1. ORIGIN, OBJECTIVES AND HYPOTHESES OF THE STUDY

This study arises from the need to publicize the reality of children with disabilities who are in a position to be adopted and that of adoptive families, both in relation to the expectations of those who apply, and the situation of families who have adopted a child with a disability. The aim is to analyze the general framework for the regulation of adoption in Chile and the international treaties ratified by Chile, linked to the issue of childhood and disability, in order to determine whether there is sufficient and adequate legal protection for institutionalized children with disabilities. According to reviewed reports, a significant number of children with disabilities remain institutionalized for a long time, even reaching adulthood.

The legislation on adoption in Chile has had multiple modifications since 1934, the year in which a law was first dictated regarding the issue of adoption in this country. Even though the principle of the "Best Interest of the Child" is the central axis of the current Law on Adoption No. 19.620, and the Right to Identity is enshrined, it should be noted that in the regulatory framework it seems that an explicit reference regarding the adoption of children with disabilities does not appear. It also explores the reform to the adoption law that is being processed in the Congress.

The research seeks to make visible the situation of the adoption of children with disabilities in Chile, noting the normative deficiency and the registration of data, seeking awareness and the generation of public policies aimed at restoring to children with disabilities the right to live as a family, on equal terms with others.

2. METHODOLOGY OF THE INVESTIGATION

For the development of the analysis of adoption legislation, the study of each of the regulations was relevant, which will be indicated below, so that the nature of the methodology is essentially exploratory and descriptive, since it attempts to encompass and compile the most amount of information that allows to arrive at congruent and precise conclusions.

The essential technique applied was the collection of legal information and systematization based on:

* National regulations and reform projects
* Foreign regulations
* Study of the national adoption process

* Study of Institutions responsible for the process.

Regarding the psychosocial analysis, the technique used was the collection of information on the subject, using databases, statistics and information collected from SENAME, UNICEF, NHRI, SENADIS, IACHR, among other national and international agencies that address the issue with different depth, as well as relevant scientific research. The study is complemented with interviews of a qualitative nature, with open questions that allow to also collect the findings not foreseen in the objectives of the research, considering the framework where the interview unfolds.

The specific methodology that was used is the semi-structured interview, basically qualitative, allowing to obtain information in depth, in a flexible format. The field units were selected through an intentional sampling of the opinion type.

It is important to highlight the role played by the theoretical framework based on the human rights model of persons with disabilities. Throughout history, societies have been giving different responses to disability. The concept of disability has varied according to the different sociocultural paradigms, experienced significant changes. The representation of disability has evolved from charitable models and welfare models to a social model currently embodied in the human rights model contained in the Convention on the Rights of Persons with Disabilities (CRPD).

3. LEGISLATION

**National:**

Law No. 5.343 of 1934

Law No. 7.613 of 1943

Law No. 16.346 of 1965

Law No. 18.703 of 1988

Law No. 19.620 of 1999

Law No. 20.422 of 2010

**International:**

Convention on the rights of persons with disabilities (CRPD)

Convention on the Rights of the Child (CRC)

Inter-American Convention for the Elimination of All Forms of Discrimination against Persons with Disabilities
4. FINDINGS OF THE STUDY

The results show the need to have an approach that conforms to the human rights model of the CRPD, the first Human Rights Treaty of the 21st century. This model provides us with a multifocal view of the conception of the subject of law: summation between the deficiency that a person can experience, including the physical, sensory, intellectual and / or psychosocial levels, the interaction with various barriers and the impact that this produces as restrictions in full and effective participation in society.

It is important to make adequate records and thus have a thorough knowledge of the situation of institutionalized children with disabilities to implement public policies that restore their right to live in family. Although the number of adoptions of children with disabilities has increased in recent years, the figures are still low. The study shows the need to train the operators of the adoption system, with a focus on human rights, aimed at the Best Interest of the Child, respect for their Identity, and respect for the evolution of their faculties, which allows them to pass that decision of conscience of the right to live in family of all children, towards those interested in adopting and towards society in general.

Children with disabilities represent within the protection network a group that requires focused, specialized and personalized attention, showing the need to generate specific lines of action aimed at guaranteeing their rights through affirmative action measures.

The barriers they experience are a key factor in which the State and society as a whole must work intensively and permanently both in the removal of obstacles and in the creation of the necessary conditions for equal opportunities and even material equality or results.

It is observed that the institutions through the professionals open the adoption of children with disabilities in a tangential way. Both these system operators and direct contact educators have an a priori perception of children with disabilities as subjects with an "uncertain future" and with a "high difficulty for independent life", which leads them to consider the adoption as a difficult alternative for these children, to the extent that they will not find "families willing to take care of them for life." In addition, "medical concerns" and "diagnoses" are added to clarify the health status and prognosis of the child to be "presented" to an adoptive family.

All this results in a prolongation of time and inertia in the residences, de facto limiting the possibility of adoption and perpetuating the institutionalization, together with transmitting these apprehensions to the applicants of an adoption.

This situation is not consistent with the reality experienced by parents who have received a child with a disability for adoption. When children with disabilities are in a family environment that responds adequately to their needs, their development and social inclusion are enhanced.
5. RECOMMENDATIONS AND GUIDELINES FOR PUBLIC POLICIES

How to make effective the obligation of the State of Chile in this matter, in order to comply with the full implementation of the rights enshrined in the CRPD and CRC in relation to the right of children with disabilities to live in family?

1º It is a priority to place on the social and public agenda the issue of children with disabilities who live institutionalized, aiming at their visibility and awareness of their right to live in family and full inclusion, theme that concerns us as a whole society.

2º Public policies should aim at alternative forms of care and protection in a family environment and at the de-institutionalization of children that guarantee the full enjoyment of their rights.

3º It is necessary to finish with the segregated institutions for children with disabilities.

4º Even though from the perspective of the CRPD it is not pertinent to describe the conditions of persons stigmatizing them, the need to have a system of efficient registration and information of children with disabilities in a situation of abandonment and institutionalized, which serves to establish strategies of action in particular for each of them and public policies adequately financed and in accordance with the needs and rights of children with disabilities in the different organizations that work with children and / or disability (SENAME, Ministry of Health, Ministry of Education, SENADIS, etc.)

5º To provide mechanisms through which these adoptions are prioritized and made effective for children with disabilities as an affirmative action measure to equalize the right to live in family in relation to other children and adolescents. The opportunity in which the Adoption Law is being reformed should be seized to consider the children with disabilities’s situation transversally in the Protection and Adoption process.

6th In the technical guidelines should be incorporated as a requirement that applicants for an adoption make a nomination without the conditions for the arrival of a son or daughter, assimilating the process to biological. In this one the sons or daughters are not chosen, there is only the wish of parenthood or marentality. We propose that during the “formative evaluation”, which is the new method to work with the applicants, the professionals will be detecting the psychosocial possibilities of the families, and with the decision of the applicants, an adoption of a child with disabilities can be specified. Also, that the training based on the model of human rights of persons with disabilities be incorporated into the workshops.

7º It is necessary to strengthen the training and qualification of professionals, technicians and direct personnel working in childhood and adoption, based on the model of human rights of persons with disabilities, which allows a change in the representation of disability, together to adapt the practices to this approach to guide the efforts to maximize the levels of development and autonomy possible in children with disabilities. The change of focus with respect to disability should be reflected in the adaptation of action protocols, in the daily work with each child with disabilities, in ending discriminatory and segregative practices, in the interdisciplinary interventions of professionals and in the evaluation and training work of the future adoptive parents. This must be regulated in the technical standards.

8th Social protection benefits must be established to promote the adoption of children with disabilities. The post-natal extension for cases of adoption of children with disabilities is a fundamental measure for
the adaptation of the family to the needs of the adopted child, which facilitates the inclusion of a child with disabilities in a family, since in general they are adopted after 6 months. In turn, provide that Health Insurance and General Insurance do not have the possibility to reject or condition the registration of a child with disabilities when it is adopted.

9º A campaign for the promotion of the rights of children with disabilities must be designed and developed: their right to live as a family and the promotion of their adoption, having as axis the model of human rights applicable to persons with disabilities and children.

**Direction of Investigation:** Prof. María Soledad Cisternas Reyes, Lawyer and Political Scientist.

**Researchers:**

Paula Arroyave Escaffi, Lawyer and Master in family, childhood and adolescence.

Nory Délano González, Psychologist and Master in Psychoanalysis

Priscila Délano González, Psychologist

Alejandra Bustos Cárdenas, Lawyer

**Contact information:** Marcela San Martín

e-mail: se.disability.secretariat@gmail.com