotidiana, el cuidado y la rehabilitación en el Área Metropolitana de Buenos Aires*, presented for a doctorate in Social Sciences at the Universidad de Buenos Aires and financed by CONICET. Its updated results were published in *La trama social de la discapacidad: cuerpo, redes familiares y vida cotidiana* (Venturiello, 2016).

3 Postdoctoral research about policies related to disability, the body, and domination in Chile’s II Region under the supervision of Carolina Ferrante, financed by the Comisión Nacional de Investigación Científica y Tecnológica (CONICYT) and the Programa Fondo Nacional de Desarrollo

disability acquires in these contexts⁴ and, in turn, the forms of inequity and social devaluation to which these populations are exposed in relation to access to health and rehabilitation.

1. Disability and rehabilitation in Argentina

In Argentina, 13% of the population has some type of disability. According to the 2010 Census,⁵ 5,114,190 individuals have disabilities, and they are more prevalent among women (14%) than men (12%) (Instituto Nacional de Estadística y Censos, INDEC, 2014). The many social inequalities faced by this population include high levels of unemployment or economic inactivity. According to CEN 2010, among the 4,701,685 persons aged 14 and older with disabilities, there is a high level of economic inactivity (52%), while the number of economically inactive individuals among the entire population is 34.4%. In addition, the economically active disabled population (48%) has a 6.5% level of unemployment (INDEC, 2014).

Social, cultural, and architectural barriers discourage persons with disabilities from participating in the labor market (Red por los Derechos de las Personas con Discapacidad, REDI; Centro de Estudios Legales y Sociales, CELS; Federación Argentina de Instituciones de Ciegos y Amblíopes, FAUCA; Federación Argentina de Entidades Pro Atención a las Personas con Discapacidad Intelectual, FENDIM; & Asociación por los Derechos Civiles, ADC, 2012; Sempertegui, 2015). Similarly, these barriers have repercussions for their employment prospects, as the data demonstrates. In contrast, the overall population has higher levels of employment, which fluctuate between 7 and 14% depending upon the age group, with the highest rates found among those 25 to 64 years of age (INDEC, 2014).

In the case of healthcare for persons with disabilities, it should be noted that the system is provided and financed through three subsystems: public, social security, and private insurance. Public healthcare is provided by the state; social security denotes health coverage that workers and their families receive through obligatory membership of a fund to which workers and employers contribute; and the private subsystem is voluntary, and the beneficiaries pay for all services. Critics of this system argue that it promotes access to healthcare that is fragmentary, inequitable, and reproduces social

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4 Since the variables in the two cases are not always identical, their contextualization here does not reflect an exact recovery of the same indicators.

5 From here on: CEN 2010.

inequalities (Findling, 2012; Belmartino, 2009). Effective coverage is essential for effective healthcare. Nevertheless, it is not equivalent to total access, since there are social and bureaucratic barriers that limit prevention, care, and treatment. At the same time, how much people earn, whether they are formally included in the labor market, risk, and geographic location all affect the possibilities of taking advantage of timely healthcare of homogeneous scope and quality (Cetrángolo, 2014).

In the framework of this system, almost 70% of persons with disabilities have some type of health coverage, which is higher than that of the total population (64%) (CEN 2010). Of those in this category, 92.5% had coverage from a social fund,⁶ which includes the Integral Medical Care Program (Programa de Atención Médica Integral, PAMI) administered by the National Institute of Social Services for the Retired and Pensioners (Instituto Nacional de Servicios Sociales para Jubilados y Pensionados); approximately 4% had voluntary coverage; and another 4% had coverage from other state health programs,⁷ which indicates that only a small percentage have access to prepaid health coverage. The inclusion of PAMI among the social funds turns out to be significant since 70% of disabled persons receive retirement benefits, pensions, or non-contributory pensions, with the corresponding healthcare coverage. It should be noted that the disabled population consists primarily of older people and, starting at age 65, the percentage who receive retirement benefits and/or pensions is over 90% (Findling & López, 2015). This high level of coverage is part of a policy of widening access to retirement benefits by the population at large (whether disabled or not), which started in 2003.

The disabled population usually requires prolonged or permanent treatment, as well as technical and human aids in order to be able to maintain a healthy quality of life. Government guarantees for such treatment and aid related directly or indirectly with health – such as access to free transport and support in the areas education and technology – are based on disability certification. In 2016, 957,610 individuals had a Unique Disability Certificate (Certificado Único de Discapacidad, CUD) (Servicio Nacional de Rehabilitación, 2017). However, the disabled population registered by CEN 2010 is approximately five times greater, numbering over 5 million

6 Of this group, 10.5% obtain their benefits through prepayment.

7 This is the Incluir Salud federal program, which provides health coverage that includes all the services described in the Obligatory Medical Plan, and mandates that a “market basket” of basic medical services must be provided according to the Superintendency of Health Services. However, given the underfunding of this program, it only provides medication and coverage in the public subsystem.

people. The relatively small number of people with CUDs indicates a lack of access to rights recognized in existing legislation; among other things, it restricts access to permanent, personalized rehabilitation.

The CUD makes it possible to access the main government programs aimed at fulfilling the needs for assistance, prevention, work, education, health, and accessibility of persons with disabilities, as provided for in Law 22431⁸ of 1981 (Fara, 2010). This law created the Comprehensive System for the Protection of Persons with Disabilities (Sistema de Protección Integral de las Personas Discapacitadas) and the National Advisory Commission for the Integration of Persons with Disabilities (Comisión Nacional Asesora para la Integración de las Personas con Discapacidad, CONADIS). In addition, in 1997, Law 24901 – Law for the System of Basic Services for Comprehensive Habilitation and Rehabilitation for Persons with Disabilities (Ley del Sistema de Prestaciones Básicas en Habilitación y Rehabilitación Integral a Favor de las Personas con Discapacidad) – was promulgated. This law defines prevention, assistance, promotion, and protection services intended to provide comprehensive coverage for the needs and requirements of this population. Nevertheless, in accordance with a policy of reducing social guarantees, this law has weak provisions for government responsibilities and focuses on those who lack resources (Fara, 2010), modifying the scope of Law 22431.

In this context, the first National Disability Survey (Encuesta Nacional de Discapacidad, ENDI), carried out in 2002-2003, revealed that families play an important role in providing equipment and financial aid to improve the quality of life and medical care of persons with disabilities. For example, families cover slightly over 50% of the cost of the equipment needed by these persons to carry out their daily activities. It should be noted that these kinds of private solutions promote the reproduction of social inequalities, given that 56.4% of those individuals who do not possess such aids state that they need them but do not have the required economic resources to buy them. At the same time, of the 646,124 people surveyed who receive or received treatment and rehabilitation, almost one-third paid for it from their household budgets (34.4%). In addition, for the 311,216 individuals who do not or did not receive rehabilitation but stated that they needed it, the primary obstacle was lack of financial means (55.8%) (INDEC, 2005).

Thus, although there are recognized rights related to healthcare and rehabilitative treatment of persons with disabilities, access is not always

8 Regulatory Decree 498/83.

effective. Various authors refer to problems related to lack of compliance with specific legislation – including the International Convention on the Rights of Persons with Disabilities (CRPD) – by different social actors (healthcare providers, government entities, etc.), and how this affects the full social participation of this population (Garcilazo, 2006; Fiamberti, 2008; Fara, 2010; Seda, 2015; Ferrante, 2015). Under these conditions, the family acquires a prominent role, which is a characteristic of Latin American societies and a familial ideology in which the family becomes the main support network in situations of crisis, illness, old age, and disability (Jelin, 1994; Ariza & De Oliveira, 2001; Findling & López, 2015).

Therapeutic itineraries of adults with motor disabilities in Greater Buenos Aires

The Greater Buenos Aires (GBA) urban area is part of the Province of Buenos Aires, which is the principal district of the Argentine Republic. This province accounts for 11% of the national territory and is the largest in the country. It is also home to 39% of Argentina's population and contributes 37% of its GDP. It is the most important industrial center and produces more than half of Argentina's manufactured products (56%). Its productive structure is diversified: industry is the most important sector, and other key sectors include transportation services (17.8%), real estate, commerce, and construction (Ministerio de Economía-Dirección Provincial de Estudios y Proyecciones Económicas, 2013).

The GBA includes the Autonomous City of Buenos Aires (CABA) and 24 districts of the Buenos Aires Conurbation. According to CEN 2010, its population constitutes 32% of the total population of Argentina (12,806,866). Twelve percent of the population of the GBA suffers from some type of permanent difficulty or limitation; the percentage of the population with disabilities in the CABA is over 10%, and is slightly higher in the GBA Conurbation. In both conurbations, the rate of disability is higher among the female population and, among those over the age of 50, it doubles in the CABA (23%) and almost triples in the 24 districts of the GBA (32%). This trend may be explained by the high level of vulnerability caused by the adverse living conditions of the majority of the population in these 24 districts in comparison with that of those who reside in the CABA (Venturiello, 2016). Another notable factor is that significant socioeconomic inequalities exist in this area and that it has the highest level of availability of rehabilitation services in Argentina since it is the largest urban concentration in the country. When it comes to the CUD, only 18.9% of the disabled population in the CABA have one, according to the 2011 Annual House-

hold Survey, Special Disability Module (Módulo Especial Discapacidad) (Dirección General de Estadística y Censos, 2013).

During our field work for the qualitative study in 2007 and 2010, we held interviews with 40 adults over 50 years of age with motor disabilities (20 men and 20 women), as well as 16 family members.⁹ This allowed us to reconstruct their perceptions about the processes of rehabilitation and the search for care. We selected the participants by quotas according to sex and socioeconomic level (middle and low). Another characteristic of this group is that half of those with disabilities were undergoing rehabilitation at the time of the interview, while the rest had undergone rehab in the past; only one stated that they did not need rehabilitation. The types of rehabilitation ranged from inpatient care, outpatient care, physiotherapy sessions in doctor's offices or public or private institutes, and finally, sessions in the patient's home.

The rehabilitation techniques mentioned by the interviewees included physiotherapy, gymnastics, and sports such as swimming and basketball. At the same time, they reported that they took part in occupational therapy activities such as drawing, painting, gardening, and dance. Not all the interviewees took part in such rehabilitation processes and the individuals from the low socioeconomic sector rarely participated in anything more than physical therapy and exercise sessions.

Rehabilitation treatments can vary according to the different stages of illness and disability and differ in their results depending on the physical problem. For example, individuals who have suffered a cerebrovascular accident (CVA) can experience significant improvement in mobility, while in the cases of those who suffer from degenerative diseases, the goal of rehabilitation is to avoid aggressive decline. This diversity of conditions can modify expectations about treatment. With the exception of those interviewed who had polio or congenital dislocation, conditions that were first diagnosed in infancy and in their family of origin, the others interviewed highlighted the search for a diagnosis of the illness alongside their spouses and children. It is also important to note that even when people are disabled from early in life, complications can worsen their condition over the years, necessitating new diagnoses and treatments.

9 As an ethical precaution, informed consent forms were required and aliases were used.

Rehabilitation experiences

Rehabilitation processes form part of the itineraries in the search for care by persons with disabilities who, in the case of those interviewed, refer to a process during which they and their family network try to reestablish a structure for their daily lives – a structure that was disturbed by the advent of a disability. During the search for treatment and well-being, individuals increase their knowledge about health services, a knowledge that it takes time to acquire: what places offer rehabilitation, how they work, what care they provide, what alternatives exist, whether they as individuals have coverage for the care required, how to obtain what is needed, who to turn to. In these processes of success and failure in obtaining care for their conditions, persons with disabilities consult friends and relatives in addition to health professionals. The links that lead to healthcare are found in various aspects of the lives of the individuals concerned, and they become facilitators to obtaining care.

Antonio, after a road accident left him with a cervical injury that causes him difficulty in walking, tells us about his wife's support and assistance during his recuperation:

[...] when you have to be handed your clothes, to be washed, you are going to stand up; [later] when you want to do something in your house, you want to be handed something, always, I mean, you manage. I went and fell in the doorway, more than once I fell in the doorway holding on to the door frame, I was shouting. She [his wife] came and helped me, brought a chair, lifted me up, she laughed, sometimes she cursed, and even today, if you want to talk, [she'll say] "can you believe this guy?" She comes in cursing and she leaves cursing, do you understand? So there are things, that is fundamental, you learn all this. You have to mourn all this, think it out, believe it [...]. It is like learning to live again¹⁰ (Antonio, 60 years old, cervical luxation).

According to this same individual, disability means experiencing both the inadequacy of one's physical abilities in a physical environment that is not adapted to one, as well as the perception of loss of control over one's own body. When disability is acquired later in life, this perception is more intense, since the person has already spent a long time living with another corporal hexis (Bourdieu, 2007). This implies that unconscious habits

10 All translations of the comments of interviewees are by *Apuntes*.

related to the functioning of one's own body must be reformulated in the face of a new corporal scheme. The emotions of "fear" and "terror" felt by people in this situation are based on this imbalance, and on the dangers that inadequately adapted environments pose to their stability. Faced with this perception of disorganization and insecurity, their treatment expectations are centered on recovering mastery over their own bodies (Venturiello, 2016).

Resignification of the body and the spatial environment occur during this process, of which different types of care and rehabilitation are part. More happens during inpatient stays and physical therapy than just biomedical intervention on bodies, since the type of care received guides the individual's revalorization or underestimation. This is why some forms of rehabilitation are better than others.

Thus, the interviewees refer to different experiences with the types of rehabilitation treatment provided by a variety of institutions, professionals, and services in relation to the type of treatment. The most valued types of rehabilitation are those that promote social contact between peers and offer recreational activities. The institutions that stand out in fulfilling these criteria are public rehabilitation centers located in the wealthiest areas of GBA: CABA and Vicente López. It should be noted that although these are public institutions, the interviewees who use them are middle class.

Raul compares two rehabilitation services: the first provides only physical therapy and the second, where he can engage in sports, also promotes interpersonal relations as part of the treatment:

[...] before, I didn't come here, unfortunately not; I didn't come here no matter what. As soon as they put me here, I went to another place near the house. And in truth I say "what a pity!" now I say "what a pity!" The other one, I can't say I didn't like it, but the truth is that it's something else, something else. Here is totally different, it looks at life in another way (Raúl, 71 years old, after-effects of a CVA).

The camaraderie and experiences in common with peers favor the creation of new social relationships in which the interviewees do not feel belittled. The feelings of "fear," "unease," and "shame" that used to come with rehabilitation were reversed in the individuals who spent time at these institutions. At the same time, the importance of being able to establish a positive link with professional health teams can be observed. A relationship of greater or lesser confidence in the doctor in charge also conditions the interviewees' predisposition to their recuperation. They emphasize sympathy, affection, shared values and friendship, as well as professional competencies (Venturiello, 2016).

In contrast to these experiences, the most criticized medical practices are those that are guided by a commercial rationale, reducing physical therapy and rehabilitation sessions to the amount of time that best suits the medical firms. The limits on the number of sessions covered by social funds or prepaid coverage are part of this mechanism. Mercedes, age 76, who has mobility limitations due to advanced arthrosis, states: “this is just a business, there is no humanity, nothing. They don’t listen to you. They charge me for the visit and that’s it.”

The number of sessions or the duration of inpatient rehabilitation treatment often corresponds to what is covered by a social fund or prepaid coverage, rather than the time required for an improvement in an individual’s condition. Although some interviewees would have liked to continue with their rehabilitation, these limits on their coverage made it impossible. Mabel, age 65, who had a CVA, was an inpatient and received rehabilitation for a year through her social fund. She remarked that: “This is what’s wrong with it: you finish a year of rehabilitation and bye. If you managed it, that’s fine; if you didn’t, too bad.”

At the same time, expenses for operations, rehabilitation, and treatments imply great economic effort which, in many cases, coincide with a decline in household income due to the unemployment or inactivity of the person with disabilities. The possibility of facing this situation depends on economic resources and on having social support networks that are capable of helping in critical situations (Venturiello, 2016).

Obstacles in the search for care

The interviewees encountered obstacles in the formal health networks they use (public rehabilitation centers, private institutions, hospitals, prepaid coverage, and social funds). The strategies developed within family networks to deal with this lack of solutions constitute part of the support provided by the next of kin. Finite household resources affect the possibility of encountering solutions given a lack of circulation of goods, services, and the wherewithal necessary to provide care (Venturiello, 2016).

In the cases of interviewees from poorer areas, the problems emphasized were those relating to lack of inputs, spaces, and apparatus for rehabilitation, as well as insufficiencies and inefficiencies in the transportation services that take them from their homes to the center or hospital where they exercise. This not only leads to deterioration in healthcare but also to disruptions in daily life, creating organizational difficulties within the family. In this regard, the families that accompany the patients in the search for care and their activities often require “management of social obstacles”; that is, actions

to overcome obstacles that are external to persons with disabilities (social, bureaucratic, physical, etc.) and constitute disadvantages for their well-being, making it harder for them to receive adequate attention and care.

Along these lines, Olivia, who is recuperating from a CVA, tells us about the center to where she goes along with her partner two days a week:

[...] Things are a bit of a mess. For example, here there are four minibuses to take us to rehabilitation and bring us back. And it's not enough, they run at different hours. For example, they tell you "we will be there at ten in the morning," so the disabled person says: "we won't have our lunch because they are coming at ten." And then it's 1 o'clock and they are not there, and so the disabled person hasn't eaten, too weak all day to exercise (Olivia, age 56, after-effects of CVA).

In addition to the inequalities that affect the service quality and access, there are difficulties related to the workings of institutional bureaucracies that translate into one of the barriers to access that persons with disabilities and their families have to face. These obstacles are based on a lack of information and the failure of institutions and funds to fulfill their responsibilities. Information is a requirement for individuals to adequately navigate health services and get the care that they need, and concerns where to be seen, whether the service is free or not, what treatments are available and which are covered by social security, and the rights that protect access to these services, among other matters. Access or lack thereof to such information can either facilitate or hinder the consolidation of social networks, especially those that are institutional or formal (Venturiello, 2016; Martins, 2008). The necessary information is not always immediately available to those who need it, and people require the cultural tools to find it.

For example, something as basic as information about the place where care is provided constitutes a good that one has to know how to find, because it is not spontaneously available nor sufficiently disseminated. Tamara recounted how long her husband had to endure the after-effects of a CVA without the necessary healthcare: after a year of searching and going through a social fund, prepaid coverage, and losing access to the neurologist who was treating him, she finally reached the rehabilitation center where her husband was being treated at the time of the interview. Once her husband had begun his treatment session, she commented on the professionals at the center:

They kind of scolded me because a year and a half had gone by since the accident, but the thing is that I didn't know. Once I found out I started to come here, and come, and come, and

now that I know the doctors, I'm more proactive (Tamara, age 54, husband had a CVA).

The lack of mediations to get treatment when it is needed can lead to blame being laid on the patient and their family and, simultaneously, to invisibilizing certain aspects of the health and sociocultural system that condition this access. Such delay is an example of the problems that users encounter and which they have to learn how to deal with.

The non-fulfillment of the services that prepaid coverage, social funds, and public hospitals are obligated to provide also constitutes an obstacle to accessing care. Among the decisions that persons with disabilities, along with their families, have to make regarding the treatment to follow are what strategies to use when confronted with service providers' evasion of their obligations. Although the legislation on disabilities stipulates the services that prepaid coverage and social funds must provide to individuals who have a disability certificate, all the interviewees, together with their families, had to insist in order to obtain these services. Thus, the effort required to obtain an unlimited number of physical therapy sessions – something that should be no more than a minor formality – can lead to situations of tension and pressure by those users who insist that their rights be respected (Venturiello, 2016). Such situations worsen the quality of life of the patient and his/her family, who have to go to extra lengths to find solutions.

Another example of obstacles are difficulties in obtaining wheelchairs that are motorized or adjusted to the physical characteristics and health of each user: often, requests for these are denied, there are delays in delivery, or the chairs provided are of inferior quality. In addition, users report excessive red tape in obtaining medication.

The first chair we got through some relatives and my brother got the other one. PAMI: no, forget it. And the diapers, they only just gave them to us now. But they are diapers that it's no use even putting on [...] it's a terrible diaper (Gisella, age 47; her 76 year old father had a CVA).

The policy of resistance by prepaid coverage institutions and social funds to providing adequate wheelchairs, delaying and offering a simpler and less costly chair, just like the brevity of physical therapy sessions, is evidence of a conflict of economic interests. This upsets patients who expect to receive care; they lose time, and family affairs are disarranged. The organization of the healthcare system, when it is governed by a commercial rationale or not duly regulated by the state, prevents the situation of persons with disabilities and of their families from being fully taken into account.

Thus, the qualitative information about the search for care by the interviewees in the GBA shows that among the principal obstacles to achieving effective access to healthcare and rehabilitation are socioeconomic factors and the bureaucratic resistance of service providers. In addition, it is the families that navigate the social obstacles to disability that interfere with this population's access to health care.

2. Disabilities and rehabilitation in Chile

Twenty percent of the adult population of Chile has some kind disability. According to the *Segundo Estudio Nacional de Discapacidad 2015*, approximately 2,606,914 adults aged 18 or older suffer from such a condition, and its prevalence is higher among women (24.9%) than men (14.8%) (Ministerio de Desarrollo Social, 2016). This sector faces multiple disadvantages. First, 60.8% of adults with disabilities are not in the labor market (among the rest of the population, this percentage is 31%). Overall, the 39.3% of persons with disabilities who are employed receive a salary that is 32% lower than that of persons without disabilities, while 24.2% engage in unskilled labor (compared with the 17.1% of the population without disabilities who do so). In the field of education, while 7.4% of persons with disabilities have received no formal education, only 1.3% of the population without disabilities suffer the same deficit (Ministerio de Desarrollo Social, 2016).

Over the last three decades, the state has made policy efforts to reverse this adverse employment situation. Progressively, and following international trends, these efforts have focused on incorporating a citizenship approach to the issue. Thus, in 2008, Chile – like Argentina – signed and ratified the CRPD. In the spirit of this international convention, Law 20422 was approved in 2010 (Law Establishing Norms on Equality of Opportunities and Social Inclusion of Persons with Disabilities, *Ley que Establece Normas sobre Igualdad de Oportunidades de las Personas con Discapacidad*), which repeals Law 19284 (Law that Establishes Norms for the Social Integration of Persons with Disabilities, *Ley que Establece Normas para la Integración Social de las Personas con Discapacidad* 1994), which had been based on a medical approach (Ferrante, 2017a). The objective of Law 20422 is to achieve the “full social inclusion”¹¹ of this sector of the population “by assuring the enjoyment of their rights and eliminating any form of discrimination based on disability” (Law 20422, 2010, art. 1). In accordance with this approach, this law makes provisions for the elimination of social barriers that restrict

11 Translations of texts from Chilean laws are by *Apuntes*.

the participation, autonomy, and independence of persons with disabilities, and establishes the National Disability Service (Servicio Nacional de Discapacidad, SENADIS) as the entity responsible for drafting policies to this end (Ossandón, 2014; Pino & Valderrama, 2015).

The main objections to Law 20422 are that the measures prescribed have not been applied in practice, nor have they had an effect on the living conditions of this population. This is due to five factors: a) limited state action; b) lack of consistency in applied policies; c) lack of accountability measures related to the fulfillment of the established rights; d) in the case of social benefits – scant coverage and abandonment of the middle classes; e) the omnipresence of charity as the dominant cultural response to disability (Organización de las Naciones Unidas, ONU, 2016; Comisión Asesora Presidencial sobre Inclusión Social de Personas en Situación de Discapacidad,¹² 2016; Pino, 2014; Faride, 2015; Ossandón, 2014; Ferrante, 2017a). In relation to the latter issue, it is essential to point out that the social meanings that disability acquired in Chile – and which permeate the searches and meanings that are acquired throughout therapeutic itineraries – have to be understood by taking into account the historical and cultural protagonism of the Teletón in Chilean civil society (Faride, 2015; Húmeres, 2017).

The Teletón is a charitable institution which was established primarily to benefit persons with disabilities in Chile. It consists of an annual televised fundraiser in which – following the format of its North American counterpart created by Jerry Lewis in 1966 – funds are raised for the rehabilitation of children with motor disabilities (Húmeres, 2017; Ferrante, 2017b). The method used to inspire donations is based on the presentation of “handicapped” infant bodies to inspire pity through the selection of a “poster child” (Húmeres, 2017). Thus, disability is configured as a personal medical tragedy that – imperatively – must be overcome through recovery of bodily activity to as close an extent as possible to what is biomedically defined as “normal” (Húmeres, 2017).

The Teletón show began in 1978 – under the military dictatorship headed by Augusto Pinochet (1973-1990) – as part of the structural reform of the health sector (Húmeres, 2017). This reform privatized and commercialized healthcare, challenging the “idea of the right to health as a social and human right” and redefined “the responsibilities of the state, the market, and the family/individual in healthcare” (Laurell, 2016, p. 3). As a result, two parallel health systems were established, which still exist: “the private health insti-

¹² From here on: Comisión Asesora.

tutions (ISAPRE) with private providers,” in which services depend on the money paid in and exclude those considered as “high risk individuals” such as the elderly, the sick, persons with disabilities; and “the public National Health Fund (FONASA) with public providers”¹³ (Laurell, 2016, p. 4), to which everyone contributes and makes copayments, with the exception of the poorest members of society (Tetelboin, 2015).

This reform led to significant deterioration in the general population’s access to healthcare (Tetelboin, 2015). By the end of the 1970s, there were multiple rehabilitation needs that were not being met (because of the inadequacies of public services, the high service costs, or refusal of coverage in the private sector). These insufficiencies, in the case of children, would go on to be resolved through the “love” and “solidarity” (a euphemism used to refer to charity) “of all Chileans” united around the “great national cause”¹⁴ (Húmeres, 2017). Over the years, the Teletón not only became synonymous with disability in Chile, but also emerged as the event that most filled Chileans with pride (Húmeres, 2017).

The continued popularity of this phenomenon is associated with the persistence of neoliberalism and a deficient health system which the return to democracy has not been able to resolve – although attempts to do so have been made. In the case of rehabilitation, since 2003-2005, the Ministry of Health has taken measures intended to facilitate access to this right, emphasizing a community-based rehabilitation strategy (Faride, 2015; Pino, 2014). Law 20422 reaffirmed this right and the obligation of the state and “society as a whole” to guarantee it (2010, art. 18). According to the 2015 Second National Study on Disability (*Segundo estudio nacional de la discapacidad 2015*), 85.9% of persons with disabilities in Chile fall within the public health system (FONASA), and only 8.3% are covered by the private system (ISAPRE)¹⁵ (Ministerio de Desarrollo Social, 2016). Access to rehabilitation is identified as one of the major problems faced by persons with disabilities on the national level. While disability does not always require permanent rehabilitation, only 19.1% of persons with disabilities received this type of treatment during the preceding year; in addition, 32.8% of Chilean persons with disabilities see healthcare services as obstacles to exercising the right to rehabilitation (Ministerio de Desarrollo Social, 2016).

13 Translation by *Apuntes*.

14 Translation by *Apuntes*.

15 Among the population who do not have disabilities, 74.3% are affiliated to FONASA and 18.3% to ISAPRE. The difference in percentages compared with persons with disabilities is undoubtedly linked to discrimination by the private system.

This situation has been associated with a set of negative factors: limited government coverage in this area, a shortage of specialists, the lack of measures to eliminate barriers to access, discrimination by the ISAPRE (which denies coverage or treatment on the grounds that disability is a “preexisting condition”), gaps in access that especially affect the adult population, and limited coverage for technical aids (ONU, 2016; Comisión Asesora, 2016).

When it comes to social welfare, the number of persons with disabilities who receive the so-called “solidarity pensions for disability” (“pensiones solidarias por invalidez”) make up 23% of the total. This scarcity in coverage is due to three factors: a) it is restricted to the poorest sector of the population; b) the payments provided are so small as to fall below the poverty line; c) it “requires registration in the National Disability Register, which is incompatible with receiving two incomes, [this] is perceived as stigmatizing, and is applied inappropriately by public institutions”¹⁶ (Comisión Asesora, 2016, p. 124; Ferrante, 2017a).

In order to receive social benefits related to disability it is necessary to undergo certification carried out by an interdisciplinary body; these rights, in many cases, are subsumed to a targeted approach. The so-called Commission on Preventive Medicine and Disability (Comisión de Medicina Preventiva e Invalidez, COMPIN), made up of multidisciplinary teams, document the degree and type of disability, issue a disability credential, and register persons with disabilities in the National Register of Disability. The same commission confers the following rights: handicapped parking passes, application to the SENADIS technical aids program (which provides prosthesis and braces according social risk criteria), discounts on the importation of vehicles and technical aids, subsidies for housing, and access to other state-provided services that require accreditation of disability.

Therapeutic itineraries of persons with disabilities in Calama

Not only does Calama face the same problems that exist on a national level, but the problems are intensified there by its regional location. The city is located in Loa Province in Chile’s Region II, in the north of the country. It is situated in the Atacama Desert, at an altitude of 2,250 meters above sea level, and has a population of 149,200 (Instituto Nacional de Estadística, INE, 2014). Calama, together with Antofagasta (the capital of the region) is a hub for world mining. Copper is the primary product and mining provides much of Chile’s revenue. Because of the high salaries of a sector of

16 Translation by *Apuntes*.

mining workers, these cities have the highest average monthly independent household income in the country (Ministerio de Desarrollo Social, 2016).

Nevertheless, although Calama is in an area that generates wealth, this is not reflected in the development of the city, since the money made is transferred to the Central Region (Santiago) and, on the local level, “priority is given to investments in Antofagasta”¹⁷ (Penaglia & Valenzuela, 2014, p. 168). Consequently, there are numerous problems that diminish the quality of life in Calama, including a lack of goods and services associated with healthcare (Penaglia & Valenzuela, 2014). This situation particularly affects the therapeutic itineraries that persons with disabilities construct in their search for care. Consequently, the characteristics of these itineraries must be analyzed by taking into account the social and economic implications that the health-illness processes acquire in this mining enclave.

According to the available municipal data, 9.5% of the population of Calama – that is, 8,830 individuals – have some kind of disability. Following national trends, the data provided by the National Socioeconomic Characterization Survey (Encuesta de Caracterización Socioeconómica Nacional), CASEN 2011, indicate that this population is disadvantaged in terms of education (the average years of schooling is only 6.6 years) and access to the labor market (73% of persons with disabilities in Calama are economically inactive) (Gaviño, 2014). As to healthcare, 76% of all persons with disabilities who live in Calama are covered by the public health system, FONASA: 46% are in the so-called “track A” (“which includes those people who are indigent or lack resources and also includes those who have basic solidarity pensions and thus receive free care”¹⁸ [Gaviño, 2014]); only 16% belong to the ISAPRE system; and 6% with some kind of permanent disability are not covered by any health system (Gaviño, 2014, p. 23).

In order to reconstruct the therapeutic itineraries, we conducted interviews between July and October 2014 with 22 persons with motor and visual disabilities living in Calama, of whom 12 were men and 10 were women, from middle and low socioeconomic levels. In addition, we interviewed 11 key disability actors on the local level, including: relatives of persons with physical or mental disabilities, representatives of organizations of persons with disabilities, health sector professionals, and officials responsible for disability policies.¹⁹ Of the interviewees with disabilities who are between

17 Translation by *Apuntes*.

18 Translation by *Apuntes*.

19 Informed consent was obtained in all cases. Aliases were used in order to assure confidentiality. The ethical aspects of the project were reviewed by the Committee for Scientific Ethics of the Universidad Católica del Norte.

31 and 68 years of age, 15 are currently receiving rehabilitation treatments, while seven used to receive such treatment but no longer do so for financial reasons. The types of rehabilitation received in the past were related to the acute phase of becoming disabled and to the hospitalization stage, usually occurring in other cities in Chile (such as Santiago and Antofagasta). In the case of those interviewees currently receiving treatment, they primarily receive physical therapy and occupational therapy aimed at their being able to carry out daily activities.

According to the interviewees, their motive for seeking treatment is the expectation of improving their physical condition which, as in the Argentine case, generates negative emotions since it restricts what is considered “normal” functioning. For example, Julio, who had a CVA as an adult, tells us that he ended up with a “dead body,” referring to the paralysis which he experienced for two years and which forced him not only to use a wheelchair but to leave his job and move in with his son, while leaving him in need of help with daily activities and seen in public as a “freak” (*un bicho raro*). The opportunity to receive rehabilitation with a group of persons with disabilities allowed him to function more independently, and this made him feel better:

I began to feel better because now there are many more things that I can do by myself. Before it was hard, for example, for me to get into the shower, it was hard, that made me feel bad and now I can get into the tub by myself. Here we have had good physical therapists, we’ve had good professionals, we’ve had them here (Julio, age 62, motor disability).

As in the case of Julio, in Calama the main space for fulfilling rehabilitation needs is that provided by civil society. This is due to the barriers for access to public or private rehabilitation. The only hospital in Calama existing at this writing (Carlos Cisternas) does not provide rehabilitation services. Two primary healthcare centers (Centros de Salud Familiar, CESFAM, Norponiente and Sur) do provide rehabilitation services, but these are not perceived as a care option by the persons with disabilities interviewed. They cite the high copays these centers charge for middle-income FONASA users, the few services provided, the short duration of the treatments offered, the shortage of professionals, and the lack of support to obtain technical aids. Felipa, a representative of an organization that brings together persons with disabilities, notes that:

It is assumed that the hospital and the tertiary area should rehabilitate people, *po’* [“Chileanism” providing emphasis] but this is scarce, very expensive. Because anyway maybe a prosthetic leg that they need costs a great deal. If I don’t have a good in-

come, where am I going to get it from? So healthcare in Chile is very bad, it's bad and in Calama it's worse (Felipa, age 61, member and representative of an organization of persons with disabilities).

Similarly, Noelia, from the healthcare sector, states:

What happens to those with disabilities? There are no options, here [referring to the hospital] there is no alternative, here there is no gymnasium, there is no occupational therapy, here there is nothing [...] For everything, the issue of prostheses is a specialty that's especially failing. Here they wait two years. Also today [there's] the issue of traumatology, the question of support in technical, therapeutic terms (Noelia, age 49, healthcare official).

Catherine, mother of a youth with mental disabilities, says that:

[In Calama] the rehabilitation that you should really find to rehabilitate yourself doesn't exist. Maybe what you can find is to help you at a difficult moment. But after that, the public health system seems to always get out of these cases, we persons with disabilities are like *cachos* [problems] (Catherine, age 45, mother of a person with disabilities, participates in an organization).

In the case of the private system, the interviewees point out two problems: the lack of specialists in the city and the high copays required to access therapies that require extended periods of time, which mean high costs for family budgets. Puri, the mother of an adolescent with a mental disability, notes:

It's so much money that you have to have that sometimes I really, I now work just to pay the educational psychologist. I take my money from here and go leave it there. I have no choice, because my salary doesn't do it. I have two more children at university and everything that you want to ask for, for example, we don't have an option for anything because my husband works [for a mining company]. So my children don't have the option of a scholarship, nothing, there are no opportunities for them, because no one knows how things are for us (Puri, age 41, mother of a person with disabilities and member of an organization for rehabilitation).

On the local level, there are more than 28 non-profit organizations of and for persons with disabilities, created with the purpose of satisfying unmet rehabilitation needs. These are small spaces and operate in houses

precariously adapted for these purposes. Some organizations have their own locale while others rent (sometimes receiving some aid from the municipality for this purpose).

These organizations were created years ago when the lack of specialized rehabilitation services forced families to separate or move to other cities (such as Antofagasta or Santiago) in search of care. In order to address this situation, these associations emerged to provide assistance to persons with motor, mental, intellectual, visual, or hearing disabilities. Some were founded by parents or friends of persons with disabilities, while others were created by those with disabilities themselves. These civil society organizations hire rehabilitation professionals (such as physical therapists, occupational therapists, or speech therapists) and provide services to the community through the payment of a small monthly fee – considerably below the market price. Generally, they provide a transport service that picks up persons with disabilities from their homes and brings them to the therapy center, thus avoiding the problem of architectural barriers.

In order to complete the financing of the organizations, an annual public fundraising event is held, following the format of the Teletón, called “Clamatón.” It began in 2009 amid civil society discontent about the large donations the city made to the Teletón through copper mining unions, which were then to build rehabilitation centers in other regions of the country. Since then, and despite the creation of an Instituto Teletón in Calama, many organizations that guarantee access to rehabilitation to persons with disabilities periodically carry out campaigns to raise funds to pay for professionals and to run their organizations. In contrast to the Teletón, it is the persons with disabilities themselves who organize the fundraising.

The Clamatón tries to avoid using the language of pity that the Teletón employs to encourage donations, though it does not always achieve this goal. While the funds raised benefit organizations that serve persons of all ages and types of disabilities, a “poster child” is used as a campaign symbol since this is a useful resource for generating donations. Still, the use of this strategy is the subject of debate among the organizers of the event, with some of the groups involved disagreeing with this approach. The reason for the opposition is that it encourages the replication of this tragic viewpoint in daily interactions. But if some persons with disabilities are offended when they are perceived in stigmatizing terms, others, driven by necessity, are guided by the maxim: “the end justifies the means” (Alfonso, age 53, representative of an organization for persons with disabilities).

Social obstacles to disabilities and their management

In Calama, the lack of government guarantees of the right to rehabilitation becomes a social obstacle associated with disability that is managed by organized persons with disabilities and their families. Alfonso, the president of an organization, states that:

Civil society is doing social policy while public policy is non-existent and focalized. There are no public policies, we are years from that coming to pass. [...] This is unjust, because it is an area that generates resources and we are living like *wifas* [excrement] (Alfonso, age 53, representative of an organization for persons with disabilities).

Government neglect is a factor that is central to shaping what disability means in Calama. Gabriela notes that:

Disabled persons are neglected here. We are left alone, we have to solve our problems all alone (Gabriela, age 61, motor disability).

What government bodies exist on the local level for dealing with disability? In terms of those dedicated solely to disabilities, SENADIS has a regional office in Antofagasta. It also has a strong presence in traditional and social media. However, according to the perceptions of the persons with disabilities interviewed, it carries out very few concrete actions, concentrating mainly on the provision of technical aids (in cases of low-income individuals) and some training. On the municipal level, there is a so-called “differential capacities” office, which provides advice on access to benefits associated with certification of disability²⁰ and helps to organize the Calamatón.

This general outlook configures “being disabled” as an experience that is “very uncomfortable” (“*harto incómoda*”), “frustrating,” or socially “difficult” because of the obstacles posed by the environment in which these persons live, as reflected in the following testimonies:

[Living with a disability in Calama] is very uncomfortable. Uncomfortable to live like this because you have to do everything yourself here. You have to *aperrarse* [be firm and persistent] to achieve a balance (Julio, age 62, motor disability).

[Living with a disability in Calama] is difficult in all environments: social, work, economic, eh, housing (Priscila, age 65, motor disability).

20 In Calama, starting in 2015, the disability credential allows its holders to obtain discounts on fares on certain public transportation routes.

Thus, disability becomes an experience associated primarily with social suffering, the type of pain caused by the perception of areas of welfare provision that should be guaranteed by the state but which, under neoliberalism, are the responsibility of individuals (Bourdieu, 2010). In this realm of experience, together with unsatisfied rehabilitation needs, multiple barriers emerge that constitute obstacles to a dignified life and participation by persons with disabilities: lack of access to public spaces and transportation, impossibility of finding employment, difficulties in access to education, discrimination, lack of recreation spaces, pensions that do not cover the cost of living, lack of economic aid to middle classes to cover the additional costs of disability, lack of understanding, and the non-fulfillment of legally recognized rights.

Through the associative movement of persons with disabilities and family support, some of these barriers are overcome. While initially these organizations provide places where persons with disabilities come looking for medical attention and where – through the opportunity to interact with other persons looking for the same things and facing the same obstacles – peers meet professionals with whom the disqualifying looks from their environment can be resignified and positive recognition can be obtained (Venturiello, 2016).

One might think that the associative movement serves to reproduce stereotypes that reduce disability to an object of charity; however, if we take into account government inaction and the death sentence signified by the state of neglect in which this sector finds itself, collective action has to be seen as a way of questioning this social destiny. Day after day, persons with disabilities along with their peers and families struggle to “survive” and collectively live a life that individuals would otherwise be condemned to face on their own and in complete isolation.

Conclusions

This article analyzes therapeutic itineraries in the search for rehabilitation in one region in Argentina and another in Chile, in order to visibilize the obstacles and supports in the care of persons with disabilities in two different contexts.

In Argentina, legal advances in the field of disability – which recognize the right to rehabilitation, healthcare, and other social aspects that influence the quality of life of this population – have been limited in their capacity to alter the social practices that influence the effective enjoyment of these rights. Socioeconomic inequalities, the persistence of multiple social barriers imposed on this population and on their participation in the labor market, fragmentation in the types of healthcare coverage, and possession of the

disability certificate as a requisite for access to care, together with the violation of legal norms, contribute to the social reproduction of unfavorable conditions for this population. At the same time, the delegation of public responsibilities to family networks, which – together with the persons with disabilities – manage the obstacles faced, results in the replication of social inequalities based on the economic and cultural means of each household to access appropriate healthcare and attention.

In this framework, in GBA, persons with disabilities interviewed follow their therapeutic itineraries with feelings of fear and physical insecurity that are associated with the lack of support from rehabilitation institutions. In contrast, those who can gain access to spaces that provide comprehensive healthcare transform these feelings into greater self-esteem and increased autonomy. Nevertheless, both the difficulty in obtaining information about their rights and the places where they can receive care, and the influence of socioeconomic inequalities on this process, mean difficulties in accessing the best services. At the same time, physical barriers, expulsion from the labor market of those who become disabled and the consequent reduction in family income, and the resistance of healthcare service providers to provide care and the appropriate material supports all create a series of obstacles in the therapeutic itineraries of persons with disabilities. They encounter these difficulties when they seek to establish a new daily routine as part of their overall health. Thus, there are discontinuities between the subjective and physical improvements provided by rehabilitation with an integral approach, and the obstacles imposed by the social environment outside rehabilitation institutions.

In these efforts, the main source of support are families that handle and “manage social obstacles” that their family members with a disability must confront at the same that they are overloaded with other responsibilities (Venturiello, 2016). Thus, although the rights of persons with disabilities are recognized in Argentina, social and economic inequalities combined with those associated with the organization of services make it hard to fully realize these rights in the country.

In Chile, the lack of state guarantees for the right of rehabilitation is a social obstacle associated with disability. The origins of this gap can be found in historical circumstances associated with three main factors: a) the effects on the health of the population resulting from the implementation of radical neoliberalism; b) the development of the Teletón as a semantic palliative for unmet rehabilitation needs (Faride, 2015); and c) the consequences of centralization in the generation of a healthcare crisis in the regions of Chile. However, persons with disabilities in Calama have not remained

passive despite the neglect to which they are exposed. They, together with their peers organized in civil society and their family members, navigate the social obstacles associated with disability. Most of their energy is centered on resorting to charity for rudimentary provision of the rehabilitation that has been denied them. Through this strategy, they arrive at a precarious solution to the problem and question the outcome of state neglect, albeit without questioning its structural foundations. The need to fight hard for access to care configures disability as an experience with a social cost that is too high. The reconstruction of therapeutic itineraries reveals that it is necessary to increase public and free rehabilitation services in Calama by increasing the number of specialists, eliminating focalization as a criteria for access technical aids, and promoting a rights-based approach to disability.

Access to healthcare and rehabilitation from an integral perspective, based on overcoming reductionist biological approaches and incorporating a rights focus, is a key element in the quality of life of persons with disabilities and in guaranteeing this group equality of opportunities. However, in the cases analyzed, when this right is not effectively guaranteed to persons with disabilities, they must employ much of their own energy – together with that of their networks – to satisfying this need, with their condition as citizens affected. This struggle has negative effects on the health, social participation, fight for rights, economic situation, and self-esteem of persons with disabilities. These circumstances often mean that disability is experienced as a personal medical tragedy, although many of its causes and effects are due to social factors. In any case, this does not imply determinism and these circumstances can be altered depending on the social networks in which each person participates (Venturiello, 2016).

While both Argentina and Chile signed the UN Convention (2006) and their public policies include efforts to incorporate a rights-based approach to disability, the reconstruction of therapeutic itineraries reveals that these policies have been insufficient or inefficient. In the case of the right to rehabilitation, this constitutes an outstanding debt that is transferred to persons with disabilities. The specificities of each situation and how these are managed are configured by the particularities of the historical, political, economic, and cultural context. For this reason it is important to promote studies that inquire into access to rehabilitation in specific spaces (OMS & BM, 2011). The concept of “therapeutic itineraries” (Pinheiro 2007, 2010; Engel Gerhardt *et al.*, 2016) can be a potent tool for reconstructing, from the point of view of the protagonists, their searches, by incorporating their formal and informal networks and detecting shortcomings and barriers within specific policies. In this sense, contributing empirically to situation

analyses permits the visibilization of the difficulties inherent in each context. Consequently, we stress the importance of avoiding the homogenization of experiences and, on the contrary, illustrate the different ways of living with disabilities with their corresponding needs, priorities, and demands, as a way to contribute, from the social sciences, to assuring respect for the rights of this population.

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