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The Social Construction of Disability in Argentina: Some Key Points

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ABSTRACT

The Argentinian State has transitioned from a biomedical approach to a rights-based approach to disability. However, structural barriers and non-compliance with regulations have meant that changes that are necessary for the dignified lives of persons with disabilities are not being realised. Here we will focus on access to health, education and personal assistance.

KEYWORDS

Disability, Argentina, Rights, Health, Education, Personal Assistance

I. Introduction

According to the 2010 Census, 13% of the total population in Argentina has some type of disability, which is equivalent to 5,114,190 people (INDEC, 2014). Also, according to a more updated survey of 2017–2018, 3,571,983 people aged 6 years and over have some kind of disability (INDEC, 2018). Currently, the existing regulatory frameworks and policies relating to disability in Argentina fail to generate actions aimed at behavioural changes in society or to improve living conditions for this group of people (Acuña and Bulit Goñi, 2010; REDI et al, 2012).

Laws and policies on disability cover various aspects of social life (health, rehabilitation, education, work, among others). Importantly, Argentina ratified the Convention on the Rights of Persons with Disabilities and its Optional Protocol in 2008 (see National Law 26378). Over time, the Argentinian State has transitioned from a biomedical approach to a rights-based approach to disability. Historically, public actions aimed at persons with disabilities were characterised as welfare-based, as part of the social and political responses to marginalised and vulnerable populations. In line with conceptual developments on the subject over time, there has been a shift away from derogatory terms that associate disability with abnormality, towards those that avoid negative connotations through a progressive concern for social barriers (Venturiello, 2017). The human rights approach implies a relatively recent recognition of the demands of persons with disabilities, and this is expressed in the aforementioned specific regulations, and in our country's adherence to general human rights treaties (Palacios, 2019). However, structural barriers and non-compliance with regulations have meant that changes proposed by the Convention that are necessary to ensure dignified lives for persons with disabilities, are not being realised. Here we will focus on some aspects of the lives of persons with disabilities related to access to health, education and personal assistance.

2. Challenges in Health and Disability Certification

Access to health care for people with disabilities encompasses and goes beyond the biomedical dimensions of diagnosis, care, treatment and/or rehabilitation. A comprehensive approach to health and care for people with disabilities implies questioning practices such as the expulsion of these populations from the productive system and the bureaucratic construction of disability by systems of social protection and health (Venturiello, Sustas, Palermo, Villarejo, Sciurano, Tiseyra and Rodríguez, 2022). In this sense, establishing actions that do not replicate the "ideology of normality" and the "rehabilitative medical model" (Oliver, 1998) requires recovering, in health institutions and related programmes and policies, the therapeutic itineraries of people with disabilities themselves and the valorisation of their own life experience (Ayres, 2001; Ayres et. al., 2008, Pinheiro, 2007; 2010, Pinheiro and Guizardi, 2008). This involves breaking down barriers associated with the social invisibility of this group, for example, in sexual and reproductive health, prevention and health promotion, and in acute and chronic rehabilitation processes. Specialised

care and rehabilitation, which in many cases must be life-long, is guaranteed by obtaining the National Disability Certificate (CUD). According to the National Study on the Profile of Persons with Disabilities (INDEC, 2018) only 33.4% of the population with disabilities has a valid CUD, which allows them access to the rights recognised by the specific regulations. Health and education institutions are the main source that drives and promotes the processing of the CUD, so that a greater presence of institutions and availability of infrastructure in various parts of the country can favour or facilitate the progress of certification.

Among the major difficulties in access to health care for persons with disabilities are financing and affordability. Argentina has a health system organised into three subsystems: public, private and social security (belonging to trade unions). Even with the disability certificate and its authorisations, qualitative studies show that bureaucratic inconveniences and fragmented approaches in the health system limit adequate physical and psychological health care for many people with disabilities and with high support requirements (Findling and López, 2015; Sustas and Venturiello, 2022, Venturiello, 2016). Even with prepaid providers, which are the most expensive and are accessed by the most affluent population, there are litigious situations that delay the delivery of prostheses, orthoses and prolonged care. Thus, care itineraries and problems of access to medical care are directly related to the combination of certification and access to coverage. People in the social security and private subsystem tend to be those who make the greatest demand for the CUD because it enables them to obtain a greater number of benefits. According to data for 2020 from the National Register of People with Disabilities Certified with CUD, the distribution of the type of health coverage shows that 43% have social security, 5% have prepaid health insurance, and the rest have different types of public coverage (public system, national and provincial programmes), showing a predominant coincidence between the possession of the certificate and national, provincial and prepaid social security coverage (Venturiello et al, 2022).

Likewise, the concentration of care centres in urban areas and their absence in the rest of the country generates a strong territorial inequality of services and human resources, which leads to a lack of medical appointments and the effective possibility of carrying out treatment in the suburbs and rural areas (Venturiello et al, 2022). In the same vein, ensuring adequate health care is hindered by inaccessible public transport, which prevents access to health care facilities. This and management of other social barriers is often left to families (Venturiello, 2016). According to the first National Survey on Persons with Disabilities (ENDI) of 2002/2003 (cited in Schiappacasse 2014), there was evidence of significant involvement of families through instrumental and financial aids to contribute to the quality of life and health care of people with disabilities. For example, through the payment of technical aids, 50% of which is covered by the household budget. It should be noted that this type of privately managed resolution reproduces social inequalities, since among those who do not use this type of aid, 56.4% state that they need it but do not have the economic resources to obtain it (Venturiello, 2017).

3. Education: Progresses and Pending Debts

Although Argentina has signed, ratified and granted constitutional hierarchy to the Convention on the Rights of Persons with Disabilities, Article 24 of which obliges the country to move towards an inclusive education system, there is still much to be done to realise this right.

The National Education Law 26206 (passed in 2006), among other norms that regulate the education system, is still informed by the medical-pedagogical model. This law establishes that special education will be in charge of those cases (i.e. students) that mainstream education cannot address due to their "specific problematics" and argues that students with disabilities will be integrated or included (using these two different terms as synonyms) "according to the possibilities of each person" (Ley de Educación Nacional N° 26.206, 2006, art. 42). This position leaves ample room to enable exclusionary educational policies, cultures and practices to continue to be sustained.

Since the enactment of this law, pre-school, primary and secondary education have been compulsory throughout the country. However, each province of the Argentine Republic, constituted as a federal state, can dictate its own education law, which must be in line with national education policy. Due to pressure from civil society organizations dedicated to making the right to inclusive education effective, in 2016 the Federal Education Council issued a resolution establishing that it is prohibited to deny enrolment to a student in regular schools on the grounds of disability and that persons with disabilities who complete their education in regular schools have the right to graduate on equal terms with non-disabled persons (Cobeñas and Santuccione, 2022).

According to UNICEF, the population of children and young people with disabilities in Argentina is between 15 and 19 % more illiterate than the population of children and young people without disabilities (UNICEF, 2021).

Additionally, according to national statistics, in 2018 at least 52% of the population of students with disabilities are still enrolled in segregated settings, impeding their access to the right to be educated in inclusive settings (DIEE, 2018). Currently, while there is an increase in the number of students with disabilities enrolled in regular schools, the net number of students attending special schools has not changed substantially (DIE, 2022).

The 2012 report of the Committee on the Rights of Persons with Disabilities has expressed concern about this situation and urged the state to change its approach (Comité sobre los Derechos de las Personas con Discapacidad, Naciones Unidas, 2012, paragraphs 37 and 38), but only one province – La Pampa – has made progress towards full inclusion of persons with disabilities in the mainstream education system. In the rest of Argentina's 23 provinces there is still a special education sub-system that continues to receive students with disabilities to be educated in segregated settings. While great efforts are being made in many provinces, albeit incipient, in the province of Buenos Aires, which contains approximately 40% of the student enrolment of the whole country, and despite the demands of organisations of families and persons with disabilities, educational policies are not moving in the direction in which Argentina has committed itself in the Convention.

Within the group of persons with disabilities, those with intellectual disabilities, multiple disabilities, deafblindness and with higher communication support requirements are among the most excluded and least listened to groups (Cobeñas, 2014, 2016, Cobeñas and Grimaldi, 2021).

Teacher training is still differentiated in almost all provinces so that future teachers can still choose whether they want to train as teachers of students with or without disabilities, and choose an orientation among the types of disabilities according to the classification of the education system, which favours the persistence of a segregated system.

There is still no support system in place, but rather a system of differently trained figures, often coming from the field of health – who have *no* didactic training – or from the field of special education, who have *very little* didactic training, who work in a disjointed and fragmented manner and with little connection to the contents of the provincial curriculum of each educational level, in regular schools. They adopt different didactic approaches and in their training have few opportunities to problematise the ableist views that are still dominant towards students with disabilities (Cobeñas and Grimaldi, 2021).

4. Personal Assistance

The right to independent living is not yet effective in Argentina. In particular, among Disabled People's Organisations (DPOs) there is a demand for the regulation and access to personal assistants, both at national and provincial level. Some organisations, such as Asociación Azul, are playing a leading role in the construction of Latin American regional networks of DPOs linked to the independent living movement These DPOs have been fighting for years for the right to independent living and access to personal assistants, but they claim not to be heard by national and provincial governments, especially those made up of people with high support requirements (as reported on the Alternate Report of Argentine civil society organiations, during the periodic review of Argentina, before the Committee on the Rights of Persons with Disabilities this year)1. Access to personal assistants is only granted through exceptional requests to some social welfare organisations, so for the moment, funding and regulations concerning who can have access to this support and for how long, come from the health area. In the face of non-payment of benefits, only middle-class families can support the appointment of personal assistants. Furthermore, it is still assumed that the figure of the personal assistant can be assimilated to other types of figures such as home carers, nurses and therapeutic companions.

5. Conclusions

The field of health and the field of education are specifically articulated with the field of disability, generating specific forms and dynamics of access and exercise of rights. This leads us to confirm segregated vias of access to health and education, still "governed" by biomedical health system and its rationalities. Although progress

¹ More information available here: https://www.vidaindependiente.ar/el-estado-argentino-sigue-incumpliendo-los-derechos-de-las-personas-con-discapacidad/

can be observed, the imprint of the health system on certification, access to education, support and independent living for people with disabilities limits their participation in community life.

Further, access to the mainstream education system, independent living supports and appropriate health care is also closely related to socio-economic inequalities. The structural socio-economic inequalities of Argentinean society, together with the expulsion of people with disabilities from the labour market, the devaluation of care and the promotion of the availability of support outside the family environment, make the challenges of guaranteeing the rights of this population part of an ongoing social dispute.

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